Research Article

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Personalized Medicine

Clinician perspectives on communication and implementation challenges in precision oncology

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Aim: To describe patient communication challenges encountered by oncology clinicians, which represent a fundamental barrier to implementing precision oncology. **Materials & methods:** We conducted three focus groups including breast, melanoma and thoracic oncology clinicians regarding their precision oncology communication experiences. Transcripts were reviewed and coded using inductive thematic text analysis. **Results:** We identified four themes: varied definitions of precision oncology exist, clinicians and patients face unique challenges to precision oncology implementation, patient communication challenges engendered or heightened by precision oncology implementation and clinician communication solutions and training needs. **Conclusion:** This study elucidated clinicians' perspectives on implementing precision oncology and related communication challenges. Understanding these challenges and developing strategies to help clinicians navigate these discussions are critical for ensuring that patients reap the full benefits of precision oncology.

Lay abstract: 'Precision oncology' has gained momentum as a term to describe cancer care that is optimized for an individual patient based on her/his unique characteristics. However, clinicians may encounter challenges with communication when delivering precision oncology care to patients and their families. We conducted three focus groups, or structured discussions, with breast, melanoma and thoracic oncology clinicians regarding their precision oncology communication experiences. Narrative transcripts of these discussions were analyzed by the research team to identify common themes. We identified four themes: varied definitions of precision oncology exist, clinicians and patients face unique challenges to precision oncology implementation, patient communication challenges engendered or heightened by precision oncology implementation, and clinician communication solutions and training needs. This study elucidated clinicians' perspectives on delivering precision oncology and related communication challenges. Understanding these challenges and developing strategies to help clinicians navigate these discussions are critical for ensuring that patients reap the full benefits of precision oncology.

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The term 'precision oncology' has gained momentum to describe care that is optimized for an individual patient based on her/his unique characteristics, such as treatment preferences, lifestyle, medical history and genomics including germline and tumor molecular profile [1,2]. This drive toward 'precision' in cancer care has been heavily influenced by broader trends in medicine including the 2015 launching of the Precision Medicine Initiative by

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President Obama [1], and ongoing efforts toward a more person-centered approach to healthcare that aims to understand and address the needs of healthcare consumers in the holistic context of their lives and identities [3]. In oncology, such person- and patient-centered strategies span a range of dimensions, including patient preferences for care options, increasing clinical significance of patient-reported outcomes such as treatment toxicities [4], the diverse needs of those with specific behavioral and medical phenotypes, pharmacogenetics, and patient testing for cancer predisposition, prognosis and tumor molecular profiles that may lead to targeted therapeutics and disease management [2,5–9]. While relevant across medicine, oncology is among the first specialties to deliver upon the promise of precision medicine, with cancer patients starting to reap some of those benefits.

Yet, a range of challenges likely arise for oncologists in the context of precision oncology. Such challenges include addressing ethical and social issues such as patient privacy when handling potentially sensitive data [10], lack of training and experience with precision oncology advances [11,12], and extensive time demands to address all the tailoring factors needed to integrate patient characteristics into treatment choice [13–17]. However, many of the demands created by precision oncology may engender or involve communication challenges with patients. For instance, clinicians may need to address patients' pre-existing beliefs such as beliefs about genetic testing, surmount challenges related to limited health literacy of many patients, and navigate patient hopes and assumptions regarding the benefits and limits of treatment. While notable progress in the development of precision oncology therapeutics and identification of biomarkers has been made, limitations do exist. For example, recent analyses suggest that approximately only a third – and often far fewer – of evaluated cancer patients harbor an actionable genomic alternation allowing for targeted treatment [18–20]. Nonetheless, precision approaches to oncology have been widely touted by the media, and such coverage may significantly impact patient beliefs and treatment expectations [21–23]. Addressing these challenges will allow for the best use of a precision approach as it becomes increasingly available to patients; yet very little is directly known about clinician perspectives of the challenges they face in the context of precision oncology.

Communication challenges represent a fundamental barrier to achieving the promise of precision oncology [24–26]. Therefore, the aims of this study were to identify the challenges that clinicians experience when discussing and implementing precision oncology with patients and families, and to describe the barriers and facilitators to these discussions. This information can ultimately shape interventions to enhance clinician capacity to address communication challenges raised or highlighted, in the context of precision oncology.

Materials & methods

This study utilized focus groups to gather information about the precision oncology communication experiences of clinicians at a National Cancer Institute (NCI)-designated comprehensive cancer center. Participants included English-speaking clinicians practicing at Memorial Sloan–Kettering Cancer Center (MSK) in three areas that the research team purposively selected to reflect disease contexts in which precision oncology approaches are commonly used: breast oncology, melanoma and thoracic oncology. MSK clinicians engage in regular disease-specific meetings that include oncologists, residents, fellows and other specialty physicians treating that illness; we conducted three focus groups during a regularly held, in-person meeting in each of these areas between January and August 2019. The use of pre-existing groups for focus group data collection is a well-established approach in qualitative methodology; it offers the unique advantage of pre-existing rapport among participants and can provide insight into "*the social context in which ideas are formed and decisions made*" ([27], page 105) [28]. Each focus group took place in a conference room at the hospital and was led by an experienced moderator (JL Hay; clinical health psychologist with more than a decade of qualitative research experience) who used a semi-structured guide to elicit discussions about clinicians' phenomenological experiences with communicating about and delivering precision oncology with patients and families. The focus group guide was developed by team members with content expertise (JL Hay, JG Hamilton, PA Parker, SC Banerjee) and qualitative research training (CM Martin). Topics covered within the guide included the perceived meaning of precision oncology among clinicians and their patients, potential limitations of precision oncology, and experiences and challenges in communicating with patients about the meaning and limitations of precision oncology (see Supplementary data). Research team members (JG Hamilton, CM Martin, PA Parker, SC Banerjee, L Sar-Graycar, J Vera; note all research team members were employees of MSK and therefore colleagues of the study participants) observed and took field notes during the focus groups, and all groups were audio recorded. Audio recordings were transcribed by a professional audio transcription service, and transcript accuracy was confirmed by triangulating field notes with the audio recordings and discussion among research team

members. Each focus group lasted 30–45 min. The MSK Institutional Review Board approved this study as exempt research, thus verbal assent to participate was obtained from focus group participants.

Participants' narrative comments were analyzed using inductive thematic text analysis [29–34] aided by NVivo software. Six team members with expertise in health psychology (JG Hamilton, JL Hay), communication (SC Banerjee) and clinical research (J Vera, L Sar-Graycar, SV Carlsson) read each transcript independently, highlighting important content and recording reflections on the transcript margins. Then, the team members met to compare their annotations and collaboratively developed a codebook. These team members then each independently applied codes to all transcripts and met to discuss and resolve any discrepancies by consensus. The team then met to generate collective findings for each transcript by consensus and met again to identify higher-order descriptive and interpretive themes across transcripts by conducting a secondary review of exemplar quotations. These quotations were identified by grouping prominent codes into conceptual categories; statements within each category were exported into a report and reviewed. The analysis was guided by a qualitative methodologist (KA Lynch), who provided initial training on the NVivo platform and inductive thematic analysis procedure. Prior to each consensus meeting, the methodologist also merged team members' individual NVivo files and reviewed the data to help identify discrepancies in the application of codes within transcripts, and made annotations to discuss during the consensus meetings. After all transcripts were coded and discussed, the methodologist conducted a quality assurance check of the coded data. This involved ensuring that inductive codes developed later in the coding process were applied to earlier transcripts and confirming that no statements were mislabeled with an incorrect code.

Results

Clinician participants across the breast (n = 36), melanoma (n = 12) and thoracic (n = 20) oncology focus groups expressed a variety of perspectives regarding the meaning, implementation and communication challenges of precision oncology. Below and in Table 1 we present four common themes and 23 subthemes (the themes are indicated by underlined text in the main text) as well as exemplar quotes regarding the topics that participants consistently expressed across groups.

Theme 1: Varied definitions of precision oncology exist

Clinician participants described a range of ways that they and their patients describe 'precision oncology' and apply it to clinical care. There was some acknowledgement that clinicians and patients tended to have different understandings of this concept.

From many participants' perspectives, precision oncology is defined by patients as tailored treatment, with patients desiring 'tailor-made treatment' that has been designed uniquely for them and is not 'cookie cutter'. Participants acknowledged that patients may not have a complete understanding of precision medicine, but they are clearly driven to seek treatments that have been designed specifically for them. While participants similarly acknowledged targeted treatments as a component and goal of precision oncology, they also described ways in which clinicians have a greater understanding of the nuances and limitations of these treatments, including that there are various ways that cancer cells can evade disruption, despite multiple precise, advanced ways of disrupting them.

Participants explained how precision oncology is a term that can be used broadly, or precisely, along a continuum of specificity. For instance, a breast clinician described it broadly as the "*right treatment for the right patient,*" including a range of factors like gender, BMI and other characteristics that help physicians select between treatments. Also, very broadly, precision approaches were noted as those that make patients feel they are being treated as individuals. Some even noted that standard chemotherapy could be thought of as a precision treatment, given that a cancer cell will be more readily targeted by a standard cytotoxic drug that blocks DNA synthesis. On the other end of the continuum, participants prioritized the use of 'precision oncology' as treatments that are preferentially attacking targets on tumor cells and not on normal host tissues, most specifically through applications of genetics or protein overexpression. One melanoma clinician provided an example of how rare some precision oncology approaches can be: "*. . . HER2 amplifications [in melanoma] or NTRK [fusion] is the most recent entry into this field. So, I would say like it must be really satisfying to find that 1% that has that fusion and then send them to [colleague] and have a 70% chance of a significant response. And, to me, that's like a concrete precision oncology.*"

Participants noted that precision oncology encompasses a variety of treatment options, such that beyond the most obvious treatment examples, other types of cancer treatments are now more precise. For example, many agreed that HER2 amplification in breast cancer and *BRAF* mutation status dictating melanoma treatment were classic, well-

Table 1. Themes, subthemes and exemplar quotations from the breast, melanoma and thoracic oncology clinician participants.

Theme 1: Varied definitions of precision oncology exist	
[Precision oncology is…] Defined by patients as tailored treatment	"*I think we tend to think of precision oncology in terms of genetics, but I do think that at least patients may think beyond that. I mean, it's individualizing care to the patient…*" – Melanoma
[Precision oncology is a…] Term that can be used broadly, or precisely, along a continuum of specificity	"*I think one way of looking at it could be a broader, just sort of the right treatment for the right patient, and part of that is biomarker driven, but it could be broader than that.*" – Breast
[Precision oncology…] Encompasses a variety of treatment options	"*I think from a radiation oncology perspective as well as the surgery perspective, our treatments have become more precise as well. We really have made technological advances. I'm not sure that's what you're referring to when you talk about precision oncology.*" – Thoracic
[Precision oncology is the…] Application of new approaches to existing goals	"*Tailor treatment for what it looks like under the microscope. So we, so now we think of it more that we're adding what – besides histologically it looks like, is genetically just another level, and we're also sort of implied in that is that we're expecting to have that result in a pretty high response rate, if we have hit the right group, but as I said, we've always done that. When I was a medical student, if you look down at the microscope and it looked like Hodgkin's disease, you had a treatment for that that had a high response rate. So now we take it one step further by saying we have genetics.*" – Melanoma
[Precision oncology means…] Using genomics as an additional source of data to guide treatment decisions	"*So if I had to use that term, I would honestly I would really limit it at this point in 2019 to decisions based on genetic somatic mutations.*" – Melanoma
[Precision oncology means…] Harnessing specific genomic alterations as the target or mechanism of action for precision treatments	"*Right, some ALK thing, or I'm specifically choosing chemo over some – platinum chemo over a fancy thing because they have a BRCA mutation, or I'm getting a PARP inhibitor because there are BRCA mutations.*" – Melanoma
[Precision oncology is…] Synonymous with personalized medicine	"*Now there's a lot more variety and its more individualized…*" – Thoracic
[Precision oncology is…] A marketing term	"*I feel like it's still a lot of hype and more PR than it is med-onc or surg-onc.*" – Melanoma
Theme 2: Clinicians and patients face unique challenges to precision oncology implementation	
Challenges encountered by clinicians	"*And so, the expectation of the clinician, the time to prepare for that client visit has just grown exponentially, and I'm not sure that we have yet to build that into our workflows.*" – Breast "*It's taking the extra time, making sure that you're not burning bridges, you're not precluding them from entering on clinical trials in the future that may be or may not be open. It's navigating clinical trials outside of our institution. What is best for you today without preventing you from entering promising trials in the future…. It takes a more nuanced and longer approach, and it's a moving target. Oh, you progressed on Drug X. Now you're asking me, what do we do next? Can I use precision medicine to determine this?*" – Breast "*And under that is not only that, but also having – getting tissue from outside hospitals to even test it… Or even delaying for a second biopsy if you didn't get a sufficient amount the first time… In our own institution just getting our own pathologists to do the stains that we need without asking them each time.*" – Melanoma
Challenges encountered by patients	"*And sometimes patients don't understand that it takes a long time sometimes to get the results. And sometimes, you did testing, and it's not enough material. And so now you've waited a couple weeks to find out, and there's not enough material.*" – Thoracic "*Or even, unfortunately, patients further out there that are seeing more rural communities that don't even know that some of these treatments exist. Their oncologists don't know that some of these treatments exist.*" – Melanoma "*But I mean but do they need to be followed by, in that case, a G.I. person or a whatever, right, for whatever incidental-oma that you found. That has consequences.*" – Melanoma
Theme 3: Patient communication challenges engendered or heightened by precision oncology implementation	
High expectations for personalization	"*Well, it makes them [patients] feel like they're being treated as individuals.*" – Melanoma
Counteracting the effects of media	"*And I have to say, part of the problem is how the media portrays cancer medicine. They'll take a case of one patient and it'll get like, 'breaking news, 24 hours.' And that's wonderful to present those kinds of cases in the research meetings to other researchers, but it's so irresponsible when they put that out there for people who come now, seeking this one amazing…. You know, the NIH case from last year. I mean, I don't know how many calls we must have all had, ask the patients about the N of 1 that was promoted.*" – Breast
Perception of the likelihood of a cure	"*I've seen patients come in with the idea that because you found this mutation, or they had this trial I'm eligible for this, it's going to be a home run thing.*" – Breast
Misperceptions about side effects	"*So, telling them that we can know a lot more about their tumor and then tailor a treatment that's very specific to them. A lot of patients come in and they're like, 'oh, I don't want chemo, because you know it killed my aunt'.*" – Thoracic
Aligning expectations with the realities of clinical trials	"*We were actually having a conversation just recently about, and I completely support clinical trials, but you reach a point where our patients have so much hope in the investigational, and they may be in the third-line setting and haven't yet had something with known benefit. And you're worried. You see their performance status kind of declining and they're sacrificing so much out of their everyday and their lives, hoping that there's the magic drug that's investigational that's really not proven yet. You kind of struggle.*" – Breast
Treatment outcomes are individualized and not necessarily predictable	"*I can also say that [colleague] here has a number of groups for the metastatic patients, younger, older. Or, the patient comes in and they've been on a trial or on a regimen for a long time, and they're doing exceedingly well. Another one doesn't do well, and you see responses vary among each other. That gives you a better understanding of how these drugs may or may not work in various individuals. It gives you hope. Oh my gosh, she's progressed on five regimens and now she's been well for the past year or two. And that allows patients to realize it's not uniform, it's different, depending on the individual. And I'm hopeful that I will be one that responds for a long time.*" – Breast

Table 1. Themes, subthemes and exemplar quotations from the breast, melanoma and thoracic oncology clinician participants (cont.).

Theme 3: Patient communication challenges engendered or heightened by precision oncology implementation	
Clarifying the range of possible treatment options	"*If I tell people, I don't know, I guess this is a little bit off topic, but in second-line or third-line therapy in melanoma, that's really where we're still in the wilderness, obviously, and if I tell them my rationale in some way is well because you had absolutely no toxicity to Ipi Nivo or response, that's why I'm kind of thinking that maybe you do need like an injectable, or you do need something to force the T-cells that – and sometimes they just really like the idea that you're thinking about their specific journey, and saying well, I've got five second-line, third-line trials there. They all have a response rate in the zero to 15% range and honestly, this is the one that has a slot open, which really is sometimes how you do it.*" – Melanoma
Sometimes precision treatments are not available	"*I think the biggest limitation of precision oncology, more broadly, is that unfortunately, the results don't frequently lead to treatments that will improve outcomes and that's where I think the disconnect is.*" – Breast
Options and outcomes can be better than patients expect	"*It's a lot easier to talk to them when we say, okay well, not everybody gets chemotherapy now. There are other treatments that are available. It depends on the IMPACT [institutional tumor-germline sequencing test] of your tumor. So that makes it a lot easier.*" – Thoracic
Managing disappointment and anger	"*I mean, you get reports back and there's nothing to do with it. And it's a short conversation and the patient's been waiting for a few weeks, and they're hopeful. And then, their bubble is burst and then you move on, and you talk about other treatment options.*" – Breast
Theme 4: Clinician communication solutions and training needs	
Communicating uncertainty	"*And I think all of us, to some degree, have a discomfort with uncertainty, but that I think for me starting out in fellowship that was one of the more difficult conversations to have with patients was when we – if you know the answer, even if it's not an answer you like, we've all had [training] on how to give bad news since day one of medical school, but uncertainty is something that even though our research is advancing us, we're actually, I think finding more uncertainty, not less.*" – Melanoma
Communicating rationale for treatment selection	"*So, when you think about communication strategies that we project or that we employ, I mean, I think it's important to say well, there really is no biomarker for CDK4 response, although we would like it, or for MTOR response. But we do have some for PI3 kinase. So, there is level setting. And so, while they may come in with certain preconceptions, they want to go out better.*" – Breast
Assessing patient knowledge and information preferences	"*Or their preconceived opinions about things. So, I'm thinking about, particularly the adjuvant conversation, you know, when you put your head on the pillow at night, are you the person who needs to know you did absolutely everything, or are you the person who is going to be really upset that you got a toxicity, and maybe no benefit?… And that's something that I have found myself saying later in the conversation and realizing that I should have said earlier in the beginning, and framed the conversation around that, as opposed to the other way around.*" – Melanoma

accepted examples of successful precision oncology. However, other developing treatment options were mentioned as being more precise than in the past and warranting inclusion in the 'precision oncology' definition. A melanoma clinician noted: "*Certainly, if you look at the evolution of surgery, which has gone from this maximal surgery and now we're down for much more precision, robotic.*" Others mentioned the use of different doses of ipilimumab, more targeted approaches to radiation treatment and trying to anticipate who might benefit from adjuvant treatments as relevant for precision oncology. Interestingly, one melanoma clinician noted that being able to anticipate and recognize certain patterns in cancer outcomes through experience, and really the art of medicine, also serves as an important element of precision oncology.

Many expressed the opinion that precision oncology is the application of new approaches to existing goals; because precision has always been important to cancer care, the current context simply follows from past thinking. What has changed is the mechanism by which approaches are made more precise. Participants noted that treatments have always worked toward precision for the patient, thus it is not the goal that has changed, but rather the tools for reaching this goal. As a melanoma clinician noted: "*Back when a pathologist would tell you, this was a lymphocytic sarcoma to the point that we now have all these subtypes of lymphoma, we treat them differently sometimes, and now we're looking at genetics. It's just a continuum.*"

Participants described that from the perspectives of clinicians and patients, precision oncology is frequently intimately linked with genomics. One key connection is using genomics as an additional source of data to guide treatment decisions, with genomic information being integrated with additional data, such as other biomarkers, histology, or patient characteristics, to help clinicians to select specific treatments over time. As one breast clinician explained, precision oncology is: "*marker driven, or protein driven, or genomic driven. Driven to make a prediction of [whether] you're more or less likely to respond to a particular drug.*" Genomic information could include both tumor and germline alterations that suggest a particular treatment may be efficacious for a given patient, or that make a patient eligible for a clinical trial of a novel therapeutic.

Further, participants cited ways in which precision oncology means harnessing specific genomic alterations that serve as the target or mechanism of action for precision treatments. Exemplar genomic alterations raised by

participants included *ALK* rearrangements, *BRCA1/2* germline mutations, *NTRK* fusions, HER2 amplifications and *BRAF* mutations, which are evaluated in their practice areas to guide precision oncology treatment decisions. In some cases, these genomic alterations are the target for a targeted therapeutic. In other cases, participants described how disrupting genomic and cellular processes can be the mechanisms of action for precision oncology treatments. Although patients may not fully understand the specifics of these alterations some level of awareness often exists, as exemplified by the following exchange among melanoma clinicians:

> Clinician A: "*It's not uncommon for patients to know a little bit and wanting to know if they have BRAF mutation, so to that extent, they understand precision...*"
> Clinician B: "*I mean, I think increasingly patients are asking, even if they don't know the word BRAF, you know, 'Are you looking at mutations in my cancer?'*"
> Clinician A: "*I had a patient come in asking about NTRK fusion.*"
> Clinician B: "*Oh, lots of patients ask about NTRK now that it was on the front page of the New York Times health section. So, I think even if they don't know necessarily the mutations that are common in their cancer, I think patients are thinking about precision oncology also in terms of genetics, particularly.*"

Precision oncology was further defined by some as being synonymous with personalized medicine, with these terms being used interchangeably to describe a shared therapeutic goal. The growth of treatment options is affording clinicians the ability to offer, and the desire among patients to receive, more individualized care. A breast clinician noted: "*patients think that it's of all the universe of treatment options. . . This is for me because of my unique situation.*" This pursuit of precise, personalized treatments is seen as an ongoing, evolving and data-driven process that is anticipated to ultimately culminate in improved patient outcomes. Participants acknowledged that achieving such personalized care is a complex process that is ideally executed by a multidisciplinary team reflecting diverse expertise. For instance, a thoracic clinician stated: "*You can get, certainly, tumor DNA. You can get SBRT [stereotactic body radiation therapy] anywhere. Surgery. . . So I think the patients really come to here, I think, for our level of expertise. And as [colleague] was hinting at, that multidisciplinary approach, because you have to sort out what does all this really mean for this patient individually.*"

Finally, participants also noted that precision is a marketing term, explaining how references to precision medicine and precision oncology are commonly encountered in health-related advertising campaigns, journal names and the popular press. These messages can both feed on and contribute to a sense of hype and optimism about the promise of individualized treatments among patients and families and do not necessary align with how clinicians think about these concepts. As a melanoma clinician explained, "*it's more of a slogan, because we've always done precision oncology, always.*"

Theme 2: Clinicians & patients face unique challenges to precision oncology implementation

All groups identified practical challenges to successfully implementing precision oncology, including challenges encountered by clinicians and challenges encountered by patients. Time was described as a barrier for both parties. Participants described how for clinicians, delivering precision oncology in the form of targeted or experimental therapeutics requires a substantial time investment for tasks including staying up to date on scientific advances, reviewing patient records, coordinating or waiting for sample acquisition and test completion, determining patient clinical trial eligibility, resolving insurance-related issues, and other challenges. As a breast clinician explained: "*. . . to educate people. That takes a lot of time. Looking at the pathology. Looking at the available clinical trials. Determining whether clinical trials are available for them elsewhere outside of MSK. Going to ClinicalTrials.gov. Emailing colleagues in the city and elsewhere. That takes a lot of time.*" Participants noted that patients can also experience difficulties due to the amount of time required to undergo testing to inform precision oncology treatments, sometimes leading to frustration and treatment delays.

Given the experimental nature of many precision oncology therapeutics, clinical trials represent a common route by which patients gain access to these treatments. Yet, participants described navigating clinical trials as burdensome for both clinicians and patients. Participants explained that clinical trials have become increasingly complex and require a great deal of clinician effort to establish that a patient is eligible for enrollment. The burden for patients can also be large, as a breast clinician stated: "*Clinical trials involve lots of visits for the patients, lots of long days. And oftentimes, they're not close to where they are living... So, it's a lot of burden in terms of commute or travel as well as lost days of work. So, the clinical trials, reasonably so because they're early-stage trials, are not necessarily very user-friendly.*"

Additional patient-relevant challenges were described, including a lack of awareness of available precision treatments among some healthcare providers. Participants described how patients who live in rural areas or receive care outside of academic medical centers may not have access to the tests and treatments included under the precision oncology umbrella. Another patient challenge involved the need for additional follow-up or management when precision oncology-related testing, such as germline DNA sequencing, identified incidental/secondary findings. Finally, difficulties with insurance coverage and treatment costs, including high co-pays, were noted as critical barriers for patients. A melanoma clinician described this challenge: "*But I think particularly with some of the targeted therapies, they're oral, their co-pays can be very high and while you're either appealing or asking for compassionate use, or whatever you attempt to do, there definitely is financial implications. The testing itself can be expensive in those places, but I think of that particularly with oral therapies and targeted therapy.*"

Theme 3: Patient communication challenges engendered or heightened by precision oncology implementation

Participants described multiple challenges faced specifically when communicating with patients and families about precision oncology approaches. A particularly salient challenge involved patients' high expectations for personalization, which were perceived as fueled by recent findings regarding tumor testing and the term 'precision oncology' more generally. A thoracic clinician noted: "*What they really care about is 'What's the plan for me?'*" Participants also mentioned increased patient expectations due to accessing the expertise and treatment at a leading center like MSK. For instance, participants described a challenging communication dynamic wherein some patients are eager to hear how the MSK-IMPACT (Integrated Mutation Profiling of Actionable Cancer Targets) tumor-germline sequencing test [35,36] will tailor their treatment and have high expectations thereof, yet clinicians can rarely can offer such tailoring. As a thoracic clinician described: "*They come with data and are digging into the reports and looking at the seventh gene on their IMPACT panel, and saying 'What does [this] mean for me?' Which is almost always nothing. But they want to know, 'How are you going to personalize treatment based on this?'*"

An additional challenge involved counteracting the effects of media. In the opinion of many participants, the media is an impetus for high expectations, as evidenced by the many patient inquiries they receive when news stories tout a new treatment. Difficulties can ensue when clinicians attempt to counter reports that are 'blown out of proportion'; as noted by a breast clinician: "*So, when you're mentioning that the response rate is actually this, and these are predictors for lack of response, and you actually would meet the criteria for someone who is unlikely to respond, it's kind of like an affront, questioning their understanding of what they've taken in from media and other sources.*" Media coverage of famous individuals who are noted to be doing well on novel therapies and anecdotal stories also inflate patient expectations about the efficacy of precision medicine. Similarly, some participants felt that media portrayals regarding new immunotherapy findings were leaving patients with the impression that these treatments were 'like a magic pill without side effects, all natural and holistic,' and potentially appropriate even in early-stage disease such as ductal carcinoma *in situ* (DCIS). The prospect of pseudo-progression in immunotherapy can also fuel optimism, with patients holding out hope that their tumors will eventually respond to treatment.

Additional communication challenges arise due to patients' perception of the likelihood of a cure with precision treatment approaches. For example, a breast clinician noted: "*I think there has been some negative repercussions too because I think a lot of people come with the expectation that their sequencing is going to dramatically change their lives*", leaving clinicians to "*be the ones to reeducate them, burst that bubble.*" These high expectations partially arise from patients linking personalized treatment with high probability of a cure, engendering a resilient hope that each successive treatment will work and that the next thing coming down the pike will be effective for them. For clinicians, having to temper or readjust these expectations and perceptions can be difficult.

Another element of this excessive optimism that complicates patient-provider communication is patients' misperceptions about side effects, such as the belief that if the treatment is more precise, it will involve fewer side effects. Patients can anticipate no side effects, or 'fewer side effects, or that it's going to be selective, or specific in a way' contrary to how clinicians think of treatment precision. In counterpoint, participants described that some patients may also be more willing to tolerate high levels of side effects because the treatment is seen as targeted. A melanoma clinician described this in the *BRAF* mutation setting: "*...Like patients are willing to put up [with] a lot of toxicity from BRAF than others, and they feel like we are treating their tumors specifically based on this mutation.*" Participants also noted pervasive negative patient beliefs about chemotherapy, given the perceived high side-effect profile, even when it might be an appropriate treatment for them.

The need for aligning expectations with the realities of clinical trials further complicates communication efforts. Building off the challenges described under Theme 2, participants perceived that the high level of preparation required for clinical trial involvement (e.g., acquiring tumor samples, confirming eligibility) can fuel unrealistic patient expectations. Some believed that patients may not appreciate the complexities of trial participation, such as the need to switch the primary treatment team, and trial team motives for collecting blood and tissue for research rather than treatment purposes. Consequently, some clinicians expressed mixed feelings about how promoting personalized treatment can implicitly or explicitly encourage patients to enroll on trials. Particularly in the investigational setting, patient expectations can be very high – even with third-line treatment – and participants expressed concerns about how to navigate conversations when they see patient functional status slipping while patients maintain high treatment expectations.

The reality that precision treatments can have diverse outcomes was a source of multiple communication challenges. One specific challenge involved explaining that treatment outcomes are individualized and not necessarily predictable. Participants discussed that although precision oncology is broadly expected to lead to better outcomes, the reality is that treatment outcomes can be diverse. When patients receive a 'precision' treatment, it is not always possible to predict who will have a favorable response and who will not. Thus, the outcomes of any given patient are not necessarily generalizable to other patients. As a thoracic clinician explained: "*I think there is a sense that if you have the lock and key for this particular tumor, then it's going to work. That it's going to work long-term. And sometimes it work[s]...and sometimes it just doesn't work.*"

Participants also discussed the nuances of clarifying the range of possible treatment options. Approved 'precision' treatments may be one option for a given patient, but other options such as traditional chemotherapy or clinical trials may also be available, and sometimes more appropriate. A breast clinician explained: "*There are patients who have gone through our research system here and been in clinical trials. At some point, they're still hoping for the next one to be the magic one so that they can stay away from standard of care and usual therapy. And I think being able to have that rapport with your patient to say, I'm going to know when a trial is the next option or when we're not going to look in that direction. And we need to get chemotherapy in here.*" Thus, clinicians must weigh and discuss how precision treatments may or may not fit into managing a patient's disease.

Further, sometimes precision treatments are not available, whether because no precision treatment exists for the diagnosis, or because a patient lacks the necessary characteristics (e.g., tumor mutations) to make them eligible for an existing precision treatment. This reality can be difficult for clinicians to explain and difficult for patients to understand and accept. A melanoma clinician described this dilemma: "*If they don't necessarily have a BRAF mutation, they're like, 'Well then what is in my cancer and what drug treats that?' Unfortunately, I don't know yet, right, or maybe I do know the driver and I don't have a drug for it, but that I think has been a difficult concept for a lot of patients, particularly in the BRAF negative space in melanoma.*"

On the other hand, participants noted how they sometimes get to communicate that the options and outcomes can be better than patients expect. Although most of the discussions related to treatment outcomes were negative in nature, participants did note that sometimes the treatment options available or anticipated therapeutic outcomes exceed patients' expectations. For instance, some patients believe that traditional chemotherapy is their only option and clinicians can have the pleasant experience of letting them know that newer precision treatments exist.

A final yet critical challenge involved managing disappointment and anger of patients and their families. Such negative emotions could arise during discussions about precision oncology where patients' expectations were unmet or acknowledged by clinicians as being inaccurate or unrealistic, as well as when treatment options were limited, data or test results were inconclusive, or disease responses uncertain. Thus, while needing to convey complex information about what precision treatments entail, clinicians also needed to be mindful of and responsive to patients' emotions.

Theme 4: Clinician communication solutions & training needs

Participants attempted to identify solutions to the myriad communication challenges associated with implementing precision oncology. A commonly cited possibility involved communicating uncertainty. Participants believed that it was difficult to explain medical and scientific aspects of uncertainty in ways that patients would understand. It was also noted that clinicians' feelings are a burden to such discussions: "*I think it's less about them and more about us. I think it's our level of discomfort and when we're uncomfortable, it's hard to frame that for them about what this result, information, prognosis, what anything means, so it's overcoming that too.*" Participants expressed concerns that by acknowledging uncertainty, they may leave patients with the impression that 'I don't know if that guy

knew what he was doing'. Consequently, participants described a strong need for training or support to develop effective communication skills to convey uncertainty clearly, and in a way that mitigates both patient and clinician discomfort.

Participants further identified the importance of communicating rationale for treatment selection, including explanations of the different treatments available, which biomarkers are relevant to a specific disease or that indicate suitability for a precision treatment, and the likelihood of successful outcomes. Participants emphasized not only the importance of ongoing navigation regarding these issues, but also expectation setting from the outset. As a breast clinician explained: "*But I think there's a lot of level setting. They come to you to basically filter all that information that's out there because I think they don't really understand it, and they're really coming to you for guidance as to how to level set all of that.*" Having good rapport with a patient allowed such discussions to progress smoothly.

Additionally, participants highlighted the importance of assessing patient knowledge and information preferences, and in turn, supporting patients in their understanding of novel, complex topics. Taking time to initially ask what patients know or anticipate, as well as where they have sought information (e.g., The Internet), can be helpful, although participants acknowledged that they did not always prioritize this. Participants noted various strategies for providing detailed, accurate information to increase patients' understanding of what to expect from precision approaches. In some cases, this could entail teaching 'Bio 101' in order to explain what precision medicine means. Additional effective communication strategies including use of analogies (e.g., 'the lock and the key for receptors and ligands, and putting something that is like putting bubble gum in the lock, blocks the receptor') and stopping to draw pictures or integrating other visuals into the discussion were cited.

Discussion

This study utilized focus groups to gather information about the experiences of clinicians across breast, melanoma and thoracic oncology regarding communication and the implementation of precision oncology with patients and families. Clinicians expressed a variety of perspectives in four overarching thematic areas: definitions of precision oncology, implementation challenges, patient communication challenges, and ideas about communication-based solutions.

The NCI defines precision medicine as the treatment approach where the right drugs or treatments are matched to the right people, based on a genetic or molecular understanding of their disease [37]. Clinicians in our study provided varying definitions of precision oncology including tailored treatments, personalized medicine, individualized care, genomics, and the right treatment for the right patient. Whereas many scholars use terms such as precision and personalized medicine interchangeably, some have recently argued for important yet subtle differences [38,39]. A different perspective was offered by some clinicians who touted precision medicine as more of a buzzword and a marketing term. Some argued that historically, cancer treatment has always been individualized based on histology, and the recent move toward adding genetic information to that individualization is what precision oncology entails. Whereas many scholars agree with the approach of treatment decisions based on histology, there is a growing consensus among clinicians and scholars on the promise of precision medicine in improving both cancer diagnostics and therapeutics [40–42]. Yet, there remain limitations in the availability and effectiveness of treatments and on the extent to which treatments can be truly customized to an individual patient. Clinicians in the present study expressed an awareness of these complexities and limitations to precision oncology, and acknowledged ways in which their interactions with patients indicated a less nuanced understanding of these realities.

Challenges in implementation included those encountered by clinicians and patients. Most of these challenges were related to organizational and structural issues including a lack of time; burdensome and logistical challenges of relevant tests, treatments and clinical trials; lack of access particularly for patients in rural or underserved areas; identification of incidental/secondary findings; and insurance-related barriers and high co-pays. Promising approaches to address some of these challenges include multidisciplinary institutional commitment to precision oncology diagnostics and therapeutics, setting up of a molecular tumor board composed of qualified multidisciplinary personnel, leveraging of electronic health records, and building capacity for technologies to manage, translate, and securely store vast genomic data [43–46].

Precision oncology implementation challenges could, in turn, contribute to communication challenges between clinicians and their patients. Multiple communication challenges were highlighted by clinicians including the high expectations that patients hold for treatment benefits (further amplified by media reports), greater likelihood of being cured, and fewer side effects. Further, communication challenges were noted when patients ask for precision treatments and they are unavailable. Some of these challenges can lead to extreme emotions including anger and

frustration from patients. These and other challenges such as dealing with uncertainty, communicating complex medical information particularly to patients with low health literacy levels, and patient (mis)understanding have been described by others [12,47,48].

Opportunities to address communication challenges

Strategies consistent with a shared decision-making framework may help clinicians to address these precision oncology communication-based challenges [24,49]. Adopting a shared decision-making approach to ensure that patients make fully informed decisions based upon their understanding of the available treatment options and a dialogue about the implications of treatment on their life would not only address patient expectations, beliefs, and fears, but also provide information that can be understood and recalled [50]. Ensuring that the patient has a clear understanding of the purpose, risks, benefits, and probabilities associated with a precision oncology treatment approach will also provide a critical foundation from which the clinician can begin to assess whether their expectations reflect an accurate appreciation of the approach [51,52]. It has been proposed that establishing such foundational understanding is ethically important for allowing clinicians to determine to what extent patients hold misperceptions that may interfere with their decision making, such as therapeutic misestimations about their likelihood of benefits and harms or unrealistic optimism spurring misplaced confidence and assumed positive outcomes, or are simply maintaining a reasonable sense of therapeutic optimism wherein they hope for the best personal outcome [51,53,54]. For instance, when patients voice inflated expectations about the likely detection of relevant biomarkers or unrealistic expectations of being cured, the clinician would ideally inquire about and check patient expectations and understanding of the testing process and treatment options. Asking open-ended questions about patients' feelings and information gathered from media and others, while encouraging them to ask questions, could lead to a discussion that is not only patient-centric and person-centric, but also closely aligned with patient understanding. Having an open dialogue about expectations would allow opportunities for the clinician to present best case, worst case, and most likely scenarios. Such an approach could present realistic outcome expectations for the patient while maintaining hope, and warrants further development and investigation.

This study provides practical insights for developing communication skills trainings for clinicians to engage in shared decision-making precision oncology conversations with patients and families. Communication skills (Comskil) training and research lab at MSK utilizes a multidisciplinary approach to designing Comskil training programs for addressing challenging conversations with patients and families [55]. Developing communication skills training modules that combine didactic presentation with an experiential component (i.e., role plays with standardized patients) to develop relevant skills identified by participants including communicating uncertainty and rationale for treatment selection as well as assessing patient knowledge and information preferences, may be a promising evidence-based approach to addressing precision oncology communication challenges [56]. Presuming such educational approaches would be efficacious in redressing precision oncology communication challenges, they would need to be situated in and supported by systemic and structural changes [46,57]. For example, the development of external policies and incentives to support clinician communication skills training or provide reimbursement and time for shared decision-making precision oncology conversations, integration of decision support tools or reminders in the electronic medical record to facilitate clinicians' execution of such conversations, electronic medical record templates to facilitate the documentation and sharing of these discussions and a clinician's conclusions among the multidisciplinary providers comprising a patient's care team, and healthcare organizational cultures that promote and climates that model acknowledging the presence of uncertainty, would all support improved future communication.

Strengths, limitations & future directions

This qualitative study allowed for in-depth analysis of the perspectives and communication experiences of clinicians across several oncology specialties that have ample experience with precision oncology approaches. However, the recruitment of clinicians who treat a limited range of malignancies among primarily adult patients from a single institution is a limitation, as is the fact that demographic or practice characteristics of the study participants were not collected. Thus, these results may not be generalizable to other cancer care settings or to interactions with different populations of cancer patients. Similarly, the communication challenges identified are unlikely to reflect a comprehensive list, but rather represent the most pressing concerns as indicated by clinicians involved in the focus groups. Data were collected in the context of pre-existing clinician meetings, which is a well-established approach in qualitative methodology [27,28]; nonetheless, possible hierarchies or patterns of interaction within these groups

may have impacted the discussion content, as may have the fact that the research team consisted of colleagues employed within the same medical institution. Deeper insight would be obtained from additional studies of the first-hand perspectives of diverse oncology care providers, as well as investigations of dyadic interactions between clinicians and patients as they navigate conversations about precision oncology.

Conclusion

Effective communication is a crucial component of delivering high-quality cancer care [58–60]. Innovations in precision oncology will undoubtedly continue to improve the ability to treat and manage cancer; however, these advances also introduce complex communication challenges for clinicians, patients and families. Understanding these challenges and developing effective strategies to help clinicians successfully navigate discussions regarding patients' expectations, fears, hopes and barriers, are critical steps toward ensuring that patients reap the full benefits of precision oncology.

Summary points

- 'Precision oncology' is a growing trend in cancer care. Yet, communication challenges between clinicians, patients, and their families represent a fundamental barrier to the implementation of precision oncology.
- Focus groups conducted with breast, melanoma, and thoracic oncology clinicians revealed four common themes related to their precision oncology communication experiences.
- Clinician participants indicated that varied definitions of precision oncology exist (Theme 1), which can be context dependent and differ across clinicians and their patients.
- Participants described how clinicians and patients face unique challenges in precision oncology implementation (Theme 2), such as time demands, burdens of navigating clinical trials, lack of awareness and access, and cost.
- Participants also described multiple patient communication challenges engendered or heightened by precision oncology implementation (Theme 3), many of which were related to patients' high or unrealistic expectations of precision therapeutics.
- Finally, participants shared clinician communication solutions and training needs (Theme 4) involving uncertainty, rationale for treatment selection, and assessing patient knowledge and information preferences.
- Future research is needed to develop strategies for helping clinicians to effectively manage these communication challenges.
- Communication approaches based in a shared decision-making framework may help clinicians to navigate these challenges, and could be taught to clinicians through communication skills training programs.

Supplementary data

To view the supplementary data that accompany this paper please visit the journal website at: www.futuremedicine.com/doi/suppl/10.2217/pme-2021-0048

Author contributions

JG Hamilton, SC Banerjee, PA Parker and JL Hay were responsible for study conception and design; JG Hamilton, SC Banerjee, SV Carlsson, J Vera, KA Lynch, L Sar-Graycar, CM Martin, and JL Hay were responsible for the acquisition, analysis, and interpretation of the study data; JG Hamilton, SC Banerjee, SV Carlsson, J Vera, KA Lynch, L Sar-Graycar, CM Martin, PA Parker and JL Hay were responsible for the drafting and revision of the manuscript, final approval of the manuscript for publication, and agree to be accountable for all aspects of this work.

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Ethical conduct of research

This study was reviewed and approved by the Institutional Review Board of Memorial Sloan Kettering Cancer Center (MSK). The MSK Institutional Review Board approved this study as exempt research, thus verbal assent to participate was obtained from all study participants.

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