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Biomarker testing communication, familiarity, and informational needs among people living with breast, colorectal, and lung cancer

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ABSTRACT

Objectives: This study aims to characterize patient experiences with biomarker testing, including history of biomarker testing, related communication and education, self-perceived familiarity and informational needs.
Methods: 436 U.S. adults diagnosed with lung (38%), colorectal (35%) or breast cancer (27%) from 2018 to 2022 completed a survey. Two logistic regressions were conducted to predict patients' familiarity with biomarker testing and informational needs.
Results: Despite high biomarker testing rates (85%), half of respondents reported low familiarity with biomarker testing and three-quarters reported outstanding informational needs. Regression models indicate those patients who have greater health literacy and report having conversations with their oncologists about biomarker testing have more familiarity with biomarker testing and less informational needs, even after controlling for important sociodemographic factors.
Conclusions: There is an opportunity to improve patients' familiarity with biomarker testing and decrease outstanding informational needs by focusing on factors such as health literacy and patient-provider communication, which could further cultivate patients' understanding of the importance of biomarker testing in cancer care.
Practice implications: These findings underscore the importance of patient-provider relationships and the need for additional tools that assist providers in assessing patients' health literacy and facilitating conversations with patients, especially those focused on complex topics such as biomarker testing.

1. Introduction

Biomarker testing has revolutionized cancer care, and along with it, the patient experience. This is especially true for cancers that have identified actionable mutations, allowing for more tailored treatments based on patients' specific genomic profiles: Genomically-matched targeted therapies have been shown to improve key cancer outcomes, including overall response rate, overall survival, and progression free survival [1–3]. Though type (single gene vs. comprehensive testing; tumor vs. liquid biopsy) and timing might vary based on several factors (type of care setting, subtype and stage of cancer, etc.), biomarker testing is now incorporated into the standard of care for many diagnoses, including breast [4,5], colorectal [6–9], and non-small cell lung [10–14] cancers.

Though the potential benefits of biomarker testing are substantive, it also creates new challenges for both health care providers (HCPs) and patients. Not only can the nuances of biomarker testing be difficult to understand due its multifunctionality—serving as a diagnostic, prognostic, or predictive tool [15]—HCPs use highly diverse vernacular when discussing biomarker testing with patients [16]. Previous research indicates that those diagnosed with cancer are more likely than the general population to request health-related information from their HCPs [17], but information-sharing from the HCPs does not always guarantee subsequent patient understanding, even if that information is coming directly from their oncologist [16]. However, HCPs are patients' preferred source for receiving information, including information

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pertaining to biomarker testing [17,18], and patients and physicians share similar priorities regarding outcomes for these discussions: the benefits of testing and how it can help determine treatment [18].

Importantly, cancer patients are motivated to learn more about biomarker testing and report understanding some of the related benefits [19–21] but also tend to have poor recall and understanding of their own biomarker testing experiences, including whether they were tested and for which specific mutations [22]. Understanding biomarker testing information and related terminology could be partially attributed to level of health literacy [23,24], which is associated with key social determinants of health including sociodemographic factors (e.g., income, education) as well as cancer clinical characteristics (e.g., age at diagnosis, cancer stage/status, family history of cancer). Low health literacy can impede patients' ability to initiate conversations with their HCPs and understand their clinical recommendations [25,26], yet HCPs often do not recognize when patients have low health literacy [27].

Patients' familiarity with biomarker testing and informational needs, as well as the sociodemographic and clinical factors that influence these outcomes, are important to explore because they speak to patients' deeper understanding of their cancer care experience and patients' understanding can result in greater involvement in their care, which has numerous benefits [28,29]. As such, the aims of the current study were to characterize patients' experiences with biomarker testing in cancer, specifically by 1) documenting their self-reported biomarker testing history, 2) describing patients' biomarker testing communication and educational experiences, familiarity, and informational needs, and 3) evaluating, through logistic regression, the relationship between biomarker testing familiarity and informational needs with prior biomarker testing communication and educational experiences as well as other key determinants of the cancer care experience (i.e., sociodemographic factors and clinical history).

2. Methods

2.1. Participants

436 cancer patients and survivors in the U.S. completed an online survey between September 2021 and January 2022 about their experiences with biomarker testing. Participants were recruited through two sources: (1) an online Qualtrics Panel (n = 347), which targeted respondents who were likely to meet key eligibility requirements (e.g., prior cancer diagnosis) and aligned with the U.S. population strata regarding gender, race, and geographic region and (2) advocacy groups serving the cancer populations of interest (n = 89). Adults ages 18 years and older who can read English and were diagnosed with breast, colorectal, or lung cancer in 2018 or later were eligible to participate. Ethics approval was obtained from Ethical & Independent (E&I) Review Services (IRB00007807; Protocol #21078). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained prior to participants beginning the survey.

2.2. Measures

Survey content was informed by interviews with patients (N = 12) who fit the same eligibility requirements as survey participants (interview data not published). All survey content was then reviewed by study investigators and vetted by a project advisory committee with experience and expertise in patient education, medical and surgical oncology, genetic counseling, nursing, and pharmacology.

2.2.1. Sociodemographic background and clinical history

Participants provided socio-demographic and clinical background information including: age, gender identity, race/ethnicity, education, employment status, past employment in health care field, household income, primary cancer diagnosis, stage at diagnosis, current cancer status (i.e., experiencing cancer for the first time, experiencing cancer recurrence/relapse, currently in remission), year of diagnosis, ever metastatic, family history of cancer, treatment status, types of treatments received, treatment setting, and health insurance type.

Participants also completed the six-item multiple choice Cancer Health Literacy Test (CHLT-6)[30], which has been demonstrated to have good validity in cancer patients, across gender identity and race/ethnic groups. Each correct response is scored as a 1, for a total possible score of 0 to 6, with higher scores indicating greater cancer health literacy (0–4 = limited cancer health literacy; 5–6 = adequate cancer health literacy).

2.2.2. Biomarker Testing History

Participants were first presented with a definition of biomarker testing to establish a base understanding of the intended area of study focus. This definition is based on Cancer Support Community (CSC)'s Precision Medicine Plain Language Lexicon [31], which was co-created by oncology experts, patients, and caregivers:

> "Biomarker testing may also be called molecular testing, tumor profiling, somatic testing, or genomic testing of cancer cells, among other things. Sometimes doctors do not use "biomarker" or any of the other terms we just went over—they may simply say they are taking a sample of tissue or blood to test for abnormalities. Biomarker testing involves collecting a sample of cancer from blood or bodily fluids or from the tissue taken during a surgery or biopsy. The sample is then sent to a lab for testing."

Participants were then asked if, based on this definition, they had received biomarker testing (yes, no, unsure) and if they knew which specific biomarkers they were tested for (yes, no).

2.2.3. Biomarker testing communication and educational experiences

Participants were asked a series of questions developed to evaluate when (e.g., prior to vs. after cancer diagnosis), how (e.g., result of healthcare experiences; incidental exposure), and with whom (e.g., healthcare team; family/friends, cancer support group, etc.) biomarker testing information was provided or discussed.

Biomarker testing shared decision-making was addressed with the Shared Decision-Making Process Survey (SDMP-4)[32], modified to focus on biomarker testing. For example: "How much did you and your health care providers talk about the reasons you might want to have biomarker testing?" Total scores across items range from 0 to 4, with higher scores indicating greater communication and shared decision-making.

2.2.4. Biomarker testing familiarity

Participants rated their self-perceived familiarity with biomarker testing on a 5-point scale (1 = *Not at all familiar*; 2 = *Slightly familiar*; 3 = *Somewhat familiar*; 4 = *Very familiar*; *5 = Extremely familiar*). Scores were dichotomized into groups for purposes of regression analysis (1–2 = unfamiliar with biomarker testing; 3–5 = familiar with biomarker testing).

2.2.5. Biomarker testing informational needs

Participants rated their overall desire to know more about biomarker testing ("*I wish I had learned more about biomarker testing*") on a 5-point Likert scale (1 = *Strongly Disagree*; 2 = *Disagree*; 3 = *Neutral*; 4 = Agree; 5 = *Strongly Agree*). Participants could also select "*Not applicable / I don't know*." Scores were dichotomized into groups for purposes of regression analysis (1–3 = low informational needs; 4–5 = high informational needs). Participants who selected "*Not applicable / I don't know*" were not included in regression analysis.

2.3. Analysis

Analyses were conducted using SPSS version 24. Bivariate relationships between hypothesized predictor variables and key outcome variables of interest (biomarker testing familiarity and informational needs) were investigated using correlations, t-tests, or ANOVAs, to substantiate inclusion in the subsequent regression analysis. After dichotomizing biomarker testing familiarity and informational needs as described above, logistic regressions were performed by retaining only predictor variables that demonstrated significant bivariate relationships. Classification analyses were also conducted, including sensitivity, specificity, positive predictive value, and negative predictive value, as a method for determining how well cases were correctly classified based on the predictor variables included in the model.

3. Results

3.1. Participants

Participants had an average age of 49 years (range = 18–83) and were predominantly women (68%), Non-Hispanic White (74%), and had a college degree (57%) (Table 1). Thirty-two percent reported an annual household income of less than $40K. Cancer diagnoses were fairly evenly distributed across groups: lung (38%), colorectal (35%), and breast (27%); 34% reported a history of metastatic disease. Sixty-one percent were receiving cancer treatment at the time of survey completion; 47% were treated at a community hospital or cancer center, and 20% at an academic/comprehensive cancer center. Based on the CHLT-6 (M = 4.8, SD = 1.2), two-thirds of the sample (66%) had adequate cancer health literacy, while the remaining 34% had limited cancer health literacy.

3.2. Descriptive Analyses

The majority of participants reported receiving biomarker testing (86%), and roughly half of these respondents (49%) indicated they knew which biomarkers/mutations they were tested for (see Table 2). Most respondents (72%) reported first learning about biomarker testing after their cancer diagnosis, with the majority of these learning about it from their cancer care team (71%). Those who first learned about biomarker testing prior to diagnosis reported this because they knew someone else with cancer (40%), because it was related to their education or career training (35%), or because someone on their healthcare team shared the information (19%).

Three-quarters of participants (75%) reported having conversations about biomarker testing with one of their oncology providers (medical, surgical, and/or radiation oncologist) and 39% indicated they had conversations about biomarker testing with their primary care physician. In addition to healthcare team conversations, respondents also indicated having conversations with cancer support groups (27%), family members (26%), friends (23%), and peer-mentors (13%). Notably, one in ten respondents (11%) indicated that they never learned about biomarker testing and 7% indicated they talked to no one about biomarker testing. Almost half the sample (46%) indicated the highest possible shared decision-making with their HCPs, with a SDMP-4 score equal to 4, while less than 10% indicated no shared decision-making, with a SDMP score equal to 0 (M = 2.82, SD = 1.36).

Half of the respondents reported low familiarity with biomarker testing terms (48% *Not at all familiar – Slightly familiar*), while the remaining respondents reported being *Somewhat – Extremely familiar* (see Table 2). Three-quarters of participants (75%) wish they had learned more about biomarker testing. There was a significant correlation between biomarker testing familiarity and informational needs in the expected direction (r = -0.25, $p < .001$), such that those who reported low familiarity reported greater informational needs.

Table 1
Descriptive characteristics of the analytic sample (N = 436).

	Category/Range	*M/n*	*SD/ %*†
Age	Range: 18–83	*M* = 49	*SD* = 13
Gender	Woman/Trans Woman	295	68%
	Man/Trans Man	136	31%
	Other/Prefer not to share	5	1%
Race	Non-Hispanic White	321	74%
	Non-Hispanic Black or African American	50	12%
	Non-Hispanic Asian or Asian American	23	5%
	Hispanic, Latino, or Spanish	20	5%
	Other/Multiple races	13	3%
	Prefer not to share	9	2%
Education	High school or less	51	12%
	Some college, trade school, or associate degree	132	31%
	Bachelor's degree	142	33%
	Advanced degree	103	24%
Employment	Full-time	169	39%
	Part-time	66	15%
	Temporary employment	45	10%
	Retired	68	16%
	Not employed, Disability	44	10%
	Not employed, Other	31	7%
	Prefer not to share	13	3%
U.S. region	South	138	32%
	Northeast	104	24%
	West	103	24%
	Midwest	91	21%
Previous employment in health care field	No	348	80%
	Yes	71	16%
	Prefer not to share/missing	17	4%
Cancer Health Literacy (CHLT-6)	Range: 0–6	*M* = 4.8	*SD* = 1.2
	Adequate cancer health literacy (scores 5–6)	289	66%
	Limited cancer health literacy (scores 0–4)	147	34%
Household income	< $20K	40	9%
	$20K - $39,999	98	23%
	$40K - $59,999	104	24%
	$60K - $79,999	61	14%
	$80K - $99,999	21	5%
	$100K - $119,999	26	6%
	$120K+	63	14%
	Prefer not to share/Don't know	23	5%
Health insurance	Employer	155	36%
	Private	62	14%
	Medicare	62	14%
	Medicaid	85	20%
	Multiple types of insurance	43	10%
	Other	20	5%
Cancer diagnosis	Lung Cancer	164	38%
	Colorectal Cancer	155	35%
	Breast Cancer	117	27%
Stage at diagnosis	0 (microscopic)	7	2%
	I (Small and removed by surgery)	89	20%
	II (extension to lymph nodes)	87	20%
	III (locally advanced)	70	16%
	IV (metastatic/widespread)	151	35%
	Other / Not Applicable	4	1%
	Don't know	28	6%
Cancer status	Diagnosed, never experienced recurrence	137	31%
	Currently experiencing recurrence	139	32%
	In remission/no current evidence of disease	122	28%
	Other	17	4%
Year diagnosed	2018	80	18%
	2019	158	36%
	2020	125	29%
	2021	72	17%
Ever metastatic	No	280	64%

(*continued on next page*)

Table 1 (*continued*)

	Category/Range	*M*/*n*	*SD*/ %[†]
	Yes	150	34%
Family history of cancer	Yes	259	59%
	No	152	35%
	I don't know	25	6%
Treatment status	I have never received treatment for my cancer	30	7%
	I am currently receiving treatment for my cancer	266	61%
	I am not currently receiving treatment for my cancer but have in the past	136	31%
	Other	3	1%
Treatment history	Chemotherapy	284	65%
	Radiation therapy	201	46%
	Surgery	190	44%
	Targeted therapy	166	38%
	Immunotherapy	139	32%
	Hormone therapy	49	11%
	Supportive or palliative therapy	35	8%
	Steroids	32	7%
	Other[††]	26	5%
Treatment setting	Community Hospital or Community Cancer Center	205	47%
	Academic or Comprehensive Cancer Center	89	20%
	Private Oncology Practice	64	15%
	Multiple sites	34	8%
	None	30	7%
	Other	10	2%
	Prefer not to share/missing	4	1%

†Percentages might not add up to 100% due to rounding or missing data. [††] Other treatments include CAR-T, topical treatment, and bone marrow/stem cell transplant, among others.

3.3. Inferential analyses

3.3.1. Biomarker testing familiarity

3.3.1.1. Bivariate Relationships. Biomarker testing familiarity did not significantly differ by race, gender, or cancer diagnosis; however, greater familiarity with testing was significantly related to younger age, higher income, having a family history of cancer, and ever being metastatic (see Table 3). Greater biomarker testing familiarity was also associated with higher cancer health literacy, more education, and having history of employment in a health care field. When considering health care setting and experiences, biomarker testing familiarity was significantly higher among those who received treatment at an academic/comprehensive care center, compared to those receiving treatment at a community care center or those who reported never receiving treatment, as well as among those who reported having greater shared decision making and who had conversations with their oncologists about biomarker testing.

3.3.1.2. Regression models. A logistic regression was performed to ascertain the combined effect of significant bivariate variables on self-perceived level of familiarity with biomarker testing. The Hosmer and Lemeshow goodness of fit test was not significant $\chi^2(8) = 13.259$, $p = .103$), as desired, and the logistic regression model was statistically significant, $\chi^2(21) = 183.106$, $p < .001$. The model explained 45.8% (Nagelkerke R^2) of the variance in biomarker familiarity and correctly classified 72.7% of cases. Sensitivity was 74.4%, specificity was 70.8%, positive predictive value was 73.5% and negative predictive value was 71.8%. The area under the ROC curve was .845 (95% CI, .810 to .880), which is an excellent level of discrimination [33].

Of the 11 predictor variables, 6 were statistically significant even after accounting for the influence of other variables in the model (see Table 3). Age, CHLT score, and SDMP-4 were significant continuous

Table 2
Biomarker testing history, education, and communication ($N = 436$).

	M/*n*	*SD*/%
Received biomarker testing		
Yes	373	86%
No	38	9%
Unsure	25	6%
Do you know which biomarkers/mutations you were tested for (e.g., BRCA1/2, HER2, EGFR, etc.)? (N = 373)		
Yes	180	49%
No	189	51%
When did you FIRST learn about biomarker testing?		
Before I was diagnosed with cancer	65	15%
After I was diagnosed with cancer	312	72%
I never learned about it	47	11%
Why/how did you FIRST learn about biomarker testing before your cancer diagnosis?		
I learned about it from my health care team (e.g., primary care physician, nurse, etc.).	12	18%
I learned about it because someone I knew had cancer.	26	40%
I learned about it as part of my job / career.	23	35%
I randomly came across the information on the internet, TV, etc.	3	5%
Other	1	2%
Why/how did you FIRST learn about biomarker testing after your diagnosis?		
My cancer care team (e.g., oncologist, nurse, etc.)	220	71%
Another doctor or medical specialist	43	14%
My family and/or friends	17	5%
My own research or reading	20	6%
A support group or peer-mentor	8	3%
Other	2	1%
I don't know / don't remember	2	1%
Who have you had conversations with specifically about biomarker testing?[†]		
Medical oncologist	260	60%
Primary care physician	172	39%
Surgical oncologist	123	28%
Cancer support group	119	27%
Family members	114	26%
Friends	100	23%
Radiation oncologist	73	17%
Spouse/partner	66	15%
Clinical nurse	64	15%
Nurse practitioner	64	15%
Cancer peer-mentor	57	13%
Genetic counselor	47	11%
Oncology social worker	29	7%
Pathologist	15	3%
No one	30	7%
What is the easiest way for patients to learn important information about their cancer, like biomarkers?		
Conversations with members of my health care team	190	44%
Websites	106	24%
Support groups	76	17%
Pamphlets	26	6%
Videos	26	6%
I don't know / Don't have an opinion	11	3%
Biomarker testing familiarity	*M* = 2.8	*SD* = 1.1
Not at all familiar	52	12%
Slightly familiar	157	36%
Somewhat familiar	109	25%
Very familiar	85	20%
Extremely familiar	33	8%
Biomarker testing informational needs: I wish I had learned more about biomarker testing.	*M* = 4.0	*SD* = .9
Strongly disagree	5	1%
Disagree	18	4%
Neutral	79	18%
Agree	181	42%
Strongly agree	125	29%
Not applicable / I don't know	27	6%
Shared Decision Making Process (SDMP-4) Range: 0–4	*M* = 2.8	*SD* = 1.4

†All options/categories presented here for descriptive purposes. Various types of oncologists (medical, surgical, radiation) are combined for regression such that 75% talked with an oncologist about biomarker testing and 25% did not.

Table 3
Bivariate and multivariate relationships between key predictors and biomarker testing familiarity and informational needs.

	Biomarker Testing Familiarity				Biomarker Testing Informational Needs			
	Bivariate analysis		Multivariate analysis		Bivariate analysis		Multivariate analysis	
Variables	Correlations (*r*) / Mean Comparisons (*t/F, M, SD*)	Sig	Coefficient (95% CI)	Sig	Correlations (*r*) / Mean Comparisons (*t/F, M, SD*)	Sig	Coefficient (95% CI)	Sig
Age (in years)	$r = -0.19$	**< .001**	**0.964 (0.944–0.984)**	**< .001**	$r = -0.07$	NS	**–**	**–**
Gender	$t = -1.611$	NS	–	–	$t = 2.605$	**< .01**		
Man/Trans man	2.6(1.0)				4.2(0.7)		Reference	
Woman/Trans woman	2.8(1.2)				3.9(1.0)		**0.544 (0.303-.977)**	**< .05**
Income	$t = -6.130$	**< .001**			$t = 2.527$	**< .01**		
< $40K	2.3(1.0)		Reference		4.2(0.7)		Reference	
$40K+	3.0(1.1)		**4.319 (2.392–7.799)**	**< .001**	3.9(0.9)		0.763 (0.420–1.386)	NS
Family history	$t = -2.916$	**< .01**			$t = 1.838$††	**< .05**		
No	2.5(1.0)		Reference		4.1(0.7)		Reference	
Yes	2.9(1.2)		1.477 (0.842–2.588)	NS	3.9(1.0)		1.000 (0.563–1.776)	NS
Ever metastatic	$t = -4.959$	**< .001**			$t = 2.314$††	**< .05**		
No	2.6(1.0)		Reference		4.1(0.8)		Reference	
Yes	3.1(1.2)		1.416 (0.809–2.476)	NS	3.8(1.0)		0.914 (0.522–1.601)	NS
Bachelor's degree	$t = -5.222$	**< .001**			$t = -.280$	NS	–	–
No	2.4(1.1)		Reference		4.0(0.9)			
Yes	3.0(1.1)		1.025 (0.607–1.729)	NS	4.0(0.8)			
CHLT score (range 0–6)	$r = 0.20$	**< .001**	**1.498 (1.157–1.938)**	**< .01**	$r = -.19$	**< .001**	**.613 (.463-.812)**	**< .001**
Health employment	$t = -5.283$	**< .001**			$t = 1.160$	NS	–	–
No	2.6(1.1)		Reference		4.0			
Yes	3.4(1.2)		**7.538 (3.254–17.461)**	**< .001**	3.9			
Had biomarker testing	$F = 8.421$	**< .001**			$F = 2.391$	NS	–	–
No	2.4(1.1)		Reference		4.0(0.9)			
Yes	2.8(1.1)		0.436 (0.168–1.129)	NS	4.1(0.7)			
Unsure	2.0(1.0)		1.882 (0.568–6.237)	NS	4.4(0.7)			
SDMP-4 (range 0–4)	$r = 0.21$	**< .001**	**1.391 (1.103–1.755)**	**< .01**	$r = 0.04$	NS	**–**	**–**
Treatment center	$F = 6.414$	**< .001**			$F = 5.098$	**< .001**		
Community	2.5(1.0)[a]		Reference		4.1(0.8)		Reference	
Academic/ Comprehensive	3.2(1.3)		1.959 (0.964–3.982)	NS	3.6(1.1)		**.500 (0.261–0.960)**	**< .05**
Private	2.8(1.1)		0.743 (0.341–1.615)	NS	4.1(0.8)		.817 (0.373 – 1.791)	NS
Other/Multiple	3.1(1.3)		1.714 (0.728–4.034)	NS	4.0(1.1)		.977 (0.419 – 2.278)	NS
None	2.3(1.0)[a]		0.948 (0.322–2.789)	NS	4.3(0.6)		1.176 (0.307–4.501)	NS
Talk with oncologist†	$t = -5.955$	**< .001**			$t = 3.876$	**< .001**		
No	2.2(1.0)		Reference		4.3(0.7)		Reference	
Yes	2.9(1.1)		**4.709 (2.288–9.689)**	**< .001**	3.9(0.9)		**0.378 (0.180–0.795)**	**< .01**

†Includes all types of oncologists combined (medical, surgical, radiation)
†† Equal variance not assumed
[a] Post Hoc Bonferroni analysis indicate significantly different from Academic/Comprehensive
NS = Not statistically significant; CHLT = Cancer Health Literacy (CHLT-6); SDMP-4 = Shared Decision-Making Process Survey
Note. Participants with missing data were coded into categorical variables as a separate category in order to retain them for the full model but their values are not reported or interpreted. Multivariate coefficients represent values from the final step of the model. Statistically significant values shown in **bold**.

predictors, such that younger age, higher cancer health literacy (CHLT), and higher shared decision making (SDMP-4) were associated with an increased likelihood of being familiar with biomarker testing. For the categorical variables, having higher income, having prior employment in healthcare field, and talking with their oncologist were all associated with increased odds of being familiar with biomarker testing. Those making $40K+ a year were 4.3 times more likely to be familiar with biomarker testing than those making less than $40K, those who had

prior employment in the health care field were 7.5 times more likely to be familiar with biomarker testing than those who did not, and those who indicated they had prior conversations with their oncologist(s) about biomarker testing were 4.7 times more likely to be familiar with biomarker testing than those who did not have those conversations.

3.3.2. Biomarker testing informational needs

3.3.2.1. Bivariate Relationships. Level of biomarker testing informational needs was not significantly different by age, race, cancer diagnosis, education, or previous employment in health care field, but greater informational needs were significantly related to gender (identifying as a man), lower income, ever being metastatic, and lower cancer health literacy (see Table 3). Biomarker testing informational needs were not significantly related to SDM score, but needs were significantly higher among those who had not received biomarker testing or were unsure if they received testing as well as those who did not have conversations with their oncologist about biomarker testing. Informational needs were lower for those who received treatment at an academic/comprehensive care center, compared to those receiving treatment at a community care center, private care center, or those who reported never receiving treatment.

3.3.2.2. Regression models. A logistic regression was performed to ascertain the combined effect of significant bivariate variables on self-perceived level of familiarity with biomarker testing. The Hosmer and Lemeshow goodness of fit test was not significant $\chi^2(8) = 7.873$, $p = .446$) and the logistic regression model was statistically significant, $\chi^2(15) = 65.327$, $p < .001$. The model explained 21.9% (Nagelkerke R^2) of the variance in biomarker informational needs and correctly classified 77.2% of cases. Sensitivity was 95.4%, specificity was 22.5%, positive predictive value was 78.7% and negative predictive value was 62.2%. The area under the ROC curve was .748 (95% CI, .696 to .799), which is an acceptable level of discrimination [33].

Four of the seven predictor variables were statistically significant, even after accounting for the influence of other variables in the model (see Table 3). CHLT score was a significant continuous predictor, such that lower cancer health literacy was associated with an increased likelihood of having higher informational needs. For categorical variables, identifying as a man and not talking with oncologists about biomarker testing were associated with increased odds of having higher informational needs, while those receiving care at an academic/comprehensive center were half as likely to have informational needs when compared to those receiving care at a community cancer center.

4. Discussion and conclusion

4.1. Discussion

Most participants reported having biomarker testing as part of the cancer care experience, but also report outstanding informational needs. This substantiates the fact that biomarker testing is quickly becoming the standard of care for those cancers with documented actionable mutations [4–14] and that patients may have poor recall of the specifics of the testing [22]. Conversations about biomarker testing typically took place with oncologists, which aligns with prior research [17,18] as well as what patients' report in the current study as being their preferred method for receiving cancer-related information.

Many participants had adequate cancer health literacy and reported high levels of shared decision making with their HCPs regarding biomarker testing, yet only half of participants reported being as least "somewhat" familiar with biomarker testing terms, and most participants also wished they had learned more about biomarker testing. Regression analyses suggest that multiple variables play a unique, significant role in the self-perceived familiarity of biomarker testing for those diagnosed with cancer, including sociodemographic variables such as age and income, knowledge variables such as cancer health literacy and prior experience working the health care field, and health care experiences such as talking with an oncologist about biomarker testing and shared decision making.

Specified predictor variables resulted in good case classification of those who report low familiarity with biomarker testing and outstanding informational needs, with positive predictive values of 73.5% and 78.7%, respectively, and excellent to acceptable case discrimination [33], with ROC values of .845 and .748, respectively. Interestingly, the only shared predictors between the two models are cancer health literacy and talking with oncologists about biomarker testing, underscoring the importance of these factors in patients' biomarker testing experiences.

4.1.1. Limitations and future directions

This study has limitations that warrant discussion. First, there are limitations regarding diversity and generalizability of findings. This sample only included patients living with a lung, colorectal, or breast cancer diagnosis and they reported a high occurrence of biomarker testing. While these cancer types were specifically selected due to the prevalence of actionable mutations and genomically-matched treatment options, the current findings may not be generalizable to the broader cancer population. Future work should examine if these findings hold true for other cancer diagnoses, including additional solid tumor types as well as hematological malignancies. Relatedly, while strategies were implemented in an effort to recruit a fairly representative U.S. sample, diversity could be improved in future work. With 90% of the current sample identifying as non-Hispanic and 57% having a Bachelor's degree or higher, these findings may not translate well for those who have less education or identify as Hispanic, Latino, or Spanish. This is especially important to explore given the relationship between these sociodemographic traits and other variables in this study, including health literacy [34,35]. Additionally, for smaller U.S. strata, future work could benefit from oversampling to make sure group representation is robust enough to provide appropriate statistical power, support generalizability of findings, and ensure representation of all patients' experiences.

Second, there are several considerations regarding study variables and analytic approach. While the patients' experiences with biomarker testing, including the primary outcome variables (self-reported familiarity with biomarker testing and informational needs), suitably characterize the subjective patient experience, these experiences were not cross-validated with other sources (e.g., electronic medical reports or data from HCPs). Future work might examine the level of alignment among self-report biomarker testing experiences and medical records. Moreover, the primary outcome variables were created specifically for this study. While they were created based on interviews with patients and vetted by an expert project advisory committee, the psychometric properties of these variables, such as reliability and validity, cannot be confirmed without additional research. These outcome variables have a 5-point ordinal scale structure but were dichotomized in the current study to allow for the use of logistic regression, in hopes of incorporating classification prediction statistics (e.g., sensitivity and specificity) and identifying those in greatest need of support, which has important clinical and practical utility. We recognize that dichotomizing the variables could have resulted in loss of information and other modeling techniques might lead to different results.

Lastly, while it is important to understand the patient experience with biomarker testing, including their perceived level of familiarity and informational needs, this may not represent the primary end point. Promoting patient understanding and involvement serves a profound purpose, as demonstrated by the documented relationships between patient activation and health-related quality of life (HRQoL) [28,29]. To this end, patients' understanding and involvement in their cancer care experience may serve as a driver for HRQoL but these measures were not included in the current study.

5. Conclusion

Navigating a cancer diagnosis comes with many challenges, one of which is patients' ability to understand the complexities of cancer information in a way that serves to enhance their patient experience. This study indicates that patients' familiarity of biomarker testing is not as robust as it could be, despite the prevalence of biomarker testing in the sample as well as patients' reported desire to learn more about biomarker testing. Low self-reported familiarity with biomarker testing and outstanding informational needs indicates that patients may not possess the foundational knowledge necessary to have a true understanding of biomarker testing or how it relates to their cancer care. While several factors influence patients' access to biomarker testing, familiarity, and informational needs, the current study highlights the importance of cancer health literacy and patient-provider communication. As biomarker testing becomes more ubiquitous in cancer care, these elements of the health care experience create opportunities for continued exploration and potential intervention.

5.1. Practice implications

Collectively, these findings give us insight into patients' experiences with biomarker testing in cancer care: Familiarity with biomarker testing cannot be assumed, and outstanding informational needs may still exist, despite having undergone biomarker testing. A number of interventions at the provider and system level are being considered and have been tested to increase the percentage of patients receiving guideline-concordant biomarker testing [36,37]. However, more of these interventions need to include tools to improve provider communication and shared decision making with patients so that they understand that biomarker test results are likely to identify their most effective treatments, and the current results indicate this is especially important to improve in certain treatment settings where we found greater informational needs (i.e., those other than academic or comprehensive care centers). For example, as community practices implement practice-wide workflows that automatically trigger biomarker testing for appropriate patients, discussion tools need to be built into their electronic health records that can prompt the provider to initiate conversations with patients.

In this same vein, it is important that the patient-facing biomarker testing result reports are understandable to patients so that they feel empowered to advocate for the targeted therapies that are most likely to provide them with the greatest clinical benefit. Existing literature posits that health literacy interventions can improve knowledge and patient-provider communication [38], thus indicating there is clear opportunity for us to build on these learnings and apply them to the biomarker testing space. However, prior to employing interventions such as these, HCPs need first be aware of when patients have low health literacy, as past research indicates this is not always obvious [27]. A brief assessment of patients' overall health literacy could help HCPs by (1) creating an opportunity to "meet patients where they are" and (2) streamlining patient-provider communications, which could ultimately help to support their familiarity and informational needs with respect to biomarker testing.

Finally, patient characteristics should also be considered when HCPs are assessing patients' familiarity and informational needs. The current work suggests those patients who are younger or are of lower income might have less familiarity with biomarker testing. This lack of familiarity could result in less patient-initiated conversations. Additionally, the gender differences found here imply that men have greater informational needs than women. While the current work cannot speak to the drivers of this relationship, prior research shows that men tend to rely more on HCPs for health information [39] and have more conversations with their HCPs regarding health information they have found online [40]. Asking patients about their self-directed learnings related to biomarker testing, including information they have found online, might serve as a good catalyst for patient-provider communications about informational needs. Lastly, while education and cancer type were not significant predictors in the current study, patient-facing resources should be written at a suitable reading level and tailored by cancer type to appropriately capture the unique genomic mutations and biomarker testing procedures relevant to each diagnosis, thus furthering patients' ability to be involved in their cancer care.

CRediT authorship contribution statement

Fortune: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project Administration, Resources, Software, Supervision, Writing – original draft, Writing – review & editing, **Zaleta**: Conceptualization, Funding Acquisition, Supervision, Writing – original draft, **Saxton**: Conceptualization, Resources, Writing – original draft.

Declaration of Competing Interest

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Data Availability

Cancer Support Community retains full control of all primary data.

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