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Communication About Negative and Uncertain Results: Interactional Dilemmas During a Genetic Telehealth Consult

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Abstract

This case study focuses on a video telehealth consult to discuss genetic testing results. Participants include a Genetic Counselor (GC) and a Patient (P) previously diagnosed with ovarian cancer who is currently undergoing chemotherapy treatments. Utilizing conversation analysis (CA), attention is first given to a series of interactional dilemmas as GC delivers and P responds to negative, uncertain, and complex test results. Specific findings address practices employed by GC to structure the encounter and establish authority, impacts on P's participation and understandings, recurring and at times problematic orientations to "negative" findings, and inherent ambiguities faced by GC and P when attempting to discern good and bad news. Close examination of these moments provide a unique opportunity to identify, describe, and explain genetic counseling as a co-produced, interactional achievement. These findings are then integrated with patient's post-counseling survey (susceptibility, anxiety, uncertainty, fear, and hope), including reported experiences which broaden understandings of the interactional environment. Specific recommendations are raised for improving counseling skills, enhancing patients' understandings, and building therapeutic alliances addressing both patients' emotional circumstances and the complexities of genetic test results.

Keywords

cancer communication; clinical encounters; delivering and receiving good and bad news; genetic counseling; uncertainty management

Recent scoping reviews address how complex cancer information gets communicated in an era when genetic and genomic testing and results are increasingly utilized (e.g., Chavez-Yenter et al., 2021; Kaphingst et al., 2019). Despite the critical importance of "enabling accessible and patient-centered approaches to returning genetic test results to their patients and families" (Kaphingst et al., 2019, p.5), understandings of the interactional organization

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of genetic counseling sessions are only beginning to emerge (Stivers & Timmerman, 2016; Timmerman & Stivers, 2017). The technological sophistication of genetic testing has outpaced research focusing on close examinations of genetic counseling as a distinctive form of institutional encounters between health professionals and patients (Beach, 2013; Drew & Heritage, 1992).

This case study closely examines initial moments from a naturally occurring, video recorded, and transcribed telehealth conference between two participants: A Genetic Counselor (GC) and a Patient (P) previously diagnosed with ovarian cancer who is currently undergoing chemotherapy to shrink tumors and make surgery possible. Interactions analyzed in their session, returning results from genetic testing, draw attention to inherent difficulties associated with GC's delivery of and P's responses to test results revealing a variant of uncertain significance (VUS) finding (Zhong et al., 2020; Zhong et al., 2021). VUS are common findings among individuals undergoing multi-gene testing for cancer risk. The standard of care for VUS results is that they are not used for medical management or risk assessment, and family members generally are not recommended to undergo testing for a VUS result. Most VUS are ultimately reclassified as benign findings, but a subset are reclassified as pathogenic (or harmful) mutations.

Genetic counseling has been defined as "the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates: 1) Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence; 2) Education about inheritance, testing, management, prevention, resources and research; and 3) Counseling to promote informed choices and adaptation to the risk or condition" (Resta et al., 2006, p.78). The classic model of cancer genetic counseling involves an initial session (pre-test) which involves the above elements. If patients elect to have genetic testing, counselors schedule a separate discussion for the return of genetic test results (Roter, 2006). Given increasing utilization of genetic test results in clinical care, multiple models of genetic counseling are being utilized to allow for greater access including telephone/video-based genetic counseling, group genetic counseling sessions, usage of videos, online modules, and "mainstreaming" testing where healthcare providers other than genetics specialists coordinate testing followed by referral to genetics specialists once results are received (e.g., Hynes, 2020; Kinney, 2014; McCuaig, 2019).

Situated within a larger genre of institutional health interactions, genetic counseling can be compared with other speech exchange systems including primary, cancer, pediatric, or disability care (Beach, 2013; Heritage & Maynard, 2006; Maynard & Turowetz, 2017). Communication between cancer patients and genetic counselors, however, gives priority to delivering, receiving, and attempting to clarify often complex news about the relationship between cancer and genetics, familial cancer risk assessment and management, and genetic testing (Maynard, 2003; Roter, 2006). A combination of educational and psychosocial counseling methods are employed (Roter, 2006). Historically, non-directiveness has been a key tenet to avoid influencing clients' decision-making (e.g., about childbirth or any values and beliefs patients and family members deem important). Cancer genetic counseling often utilizes more directive approaches, as increasing priority is given to enacting relationally sensitive behaviors to advance good and reduce harm for patients (Jamal et al., 2020). For

example, evidenced-based interventions can be clearly recommended to reduce the risk of advanced cancer in patients and their family members.

Two methods are employed for this study. First, using conversation analysis (CA), close examinations are provided of selected interactions between GC and P within the initial 4:24 minutes of a 20 minute videorecorded post-test genetic counseling session. Second, following the post-session, P completed a survey to report perceptions about the encounter and her health experiences. P's responses to survey measures provide a unique opportunity to integrate her cancer experiences with patterns of interaction during the encounter. These perceptions broaden understandings of patient-centered concerns during a genetic counseling session. Quantitative analysis is provided to assess and integrate P's reports with interactional orientations displayed during the session.

Methods

This case study is part of a larger research collaboration between two NCI designated Comprehensive Cancer Centers and three research universities in the western United States.

Procedures

Patient participants were introduced to the study at their pre-test genetic counseling consultation, then recruited with follow-up contacts by research assistants. Participants, including genetic counselors, patients, and their family members, signed consent forms prior to data collection. Consent was given to video record post-test genetic counseling sessions and subsequent family discussions, and for survey data collection. Study protocols were approved by Institutional Review Boards (IRBs) at participating institutions.

P chose to have germline genetic testing to inform treatment, determine possible hereditary causes of her cancer, and identify potential increased cancer risks for her biological family. Interactions examined herein occur during their second appointment, which was scheduled for the return of test results. GC and P previously met for a pre-test genetic counseling session, which typically include a personalized risk assessment, implications of possible test results for the patient and their family members, and navigation of the genetic testing process. The post-test genetic counseling session examined for this investigation represents one of a total of six sessions in the data set, and includes two of 21 participants enrolled in the study.

Conversation Analysis—CA was conducted on the interactional materials (Atkinson & Heritage, 1984; Sacks, 1992; Sidnell & Stivers, 2013). CA is an inductive and naturalistic qualitative method that involves repeated and detailed examinations of recorded and transcribed interactions to identify key practices displayed by participants when organizing interactions. Attention is given to identifying and analyzing interactional practices, building and analyzing collections of instances, and advancing warrantable claims for patterns of social action from these collections. The 4:24 excerpt examined for this present study is drawn from a 20:24 return of genetic test results telehealth session. This particular excerpt was selected because it represents opening and different orientations displayed by GC and P, inherent problems that emerge when describing and explaining complex

genetic test results, and raises possibilities for improving genetic counseling care. Single case analyses of specific moments allow for detailed examinations of new and novel areas of inquiry, identifying social actions that are often overlooked and thus taken-for-granted. A primary goal of single case studies is to create an empirical foundation for building more generalizable collections of instances as warrantable claims for patterns of social interactions.

Survey Measures—Following the appointment, P was asked to complete a survey. The survey began by dichotomously asking (yes/no) whether GC met P expectations. Next, two open-ended questions were used to assess what P enjoyed, and what could have been improved about the genetic counseling session. Following these questions, P self-reported about her overall health and shared information related to her cancer diagnosis. The remainder of the survey assessed P's perception about her likelihood of developing other cancers, as well as specific cancer fears, and included unidimensional measures of anxiety, hope, and uncertainty. When possible, the larger dataset was used to determine Cronbach's alpha (α), however, all scores reported in the present case study are for the patient involved in this case study only.

Perceived Susceptibility to Other Cancers measured P's concern toward developing seven other cancer types in their lifetime as compared to others of similar gender, age, and race Responses were on a 7-point scale (1 = *a lot less likely*, 7 = *a lot more likely*). *State Anxiety* (α = .95) was measured with 6-items (e.g., "I feel upset" and "I am worried") from Spielberger's larger State-Trait Anxiety Inventory (Spielberger et al., 1970) and these items utilized a 5-point response scale (1 = *not at all*, 5 = *very much*). *Hope* (α = .87) was measured using 7-items (e.g., "I believe each day has potential") from the Herth (1992) Hope Index and utilized a 5-point response scale (1 = *strongly disagree*, 5 = *strongly agree*). *Uncertainties in illness* (α = .96) were measured using 7-items (e.g., "I am unsure if my illness is getting better or worse") from a larger uncertainty index developed by Mishel (1997) and revised by Beach and Dozier (2003) utilizing a 5-point response scale (1 = *strongly disagree*, 5 = *strongly agree*). *Fear* was measured using a modified seven-item cancer fear index originally developed by Facione (1993), and although previous research has documented its unidimensionality, we analyzed these responses as single items given the case study nature of this research. Items in this index utilized a 7-point response scale (1 = *not fearful*, 7 = *extremely fearful*), and assessed fears related to chemotherapy, cancer spreading, the unknowns of cancer, isolation, loss of control, entering a submissive role, and death.

Results

We begin by presenting CA results of the return of results session excerpt. We then present P's survey responses and discussion how findings from two methods can be integrated.

Initial Preview, Delicate Lack of Understanding, and Setting the Protocol

The following and initial excerpt occurs after the patient provides a brief update that she is currently undergoing chemotherapy, expresses hope that her tumors will shrink so that

surgery will be possible, and GC responds “We’ll keep our fingers crossed.” The topic then switches to GC’s initial description of genetic test results:

28) Zoom: GC1/P1:2

GC: So I know we had talked- you know, a few weeks ago: and we were doing the genetic testing. = > You know, anytime we have a diagnosis < u:m of o↑varian cancer we want to know if it could be hereditary? So the testing uh- didn’t identify any genetic changes that we think < increase cancer ↑ risk. > Um, it did find one of the variants of uncertain sig↑nificance that we talked about a ↓ few weeks ago.

P: Uhkay. You’re going to have to remind me of what–

GC: [[Yeah]

P: [[All–] £ This is all new to £ [me, so heh eh heh.

GC: [Ya (hhhh). You are to:tally fine. I just– We try to get it o::ut in- in kinda o:ne and then let me talk about what all of that means.

P: Mmka:y.

In this excerpt, GC frequently (lines 1-4, 9) uses a bureaucratic “we” (Drew & Heritage, 1992; Sacks, 1992), a reference to “invoke an institutional over a personal identity, thereby indicating that they are speaking as representatives, or on behalf, of an organization.” (Drew & Heritage, p.30). GC is not just rendering personal opinions, but speaking as an incumbent of two related institutional groups: The medical team actually conducting and evaluating outcomes from the testing procedures for this specific patient (e.g., in line 1 “we were doing the genetic testing”); the collective discipline of genetic researchers and genetic counselors, professionals who generate and disseminate information and knowledge about genetic testing and risks (e.g., in lines 9-10, “We try to get it o::ut”). When employed alone or together GC uses lexical “we” (and as will be seen, “they”) to establish an authoritative basis for reporting and making knowledge claims. These stances reflect the institutional communities she represents.

By avoiding personal I-centered statements (though see line 9, discussed below) about reported findings and genetic risk assessments, a recurring pattern is evident throughout the subsequent interactions examined for this study. First, by focusing on summaries of communal professional positions and the test report generated by the laboratory, the absence of personal statements situates GC in an institutional role that simultaneously limits her individual authority – not just to implement medical recommendations, but to interpret the genetic results related to patient’s condition. Second, GC minimizes individual responsibility for possible consequences arising from delivering and explaining complex genetic information.

In line 1 GC refers to talking with patient “a few weeks ago:”, followed by a preliminary overview of issues to be addressed. In response (line 6), patient’s “remind me” request displays not remembering the possible types of genetic test results. Patient treats her lack of

knowledge and understanding as potentially embarrassing (Heath, 1988): A cancer patient undergoing treatment that needs reminding of some of the information discussed in their first meeting, and in general is having difficulty remembering recent and key information about genetic testing. P's next "£This is all new to £ [me, so heh eh heh." (line 8) reveals both the delicacy and awkwardness of her situation. This utterance begins with a smile voice (£), followed by laughter particles "heh eh heh", actions displaying that she is managing troubling and challenging circumstances (Beach & Pricket, 2017; Glenn, 2003; Jefferson, 1984). She is also portraying herself in what Haakana (2001, p.218) describes as an "unfavourable light". And GC does not laugh, but with "Ya (hhhh)." (line 9) provides a brief and aspirated acknowledgment before stating "You are to:tally fine.". This utterance is designed to reassure P that her need to be reminded, and being "new" to genetic test results, is not a problem.

Rather than further addressing P's feelings and circumstances (Beach, 2022a; Frankel & Beckman, 1988; Sinclair et al., 2020), GC moves immediately to describe her approach to delivering news about genetic testing. GC's "I just-" is cut-off and quickly repaired (Kitzinger, 2013) to "We try" (line 9), a shift from first person reference to the bureaucratic "We." GC then describes to patient that the priority is to "get it o::ut in- in kinda o:ne" (line 10), a course of action when genetic counselors produce longer narratives for patient's consideration, then continues with "let me talk about what all of that means." (line 10). In these ways GC describes how she will proceed by offering a lengthy description of genetic findings, then tell the patient what the delivered information means. Her "let me talk" emphasizes an uninterrupted narrative with little or no contributions by patient, including P's ability to seek clarification or express what these findings might mean for her condition. In response, patient's "Mmka:y." is a reflective acknowledgment, but she does not resist or challenge the protocol GC has elaborated.

Whose Test is Being Discussed?

In Excerpt 2, GC provides additional background and details about genetic testing:

2) Zoom: GC1/P1:2

GC: So, if we think about (.) u:m genetic te:sting, we're going through and looking for::changes in our genetic co::de, anything that could be added or missing. U:m and sometimes they come across genetic cha::nges, and they don't kno::w if it is a genetic change that just makes us who we ↑a:re and so, it's beni::gn? = Cuz we have mi:llions of benign changes in our body that make us different from one another? O:r:: .hh is it a genetic change that kind of increases our risk for cancer and actually does put us at increased risk. (.)

P: Ka:y?

GC: .hh So the gene that they found, = we looked at- you know thirty-some ge::nes, and the gene that they found [this genetic–]

P: [And you're] talking about my particular (0.2) test?

GC: [[Yes.

P: [[Is this- (.) uh- okay.

Bureaucratic references to “we” and “we’re” (lines 1, 9) continue to depict the kind of “thinking about” and “looking for” procedures employed by genetic professionals. References to “they” (lines 3, 9) are also characterized as anonymous genetic experts who may identify changes that could be benign, or determine that an increase in cancer risks does actually exist (lines 2-7).

Descriptions of the ambiguities faced by genetic professionals, and consequently the patient, include an additional type of “who we ↑a:re” (line 4). Collectively, “we” are all human beings whose bodies have “mi:llions of benign changes” (line 5) that can be examined to distinguish one person from another. Certain genetic changes increase “our” cancer risks, thus putting “us” in jeopardy.

Following a brief pause in line 9, P’s upward intoned “Ka:y?” displays some uncertainty about GC’s prior turn, including the immediately preceeding comment by GC that there could be “a genetic change that kind of increases our risk for cancer” (line 6). P’s “Ka:y?” also projects what will be a next-positioned and interruptive clarification (Beach, 1993). As GC moves forward with her “they/we” explanation (lines 9-10), patient takes the initiative to interrupt GC’s talking by asking, “And you’re talking about my particular (0.2) test?” (line 12). This patient-initiated question is a deep intrusion into GC’s unfinished turn-at-talk (Jefferson, 1973), a marked shift from the protocol GC had pronounced and patient’s prior minimal contributions. Her question attempts to determine the relevance of GC’s previous genetic testing overviews (e.g. about “changes in our body” and “increases our risk for cancer” in lines 5-6) to her “particular (0.2) test?” (line 12). GC’s next “Yes.” confirmation (line 13) is treated by P as sufficient to not pursue further clarification.

Continued Explanations and Responses to Complex Genetic Test Results

GC then accommodates patient by stating “yo:ur test”:

3) Zoom: GC1/P1:3

GC: So yo:ur u::mm (.) yo:ur test we looked at thi:rty six different genes. Um and the-all of them came back negative, except for this uncertain result that we found in one ge:ne,=which is the BRCA2 or the ↓braca two gene. (0.2)

P: Uhkay?

GC: Okay. So anytime we find an uncer:tain resu:lt, we ask ourself “Is it- is this u::h u:m, is this just a beni:gn change that makes us who we a::re?” O::r right “Is this something that increases our risk.” And we kno:w that over ninety percent of the time, uncertain results turn out to be negatives.=They turn out to be something that’s beni::gn.

P: Umkay.

GC: .hh And when we look at the genetic change that they found in ↑yo::u:, essentially if we think about it, the genetic co::de codes for proteins, right if I have one hundred different letters, that's going to code for about thirty different kind of- chunks that result in this bigger pro:te::in. And essentially, the uncertain result is they (0.2) think that o:ne small chunk of the protein is missing. So. nothing- like it's not like the protein isn't working? It's not like it's really short or it's you know not its normal size. It just thinks there's one small chunk missing.

P: [[O:kay.]

GC: [[And so] in that scenario, we think that is more likely to be a negative test result down the road.

P: [[°Okay.°

GC: [[One, because we know over ninety percent of these test results become negative and two::, based on the type of genetic change and where it's lo:cated, we think that that's more reassuring that this is most likely just a negative test result. (0.2)

P: Mmkay.

Throughout this excerpt, P's various "Okays" (Uhkay, Umkay, Mmkay) are acknowledgment tokens reflecting close monitoring of GC's explanations of genetic test results. These "Okays" facilitate GC's elaborations with brief yet well-timed responses, but they do not claim knowledge or understanding of GC's descriptions. Nor are these "Okays" preparatory to topic or speaker shift (Beach 1993, 1995). P passes on opportunities to initiate and pursue related concerns, topics, questions, or stances about information offered. But certain subtle actions do occur. For example, in lines 4-5 patient's slight (0.2) pause and upward intoned "Uhkay?" display a hint of uncertainty and possible incongruity with GC's prior turn (Beach, 2020). P treats some details in GC's overview about testing thirty six genes – all negative with one BRCA2 uncertain result – as not known or understood. But P does not ask a question, offer a comment, or draw attention to one or more specific issues.

The details being raised by GC are consequential, detailed, and complex. For GC, uncertainties arise from limitations in understanding, and inability to always accurately predict, how current scientific knowledge might apply to evolving contingencies of P's test result. In contrast, P displays close monitoring of GC's descriptions of what current scientific knowledge may exist, especially how it applies to her given case. But at this juncture in the session, she does not explicitly claim a lack of expertise and experience to comprehend these complex details.

Uncertainties are critical because while P's current and future health is the primary focus, threats to health and well-being (for P and loved ones) are possible. Both GC and P can thus have difficulty understanding issues raised: Negative and uncertain genetic results; identification of a variant of uncertain significance (VUS) in the *BRCA2* gene; genetic changes for this patient; and how genetic codes for proteins (specific to the VUS result) impact negative and uncertain test results. Attempting to make sense of this series of

interwoven issues can, at least in part, explain patient's multiple "Okays" and withholdings of longer responses.

Two specific resources are employed by GC to establish her authority for offering these explanations, actions that can establish credibility yet also constrain patient's response.

First, as previously discussed, in Excerpt 3 (above) the word "we" is invoked eleven times (lines 1,2,6,7,11,12,19,22,24). References are to 1) the clinical and laboratory teams actually conducting and evaluating outcomes from the testing procedures for this specific patient (e.g., in line 1 "we looked at thi:rty six different genes"); and 2) the collective discipline of genetic testing laboratories, researchers, and genetic counselors, professionals who generate and disseminate information and knowledge about genetic testing and risks (e.g., in lines 22-23 "we know over ninety percent of these test results become negative").

Second, GC avoids speaking in the first person in lieu of a collective voice by directly quoting what fellow professionals might say or think (e.g., in lines 6-7 "we ask ourself… is this just a beni:gn change that makes us who we a::re?"). She also describes testing results by referencing "they" (e.g., in lines 15-16 "the uncertain result is they (0.2) think that o:ne small chunk of the protein is missing."). What is thought, or known, about knowledge related to P's condition emanates from unspecified persons and/or groups characterized by "we's" and "they."

Throughout this excerpt, however, GC works to balance the uncertainty of the identified variant in the *BRCA2* gene by repeatedly (lines 2-3, 8-10, 15-18, 21-22, 24-27) offering what amounts to as potential good news: There is a high likelihood that the variant will be reclassified as benign. These explanations are designed to contextualize and demystify the uncertainty, providing clear answers to assist P whenever attempts are made to discern testing results as good and/or bad news.

Yet P's "Okay" responses do not more proactively affirm or even celebrate GC's interpretive efforts. It is not uncommon for patients to remain quiet and even passive when receiving diagnostic news (Byrne & Long, 1976; Heath, 1992; Heritage & McArthur, 2019), moments when patients "absorb their diagnoses with silence or minor acknowledgments" (Koenig & Beach, 2021, para 65) in the face of medical authority. Of course, counseling about underlying genetic factors contributing to cancer as a disease is not an initial nor technical diagnosis of the presence or type of cancer P is faced with. But a basic asymmetry in knowledge and expertise exists nonetheless, and is essential for preserving GC's authority as complex and uncertain genetic explanations are offered. With "we" and "they," GC asserts her professional membership and disciplinary knowledge as resources when making evidential claims for patient's consideration. These actions are in marked contrast to findings from medical areas such primary and oncological care, where "doctors treat themselves as accountable for the evidential basis of their diagnosis (Peräkylä, 1998, p.318). In this genetic counseling session, GC repeatedly refers to the collective knowledge of her colleagues and discipline without claiming her own personal expertise about matters related to P's condition.

The noticeable absence of GC's personal knowledge and positions may contribute to Parsons' (1951, p.441) early description of a primal "communication gap" between sick persons and medical professionals, encounters "in which the patient is unable to help himself and is ignorant of both the nature and the treatment of the disease." (Heath, 1992, p.236). If P cannot ask GC directly about her test result, without GC repeatedly making reference to others' expertise, it places P in a more likely position of accepting what GC treats as authoritative and external genetic explanations.

It is also the case, however, that considerable efforts are invested by diverse medical experts to offer factual and objective assessments, and patients routinely do not give detailed responses. This pattern is also evident in this case study. For example, on occasions when diagnostic information is briefly stated en route to treatment recommendations (Heritage & McArthur, 2019), which occurs frequently in primary and cancer care, it is not uncommon for patients to not be provided the opportunity to more fully address details about their condition. In the context of genetic counseling, when GC elaborates on specific and complex genetic issues, P remains essentially quiet even when being presented with information that can be considered as good news. Her actions are symptomatic of not knowing when or how to respond to genetic nuances, complex issues that can be overwhelming and thus not only difficult to understand but constraining an informed response.

In summary, by offering a lengthy (0:37) explanation, Excerpt 3 (above) exemplifies repeated attempts by GC to enhance patient's knowledge. Excessive information is conveyed that is comprised of technical jargon and complex genetic concepts that other professionals take positions on. These actions by GC risk patient overload and confusion. By GC's enacting a teaching model emphasizing patient education, P is cast into the role of a passive listener. Elaborated interactions addressing patient's understandings and concerns do not occur during these, nor later phases, of the telehealth consult.

Not Knowing What to Ask

At this juncture GC explicitly recognizes her lengthy explanations:

4) Zoom: GC1/P1:3-4

GC: Okay. I know I just like spo:ke a to[:n. Let me pa:use. What £questions can I a:nswer£]?

P: [°Ha ha he he heh he he hhh ha ha heh heh heh.°]

P: So (1.2) u::mm, I don't even know what to [a::sk].=

GC: [°Okay.°]

P: Wi- I'm just so uneducated with all of it that it's- but so basically it's- (0.4) is that ↑go:::od that it's ne:gati:ve?

In overlap with GC's "spoke a to:n" (line 1), patient initiates extended and quietly produced laughter (line 2). Her drawn out laughter acknowledges and agrees with GC's "to:n"

description, but also begins to claim personal impact: She treats GC's "spoke a to:n" as an understatement, while also displaying that she is not a consociate teller who possesses shared knowledge and can assist with GC's elaborate description (Goodwin, 1984; Lerner, 1992).

In marked contrast, she is an *unknowing* recipient of GC's detailed and lengthy elaborations. GC's offering to "pa:use" is responsive to the onset of patient's laughter, as is GC's "What £questions can I a:nswer£?" (line 1). Produced with a 'smile voice' (£), GC solicits questions in a way that "constitutes some mid-point between laugh along and declining to laugh…display[ing] willingness to go there." (Glenn, 2003, p.72). In this way, GC displays recognition that patient is using laughter to take a stance: She has experienced difficulty attempting to make sense of GC's repeated attempts to explain uncertain test results, and an opportunity to clarify these results is needed. Their precisely timed overlap (Jefferson, 1973), evident in lines 1 and 2, confirms that the patient is closely monitoring the talk to address an emergent problem: Patient does not understand what GC has invested a "to:n" of time and effort to describe.

The dilemma P is experiencing is made clear when she next states "I don't even know what to a::sk." (line 3). Prefaced by an extended pause and searching "u::mm" patient's listening to 3 minutes of GC's descriptions, from the beginning of the consult, has resulted in her inability to formulate even a single question GC solicited. As P continues she explains "I'm just so uneducated with all of it" (line 5), an utterance reflecting her momentary inability to formulate a question. This is not uncommon across diverse types of medical care as patients routinely defer and subordinate to medical authority (Beach, 2021; Heritage, 2005; Peräkylä, 1998, 2002) . Patients may believe that they are entitled to know and ask about their health conditions, yet at times also "downplay their knowledge" (Gill, 1998, p.342), do not seek explanations for potential health problems, or as in this case, reference their lack of education as a reason for not knowing what to ask.

As P continues (lines 5-6), her repeatedly cut-off words (−) and hesitations continue to display speech dysfluencies. These actions are symptomatic of lay persons who are cautious and uncertain about "asking" health professionals questions, or initiating other actions revealing their lack of knowledge. On these occasions, patients treat medical experts as authorities who may evaluate their inquiries as unmerited, inappropriate, and possibly revealing their ignorance. These are primary orientations restricting shared and open participation during clinical encounters (Street et al., 2001; Street et al., 2005).

Are Negative Findings Good?

In this genetic counseling session, following the patient's uneducated caveat, she does ask a question with "is that ↑go:::od that it's ne:gati:ve?" (line 6; repeated in Excerpt 7, below). With "↑go:::od" she pursues an assessment by GC of the bottom-line valence of her prior descriptions: Does is it all add up to a good/positive or bad/negative (in lay terms) evaluation of her genetic test results? P reflects a preference for a hopeful outcome of her genetic testing, a fundamental concern for the future of her own and family's health. The excerpt below continues with GC's response in line 7:

5) Zoom: GC1/P1:3-4

P: Wi- I'm just so uneducated with all of it that it's- but so basically it's- (0.4) is that ↑go:::od that it's ne:gati:ve?

GC: (.hhh) Yeah ((averts and closes eyes; makes grimaced face)). So, that is- u:mm, I find that that's really actually patient-specific.=Some people take a look at this and feel like "I'm really relieved, that I don't- like, I don't think that family members have greatly increased ↑cancer risks." Right, that can be reassuring. And [on the other hand-]

P: [Now that's what] I was hoping for. =

GC: =That's what you're hoping for.

P: (( )) for my grandchildren- and I didn't know if this was just female-related or it could be males too.=So, I was concerned with like my kids and my grandkids and-

GC: Yes. Right, and we know that some of the genetic changes we ↑fi:nd that put people at increased risk for cancer affect men and women.=Actually, most of them affect men and women. And so, you're right. In this scenario, we don't have any reason to believe that yo:ur ↑children need genetic testing or that they're at greatly increased risk for cancer.

P: °Okay.°

GC: [[Oka:y–]

P: [[So I wa]s– I'm luck of the draw. Heh [heh heh.]

GC: [Well, as far] as we know, right?=There could be ge:nes that we don't ↑kno:w abo:ut. There could be:- u:mm, you know, th– again, mostly like things we haven't dis↑covered yet. But for now, we don't have any good explanation for why this happened.

P: °Okay.°

With "Yeah" and noticeable facial displays (e.g., averted gaze, closed eyes, and a grimaced face), GC begins to delicately formulate a response that does not offer a straightforward confirmation of patient's query. Rather, GC displays potential rejection of the possibility that negative results are "↑go:::od" (Davidson, 1984; Pomerantz, 1984). Her prefaced utterance, marked by halting and searching dysfluencies (line 7), give rise to a qualified "patient-specific" assessment (lines 8-11): "Some" may be relieved that the cancer risks for family members have not increased, which can be reassuring.

In overlap with GC's next "And on the other hand-", likely en route to an explanation of why negative and VUS results are not good, patient states "Now that's what I was hoping for. =" (lines 12-13). This hopeful utterance derails GC's describing negative impacts of negative and VUS results. By repeating patient's hopeful stance (line 13) GC displays a willingness to talk about family issues, which patient next elaborates (lines 14-15) by focusing on her kids and grandkids (female and male). After explaining that genetic

changes can affect men and women (lines 16-18), GC's "you're right" offers agreement with patient's gendered concerns. Further, but with an "In this scenario" (line 18) qualification, GC informs patient that her children do not require testing or face greatly increased cancer risks. This announcement of good news aligns with patient's hopes, even though these hopes require qualification: Not all discoveries have been made, and no good explanation yet exists for why P developed cancer. These key issues remain unarticulated, creating additional sources of uncertainty not addressed in this case study nor throughout the entire interview.

At least for the moment, patient's concerns about her kids and grandkids are minimized and evident in her following quiet "°Okay.°" (line 21). As GC's "Oka:y-" begins to close down prior topics and move the agenda forward (Beach, 1993), however, patient draws attention back to herself by stating "So I was- I'm the luck of the draw. Heh heh heh." (line 23). This self-assessment depicts a chance occurrence that could not be controlled. Her subsequent laughter displays resistance to these troubles (Jefferson, 1984), but also a recognition that there was something "possibly inadequate, troublesome, or problematic" (Davidson, 1984, p.104) about the prior discussion of kids and grandkids. An explanation for patient's genetic condition, and possible impacts on cancer diagnosis and treatment, remain unresolved.

In response GC does not treat patient's laughter as an invitation to share laughing. Rather, she declines to laugh by providing a serious response (lines 24-27) that summarizes what is known and not known about her test results. She stagtes there is insufficient knowledge (Beach & Metzger, 1997) about unknown genes not yet discovered, and brings her utterance to a close with "But for now, we don't have any good explanation for why this happened." (lines 26-27). This explanation generates further uncertainty about the cause of the patient's cancer diagnosis. And once again, patient's quiet "°Okay.°" (line 28) acknowledges indefinite information provided by GC, an expert with greater access to knowledge than P who is undergoing chemotherapy for cancer that has been diagnosed but has no known cause.

Survey Results

A summary of P's post-session reports about her perceptions and experiences with the encounter, and overall health, are summarized below.

First, on a 1-7 response scale the only 7 response on 'Susceptibility to Developing Other Cancers' was for Ovarian Cancer, her current diagnosed condition. Such an extreme response likely reflects the possibility of metastasis, further spreading of the disease, and thus increased instability controlling an already serious cancer diagnosis for which she is currently being treated. However, other reported cancer threats were moderate or low (overall $M = 3.29$): Comorbidity of simultaneous cancer types and locations was not a primary concern, at least during the moments analyzed for this case study and (on review) also across this entire counseling session.

Second, sub-scales (1-5) on 'State Anxiety, Hope, and Uncertainty in Illness' reveal a moderate overall score (3.39) score. P is moderately anxious (3.17). And the obvious and ongoing uncertainties examined in the interactions were only partially reflected in P's perceptions about the encounter (3). A stronger reporting is that she remains Hopeful (4)

about not only about the possibilities of effective treatments and eventual remission, but reduced cancer risks for family.

Third, P's fear responses (1-7) reflect the strongest set of reactions (M = 5.86). Her least reported fear was chemotherapy (2), likely because she is already undergoing these treatments and thus able to knowingly report on those experiences. Immediately prior to the interactions examined herein, P also states she is willing and hopeful to receive additional chemotherapy (if necessary) to further shrink tumors, clearing the path for surgery and tumor removal.

If the 2 score for chemotherapy were removed, the remaining six fear concerns (cancer spreading, the unknown of cancer, isolation, loss of control, entering a submissive role, death) average a striking 6.5 response. The spreading of her cancer, cancer unknowns, and death all received extreme 7 scores, while the remaining categories received high 6 responses. Across all survey results, P's reported fears provide the most consistent and powerful insights into her personal experiences and concerns occasioned by the threats of ovarian cancer.

Triangulating Survey Results with Conversation Analytic Findings

Despite interactional issues that have been identified in the previous analysis of the initial 4:24 of this counseling interaction, P indicated that the genetic counselor met her expectations. During the remaining 15:00 of this session, not analyzed in detail for this study, there was not a notable increase in clarifications, more forthcoming questions, displays of understanding by P, or emotional support provided by GC that may have significantly influenced this assessment of met expectations.

When asked what P enjoyed about the genetic counseling session, she answered "Finding out the results and having my questions answered." This was reported even though interpretation of the results and reasons for her diagnosis were often described by GC as uncertain. And answers to P's limited questions tended not to be direct and unambiguous, based on GC's understandings of current scientific knowledge. And when asked about what could have been improved, P did not indicate any criticism but remarked that the "session was good." These reports raise the possibility that P holds socially desirable expectations for genetic counseling. However, as discussed below, P did report a high level of concern about her ovarian cancer and several key dimensions about cancer fears.

P's self-reported experiences interface with previously reported CA findings in several interesting ways. The most prominent findings involve uncertainties, hopes, and fears. First, within the examined interactions 'uncertainties' were frequently raised by both GC and P. In Excerpt 2, GC refers to uncertainties about genetic changes, and P inquires about whose test is being referenced. In Excerpt 3, GC describes how both the interpretation of the BRCA 2 test result is uncertain (benign or increased risk?), and that information about missing protein regions is incomplete. In Excerpt 4 P states not even knowing what to ask, then queries "is that ↑go:::od that it's ne:gati:ve?" (lines 5-6). And in the final Excerpt 5 P displays uncertainty about cancer risks for females and males, and her condition being "luck

of the draw" (line 23). In response, GC states further uncertainties about unknown and not yet discovered genes that may account for P's condition.

Taken together, uncertainties were recurring and very important issues contributing to the interactional organization of attempts to offer basic descriptions, create shared understandings, and raise key implications about genetic test results for P and her family. However, P's post-survey reports about uncertainty are discrepant. A moderate score (3/5) about 'uncertainty in illness' was provided, yet an extreme reaction was given to the 'unknowns of cancer' (7/7).

Second, regarding hope, P explicitly states "Now that's what I was hoping for." (Excerpt 5, line 12) when hearing that her kids and grandkids were not facing increased cancer risks. This hopeful utterance was initiated by P and stated with strong feeling and emotion. Her reports about hope (4/5) mirror these reactions.

Third, P did not explicitly state being fearful, nor did GC ask or otherwise make reference to fears about cancer or genetic testing results. At one point P did address being "concerned" about her kids and grandkids (Excerpt 5, line 12), which could be considered an indirect fear display. This absence of fearful actions stands in marked contrast to P's high level of reported fear. As noted, aside from chemotherapy, P reported extreme fears (7/7) about the possibilities of cancer spreading, cancer unknowns, and death (Beach, 2022b). Being isolated, losing control, and managing submission to cancer received very strong reactions (6/7).

Discussion

A case has been made that GC and P collaborate in producing a series of interactional dilemmas inherent in delivering and receiving genetic test results. Findings from this study raise a series of key questions and issues, and provide an empirical foundation for examining more diverse genetic counseling sessions.

First, how much and what type of information is necessary to share with patients during genetic counseling sessions? Excessive and highly complex information can become counter-productive, creating confusion and overwhelming patients (who may simultaneously be undergoing cancer treatments) rather than facilitating basic and pragmatic understandings. As noted previously, counselors are tasked with "helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease." (Resta et al., 2006, p.78). Finding optimal ways to address these distinct yet interrelated challenges can be daunting for counselors and patients alike.

Second, a related question: What protocols and practices are enacted by counselors at the outset, and throughout sessions, to facilitate patients' abilities to understand and adapt to genetic conditions? We have documented how this GC began the encounter by pronouncing "We try to get it o::ut in- in kinda o:ne and then let me talk about what all of that means." (Excerpt 1, lines 9-10). This protocol provides GC with a resource for reporting detailed information and advancing knowledge claims. Yet by offering extended descriptions, followed by GC's summary of what this "means" (and from her perspective), we revealed

two practical and important consequences: Patient repeatedly did not comprehend complex information GC provided, nor was patient invited at the outset to ask questions and seek clarification. One viable alternative is to provide shorter and segmented descriptions, followed by opportunities to solicit, facilitate, and confirm P's understandings at any point as the session unfolded. Techniques such as teach-back (Klingbeil & Gibson, 2018), when patients are asked to formulate in their own words what has been discussed, may be useful to establish shared understandings.

Third, other specific practices are also employed by GC to establish credibility. For example, GC repeatedly invokes institutional authority by reference to "we/they" throughout this session. Referencing membership and alignment with her professional community enforces GC's authority to report genetic findings with institutional knowledge and priorities. It also minimizes her own accountability about the information and news she is delivering, actions which may reflect GC's counseling limitations and uncertainties about scientific knowledge.

Over the past few decades, however, positions have also been taken that question whether or how behavioral orientations such as non-directive counseling (ND) can, or should be accomplished during actual counseling sessions (Louhiala & Launis, 2013). Is it possible or preferable for counselors to provide information without offering advice, remain neutral in response to patients' emotional circumstances, withhold their own opinions about patients' decisions, and enact resources for limiting professional responsibility and accountability (Jamal et al., 2020)? These and related questions raise key gaps and opportunities (Chavez-Yenter et al., 2021), since utilizing ND and similar methods "remains unclear and contested…difficult or impossible to achieve for many reasons." (Elwyn et al., 2000, p.135).

We have also examined how GC's frequent "we/they" references can add to an environment constraining P's abilities to understand important information, seek clarification, or possibly even challenge GC's assertions. P needs reminding about discussions during a recent session, confused about whose tests are being discussed, uncertain about GC's delivered news, and repeatedly reveals her delicate and awkward situation. When P asks a question displaying that she does not understand what some patients might see as good news about negative and VUS findings, GC did not treat the news as positive. In response to P's question "is that ↑go:::od that it's ne:gati:ve?" (lines 5-6, Excerpts 4 & 5), GC neither confirms nor denies the good/bad valence of the negative results. Rather, she provides cautious reassurance and emphasizes that patients can respond to same results in different ways.

Research has shown that patients do not always perceive negative genetic test results as good news, so genetic counselors are often trained to initially present genetic test results as neutral (Smith, 1999). A negative genetic test result does not necessarily eliminate residual elevated cancer risks for the patient's relatives. A VUS finding may also affect the potential valence of news as well. Indeed, family members may be recommended to undergo increased cancer surveillance based on their family history (Himes, 2019). Genetic counselors may fear that presenting negative genetic test results as good news will overshadow this cautionary information and lead to inaccurate dissemination of information to family members (Himes, 2019). Given the lack of effective ovarian cancer screening for individuals at mildly elevated

risk due to family history alone, a negative or VUS result in this specific patient's scenario does not lead to increased cancer screening recommendations for the patient's relatives.

This tendency to communicate negative genetic test results as neutral information (neither good nor bad) can also further complicate the discussion of variants of uncertain significance (VUS). Findings suggest that patients and non-genetics healthcare providers alike can misunderstand the clinical implications of VUS due to their inherent uncertainties (Culver et al., 2013). Further, P does briefly and quietly acknowledge that while her children may face an increased risk for cancer because of the family history, that risk is not increased because of the genetic test result. P then quickly shifts topics to propose that she is "the luck of the draw" followed by delicate laughter (Excerpt 5, line 23). GC's response, however, does not address P's illness circumstances raised by "luck of the draw". Rather than overtly verbalize empathy, sympathy, or compassion for P's dilemma, GC again describes a lack of scientific knowledge and states there is no good reason why this happened.

Fourth, specific attention should be given to how genetic counselors can build therapeutic alliances with patients, within single and across a series of counseling sessions, paying close attention to patient's lived-world circumstances and emotions that are not just experienced but displayed and consequential for care (e.g., Beach, 2014; Peräkylä & Ruusuvuori, 2013; Sorjonen, 2012). The delivery of complex genetic information requires communication skills for addressing and understanding patients' emotions (Ellington et al., 2011).

Throughout this session, GC's proposed structure and authoritative claims do not solicit information from P about her feelings or circumstances, except very briefly before the actual consult began. And as noted, GC does not pursue other personal or emotional issues as the delivery of news unfolds. While psychosocial assessment is often a part of pre-test genetic counseling (which P underwent with GC prior to this post-test session), this interaction highlights opportunities for further assessment during post-test counseling (Roter, 2006). The actions displayed by GC during the post-test session thus do not give priority to what these results might mean as described by and experienced by the patient. For example, GC did not utilize open-ended questions soliciting P's perspectives about her condition, attempt to discuss and assess P's fearful emotions, or even describe how normal it is for patients to be fearful. Rather, more attention was given to technical understandings of genetic testing results that only a genetic counselor can provide as an informed expert. And this pattern continued throughout the remainder of the interview.

These findings mirror a wide variety of health-related interviews when agendas get pursued by health professionals, and asymmetries in knowledge and expertise create dilemmas for patients seeking to initiate actions and have their personal concerns addressed (e.g., Beach, 2021; Drew et al., 2021; Heritage & McArthur, 2019). Repeated evidence has been provided that it is also not uncommon for health professionals to enact and pursue structured agendas, actions creating problems balancing biomedical protocols with patient-centered actions, issues, and concerns (Beach, 2013; Byrne & Long, 1976; Heath, 1984; Heritage & Maynard, 2006; Roter et al., 2007). For example, a recent and extensive UK study of Psychological Wellbeing Practitioners and patients revealed "a tension between a protocol-driven agenda, and a flexible and patient centred engagement…to legitimize a patient's illness experience…

to encourage fuller participation by patients, and greater opportunity for the patient's voice and experience." (Drew et al., 2021, p.8). We have provided additional and grounded evidence that these problems also persist in the context of genetic counseling.

Across diverse areas of healthcare (e.g., pediatric, primary, oncology, psychotherapy, palliative) systematic attention is being given to methods for personalizing communication between patients and providers (e.g., Antaki & Vehviläinen, 2008; Beach, 2022a; Sinclair et al., 2017; Sinclair et al., 2020). Increased attention should be given to training innovations to enhance genetic counselors' abilities to provide and balance complex news deliveries with resources for soliciting and responding to patients' psychosocial concerns. Key to such training are skills for identifying awareness of what counts as 'good and bad news,' recognizing that tests results can simultaneously be both good and bad, managing the inevitability of genetic uncertainties, and partnering with patients facing often difficult and challenging emotions about unknown and potentially dreaded futures.

Specific attention should also be given to addressing what patients need, optimizing patient-specific information with psychosocial concerns. A wide range of informational needs exist for patients, and identifying whether a patient prefers to have simple "top-level" information or extensive details can allow for better alignment. This concept of "monitoring" and "blunting" may be increasingly important as genetic test offerings and possible results become more complex (Plamann et al., 2021).

Immediately following the counseling session, P's reporting of extreme fears about her ovarian cancer, and hopes about increased family risks, clearly evidence emotional orientations not raised nor addressed in the interactions examined. Prior research demonstrates the significance of uncertainties, hopes, and fears for cancer patients (e.g., Beach & Dozier, 2015).

What if patients completed a similar survey prior to counseling sessions? Genetic counselors could read survey results before the session, gain an increased awareness about patients' reported issues/concerns (such as P's extreme fears), and work toward discussing patients' reports at appropriate times – and in sensitive ways – that could advance patient-centered personalized care. Patients who reported their perceptions and experiences may well be predisposed to discuss them in meaningful ways with genetic counselors. Doing so, however, would not be mandated but at patients' discretion.

Addressing these and other unresolved issues can promote enhanced communication competencies through continuous research, grounded training, and innovative education for genetic counselors.

Appendix

Transcription Symbols

In data headings such as "OC11: 1:32-33", "OC" stands for "Oncology", "11" represents a particular doctor, "1" is the first patient seen by this doctor, and "32-33" are the transcription pages for that interview. The transcription notation system employed for data segments is an

adaptation of Gail Jefferson's work (e.g., Atkinson & Heritage, 1984; Hepburn & Bolden, 2017; Sidnell & Stivers, 2013). The symbols may be described as follows:

:Colon(s): Extended or stretched sound, syllable, or word.

_Underlining: Vocalic emphasis.

(.)Micropause: Brief pause of less than (0.2).

(1.2)Timed Pause: Intervals occurring within, or between same or different, speaker's utterance.

(( )) Double Parentheses: Scenic details.

……Continuous: Nodding, gazing, standing. May or may not occur simultaneously with talk.

( )Single Parentheses: Transcriptionist doubt.

.Period: Falling vocal pitch.

?Question Marks: Rising vocal pitch.

↑↓Arrows: Pitch resets; marked rising and falling shifts in intonation.

↓↓Very high pitch

° °Degree Signs: A passage of talk noticeably softer than surrounding talk.

°° Whispering voice: Occurs while crying.

= Equal Signs: Latching of contiguous utterances, with no interval or overlap.

[ ] Brackets: Speech overlap.

[[Double Brackets: Simultaneous speech orientations to prior turn.

! Exclamation Points: Animated speech tone.

- Hyphens: Halting, abrupt cut off of sound or word.

> < Less Than/Greater Than Signs: Portions of an utterance delivered at a pace noticeably quicker than surrounding talk.

OKAY CAPS: Extreme loudness compared with surrounding talk.

hhh H's: Audible outbreaths, possibly crying or laughter. The more h's, the longer the aspiration. Aspirations with periods indicate audible inbreaths (e.g., .hhh). H's within parentheses (e.g., "b(h)a:d") mark within-speech aspirations, and possible sharper and more plosive sounds during crying or laughter.

>(HH)< Sobbing: Combinations of hh's that, when sharply inhaled or exhaled, are marked with greater/less than symbols (> <).

.shih Wet sniff: Hearable nasal congestion.

.skuh Snorty sniff: Short, cut-off inhalation.

pt Lip Smack: Often preceding an inbreath.

hah Laugh Syllable: Relative closed or open position of laughter.

heh hoh

£ Smile Voice: Laughing/chuckling voice while laughing and talking

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Table 1

Post Genetic Counseling Survey Results

Variables:	Response Scale	Patient Score
Susceptibility to developing other cancers	1-7	*M* = 3.29
Breast cancer	1-7	4
Colon cancer	1-7	3
Pancreatic cancer	1-7	1
Stomach cancer	1-7	4
Melanoma	1-7	1
Ovarian cancer	1-7	7
Uterine cancer	1-7	3
State Anxiety	1-5	*M* = 3.17
Hope	1-5	*M* = 4.0
Uncertainty in Illness	1-5	*M* = 3.0
Fear	1-7	*M* = 5.86
Chemotherapy	1-7	2.0
Cancer spreading	1-7	7.0
The unknowns of cancer	1-7	7.0
Isolation	1-7	6.0
Loss of control	1-7	6.0
Entering a submissive role	1-7	6.0
Death	1-7	7.0