

ORIGINAL RESEARCH

Sharing Genomic Tumor Sequencing Results With Patients: Experiences of Advanced Practice Oncology Providers

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Abstract

Background: Patients with cancer routinely undergo genomic tumor sequencing, a component of molecular profiling (MP), to better characterize their cancer and identify potential targetable alterations. Targeted treatments potentially confer higher response rates and better efficacy. With increasing complexity, patients may require detailed explanations of MP results. Patient understanding of MP results increases the likelihood that eligible patients receive targeted treatment. Advanced practice providers (APPs), defined as nurse practitioners, physician assistants, and pharmacists, frequently review and discuss MP results with patients. **Purpose:** The aim of this study is to understand APP experiences discussing MP results with adult cancer patients. **Methods:** A qualitative study was conducted through virtual semi-structured interviews with APPs recruited via study invitation shared through the Advanced Practitioner Society for Hematology and Oncology (APSHO). Eligibility criteria included APPs with > 1 year of oncology experience and involvement in discussing MP results. Data were analyzed utilizing a constant comparative analysis and coded in three stages: open, axial, and selective. **Results:** Thirteen participants were enrolled from across the United States. Participants discussed learning to understand and explain MP findings primarily through on-the-job experiences. Barriers to patient education were also described. Initially coded participant statements (open codes) produced six themes (axial codes). **Conclusions:** With MP now standard practice in oncology, APPs frequently discuss these results with patients. This study highlights that additional and continuing education related to MP is needed in communicating complex results. Patient educational tools, specific to patients' MP findings and tailored to their preferences and literacy levels, are critically needed.

Approximately two million people have been diagnosed with cancer in the United States in 2024 (Siegel et al., 2024). Of these patients, a significant portion will have genomic tumor sequencing, a component of molecular profiling (MP; the testing of blood, tissue, or other body fluids to identify cancer biomarkers). Molecular profiling can assist in diagnosis, predict prognosis, and identify alterations that can be targeted for treatment with specific drugs (Best et al., 2019). Molecular profiling has grown exponentially over the past few years and can consist of germline or somatic testing. Germline mutations are DNA changes in the gametes (sperm or egg cells) that can be passed to offspring. Somatic mutations are genetic alterations in all body cells other than gametes that occur after conception and are often linked to cancer or other disease processes (National Cancer Institute, n.d.). The National Comprehensive Cancer Network (NCCN) Guidelines now recommend universal germline testing for patients with select cancers that have high rates of pathogenic germline mutations, such as pancreatic cancer (15%) and triple-negative breast cancer (23%), as well as somatic testing (Crowley et al., 2023; Metcalfe et al., 2023; NCCN, n.d.).

Treatment options for oncology patients are rapidly evolving, with multiple targeted oncologic treatments approved annually in the United States for newly identified molecular mutations. The American Association of Cancer Research (AACR) Cancer Progress Report (2023) stated that the US Food and Drug Administration (FDA) approved seven new drugs in the last year as molecular therapies and expanded indications of use for nine previously approved drugs. The availability of new therapies has significant implications for patients as targeted therapies typically have higher response rates and improved outcomes for patients with cancer (Cobain et al., 2021; Roberts et al., 2023a, 2023b).

When MP is indicated, advanced practice providers (APPs), including nurse practitioners (NPs), physician assistants (PAs), and pharmacists, frequently share molecular findings with patients and their families. Recent advances in molecular profiling and novel therapies increase the impor-

tance of APPs remaining knowledgeable and up to date on testing and results reporting. As essential members of the interdisciplinary oncology care team, APPs must integrate MP into clinical care for all qualifying patients and overcome any obstacles to testing, reporting, and educating patients (Moore & Guinigundo, 2023). It is important that patients are aware of their MP results, as patients who know their results are more likely to receive the most appropriate targeted therapy (Freedman et al., 2015; Yanes et al., 2019). More published literature is needed to address the APP's perspective of sharing molecular results with patients. This study aimed to understand the APP experience in discussing MP results with adult oncology patients and their families.

METHODS

A qualitative study design was selected for this study to gain in-depth insight into the experiences of APPs in sharing MP findings with patients. The Institutional Review Board at Clemson University reviewed and approved the study. All participants provided consent prior to data collection (interviews). Participant recruitment occurred through a study invitation shared through the Advanced Practitioner Society for Hematology and Oncology (APSHO) organization. Interested individuals contacted the study team to discuss consent and confirm eligibility. Eligibility criteria for participation included APPs working in oncology for at least 1 year, with involvement in discussing MP results with patients. Interviews were prioritized to increase sample diversity, with priority given to individuals in varying clinical roles and dispersed across geographic locations. Interviews ceased when data saturation was reached, meaning no new themes emerged that changed or increased understanding of previous interviews. Participants completing the interview session received a \$40 incentive card.

A semi-structured interview guide was developed by the research team and utilized to guide discussions with participants. All interview sessions were audio recorded via Zoom. The auto-transcription feature was turned on to produce a written transcript. Transcripts were then verified and corrected by listening to the audio recordings of the session and ensuring transcript accuracy.

All identifiable information was removed during this verification process to produce a de-identified transcript, which was used for data analysis.

DATA ANALYSIS

Demographic details for the participants were summarized to describe the sample population. Participant statements from the interviews served as the research data. Data were analyzed at the statement level, utilizing a constant comparative analysis (CCA) method where all new data was compared to previously collected and analyzed data (Fram, 2013). Following a process previously outlined by Dantas and colleagues (2009), participant statements were independently reviewed and coded in three stages (open, axial, and selective coding) by the research team (Dantas et al., 2009). Team members met to discuss the developed open codes and reached a consensus. After the first consensus discussion, a code book for all generated codes and their definitions was developed and continuously revised as new interviews were reviewed.

The second stage of coding was initiated to develop axial codes. Open codes were evaluated based on similarities and relationships, then grouped using new axial code names and definitions. The final state of coding (selective coding) evaluated the data and identified the overarching themes related to providers' experiences discussing MP with oncology patients. Throughout the process of collecting and coding data, the research team ensured study rigor through formal team training for conducting interviews and analyzing data, building trust with the research participants during the interview process, documenting study processes and decision points to produce an audit trail, and confirming participant statements through a process called member checking (verification of participant statements and the interviewer's understanding of what was meant by the statement).

RESULTS

The study enrolled thirteen participants (labeled 2–14). The APPs were primarily female and included 11 NPs and 2 PAs from across the United States (Table 1). Participants reported multiple years of oncology experience, with an average of nearly 16 years (range 1–40).

Table 1. Demographic Characteristics of Participants (N = 13)

Characteristics	Value
Discipline, <i>n</i> (%)	
Nurse practitioner	11 (85)
Physician assistant	2 (15)
Gender, <i>n</i> (%)	
Male	1 (8)
Female	12 (92)
Years of work experience, mean, median (range)	15.77, 14 (1–40)
State of practice, <i>n</i> (%)	
Arizona	2 (15)
Colorado	3 (23)
Kentucky	1 (8)
North Carolina	1 (8)
Maryland	1 (8)
Pennsylvania	1 (8)
Tennessee	2 (15)
Washington	1 (8)
West Virginia	1 (8)

The selective code “experiences of APPs sharing molecular profiling results with patients” was the overarching theme of this study. The supporting axial codes were labeled APP Training, APP Perceptions, Communicating Results, Patient Understanding, Preferences and Tools, Impediments to Communication, and Education, Teaching Tools, and Resources (Table 2). Exemplar quotes to support and describe each axial code are included (Table 3).

APP Training

All participants described on-the-job training to deliver MP results. Experience in understanding and sharing MP results was typically gained from working with physician colleagues who shared their knowledge. One participant attended the Intensive Course in Genetic Cancer Risk Assessment offered by the City of Hope (Table 3, exemplar 1). In addition, APPs described receiving education from company representatives (both diagnostic and pharmaceutical) and attending conferences (Table 3, exemplar 2). Most APPs mentioned learning through self-study (Table 3, exemplars 3 and 4). None of the APPs expressed that they were

Table 2. Definitions for Selective, Axial and Associated Open Codes

Code type	Code title	Definition	Associated open codes
Selective	Experiences of APPs Sharing Molecular Profiling Results with Patients		
Axial	APP Training	Education and Instruction that Clinicians Have Received in Order to Discuss Molecular Profiling Results	<ul style="list-style-type: none"> • APP Training
Axial	APP Perceptions	Clinician Assessments of Patient Reactions and Understanding of Molecular Profiling Results	<ul style="list-style-type: none"> • Provider Perception of Patient Understanding • Provider Perception of Patient Reaction
Axial	Communicating Results	Person Responsible for Relaying, Discussing, and Explaining Genomic Profiling	<ul style="list-style-type: none"> • Education Provider • Genetic Counsellor
Axial	Education, Teaching Tools, and Resources	Methods, Techniques, and Materials Used in the Provision of Molecular Profiling Results to Promote Patient Comprehension, including Customization of Content and Delivery	<ul style="list-style-type: none"> • Education: Reason for Testing • Patient Education • Education Resource • Suggested Resources • Tailoring Information • Tailoring Information: Repetition • Teach Back • Family Inclusion
Axial	Impediments to Communication	Factors and Obstacles that are Detrimental to the Exchange of Information between Providers and Patients	<ul style="list-style-type: none"> • Barriers: Economic • Barriers: Health Literacy • Barriers: Psychological • Dearth of Resources • Provider Challenge • Education: Information Complexity
Axial	Patient Understanding, Preferences, and Tools	Patient Comprehension and Genomic Health Literacy, Inclination and Choices around Knowledge Acquisition, and Resources	<ul style="list-style-type: none"> • Patient Information Preference • Patient Understanding • Patient Web Use • Provider-Patient Relationship • Patient Awareness of Testing

ill-prepared or incapable of explaining the results but did detail additional steps that they took to stay informed of new MP findings and implications for practice.

APP Perceptions

Perceptions of APPs included the provider's assessment of the patient's reaction and understanding of the MP results. The most common descriptive words used in this category were statements about the patients being "overwhelmed" by the information they received. Advanced practice providers also described patients as being confused, nervous, and anxious (Table 3, exemplars 5 and 6). One APP noted that patients are happy when a targetable mutation is found (Table 3, exemplar 7).

Communicating Results

Communication of MP results was described as discussions by the providers. Occasionally, genetic counselors were involved in these discussions; however, across interviews, APPs described referring patients to genetic counselors for mainly germline findings. Some APPs said they would also send patients to genetic counselors if the report posed a difficult question or if the patient was "high-risk" (Table 3, exemplar 8). One APP stated they did not have access to a genetic counselor, so all education was provided through providers at the oncology center. Communication of MP results to patients during office visits was reported through a team meeting or through an individual provider,

Table 3. Exemplar Quotes

Exemplar number	Open code category	Participant ID	Participant statements
1	APP Training	6	"I finished the City of Hope certified genetics intensive course in 2018."
2	APP Training	2	"So that [MP education] has just been through journal review and talking to other providers and things like that, and then just looking up drugs that are available for different alterations."
3	APP Training	11	"And I also go to the Internet, you know, if it's a gene I've never heard of, I'll look it up and see what I can learn."
4	APP Training	14	"I think the biomarker database through ONS [Oncology Nursing Society] is super helpful."
5	APP Perceptions	2	"Occasionally, someone will understand some of their findings, but for the most part, I think it's confusing; I think half of them probably do, and half of them probably don't."
6	APP Perceptions	5	"I would imagine in my mind that they're probably...patients are probably really only absorbing, like 50% of what we tell them. Sometimes I say, you know, does that make sense? Are you understanding? You know, and they'll nod yes, but I'm wondering...if patients really understand or not."
7	APP Perceptions	9	"If they have a targetable mutation, they're really happy about it." (gaining a treatment option)
8	Communicating Results	2	"If it's a gene, I don't know then I would refer them to a genetic counselor every time if they wanted."
9	Communicating Results	14	"Then again, it's either me or the oncologist."
10	Education, Teaching Tools, and Resources	10	"I think they need a second family member with them....to take notes, making sure that they understand what we're doing."
11	Education, Teaching Tools, and Resources	13	"I generally just show them results....start at the top and review it from the top through the end, with what results have come back."
12	Education, Teaching Tools, and Resources	5	"So if someone's report comes back with a bunch of mutations, but none are currently targetable and we're not going to do a clinical trial right now, I don't get into a lot of detail about well, you have this 7P53 mutation, blah, blah, blah. That may or may not mean anything right now, you know, I don't really get into too many details about that."
13	Education, Teaching Tools, and Resources	8	[MP reports are] "varied so much from company to company, from platform to platform, and the most critical information it might be like a 9- or 13-page report where the headline is buried in a lot of minutia."
14	Education, Teaching Tools, and Resources	4	"I think if there was like some way to give them a one-page summary of what the results are and what it might mean, that that would be nice."
15	Education, Teaching Tools, and Resources	3	"I say it's two-fold. One to see if this isn't a hereditary cancer for you and your family members. And then, secondly, we look for a mutation that we could actually target for treatment. Another treatment option that we may not have known about [without testing]."
16	Education, Teaching Tools, and Resources	12	"It's important to tell them we did do testing on your tumor, and it did not reveal any actionable biomarkers."
17	Education, Teaching Tools, and Resources	7	"I really just try to keep it as simple as possible. So just kind of use very easy language that is not so doctored up."

Table 3. Exemplar Quotes (cont.)

Exemplar number	Open code category	Participant ID	Participant statements
18	Education, Teaching Tools, and Resources	12	"Sometimes I will address it 3 and 4 times at 3 and 4 different visits to make sure that the patient specifically understands."
19	Education, Teaching Tools, and Resources	8	"You know your family is going to ask you about this. So how are you going to tell them [your family about this type of cancer]? And that's one way to get the teach-back."
20	Education, Teaching Tools, and Resources	11	"So I think, having significant others or somebody else in the room that can help people remember what we talked about."
21	Impediments to Communication	14	"I have all walks of life, all levels of education. But if I had to give you a snapshot of my overall population that I do teaching with there's a very low level of health literacy, and especially related to cancer, and something as complicated as genomic profiling."
22	Impediments to Communication	8	"You know, I wish I had something that that I could hand to patients."
23	Impediments to Communication	5	"Those [MP reports] are hard for even us who work in the field to decipher."
24	Impediments to Communication	2	"If they have like a <i>BRCA</i> mutation, and you have to try to explain the difference between somatic mutations and germline mutations and what it means for them."
25	Impediments to Communication	4	"There are very uncommon things that I'll have to look up and then the oncologist has to look up too. It's already complex. It's getting more complex."
26	Patient Understanding, Preferences, and Tools	4	"The best you can do in my mind is to ask, 'Do you have any questions?' 'Does that make sense?'"
27	Patient Understanding, Preferences, and Tools	7	"I think scripting upfront is very important so that patients are aware and not caught off guard in terms of their expectations."
28	Patient Understanding, Preferences, and Tools	13	"I think, first of all, trying to understand from the patient like I said, what they want to know, and then trying to give the information that they do want to know."
29	Patient Understanding, Preferences, and Tools	8	"Now there are others who have already been on Doctor Google and have, you know, tried to educate themselves. That sometimes raises anxiety more than it helps."
30	Patient Understanding, Preferences, and Tools	6	"I feel like a lot of times, they just trust me to do [follow] the guidelines."

typically either the oncologist or an APP (Table 3, exemplar 9).

Education, Teaching Tools, and Resources

Advanced practice providers shared how they provided MP education to patients and their families, discussing suggested educational resources and tips for tailoring information (such as repetition of teaching). The inclusion of family members during discussions of patient results was felt to be helpful because they often take notes and assisted patients with remembering key information (Table 3, exemplar 10).

Resource-wise, most APPs mentioned using the actual MP reports to share findings, but there were many concerns regarding the report contents (e.g., too long, too variable, and not user-friendly; Table 3, exemplars 11, 12, and 13). The most suggested resource recommended for enhancing communication of MP results with patients was a simplified, patient-friendly report (Table 3, exemplar 14).

When educating patients on the reason for testing, nearly all the APPs discussed the possibility of finding a molecular target for drug therapy that could dictate subsequent lines of therapy or be informative for the patient's family members (Table 3, exemplar 15). For patient education, APPs described how testing helped to understand what was unique about the patient's type of cancer. Many APPs said they informed patients when testing results were negative as well (Table 3, exemplar 16).

When tailoring patient information, participants mentioned simplifying and using plain language (Table 3, exemplar 17). Nearly all participants said they used repetition in the educational process to share information (Table 3, exemplar 18). Participants also reported using the "teach-back" method to assess patient understanding of provided education (Table 3, exemplar 19). Including family members in the educational sessions was also mentioned as helpful (Table 3, exemplar 20).

Impediments to Communication

Advanced practice providers described perceived barriers to patient communication, including socioeconomic, psychological, and health literacy. They cited the complexity of MP results and the dearth of helpful teaching tools as challenges that

impede communication with patients. Economic barriers were mentioned related to insurance coverage of MP testing. From a health literacy standpoint, the most common detriment noted was low education levels, followed by language barriers and poor overall literacy. Several APPs noted a wide range of educational levels among their patients (Table 3, exemplar 21). They also mentioned that a patient's psychological state, such as those patients overwhelmed by a new diagnosis of cancer or those with anxiety, were perceived as having additional obstacles to overcome in the communication process.

Most participants noted a need for more resources to assist with communicating results (Table 3, exemplar 22). Advanced practice providers reported being challenged by time constraints during clinic visits as well as complicated information (Table 3, exemplar 23). Information complexity was a universal impediment noted by participants. Specifically, variants of unknown significance, non-actionable mutations, co-mutations, and unusual findings, were cited as challenging information to communicate to patients. Several APPs mentioned having to explain the difference between somatic and germline findings (Table 3, exemplar 24). The fast-changing landscape for interpreting MP findings adds to the complexity of understanding and sharing results (Table 3, exemplar 25).

Patient Understanding, Preferences, and Tools

To assess patient understanding, APPs reported actively soliciting patient questions (Table 3, exemplar 26). They also mentioned the importance of managing patient expectations related to MP testing, as not all tests yield useful results (i.e., targetable mutations; Table 3, exemplar 27). Many participants reported asking patients about their information preferences (Table 3, exemplar 28). Several participants reported that patients use the internet routinely, including Google and the patient portal to review their own electronic health record (Table 3, exemplar 29). Advanced practice providers also used published guidelines for patient teaching, such as the NCCN. A few participants mentioned a trusting patient-provider relationship as helpful (Table 3, exemplar 30).

DISCUSSION

An important finding from this study is that all APPs reported learning how to share MP results through on-the-job training. This is not surprising, considering that the APPs interviewed in this study had an average of nearly 16 years of experience and were already employed as oncology APPs when MP testing became routine. Only one of the study participants had received more formal training through the City of Hope, which enabled her to function as the *de facto* genetic counselor for the practice organization. This finding highlights the need for embedded education in APP training programs specific to the clinical implications of MP results. Calzone and colleagues (2018) and Patterson and colleagues (2023) elucidate the current landscape of genetics/genomics education in NP and PA programs, respectively, describing deficits and the need to enhance genetic/genomic education during student training to create genetic/genomic competent APPs.

Ongoing clinician education is also needed. New biomarkers and targetable alterations are being identified rapidly, challenging clinicians to remain current on new findings. In a precision medicine survey of 20 health-care institutions across the country, respondents identified the biggest challenge as being able to keep up with the pace of new biomarkers and changing guidelines (Ray, 2021). This highlights the need for APP continuing education related to genetic/genomic findings in oncology. Studies show that APPs want to improve their genetics/genomics knowledge and confidence through educational opportunities (Calzone et al., 2018; Patterson et al., 2023). For new tests and targeted medications, APPs in this study reported reaching out to medical science liaisons for education and questions, both from diagnostic and pharmaceutical companies. Several APPs discussed ongoing training around biomarkers through their employers, conferences, self-study, and discussions with oncologists and industry representatives. This group of APPs was recruited from a professional organization focused on education and all seemed well prepared to deliver MP results. Other APPs may have barriers to receiving additional education such as access, costs, or technology deficits. Given that APPs are responsible for sharing detailed MP information,

educational programs and resources to appropriately train providers are needed. This is especially needed in centers with limited resources (i.e., no access to genetic counselors).

Participants in this study reported a paucity of available educational materials specific to sharing MP findings with patients. The MP test report was the most utilized resource during MP discussions, and APPs shared multiple limitations using this report as a teaching tool (e.g., length and complexity). Currently, there are few resources available for patient education on specific MP findings, but there are general resources and websites for patients around biomarkers, such as *Understanding Biomarker Testing: A Guide for Patients with Cancer* (<https://patiented.advancedpractitioner.com/understanding-biomarker-testing-a-guide-for-patients-with-cancer>; *Journal of the Advanced Practitioner in Oncology*, 2023).

Advanced practice providers relayed that the reason for MP testing is a key part of the educational process for patients, especially given the implications for informing treatment. Having this conversation early in the oncology process was considered advantageous. Advanced practice providers stressed how important it is for patients to know and understand their molecular results. The process for sharing test results with patients varied by the provider, but a common element pertained to tailoring the information delivery to each individual (i.e., considering a patient's information preferences, literacy level, and emotional status). Using understandable "plain language" and the teach-back method were common practices in sharing MP results. These practices are supported by research (Talevski et al., 2020).

Many patients are overwhelmed by the MP results, and APPs perceive lower literacy and higher anxiety in patients as a barrier to education. This perception is supported by literature, with a patient's recall of information being negatively impacted by lower education, older age, and anxiety (Nguyen et al., 2019). Many of these communication challenges are shared by health-care providers outside of oncology (Stein et al., 2022), but the complexity of oncology results can magnify issues, making communication less effective. Most APPs reported using techniques to enhance the update of new information, such as repeating information

during the teaching process, using lay language, and including additional family members in the educational setting. These practices are supported by literature and are encouraged for clinical implementation to support learning (Choi & Choi, 2021; Friend et al., 2021).

STUDY LIMITATIONS

This study contained limited gender diversity among study participants and may not represent the larger community of APPs. Although pharmacists were eligible to participate, none were recruited, and their experiences may differ. The sample size was small ($n = 13$) but reached data saturation, supported by findings from a recent qualitative study showing that an average of 12 to 13 participants was sufficient across multiple studies to achieve data saturation (Hennink & Kaiser, 2022). An additional limitation included the recruitment of participants through one organization that is geared toward educational topics such as this, which may have biased our sample to more experienced APPs and, therefore, not capture the experiences of newer providers and their more recent educational preparation to understand MP reports. Despite the noted limitations, this study had multiple strengths, including representation from a large geographical area with community and academic sites and multiple specialty areas. Additionally, providers offered robust discussion, allowing for data saturation and identifying overarching themes.

IMPLICATIONS FOR PRACTICE

Molecular profiling should be a component of initial and continuing education for APPs in hematology/oncology. Annual education of new therapeutics for APPs should include special attention to medicines with a companion diagnostic molecular marker. For patient education around MP results, efforts should continue to develop applications that can generate a personalized patient-friendly report, such as the HOPE-Genomics tool, currently under study in a phase III clinical trial (Solomon et al., 2020). Advanced practice providers are encouraged to advocate for patient-friendly educational tools through clinical trials, molecular testing companies, and the pharmaceutical industry. Additional research is needed to explore

the most effective means of educating patients on MP results. Exploration of artificial intelligence to generate MP personalized reports specific to the patient's literacy level and noted mutations is another area ripe for future research (Khaja, 2023).

CONCLUSIONS

Molecular reports in oncology are now a standard of practice requiring APPs to be able to understand, interpret, and communicate these complex findings with patients. To be prepared to meet this clinical need, APPs require genomic education in initial training programs and ongoing continuing education programs specific to APP needs and rapidly changing MP diagnostics and treatment implications. Additionally, patient-friendly educational tools are needed to assist patients in understanding complex MP results and any associated treatment options. ●

Disclosure

The authors have no conflicts of interest to disclose.

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