



More Than a Diagnosis: An Untold Story of Quality of Life

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Background

While cancer treatments have advanced considerably since the advent and availability of targeted therapies, significant short and long-term treatment side effects can be challenging or even devastating to an individual's quality of life (QoL). A recent survey across oncology community stakeholders listed patient QoL the highest priority, however, patients were not the majority respondents¹. Furthermore, 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. **Advocates for Collaborative Education**, a global coalition of patient, community, research, and policy advocates, initiated a project to co-create and disseminate an anonymous, 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 **More Than A Diagnosis: A Quality-of-Life Survey for Individuals with a Diagnosis or History of Cancer** project objectives were to:

1. Gather a diverse group of patient advocates from a variety of cancer types², ages, stages, and demographics to **identify issues that are relevant to the patient and survivor community with regard to their QoL**;
2. **Co-create and disseminate an electronic, anonymous survey to:**
 - Gain a greater understanding of the impact of cancer treatments and treatment side effects on the QoL of individuals;
 - Gather information on what matters most to individuals in terms of supportive care for addressing QoL impacts;
 - Provide valuable data for research and clinical care in improving the well-being of individuals with cancer.

Methods and Materials

A four-phased approach was used

Phase 1: DISCOVER: One-on-one interviews were held with Advocate Collaborative members to ask about QoL pillars and priorities. A list of treatment-related side effects, late and long-term side effects was created and the aspect of cumulative effects and duration of effects, especially from those with metastatic disease, was noted. Finally, the need for assessing an individual's overall perception of QoL was documented.

Phase 2: DESIGN

The information gathered from patients, survivors, and patient advocates was used to co-create a six-section, 93-question survey. **Co-creation was instrumental in determining categories, specific questions, and measurement scales used to assess severity and impact of QoL challenges.** Beyond demographic, treatment, and cancer diagnosis data, **co-creation participants**

Methods and Materials

identified seventeen (17) treatment-related side effects. Survey questions were designed to ask about these side effects, their perceived severity, how well informed they felt about possibilities of experiencing these side effects, supportive care access, side effects of supportive care therapies, and personal preferences for receiving cancer-related information.

Phase 3: DEVELOP

The survey was built in Google Forms and the survey link was available on a study landing page on the Advocates for Collaborative Education website. Non-profit advocacy partners of Advocates for Collaborative Education were invited to self-select as identified beneficiaries. IRB exemption was granted by Pearl IRB.

Phase 4: DEPLOY

Recruitment efforts were conducted through social media platforms Twitter/X, Facebook, and advocacy partner outreach (email, newsletters, social, etc.)

To compensate potential respondents but maintain anonymity necessary for our IRB exemption, it was determined that, upon completion of the survey, respondents would be invited to choose a 501c3 as the beneficiary of financial compensation for their time and effort.

Results

Across a wide range of demographic subsets, including age, race, ethnicity, stage of cancer, and treatment status, and treatment modalities (See Table 1), **334 respondents with a history of breast cancer** reported a decline in QoL scores pre cancer vs post cancer **according to the co-created measurement tool³** (See Chart 1).

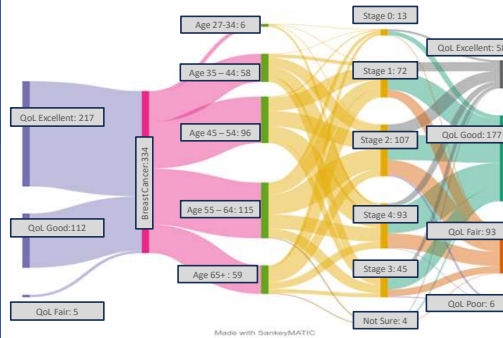


Chart 1. Sankey plot examining reported QoL pre-cancer; diagnosis of breast cancer; stratification by age range; stratification by stage at diagnosis; and finally reported QoL post-cancer.

Results

Physical and emotional well-being emerged as top priorities for most respondents, 47.9% and 27.5% respectively.

Side Effects: Of 17 listed side effects, respondents cited **fatigue (49%), muscle/joint pain (36%), and emotional distress (35%) as primary concerns**, with sexual dysfunction and cognitive impairment ranking prominently in the Top 3 QoL Impacts but much lower in the Top 1 QoL Impact (See Table 2).

Informed/Prepared: Many felt uninformed and/or unprepared for side effects. Nearly half (**46%**) of respondents reported **severe to very severe emotional distress⁴**, however, **only 55% of those felt informed or well informed** about the possibility of emotional distress. Among those reporting emotional distress, **only 41% received a plan** to address emotional distress.

While **54% of individuals experienced diarrhea or fecal incontinence** as a treatment side effect, **22% of affected individuals did not feel informed** about the possibility of such side effects.

Cascading Effects of Side Effect Treatments: Survey findings also highlight consequences of treatments to manage side effects. For example, **37% of respondents were prescribed treatment to address diarrhea and 100% of these patients reported additional side effects stemming from this supportive care** including nausea, constipation, and fatigue.

Additional learnings exist in each side effect vertical and in stratification based on current treatment status.

Side Effects with Top QoL Impact (All Breast Cancer, Stages, Ages)

	Select Top 3		Select Top SE	
	Count	%	Count	%
Cardiac (Heart) Issues	20	5.7	4	1.2
Cognitive impairment (trouble thinking/remembering)	94	26.7	25	7.5
Constipation	29	8.2	1	0.3
Cramping	7	2.0	1	0.3
Diarrhea / Fecal incontinence	54	15.3	20	6.0
Dizziness	11	3.1	1	0.3
Emotional distress	123	34.9	47	14.1
Fatigue	174	49.4	63	18.9
Financial distress	65	18.5	22	6.6
Muscle Joint Pain	126	35.8	41	12.3
Nausea and vomiting	34	9.7	8	2.4
Pain/Neuropathy	82	23.3	35	10.5
Sexual dysfunction	94	26.7	27	8.1
Spiritual distress	11	3.1	0	0.0
Vision Issues	13	3.7	2	0.6
Weight Changes	92	26.1	23	6.9
Other	27	7.7	24	7.2

Table 2. Respondents (breast only) asked to rank "Top 3" and "Top 1" side effect(s) impacting QoL

MTAD (Breast)

Category	Response	Count	%
Respondents	Consented	334	100
	0	13	3.9
	1	72	21.6
	2	107	32.0
	3	45	13.5
Stage @ Dx	4	93	27.8
	IDK	4	1.2
	18 - 26	0	0
	27 - 34	6	1.8
	35 - 44	58	17.4
Current Age Range	45 - 54	96	28.7
	55 - 64	115	34.4
	65+	59	17.7
	Newly Dx (w/in 90 days)	3	0.9
	Active Tx	29	8.7
Current Tx Status	Maintenance Tx	71	21.3
	Post Tx (Tx ended w/in 5 yrs)	36	10.8
	Long Term survivor (5+ yrs post active tx)	53	15.9
	Metastatic disease	142	42.5
	AAP	31	9.3
Race	Black/AA	48	14.4
	Mixed Race	14	4.2
	White	236	70.7
	Native American	0	0
	Prefer not to share	5	1.5

Table 1. Demographic information from breast-only respondents.

Conclusions

This study sheds light on an underexplored area of cancer research. Management of treatment side effects is integral to supportive care, yet supportive medications can introduce a cascade of their own side effects, exacerbating the overall burden on patients. Information and education are critical to bridge the gap. This collaboration with patients and survivors represents a pivotal step in determining areas that demand attention for improving QoL and offers valuable insights aimed at enhancing the well-being of individuals affected by cancer. Deeper detail, beyond what would fit on a poster, is available and we will look to publish based on additional stratification by side effect, treatment modality, and current status.

Acknowledgements

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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., Smietalska, 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. *COO oncology practice*, 19(10), 932-938.
2. Only breast cancer related responses are presented as part of this poster.
3. Co-created measurement included a scale of 1-10: 1-2: POOR, 3-5: FAIR, 6-8: GOOD, 9-10: EXCELLENT
4. "Severe" defined as frequent & highly disruptive; "Very severe" defined as constant & severely impacting quality of life

