Patients’ Expectations of Benefits From Large-Panel Genomic Tumor Testing in Rural Community Oncology Practices

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PURPOSE Large-panel genomic tumor testing (GTT) is an emerging technology that promises to make cancer treatment more precise. Because GTT is novel and complex, patients may have unrealistic expectations and limited knowledge of its benefits. These problems may limit the clinical value of GTT, but their prevalence and associated factors have not been explored.

METHODS Patients with cancer enrolled in a large initiative to disseminate GTT in community oncology practices completed surveys assessing their expectations, knowledge, and attitudes about GTT. The study sample (N = 1, 139) consisted of patients with a range of cancer types (22% gynecologic, 14% lung, 10% colon, 10% breast, and 46% other malignancies) and cancer stages (4% stage I, 3% stage II, 15% stage III, and 74% stage IV). Mean age was 64 years (standard deviation = 11); 668 (59%) were women; 71% had no college degree; 57% came from households with less than $50,000 US dollars household income; and 73% lived in a rural area.

RESULTS Generally, patients had high expectations that they would benefit from GTT (M = 2.81 on 0-4 scale) and positive attitudes toward it (M = 2.98 on 0-4 scale). Patients also had relatively poor knowledge about GTT (48% correct answers on an objective test of GTT knowledge). Greater expectations for GTT were associated with lower knowledge (b = −0.46; P < .001), more positive attitudes (b = 0.40; P < .001), and lower education (b = −0.53; P < .001).

CONCLUSION This research suggests patients have high expectations that they will benefit from GTT, which is associated with low knowledge, positive attitudes, and low education. More research is needed to understand the concordance between expectations and actual clinical outcomes.

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INTRODUCTION

Genomic tumor testing (GTT) using next-generation genomic sequencing technology promises to improve cancer treatment, and has already led to targeted, precision treatments for some cancers, including specific tyrosine kinase inhibitors for epidermal growth factor receptor–mutant lung cancer and BRAF V600E–mutant melanoma.1,2 Large-panel genomic tumor tests (GTT) can test for variants in hundreds of genes at once and have been increasingly used in clinical practice. However, for many of the variants identified by large-panel GTT, no current US Food and Drug Administration (FDA)-approved treatments exist; it is thus unknown whether individual patients benefit from it. An estimated 1%-26% of patients who receive GTT go on to receive targeted, genomically guided treatment depending on the population.3 Furthermore, the benefits of such treatment for many patients with cancer are uncertain.4 However, this uncertainty is not often acknowledged by the news media, which tends to exaggerate the value of precision medicine initiatives.5 As a result, patients with cancer are at risk of unrealistically high expectations of the benefits of GTT.6,7

Such expectations can have undesirable effects when they are not realized. For example, Zikmund-Fisher8 described a patient where an actionable mutation was identified that could qualify her for a clinical trial. However, the patient was disqualified because of other circumstances. For this patient, the good news of finding an actionable mutation quickly turned into heartbreak when she was unable to receive the experimental treatment. This example illustrates how patients’ incomplete understanding of strict eligibility criteria for clinical trials, combined with unrealistic expectations for targeted treatment, might lead to negative patient experiences with genomic testing. The majority of patients in another study expected to receive several direct benefits from GTT, despite being informed they might not; these expected benefits included receiving written reports of sequencing findings, understanding the causes of their cancer, and
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Key Objective
Next-generation large-panel genomic tumor testing (GTT) promises to make cancer treatment more precise. However, because this technology is novel and complex, many patients may have unrealistic expectations and limited knowledge of its benefits, which distort value-aligned decision making. This study explored the expectations and knowledge for 1,139 community oncology patients receiving GTT as part of their care.

Knowledge Generated
Patients had high expectations of benefit and relatively poor knowledge of GTT. Regression models found that greater expectations for GTT were associated with lower knowledge about the testing technology and lower educational attainment.

Relevance
High expectations of benefit and low knowledge of GTT are common, particularly among patients with cancer with lower education levels. Future efforts to disseminate and implement GTT should focus on educating patients about both its benefits and limitations.

being eligible for clinical trials. In most cases, however, patients did not realize these benefits by study completion. Unrealistic expectations of benefit may be reinforced by media portrayals that genomics will revolutionize care. Much remains unknown about the extent of such expectations and the factors that contribute to them.

Patients’ knowledge and attitudes regarding GTT are potentially important factors influencing their expectations of benefit. Patients have been found to have poor knowledge of genomics in general and GTT in particular, although the evidence is mixed. Furthermore, patients may have positive attitudes toward GTT regardless of their knowledge of it and may perceive that there are no downsides to GTT. These attitudes partly reflect patients’ beliefs that GTT will lead to effective genomically guided treatment and improved survival, which is the main reason patients report pursuing GTT. However, positive attitudes also reflect other beliefs that GTT (1) empowers patients to manage their own health; (2) contributes to science; (3) legitimates their suffering; and (4) provides a feeling of closure or of having done everything one could.

Sociodemographic characteristics may also influence expectations, and patients’ education level may be particularly influential. Patients with higher levels of education are less likely to pursue GTT for personal benefit, presumably because they had lower expectations they would benefit. Educational achievement is correlated with basic health literacy and critical thinking skills that may be needed to have appropriate expectations of interventions such as GTT. Other sociodemographic factors, including income and rurality, may also influence expectations through their effects on access to health care and health information. Clinical characteristics, including cancer type and stage, might also influence expectations through their effects on patients’ actual and perceived prognosis.

For all of these reasons, it is important to understand the extent and nature of cancer patients’ expectations of GTT, and the factors that influence these expectations. Although useful in identifying this problem, prior research studies have been limited in number and scope, and have been conducted primarily in relatively urban, affluent populations with high levels of education. To address these gaps, we conducted a study of patients receiving care in community oncology practices serving predominantly rural communities. This study leveraged the Maine Cancer Genomics Initiative (MCGI), a multiyear, longitudinal, statewide initiative aimed at disseminating GTT.

The goal of this study was to describe the nature and extent of patients’ expectations regarding GTT, and to explore factors associated with expectations. We tested two specific hypotheses: (H1) Greater knowledge of GTT will be associated with lower expectations of benefit; (H2) positive attitudes about the value of GTT would be associated with higher expectations of benefit. We also explored how other sociodemographic and clinical factors, including education level, age, sex, cancer type, and cancer stage, were associated with expectations, to generate hypotheses for future research.

METHODS

Study Population and Design
Survey data were collected through the MCGI. The study sample consisted of patients of participating Maine oncologists, including neuro-oncologists and gynecologic oncologists. Clinicians were recruited to MCGI by the research team via site visits, telephone, and personal contact. Oncology clinicians, once enrolled, were able to offer free large-panel GTT to their patients through the MCGI. Clinicians offered GTT to their patients as part of their options for care in an unscripted manner and were provided a brochure describing the nature, benefits, and limitations of GTT (see Data Supplement, online only). Patients who agreed to GTT were then offered the possibility of participating in the MCGI study, which offered GTT free of charge.
to the patient. The MCGI study consisted of completing periodic surveys and sharing abstracted data from medical records. Interested patients provided informed consent for participation. The MCGI study protocol was reviewed and approved by the Western IRB.

The MCGI used three solid tissue genomic tumor tests: ActionSeq Plus, ActionSeq 2.0 Plus (both by The Jackson Laboratory), and TruSight Tumor 170 (Navican TheraMap). These tests report variants in 156-501 cancer-related genes, and later tests reported tumor mutation burden and microsatellite instability. GTT reports to clinicians identified gene variants, associated therapies, and potential clinical trial options.

Before testing, patients completed surveys either online through the REDCap Cloud data platform, or by paper with responses entered by research coordinators. The cohort for the current study included participants who had consented, registered, and enrolled in MCGI between July 2017 and October 2020, and completed the survey instruments described below within 14 days of consent.

Measures

The survey contained measures of multiple constructs summarized below. The complete measures and response options are in Data Supplement.

Expectations of Benefit From GTT

Expectations of benefit from GTT were assessed using seven questions (Cronbach’s $\alpha = .92$), adapted from prior research, which asked participants about the likelihood they would benefit directly from GTT (Fig 1). Responses used a five-point Likert scale, from 0 = extremely unlikely to 4 = extremely likely. A summary score was calculated by averaging answers, and ranged from 0.00 to 4.00, with higher scores indicating greater expectations of benefit.

Knowledge About GTT

Knowledge about GTT was assessed by four statements about GTT, adapted from prior research, to which the participants answered True, False, or Unsure. The statements were (1) GTT can identify DNA mutations of uncertain meaning or significance for my treatment (correct answer = true); (2) if there is a DNA mutation that can cause my tumor to grow, GTT will always detect it (false); (3) if there is a DNA mutation that can cause my tumor to grow, the problem can always be treated (false); and (4) even if someone has a DNA mutation in their tumor, the tumor may not always grow or cause problems (true). The proportion of each patient’s correct responses was computed, with unsure responses counting as incorrect. Summary scores ranged from 0% to 100%, with higher scores indicating greater knowledge of GTT.

Attitudes About the Value of GTT

Attitudes regarding the general value of GTT were assessed by using nine questions (Cronbach’s $\alpha = .74$), adapted from prior research and used in a previous study, which asked patients to rate their agreement with four positively and five negatively valenced attitudes. The questions began with, GTT seems, which was then paired with different adjectives (beneficial, harmful*, uncertain*, accurate, trustworthy, unproven*, complicated*, inefficient*, and worthwhile). Ratings used a five-point Likert response scale from 0 = strongly disagree to 4 = strongly agree. Negative items (identified above with an *) were reverse-coded so that higher values corresponded to more positive attitudes. A summary score was calculated by averaging answers, and ranged from 1.33 to 4.00.

Sociodemographic and Clinical Variables

Education, age, sex, and other sociodemographic variables were assessed by self-report. Education level was assessed using five response categories: Less than high school, high school graduate or GED, some college or trade school, bachelor’s degree, and graduate degree (Masters or PhD, etc). For this analysis, the bachelor’s degree and graduate degree levels were collapsed because of small numbers in each category. Household income was assessed by participants’ self-reported household income categories. The rurality of each participant’s primary residence was determined via the USDA’s Rural-Urban Commuting Area codes, which uses measures of population density, urbanization, and daily commuting to map ZIP codes to urban or rural categories. Because of small numbers of participants in some categories, we collapsed into three categories: 1 = metro, 2-6 = large rural, and 7-10 small isolated rural. Cancer locations were grouped by the following categories: lung, breast, colon, prostate, gynecologic, brain, and all other.

Data Analysis

Descriptive statistics were calculated for the expectations, knowledge, attitudes, and demographic variables (Table 1). To test the two study hypotheses, we conducted linear regression analyses with the summary score of expectations of benefit as the dependent variable. Primary independent variables were participant knowledge and attitudes. We fit both unadjusted models and models adjusting for age, sex, stage, and type of cancer. We also conducted exploratory regression analyses of sociodemographic and clinical factors associated with expectations of benefit. Education and income were treated as ordinal variables. All analysis used R version 3.5.1.

RESULTS

Of the 1,605 participants who had consented, registered, and enrolled in the MCGI study, 1,139 (71%) completed the survey items used in this analysis (descriptive statistics are presented in Table 1). The sample contained slightly more female participants (59%) and had an average age of 64.3 years (range 22-97 years). A majority of patients had not completed a college degree (71%), came from households...
with less than $50,000 US dollars annual household income (57%), and lived in a rural setting (73%). Sixty-seven physicians (affiliated with 16 practices) enrolled at least one patient in the study (mean number of patients enrolled = 24.0, standard deviation [SD] = 26.8).

Overall, participants had relatively high expectations of benefit from GTT (Fig 1; M = 2.81, SD = 0.83 on a 0-4 scale). The most frequently endorsed expectation was that GTT would help doctors choose the best treatment; 49% of patients reported this outcome was extremely likely. The least-endorsed expectation was that GTT would improve patients’ quality of life; 24% endorsed this outcome as extremely likely.

Participants also had generally positive attitudes about the value of GTT (Fig 2; M = 2.98, SD = 0.54 on a 0-4 point scale). They endorsed high levels of agreement that GTT is worthwhile, beneficial, and trustworthy, and high disagreement that GTT is harmful, inefficient, and uncertain. Participants’ objective knowledge about GTT was low: they answered about half of the questions correctly (M = 48%, SD = 31 percentage points). The question with the lowest correct response rate (30% correct) was If there is a DNA mutation that can cause my tumor to grow, GTT will always detect it (the correct answer is false).

Association Between Knowledge and Expectations for GTT

We tested the hypothesis that patients with lower levels of knowledge about GTT would have higher expectations of benefit from GTT (H1). Consistent with our hypothesis, we found a significant negative relationship between knowledge and expectations (b = −0.46; 95% CI, −0.62 to −0.30; P < .001) controlling for age, sex, and stage and type of cancer (Fig 3). The same pattern of effects was found when not controlling for those factors.

Association Between Attitudes and Expectations for GTT

Consistent with our hypothesis that more positive attitudes toward GTT would be associated with greater expectations of benefit (H2), we found a significant positive association when controlling for age, sex, and stage and type of cancer (b = 0.40; 95% CI, 0.31 to 0.50; P < .001; Fig 4). A similar pattern was found in analyses that did not control for age, sex, stage, and type of cancer.

Exploratory Analysis of Factors Associated With Expectations for GTT

Exploratory bivariate regression analysis showed that expectations were significantly associated with education, age, and household income. In particular, lower educational attainment was associated with higher expectations (b = −0.528; 95% CI, −0.740 to −0.317; P < .001). Older participants had higher expectations of GTT benefit (b = 0.01; 95% CI, 0.00 to 0.01; P = .01). Lower household incomes were associated with higher expectations (b = −0.51; 95% CI, −0.70 to −0.32; P < .001). There was a trend that participants living in urban areas had higher expectations that GTT would benefit them, compared with participants living in large rural (b = −0.12; 95% CI, −0.25 to 0.01; P = .07) but not small rural areas (b = −0.05; 95% CI, −0.18 to 0.08; P = .43). Interestingly, there was no association between expectations and the clinical variables of either cancer stage (b = 0.09; 95% CI, −0.27 to 0.45; P = .63) or cancer type (b = −0.12; 95% CI, −0.29 to 0.05; P = .15).
Fitting a multivariable model including all of the independent variables such as knowledge, attitudes, education, age, sex, income, rurality, stage of cancer, and type of cancer as predictors revealed results consistent with the analyses described above (no change in significant associations; Data Supplement). When including the patient’s clinician as a random effect in this final model, the results were similar, indicating that patient expectations did not vary depending on their clinician (see Data Supplement).

**DISCUSSION**

This study examined cancer patients’ expectations of personally benefiting from large-panel GTT, and how those expectations relate to various factors including knowledge and attitudes about GTT. To our knowledge, this is the first study to examine these factors in rural community oncology practice settings, and we believe the findings have important implications for implementation of GTT in clinical practice.

First, patients had relatively high expectations that GTT would directly benefit them. Many patients reported believing it was likely that GTT would lead to access to experimental treatment, help control their cancer, increase the length of their life, and improve their quality of life. Patients also had positive attitudes about the general value of GTT, consistent with previous qualitative work. This finding is also consistent with our research with clinicians using the same scale. We also found patients’ knowledge about GTT to be low, with patients answering only about half of questions correctly, also consistent with other research. Interestingly, Roberts et al found much higher patient knowledge, which could be because of differences in study populations (this study was enriched with low-

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**TABLE 1.** Demographics

| Characteristic          | N = 1,139 |
|-------------------------|-----------|
| Age, years              | 64 (11)   |
| Missing                 | 8         |
| Sex                     |           |
| Male, No. (%)           | 462 (41)  |
| Female, No. (%)         | 668 (59)  |
| Missing                 | 9         |
| Ethnicity               |           |
| Hispanic, No. (%)       | 15 (1.3)  |
| Non-Hispanic, No. (%)   | 1,101 (99) |
| Missing                 | 23        |
| Race, No. (%)           |           |
| White                   | 1,087 (95)|
| African or African American | 4 (0.4) |
| Asian                   | 4 (0.4)   |
| American Indian or Alaskan Native | 6 (0.5) |
| Not given or other      | 24 (2.1)  |
| Multiple                | 14 (1.2)  |
| Education, No. (%)      |           |
| Less than high school   | 70 (6.4)  |
| High school graduate or GED | 344 (31) |
| Some college or trade School | 362 (33) |
| Bachelor’s or advanced degree | 323 (29) |
| Missing                 | 40        |
| Household income, USD, No. (%) |         |
| < $25,000               | 291 (27)  |
| $25,000 to $49,999      | 321 (30)  |
| $50,000 to $74,999      | 199 (18)  |
| $75,000 to $100,000     | 100 (9.3) |
| > $100,000              | 98 (9.1)  |
| Do not know             | 72 (6.7)  |
| Missing                 | 58        |
| Insurance, No. (%)      |           |
| Medicare and Medicaid   | 76 (6.7)  |
| Medicare                | 523 (46)  |
| Medicaid                | 53 (4.7)  |
| Private                 | 338 (30)  |
| Unknown                 | 149 (13)  |
| Rurality, No. (%)       |           |
| Metro                   | 288 (27)  |
| Large rural             | 395 (36)  |
| Small or isolated rural | 403 (37)  |
| Missing                 | 53        |
| Cancer stage, No. (%)   |           |
| I                       | 46 (4.0)  |
| II                      | 37 (3.3)  |

(Continued in next column)
education, low-income, rural-dwelling patients). Another difference was the items used to test knowledge. The items in this study focused on uncertainty related to GTT, whereas the items used by Roberts et al included questions about germline and risk beyond cancer.

Supporting our hypothesis, lower knowledge about GTT was associated with higher expectations of benefitting from GTT (H1). This suggests that educational interventions might be an effective means or promoting more realistic expectations. This relationship has not been tested before, to our knowledge, but is consistent with another study, which found that patients with higher education levels were less likely to pursue GTT for the direct benefits—presumably because they had lower expectations of directly benefiting.9 Here, we also found that higher education was associated with lower expectations. Also consistent with our hypothesis, more positive attitudes about the value of GTT were associated with higher expectations (H2).

In our exploratory analyses, older patients and lower-income patients also had higher expectations. Given that patients’ expectations were generally high, these observations suggest that older, lower-education, and lower-income individuals may face greater risk of unrealistically high expectations. Alternatively, younger, higher-education, higher-income participants may be more aware of the barriers to accessing cutting-edge, genomically informed cancer treatment. Patients’ age, education, and income may influence how clinicians communicate with them about GTT—a possibility that should be tested in future research. Additionally, there was a trend that patients living in urban areas had higher expectations of benefitting from GTT compared with patients living in large rural areas (but not small rural areas). This finding should be explored further, but one potential explanation is that participants living in rural areas are aware of the barriers they face in receiving genomically informed cancer care, which may include traveling for appointments or clinical trials.

We found no other consistent associations with clinical variables (ie, cancer stage or type). These null findings are interesting, given that GTT is often used differently depending on those clinical factors. For instance, for primary brain tumors, there are currently few FDA-approved indications based on mutational profile (although the evidence and clinical trial options are rapidly changing); therefore, patients’ expectations that GTT would change their treatment might be relatively low in this context. For non–small-cell lung cancer, however, a number of FDA-approved therapies are available based on mutational profile, making it reasonable for patients to have higher expectations of benefitting from GTT. Possible explanations include a lack of patient understanding or clinician
FIG 4. Relationship between patient attitudes and expectations. Each dot represents a participant’s response. The line is a linear model fitted for the participants. The error ribbon represents 95% CI of the linear model.

communication of tumor-related differences in the existence of genome-informed therapies.

This study had several limitations that qualify the findings and call for further research. First, the study was conducted as part of a broader implementation initiative that offered free GTT, which may have influenced expectations and attitudes about GTTs. To be included in the study, participants already decided with their clinician to receive large-panel GTT, so our sample is likely biased toward people with more positive attitudes and expectations about GTT. Additionally, because this is a relatively new field, many of the measures used in this study were newly developed and have not been formally validated (although our summary scales showed good reliability). Additionally, although the study sample was quite large, it was limited to a single state; however, the study did enroll nearly all oncology practices in the state and was thus regionally representative. There was little diversity in race and ethnicity, which limits the generalizability to other populations. In the present analysis, actual benefits from GTT were not measured. This will be done in a planned future study; however, because it was not currently possible to compare participants’ expectations with their actual outcomes, the current study could not determine whether patients’ expectations were realistic.

In conclusion, our study provides seminal evidence on community cancer patients’ expectations for GTT. In general, patients have high expectations—perhaps higher than what the previous studies have indicated. This raises the questions of what are appropriate expectations for patients undergoing GTT, and how might they be promoted. These will be increasingly important questions for clinicians, researchers, and health policymakers as this new technology becomes more commonplace.

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DISCLAIMER

The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

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AUTHORS’ DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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Open Payments is a public database containing information reported by companies about payments made to US-licensed physicians (Open Payments).
Expectations for GTT

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Patents, Royalties, Other Intellectual Property: Spouse has shared IP in several patents related to robotic gait assistance devices. (I)

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APPENDIX 1. ADDITIONAL MEMBERS OF THE MAINE CANCER GENOMICS INITIATIVE ARE AS FOLLOWS

Maine Cancer Genomics Initiative Steering Committee Members

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