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Discussing molecular testing in oncology care: Comparing patient and physician information preferences

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Abstract

Background—Molecular testing to inform treatment and clinical trial choices is now standard of care in several types of cancer. However, no established guidelines exist for the type of information physicians should cover during discussions with the patient about the test or its results. The objectives of this study were to identify physician and patient information preferences, as well as their preferences on who should communicate this information and how, to inform guidelines for these conversations.

Methods—Physicians and patients that participate in discussions regarding molecular testing were asked to choose 8 topics of most relevance out of a list of 18. McNemar's test was used to determine their top preferences. Patients were asked who/what should inform them and physicians were asked to identify the best aid to communication.

Results—Sixty-six patients identified 12 preferred topics: benefits of testing(88%); how testing determines treatment(88%); implications for family(71%), if test shows seriousness of disease(68%), purpose(64%), incidental findings(56%); explanation of cancer genetics(53%), how the test is done(46%), limitations(44%), explanation of biomarker(42%), risks(42%), and uninformative result(38%). Physicians added cost(59%). Patients preferred receiving information

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Ana Pinheiro: conceptualization/design of the study, conducted prospective interviews and qualitative analysis, drafted initial manuscript, and approved final manuscript.
Rachel H. Pocock: conducted interviews, qualitative analysis, and approved final manuscript.
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about molecular testing from their nurse or physician(85%) and physicians preferred using a pamphlet(67%) to augment communication.

Conclusion—The topics identified as important to discuss can inform future guidelines as well as contribute to effective communication regarding molecular testing.

Keywords

molecular testing; patient preference; communication; informed consent

Introduction

Tumor molecular testing has led to a re-evaluation of oncologic paradigms in which mutations that occur in key oncogenic pathways and alter a cell's growth lead to cancerous tumors[1,2]. The use of molecular testing to identify targetable alterations for treatment is currently used to direct therapy in a variety of cancers[3,4] and the search for other treatable targets is being pursued rigorously. The National Cancer Institute basket trial MATCH, for example, uses molecular testing to match patients' tumor mutations to targeted treatments[5].

Guidelines exist to help direct discussions on germline genetic testing[6] but with the exception of incidental findings(IF) directives, there are no established guidelines for informational and results-oriented discussions about tumor molecular testing[7-13]. For example, in the recently updated American Society of Clinical Oncology(ASCO) guidelines for genetic and genomic testing for cancer susceptibility[14], the discussion of somatic molecular testing focuses on the discovery of incidental hereditary findings. Guideline development committees usually consist of experts, physicians, stakeholders and patient advocates. The National Comprehensive Cancer Network(NCCN) and ASCO recommend panels include at least one patient and/or patient advocate [15-17]. However, multiple current patient opinions are not included.

We believe the addition of patient voices in the creation of communication guidelines is important because preferences can vary greatly among individuals and the inclusion of multiple voices better expresses real patient preferences. In clinical observations, discrepancies have been found between physician practice and patient preference for information. For example, while a majority of cancer patients report prognostic information as important and necessary[18-21], physicians frequently omit this information[18,22,23].

Existing patient and physician barriers to adequate communication exacerbate molecular testing communication gaps. For patients, inadequate health literacy and lack of understanding of complex genetic information make it difficult to fully understand molecular testing and results[24], and often lead to confusion between hereditary and somatic mutations[25,26]. Misunderstandings about somatic testing can also contribute to patient concerns[27]. Barriers also exist on the physician's side including a lack of clear understanding of tumor molecular testing[28,29] resulting in difficulty determining which test to send and how to interpret results[28,30,31], not providing the right amount and type of information for each patient [4,17], difficulty translating technical concepts into lay language[32-34], and difficulty assessing patient's understanding and information preferences[35-39]. Recognizing

patient preferences is particularly difficult because physicians expect patients to express their preferences[40], but patients often do not speak up and physicians do not readily recognize indirect expressions of concern[41].

The difficulty physicians have in knowing the amount and type of information to discuss[4,17] and the well-documented discordance between physician and patinet informational preferences in other areas[18-23,42-46], combined with a lack of research on molecular testing communication, make it vital to include patients' voices in guideline development. Therefore, we conducted a study to identify patients' and physicians' top preferences for molecular testing information, and who and how this information is communicated, to inform future guidelines for tumor molecular testing discussions.

Methods

Physicians who discuss molecular testing or results at Winship Cancer Institute at Emory University Clifton Campus, St. Josephs' and John's Creek Hospitals were consented and then completed a short questionnaire. They were asked to contact the ethics team when a molecular testing conversation would occur. Upon this notification, the ethics team member offered the study to the patient who would be involved in the conversation. With consent, the conversation was observed and audio recorded. The patient completed a short questionnaire, either in person immediately after the conversation or by phone within one week.

Questionnaire Development

The patient questionnaire included a pick-list of 18 topics from which patients were instructed to choose the 8 topics they most wanted to be discussed. We, along with others, have successfully used this format in prior studies assessing informational preferences[35,47,48,49]. Sixteen of the topics were adapted from the physician competencies for somatic testing outlined by the Inter-Society Coordinating Committee for Physician Education in Genomics[50]. These were reviewed by 3 physicians and three topics (how the testing is done, who will do it and what a biomarker is) were added. This draft was cognitively tested with 15 patients to determine if the pick-list format was acceptable and if the simplified rephrasings of the competencies were clear. Minor editing was done and one topic was eliminated as duplicative of #8, implications for family. Patients also chose 2 preferred methods of receiving information about molecular testing from a list of 4 methods used at Winship in other settings: written information; short video; website; from doctor/nurse; and one method suggested during cognitive testing: from another patient. The physician questionnaire included the pick-list, from which physicians were asked to choose the 8 topics which were most important to communicate about molecular testing. It also included one question asking which 2 of 4 options used at Winship to assist in communication were most useful in this setting: 1)patient video; 2)pamphlet; 3)scripts for providers; 4)website. The 18 pick-list topics covered three domains (see Table 1).

Quantitative Analysis

Descriptive statistics were generated for patient characteristics, including frequency and percentages for categorical variables, and mean and standard deviation for numerical

variables. Proportions of patients and physicians selecting each of 18 topics were reported. In order to determine which topics were most important to discuss, we identified optimal cut points between the 1st and 18th ranked topics using the maximum odds ratio derived from McNemar's test for comparing paired differences in proportions using the R package "exact2×2"[51]. Topics were ranked by the proportion of patients selecting each, testing the difference in proportions between #1 and #2, to #17 and #18 using McNemar's test[52,53]. Also reported was the odds ratio, defined as P10/P01, where P10 is the proportion of patients selecting the higher ranked topic (#6, for example) but not the lower ranked topic (#7, for example), and P01 is the proportion of patients selecting the lower ranked topic (#7, for example) but not the higher ranked topic (#6, for example). At least 1 and at most 17 topics were to be included on the patient list. Fisher's exact test was used to determine if there were significant differences between the preferences chosen by patients receiving results and those who were being introduced to molecular testing. A similar analysis was performed to identify a cut off point for physician preferred topics.. The proportion of patients selecting each topic was correlated with the proportion of physicians selecting each topic using Pearson's correlation coefficient. Chi-square or Fisher's exact tests were used to compare preferred topics between the patient and physician groups. To identify cut off points, significance was assessed at the 0.1 level; otherwise, significance was assessed at the 0.05 level. All tests performed were two-sided, where applicable. The analysis was performed using SAS 9.4 (SAS Institute Inc., Cary, NC) and R 3.3.0 (R Foundation for Statistical Computing, Vienna, Austria).

Simple frequencies were figured for the questions about how and by whom the information was communicated.

Power Analysis

Since we anticipated a small sample size of physicians, we conducted the power analysis for the patient population. Assuming a Type 1 error of 0.1 and a percent discordant of 0.4 (P10 + P01), we had 80% power to detect an odds ratio between two consecutive ranked topics of 3.0 with 66 patients. The same test had 97% power to detect an odds ratio of 5.0 with 66 patients.

Results

Participants

Of 74 patients approached, 70(95%) consented. Two conversations did not discuss tumor molecular testing and 2 consented patients withdrew, for a final sample size of 66. Twenty-eight physicians participated: 6(21%) were community oncologists, 22(79%) were academic oncologists from the following specialties: breast(4;18%); aerodigestive(6;27%), melanoma(3;14%), gastro-intestinal(3;14%), myeloma(5;23%) and lymphoma(1;5%). Twenty-seven(96%) physicians completed the questionnaire, and clinic conversations were recorded with 19(68%) physicians.

The median patient age was 62 years, 46(70%) were female, 44(67%) white, 39(59%) college educated and 32(49%) earning a yearly wage of $60,000 or greater(Table 2). Their

types of cancers included: lung(20;30%), colorectal(17;26%); breast(12;18%); melanoma(6;9%); gastric(4;6%); liver(2;3%); others(5;8%). This was the first molecular testing for 44 patients; 22 of these conversations occurred before and 22 after the testing. Twelve of the conversations discussed testing that had been done elsewhere and were reviews of what the patient had already been told. Of these, five focused on results and 7 on descriptions of the tests. Ten of the conversations discussed new expanded testing beyond the original standard of care testing to assess eligibility for clinical trials. In short, 27 conversations focused on return of results and the remaining 39 on what molecular testing is, how it is done and its implications.

Informational Preferences

Patients' top two preferred topics were the benefits of testing(88%) and how testing determines treatment(88%). Patients also chose 10 additional topics: implications for family(71%), if test shows seriousness of disease(68%), test purpose(64%), incidental findings(56%); explanation of cancer genetics(53%), how the test is done(46%), limitations(44%), explanation of biomarker(42%), risks(42%), uninformative result(38%) (See Table 3 for statistical analyses). There were no significant differences between preferences chosen by patients receiving results and those who weren't. Physicians' top choices were: how the test determines treatment(100%), test purpose(93%), and benefits(89%). Physicians also chose limitations(70%), explanation of biomarker(63%), cost(59%), how the test is done(56%), risks(56%), and prognostic information(52%). (See Table 4 for statistical analyses).

The combined patient/physician list of 13 topics is identified in Table 1 by asterisks, and includes all of the patients' 12 topics plus cost.

Statistically significant differences in the proportion of patients vs. physicians selecting topics are summarized in Table 5.

Patient preference for method of receiving information

Patients most frequently selected a discussion with their nurse or physician(85%) and written information(67%) as their preferred methods for receiving information. Less preferred methods included internet(29%), short video(12%), and receiving the information from another patient(8%).

Physician preference for communication aids

The physicians' preferred aids to communication were pamphlets(67%); followed by a website explaining key facts(44%); patient video(41%); and scripts for them to use(26%).

Discussion

Molecular testing to inform treatment choices is now standard of care in several types of cancer. However, there are neither established communication guidelines for the information physicians should include during these discussions[14,17,50], nor patient-physician consensus on the most important information to discuss [18-23,42-46]. It is therefore vital that current

patients' voices and preferences be included in creating molecular testing guidelines. This study successfully identified patients' and physicians' preferences for molecular testing communication, patients' preferences for the method of receiving information, and physicians' preferences for communication aids.

The two most frequently chosen topics of information for both patients and physicians were the benefits of the test and how the test determines treatment, revealing a consensus for at least two crucial pieces of information to share. Patients' third choice, how their results may help family members determine their risk of cancer and other diseases(71%), highlights the importance of physician-patient discussions of the differences between germline and somatic testing and what molecular testing can and cannot accurately reveal about a patient and a patient's family members[14,50]. We therefore recommend that the differences between somatic and germline mutations be emphasized during molecular testing discussions in accordance with ASCO's recommendations[14]. Patients' next preferred topic, how serious my disease is(68%), demonstrates the importance of discussing the difficult topic of prognosis[22,23]. Additionally, the differences in physician and patient preferences for discussing IFs reflect the current literature[54-63]. This suggests that, similarly to potentially clinically significant IFs in genetic and full exome testing, patients undergoing molecular testing also prefer disclosure of IFs. This finding expands the clinical settings in which IFs are of significant importance to patients, even if such findings are rare.

There was important consensus between patient and physician preferences about the most essential pieces of information to discuss during molecular testing conversations(Table 1). Twelve of these topics were those chosen by patients: the one addition added by physicians was cost. There were also five statistically significant differences(Table 5). Physicians selected purpose(#1), limitations(#4) and cost(#5) with a greater statistical frequency, while patients selected implications for family members(#8) and IFs(#10) with a greater statistical frequency. Additionally, uninformative result(#9) and explanation of biomarkers(#15) were only included above the second break point for patients(Table 5). All the items physicians chose as important to discuss more frequently than patients were in the foundational informed consent domain(#1-#5). In contrast, the items patients chose to discuss were mostly in the treatment and results domain(#6-#10). (See Table 1 for distribution of domains). We therefore recommend emphasizing the latter domain, treatments and results, in molecular testing discussion guidelines to ensure physicians discuss topics of high importance to patients.

Limitations and Future Studies

Because this study was conducted using a convenience sample with a modest number of oncologists and healthcare settings, we cannot generalize these findings beyond our sites. The findings from our study could be driven by local practice patterns and preferences relevant to the catchment area of Winship Cancer Institute. Further studies in larger and diverse patient groups will be necessary to generalize our findings.

Future research

A larger multi-institutional study assessing patient and provider informational preferences could expand upon this data and further inform the creation of molecular testing guidelines. In addition, given the physician preference for pamphlets to communicate this information, creation and testing of such a pamphlet, or flip chart as used by genetic counselors, could be fruitful.

Conclusions

The 12 topics chosen by patients should be discussed with the possible of addition of cost. These results can inform future guidelines as well as contribute to effective communication regarding molecular testing.

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Significant conclusion

This study provides important information regarding the topics that cancer patients perceive as being most relevant in their discussions on molecular testing. We recommend that their 12 preferred topics be discussed.

Table 1

Patient and Physician Preference List

Domain	ID	Full Question	N (%) chosen	
			Patient (66)	Physician (27)
Foundational consent information	1*	Why my physicians are testing for biomarkers	42 (64)	25 (93)
	2*	What the benefits of testing for biomarkers are	58 (88)	24 (89)
	3*	What the risks of testing for biomarkers are	28 (42)	15 (56)
	4*	What the biomarker test won't do for me and other limitations	29 (44)	19 (70)
	5*	If the biomarker testing will cost me anything	16 (24)	16 (59)
Treatment and results	6*	If the biomarker test will help decide my treatment	58 (88)	27 (100)
	7*	If the biomarker test will tell me how serious my disease is	45 (68)	14 (52)
	8*	If the biomarker test will help my family members learn about their risks of cancer or other diseases	47 (71)	7 (26)
	9*	What will happen if the biomarker test doesn't show anything	25 (38)	10 (37)
	10*	What will happen if the biomarker test shows something about me that is important for my health but has nothing to do with the cancer I have now	37 (56)	5 (19)
Additional information	11*	How the biomarker test is done (what will they do to me, like take blood, do a biopsy etc.)	30 (46)	15 (56)
	12	Who will test the tissue or blood sample that I give for the biomarker test	7 (11)	1 (4)
	13	Who will know and have access to my results	11 (17)	8 (30)
	14	What happens to the tissue or blood sample after the biomarker test is done	8 (12)	1 (4)
	15*	A short explanation of cancer genetics	35 (53)	9 (33)
	16*	What a biomarker is	28 (42)	17 (63)
	17	A referral to a genetic counselor or other person who can explain biomarker tests	16 (24)	2 (7)
	18	Information about how I can get extra support (ex: social workers, psychologists, other cancer patients)	8 (12)	1 (4)

*Items in combined patient/physician preference list. The patient/physician correlation was statistically significant (correlation coefficient: 0.71, 95% CI: 0.37, 0.88), p=0.001).

Table 2

Patient Demographics

Variable	Level	N = 66	%
Age	Median	62	-
Gender	Female	46	69.7
	Male	20	30.3
Ethnicity	White	44	66.7
	Other	22	33.3
Education level	College graduate	39	59.1
	<College degree	27	40.9
Income	$60K+	32	48.5
	<$60K	34	51.5

Table 3

Patient ranked topics by proportion. The only significant cut off point found by the patient quantitative analysis occurred between #2 and #8 (OR: 2.8, 90% CI: (1.22, 7.32), p=0.03) and the next highest odds ratio occurred between #9 and #17 (OR: 1.75, 90% CI: (0.92, 3.44), p=0.16). Cut off points denoted by line.

Topic	Proportion
#6	0.879
#2	0.879
#8	0.712
#7	0.682
#1	0.636
#10	0.561
#15	0.53
#11	0.455
#4	0.439
#16	0.424
#3	0.424
#9	0.379
#17	0.242
#5	0.242
#13	0.167
#18	0.121
#14	0.121
#12	0.106

Table 4

Physician ranked topics by proportion. No odds ratios were significantly different than 1 (p>0.1). The maximum odds ratio occurred between #2 and #4 and the next highest odds ratio occurred between #7 and #9 (OR: 1.57). Cut off points denoted by line.

Topic	Proportion
#6	1
#1	0.926
#2	0.889
#4	0.704
#16	0.63
#5	0.593
#11	0.556
#3	0.556
#7	0.519
#9	0.37
#15	0.333
#13	0.296
#8	0.259
#10	0.185
#17	0.074
#18	0.037
#14	0.037
#12	0.037

Table 5

Differences between physician and patient preferences.

Chosen by patients with greater statistical frequently		Chosen by physicians with greater statistical frequently	
#8 *	Implications for family(71% vs. 26%, p<0.001)	#1 *	Purpose(93% vs. 63%, p=0.005)
#10 *	Incidental findings(56% vs. 19%, p<0.001)	#4 *	Limitation(70% vs. 44% p=0.021)
		#5 *	Cost(59% vs. 24%, p=0.001),

Above Patient but not Physician odds ratio cut off point		Above Physician but not Patient odds ratio cut off point	
#8	Implications for family members	#5	Cost
#9	Uninformative results		
#10	Incidental findings		
#15	Explanation of cancer genetics		

* p-value< 0.05