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Health care provider perceptions of caring for individuals with inherited pancreatic cancer risk

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Abstract

Introduction: Recent national guidelines recommend genetic risk assessment for all patients diagnosed with pancreatic cancer, yet individuals with pancreatic cancer obtain genetic testing at suboptimal rates. Both patient and provider factors play a role in adherence to genetic testing recommendations. The purpose of this study was to understand health care provider perspectives of caring for patients with inherited pancreatic cancer risk.

Methods and Materials: Cross-sectional mixed method qualitative interview and survey study including health care providers who provide care for patients with pancreatic cancer or inherited risk. Qualitative data were analyzed using content analysis, while quantitative data were summarized using descriptive statistics.

Results: Thirty participants had complete interview data and 29 completed a survey. The sample was comprised of physicians (n=17), genetic counselors (n=6), nurses (n=3), and social workers (n=3). Respondents were less confident in their ability to identify patients with inherited pancreatic cancer risk compared to other hereditary cancer syndromes. Several challenges were identified including the pancreatic cancer illness trajectory; lack of evidence-based practice guidelines; difficulty interpreting genetic test results; and difficulty following up on referrals. Participants perceived a lack of educational resources for patients with inherited pancreatic cancer risk.

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Conclusion: Health care providers who care for individuals with inherited pancreatic cancer risk face challenges that are distinct from those encountered during the care of individuals for other hereditary cancers. There is a need for additional resources at the patient-, provider-, and systems-level.

Keywords

pancreatic cancer; inherited risk; health care provider perspective; qualitative research

Introduction

Recent advances in genomics and increased adoption of next-generation gene sequencing technologies have made it possible to identify individuals with inherited risk for pancreatic cancer.[1,2] Hereditary cancer syndromes and associated gene mutations account for between 10-15% PDAC cases.[3] Specifically, pathogenic changes in genes including *BRCA1*, *BRCA2*, *CDKN2A*, *EPCAM*, *MLH1*, *MSH2*, *MSH6*, *PALB2*, *PMS2*, *STK11*, *ATM*, and *TP53* [4,5,3,6,7] are associated with inherited pancreatic cancer risk and can be present even in the absence of a family history of cancer[8]. In addition to having a known hereditary cancer syndrome, individuals are at risk based on family history.[2] In a large prospective registry study of 5,179 individuals from 838 families, pancreatic cancer was seen more frequently in individuals with a first degree relative with pancreatic cancer compared to those with sporadic cancer. The risk of developing cancer increased 4.5- to 32-fold as the number of affected family members increased from one to three.[9]

Identification of individuals with inherited pancreatic cancer risk is essential to the adoption of precision health strategies in the pancreatic cancer care setting. Identifying individuals who harbor a pathogenic gene mutation associated with a cancer syndrome (for example, *BRCA1/2* for Hereditary Breast and Ovarian Cancer Syndrome or Mismatch Repair (MMR) Genes for Lynch Syndrome) presents an opportunity for multiple cancer risk reduction and early detection outside of pancreatic cancer, which has implications for the individual and family members. Individuals without a diagnosis of cancer who are aware of inherited risk for pancreatic cancer may engage in risk-reducing lifestyle modifications or undergo pancreatic cancer screening via endoscopic ultrasound and magnetic resonance imaging. [10-12] Due to the potential for patient and family benefit, germline genetic testing is now recommended for all patients with pancreatic adenocarcinoma (PDAC).[13,6,14]

In preliminary research, patient perceptions and psychosocial outcomes of living with inherited pancreatic cancer risk were described,[10,15] and it was clear that health care provider recommendations and patient engagement in health care were critical to shaping the patient experience. Therefore, in this study, we sought to (a) understand the typical practice of providers when identifying and communicating about inherited pancreatic cancer risk; (b) describe what providers perceive to be the most common or most significant challenges of caring for patients with or at risk for pancreatic cancer; and (c) identify the clinical resources utilized by providers who care for patients with inherited pancreatic cancer risk.

Methods and Materials

Study Design and Theoretical Framework

The study utilized a cross-sectional mixed qualitative and quantitative research method. Data collection and interpretation were informed by the theory of Patient-Centered Communication[16].

Sample

Health care providers who care for patients with inherited pancreatic cancer over the past five years were recruited from three academic medical centers. A health care provider was defined as a physician, nurse, nurse practitioner, physician assistant, social worker, or genetic counselor and 95 potentially eligible participants were identified from publicly available data.

Recruitment Procedures

Eligible individuals were emailed an information letter containing all elements of consent to consider participating in telephone or in-person interviews followed by survey data collection.

Data Collection

Interview.—One-time semi-structured individual interviews were completed in person or over the telephone by author MU from 09/2016 through 01/2017. An open-ended interview guide was used to provide prompts for the discussion. Each interview began by asking the participant to describe their practice with patients that have pancreatic cancer or pancreatic cancer risk and how genetics or genetic counseling is discussed as part of this practice. Interviews lasted 15-60 minutes and were audio-recorded, de-identified, and transcribed for analysis.

Survey.—The study team-developed brief self-report survey included demographic questions (i.e. gender, clinical field and specialty, years of experience, frequency of patients seen or referred to genetic counseling in the patient 6 months, types of hereditary cancer syndromes commonly seen in their practice) and items about the participant's perceptions, awareness, and confidence in recognizing and managing inherited pancreatic cancer risk.

Analysis

The qualitative analysis software Nvivo 11 (QSR International) was used for data management and extraction of exemplar quotations. Analysis of the interviews was done using a content analysis method typically applied in qualitative research to identify patterns, consistencies and differences noted throughout the interviews as a whole.[17,18] Authors MU and MY independently reviewed and analyzed 20% of the interviews. Authors MU and RP each completed analysis on the remaining transcripts and discussed the results until consensus was reached. Survey data responses were summarized descriptive statistics.

Results

Of the 95 individuals recruited, 34 responded and agreed to participate (36% response rate). Two participants were lost to follow up prior to completing an interview. Of the remaining 32 participants, 30 had interview data for analysis and 29 completed and returned a survey.

Summary of Quantitative Findings

Respondent characteristics are summarized in Table 1. Of note, 41.4% (n=12) had completed continuing education including information about inherited pancreatic cancer risk in the past five years. Most felt comfortable identifying Lynch Syndrome (82.8%, n=24) and hereditary breast and ovarian cancer syndromes (HBOC; *BRCA1/BRCA2* mutation) (79.3%, n=23). Less than half felt comfortable identifying hereditary pancreatitis (48.3%, n=14) or familial atypical multiple mole melanoma (*FAMMM*) (44.8%, n=3).

Survey results describing provider reported confidence with inherited pancreatic cancer risk is provided in Table 2. Slightly more than half of respondents were confident in their understanding of inherited pancreatic cancer risk (58.6% agreed or strongly agreed, n=17) and felt that they were adequately prepared to identify individuals with inherited pancreatic cancer risk (65.5% agreed or strongly agreed, n=19). Approximately half of respondents reported feeling confident in their knowledge of available pancreatic screening procedures (51.7% agreed or strongly agreed, n=15).

Summary of Qualitative Findings

Four major themes related to the unique experience of caring for individuals with inherited pancreatic cancer risk were identified. Exemplary quotes for each theme are provided in Table 3. Two interviews had failed audiorecordings and therefore transcripts were not available, only field notes. These two interviews were excluded from the analysis.

Theme 1: Responsibility of identifying inherited pancreatic cancer risk.

The extent to which participants described identifying inherited pancreatic cancer risk varied by participant profession and specialty. Medical doctors, particularly those specializing in medical oncology and gastroenterology, often perceived a responsibility to identify patients with inherited pancreatic cancer risk. These participants reported initiating conversations with patients about family history, typically during the first visit. The first visit was described as a key referral point, and if the referral was not made during that visit it might not occur.

Though most participants discussed inherited pancreatic cancer risk in the context of a patient with pancreatic cancer, genetic counselor participants also discussed implications for unaffected family members with inherited pancreatic cancer risk and the importance of testing. The importance of referring and managing the psychosocial stress of the unaffected individual was important, typically because these individuals were referred to genetic counseling following the death of a loved one. Gastroenterologists also described facilitating referral for genetic counseling as needed when risk was discussed in the context

of pancreas imaging. Other professionals interviewed, such as social workers, nurses, and radiation oncologists, did not refer potentially at-risk patients.

Theme 2: Challenges of caring for patients with inherited pancreatic cancer risk.

Barriers to genetic risk assessment.

Pancreatic cancer illness trajectory.: Among participants who care for patients with PDAC, the unique trajectory of the disease was perceived to limit the extent to which risk assessment could be prioritized. Concerns about the severity of illness and rapid disease progression caused some participants to view identification of inherited pancreatic cancer risk as a “secondary concern” over which to the need to plan and initiate treatment takes precedence. Genetic counselors and medical oncologists also explained that in some cases, patients do not survive long enough to complete a genetics referral—a problem that is sometimes compounded by long wait times in the genetics clinic. Genetic counselor participants further expressed that referral was a challenge and there were times when patients with low risk were referred or when those with potentially high risk were missed and then never seen due to illness progression.

Provider knowledge and confidence.: Across practice settings, physician participants reported confidence identifying and referring for genetic risk assessment individuals diagnosed with PDAC at a “young age” and those with a “strong family history” of PDAC. In the absence of these clinical characteristics, however, participants were less confident in deciding when to refer. Apart from genetic counselors, participants from every profession expressed that having limited knowledge of the inherited genetic basis of PDAC hindered the extent of care. Medical oncologists and gastroenterologists cited a lack of standard referral guidelines as a major barrier to the identification of patients with inherited pancreatic cancer risk. Participants questioned whether referrals made were “appropriate” and wondered whether patients had been “missed” who ought to have been referred. Physician participants from every practice setting perceived a lack of systems-level support for genetic risk assessment, limited time during the clinic visit to review family history, and a lack of prompts to refer eligible patients for genetic risk assessment. Providers shared that due to limitations to availability of genetic counselors, lack of prompts in the medical record, and challenges with documenting family history risk assessment, referral for genetic risk assessment was often missed.

Challenges following genetic risk assessment.

Difficulty interpreting results.: Medical oncologists and genetic counselors alike found it challenging to interpret certain genetic test results. It was difficult to quantify the risk associated with certain gene mutations, interpret variants of unknown significance, or explain a negative result in the context of a “strong” family history. Overall, participants felt that they were not yet able to fully interpret or apply all information that came from genetic testing in this context because scientific understanding of the implications of germline genetics in PDAC is still emerging.

Challenges associated with PDAC screening in high risk individuals.: Genetic counselors and physician participants from every practice setting acknowledged that there is a lack of

evidence-based pancreatic screening protocols for healthy patients with inherited pancreatic cancer risk. Although most participants perceived that patients felt benefit from “doing something,” other participants were ambivalent about engaging patients in pancreatic screening when the associated reduction in pancreatic cancer risk is unknown. Gastroenterologists who engage patients in pancreatic screening procedures perceived that most patients experience anxiety prior to and during screening. These participants explained that patient anxiety in the pancreatic screening context is more often related to potential findings than the procedure itself. Following screening procedures, gastroenterologists described being challenged to interpret, formulate a plan of care to address, and communicate with patients about “mildly abnormal” findings.

Difficulty “closing the loop.”: Some conversation was focused on the larger process of genetic consultation, not unique to PDAC. Following referral for genetic risk assessment, medical oncologists routinely found it difficult to determine whether a patient had been seen in the genetics clinic, whether genetic testing had been done, whether results had been communicated to the patient, and whether the patient had been referred for any recommended screening.

Theme 3: Perceived needs of patients with inherited pancreatic cancer risk.

Regardless of profession or practice specialty, participants observed that many individuals with inherited pancreatic cancer risk have experienced the loss of a relative to pancreatic cancer. Most participants described an interdisciplinary approach to meeting the needs of patients with inherited pancreatic cancer risk. For example, medical oncologist participants reported that they support patients’ psychosocial needs by referring them to a social worker and, if appropriate, for genetic risk assessment or pancreatic cancer screening. Medical oncologists, gastroenterologists, social workers, and genetic counselors specifically described genetic risk assessment and pancreatic cancer screening as opportunities for patients to feel as though they are “doing something” for their family members or themselves. Participants from every profession and practice setting cited a lack of educational resources for patients with inherited pancreatic cancer risk.

Theme 4: Recommendations for improving practice.

Genetic counselors, medical oncologists, and gastroenterologists wanted increased support on a systems-level for assessment and referral. Medical oncologists sought data-driven ways to identify and quantify inherited pancreatic cancer risk that are embedded in clinical systems. Specifically, these participants desired streamlined processes for collecting and documenting a patient’s family history, flagging criteria for immediate referral, referring a patient for genetic risk assessment, following up on referrals, interpreting genetic test results, and referring a patient for pancreatic cancer screening. Genetic counselors wanted oncologists and other providers to be more knowledgeable about the role of genetics in pancreatic cancer.

Discussion

Participants in this study perceived that individuals with inherited pancreatic cancer risk face challenges that are distinct from those faced by individuals with or at risk for other hereditary cancers. In turn, health care providers and patients must contend with a health care infrastructure that was developed to meet the needs of a dissimilar patient population. Central to the themes described above is a need to prepare providers to face the ever-changing field of cancer genetics and to meet the needs of this severely ill patient population. Recommendations include education to support health care providers to navigate the ever-changing and complex field of inherited pancreatic cancer genetics as well as creating systematic mechanisms to support facilitating genetic testing in patients with pancreatic cancer.

The timing of addressing such restructuring and education is now critical. Since completion of this study, guidelines published by the National Comprehensive Cancer Network[13] and supported by the American Society of Clinical Oncology[6] recommend consideration of referral of all individuals diagnosed with PDAC for further genetic testing regardless of age or family history. Data support utilizing multigene panel genetic testing to evaluate inherited cancer risk.[7,19] Therefore, health care providers are now urged to address inherited pancreatic cancer risk as part of the standard of care.

Guidelines provide an opportunity to improve the standard of care. However, it is well understood that establishing guidelines does not automatically lead to the intended outcome of adherence to guidelines-based care.[20-22] Though there have been guidelines in place recommending genetic testing in the context of ovarian cancer since 2007,[23] only 1 in 5 women in the U.S. who have ovarian cancer obtain genetic testing.[22]

In the context of PDAC, where inherited risk can arise from multiple genes and cancer syndromes, the process is likely to be even more challenging given the illness trajectory, as well as other issues such as provider confidence, systems level processes, and barriers to genetic information interpretation as outlined in the current study results. Therefore, the first step of clarifying who should be referred has been addressed through the recently established guidelines. It is noteworthy that all individuals with cancer continue to be referred to genetics at suboptimal rates[24,25,20] and that a substantial proportion of health care providers in the oncology setting experience challenges communicating about genetics and interpreting germline genetic test results.[26-28] This could in part be due to the structure of health systems and system reimbursement. The time allotted for encounters is often brief and dictated by reimbursement, making a detailed and in-depth discussion of germline genetic testing and testing implications by the oncologist in the context of a complex diagnosis a challenge.

In one recent study, a traditional model of genetic counseling and testing, which includes pre-test genetic counseling, testing, and post-test results disclosure and counseling if positive, was implemented for all patients with PDAC over an 11-month period. Over this period 26% of PDAC patients were referred for genetic counseling and 92% of those referred had counseling and testing. Though once referred it was feasible to see the patient,

even within a structured universal testing process, clinician referral remained a critical barrier to achieving optimal success.[29] As discussed by health care providers participating in the current study, the severity of PDAC and significant illness experienced place competing demands on the provider which may lead to a missed opportunity for genetic testing. Our findings in conjunction with such data strongly suggest that traditional models of genetics care delivery will likely fail to meet patient and provider needs within in this clinical context.

There are novel alternative models to provide cancer genetic counseling outside of the traditional pre-and post-counseling framework. Telegenetics is one model that is effective at reaching patients and providing increased access to genetic counselors, particularly in the context of *BRCA1/2*. [30,31] Having cancer genetic counseling embedded within a clinic and completed by the patient's oncology team has also been demonstrated as potentially effective in increasing access to testing. [31,32] There are limitations to the scalability of both the telegenetics and embedded approach and the resources required to successfully implement this in practice. Additionally, an abbreviated or streamlined care model, [33-35] which reduces pre-test counseling by providing the minimum necessary information and focuses on post-test counseling based on results might also be a consideration in pancreatic cancer, an already highly clinically burdened patient group. [31] Using ovarian cancer genetic testing again as a model, [23] one study found that the implementation of a structured referral system embedded within the electronic medical record led to increased rates of referral [36] and testing. [37] Therefore, systems-level interventions are likely a key to successfully addressing inherited pancreatic cancer risk within a clinical context. Though there are some alternative strategies to consider, more research is needed to understand how to implement and sustain novel models of clinical care and the impact on patient outcomes within the pancreatic cancer setting.

In summary, there are key recommendations for health care providers and health care systems that come from this study. First, it is critical that providers who care for patients or families with PDAC understand recent guidelines and implications of genetics on the patient and family and access genetic testing accordingly. Second, health systems should develop strategies to systematically incorporate risk assessment and testing into the structure of standard care. Finally, novel, brief and targeted counseling and testing mechanisms to inform and test patients should be evaluated for efficacy and if warranted implemented so that all patients and families can access the benefits that come from awareness of inherited pancreatic cancer risk.

Limitations.

The study was conducted prior to publication of updated NCCN guidelines and ASCO clinical practice recommendations, which recommend universal genetic testing for all patients with pancreatic cancer adenocarcinoma. Therefore, practice perceptions may have changed since completion of data collection, however, given what historically has been seen in the context of ovarian cancer providing a guideline does not systematically translate into patient care and likely there is still much to be addressed as identified in this study. Additionally, the experiences and perceptions of providers without access to a specialty

genetics care within academic medical centers are likely to be different, but given that academic medical centers are typically the model for practice change challenges identified in this study are likely amplified in a clinical setting. The response rate of participants was only 36% and there were limited responses from non-oncologist or genetic counseling professionals. Finally, the focus of this work was on germline genetic testing, not somatic testing and should therefore be interpreted as such. Future work should further characterize the experiences of providers from a variety of different professions and practice settings.

Conclusions

The complexities of cancer genetics care in the context of PDAC present many opportunities for growth within this domain. Several key areas to tailor care to the needs of patients with PDAC were identified, including the need for targeted provider education about inherited pancreatic cancer risk, systematic risk assessment, improved family history documentation, streamlined referral, and a structured and evidence-based way to follow up and provide patient resources upon identification of inherited risk.

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Table 1.**Respondent Characteristics**

N = 29	n	(%)
Gender		
Female	15	(51.7)
Male	14	(48.3)
Profession		
Medical doctor	17	(58.6)
Genetic counselor	6	(20.7)
Social worker	3	(10.3)
Registered nurse	2	(6.9)
Nurse practitioner	1	(3.4)
Clinical practice setting		
Medical oncology	16	(55.2)
Genetics and cancer prevention	6	(20.7)
Radiation oncology	3	(10.3)
Gastroenterology	2	(6.9)
Surgical oncology	1	(3.4)
Other	1	(3.4)
Years of practice experience		
1-5	7	(24.1)
6-10	7	(24.1)
>10	15	(24.1)
Years of experience caring for individuals with inherited pancreatic cancer risk		
1-5	9	(31)
6-10	8	(27.6)
>10	12	(41.4)
Have you completed continuing education including information about inherited pancreatic cancer risk in the past 5 years?		
Yes	12	(41.4)
No	17	(58.6)
Number of patients referred to genetic counseling related to inherited pancreatic cancer risk in the last 6 months		
0	10	(34.5)
<5	7	(24.1)
6-10	7	(24.1)
>10	4	(13.8)

Table 2.**Self-Reported Preparedness to Care for Individuals with Inherited Pancreatic Cancer Risk**

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
N = 29	n (%)	n (%)	n (%)	n (%)	n (%)
I am confident in my understanding of hereditary or familial pancreatic cancer risk.	1 (3.4)	6 (20.7)	5 (17.2)	13 (44.8)	4 (13.8)
I feel that I am adequately prepared to identify individuals at hereditary or familial risk for pancreatic cancer.	3 (10.3)	3 (10.3)	4 (13.8)	14 (48.3)	5 (17.2)
I feel that I am adequately prepared to refer individuals at hereditary or familial risk for pancreatic cancer for genetic evaluation.	1 (3.4)	1 (3.4)	3 (10.3)	13 (44.8)	11 (37.9)
I feel confident in my ability to refer family members of patients that are at hereditary or familial risk for pancreatic cancer for genetic evaluation.	1 (3.4)	3 (10.3)	4 (13.8)	11 (37.9)	10 (34.5)
I am aware of resources available at my institute related to genetics and pancreatic cancer risk.	1 (3.4)	1 (3.4)	4 (13.8)	10 (34.5)	13 (44.8)
I feel prepared to address the psychosocial needs of individuals at hereditary or familial risk for pancreatic cancer.	2 (6.9)	1 (3.4)	8 (27.6)	13 (44.8)	5 (17.2)
I am aware of screening options for patients at hereditary or familial risk for pancreatic cancer.	1 (3.4)	4 (13.8)	6 (20.7)	12 (41.4)	5 (17.2)
I am confident in my knowledge of available screening procedures for patients at hereditary or familial risk for pancreatic cancer.	2 (6.9)	6 (20.7)	6 (20.7)	10 (34.5)	5 (17.2)
I believe that patients at hereditary or familial risk for pancreatic cancer would benefit from screening or surveillance.	0 (0)	0 (0)	11 (37.9)	11 (37.9)	7 (24.1)

Table 3.

Summary of Qualitative Findings and Exemplar Quotations

Themes / Subthemes	Exemplary Quote(s)
Theme 1. Responsibility for identifying inherited pancreatic cancer risk	<p>I would say that even though we try to get some family history from patients, it doesn't factor into a lot of how I care for patients with pancreatic cancer. (Physician, radiation oncology)</p> <p>I always take a family history in my initial visit. If they either have had a first-degree relative with pancreatic cancer, or breast, or ovarian or other gastric—others that we tend to think of as running in hereditary syndromes—if multiple family members have been affected by cancers, melanoma too, or just if they're at a young age and it seems surprising. Then we often will say, "you probably should talk to the genetic counselor." (Physician, medical oncology)</p> <p>...The usual circumstance is probably where the pancreas cancer is kind of secondary— to either breast or colon or something else. ...it's often because it's in a first degree relative or more than one other relative [with pancreatic cancer]; there's a known mutation in the family; or perhaps the patient comes in with that as a primary concern because they were a caretaker or close to someone in the family who had the disease. (Genetic counselor)</p> <p>And most often what we'll do is refer to the genetics program to kind of piece together the emotional support from us and then more of the information from geneticists. (Social worker)</p>
Theme 2. Challenges of caring for patients with inherited pancreatic cancer risk	<p><i>Barrier to genetic risk assessment: lack of clear guideline s for referral</i></p> <p>I don't have absolute criteria [to refer for genetic risk assessment] ...certainly younger age with a family history, and then I'm not sure that I have a consistent criterion for younger age; you know, is it less than 55, less than 60, less than 65? (Physician, medical oncology)</p> <p>I think pancreas has been a little bit more challenging, because I'm not sure we... have sort of the checklist of like, "Well, if there's one, but it's like a cousin, should they see those people, or what age should they automatically see [a genetic counselor]?" (Physician, medical oncology)</p> <p><i>Barrier to genetic risk assessment: pancreatic cancer illness trajectory</i></p> <p>It takes a long time to get in [to the genetics clinic], and when you have pancreatic cancer, you don't have that long to wait. ... it's tough because people die so quickly. Whereas with colon cancer, you've got plenty of time usually to get it right. (Physician, medical oncology)</p> <p>It does take a while, because you know in the beginning when someone is just diagnosed and undergoing treatment, it takes a lot to get going, and there's a lot of appointments and tests and procedures involved. ...And so this [genetic risk assessment] does get pushed a little bit to the wayside. (Physician, medical oncology)</p> <p><i>When meeting with a patient with pancreatic cancer, I think the biggest issues that I have are that they're almost always very, very sick.</i> (Genetic counselor)</p> <p><i>Barrier to genetic risk assessment: provider knowledge/ confidence</i></p> <p>...for pancreatic cancer... I feel much less confident. Like, with the BRCA, I have a pretty good sense of "they're going to have breast cancer. They're going to have ovarian cancer." There's a pretty high risk there, and I can—it's quantified and it's a number I can look up and know. I don't have that same sense that if they're "my grandma had pancreatic cancer, and do I know that it increases my risk?" I don't know. I don't know whether that's a really big risk. (Physician, radiation oncology)</p> <p>I find that it's hard to keep up. Unless you're a geneticist, it's hard to keep up with all the developments, and the gene mutations—and associating them. Like, I don't know of a good resource to stay abreast of that. (Nurse practitioner, medical oncology)</p> <p><i>Challenges associate d with pancreatic screening for</i></p> <p>All these tests are—as I said, most of the time we're doing it—negative, but does it help people? Does it not help people? I don't want to put people through tests that they don't truly need. So, I don't know. (Physician, gastroenterology)</p>

Themes / Subthemes Exemplary Quote(s)		
	<i>high risk individuals</i>	<p>We don't have the numbers. We're [not going to use] that kind of data. So, that's one limitation. And then their limitation in terms of surveillance or screening is inherent in the fact that we don't have guidelines to fall back on to the best ways of screening. (Genetic counselor)</p>
	<i>Difficulty "closing the loop"</i>	<p>So, I've referred you out, and then it's like five months down the line, "Well, did you ever go to Genetics?" ...And then by the time the testing is complete, so much has happened with your index patient, that you are not as concerned about genetics anymore. (Physician, medical oncology)</p>
Theme 3. Perceived needs of patients with inherited pancreatic cancer risk	<i>Challenges interpreting genetic test results</i>	<p>When you have a family, who has three or four people with pancreatic cancer and you go through the pancreatic cancer panel, and the testing comes back negative, you can't tell them, "you're not at risk." Like, something is definitely going on. (Genetic counselor)</p> <p>I think it just highlights our own limitations and our own feelings of impotence when we can't say to the person, "yes, you have an elevated risk of pancreas cancer, and there's very little-- at the moment, you know, to do about it." ...It sort of is selfish in a way that makes me feel like I can't give them anything. It is a source of discomfort. (Genetic counselor)</p> <p>As I am sending them on their way, either with this genetic test that was uninformative, or have not offered genetic testing, they're still really anxious or they feel like they came to us and got nothing out of it. So, I think having either like written [material], or a website to go to...would be really helpful. (Genetic counselor)</p>
Theme 4. Recommendations for improving practice		<p>The harder ones are the people whose parents just passed away. And maybe they have another relative who also had pancreatic cancer, and they see how fast it can be between diagnosis and dying. And those are the people who are the most scared, and so regardless of whether they have advice where we do genetic testing, we offer them screening. When somebody knows, they have a plan, even if you say it's not a perfect plan and it's not the best plan that we could ever come up with, but it's the plan we have. I think it gives people, "I'm doing something." (Genetic counselor)</p> <p>With pancreatic patients, mostly they're worried about other family members, I would say. Especially when they have had pancreatic cancer in their family already. "My uncle had it, now I have it. Is this going to be a risk for my children in the future, and what can I do to test for it?" (Registered nurse, medical oncology)</p> <p>I think a uniform approach across the—certainly at least the institutions—would be nice. ...even just guidelines... I think that physicians that would respond to that kind of thing well. (Physician, medical oncology)</p> <p>I think if there was a more automated way that family history somehow was taken and recommendations were made to the doc about referrals to genetics, I think that would be helpful. (Physician, medical oncology)</p> <p>...the likelihood of finding a gene mutation is so small, that I feel like a lot of patients, especially with, pancreatic cancer and pancreatic cancer risk...often get disappointed in genetics. And I feel like if we could educate the doctor actually seeing them before us, they could manage their expectations a little better. I also feel like the patients would come in to us in a better place to listen and understand. (Genetic counselor)</p> <p>...the whole Pandora's box of "what you do when you find that somebody's got a high-risk condition for pancreatic cancer?" The whole screening field is sort of in flux. You're [relying on] consensus-based recommendations. Nobody has any evidence-based recommendations that I'm aware of. (Physician, medical oncology)</p>