



Definitions of value among multiple myeloma patients in a cancer registry

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Background and Objectives

- Patients with multiple myeloma have seen major advances in treatment, and nearly half now survive 5 years.¹
- However, treatment costs are reportedly high and patients can experience financial burden, debilitating symptoms and quality of life deficits.^{2, 3}
- Given the changing landscape in treatment, measurement of value and effective communication around value are especially important for people living with multiple myeloma.

Methods

In 2014, the Cancer Support Community launched the Cancer Experience Registry: Multiple Myeloma. We asked registrants in the Cancer Experience Registry:

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

Guided by Grounded Theory, two researchers categorized responses of myeloma patients (*N* = 157). 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

Inter-rater reliability was 88% agreement.

Participants

Sample Characteristics (<i>N</i> = 157)	
Median Age	63 years (SD: 10.11)
Female	55%
non-Hispanic white	92%
College degree or higher	69%
Received some care at an academic/comprehensive cancer center	53%
>5 years from diagnosis	41%
Bone marrow transplant recipient	68%
Currently receiving treatment	79%

Results

- 19.8% did not understand the question, 8.3% provided an unclear response, and 0.6% reported a non-health benefit/cost response.
- No demographic or disease characteristics were significantly associated with personal (42%) or health-specific (29.3%) definitions.

Personal (42% of Responses)

Personal value responses were categorized as:

- Holding onto a principle: 57.6%
 - “Life is a value. You cannot put a price on it.”
- Existential benefit: 25.8%
 - “Allowed me to look at life and appreciate what I have and the commitment I have to the Lord. Given me the ability to freely talk with other patients or newly diagnosed people.”
- Relational benefit: 16.7%
 - “Family and friends; time with my son alone; doing things I want and can do.”

Health-Specific (29.3% of Responses)

Health-specific responses were categorized as:

- Practical health benefit: 43.2%
 - “Obviously, having an oncologist who makes the best treatment choice, best meaning effective, non-invasive, manageable long-term.”
- Quality of life: 29.5%
 - “Value is quality of life.”
- Relational benefit: 15.9%
 - “Being treated as an individual with unique needs, not just myeloma #123,456,789. My life is worth saving, and I have a purpose.”
- Benefits/cost: 5.0%
 - “The recognition of a patient’s questions, concerns, complaints are...not just “goals” for the visit.”

Implications and Conclusions

- Given 42% defined value in personal terms, these findings suggest a disconnect in understanding value even as medical value becomes increasingly important.
- When defined in health terms, patients most often cited practical benefit, suggesting a desire for improved health and survival.
- However, nearly 30% also cited QOL, suggesting that QOL – and what that means to each patient – may be as important in treatment decisions as efficacy and cost transparency alone, and should be incorporated into the value construct.



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

Acknowledgments

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References

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