SEEING THE PERSON THROUGH THE FOREST PLOT: A CO-CREATED QUALITY-OF-LIFE SURVEY

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Background

While clinical research celebrates new treatment efficacy, often characterizing adverse events as “manageable and tolerable,” there remains minimal input from people receiving these treatments. A 2023 survey across oncology community stakeholders listed patient quality of life (QoL) as the highest priority, however, patients were not the majority respondents[1]. Additionally, many current health-related quality of life (HRQoL) measurement tools including EQ-5D-5L Quality of Life Questionnaire and the Quality of Life Scale (QOLS) do not always capture the nuances that cancer patients and survivors feel are relevant to their quality-of-life.

In response, ***Advocates for Collaborative Education***, a global coalition of patient, community, research, and policy advocates, initiated ***More Than A Diagnosis: A Quality-of-Life Survey for Individuals with a Diagnosis or History of Cancer (MTAD survey)*** to co-create and disseminate an anonymous, IRB-exempt, online survey to assess QoL impacts related to a cancer diagnosis and cancer treatment with the intent of gathering data to better inform research, clinical care, and the broader cancer community.

Objectives

The primary aim of the MTAD Survey Project was to collaboratively develop a QoL survey with patient advocates representing diverse cancer types, stages, ages, and demographic backgrounds. The survey was designed to generate meaningful insights that could inform and enhance supportive care strategies for individuals affected by cancer.
Specific objectives included:

- Gain deeper insight into how cancer treatments and their side effects affect the QoL of individuals across a broad spectrum of experiences.
- Identify patient-informed perspectives on what matters most in terms of supportive care
- Generate valuable data that can guide research initiatives and clinical interventions aimed at improving the overall well-being of people living with cancer

Methods and Materials

A six section, 93-question survey was co-created by people with lived experience to determine relevant categories, questions, and measurement scales to assess severity and impact of QoL challenges. In addition to demographic and diagnosis data, the survey collected information on17 treatment-related side effects, perceived severity, potential side effect education, unintended side effects of supportive care interventions, and personal preferences for how to receive cancer-related information. The survey was disseminated via social media through and via a variety of organizational members of Advocates for Collaborative Education.

Results

Over 500 demographically and diagnosis diverse individuals, with a history of cancer, completed the survey *(See Table 1)* and reported a decline in QoL scores pre cancer vs post cancer **according to the co-created measurement tool[2]** (*See Chart 1*). **Respondents reported an average pre-diagnosis QoL score[2] of 8.87 out of 10, which declined to 6.41 when asked about current QoL.** When considering QoL factors of importance, **physical well-being was a top priority for most respondents (51.5%), followed by emotional well-being (25.4%).**

Current Disease Status	Respondents # / % (n =515)
Newly Dx (w/in 90 days)	4 / 0.1
Active Tx	77 / 15
Maintenance Tx	82 / 15.9
Post Tx (Tx ended w/in 5 yrs)	77 / 15
Long Term survivor (5+ yrs post active tx)	76 / 15
Metastatic disease	199 / 39

Cancer Type	Respondents # / % (n =515)
Prostate	7 / 1.4
Pancreatic	8 / 1.6
Leukemia/ Lymphoma	10 / 2
Gynecological	10 / 2
Other*	27 / 5.2
Colorectal	37 / 7.2
Lung	82 / 16
Breast	334 / 64.9

** includes Bladder, Brain, Rare, Liver, Skin, Stomach/Esophageal, Thyroid cancers*

Race	Respondents # / % (n = 515)
Caucasian / white	398 / 77.1
Black / African-American	53 / 10.3
Asian American / Pacific Islander	38 / 7.4
Mixed Race	18 / 3.5
Native American	0 / 0
Prefer Not to Answer	8 / 1.6

Table 1. Self-reported demographics including current diagnosis status; cancer type, and race. Majority or respondents were being treated for metastatic disease and individuals from over 20 unique cancer types completed the survey.

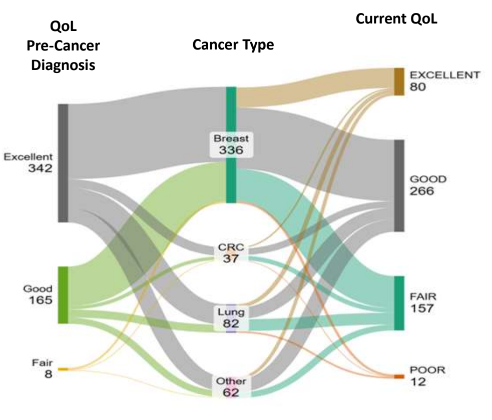

Chart 1. Sankey plot examining reported QoL pre-cancer; diagnosis of cancer with sample sizes fewer than 30 being included in broad “Other” category, reported QoL post-cancer.

Results

Across all cancer types and stages, a variety of side effects were reported with varying degrees of severity[3]. When asked to **select the single most negatively impactful side effect,** across the co-created list **fatigue (21%) was the most reported negative impact to QoL, followed by emotional distress (13%), and pain/neuropathy (12%). (See Table 2)**

Top QoL Impact n = 515	**Fatigue**	**107**	**21%**
	Emotional distress	**69**	**13%**
	Pain/Neuropathy	**62**	**12%**
	Muscle Joint Pain	53	10%
	Cognitive impairment	36	7%
	Diarrhea / Fecal incontinence	35	7%
	Sexual dysfunction	33	6%
	Other*	120	23%

*cardiac issues, constipation, cramping, dizziness, financial distress, nausea/vomiting, spiritual distress, vision issues, weight changes, other

Table 2. Respondents asked to rank “Top 1” side effect impacting QoL from co-created list of 17

Results

When examining the responses for only the metastatic (n=199) vs. non-metastatic population (n=316), **results were concurrent across the top three side effects** but **diverged at the fourth with diarrhea being the next top concern for individuals with metastatic disease (10%) and muscle / joint pain being the next top concern for individuals treated for non-metastatic disease (12%).**

	Individuals with Metastatic Disease # / % (n = 199)	Individuals with Non-Metastatic Disease # / % (n = 316)
cardiac	3 / 2.0	3 / 0.9
cognitive	11 / 5.5	25 / 7.9
consitpation	2 /1.0	1 / 0.3
cramping	0 / 0	1 / 0.3
diarrhea	**19 / 9.5**	16 / 5.0
dizziness	2 / 1.0	1 / 0.3
emotional distress	**25 / 12.6**	**44 / 13.9**
fatigue	**51 / 25.6**	**56 / 17.7**
financial distress	12 / 6.0	16 / 5.1
muscle joint pain	16 / 8.0	**37 / 11.7**
nausea vomiting	5 / 2.5	10 / 3.2
other	11 / 5.5	18 / 5.7
pain/neuropathy	**21 / 10.6**	**41 / 13.0**
sexual disfunction	9 / 4.5	24 / 7.6
spiritual distress	0 / 0	1 / 0.3
vision changes	1 / 0.5	1 / 0.3
weight issues	11 / 5.5	21 / 6.6

Table 3. Top Side Effect affecting QoL, stratified by metastatic and non-metastatic disease state

Conclusions

This study identifies the substantial effects of cancer treatment on an individual’s QoL, an area of research that receives little attention in relationship to its importance to patients. Interestingly, the top three side effects identified were consistent across respondents with metastatic and non-metastatic disease. Additionally, the research begins to uncover cascading side effects occasionally caused by supportive interventions. This co-created study offers valuable insights for enhancing the well-being of individuals affected by cancer.

Acknowledgements

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Contact

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More Than A Diagnosis: A Quality of Life Survey for Individuals with a Diagnosis or History of Cancer; IRB ID: 2023-0256

References and Definitions

1. Allen, C. J., Snyder, R. A., Horn, D. M., Hudson, M. F., Barber, A., Smieliauskas, F., Spears, P. A., Edge, S., & Greenup, R. A. (2023). Defining Priorities in Value-Based Cancer Care: Insights From the Alliance for Clinical Trials in Oncology National Cooperative Group Survey. JCO oncology practice, 19(10), 932–938.
2. Co-created measurement included a scale of 1 – 10: 1-2: POOR; 3-5:FAIR; 6-8: GOOD; 9-10: EXCELLENT
3. ‘Severe’ defined as *frequent & highly disruptive*; ‘Very severe’ defined as *constant & severely impacting quality of life*