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Preference-Based Assessments

Perspectives of Patients With Cancer on the Quality-Adjusted Life Year as a Measure of Value in Healthcare

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ABSTRACT

Objectives: Healthcare expenditures in the United States continue to grow; to control costs, there has been a shift away from volume-focused care to value-based care. The incorporation of patient perspectives in the development of value-based healthcare is critical, yet research addressing this issue is limited. This study explores awareness and understanding of patients with cancer about the quality-adjusted life year (QALY), as well as their perspectives regarding the use of the QALY to measure value in healthcare. **Methods:** This cross-sectional study used survey methodology to explore patient awareness, understanding, and perspectives on the QALY. A total of 774 patients with cancer and survivors completed this survey in June and July of 2017. Quantitative and qualitative analyses were conducted. **Results:** Results showed that there is limited awareness of the QALY among patients with cancer and survivors and minimal understanding of how the QALY is used. Only one quarter of respondents believed that the QALY was a good way to measure value in healthcare. Some participants (5%) stated that the QALY could be personally helpful to them in their own decision making, indicating the possible usefulness of the QALY as a decision aid in cancer care. Nevertheless, participants expressed concern about other decision makers using the QALY to allocate cancer care and resources and maintained a strong desire for autonomy over personal healthcare choices. **Conclusions:** Although participants believed that the QALY could help them make more informed decisions, there was concern about how it would be used by payers, policymakers, and other decision makers in determining access to care. Implications for policy and research are discussed.

Keywords: cancer, oncology, patient perspectives, QALY, value

Introduction

Cancer care makes up a significant portion of overall healthcare spending, rising more quickly than costs in other medical sectors.[1] The annual total of cancer care costs is expected to be $173 billion by 2020.[2] Per-person costs exceed all other diseases,[3] and in addition to the financial burden to the US healthcare system, many patients are faced with rising out-of-pocket costs and ensuing financial toxicity, which has been used to describe the fiscal hardships faced by patients with cancer.[4] Financial toxicity can lead to behaviors that put patients at physical, emotional, and financial risk such as skipping doses,[5] exhausting savings, or facing bankruptcy.[6]

Further, there is now a wide array of treatment options available to patients with cancer and providers, with only limited differences in efficacy and toxicity.[7] These treatments can vary widely in cost,[7] and some experts argue that certain drug prices are not consistent with potential benefits.[6] As a result of the rising costs of cancer therapies and the concordant financial toxicity for patients combined with variable health outcomes, a shift in healthcare from volume (based on a traditional fee-for-service system) to value (based on achieving desired health outcomes) is occurring. In simple terms, "value" is defined as treatment benefit weighed against financial cost.[8] Nevertheless, the concept is multifaceted; thus, it is a challenge to classify "valuable" healthcare interventions when different stakeholders (eg, patients, providers, payers, manufacturers, policymakers) may each identify the concept differently.

In response to this shift from volume to value, some nonprofit organizations, professional associations, and

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healthcare institutions have begun to assess the perceived "value" of oncology treatment options. Some value assessment tools produced by these organizations incorporate the quality-adjusted life year (QALY), which was created as a theoretical tool to measure cost-effectiveness in healthcare.[9]

The QALY combines morbidity (quality of life) with mortality (quantity of life) to estimate the value of specific health interventions. The QALY and cost-per-QALY inform discussions and policy decisions regarding the allocation of healthcare resources.[10] The QALY is used in various settings, including governmental agencies, managed care organizations, and with healthcare payers.[11] Nevertheless, it is important to note that the QALY does not allow for changing patient preferences over time[12] or other objectives such as equity, fairness, or political goals.[9] As such, the QALY was never intended to be used as an individual decision-making tool.[9] These limitations create valid ethical, conceptual, and operational concerns regarding the reliance on the QALY to determine healthcare value.[13] Although the QALY is theoretically based on patient preferences, these preferences are determined by surveying samples of various populations—not by those who are actually making real-time decisions regarding cancer care.[9]

Although the interest in value assessments gains traction, there is a lack of consensus regarding the appropriate structure and components of these tools.[14] As the field of value assessment moves forward, the patient-centered aspect of such analyses must be at the forefront.[15] The American Society of Clinical Oncology (ASCO) and the National Cancer Institute Cancer Outcomes Measurement Working Group (COMWG) recommend that patient-centered and clinical outcomes should both be used to determine the quality of cancer care,[16] yet there has been limited research examining the perspectives of patients with cancer and survivors regarding the QALY and its use in cancer care decision making. This study aims to address this gap in the existing literature by examining the following: (1) awareness of patients with cancer regarding the QALY and sociodemographic characteristics associated with awareness, (2) patient understanding of the QALY, and (3) patient perspectives regarding the use of the QALY to measure value in healthcare.

Methods

Study Design

This cross-sectional study used survey methodology to collect quantitative and qualitative data from individuals who had received a cancer diagnosis at some point in their life. Participants were recruited for this study via nonprobability convenience sampling by the Cancer Support Community (CSC), a nonprofit advocacy organization for patients with cancer. Recruitment methods included reaching out to potential participants via CSC's stakeholder email lists and social media platforms, both of which are open and available at no cost to any interested stakeholder. In 13 days, 774 patients with cancer and survivors completed the online survey. Eligibility criteria included the following: (1) age 18 years or older, (2) can read the survey in English, and (3) has received a cancer diagnosis in his or her lifetime. The survey (see Appendix A in Supplemental Materials found at https://doi.org/10.1016/j.jval.2018.09.2844) was open from June 28, 2017, to July 10, 2017, and informed consent was provided by participants before survey administration. The study protocol was approved by Ethical and Independent Review Services (E&I, Independence, MO), an outside institutional review board (IRB).

Measures

Sociodemographic and health characteristics

Study participants were asked to provide sociodemographic information (eg, age, race/ethnicity, sex, educational background, income range, and insurance type) and clinical history (cancer diagnosis and stage, as well as details on their current health status). To determine personal preferences when facing treatment decisions, participants were also asked what factors they take into account when they are making cancer treatment decisions.

Health literacy and patient perspectives on the QALY

To determine participants' level of understanding of complex health concepts such as the QALY, we examined health information knowledge levels of participants to establish a baseline measure of health literacy. Participants were also asked whether they had ever worked in a healthcare field. Two measures of health literacy were then used to determine participants' understanding of health concepts: *Brief Questions to Identify Patients with Inadequate Health Literacy*[17] and the *Cancer Health Literacy Test-6 (CHLT-6)*.[18] To explore patient perspectives on the QALY, participants were invited to complete questions assessing their awareness, understanding, and views of the QALY. Participants were then provided with a brief explanation of the QALY (see Appendix B in Supplemental Materials found at https://doi.org/10.1016/j.jval.2018.09.2844) and subsequently asked 2 questions assessing their understanding and opinion of using the QALY to measure value in healthcare. Detailed information on these measures is shown in Table 1.

Qualitative items

Participants were asked to complete one open-ended question at the end of the survey, inviting them to share their "opinions of QALY or value in healthcare."

Analysis

Descriptive statistics were calculated for sociodemographic, clinical history, and other study variables. The chi-square test of differences and independent samples *t*-tests were used to examine differences between participants who had or had not heard of QALY, did or did not think that QALY made sense, and did or did not believe that QALY was an appropriate way to measure value in healthcare. Logistic regression models were used to determine whether differences between participants on QALY items were maintained after controlling for sex, race, education level, healthcare work experience, health status, and both measures of health literacy. All quantitative analyses were completed in SPSS®, Version 25.0. A total of 165 open-ended responses to the final survey question regarding additional thoughts on the QALY or value in healthcare were analyzed and thematically coded independently by 2 study authors, who then discussed and reconciled codes until consensus was reached on final themes.

Results

Participant Characteristics

Study participants were predominantly female (82%) and white (88%); approximately half of the sample was between the ages of 60 and 74 years (Table 2). Participants were largely well educated, with 54% having a bachelor's degree or higher and 28% reported an annual income greater than $80,000. In terms of insurance coverage, the majority of respondents had employer coverage (49%) or Medicare (41%). The most common cancer diagnoses were breast cancer (48%), followed by leukemia (8%), lung (7%), and melanoma (6%). The stages at which participants were found to have cancer were distributed across the continuum, with 22% reporting stage IV (metastatic disease) at diagnosis. Over 70% of

Table 1 – Health literacy and patient perspectives on QALY

Construct	Items, response options, and score calculation
Health literacy	
Brief Questions to Identify Patients with Inadequate Health Literacy—3 items	Participants were asked about the level of confidence (1 = *very confident;* 4 = *not at all confident*) in reading and understanding medical documents and filling out medical forms by themselves; responses were reverse coded. Participants were asked one question about how often (1 = *always;* 5 = *never*) they had problems learning about their medical condition because of difficulty understanding medical information. All 3 responses were summed such that higher scores indicated greater levels of health literacy.
Cancer Health Literacy Test-6 (CHLT-6)—6 items	Participants were asked specific cancer-related health literacy questions. Items were scored as correct or incorrect. The number of correct answers were summed such that higher scores indicated greater levels of cancer-related health literacy.
Patient perspectives on the QALY	Participants were asked the question, “Have you ever heard the term *quality-adjusted life year* or QALY before?” with response options of “Yes,” “No,” and “Unsure.” Participants were also asked to rate the following 4 statements inquiring about (1) whether or not it made sense to think of treatment value in terms of quality and quantity of life, (2) other factors that are important in assessing value of treatment, (3) whether or not quality and quantity of life were the important only factors to consider, and (4) the usefulness of assigning a number to represent the value of treatment. All 4 statements were rated on a 5-point Likert scale (1 = *completely disagree;* 5 = *completely agree*) to determine their initial stance on the concepts of quality and quantity of life. No summary score.

QALY indicates quality-adjusted life year.

participants indicated that they were in good, very good, or excellent health.

Health Literacy

Almost 40% of participants had worked in at least one healthcare position. Most participants scored highly on the *Brief Questions to Identify Patients with Inadequate Health Literacy* with a mean score of 9.9 (SD = 2.1) out of a maximum possible score of 13. Participants also scored highly on the *CHLT-6*,[18] as evidenced by correct answers over 90% of the time on all 6 questions. The results from these 2 health literacy measures suggested a participant population with the potential to understand complex health and cancer care topics such as the QALY.

Participant Awareness, Understanding, and Perspectives of the QALY

Bivariate findings

Bivariate findings regarding sociodemographic and health-related differences in relation to participant awareness, understanding, and perspectives of the QALY are shown in Table 3.

Awareness

Overall, initial participant awareness of the QALY was very low, with fewer than 7% of respondents indicating that they were aware of the QALY. Participants who reported that they were aware of the QALY before survey administration were significantly more likely to report having worked in a healthcare setting (χ^2 [1] = 8.34, *P* = .004) and had greater levels of overall health literacy (*Brief Questions to Identify Patients with Inadequate Health Literacy, t* (668) = 5.77, *P* < .001).

Understanding

After reading the brief explanation of QALY, 19% of participants indicated that they understood the QALY. Participants who had a bachelor’s degree or higher level of education (χ^2 [1] = 14.58, *P* < .001) and participants with annual household incomes greater than $100,000 ($\chi^2$ [1] = 10.59, *P* = .001) were more likely to report that they understood the QALY (Table 2). Participants with greater levels of overall health literacy were also more likely to report that they understood the QALY (*Brief Questions to Identify Patients with Inadequate Health Literacy, t* [580] = 4.64, *P* < .001; *CHLT-6, t* [581] = 2.54, *P* = .011).

Perspectives

After review of an explanation of QALY, 76% of participants stated that they either did not believe or were unsure whether the use of the QALY was a good way to measure value in healthcare. Women were significantly more likely to say that the QALY was not a good way to measure value in healthcare or that they were unsure, with 78% of women indicating this, compared with 65% of men (χ^2 [1] = 6.97, *P* = .008). Participants who reported annual household incomes of less than $100,000 were significantly more likely to believe that the QALY was not a good way to measure value in healthcare or that they were unsure (χ^2 [1] = 5.17, *P* = .023). Participants with greater levels of health literacy were more likely to state that the QALY was a good way to measure value in healthcare (*Brief Questions to Identify Patients with Inadequate Health Literacy, t* [582] = 2.49, *P* = .013).

Multivariate findings

Multivariate findings regarding sociodemographic and health-related differences in relation to participant awareness, understanding, and perspectives of the QALY are shown in Table 4. Model fit for participant awareness of the QALY was statistically significant ($\chi 2$ [9] = 24.28, *P* = .004). The only significant factor associated with QALY awareness was health literacy (*Brief Questions to Identify Patients with Inadequate Health Literacy*), such that higher levels of health literacy were associated with being aware of QALY (B = 0.37, OR = 1.45, *P* = .001). Model fit for understanding of the QALY after reading the explanation provided was also statistically significant (χ^2 [9] = 41.65, *P* < .001). Education level and health literacy (*Brief Questions to Identify Patients with Inadequate Health Literacy*) were both significantly associated with understanding of the QALY. Participants with a bachelor’s degree or higher (B = 0.68, OR = 1.98, *P* = .001) and participants with greater health literacy (B = 0.14, OR = 1.15, *P* < .001) were more likely to indicate the QALY made sense. The model examining factors associated with participant indication that the QALY is a good way to measure value in healthcare was nonsignificant.

Table 2 – Participant sociodemographic and health characteristics ($N = 774$)

	% (*n*)
Sex	
Male	17.3 (132)
Female	82.7 (632)
Race	
White	87.7 (656)
Nonwhite	12.3 (92)
Hispanic ethnicity	
Hispanic	4.1 (30)
Non-Hispanic	95.9 (710)
Age	
18-24 years	6.4 (49)
45-59 years	37.4 (287)
60-74 years	50.0 (384)
75 years or older	6.3 (48)
Highest level of education	
HS/GED or less	16.2 (123)
Some college	28.9 (220)
Bachelor's degree	28.2 (214)
Graduate degree	26.7 (203)
Annual household income	
Less than $20,000	15.8 (97)
$20,000 to $59,999	35.2 (216)
$60,000 to $99,999	26.3 (161)
$100,000 or more	22.7 (139)
Worked in healthcare setting	
Yes	38.2 (296)
No	61.8 (478)
Most common cancer diagnoses[*]	
Breast	44.2 (342)
Leukemia	7.1 (55)
Lung	6.2 (48)
Melanoma	5.2 (40)
Overall health status	
Excellent	6.0 (43)
Very good	28.0 (200)
Good	36.3 (259)
Fair	23.9 (171)
Poor	5.8 (41)
	M (*SD*)
Health literacy[†] (range: 3-13)	9.93 (2.13)
Health literacy[‡] (range: 0-6)	5.62 (0.81)

Note. M, mean; *SD*, standard deviation.
[*] Participants could select more than one type of cancer.
[†] *Brief Questions to Identify Patients with Inadequate Health Literacy*.
[‡] *Cancer Health Literacy Test-6*.

Participant Thoughts on the QALY and Value in Healthcare

Three major themes emerged from the subset of 165 participants who provided qualitative views about the QALY and value in healthcare (Table 5). The themes were as follows: (1) measuring value, (2) opinions on QALY, and (3) value in healthcare and decision making. Although most respondents did not provide additional views regarding the QALY and value in healthcare, these respondents did not differ significantly from the demographics represented in the smaller sample.

Measuring value

Over half of participants (54%; $n = 89$) discussed the measurement of value in healthcare and 3 subthemes emerged: concerns over quantitative scoring, the multifaceted nature of value, and imperfect measurement. Of those who discussed measurement, 60% ($n = 54$) discussed the issue of using a quantitative score to determine the value provided by a given treatment or the value of one's life. Thirty-four participants stated that it was not possible to use generalized numbers to calculate individual value. One participant stated, "A measure like QALY cannot be applied in the same way to people of varying circumstances." These participants believed that decisions that could affect human life could not be captured by what one participant referred to as "hard data." Twenty participants stated that it was unsuitable to place a numeric value on anyone's life or cancer treatment. Some participants felt that a primary focus on cost was "ethically inappropriate" and "immoral." Another participant wrote, "Life is precious and should not be assigned a number to determine if that life is worth living."

Of those who discussed measurement, 25% ($n = 22$) referenced the multifaceted nature of determining value, which goes far beyond looking at the cost of treatment and the quality and quantity of life associated with it. These participants indicated that many other factors should be taken into account when determining value or QALY. Fifteen percent ($n = 13$) of those who commented on the measurement of value noted that the mechanisms used to measure value in this context are imperfect. These comments all noted that people can outlive life expectancies and that these figures are simply a best guess and not an absolute fact. Therefore, participants felt that the QALY was problematic because it uses information that is not always accurate. Multiple participants shared their own stories as evidence that prognostication around survival is imperfect, such as the participant who stated, "I was told I had 12 to 18 months to live based on a Stage IV diagnosis. That was 12 years ago."

Opinions on QALY

In this theme, 36% ($n = 59$) of participants expressed opinions specifically about the QALY, with 85% ($n = 50$) of these respondents responding in a negative manner. These responses included concern about the QALY and how it would be used ($n = 18$), confusion about QALY ($n = 10$), disagreement with how the QALY is calculated ($n = 10$), and comments stating that the QALY is too subjective ($n = 6$) and general statements expressing dislike for the QALY ($n = 6$). Participants were concerned that the QALY could be a tool for external decision makers to use in making judgments about a patient's cancer care that may have a negative impact, with one response stating, "I am afraid that if the QALY is used to determine treatment, some patients will not be given treatments that may help them." The remaining 15% ($n = 9$) responded positively, noting that the QALY could be a useful tool for healthcare decision-making or controlling cancer care costs. For instance, one participant stated, "QALY may help an analytical person like me weigh treatment options."

Value in healthcare and decision making

A total of 76% ($n = 126$) of participants mentioned the relationship between value in healthcare and decision making. Within this larger theme, there were 3 subthemes: patient autonomy, concern about external decision makers, and cost. Of those who discussed the relationship between value and decision making, 55% ($n = 69$) talked about patient autonomy. This included 61 people whose response centered around the idea that cancer treatment and care decisions should be made by patients, noting that these decisions were personal and individual and should remain that way. Participants overwhelmingly focused on the importance of personal choice in the selection and value assessment of cancer treatments. Eight respondents also noted that information regarding

Table 3 – Participant differences in awareness of QALY, understanding of QALY, and perspectives on the use of QALY to measure value in healthcare (*N* = 774)

	Have you heard of QALY?			Does QALY make sense?			Is QALY a good way to measure value in healthcare?		
	No/unsure, % (*n*)	Yes, % (*n*)	χ^2	No/unsure, % (*n*)	Yes, % (*n*)	χ^2	No/unsure, % (*n*)	Yes, % (*n*)	χ^2
Sex			0.07			0.28			6.97[†]
Male	92.9 (104)	7.1 (8)		48.5 (49)	51.5 (52)		65.3 (66)	34.7 (35)	
Female	93.5 (521)	6.5 (36)		45.6 (219)	54.4 (261)		77.8 (374)	22.2 (107)	
Race			0.04			1.55			0.67
White	93.7 (546)	6.3 (37)		45.7 (232)	54.3 (276)		74.7 (380)	25.3 (129)	
Nonwhite	93.1 (67)	6.9 (5)		54.0 (34)	46.0 (29)		79.4 (50)	20.6 (13)	
Hispanic ethnicity			0.04			0.02			2.25
Hispanic	92.9 (26)	7.1 (2)		48.0 (12)	52.0 (13)		88.0 (22)	12.0 (3)	
Non-Hispanic	93.8 (585)	6.2 (39)		46.7 (253)	53.3 (289)		74.8 (406)	25.2 (137)	
Age			0.71			3.09			0.83
18-24 years	95.0 (2)	5.0 (2)		33.3 (11)	66.7 (22)		75.8 (25)	24.2 (8)	
45-59 years	92.4 (232)	7.6 (19)		45.7 (100)	54.3 (119)		77.8 (172)	22.2 (49)	
60-74 years	93.6 (320)	6.4 (22)		47.7 (143)	52.3 (157)		74.6 (223)	25.4 (76)	
75 years or older	95.0 (38)	5.0 (2)		52.9 (18)	47.1 (16)		73.5 (25)	26.5 (9)	
Highest level of education			2.61			14.58[‡]			0.41
<Bachelor's degree	95.2 (276)	4.8 (14)		55.7 (137)	44.3 (109)		76.9 (190)	23.1 (57)	
≥Bachelor's degree	92.0 (347)	8.0 (30)		39.7 (133)	60.3 (202)		74.6 (250)	25.4 (85)	
Annual household income			3.74			10.69[†]			5.17[*]
<$100,000/year	94.5 (392)	5.5 (23)		50.7 (181)	49.3 (176)		76.0 (273)	24.0 (86)	
≥$100,000/year	89.5 (111)	10.5 (13)		33.0 (37)	67.0 (75)		65.2 (73)	34.8 (39)	
Worked in healthcare setting			8.34[†]			0.03			0.11
Yes	89.8 (228)	10.2 (26)		46.8 (167)	53.2 (190)		76.4 (175)	23.6 (54)	
No	95.5 (402)	4.5 (19)		46.1 (106)	53.9 (124)		75.2 (270)	24.8 (89)	
	M (*SD*)	*M* (*SD*)	t-test	*M* (*SD*)	*M* (*SD*)	t-test	*M* (*SD*)	*M* (*SD*)	t-test
Health literacy[§]	9.9 (2.1)	11.4 (1.6)	5.77[‡]	9.6 (2.3)	10.4 (2.0)	4.64[‡]	9.9 (2.1)	10.4 (2.1)	2.49[*]
Health literacy[‖]	5.6 (0.8)	5.7 (1.0)	0.64	5.6 (0.8)	5.75 (0.6)	2.54[*]	5.7 (0.7)	5.7 (0.7)	−0.30

M indicates mean; *SD*, standard deviation.

[*] P < .05

[†] P < .01

[‡] P < .001

[§] *Brief Questions to Identify Patients with Inadequate Health Literacy*.

[‖] *Cancer Health Literacy Test-6*.

value should be made available to patients to help with their personal decision making. One participant noted:

> I feel the decision for how long you live and how you are willing to live should be decided by the patient… Many patients would not want to live longer if they felt they had no quality of life and others would like to live as long as possible regardless of the quality of life they have…

Thirty-four percent (*n* = 43) of participants who discussed decision making and value referenced external decision makers. Of these responses, participants overwhelmingly believed that external parties (eg, insurance companies, managed care companies) should not be involved in cancer treatment and care decisions, with 39 participants endorsing this viewpoint. One participant stated, "Insurance companies should not be the ones to decide to treat or not to treat." Only 4 participants believed that external decision makers should be involved in treatment and care decisions related to the value of such care. Nevertheless, these participants specifically noted that decision makers should be involved alongside patients—not in place of them; for example, one person said, "There should be a lot of physician input into this… This needs to be patient centered." The third subtheme was cost, with 15% (*n* = 19) of respondents noting that cost should not be a factor in any cancer care decision, as evidenced by the participant who said, "Healthcare should not be about money."

Discussion

This study explores awareness, understanding, and perspectives of patients with cancer regarding the use of the QALY as a measure of value in healthcare. The use of the QALY has far-reaching effects, as various organizations and researchers use the measure in the development and promulgation of value assessment frameworks and tools. Nevertheless, it is critical to understand patient perspectives on existing measures, such as the QALY, in order to deliver true patient-centered care.[15]

Despite the fact that the QALY has been around for decades, the majority of patients with cancer in this study, although highly educated and health literate, were not aware of, nor did they completely understand, the QALY. Once they were presented with more information about the QALY, about half of participants

Table 4 – Logistic regression models predicting participant responses to QALY items

Variable	Model 1: Heard of the QALY			Model 2: QALY makes sense			Model 3: QALY is a good way to measure healthcare value		
	B	*SE*	OR	B	*SE*	OR	B	*SE*	OR
Sex (male = 1)	.42	.49	1.52	−.18	.26	.84	.34	.27	1.41
Race (white = 1)	.31	.65	1.37	.38	.33	1.46	.49	.40	1.63
Age	−.02	.27	.98	−.20	.14	.82	.12	.16	1.13
Income	.04	.12	1.05	.03	.06	1.03	.03	.07	1.03
Education (bachelors or more = 1)	.63	.44	1.88	.68[†]	.21	1.98	.02	.23	1.02
Health status	−.14	.20	.87	.04	.11	1.04	.03	.12	1.03
Worked in healthcare setting (yes = 1)	.44	.39	1.56	−.07	.22	.94	−.13	.23	.88
Health literacy[§]	.37[†]	.12	1.45	.19	.05	1.21	.15	.06	1.16
Health literacy[‖]	.42	.46	1.52	.14[‡]	.16	1.15	−.04	.18	.96
Model summary									
N		515			451			453	
Nagelkerke R^2		*.122*			*.118*			*.044*	
Omnibus χ^2 (*df*) = P value		*24.28(9) = .004*			*41.65(9) ≤ .000*			*13.80(9) = .130*	

B indicates unstandardized regression coefficient; *OR*, odds ratio; *SE*, standard error.

[*] $P < .05$

[†] $P < .01$

[‡] $P < .001$.

[§] Brief Questions to Identify Patients with Inadequate Health Literacy.

[‖] Cancer Health Literacy Test-6.

indicated that the QALY concept made sense; however, only about one quarter of participants believed that it was a good way to measure value in healthcare. After controlling for multiple sociodemographic and health-related participant characteristics, the relationship among health literacy, awareness of the QALY, and understanding of the QALY was maintained. In addition, the relationship between higher levels of education and participant understanding of the QALY was maintained after controlling for sociodemographic and health-related participant characteristics. Qualitative findings revealed that participants were open to using the QALY in their personal decision-making process, showing that the QALY has the potential to be a valuable decision aid for patients with cancer, by potentially providing a mechanism to balance benefits, risks, and costs during their individual treatment-making experience.[19] Yet, participants were highly reticent of the use of the QALY by external decision makers, who would have the ability to impact their access to care.

Our results suggest that patients and survivors believe strongly that they should maintain autonomy over treatment decisions, with input from their healthcare team and family, when appropriate. This is consistent with previous research showing that patients with cancer want to take an active role in making decisions related to their care.[20] Previous research has also shown that patients with cancer look beyond cost and treatment outcomes to determine value.[21] Indeed, many participants in this study expressed concern that quantitative scores might be used

Table 5 – Qualitative themes and codes regarding perspectives on QALY and value in healthcare (N = 165)

Major theme	Subtheme	Code[*]
Measuring value	Quantitative scoring	Using a number to value life/quality of life is wrong (*n* = 20)
		Individual situations cannot be captured with a number (*n* = 34)
	Multifaceted	Many factors should be considered beyond cost, quality of life, and life expectancy (*n* = 22)
	Imperfect	Life expectancy/prognosis not always accurate (*n* = 13)
Opinions on QALY	Negative	Concerning (*n* = 18)
		Confusing (*n* = 10)
		Disagrees with how it is calculated (*n* = 10)
		Too subjective (*n* = 6)
		Don’t like QALY (*n* = 6)
	Positive	Useful (*n* = 9)
Value in healthcare decision making	Patients	Cancer treatment/care decisions should be made by patients (*n* = 61)
		Patients should have access to all available information (*n* = 8)
	External decision makers	Should not be involved in treatment/care decisions (*n* = 39)
		Should be involved in treatment care decisions (*n* = 4)
	Cost	Should not be a factor (*n* = 19)

[*] Participant comments sometimes contained more than one code, and so *n*’s add up to more than 165.

by external decision makers to ration care in some way and that assigning a quantitative value to an inherently personal and nuanced decision, such as treatment decision making, was inappropriate. Ultimately, this study found that patients with cancer believed that the QALY does not reflect the diversity of their experiences, needs, and beliefs.

When interpreting the results of this study, several study limitations should be considered. This study was exploratory and cross-sectional in nature; causality could not be established. Participants were predominately white and well educated, with good health literacy and moderate to high socioeconomic statuses; this makes future studies with greater diversity important. Participants in this study were cancer survivors, and this may have introduced bias in responses, and findings may not apply to other patient groups. In addition, many participants in this study had been, or were currently, employed in the healthcare field, and this may have affected responses. Given the small percentage of participants who indicated an awareness of the QALY, the logistic regression model examining associations with this outcome is likely underpowered; nevertheless, the model was significant that it is possible that we were unable to detect other significant associations. Lastly, the introductory paragraph containing the definition of the QALY provided to participants should have stated that the QALY value is determined based on both the financial cost and the expected effect on health status. Although the method for calculating the QALY was explained clearly in subsequent paragraphs, participants who did not read the full explanation may not have developed a full understanding of how the QALY is calculated.

Despite these limitations, this study provides an important first step to better understand how patients with cancer and survivors define healthcare value for themselves and whether or not they see the QALY as a useful tool in value assessments. The feedback provided by patients with cancer and survivors in this study provides key insights for individuals and organizations assessing cancer care value, as multiple perspectives are needed to represent the interests of all participants in value-based decision making.[14] The patient voice, in particular, is often missing or even at odds with the economic, academic, and structural ways in which we evaluate cancer care value.

A recent report issued by the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Special Task Force suggested that cost-effective analysis be the primary driver for reimbursement and coverage decisions made by health plans,[22] which is exactly what patients in this study are worried about having to contend with in accessing care. Further, the ISPOR Special Task Force emphasized the use of the QALY as a key factor in cost-effective decision making, placing its importance above other patient-centered factors.[22] The Institute for Clinical and Economic Review (ICER), an organization dedicated to evaluating the clinical and economic value of drugs and devices, also uses the QALY in its value assessments. The ISPOR initiative and the Institute for Clinical and Economic Review report highlight the need for the development of value frameworks incorporating the patient voice,[23] and it is essential that such measures incorporate multiple components (ie, resource use, clinical performance, patient experience, and outcomes).[24]

To address this, in 2016 the National Health Council (NHC) proposed a patient-centered value model rubric with 6 key components: patient partnership, transparency to patients, inclusiveness of patients, diversity of patients/populations, outcomes patients care about, and patient-centered data sources.[25,26] This framework provides an important foundation from which we can begin to define and measure value in cancer care in a patient-centric manner. As critical healthcare decisions are made that will have serious repercussions in the lives of patients with cancer, it is vital to consider their needs, preferences, and values.

Value frameworks are needed that not only consider definitions of value from the societal perspective, but also core personal definitions that are applicable to individual patients and point-of-care discussions.[15] This study provides important insights into the QALY and ways in which patients with cancer and survivors understand and conceptualize this concept. As payment reform continues to evolve, with value being at the center of key decisions, and with patients bearing more of the cost and risk sharing burden, it is imperative that policy and decision makers are aware of the elements of care deemed most important—as identified by patients.

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Supplemental Materials

Supplementary data associated with this article can be found as a hyperlink at https://doi.org/10.1016/j.jval.2018.09.2844.

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