# Valued Outcomes in the Cancer Experience (VOICE™): Developing and Validating a Measure of Patient Experience

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## Background and Aims

- Despite recognition that patient perspectives should inform cancer care, validated measures that meaningfully capture the patient experience across the cancer continuum remain limited.
- We developed Valued Outcomes in the Cancer Experience (VOICE), a measure of cancer patients' perceived control over personal priorities relevant to cancer.
- This study presents critical steps in VOICE scale construction and evaluation.

## Methods

### Exploratory Analysis and Item Reduction

- 623 adult cancer patients and survivors across the U.S. completed an online survey, rated current level of importance and perceived control for 35 VOICE items (0=*Not at all* to 4=*Very much*), and 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.
- Item descriptive statistics, exploratory factor analysis (EFA) of control ratings, Pearson correlations with convergent validity measures, and content validity assessment informed factor extraction and item reduction.

### Confirmatory Analysis

- 515 unique cancer patients and survivors across the U.S. completed a second online survey, rated their current level of perceived control for 21 VOICE items, and completed relevant cross-validation measures of hope, perceived health competency, resilience, and quality of life.
- Confirmatory factor analysis (CFA), Pearson correlations with convergent validity measures, and internal reliability analysis support the final 21-item measure.

### Participants

| Participants | EFA sample (N=623) | | CFA sample (N=515) | |
|---|---|---|---|---|
| | Mean / n | SD / % | Mean / n | SD / % |
| Age (years) | 55.6 | 13.3 | 60 | 12.2 |
| | Range: 18 – 90 | | Range: 20 – 88 | |
| Female | 455 | 73% | 386 | 75% |
| Non-Hispanic White | 461 | 76% | 409 | 79% |
| **Cancer Diagnosis** | | | | |
| Breast | 170 | 27% | 145 | 28% |
| Blood | 60 | 10% | 151 | 29% |
| Lung | 31 | 5% | 28 | 5% |
| Prostate | 19 | 3% | 31 | 6% |
| Ovarian | 37 | 6% | 20 | 4% |
| Time Since Diagnosis (years) | 6.0 | 6.3 | 6.5 | 5.5 |
| | Range: 0 – 41 | | Range: 0 – 56 | |
| **Current Disease Status** | | | | |
| Metastatic | 118 | 19% | 78 | 10% |
| Recurrence/Relapse | 89 | 14% | 85 | 17% |
| Remission | 351 | 56% | 314 | 61% |
| **Treatment History** | | | | |
| Surgery | 502 | 83% | 382 | 75% |
| Chemotherapy (past/current) | 388 / 91 | 66% / 15% | 365 / 68 | 71% / 13% |
| Radiation therapy (past /current) | 358 / 13 | 61% / 2% | 281/ 12 | 55% / 2% |
| Hormonal therapy (past /current) | 128 / 82 | 24% / 14% | 97/ 52 | 19% / 10% |

| Factors and Scale Items | % Quite a Bit or Very Much Control | Mean (SD) | Cronbach's Alpha (α) | Average Inter-Item Correlation | Herth Hope Index | Perceived Health Competence Scale | Connor-Davidson Resilience Scale | PROMIS® (Patient-Reported Outcomes Measurement Information System) v2.0 | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Depression | Anxiety | Social Function | Physical Function | Pain Interference | Fatigue | Sleep Disturbance |
| **PERSONAL IDENTITY** | | | | | | | | | | | | | | |
| you have a sense of purpose in your life? | 64.1 | | | | | | | | | | | | | |
| you feel hopeful about the future? | 58.1 | 2.78 (.98) | .89 | .73 | .69 | .55 | .52 | -.56 | -.44 | .31 | .32 | -.27 | -.35 | -.25 |
| you feel your life has value and worth? | 69.5 | | | | | | | | | | | | | |
| **FUNCTIONAL CAPACITY** | | | | | | | | | | | | | | |
| you live without physical discomfort (pain, nausea, bloating, etc.)? | 47.2 | | | | | | | | | | | | | |
| you do activities that you enjoy? | 43.1 | 2.28 (.95) | .67 | .41 | .43 | .51 | .38 | -.38 | -.34 | .41 | .44 | -.43 | -.41 | -.28 |
| you are well enough to attend important family events (graduations, weddings, etc.)? | 47.6 | | | | | | | | | | | | | |
| **DISEASE PROGRESSION** | | | | | | | | | | | | | | |
| your illness does not get worse or come back? | 19.4 | | | | | | | | | | | | | |
| you have a long life? | 22.7 | 1.65 (.93) | .67 | .41 | .38 | .46 | .30 | -.28 | -.24 | .31 | .27 | -.22 | -.33 | -.20 |
| you have other treatment options if your treatment does not work? | 35.7 | | | | | | | | | | | | | |
| **QUALITY CARE** | | | | | | | | | | | | | | |
| your health care team understands your values and goals for care? | 54.0 | | | | | | | | | | | | | |
| you see a doctor who specializes in your illness? | 67.0 | 2.48 (.93) | .75 | .51 | .44 | .46 | .38 | -.36 | -.29 | .26 | .27 | -.28 | -.24 | -.27 |
| your medical providers work together to plan your care? | 41.9 | | | | | | | | | | | | | |
| **ILLNESS KNOWLEDGE** | | | | | | | | | | | | | | |
| you understand how to manage your own symptoms and side effects? | 65.6 | | | | | | | | | | | | | |
| you understand your own diagnosis? | 76.3 | 2.79 (.84) | .77 | .52 | .42 | .43 | .40 | -.33 | -.28 | .23 | .26 | -.25 | -.22 | -.20 |
| you understand the short-term and long-term side effects of your treatment? | 55.5 | | | | | | | | | | | | | |
| **SOCIAL SUPPORT** | | | | | | | | | | | | | | |
| you have people you can turn to for emotional support? | 52.8 | | | | | | | | | | | | | |
| you have family or close friends involved in making decisions with you about your illness? | 61.2 | 2.59 (.95) | .79 | .56 | .52 | .43 | .38 | -.38 | -.31 | .28 | .28 | -.27 | -.26 | -.24 |
| you have people you can turn to for help with day-to-day needs? *New item* | 53.6 | | | | | | | | | | | | | |
| **FINANCIAL CAPABILITY** | | | | | | | | | | | | | | |
| you understand the costs of your own illness and treatments? | 55.5 | | | | | | | | | | | | | |
| you are able to afford your medical expenses? | 50.1 | 2.33 (1.0) | .69 | .43 | .39 | .47 | .43 | -.47 | -.40 | .34 | .36 | -.39 | -.38 | -.33 |
| you can get the medical care that you need no matter how much it costs? *New item* | 40.6 | | | | | | | | | | | | | |
| **VOICE total score (21 items)** | | 2.40 (.73) | .93 | .37 | .61 | .61 | .52 | -.51 | -.43 | .40 | .41 | -.39 | -.41 | -.33 |

*Note: All correlations above are significant at a p-value of <.001.* r = .20-.29 | r = .30-.49 | r = .50+

## Item Reduction from 35 to 21 items

### Reworded items:
1. you live without physical discomfort (e.g., pain, nausea, bloating)?
2. your medical providers (e.g., specialists, primary care) work together to plan your care?
3. you understand the side effects of your own treatment and how long they will last?
4. you understand your own insurance coverage and costs for your illness and treatments?

### Removed items:
1. you maintain your independence?
2. you have energy to do things that are important to you?
3. your medical team coordinates your follow-up appointments and referrals?
4. your symptoms and side effects are well-managed?
5. you have a strong relationship with God or a higher spiritual power?
6. you belong to a spiritual or religious community?
7. you are offered treatments to provide relief from your symptoms and side effects?
8. you have your affairs in order (e.g., estate planning, will, advance directives)?
9. you make decisions for yourself?
10. you maintain relationships with family and friends?
11. you participate in research studies about your illness?
12. you support others who have your illness?
13. you talk with your health care team about planning for end of life?
14. you talk with your health care team about realistic care goals?
15. you have a personal sense of control over your health?
16. your health care team asks you how you are coping emotionally with your illness?

## Summary of Scale Refinement

### Exploratory Analysis and Item Reduction (N = 623)

- A series of iterative exploratory factor analyses (EFAs) and thematic review of 35 VOICE items supported a 20-item, 7-factor structure.
- Items that did not load in the EFA at a level of .30 or greater, had low communality, were redundant with other items, or were not associated with conceptually relevant validation measures, were removed from analyses.
- The final EFA of 20 items explained over half of the variance in the data (54%) and demonstrated good fit, with absolute and relative fit indices in established acceptable to strong ranges (RMSEA=0.027, 90% CI=0.015–0.038; RMSR=.01; TLI=0.982).

### Confirmatory Analysis (N = 515)

- Leveraging findings from the EFA, 4 items were reworded and 2 items were added (noted in table above) to ensure that conceptual domains were adequately represented across factors.
- The refined VOICE measure, including new and reworded content, comprised 21 items representing 7 factors, and was tested via confirmatory analyses including confirmatory factor analysis (CFA).
- The CFA of the 21-item VOICE measure demonstrated good fit with absolute and relative fit indices in established acceptable ranges (RMSEA=0.078, 90% CI=0.072–0.084; SRMR=.051; TLI=0.871; CFI=0.897, $\chi^2(168)$=699.78, p<.01); the scale and factors also demonstrated adequate reliability, and medium to large associations with convergent validity measures.

## Implications and Conclusions

- VOICE measures patients' perceived control over a diverse range of personal priorities relevant to cancer, creating a platform for elevating patient perspectives across the cancer continuum and identifying pathways for empowerment and hope.
- Next steps include testing the VOICE measure in real world conditions and validating the responsiveness of VOICE in detecting and benchmarking meaningful changes in perceived control over time.

## References
1. Zaleta, A. K., McManus, S., Buzaglo, J. S., Yuen, E. Y. N., Olson, J. S., Miller, M. F., Hurley, K., Shockney, L. D., Goldberger, S., Golant, M., & Stein, K. (2019, March). Valued Outcomes in the Cancer Experience (VOICE™): Scale development and initial validation. Poster presented at the NCCN Annual Conference. Orlando, FL.
2. Bailo, L., Guiddi, P., Vergani, L., Marton, G., & Pravettoni, G. (2019). The patient perspective: investigating patient empowerment enablers and barriers within the oncological care process. *Ecancermedicalscience, 13*, 912. doi:10.3332/ecancer.2019.912
3. DeRouen, M. C., Smith, A. W., Tao, L., Bellizzi, K. M., Lynch, C. F., Parsons, H. M., Kent, E. E., & 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. doi: 10.1002/pon.3730
4. Náfrádi, L., Nakamoto, K., & Schulz, P. J. (2017). Is patient empowerment the key to promote adherence? A systemic review of the relationship between self-efficacy, health locus of control and medication adherence. *PLoS One, 12*(10), e0186458. doi: 10.1371/journal.pone.0186458
5. Corn, B. W., Feldman, D. B., & Wexler, I. (2020). The science of hope. *Lancet Oncology, 21*(9): e452-459. doi: 10.1016/S1470-2045(20)30210-2

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