

# Valued Outcomes in the Cancer Experience (VOICE™): Scale Development and Initial Validation

Alexandra K. Zaleta, PhD<sup>1</sup>, Shauna McManus, BS<sup>1</sup>, Joanne S. Buzaglo, PhD<sup>2</sup>, Eva Y. N. Yuen, PhD<sup>1</sup>, Julie S. Olson, PhD<sup>1</sup>, Mellissa F. Miller, PhD, MPH<sup>1</sup>, Karen Hurley, PhD<sup>3</sup>, Lillie D. Shockney, RN, BS, MS<sup>4</sup>, Sara Goldberger, LCSW-R<sup>5</sup>, Mitch Golant, PhD<sup>6</sup>, Kevin Stein, PhD, FAPOS<sup>1</sup>

<sup>1</sup>Cancer Support Community, Research and Training Institute, Philadelphia PA; <sup>2</sup>Concerto HealthAI, Memphis, TN; <sup>3</sup>Center for Behavioral Health, Case Comprehensive Cancer Center, Cleveland Clinic, Cleveland, OH; <sup>4</sup>Johns Hopkins Breast Center, Johns Hopkins School of Medicine, Baltimore, MD; <sup>5</sup>Cancer Support Community, New York, NY; <sup>6</sup>Cancer Support Community, Washington, DC

## Background

- Despite growing recognition that patient preferences and values should inform cancer care, patients' views continue to be underrepresented
- We developed a quantitative tool, Valued Outcomes in the Cancer Experience (VOICE), to measure patient priorities and to understand discrepancies between what matters most to patients and what patients believe they can control

## Aims

- This study presents the development and initial psychometric validation of the VOICE measure

## Methods

- 459 cancer patients completed an online survey and rated level of importance and perceived control for 54 items included in the preliminary VOICE measure (0=Not at all-4=Very much)
- Items were derived from patient and caregiver focus groups and interviews, and included themes such as independence, functional abilities, planning for the future, symptom management, health knowledge, and social support
- Participants also completed validated measures of hope, optimism, quality of life, financial toxicity, spiritual well-being, illness perceptions, social support, self-efficacy, intolerance of uncertainty, and cancer-related distress
- Iterative exploratory factor analysis with direct oblique rotation, magnitude of importance and control ratings, and Pearson correlations between items and validation measures were used to inform scale refinement

## Participants

	Mean / n	SD / %
Age (years)	60	10
	Range: 29 – 83	
Female	362	79%
Non-Hispanic White	384	86%
Cancer Diagnosis		
Breast	172	38%
Blood	81	18%
Lung	43	9%
Prostate	42	9%
Ovarian	20	4%
Time Since Diagnosis (years)	6.5	5.5
	Range: 0 – 41	
Current Disease Status		
Metastatic	98	22%
Recurrence/Relapse	83	19%
Remission	239	54%
Treatment History		
Surgery	352	80%
Chemotherapy (past / current)	280 / 81	67% / 23%
Radiation therapy (past / current)	244 / 8	60% / 2%
Hormonal therapy (past / current)	106 / 87	29% / 24%

## Results

Original Scale Item	Loading	Factor #	Importance	Action
<b>ACCESS TO CARE AND TREATMENTS</b>				
Seeing a doctor who specializes in your illness	.67	10	97%	Retain
Having other treatment options if your treatment does not work	.49	10	92%	Retain
<b>CARE COORDINATION</b>				
Having your medical providers communicate with each other about your care	.49	12	94%	Reword <sup>1</sup>
Having your medical team coordinate your follow-up appointments and referrals	.40	12	84%	Retain
<b>MANAGING COSTS OF ILLNESS</b>				
Being able to afford medical expenses	.91	6	96%	Retain
Understanding insurance coverage and payments for your illness and treatments	.45	6	90%	Retain
<b>UNDERSTANDING ILLNESS</b>				
Understanding how to manage your symptoms and side effects	.89	3	95%	Retain
Understanding side effects of treatment and how long they will last	.64	3	95%	Retain
Understanding your illness	None >.30	N/A	98%	Reword <sup>2</sup>
<b>SYMPTOM MANAGEMENT</b>				
Living without pain or physical discomfort (e.g. nausea)	None >.30	N/A	96%	Reword <sup>3</sup>
Being offered treatments that can increase your comfort	None >.30	N/A	84%	Reword <sup>4</sup>
<i>Having your symptoms and side effects be well-managed</i>	New	New		Add
<b>SHARED DECISION MAKING</b>				
Having others respect your decisions about your illness	.50	8	94%	Retain
<i>Having your healthcare team understand your values and goals for care</i>	New	New		Add
<b>LONGEVITY</b>				
Having your illness not get worse or come back	.75	2	96%	Retain
Feeling hopeful about the future	.65	2	94%	Retain
Having a long life	.54	2	77%	Retain
<b>BEING PREPARED FOR END OF LIFE</b>				
Talking with your health care team about realistic care goals	.64	4	83%	Retain
Talking with your health care team about planning for end of life	.63	4	42%	Retain
Having your affairs in order (e.g., estate planning, will, advance directives)	.52	4	87%	Retain
<b>MAINTAINING CONTROL AND INDEPENDENCE</b>				
Making decisions for yourself	.64	5	99%	Retain
Maintaining your independence	.54	5	98%	Retain
Having a personal sense of control over your health	.38	5	96%	Retain
<b>PURPOSE</b>				
Having a sense of purpose in your life	.72	9	93%	Retain
Feeling your life has value and worth	.41	9	95%	Retain
Having energy to do things that are important to you	None >.30	N/A	98%	Retain
<b>MEANINGFUL ENGAGEMENT</b>				
Being able to plan for the future (e.g., family events, travel, work)	.63	11	92%	Reword <sup>5</sup>
Doing activities that you enjoy (e.g. hobbies, travel)	None >.30	N/A	95%	Reword <sup>6</sup>
<b>ILLNESS COMMUNITY ENGAGEMENT</b>				
Supporting others who have your illness	.95	7	80%	Retain
Participating in research about your illness	.31	7	73%	Retain
<b>SOCIAL AND EMOTIONAL SUPPORT</b>				
Feeling emotionally close to family or friends	.68	8	91%	Reword <sup>7</sup>
Having family and friends treat you like your usual self	.36	8	94%	Reword <sup>8</sup>
Being able to cope emotionally with your illness	None >.30	N/A	95%	Reword <sup>9</sup>
<b>SPIRITUALITY</b>				
Having a strong relationship with God or a higher spiritual power	.88	1	66%	Retain
Belonging to a spiritual or religious community	.93	1	54%	Retain

• **Importance rating represents the percentage of participants who indicated the item was Quite a Bit to Very Much important**  
 • *The final EFA explained over half of the variance in the data (55%) and demonstrated good fit, with absolute and relative fit indices in established acceptable ranges (RMSEA=0.028, 90% CI=0.012–0.035; SRMR=.002; TL=0.956;  $\chi^2(157)=199.36, p<.01$ )*

## Summary of Scale Refinement

- **Exploratory factor analysis (EFA)** and thematic review suggested that VOICE items are distributed across fourteen factors

- **Items that did not load in the EFA at a level of .30 or greater, had low importance ratings, or were not associated with conceptually relevant validation measures**, were reworded or removed to eliminate redundancy

### Reworded items include:

- <sup>1</sup> Having your medical providers (e.g., specialists, primary care) work together to plan your care
- <sup>2</sup> Understanding your diagnosis
- <sup>3</sup> Living without physical discomfort (e.g., pain, nausea, bloating)
- <sup>4</sup> Being offered treatments to provide relief from your symptoms and side-effects
- <sup>5</sup> Being well enough to attend important family events (graduations, weddings, etc.)
- <sup>6</sup> Doing activities that you enjoy
- <sup>7</sup> Having people you can turn to for emotional support
- <sup>8</sup> Maintaining relationships with family and friends
- <sup>9</sup> Having your health care team ask you how you are coping emotionally with your illness

### Removed items include:

- Having your health care team talk to you in a way that makes sense to you
- Talking honestly with your health care team about your illness
- Maintaining a sense of humor
- Keeping up with your home or work responsibilities
- Being able to eat foods that you enjoy
- Being able to choose your health care provider
- Understanding your prognosis (the likely course of your illness)
- Being able to take care of yourself physically
- Being able to take care of others
- Having your family be taken care of no matter what happens to you
- Talking with others who have your illness
- Being treated with dignity and respect by others
- Having people you can rely on for help when you need it
- Having physical intimacy with a partner
- Having someone you trust to make decisions if you can't make them for yourself
- Feeling satisfied with your physical appearance
- Leaving a legacy when you are gone
- Having financial security
- Finding comfort in your faith and spiritual beliefs
- Having access to the best treatments for your illness
- Having a death free from suffering

- **2 items were added to ensure conceptual domains are adequately represented**; performance of new items will be evaluated in the next round of scale development and refinement

- **The refined VOICE measure, including new and reworded content, comprises 35 items, covering 14 theoretical and data-driven domains**

## Implications and Conclusions

- The study results demonstrate a framework for developing VOICE, a quantitative, multidimensional measure of patient values
- By understanding what matters most to patients, VOICE is positioned to bring patient preferences to the foreground of cancer care, contribute to shared decision making, and enhance care
- Next steps include further scale reduction and refinement, as well as validation of VOICE in diverse settings, including oncology practices and community-based organizations

## Acknowledgments

This work is made possible thanks to generous support from Pfizer Oncology.

## References

1. Zaleta, A. K., S. McManus, M. F. Miller, E. Yuen, K. Stein, K. Hurley, L. D. Shockney, S. Goldberger, M. Golant and J. S. Buzaglo. 2018. Valued Outcomes in the Cancer Experience: Patient priorities and control. American Society of Clinical Oncology Quality Care Symposium. Phoenix, AZ.
2. Alidina, K., & Tettero, I. (2010). Exploring the therapeutic value of hope in palliative nursing. *Palliat Support Care*, 8(3), 353-358. doi:10.1017/s1478951510000155
3. DeRouen, M. C., Smith, A. W., Tao, L., Bellizzi, K. M., Lynch, C. F., Parsons, H. M., . . . Keegan, T. H. M. (2015). Cancer-related information needs and cancer's impact on control over life influence health-related quality of life among adolescents and young adults with cancer. *Psycho-Oncology*, 24(9), 1104-1115.
4. Finset, A. (2017). Patients' values and preferences and communication about life expectancy: Combining honesty and hope. *Patient Educ Couns*, 100(10), 1777.
5. Olver, I. N. (2012). Evolving definitions of hope in oncology. *Curr Opin Support Palliat Care*, 6(2), 236-241..