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ORIGINAL ARTICLE

Diagnostic uncertainties, ethical tensions, and accounts of role responsibilities in genetic counseling communication

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Abstract

Diagnostic uncertainties are intricately associated with genomic testing—especially concerning new technologies such as exome sequencing—with test results being either inconclusive or generating secondary findings or showing variants of uncertain significance. In the process of genetic counseling, diagnostic uncertainties have to be managed even when test results for an individual client are either positive or negative because of differential implications for family members. Previous studies have investigated diagnostic uncertainties in relation to clients wanting to know or not know the test results; here, we extend this line of research by addressing how genetic counselors and clients account for the management of diagnostic uncertainties vis-à-vis the attendant ethical tensions in the complex communicative environment in the clinic setting. Our dataset from the Norwegian context is longitudinal, consisting of ten audio-recorded pre-test genetic counseling sessions. It involves one extended family with a high burden of colorectal cancer. Through theme-oriented discourse analysis, we demonstrate how diagnostic uncertainties give rise to tensions concerning risks and benefits of knowing in both professional and familial spheres, which then map onto accounts of various role responsibilities. For instance, in looking for certainty via advanced genomic testing to reduce diagnostic uncertainty for clients, genetic counselors are confronted with tensions regarding what can be communicated and made known because of their role responsibilities toward what may be regarded as *scientific others* and *clinical others*. Likewise, clients are faced with tensions concerning wanting to know/not know, which invokes various *familial others* and may align or not align with genetic counselors' preferences, especially relating to management of diagnostic uncertainties and secondary findings.

KEYWORDS

benefits and risks of knowing, communication, diagnostic uncertainty, ethical tensions, exome sequencing, genomic testing, genetic counseling, role-responsibility, wanting to know/not know

1 | INTRODUCTION

Diagnostic uncertainties are common for many genetic conditions affecting clients and their families—what Barlow-Stewart (2018) aptly calls 'the certainty of uncertainty in genomic medicine'. Fueled by new genomic technologies such as exome sequencing, the ethos of uncertainty is generated and sustained through inconclusive test results as well as secondary findings inclusive of variants of uncertain significance (VUS), with wide-ranging implications for clients and their close family members. Paradoxically, new forms of genomic testing are aimed at reducing diagnostic uncertainties but the proliferation of such new testing technologies contributes to generating further uncertainties. More generally, genetic tests give rise to primary and secondary findings[1] and it is the secondary findings which may be part of a diagnostic process in a clinic setting or in pursuance of targeted scientific research.

In the clinic setting, there is a call for shifting the focus from reduction of uncertainty to management of uncertainty within a positive frame (Barlow-Stewart, 2018; Newson, Leonard, Hall, & Gaff, 2016), while attending to emergent ethical dilemmas (Balcom, Kotzer, Waltman, Kemppainen, & Thomas, 2016). Framing is a key concept here. Like risk, uncertainty can be framed in beneficial or harmful ways, thus making clients' desire to know or not know specific genetic test results rather nuanced. Focusing on the nexus of uncertainties and attendant ethical tensions, in this paper we examine how diagnostic uncertainties occasion clients' accounts of wanting to know or not know, including the risks and benefits of knowing, via orientations to self-other role responsibilities. Our main focus is the ways in which genetic counselors and clients communicatively manage the emergent ethical tensions in the face of diagnostic uncertainties. Our research questions are the following: (i) How do diagnostic uncertainties give rise to articulations of wanting to know/not know; and (ii) how do the ethical tensions surrounding wanting to know/not know invoke orientations to different trajectories of role responsibilities by genetic counselors and clients?

2 | LITERATURE REVIEW

Uncertainty management is not unique to genetic counseling, but integral to healthcare delivery more generally. More than 50 years ago, Fox (1957) identified two basic types of uncertainty in the practice of medicine: (a) uncertainty due to incomplete and imperfect mastery of available medical knowledge at the individual level; and (b) uncertainty due to the limitations of present medical knowledge. A further type of uncertainty stems from 'the difficulty in distinguishing between personal ignorance or ineptitude and the limitations of present medical knowledge' (Fox, 1957: 208–209). The scenario of 'limitations of present medical knowledge' mostly prevails in genetic counseling when rapid advances in genomic knowledge are not only beyond the reach of individual practitioners but also that certain new knowledge, as in the case of new testing technologies, does not necessarily translate into daily practice, thus generating further uncertainties.

Atkinson (1984) has drawn attention to the nuances underpinning the concept of uncertainty by stressing that it must be understood as a relational category vis-à-vis certainty in medical (scientific) knowledge on the one hand and clinical (experiential) knowledge on the other. In a later study, Atkinson (1995: 114) asserts that 'personal knowledge and experience are not normally treated by practitioners as reflections of uncertainty, but as warrants for certainty'.

In the context of cancer clinics, McIntosh (1978) points out how, in addition to diagnostic and prognostic uncertainties, doctors have to cope with two other forms of uncertainty relating to patients: (a) uncertainty about patients' genuine desire to know a bad diagnosis and prognosis; and (b) uncertainty about how patients might react to bad news, whether diagnostic or prognostic. These two dimensions of uncertainty which foreground the client perspective are of particular relevance for our study in that individual clients in the genetic counseling setting may orient to diagnostic uncertainties differently, expressed through their desire to know or not know what can be known.

Hallowell, Hall, Alberg, and Zimmern (2015) argue that exome sequencing, in particular, raises ethical concerns for genetic counselors regarding disclosure of genetic findings. Disclosure of primary findings in the clinical context may be a straightforward case, whereas any disclosure of secondary findings that may arise during the sequencing process will be influenced by clinical matters such as severity and treatability. The authors suggest that genomic testing increases the need to involve family members in order to clarify secondary findings. According to them, communication of results in a research setting may differ along different types of feedback policies and associated degrees of client autonomy, while demanding explanations from researchers that facilitate informed choice. Hallowell et al. (2015) rightly claim that the distinction between research and clinical activities are becoming blurry and suggest that the context at hand should serve as a guide for what ethical principles might be relevant when discussing with clients the potential risks and benefits of knowing a test result.

Uncertainty management has been studied in the genetic counseling context, mainly using interview and questionnaire data (e.g., Babrow & Kline 2000; Kenen, Ardern-Jones, Lynch, & Eeles, 2011; Skirton & Bylund, 2010; van Zuuren, Van Schieb, & Van Baarenc, 1997; Van Zwieten, Willems, Knegt, & Leschot, 2006) rather than through the close analysis of clinical encounters. For instance, Van Zuuren et al. (1997) draw attention to how information is provided to clients in the face of uncertainty. By focusing on framing biases in risk perception, they pay attention to the information delivery process, but not from a discourse-analytic perspective.

The discourse-analytic studies focusing on clinical encounters address the notion of uncertainty in relation to risk communication (Aasen & Skolbekken, 2014; Brookes-Howell, 2006; Henneman, Marteau, & Timmermans, 2008; Sarangi, 2002; Sarangi, Bennert, Howell, & Clarke, 2003; Thomassen & Sarangi, 2012). In emphasizing the interrelationship between uncertainty and risk, Sarangi (2002: 8) notes that 'genetic

risk explanations of what might and might not happen […] necessarily border on the notion of uncertainty and probability, resulting in the production of warrants'. This position echoes Mary Douglas's (1986: 42) classic statement that 'a great deal of risk analysis is concerned with trying to turn uncertainties into probabilities'. As Rapp (1988: 148) points out in the context of prenatal diagnosis, 'the language of genetic counseling is resolutely statistical; it is an axiom of good counseling that a patient must be told her risks before she can decide to take or refuse the test'. Here, we have a juxtaposition of two viewpoints: the language of probability may pose difficulties of understanding for clients (Adelswärd & Sachs, 1996), but clients have the right to know what can be known, including uncertain test results.[2]

Genomic testing often reveals ambiguous findings (Smith, Michie, Allanson, & Elwy, 2000), and genetic counselors are expected to manage 'boundaries of uncertainty' during the consultation (Stivers & Timmermans, 2016). In analyzing video-recorded genetic counseling sessions of families undergoing exome sequencing, Stivers and Timmermans (2016) find that geneticists give parents access to their reasoning when dealing with ambiguous results, followed by questions, and sometimes challenges, from parents. Diagnostic uncertainties stemming from inconclusive evidence may influence clients' decisions in favor of more testing and surveillance (Thomassen & Sarangi, 2012) as finding a diagnostic label becomes a prerequisite to manage uncertainty societally (Brookes-Howell, 2006). Both Aasen and Skolbekken (2014) and Henneman et al. (2008) argue that clinical experience is crucial for counselors whether aiming at reduction of uncertainty or acceptance of uncertainty in light of individual client needs.

Weighing both the risks/uncertainties and the benefits/gifts of knowing constitutes an integral aspect of genetic counseling (Sarangi et al., 2003). In the management of uncertainty vis-à-vis risk communication, Sarangi et al. (2003) observe that genetic counselors use specific discourse strategies to relativize risk along the lines of 'risk of occurrence' and 'risk of knowing'. The former is related to risk assessment and the likely scenarios following a genetic test, whereas the latter is concerned with clients' coping strategies when presented with uncertain/ambivalent test results. It seems genetic counselors typically explore benefits and risks associated with genetic knowledge whether it is before or after genetic testing. In the context of family testing, benefits may be to others than own self and may thus be seen as gifts of knowledge arising from new tests (Shipman, Sarangi, & Clarke, 2014). This desire to help others can extend to family members but also to researchers. For genetic counselors, the positive framing of benefits of knowing may be a way of selling the idea about participation in clinical trials or decisions regarding genetic tests. As far as clients are concerned, becoming aware of benefits could be seen as part of managing risk through some level of certainty regarding decision-making. However, the scenario of 'risk of knowing' is very real and it is something that genetic counselors prioritize when diagnostic uncertainties and secondary findings cannot lead to any treatment or prevention (Townsend et al., 2012). According to Arribas-Ayllon and Sarangi (2014:171), genetic professionals shift between non-directive and directive stances to 'explore whether clients can be trusted to make autonomous decisions within a climate of uncertainty'. As Clarke and Wallgren-Pettersen (2018) suggest, ethical considerations should be met with communicative strategies such as 'what if…?' hypothetical scenarios to challenge and support clients when handling diagnostic uncertainty.

Various studies have addressed clients' orientation to family members' best interests when undertaking genetic testing (Arribas-Ayllon, Sarangi, & Clarke, 2008a, 2008b; Hallowell, 1999). Orientation to others is also a key component of genetic counselors' communicative practice in balancing non-directiveness and client-centeredness (Sarangi, 2010a). As we will see in our analysis, such other-orientations take several forms: family others, scientific others, clinical others, and ethical/legal others. In the context of genetic counseling, both counselors and clients occupy and shift between what Merton (1968) conceptualizes as 'role-set', that is, 'an array of roles'. In this regard, genetic counselors may orient to their role-set as biomedical expert, psychosocial counselor, therapist, service provider, gatekeeper, mediator, etc. This role-set can be expanded to include different others such as colleagues, laboratory-based researchers, and the ethics committees regulating the provision of genetic/genomic tests and disclosure of test results. On their part, clients may orient to their role-set as partner, parent (of at-risk versus affected versus normal child), sibling, etc., which may also be supplemented by an orientation to scientific others, clinical others, and legal others. In our analysis, we will focus on how genetic counselors and clients account for their differential role responsibilities vis-à-vis risks and benefits of knowing genetic test results in the management of diagnostic uncertainties, while mitigating or heightening emergent tensions.

3 | METHODS

3.1 | Participants

Ten pre-test consecutive genetic counseling sessions concerning one extended family were audio-recorded within a hospital department of medical genetics in Norway.[3] The clients were from a family with a high burden of colorectal cancer; they had previously been tested for known cancer genes, with negative results. Ten different family members attended the pre-test clinic sessions. Two counselors were involved across the clinics, and both had undergone a 2-year university Masters level program for genetic counselors, which incorporated essential aspects of genetics as well as communication training. Although both counselors were present in a given clinic, one of them took on a passive observer role.

3.2 | Recruitment procedure and data collection

Exome sequencing was offered to explore and explain the cancer predisposition in this extended family. The study design was

approved by the Regional Committee for Medical Research Ethics and the participants were recruited by means of a personal letter explaining the aim and scope of the study. Participation was based on written informed consent, emphasizing its voluntary nature, that is, their right to leave the study whenever they chose to, without having to explain their decision.

The data were collected over a period of fourteen months, between 09/13 and 11/14. The audio recordings in Norwegian were first transcribed verbatim and then translated in to English by the first author and later verified by a competent bilingual speaker.[4] The names and places have been anonymized to protect confidentiality. The following simplified transcription conventions were used.

[ ]	Overlapping talk
Okay	Marked stress
Question mark [?]	Raising intonation
OKAY	Increased volume
okay::	Lengthening of the preceding sound
.hh	Inbreath
(2)	Timed pause in seconds
(.)	Pause of less than 0.5 s
-	Abrupt cut-off
((turns))	Transcriber's comment

3.3 | Analytical framework

We broadly adopt theme-oriented discourse analysis (ToDA, Roberts & Sarangi, 2005), which attests the jointly accomplished nature of interaction through participation structure (Goffman, 1981). The joint nature of the interaction is explored through: Mapping the structural, interactional and thematic trajectories; identifying key interactional events within the context of interest; analyzing interaction within and across phases in terms of focal themes (e.g., decision-making) and analytical themes (linguistic/rhetorical devices); and connecting the findings to outcomes.

A first step in our analytical procedure is to identify 'focal themes', similar to the grounded theory approach (Glaser & Strauss, 1967; see also Braun & Clarke, 2006). The next step involves a selection of 'analytical themes' or rhetorical devices that are utilized in the articulation of the focal themes. In ToDA, it is important to map the analytical themes onto the focal themes and assess their rhetorical import. Through iterative readings of the transcripts and thematic mapping (Sarangi, 2010b) involving the first two authors, the following three inter-related focal themes emerged: diagnostic uncertainties, risks, and benefits of knowing and role relationships. This pre-analytic process constitutes a form of coding, not with an aim to quantify the occurrences of the focal themes but to reach consistency in terms of theoretical salience, with the possibility of identifying their nuanced discursive manifestations in the data. As will be evident in our analysis, a suite of rhetorical devices is deployed by the genetic counselors and the clients in their accounts (Sarangi & Clarke, 2002; Scott & Lyman, 1968), for example, contrast, extreme case formulation, reported speech, hypothetical construction and pronominal reference.

Table 1 below provides illustrative examples of the three focal themes and their interrelationship, supplemented by corresponding analytical themes.

The examples for in-depth discourse analysis are taken from the 10 pre-test sessions, where recruitment of clients to ongoing research studies features in the discussion. As we will see, clients' desire to know includes their right to access available genetic information. The topic of uncertainty comes to the fore as the research studies are aimed at reducing prevailing diagnostic uncertainties.

4 | DATA ANALYSIS AND FINDINGS

In our analysis, we focus on how genetic counselors and clients articulate diagnostic uncertainties both in terms of benefits and risks of knowing and the desire to know or not know—at the professional and familial levels—and the extent to which self-other role responsibilities are invoked in respective accounts.

We first present an extended extract on how diagnostic uncertainties trigger tensions for both clients and counselors (4.1), followed by a scenario where diagnostic uncertainties give rise to ethical tensions for both parties (4.2). We then introduce selected extracts where diagnostic uncertainties lead to clients' orientation to familial others vis-à-vis their justifications for wanting to know (4.3), followed by an example which concerns diagnostic uncertainties and genetic counselors' orientation to scientific and clinical others in justifying clients' right to be given certain information (4.4). The illustrative examples below are representative of the data corpus as a whole.

4.1 | Tensions surrounding diagnostic uncertainties

Our first case in Extracts 1a and 1b concerns a female client (CF), in her late 50s, who is already affected with breast cancer and has had several polyps removed. CF has expressed her intention to remain informed about her progressive condition. She is also keen for her son (aged 29)—who has a serious illness that is not cancer related—to be considered for surveillance for potential colon cancer. CF's brother has had prostate cancer. The genetic counselor (GC) describes the nuances surrounding secondary findings as a by-product of exome sequencing in the ongoing research study in which CF participates. She raises the issue of the client's right to have access to the potentially beneficial health information from the test result, while alerting her to the risk of knowing 'that kind of information'.

TABLE 1 Discursive manifestations of the three focal themes and their inter-relatedness: Diagnostic uncertainty; risks and benefits of knowing; and role-responsibilities

Focal theme	Data examples	Analytical themes
Tensions surrounding diagnostic uncertainty	'those who may be a bit prepared […] and a person who has not experienced illness' (GC)	Contrast and pronominal reference
	'the worst thing there is for us […] no one wants negative messages'(CF)	Extreme case formulation and pronominal reference
	'It is because the ethics committee says that as long as there is no treatment […]' (GC)	Reported speech
	'if we were to have incidental findings in which there is serious risk to life […] we are not going to give you feedback if we find anything that has no treatment' (GC)	Hypothetical construction and pronominal reference
Orientation to risks and benefits of knowing vis-á-vis diagnostic uncertainty	'If anything could be picked up at an early stage […] maybe I don't die of cancer' (CM)	Hypothetical construction
	'I can live my life now before I get it' (CM)	Contrast
	'The way I am as a person […] my brother sweeps everything under the rug' (CF)	Contrast
	'if I say that I do want to have it can't I get it then?' (CM)	Hypothetical construction
	'we will have so much information and the question is what benefit does one have of all this […] what is important' (GC)'I have tried to say to the person in the lab […] that we	Hypothetical construction and pronominal reference
	need to turn this into practice (.) what does it mean for people?' (GC)	Reported speech
Orientation to role-responsibilities vis-á-vis diagnostic uncertainty	'If you decide you do not want to know and your sister decides that she does want to' (GC)	Hypothetical construction and contrast
	'OK now I must basically speak for myself but now after all I know my sister so well that (1.0) for us I don't think there's a problem' (CM)	contrast
	'after you said that now we are actually looking at my family (.) that strengthens even more and want to be involved' (CM)	reported speech, contrast, and extreme case formulation
	'Me and my wife discussed it when I received the letter […] but I am positive' (CM)	Reported speech

Extract 1a	
01 GC:	the disadvantage of such a broad study is that you might find things you were not looking for.hh eh what we call incidental findings (.).hh that means that if we then find any common genes (.) go in and look for more (.) find a change that we think might lead to disease.hh in a gene that might for example cause a risk of sudden cardiac death (1.5).hh eh there (.) are genes like that do exist (.) there are families where that kind of disease accumulates.hh and many of those who come to us they do- are maybe a bit prepared when we start looking for that kind of thing because they know it's a relevant issue.hh but as far as I know that is not a relevant issue for you.hh and then the question is like what would you think about getting that kind of information?
02 CF:	I have a very clear answer to that yes because I guess you understand with both my son and myself then everything that you know is fine
03 GC:	mm
04 CF:	no so that (.) that's absolutely (.) no now I've reached this age I mean that.hh every year is in a way a plus.hh so no that (.) I would not see that as negative in any way
05 GC:	no
06 CF:	well one (.) first of all you have the risk for all diseases that all people have
07 GC:	yes
08 CF:	whether you have inherited it or not (.) and then if you have inherited something then- then (.) you can take precautions (.) yes (.) so I have a very clear view on that (.) that's absolutely not a problem for me
09 GC2:	mm
10 CF:	.hh and one could say that when you are healthy and you don't know how you would react if you were told (.) something like- we have thought of that
11 GC2:	no
12 CF:	yes (.) so

At the outset in Extract 1a , 'incidental findings'—glossed as 'things you were not looking for'—are implicitly contrasted with 'expected findings' through a test procedure (turn 01). The assumption is that while 'incidental findings' can generate uncertainty, 'expected findings' would serve as a step toward diagnostic certainty. GC then offers an expanded explanation of what actions might follow the secondary findings. The potential problem of knowing is underlined and a contrast is made between test results being uncertain and how uncertain test results may be received by different clients (cf. McIntosh, 1978). The current circumstances of CF are contrasted with those who 'may be a bit prepared', thus implying that she might get information she is not prepared for. This contrast serves as a background for GC's question (turn 01) where she seeks CF's opinion of whether she wants access to the information surrounding secondary findings. The question serves a rhetorical function where the topic of wanting to know 'that kind of information' is linked to a risk of knowing scenario.

CF responds by saying that she would exercise her right to access all test-related information including diagnostic uncertainties ('what is there to be known'). She upgrades her preparedness for uncertainty cumulatively: 'everything that you know is [absolutely] fine'; 'I've reached this age where every year is a plus'; and 'nothing can be seen as negative'; 'that's absolutely not a problem with me'. This justification implies that CF can cope with all information, even if nothing is conclusive. In the latter part of turn 08, she signals the 'benefits of knowing' ('you can take precautions') and reasserts her stance to access all available information through an extreme case formulation ('that's absolutely not a problem with me'). In essence, she expresses her resilience and readiness to deal with uncertainty. CF also alludes to consensual familial communication ('we have thought of that'), signaling that she is not simply exercising her individual desire to know but also speaks for the family.

The interaction continues as follows in Extract 1b, with GC questioning CF's desire for accessing information in the context of diagnostic uncertainties arising from genomic testing.

Extract 1b	
13 GC:	then there are also other illnesses that relate to you a bit then and that is that one can also find for example something that might explain hereditary breast and ovarian cancer.hh and (.) (1.5) in relation to this kind of illness then you can say that heart disease (.).hh where it can sometimes be prevented because one should then avoid medicines that might trigger eh heart rhythm disorders.hh eh and (2.0) some people also have a both a pacemaker implanted and possibly an ICD a kind of heart starter.hh one also gets some diet- life- eh (.) recommendations about lifestyle (.) some of these sudden-death cardiac genetic defects.hh can after all also be triggered by sudden sounds (.) like alarms and.hh one might be recommended to maybe have an alarm clock with birds chirping instead. hh eh then it might be best to avoid competitive sports and things like that.hh when it comes to hereditary breast and ovarian cancer then we are thinking more about what type of preventive measures that maybe might involve [removing] an organ preventively
14 CF:	[mm]
15 GC:	.hh is that the kind of thing you would like to know [if it?]
16 CF:	[yes I] (.) we would really like to know what it's possible to know to put it that way (.) for us uncertainty is in a way the worst thing there is for us
17 GC:	mm
18 CF:	eh (.) obviously there's no one who wants (1.0) [any] negative messages like that
19 GC:	[no]
20 CF:	but if things are the way they are then I want (.) at least I want to know that

In turn 13, GC latches on to the 'benefits of knowing' as she lists hypothetical scenarios where preventive measures can be taken (e.g., avoidance of certain medication; implantation of pacemaker and ICD; modification to alarm sounds; refraining from competitive sports). Following this long explanation/information sequence, in turn 15, GC returns to the question (as posed in turn 01) of whether CF wants to receive health information, but this time she draws attention to a possible tension between CF's desire for knowledge and the future scenarios to cope with such knowledge. By pursuing the 'risks of knowing', GC underlines the need to clarify secondary findings in the context of family testing (Hallowell et al., 2015). As earlier, CF reasserts her wanting to know what can be known. Note that she uses the inclusive 'we' to characterize the family as uncertainty averse and formulates an extreme case scenario ('the worst thing for us', turn 16). In turn 18, CF offers another characterization via extreme case formulation—'no one wants negative messages'. Turn 20 echoes CF's wanting to know stance as in turn 16, while acknowledging the delicacy of the question at hand.

Let us consider the last part of this extended extract (Extract 1c) where GC returns to CF's stance and seeks additional risk information.

Extract 1c	
21 GC:	yes (.) [do you think] it would be the same for a person who has not experienced illness the way you have who is completely healthy or? (5.0)
22 CF:	[yes] yes (.) hard to say
23 GC:	.hh do you think it's because of your experience that you have that attitude?

(Continues)

Extract 1c Continued

Extract 1c	
24 CF:	.hh yes maybe maybe a bit- a bit like that hh.hh yes when all this started to strike you could say I was a bit lucky in a way because that was sort of my perspective on this with life and so on then
25 GC:	yes
26 CF:	that I have (.) yes
27 GC:	yes
28 CF:	a bit the way I am as a person
29 GC:	mm
30 CF:	eh for my- after all it's quite clear that we tackle these things in very different ways
31 GC:	mm
32 CF:	me and my brother are very different
33 GC: mm	
34 CF:	my brother is not interested
35 GC:	no I see
36 CF:	no
37 GC:	yes
38 CF:	he is ((X)) (.) he sweeps everything under the rug

In turn 21, GC continues with her query to ascertain what makes CF so resilient with regard to accessing (potentially) uncertain health information and if this is due to her experience of living with cancer, which is implicitly contrasted with the healthy population's lack of illness experience. The underlying question is: Would healthy individuals and affected individuals respond to diagnostic uncertainties differently? CF's response in turn 22 ('hard to say') is somewhat hesitant, but when pursued further by GC in turn 23, CF characterizes herself as 'a bit lucky'. She underscores how wanting to know or not know may be premised on different motives and then makes a contrast between her positive attitude to life (turn 24) and the healthy population's potentially ambivalent attitude to life. In turn 30, CF again returns to generalization with the use of 'we', this time as a marker of differentiation between herself and her brother—'we tackle these things in different ways'. The fact that the brother is not interested in knowing his genetic risk could be construed as implicit blame. This works to frame CF as the kind of person who wants to take responsibility for knowing additional risk information. For exemplification, CF uses contrast to juxtapose her way of managing uncertainty ('the way I am as a person', turn 28) to that of her brother's ('who sweeps everything under the rug', turn 38), thus alluding to possible familial tensions surrounding genomic testing. Some of the tensions encompassing diagnostic uncertainties can be ethical in nature, to which we turn next.

4.2 | Ethical tensions surrounding diagnostic uncertainties

In Extract 2a, the male client (CM), in his mid-forties, has been part of a surveillance system where he is going through colonoscopy every second year. He has had several polyps removed in the process. The extract opens with GC explaining that the exome sequencing test can generate secondary and uncertain findings, raising ethical issues about what information clients can be given access to. Prior to the opening of the extract, GC and CM have already touched upon the topic of recruitment for the ongoing research study.

Extract 2a	
01 GC:	yes (.) and here we come to something that is important (.) and this is about whether (.) but now you have said quite a bit about it yourself (.).hh in relation to (1.0) would you like (.) feedback if we find the cause of the high occurrence in your family (.).hh and (.) if we were to have secondary findings (1.0) in which there is serious risk to life and health and that there are preventive measures available.hh that means (.) we are not going to give you feedback if we find anything that is serious that has no treatment (1.5) it is (.) and there is a kind of ethical perspective in all of this (.) because (.) if you suspect that there is some hereditary condition in your family (.) then we should rather look at that in a separate counselling session (.) first of all then (1.0) take it away from the research project itself.hh but (.) I don't know if you have heard about a disease called Huntington?
02 CM:	I don't think
03 GC:	no ok
04 CM:	no
05 GC:	there is no cure.hh and (.) it is like a serious condition which we are not going to give you an answer about if we were to find that genetic defect in you
06 CM:	why not?
07 GC:	yes because [I say]
08 CM:	[so if] I say that I do want to have it
09 GC:	yes
10 CM:	can't [I get it then?]
11 GC:	[no] it is because the ethics committee says that as long as there is no treatment we are not allowed to (.) […] because we discussed […] whether we should have a clause that one would like feedback about serious illness for which there was no treatment for (.).hh and it- and here one has like come to the conclusion that it would be unethical

(Continues)

Extract 2a Continued

Extract 2a	
12 CM:	they're wrong about that
13 GC:	yes
14 CM:	absolutely wrong
15 GC:	and that's something you must [feel free to say] and then you can feel free to say it loud and clear ((laughs))

In turn 01, GC provides institutional guidelines surrounding what information can be made known, and through a contrast she demonstrates what may count as 'benefit of knowing' versus. 'risk of knowing' (Sarangi et al., 2003) with regard to secondary findings. GC justifies a collectively shared 'ethical perspective' ('if we find anything'), although it is somewhat unclear what the referent of 'we' is here. Does it collectively represent the counselors' and the researchers' points of view or only of the former? GC's account comes across as a tendency to safeguard the institutional guidelines and their gatekeeping function with regard to available information ('we are not going to give you an answer'). GC enhances her ethical stance through contrast: knowing in order to take 'preventable measures available' and avoid 'serious risk to life' versus. knowing 'anything that is serious that has no treatment'. The issue of clients' wanting to know becomes a part of her role responsibility, where GC orients to both scientific others ('we find the cause') and familial others ('your family') before shifting to clinical others vis-à-vis the ethical tensions outside of the research project ('disease without treatment').

The ethical tensions regarding how the intervention regime would unfold and who would have the right to what can be known if there are any secondary findings are placed in the family context. Due to the hybrid nature of the counseling session, GC is ethically torn between being client-centered in order to reduce diagnostic uncertainty (i.e., arranging 'separate counseling session') while, simultaneously, attempting to recruit clients for research to accomplish scientific (epistemic) certainty (i.e., encouraging 'participation in research project'). This tension between the clinical setting and the research setting confirms the relevance of how differential ethical principles should be operative in these two contexts (Hallowell et al., 2015).

In turn 05, GC reaffirms her ethical position concerning non-disclosure of diagnostic findings for which 'there is no cure'. 'Risk of knowing' serves as a justification for non-disclosure of 'irrelevant' test results. The tension between CM's desire to know and GC's ethical concerns is articulated through a hypothetically framed question pointing to the contrasting stance: 'if I say that I do want to have it can't I get it then?' (turns 8, 10). GC justifies her stance on non-accessibility through the use of reported speech ('the ethics committee's perspective'), which indexes an ethical dilemma in that certain test results can be irrelevant and cause anxiety, which may border on 'risk of knowing'. However, CM manifestly disagrees with the ethics committee's non-disclosure policy through extreme case formulation ('they are [absolutely] wrong', turns 14, 16) and affirms his preference regarding disclosure of any test result. In turn 15, GC aligns with CM and his right to access genetic knowledge while she also feels compelled to uphold the ethics committee's injunctions about non-disclosure, which counts as an ethical dilemma.

The interaction continues as follows in Extract 2b.

Extract 2b	
19 GC:	[eh and so] because it is interesting for us to actually do what you think about it
20 CM:	yes I have a very clear opinion about that yes (.) eh if I for some unknown reason get or eh (.) what should I say then (.) genetically predisposed or am going to get a serious illness (.) then for me it is completely irrelevant whether this is because of a bad cancer gene or something else (1.0) I want to know it anyway
21 GC:	mm
22 CM:	if I get to know something that is part of this study or your research (0.5) ehm well that is fine too (.) but if it it is not what you are doing research on I still want to know it
23 GC:	[mm]
24 CM:	so for me what caused is not important (.) for me it is (.) if I get to know that I may have or have huge possibilities to get Alzheimer
25 GC:	mm
26 CM:	then I will of course want to know it
27 GC:	mm
28 CM:	why shouldn't I want to know? (.) then I can well of course (.) well then I can live my life now [before I get it]
29 GC:	[laughs]
30 CM:	well it is after all my assessment then what I will do with it (.) and [why]

In turn 19, GC alludes to other clinicians' and the ethics committee's collective stance on this delicate matter. Through a reasoned demand ('I want to know it anyway'), CM justifies his stance again through contrast: 'A genetically predisposed […] illness' is implicitly contrasted with an accidental 'bad cancer gene'. CM's account signals that disclosure about inheritance is in the welfare of him as a client and this serves as a justification for demanding access to health information (turn 22). CM upgrades his desire for diagnostic certainty while underlining his ability to cope with epistemic uncertainty linked with hereditary conditions that have no treatment (turns 24, 26). As in extract 2a, in turn 28, CM disagrees with the

official protocol about non-disclosure and voices his strong critique, with a rhetorical question—'why shouldn't I want to know?'—followed by a temporal contrast: 'I can live my life now [before I get it]'. CM justifies his right to access information which he can act on and thus demonstrates that he has the capability to assess and cope with uncertain knowledge. As a final gesture, in turn 30, CM asserts his autonomous stance toward both knowing and what to do with his knowing.

In what follows, we consider how clients and counselors orient to their role responsibilities as a way of foregrounding the ethical tensions surrounding diagnostic uncertainties, while justifying their respective role responsibilities regarding what can be known.

4.3 | Clients' orientation to familial others vis-à-vis diagnostic uncertainties

Extract 3 is from the same encounter as extracts 2a & 2b, and here we focus on the client's (CM's) orientation to self-other relations when exercising his desire to know in the event of diagnostic uncertainties. It is worth reiterating that the client and his extended family had previously been tested for known cancer genes, with negative results. Exome sequencing was offered to further explore and explain the cancer predisposition in this family. Previously, GC and CM have talked about the rationale behind exome sequencing, as illustrated in prior extracts, and about researching for certainty to reduce uncertainty in this specific family. GC initiates the topic of disclosure of test results, and she articulates diagnostic uncertainty as part of the family history ('a family where we don't know the details'). In framing such disclosure as a sensitive issue, GC simultaneously dwells on the specific value of targeting the research study on one particular family.

Extract 3	
01 GC:	but then I could (.) if it would be OK with you to ask you about one thing
02 CM:	mm
03 GC:	because eh you say that it is a strength you think and we think so too that you are related (.) and there is after all a family where we don't know the details so that it is also something.hh one of those that in a way has been on my mind in terms of is it possible to find out something more here
04 CM:	mm
05 GC:	.hh but then the thing is this that when we discussed this here with the ethics committee they thought that it might become a burden for you (0.5).hh because how would it be if you for example decide that you do not want to know anything (1.0).hh and then maybe (0.5) your sister decides that she does want to (.) and then how will you be able to handle it (1.0)
06 CM:	.hh [eh]
07 GC:	[do you see] that it might be a=

(Continues)

Extract 3 Continued

Extract 3	
08 CM:	no OK now I must basically speak for myself but now after all I know my sister so well that (1.0) for us I don't think there's a problem- problem situation (.) myself I am strong enough (.) but I mean (.) eh that I will handle it anyway (.) whatever the outcome whatever I am told know whatever (.) all information is better than no information (.) the way I see it (.) I am curious enough by nature too I (.) that you are welcome to explain a bit to me (.) don't need to go far far down into the depths (.) but I understand enough that I can pick up some valuable info then (0.5).hh and (0.5) I am absolutely sure at the end of your questions here that I want to know everything
09 GC: mm	
10 CM:	absolutely sure
11 GC:	yes
12 CM:	I've come to terms with those thoughts before I came here or when I got this here and thought through it then (.) this has two sides for me (1.0) after you said that now we are actually looking at my family (.) that strengthens even more and want to be involved (1.5) precisely because it is cool to be able to contribute to research that others may benefit from (.) that's maybe the cherry on the top here then
13 GC:	mm
14 CM:	but of course I am egoistic enough as well (.) that I would like to get hold of all information that concerns myself (1.5) if anything could be picked up at an earlier stage that could maybe (.) get something started that would mean I maybe I don't die of cancer (.) early (1.0) maybe later or I mean
15 GC:	mm
16 CM:	everything that could improve my life situation

The extract opens with GC's account of 'risk of knowing' ('might become a burden to you'), followed by a contrast: 'you do not want to know' versus. 'she [sister] wants to know'. Wanting to know available test results is foregrounded as a sensitive—and even divisive—issue in the family sphere. GC formulates a potential ethical dilemma regarding familial differences by sketching a hypothetical future scenario. In other words, GC raises the ethical concerns about CM's coping strategies when dealing with certainty/uncertainty (turns 05–07) through use of reported speech ('ethics committee thought it might be a burden to know', turn 05). Our analytical interest here is how CM responds to such an ethical framing. As before (see extract 1c in particular), the rhetorical device of contrast becomes a resource to orient to familial others' attitude to uncertainty in test results. In turn 08, CM disregards the ethical concerns and justifies his stance toward wanting to know ('I am strong enough'; 'I am curious enough by nature too'). The sister is implicated as he exercises his right to access health information ('I know my sister so well that for us I don't think there's a problem'). Unlike in extract 1c, the brother and the sister are presented as a unity, rather than being differentiated. CM upgrades his certainty about wanting to

know as opposed to the diagnostic uncertainty announced by GC through extreme case formulations ('I will handle it anyway'; 'I want to know everything […] 'absolutely sure'), thus characterizing himself as someone who can cope with the 'risk of knowing'.

As can be seen in turn 12, CM orients to both his own and his family's future wellbeing in an altruistic manner ('looking at my family […] strengthens even more […] it is cool to contribute to research that other may benefit from'). The rationale underpinning his decision to want to know does not fully acknowledge the embedded dilemma as indicated by GC (turn 12). In turn 14, CM simultaneously characterizes himself ('I am egoistic') and points to a hypothetical future event which is preventable through knowing ('maybe I don't die of cancer early'). This constitutes an essential part of CM's justification for wanting to know because of the benefits of knowing as well as the timing of knowing ('if anything could be picked up at an earlier stage that could maybe get something started'), while orienting to both self and familial others.

4.4 | Counselors' orientation to scientific and clinical others vis-à-vis diagnostic uncertainties

Our final case in Extract 4 concerns a male client (CM) in his early 30s, who is the youngest in this extended family. He has just started with colonoscopy and has had some polyps removed. His father is seriously ill with colon cancer. Previously, the genetic counselor (GC) has mentioned the amount of uncertain information the exome sequencing test may generate. However, in this case, as opposed to extract 3 where we drew attention to the client's self-other-orientations, we look into GC's other-orientations to manage the tensions surrounding diagnostic uncertainties. In the encounter, GC repeatedly mentions CM's right to access genetic information in light of this family dealing with diagnostic uncertainty and their right to get answers and explanations. It is worth noting that CM is a participant in the research study, and that GC has an obligation to disclose to him any findings resulting from the research study. The question of access to information is foregrounded in the interaction.

Extract 4	
01 GC:	mm (.) yes.hh and well in this study her then then it will be- which means you will
have right of access	
02 CM:	mm
03 GC:	.hh which means you will be able to get feedback if we have found anything of
04 CM:	Mm
05 GC:	of significance healthwise
07 CM:	[mm]
08 GC:	.hh but you have also right of access which actually means that you can ask for access about what we have found
09 CM:	[mm]

(Continues)

Extract 4 Continued

Extract 4	
10 GC:	[.hh] but at the same time we rather see you don't do that because [then] we will have so much information
11 CM:	[mm] mm
12 GC:	and the question is (.) what benefit does one have of all this before one kind of [has managed to] pick out what is
13 CM:	[yeah yeah yeah] No I don't need- [I will not ask about it]
14 GC:	[important knowledge but] you have right of access as it is called
15 CM:	yes
16 GC:	at the same time as we say we wish you will not (.) eh eh take (.) what is it called (.) take it into use
17 CM:	mm
18 GC:	eh (1.0) do you think (.) what do you think? Is this [something you find a little bit strange]
19 CM:	[I am not going to take it into no] (.) I am not going to require access or like into the matter (.) I will just as I say if there is anything [then] it is just that one get answers or
20 GC:	[yes] mm
21 CM:	it is [no more than that]
22 GC:	[we we- I don't sit] here saying that you shouldn't ask for it [like well]
23 CM:	[no no no]
24 GC:	but because you do have right of access (.) well you [have]
25 CM:	[yes]
26 GC:	that is like indisputable
27 CM:	yes
28 GC:	it is just that well then
29 CM:	I don't understand any of it anyway I think
30 GC:	well (.) I don't know if I would either if [I should] ask for access
31 CM:	no
32 GC:	because I think it's going to be a lot
33 CM:	complicated arrangement [I think]
34 GC:	[a lot of] material that will take a long time to process
35 CM:	mm
36 GC:	after all there are some who sit and work only to try and interpret the findings

GC begins by issuing a statement of what is there to be known in the context of exome sequencing based on an implicit contrast between what is 'of significance healthwise' and the findings that are not considered significant (turn 01, 03, 05). GC has a twofold other-orientation: first she affiliates with the scientific others who are alluded to through 'this study'; and then with both clinical others and scientific others ('feedback[…] of significance healthwise'). The label 'of significance healthwise' indexes the client's right to be given

certain information about secondary findings that would possibly affect his health and thus serves as a justification for CM's future right to access information that falls within this label. She orients to scientific others ('we have found') in the generation of new genetic knowledge (turn 08). Rather paradoxically, CM is armed with the right of access to all available information but is simultaneously disarmed when urged not to exercise this right. That is, CM is framed as being autonomous, with the disclaimer that he must act responsibly.

In turn 10, GC orients to clinical others when implying an inclusive preferred action ('we rather see you don't') in light of lots of uncertain—even irrelevant—information. In turn 18, she inquires about CM's stance on this matter. As can be seen, in turn 19, CM claims, contrastively, that he is not after information per se but in search of answers. CM further elaborates his position ('as I said') and offers a justification via orientation to general others through the pronominal choice 'one' ('that one get answers'). Through this orientation his role responsibility aligns with clinical others and other-others, all of whom are implicated in the management of uncertainty. In adding 'it is no more than that', he acknowledges the complexity of the issue (turn 21).

In turn 22, GC once again reaffirms CM's moral and legal 'indisputable right' but uses self-reported speech to foreground the role relationships between them as clinicians and the client ('we don't sit here saying you should not ask for it'). CM responds by acknowledging the clinicians' dilemma through his limited understandings as a client (turn 29). GC then responds with a hypothetical construction: whether CM as a research subject would act on his right to access information ('if I should ask for access'). This hypothetical scenario is, however, embedded in the specific context of exome sequencing producing a set of genetic findings ('it is going to be a lot') that needs to be sorted out ('will take a long time to process'). CM aligns with GC's stance on exome sequencing as producing a lot of information framed as 'complicated arrangement', which alludes to benefits of not knowing. By upholding this complex future event, GC justifies against disclosure or 'risks of knowing', as she explicitly comments on the hybrid nature of the encounter as a research study and a clinical encounter (see also extract 2b). This is in line with Hallowell et al.'s (2015) injunction about the need for different ethical guidelines regulating study findings vis-à-vis disclosure of such findings in research versus clinic settings.

5 | DISCUSSION

New diagnostic technologies for genomic testing such as exome sequencing no doubt offer promises but they generate certain kinds of *significant* uncertainties that pose ethical dilemmas both for genetic counselors in the clinic setting (Balcom et al., 2016) and for clients in the clinic as well as family settings. A key aspect is that epistemic certainty that may be achieved through new technologies, such as secondary findings, does not necessarily come with treatment options and can thus be deemed practically irrelevant for counseling purposes. However, the fact that secondary findings can surface through test procedures raises the perennial question about who has the right to such information and whether ethics committees are justified in denying clients access to such information on the ground of unavailability of treatment options (extract 2a). The tension is further heightened when the client's role-set includes participation in an ongoing research study. Our analysis points to the claim that new diagnostic knowledge gives rise to uncertainties and triggers orientation to self-other responsibilities—for both clients and genetic counselors—which constitute complex role-sets intersecting the domains of familial, scientific and clinical practices. We have also seen, as in the case of extract 3, epistemic certainty (what can be known scientifically) cannot guarantee diagnostic or prognostic certainty at the individual level.

With regard to genetic/genomic science, genetic counselors' participation in ongoing research is instrumental to the development and assessment of new genetic/genomic test technologies. In such scenarios, genetic counselors may be torn between competing interests—to help advance scientific knowledge by following strict protocol on issues regarding clients' right to access genetic information including secondary findings on the one hand, and to foreground the benefits of genetic/genomic tests extending to all at-risk family members, on the other. The inherent ambivalence of recruiting a client or his/her family to exome sequencing puts genetic counselors in a difficult position in terms of balancing their provider–client role relationship and their role as collaborators with laboratory-based genomics researchers and their professional relationship with fellow genetic counselors.

With regard to clients, some may foreground their perceptions of 'benefits of knowing' pertaining to new knowledge which has the promise of reducing uncertainty and/or in their pursuit of certainty about their own and family members' at-risk status. As can be seen in extract 4, CM claims he is not after information per se but in search of answers ('that one get answers'). This distinction between 'information' and 'answer' could also be seen as a distinction between research study (information) and the clinical setting (answer), manifesting a nuanced perspective on the principle of client autonomy. It appears that those clients who exercise their desire to know are after information per se, not answers. Consequently, revealing results from exome sequencing showcases differences between clinical and research settings when it comes to disclosure of genetic information, which requires adjustment at the communicative level, echoing Hallowell et al.'s (2015) appeal for context sensitivity. Other empirical studies concerning the right to know in the clinic setting (Forrest et al., 2003; Hallowell et al., 2003) and in the research setting (Barton, 2007; Shipman et al., 2014) highlight difficulties in communicating genetic information within families (Clarke et al., 2005; Featherstone, Atkinson, Bharadwaj, & Clarke, 2006; Mendes et al., 2018) and/or issues regarding gendered responsibility (d'Agincourt-Canning, 2001). It raises an important issue at a practical level: should genetic counselors communicate test results (and secondary findings) differently to those clients who are recruited as study participants and those who are not?

In our analysis, we have primarily focused on clients' desire/wanting to know or not know, although at times there is an

inevitable slippage between 'desire to know/not know' and 'right to know/not know'.[5] Clients' right to know/not know what can be known remains a contentious issue in genetic counseling research and practice. This issue has attracted a lot of attention, usually from legal and moral perspectives foregrounding autonomy (Chadwick, Lewitt, & Shickle, 2014; Wilson, 2005) and as part of information/consent that attests/respects both standpoints, that is, the right to know and the right not to know. In the context of exome sequencing, it is conceivable that the test results would be of greater potential significance to the individual client (Clarke & Wallgren-Petterson, 2018; Husted, 2014; Kaye, Boddington, Wries, Hawkins, & Melham, 2010). As our findings attest, individual clients tend to express a desire to know by asserting their rights of access to available information. Whatever option they choose in a given circumstance, they account for their decision, especially as justification. For counselors, diagnostic uncertainties also pose challenges in terms of what can be communicated and what further courses of action can be pursued, while still trying to uphold their non-directive stance.

At the discursive level, the rhetorical devices of contrast and extreme case formulation, among others, are deployed by both counselors and clients to engage in discussions regarding disclosure of secondary findings as a potentially divisive matter in the family context (extract 1a, extract 3). Especially when orienting to family others in uncertainty management, the rhetorical device of contrast assumes significance. It becomes a central component in stating a role responsibility ('the way I am as a person') and infuses a moral character to CF's responsibility in contrast to her brother ('he sweeps everything under the rug'). We also notice the rhetoric of contrast between ('looking at my family') and ('research that others may benefit from') being constitutive of role responsibility that goes beyond familial others and extends to general others and researchers as part of an altruistic motivation (Shipman et al., 2014).

Because of prevailing uncertainty, orientation to different others is necessary in the context of genetic counseling. As we have seen, the client may orient to himself/herself or familial others, whereas the genetic counselor may orient to the client as well as to different others, for example, familial others, scientific others, and clinical others. The scientific others, however, are not just one community but a dispersed entity. Likewise, the label 'others' may refer to first degree family members or may refer to more 'general others', like 'people in your situation'. Other-orientations seem primarily aimed at helping clients' decision-making as well as coping processes.

A theme-oriented discourse analysis of the kind undertaken here shows how diagnostic uncertainties give rise to tensions, including ethical ones, in both professional and familial spheres, and how accounts of orientations to others illustrate that both clients and counselors strategically switch between different role responsibilities. There are parallels here to accounts of ethical dilemmas *qua* role responsibilities in the context of childhood genetic testing where views of the child's best interest get entangled in competing perspectives across parental preference and professional judgement (Arribas-Ayllon, Sarangi, & Clarke, 2009; Clarke, Sarangi, & Verrier-Jones, 2011; Sarangi & Clarke, 2002). The resultant professional ambivalence goes beyond clinicians' awareness of general ethical principles and requires expertise at the interactional, contingent level. Our findings echo these studies concerning the interface between uncertainty management and desire/right to know and not know but also extend the discussion to include how genetic counselors and clients can be strategic in their other-orientations vis-à-vis the role responsibilities affordable within a given role-set.

6 | CONCLUSION

In this paper, we began with the observation that genetic counselors and clients are increasingly confronted with uncertainties as a by-product of new diagnostic technologies and this leads to complex communicative environments in both clinical and familial spheres. In addressing our research question as to how diagnostic uncertainties are managed communicatively, we have focused on the accounts of both genetic counselors and clients underpinning the access to genetic information. The accounts draw on a range of rhetorical devices (e.g., contrast, extreme case formulation, pronominal reference, reported speech, hypothetical construction) as forms of justification but also as a means to address sensitive issues in a delicate manner. We conclude by pointing to how new genomic knowledge can give rise to diagnostic uncertainties as well as ethical tensions concerning accessing/disclosing what can be known and trigger other-orientations vis-à-vis role responsibilities, intersecting the scientific, clinical and familial spheres. It is perhaps helpful to consider certainty and uncertainty as relational categories and as part of a continuum, while acknowledging the ever-widening gap between epistemic (un)certainties at the population level and diagnostic uncertainties at the individual/familial level.

6.1 | Study limitations and practice implications

Our study has several limitations, typical of any qualitative study, in that the findings are not generalizable across genetic conditions and across clinical settings and families. While not generalizable, the findings are potentially transferrable to other research settings addressing the interface of new technologies of genomic testing and the communicative challenges facing genetic counselors in the clinic setting. In genetic counseling, dealing with uncertainty is not merely a matter of providing warrants for what is certain and known, but also a matter of managing diagnostic and epistemic uncertainties and the attendant ethical tensions through accounts of role responsibilities.

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AUTHOR CONTRIBUTIONS

GH and SS contributed equally to the study design and the drafting and redrafting of the manuscript, including data analysis. IB collected the audio recordings and GH transcribed the recordings. GH was primarily responsible for the selection of the data extracts. In addition, GH has operationalized the theoretical concepts of uncertainty and role responsibility in the Norwegian genetic counseling context. IB offered input where relevant. GH, SS, and IB have approved the final version.

COMPLIANCE WITH ETHICAL STANDARDS

Conflict of interest

Gøril Thomassen Hammerstad, Srikant Sarangi, and Inga Bjørnevoll declare that they have no conflict of interest.

Human studies and informed consent

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

Animal studies

No animal studies were carried out by the authors for this article.

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ENDNOTES

[1] We are grateful to Reviewer 2 for drawing our attention to the distinction between 'incidental findings' and 'secondary findings', following the deliberations of the ACMG (American College of Medical Genetics) and other organizations. We use the term *secondary findings* in our analytical commentary but retain the term *incidental findings* in the original data extracts.

[2] In the Discussion section we return to the terminological nuances surrounding 'wanting/desire to know or not know' and 'right to know or not know'.

[3] The larger dataset consists of 18 sessions, including 8 post-test sessions.

[4] The original transcripts can be made available upon request from the first author.

[5] We acknowledge Reviewer 1's remark that 'rights involve attendant obligations in the ways that desires do not'.

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