

Living Well at the End of Life Poll – Topline Results

Sample of 500 BOARD-CERTIFIED PHYSICIANS

Interviews Conducted Via Online Survey October 28 – November 2, 2011

National Survey Conducted February 2011 - Reported Where Applicable (NAT)

State Surveys Conducted June 2011 – Reported Where Applicable (OR / WA)

1. In your practice, how often do you personally interact with patients? Would you say...

96% Regularly
3% Occasionally
1% Infrequently
-- Never

2. In your discussions with patients and their families about care and treatment options, **how often do you personally raise the issue of the cost of care or treatment?**

51% Regularly
35% Occasionally
11% Infrequently
2% Never

86% Regularly / Occasionally
14% Infrequently / Never

3. In your discussions with patients and their families about care and treatment options, **how often do patients ask about the cost implications of care or treatment?**

42% Regularly
40% Occasionally
17% Infrequently
2% Never

82% Regularly / Occasionally
18% Infrequently / Never

From your experience, do you believe that the availability of the following options for seriously ill patients is Excellent, Good, Only Fair, or Poor?

	EXC / GOOD	FAIR / POOR	EXC	GOOD	FAIR	POOR	DK	REF
4. Options to extend life as long as possible								
DOC	81%	19%	35%	47%	16%	3%	NA	NA
OR	66%	22%	19%	47%	18%	4%	11%	1%
WA	66%	25%	17%	48%	20%	6%	8%	1%

5. Options to ease pain and suffering and focus more on the quality of life								
DOC	68%	32%	22%	46%	28%	4%	NA	NA
OR	66%	23%	22%	44%	18%	4%	11%	--
WA	63%	30%	16%	47%	21%	9%	7%	*

6. Options to choose when and where to die								
DOC	41%	59%	10%	31%	41%	18%	NA	NA
OR	62%	25%	23%	39%	19%	6%	12%	*
WA	52%	36%	12%	40%	20%	16%	11%	1%

7. And, which of these statements more closely reflects your beliefs?

NAT	OR	WA	DOC	
71%	85%	83%	96%	It is more important to enhance the quality of life for seriously ill patients, even if it means a shorter life?
				...OR...
23%	11%	14%	4%	It is more important to extend the life of seriously ill patients through every medical intervention possible?
3%	3%	2%	NA	DON'T KNOW
3%	1%	2%	NA	REFUSED

8. And, which of the following statements do you agree with more?

NAT	OR	WA	DOC	
37%	50%	47%	79%	The health care system spends far too much trying to extend the lives of seriously ill patients which diverts resources from other priorities, adds to our country's financial difficulties, and increases the cost of health care for everyone.
				...OR...
55%	35%	44%	21%	The health care system in this country has the responsibility, the medical technology, and the expertise to offer treatments to seriously ill patients and spend whatever it takes to extend their lives.
5%	11%	5%	NA	DON'T KNOW
3%	4%	4%	NA	REFUSED

Please review the following list of different types of care and, for each one, please indicate the degree to which you personally are involved in providing that type of care to patients?

	DIRECTLY INVOLVED	NOT DIRECTLY INVOLVED BUT VERY FAMILIAR	NOT DIRECTLY INVOLVED BUT SOMEWHAT FAMILIAR	NOT DIRECTLY INVOLVED AND UNFAMILIAR
9. Palliative Care	29%	35%	29%	7%
10. End-of-Life Care	31%	28%	28%	13%
11. Hospice Care	18%	44%	29%	9%

Now, focusing specifically on Palliative Care...

Palliative Care has been defined as any kind of care or treatment for seriously ill patients which focuses on improving quality of life and reducing the severity of symptoms rather than attempting to reverse progression of the illness or provide a cure.

The goal of palliative care is to provide physical, emotional, and spiritual support to patients and also their families. Palliative care can be provided alongside of curative treatment and is commonly provided at home, at a hospital, or at a nursing home.

An important part of palliative care is end-of-life care, which focuses specifically on improving care for patients approaching death. This includes discussing their preferred treatment options and reducing their pain and suffering.

12. From your experience, to what extent do you agree or disagree with this definition of Palliative Care?

71% Strongly Agree
26% Somewhat Agree
2% Somewhat Disagree
1% Strongly Disagree

96% TOTAL AGREE
4% TOTAL DISAGREE

13. [ASKED Q13 IF Q12:3-4 – DON'T AGREE WITH THE DEFINITION GIVEN, N = 18]

And, what are the most important reasons why you disagree with this definition of Palliative Care?

Respondent Verbatims
As this is defined, it does not really differentiate itself clearly enough from routine care since curative care is still included.
Emotional support and ease suffering
I agree with the definition except that there are real problems in working alongside while curative treatments are in progress since they often conflict.
I have not seen palliative care work alongside curative care.
In my experience it usually isn't provided along with curative measures. It is after those avenues have failed.
It not accurate.
Make end of life more comfortable.
Must include more factors.
Not comprehensive enough.
Only in that I am not exactly sure about it.
Other physicians can do the same. It is part of the care we provide everyday.
PALLIATIVE CARE ACCORDING TO MY UNDERSTANDING IS DOCTORS HAVE GIVEN UP ON THIS PATIENT.
Palliative Care physicians imply that they should be the person to coordinate care and provide service to any patient with any type of chronic condition. I believe they have their role but they shouldn't take the place of physiatrists in the area of disability, etc. They are not thr only physicians who coordinate care - many physiatrists, developmental pediatricians, geriatricians, etc. provide this type of care. I would prefer that Palliative care focus on the specific areas novel to them - end of life, pain management, etc.
Quality of life.
Remove death as end point.
Some conditions are reversible and with treatment we can't just throw in the towel.
Some conditions are reversible with advanced therapy like chf.
The stance to me is unclear, why not just go to hospice or conservative tx.

14. And, to what extent do you agree or disagree with the following statement?

The health care system in this country should place a higher priority on providing palliative care to all patients who need it and want it.

67% Strongly Agree
 28% Somewhat Agree
 3% Somewhat Disagree
 1% Strongly Disagree

96% TOTAL AGREE
4% TOTAL DISAGREE

Z1. As you may know, the implementation of palliative care in the United States has increased significantly over the past decade.

Do you attribute this increase more to...

16% Higher demand for palliative care from patients and their families

18% Greater familiarity with palliative care among physicians

66% Both of these factors about equally

Z2. And, do you see palliative care more as...

59% A positive innovation in clinical care

40% A continuation of existing clinical care practices

1% A move in the wrong direction for clinical care

15. Regardless of your own level of involvement with palliative care, how prepared would you say you are to discuss palliative care treatment options with patients and their families?

35% Very Prepared

49% Somewhat Prepared

13% Not Very prepared

3% Not At All Prepared

84% TOTAL PREPARED

16% TOTAL NOT PREPARED

16. And, how prepared would you say you are to counsel patients and their families about their options for end of life care?

30% Very Prepared

45% Somewhat Prepared

18% Not Very prepared

7% Not At All Prepared

75% TOTAL PREPARED

25% TOTAL NOT PREPARED

As you know, palliative care is often administered alongside of curative care. However, there are times when physicians recommend discontinuing curative treatment in favor of palliative care and also times when physicians recommend continuing curative treatment and not pursuing palliative care.

17. Please tell me to what extent you agree or disagree with the following statement:

As a physician, I see my primary responsibility as curing patients and helping them recover. I am therefore reluctant to recommend discontinuing curative treatment in favor of palliative care because it would amount to an admission that I am unable to cure the patient.

3% Strongly Agree
18% Somewhat Agree
37% Somewhat Disagree
42% Strongly Disagree

21% TOTAL AGREE
79% TOTAL DISAGREE

18. And, please tell me if you agree or disagree with the following statement:

As a physician, I am reluctant to recommend palliative care because patients and their families may conclude that I am not doing everything possible to extend the patient's life.

2% Strongly Agree
22% Somewhat Agree
41% Somewhat Disagree
36% Strongly Disagree

24% TOTAL AGREE
76% TOTAL DISAGREE

Thinking some more about the type of conversations you may have had with patients...

19. How often do you personally discuss palliative care or end-of-life care treatment options with patients and their families?

- 24% Regularly
- 36% Occasionally
- 29% Infrequently
- 12% Never

59% Regularly / Occasionally

41% Infrequently / Never

20. [ASKED Q20 IF Q19:3-4 – INFREQUENTLY OR NEVER DISCUSS PALLIATIVE CARE, N = 203] Do you (Infrequently / Never) discuss these treatment options with patients and their families because it is not relevant to your field of practice, or is it for some other reason?

- 86% Not relevant to practice
- 14% Some other reason

21. [ASKED Q21 IF Q20:2 – SOME OTHER REASON, N = 29] What specific reasons would you cite for not discussing these treatment options with patients and their families?

Physician / Practice

- 34% It does not come up in my practice / focus on patient care in my office
- 22% Leave it to the Palliative Care Specialists / Patients expect to have this talk with a primary care provider
- 8% Uncomfortable / Insecure
- 7% Lack of time
- 6% Not familiar with treatment options
- 2% They think I have given up on them if I bring it up

Patient / Family

- 21% They bring it up when they are ready / still want to fight for a cure / they have to believe all other options have been exhausted / most families / patients are not ready to discuss these options
- 6% Religious beliefs

Availability of Care

- 1% Availability is poor / degree to which ongoing care can be provided
- 5% Other

[ASKED Q22 – Q28 ONLY IF Q19:1-3 – DISCUSS PALLIATIVE CARE WITH PATIENTS, N = 442]

22. In your discussions with patients and their families about palliative care and end-of-life care treatment options, how often do you personally raise the issue of the cost of care or treatment?

18% Regularly
32% Occasionally
34% Infrequently
17% Never

50% Regularly / Occasionally
50% Infrequently / Never

23. And, in your discussions with patients and their families about palliative care and end-of-life care treatment options, how often do patients raise the issue of the cost of care or treatment?

23% Regularly
35% Occasionally
29% Infrequently
13% Never

58% Regularly / Occasionally
42% Infrequently / Never

24. And, from your experience, how well informed about palliative care and end-of-life care treatment options are patients and their families in advance of your initial consultation with them?

3% Very Informed
30% Somewhat Informed
57% Not Very Informed
10% Not Informed at All

33% Total Informed
67% Total Not Informed

25. Which of the following have you personally encountered when discussing treatment options with patients and their families?

- 13% The patient and/or their family rejected my recommendation to focus on palliative care and discontinue curative treatment.
- 3% The patient and/or their family rejected my recommendation to continue curative treatment and they chose to pursue palliative care.
- 59% Both of These
- 25% Neither of These

26. **[ASKED Q26 IF Q25: 1 OR 3 – REJECTED RECOMMENDATION TO FOCUS ON PALLIATIVE CARE, N = 317]** From your experience, how often do patients and their families reject your recommendation to discontinue curative treatment in favor of palliative care?

- 11% Regularly
 - 56% Occasionally
 - 33% Infrequently
 - * Never
- 66% Regularly / Occasionally**
34% Infrequently / Never

27. **[ASKED Q27 IF Q26:1-3 – PATIENTS HAVE REJECTED RECOMMENDATION, N = 316]** What reasons have patients and their families given for rejecting your recommendation to discontinue curative treatment in favor of palliative care?

- 75% Unwillingness to accept that curative treatment was ineffective
- 74% Disagreement from family members about discontinuing curative treatment
- 63% Preference for more aggressive curative treatment options
- 42% Religious hesitations or objections
- 37% Disagreement with the diagnosis or wanted a second opinion
- 1% Other

28. In your experience, how often is there disagreement within a patient’s family, either between family members or with the patient themselves, about whether to pursue palliative care or continue curative treatment?

- 23% Regularly
- 57% Occasionally
- 19% Infrequently
- 1% Never

80% Regularly / Occasionally
20% Infrequently / Never

Turning now to some questions about your education and training... To what degree were you exposed to education and training about palliative care during the following stages of your medical training?

	GREAT DEAL / ONLY SOME	NOT VERY MUCH / NOT AT ALL	GREAT DEAL	ONLY SOME	NOT VERY MUCH	NOT AT ALL
29. Medical School	33%	67%	6%	27%	33%	34%
30. Residency	45%	55%	13%	33%	35%	19%
31. Continuing Education since entering practice	60%	40%	20%	40%	28%	12%

32. **[ASKED Q32 IF Q29:1-3 OR Q30:1-3 OR Q31:1-3 – EXPOSED TO PALLIATIVE CARE EDUCATION AND TRAINING, N = 473]** And, from what you recall, what specific aspects of Palliative Care were covered during your medical training?

- 70% **Moral and Ethical**, including physicians’ responsibilities to the patient
- 56% **Psychosocial** including input and participation of patients and their families and emotional, psychological, and spiritual dimensions of care
- 54% **Clinical**, including treatment of symptoms and patient communication
- 36% **Institutional**, including working with other members of the healthcare team and within the healthcare system
- 35% **Societal**, including legal issues, public policy and community involvement
- 18% **Operational**, including pros and cons of different types of palliative care programs
- 16% **Financial**, including cost of care and issues related to reimbursement
- 12% None of These

33. And, looking back, which one of these aspects of Palliative Care should have received more emphasis than it did?

- 55% **Financial**, including cost of care and issues related to reimbursement
- 53% **Psychosocial** including input and participation of patients and their families and emotional, psychological, and spiritual dimensions of care
- 53% **Operational**, including pros and cons of different types of palliative care programs
- 52% **Clinical**, including treatment of symptoms and patient communication
- 49% **Societal**, including legal issues, public policy and community involvement
- 46% **Institutional**, including working with other members of the healthcare team and within the healthcare system
- 44% **Moral and Ethical**, including physicians' responsibilities to the patient
- 5% None of These

Thinking about the different groups that play a role in determining successful palliative care outcomes for patients, how important is the involvement of each of the following groups to ensuring successful outcomes?

	TOTAL IMPORTANT	TOTAL NOT IMPORTANT	EXT IMP	VERY IMP	SMWT IMP	NOT VERY IMP	NOT AT ALL IMP
34A. Physicians	95%	*	61%	34%	5%	*	--
34B. Nurses and other health care professionals	87%	2%	47%	40%	11%	2%	*
34C. Health Insurance Providers	55%	20%	25%	30%	25%	12%	8%
34D. Hospital Administrators	35%	31%	11%	24%	34%	22%	9%
34E. The Patients themselves along with their families	95%	1%	74%	21%	5%	*	*
34F. Elected Officials and Policymakers	36%	36%	11%	25%	28%	21%	15%

NOTE: Due to rounding, "Totals" may not necessarily equal sums.

And, how well do you believe each of the following groups actually perform at ensuring successful palliative care outcomes for patients?

TOTAL WELL	TOTAL NOT WELL	EXT WELL	VERY WELL	SMWT WELL	NOT VERY WELL	NOT AT ALL WELL
YA. Physicians						
49%	10%	14%	35%	41%	9%	1%
YB. Nurses and other health care professionals						
63%	8%	21%	42%	30%	6%	1%
YC. Health Insurance Providers						
12%	61%	3%	9%	27%	39%	22%
YD. Hospital Administrators						
14%	52%	3%	12%	34%	33%	18%
YE. The Patients themselves along with their families						
43%	18%	13%	31%	39%	14%	4%
YF. Elected Officials and Policymakers						
7%	75%	2%	6%	18%	38%	37%

35. From your perspective, are palliative care treatment options and services...

OR	WA	DOC	
23%	19%	31%	Widely available to almost all patients who need it and want it
43%	47%	51%	Available but only for patients with the right insurance or resources
5%	7%	16%	Available to only a small number of patients
6%	8%	2%	Mostly unavailable
23%	19%	NA	DON'T KNOW
*	--	NA	REFUSED

NOTE: Due to rounding, "Totals" may not necessarily equal sums.

And, how would you rate the following as barriers or obstacles to providing palliative care to all patients who need it and want it?

	TOTAL IS A BARRIER	TOTAL ISN'T A BARRIER	SIG	SMWT	NOT VERY MUCH	NOT AT ALL
36A. Patients don't have the resources to afford the care	78%	22%	32%	45%	20%	2%
36B. Health Insurance companies and Medicare don't reimburse adequately for consultations	82%	18%	39%	43%	14%	3%
36C. There are not enough palliative care physicians and services in hospitals or outpatient settings	78%	22%	29%	49%	19%	4%
36D. Patients are not adequately informed about palliative care and don't ask for it	91%	9%	36%	55%	8%	1%
36E. Patients are reluctant to accept palliative care because it means admitting they may not recover	84%	16%	33%	51%	15%	1%

Finally, please tell me to what extent you agree or disagree with the following statements regarding Palliative Care?

	TOTAL AGR	TOTAL STR DISAGR	SMWT AGR	SMWT AGR	STR DISAGR	DK / DISAGR	REF
36. Seriously ill patients should be allowed to choose treatment options that most align with their goals and values including choosing to decline life-extending treatment options.							
DOC	95%	5%	73%	21%	4%	2%	NA
OR	94%	4%	85%	10%	2%	2%	2%
WA	93%	6%	81%	13%	1%	5%	1%
37. Palliative care should be available to all seriously ill patients who need it and want it and this treatment should be fully covered by health insurance.							
DOC	95%	5%	70%	26%	3%	2%	NA
OR	87%	10%	72%	15%	7%	3%	3%
WA	83%	13%	65%	19%	8%	4%	4%

38. Palliative care should be available to all seriously ill patients who need it and want it and this treatment should be fully covered by Medicare.

DOC	94%	6%	68%	26%	4%	2%	NA
OR	89%	9%	69%	19%	5%	4%	2%
WA	86%	11%	67%	19%	5%	6%	3%

39. While palliative care and end-of-life care may be appropriate options for many patients, I worry that emphasizing this care could interfere with doing whatever it takes to help patients extend their lives as long as possible.

DOC	42%	58%	8%	34%	34%	24%	NA
OR	38%	55%	12%	26%	26%	29%	6%
WA	36%	59%	12%	25%	31%	29%	5%
NAT	47%	49%	21%	26%	26%	22%	3%

40. It is important that patients and their families be educated about palliative care and end-of-life care options available to them along with curative treatment.

DOC	96%	4%	76%	20%	3%	2%	NA
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41. Palliative care should be available to all seriously ill patients who need it and want it and this treatment should be provided alongside curative intent treatment.

DOC	94%	6%	66%	28%	4%	2%	NA
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DEMOGRAPHIC QUESTIONS

D1. Are you currently practicing as a board certified physician?

- 100% Yes
- No

D2. Which of the following best describes the type of medicine you practice?

45% General Practice

- 13% Family Practice
- 17% Internal Medicine, General
- 8% Pediatrics
- 7% Obstetrics/Gynecology

55% Specialists

- 2% Allergy and Immunology
- 5% Anesthesiology
- 3% Cardiology
- 3% Dermatology
- 2% Emergency Medicine
- * Endocrinology
- 1% Gastroenterology
- 1% Infectious Disease
- 1% Neonatology/Perinatology
- 2% Neurology
- 1% Neurosurgery
- 1% Occupational Medicine
- 1% Oncology
- 1% Ophthalmology
- 3% Orthopaedic Surgery
- 1% Otorhinolaryngology
- 2% Pathology
- 1% Physical Medicine/Rehabilitation
- * Preventive Medicine
- 7% Psychiatry
- 2% Radiation Oncology
- 3% Radiology, General
- * Radiology, Vascular and Interventional
- * Rheumatology
- 1% Surgery, Cardiac/Thoracic
- 5% Surgery, General
- 1% Surgery, Plastic
- 1% Surgery, Vascular
- 1% Urology
- 1% Other

D3. For how many years have you been practicing?

6% 5 Years or Less
18% 6-10
22% 11-15
16% 16-20
17% 21-25
14% 26-30
6% 30 Years or More

D4. In which state is your primary practice?

32% Northeast
21% Midwest
30% South
18% West

D5. What is your gender?

72% Male
28% Female

D6. What is your age?

1% 30 Years or Younger
17% 31-39
30% 40-49
37% 50-59
15% 60 Years or Older

D7. And, on political issues, do you consider yourself to be...

29% A Republican
23% A Democrat
32% An Independent or No Party Affiliation
1% Some Other Party
15% Prefer Not To Say