



# Definitions of value among a diverse sample of cancer survivors: Differences according to sociodemographics

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## Background and Objectives

A number of healthcare professional organizations are challenged with defining value frameworks, including: ASCO, NCCN, ICER and others.<sup>1,2</sup> However, patient perspectives on value are less understood and not necessarily reflected in these value frameworks.

Previous work suggests that metastatic breast cancer patient stakeholders have different understandings of “best care,” warranting further exploration among a diverse set of survivors.<sup>3</sup>

## Methods

Using the Cancer Support Community’s Cancer Experience Registry, an online initiative to capture the experiences of patients and caregivers impacted by cancer, we asked patients the following question:

**“When considering your cancer experience, how would you define value?”**

Guided by Grounded Theory, two researchers categorized responses of U.S. cancer survivors (N = 1,415). The following categories emerged:

- 1) personal; 2) health-specific; 3) non-health benefit/cost; 4) uninterpretable; 5) no value; or 6) lack of understanding.

### Personal responses were further categorized as:

- Existential benefit
- Relational benefit
- Important principle

### Health-specific responses were further categorized as:

- Practical health benefit
- Quality of life
- Relational benefit
- Benefits/cost
- Shared decision-making

Inter-rater reliability was 88% agreement.

## Participants

Sample Characteristics (N = 1,415)	
Median Age	56 years (SD: 12.20)
Female	82%
Non-Hispanic white	91%
College degree or higher	61%
Received some care at an academic/comprehensive cancer center	45%
>2 years from diagnosis	72%

Represented cancer diagnoses include: non-mBC (26%), mBC (27%), multiple myeloma (11%), ovarian (4%), and prostate (3%)

## Results

- A significant portion of respondents (29%) had difficulty conceptualizing value as a concept related to their healthcare experience (16% did not understand, 8.7% gave unclear response, 2.6% reported “no value,” and 1.3% gave a non-health benefit/cost response).
- An additional 40% of participants defined value in the context of personal beliefs. Only 31% of the sample conceptualized value as specifically relating to their healthcare experience.

### Personal (40% of Responses)

Personal responses fit into the following categories:

- Holding onto a principle: 31.6%
  - “Value is making the most of each day to serve others.”
- Existential benefit: 29.8%
  - “I am not happy I had cancer, but I value the results of the experience; living each day to the fullest and being able to connect with others in a more meaningful way.”
- Relational benefit: 28.9%
  - “Value to me during this journey is my family and friends and every day I get to be with them is a gift. My life is full, yet I may not be here in a year, I have so much to be thankful for, so I smile and feel loved.”

### Health-Specific (31% of Responses)

Health-specific responses fit into the following categories:

- Practical health benefit: 41.6%
  - “Value - the best possible cancer treatment center available that has the best forward looking/educated team of oncologists.”
- Quality of life: 26.4%
  - “Value is quality of life. If I had a 20% chance of survival but had to go through chemo or radiation, I would not do it.
- Relational benefit: 20.5%
  - “This comes to mind...one particular nurse was so wonderful. Just holding my hand helped. It was the personal touches. I don't think of money with the word value in this case... but what helped me as a person.”
- Benefit/cost: 10.1%
  - “Expert support at a reasonable cost.”
- Shared decision-making 1.4%
  - “Being informed, empowered, and part of the decision making.”

## Implications and Conclusions

Findings among this sample of diverse cancer survivors highlights a disconnect in the way cancer patients perceive value and in the way healthcare payers and providers define value.

- The majority of patients, when asked, do not interpret value as a trade-off or a ratio between quality and cost.
- 40% of patients consider value in terms of personal benefit, and 31% define value within the context of their health, suggesting that what matters most to patients frequently is connection to their loved ones and the trusted relationship with their healthcare provider. While efficacy is essential to value-based care for many patients, QOL and the quality of the relationship with HCT may also be part of “best care.”
- Survivors with less education were more likely to define value in personal rather than health terms, suggesting that increased efforts must be made to address how to communicate value to diverse cancer populations.
- Innovative efforts are needed to find a common language to assess patient value so that patient perspectives can be effectively reflected in the development of truly patient-centered value frameworks.



The Cancer Experience Registry is an online research initiative that captures the immediate and ongoing or changing social and emotional experiences of cancer survivors and their caregivers.

- The Registry is for all cancer survivors and caregivers, but also includes 11 disease-specific surveys.
- Findings contribute toward advancing research, health care and policy.
- Over 10,100 cancer survivors and caregivers are registered in the Cancer Experience Registry.

Learn more or join the Registry at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org)

## Acknowledgments

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