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"We are just not sure what that means or if it's relevant": Uncertainty when gathering family history information in South African prenatal genetic counseling consultations

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ABSTRACT

Uncertainty impacts the process of health communication. The management and tolerance of uncertainty during healthcare discussions have gained renewed focus due to the growing challenge of obtaining and delivering complex health information, and the offer of health services in diverse contexts. Prenatal genetic counseling (GC) provides education, support and testing options for patients and couples facing a genetic or congenital diagnosis or risk during pregnancy. Gathering detailed and accurate family history information is essential to determine a patient's genetic risk. In South Africa, contextual factors such as patient literacy, language diversity, limited written patient health records, and a lack of familiarity with GC services may increase the potential for misunderstandings during GC consultations. This study uses a qualitative sociolinguistic approach to analyse 9 video-recorded South African prenatal GC consultations to understand the impact of uncertainty on the process of gathering family history information. The findings reveal uncertainty is introduced in different ways during family history taking. This includes when patients have no knowledge about their family history; when they have some knowledge but the details are unclear; or when patients have knowledge but the details are confusing. Uncertainty can lead to interactional trouble in the form of knowledge asymmetries, interrogative questioning, reversals in epistemic authority, and the potential for mistrust. Suggestions are made for how genetic specialists can manage uncertainty in GC family history taking. These include recognizing contextual sources of uncertainty, understanding how patients may respond to uncertainty and being aware of personal responses to moments of discomfort. Specific communication training recommendations and video-based sociolinguistic methods to enhance reflection and communication practice are highlighted. These approaches may enhance the effectiveness of GC communication and strengthen patient-specialist relationships, especially in diverse settings.

1. Introduction

1.1. Uncertainty in genetic counseling

Uncertainty is common in healthcare. Due to its frequent, and at times unavoidable presence, the relational and interactional management, rather than elimination, of uncertainty has become of particular interest to researchers and healthcare practitioners (Han et al., 2011; Hogan and Brashers, 2015; Zhong et al., 2020). However, there remains a lack of knowledge on how uncertainty manifests in daily interactions, how participants respond to it, and how healthcare professionals and patients cope with uncertainty (Epstein and Street, 2007; Han et al., 2011; Pilnick and Zayts, 2014). Genetic counseling (GC) is a medical service that provides psychological support, risk assessments and education on genetic risks, inheritance patterns and testing options for individuals and families affected by, or identified as being at risk for a genetic condition (Biesecker et al., 2019; Resta et al., 2006). Genetic risk information is inherently uncertain (Medendorp et al., 2020; Thomassen Hammerstad et al., 2020), making communication in GC consultations particularly challenging (Hashiloni-Dolev et al., 2019; Pilnick and Zayts, 2014). Prenatal genetic counseling is offered to pregnant individuals, or to couples where a genetic risk has been identified. Uncertainty often occurs in these consultations since several prenatal procedures are screening-based rather than diagnostic, with results produced as risk

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probabilities (Pilnick and Zayts, 2014). Prenatal diagnostic genetic tests also have the potential to create uncertainty, for instance, the detection of a variant of uncertain clinical significance (VUS) (Hashiloni-Dolev et al., 2019; Pilnick and Zayts, 2014).

1.2. Examining uncertainty in GC family history through interactional research

Accurate family history information is crucial for determining genetic risk. Studies have shown that family histories may include conditions with potential genetic components of which a patient may be unaware (Rose et al., 1999). Using a three-generational pedigree is thus a cost-effective way for genetic specialists to reveal previously unknown, potentially relevant genetic risks (Frezzo et al., 2003; Schuette and Bennett, 1998). Although uncertainty is known to impact the outcome of GC (Patch and Middleton, 2018), information-giving (Pilnick and Zayts, 2014; Rauscher, 2017) and decision-making (Thomassen Hammerstad et al., 2020), less is known about how uncertainty affects communication in the context of gathering family history information.

Interactional qualitative research methods capture naturally occurring talk-based activities (Flick, 2013). These communication processes include how language is produced, responded to, and utilised to achieve various goals such as upholding self-image, obtaining information, negotiating meaning, resolving trouble, and ensuring mutual understanding (Chiu and Qiu, 2014; Heller et al., 2017; Heritage and Maynard, 2006; Lambert et al., 1997). Pauses, silences, non-verbal gestures, and props are also highlighted (Heath et al., 2010; Heritage and Maynard, 2006; Toerien, 2014).

1.3. GC services in South Africa

South Africa faces challenges in health communication due to its cultural, linguistic and socioeconomic context. Language and literacy differences (Kromberg et al., 2013; Shingwenyana, 2020), cultural beliefs (Penn and Watermeyer, 2018) and geographical barriers with limited contact with biological relatives (Mtshali, 2016) may impact patients' abilities to provide information about family members as well as how they understand genetic risk. There has been little South African GC interactional-based research, with existing interactional GC studies primarily focused on risk information giving (Perrott, 2010) and decision-making (Wessels et al., 2014; Wessels and Koole, 2019).

1.4. The current study

This paper explores the introduction and presence of interactional uncertainty during the family history information-gathering phase of South African prenatal GC consultations, highlighting potential causes, and its communicative impact. Practical suggestions for managing uncertainty in a South African context are made.

2. Materials and methods

2.1. Research design

The paper forms part of a wider qualitative study that examined how risk is communicated and uncertainty is managed during GC consultations in a South African public healthcare context. The study used a blended sociolinguistic framework to analyse video-recorded GC consultations, genetic specialist (genetic counselor and medical geneticists) interviews and researcher field notes from genetic clinics at three tertiary public hospitals in Cape Town. GC consultations included prenatal, pediatric, and adult-focused conditions for a wide range of genetic risks and concerns. All relevant ethical procedures were followed and written consent was obtained from participants.

2.2. Participants

The inclusion criteria for the study included any GC consultation where genetic risk was discussed, and with patients and qualified genetic specialists who were willing to participate. The study had no exclusion criteria regarding the types of genetic conditions or types of public genetic clinics. However, patients who were visibly upset due to the diagnosis of a severe foetal anomaly or who were referred to discuss a possible termination of pregnancy were not approached to minimise additional psychological distress.

2.3. Data collection

The study used convenience sampling to collect data from first-time and follow-up GC consultations. Most patients were Mixed Ancestry or Black African individuals, Afrikaans and isiXhosa first language speakers, and predominantly from lower socioeconomic backgrounds. All patients were referred by other health practitioners within the South African public healthcare system. All GC consultations that met the study inclusion criteria were selected regardless of the language in which the consultation was conducted. Genetic specialists included medical geneticists and genetic counselors, with the majority being female, Caucasian, English and Afrikaans first-language speakers, whose ages ranged from the mid-20s to 50 years of age.

Video-recording equipment was used to collect data from the GC consultations. The first author attended the genetic clinics and invited participants to participate. Genetic specialists were initially invited and it was explained that the purpose of the study was to understand the process of risk and uncertainty communication in a South African GC context. Regarding patient recruitment, after receiving consent from the genetic specialists, the first author was shown a list of patients referred to each clinic on the day, and their reason for referral. Upon receiving permission from the specialist assigned to a specific patient, the first author approached each patient and invited them to participate in the study. Potential patient participants were given time to think about their decisions and to ask questions. The main author emphasized the voluntary nature of participation and anonymity to all potential participants. After consent, enrolled patients waited for their names to be called by the relevant genetic specialist for their consultation. At the start of the consultation, the first author set up the recording equipment in the corner of the room and then left the room. Genetic specialists were instructed to proceed with the consultation in their usual manner to allow a natural interaction. Consultations typically took place in English or Afrikaans, and in some cases, isiXhosa (with the help of an interpreter). All participants were provided with the researchers' details if they decided to withdraw from the study retrospectively. No participants made contact with the researchers thereafter. During participant recruitment, one patient declined participation as they felt that study participation would prolong their time at the clinic. One genetic specialist declined participation stating their discomfort with the recording equipment.

For this paper, only data from prenatal video-recorded consultations were used, specifically moments where family history information is gathered for a risk assessment. A total of 9 video-recorded prenatal GC consultations were collected. Most of the prenatal consultation referrals were for advanced maternal age (AMA) (pregnant women older than 35 years age (Hoque, 2012) or identification of a foetal soft marker for aneuploidy.

2.4. Analysis

The study used conversation analysis (CA) (ten Have, 2007) and theme-orientated discourse analysis (TODA) (Roberts and Sarangi, 2005) principles to analyse the recorded data. Content logs (Goodwin, 1994; Jordan and Henderson, 1995; ten Have, 2007) were created after watching each recording and included participant details, location,

referral reason, the family pedigree, types of discussions and contextual considerations. The consultations followed the typical approach used in South African GC training and practice with identifiable phases including an opening, information gathering, information giving, decision-making, psychosocial counseling, and a closing (Wessels et al., 2014). The content logs aided in selecting segments that specifically dealt with family history gathering and moments of uncertainty. These segments were transcribed using Jeffersonian CA conventions (Hepburn and Bolden, 2012; Jefferson, 2004) (Appendix A). Uncertainty markers drawn from previous interactional research (Barr, 2001; Pilnick and Zayts, 2014; Sarangi and Clarke, 2002; Steel et al., 2014; Stivers and Timmermans, 2016) aided in identifying uncertainty. These comprised auxiliaries (e.g. could, might, maybe), adverbs (e.g. about, approximately), filler words (e.g. uhm, uh, well) and discourse strategies such as hedging or mitigation. Turn-taking, turn-designs, repair and sequence organisation such as speech dysfluencies, re-starts, pauses and prosody (e.g. speech rate, pitch and intonation) were also noted. For non-English consultations, linguistically matched and trained research assistants transcribed and translated this data, using a two-line transcription (Hepburn and Bolden, 2012) process. The authors curated collections of similar interactional features and patterns to demonstrate that conversations are jointly constructed by participants and are influenced by surrounding conversational features (Curl, 2006; Toerien, 2014). All data and findings were discussed and corroborated amongst the authors and verified through anonymized data consultations with academic colleagues.

3. Results

The results show that interactional uncertainty is introduced and maintained during the collection of family histories in South African GC prenatal consultations. Due to the absence of written medical records, genetic specialists rely on verbal patient accounts to access family history information. Using three examples, we demonstrate three ways in which uncertainty can be introduced: 1) When patients don't know anything about their family history, 2) When they know something about it, but not in enough detail, or 3) When they have information, but the information does not make sense to the specialist and the specialist challenges this information.

Example 1. When a patient claims to have no knowledge

Example 1 shows how the lack of information on the cause of death of the patient's young child creates uncertainty for the genetic specialist on its relevance to the patient's pregnancy. This is particularly evident when the patient claims to not know any further information. The consultation involved a 39-year-old Mixed Ancestry woman who was 13 weeks' pregnant, who was referred for her age and the identification of a foetal soft marker for aneuploidy. The consultation was conducted in Afrikaans, the patient's home language.

Example 1:1 S = Specialist; P = Patient.

19	P:	En die meisiekind is oorlede 4 maande
		And the girl passed away at 4 months
20	S:	En waarvan is sy oorlede?
		((stops writing in patient file and looks up with puzzled expression))
		And what did she pass away from?
		((stops writing in patient file and looks up with puzzled expression))
21	P:	°natuurlike oorsake°
		°natural causes°
22	S:	Se gou weer?
		Say again?
23		(0.5)
24	S:	natuurlike oorsake?
		natural causes?
25	P:	Ja
		((small head nod))
		Yes
		((small head nod))

(continued on next column)

(continued)

19	P:	En die meisiekind is oorlede 4 maande
26	S:	Okay↑ (.) wanneer was dit gewees?
		Okay↑ (.) when was that?
27		(5.0)
		((patient looking down and gazing at floor))
28	P:	Twintig viertien
		Twenty fourteen
29-65		((patient provides further details about her baby's premature birth and low weight. She explains that when her daughter was four months old, she returned from work and noticed that her daughter was tearful. She gave her daughter a bath, a bottle and put her to bed. When her husband got home, he went to wake up his daughter and found her dead))

During the discussion on the patient's child's death in example 1:1, the patient's whispered tone (line 21) and 0.5-s pause (line 23) may indicate discomfort with the specialist's inquiry. Trouble due to interactional uncertainty is further evidenced by the specialist's turn designs when they attempt conversational repair by requesting the patient to repeat their statement (line 22) and then restating what they think they heard the patient say (line 24). In line 25, the patient provides a passive confirmation (a head nod). Similar interactional findings have been reported where pauses (Jefferson, 1989) and continued repair sequences (Robles, 2017; Schegloff, 1992) are used by participants in attempts to establish understanding. Eye contact also plays a role in trust, anxiety, satisfaction, and relationship building (Farber et al., 2015; Pieterse et al., 2007). The patient's lack of eye contact (together with a lengthy 5-s pause) in line 27 creates further interactional uncertainty between herself and the genetic specialist.

Example 1:2 S = Specialist; P = Patient.

66	S:	Dis:s (0.2) dis 'n verskriklike ding om te moet (.) deur gaan
		That's:s (0.2) that is a terrible things to have to (.) go through
67	P:	°Dit is°
		((head nod))
		°It is°
		((head nod))
68	S:	Seker ook (.) veral as 'n mens nou nie weet wat [>presies<]
		Probably too (.) especially if a person doesn't know what >exactly<
69	P:	[wat]
		[what]
70	S:	wat het gebeur [nie ne?]
		What happened [hey?]
71	P:	[gebeur]
		((head nod))
		[happened]
		((head nod))
72		(1.0)
73	S:	Sjoe
		Wow
74		(6.0)
75	S:	So sy was nooit eintlik siek gewee:es?
		So she was:s never actually sick?
76	P:	°nee°
		°no°
77		(0.5)
78	S:	Mevrou se sy was so bietjie 'n klein↑ babatjie (0.2) was sy vroeg
79		gebore?
		Ma'am you say she was a little bit of a small↑ baby (0.2) was she born early?
80	P:	Ja sy was prem gewees
		Yes she was prem
81	S:	Ho (.) hoe (.) hoe oud was sy toe sy? (0.2) Hoe oud was sy (.) Hoe
82		veel weke was sy toe sy gebore is?
		Ho (.) how (.) how old was she? (0.2) How old was she (.) How many many weeks was she when she was born?
83	P:	Sy's gebore op agt maandes
		She was born at eight months
84	S:	Okay
		((head nod))
85		(2.0)
86	S:	Wat was haar naam?

(continued on next page)

(*continued*)

66	S:	Dis:s (0.2) dis 'n verskriklike ding om te moet (.) deur gaan
		What was her name?
87		(1.0)
88	P:	Janine*
89	S:	Janine*
		((smiles))
90		(5.0)
		((writing down information in family pedigree))
91	S:	°sjoe°
		°wow°
92		(4.0)
		((specialist staring at drawn family pedigree on their lap))

*Pseudonym.

In example 1:2 the specialist continues to grapple with the daughter's death. The specialist's uncertainty is evidenced in lines 68–70 when they state that a person doesn't know what happened together with prolonged silence (lines 72 and 74) and the utterance 'Sjoe' (an expression of surprise in the local Afrikaans language) (line 73). The patient's quiet response in line 76, attempts for further information from the specialist (lines 75, 78, 79, 81 and 82), a second 'sjoe' utterance from the specialist, as well as additional interactional pauses and silences (lines 85, 87, 90, 92) perpetuate the interactional uncertainty. The atmosphere (Langewitz, 2022) of the interaction concludes in a somewhat dejected state as both the patient and the specialist remain in a 'not knowing' predicament.

Example 2. When a patient claims to have some knowledge but the detail is insufficient

In the second example, the specialist and the patient are aware of the cause of death for the patient's child. However uncertainty is introduced and maintained when the patient cannot provide additional details required by the specialist for risk assessment purposes. The consultation involved a 41-year-old Black isiXhosa-speaking woman who was at 21 weeks' pregnant. She was referred for her age and attended the consultation with her new partner.

Example 2:1 S = Specialist; P = Patient; F = patient's partner.

65	S:	Ok (0.4) .hhh so I'm just gonna ask some questions about your
66		family↑ if that's ok↑?
67	P:	((small head nod))
68-85		((specialist looks at patient's hospital file and mentions to patient that it says in her records that she has had two previous pregnancies, a healthy daughter who is now 12 years of age))
86	S:	And your son who passed away↑ (0.4) was he (0.3) born in 1991? ((checking hospital file again))
87	P:	Yes:s
88		And (.) and what age did he die?
89		(0.5)
90	P:	(° °) ((shifts gaze from specialist to father, smiles awkwardly and whispers something inaudible in isiXhosa))
91	F	(0.3) Konje ubenangaphi? (.) twelve? (0.3) So what age did he die? (.) twelve?
92	P:	Aha:a:a ((looking at father and shifting uncomfortably in her chair))
93	F:	Bow'ngeka fiki? ((looks at mother and has a puzzled facial expression)) Before you arrived? ((interpreted as before they had met/commenced their relationship)) ((looks at mother and has a puzzled facial expression))
94	P:	No:o:o↑ he was old (0.2) Uhm ((smiling awkwardly and moves eye gaze between her partner and the specialist whilst scratching her head))
95	S:	It uh (0.2) it says here that he died in 2011?
96	P:	Yes:s [(0.3) He [was born in 91]
97	F:	[it was when he was ___]
86	S:	And your son who passed away↑ (0.4) was he (0.3) born in 1991? ((checking hospital file again))
98	S:	Okay so he was twenty?
100	P:	Uh huh

(*continued on next column*)

(*continued*)

65	S:	Ok (0.4) .hhh so I'm just gonna ask some questions about your
101	S:	And what happened?
102		(0.5)
103	P:	He died of the eh (0.3) kidney failure.
104		(1.0)
105	S:	Oka:ay↑ (0.3) Do you know why he had kidney failure?
106		(1.0)
107	P:	Mmm (0.2) I think at the age of nine (0.4) he suffered from epilepsy
108		(.) but the reason (.) I really don't know now.
109-123		((Patient discusses the different hospitals that her son used to attend and explains that he was also diagnosed with epilepsy at the age of nine years of age.))
124	S:	Oka:ay [(0.5) uhm
125		(2.5) ((writing down information on family pedigree))
126		Okay (0.2)and could you tell me WHY he got epilepsy?
127	P:	Mmm (0.2) I [can't] ((shakes head)) ((smiles))
128	F:	[no reason] ((clears throat))
129	S:	(0.4) Ok (.) so he had epilepsy at the age of 9 and then (.) he
130		was diagnosed with renal fail. Failure at the age of twenty?
131	P:	Ja and (.) and at that time he was not (.) that bad ((nods head))
132		epilepsy (0.2) I think the the tablets were controlling
133	S:	Okay
134	P:	Yes (.) it was under control.
135	S:	Okay (0.3) alright (0.2) uhm

In example 2:1 the specialist enquires about previous pregnancies and children, using the patient's hospital file to obtain information. Line 88 provides evidence that there is missing information in the file, as they ask the patient about her son's age at the time of his death. The patient's potential discomfort in answering the genetic specialist's request is displayed in lines 89–94 through non-verbal gestures (awkward smile, altering her gaze away from the specialist, and shifting her body in her chair) and altered speech volume (whispering something indiscernible to her partner). Her partner (F) also seems uncertain in lines 91 and 93 and provides verbal and non-verbal displays that this information about her son and his death is new to him. The partner's questions in lines 91 and 93 are directed to the patient (P) and accompanied by hesitations and a puzzled facial expression. His statement 'Bow'ngeka fiki?' (translated as 'before you arrived') in line 93, is further evidence that these events occurred before their relationship commenced and that he has little/no knowledge of these past events. The use of isiXhosa by the patient and her partner could be an attempt to have a private discussion, as the specialist cannot speak the language. This 'aside' talk (Penn and Watermeyer, 2012 p. 391) could be a face-saving (Mondada and Peräkylä, 2023) performance by the patient to keep a positive image in front of the specialist. The partner's puzzled expression and lack of knowledge about the son and his age of death could further indicate that this is new knowledge that may not have previously discussed or mentioned to him, and the specialist's question has put the patient in a challenging position.

The patient uses further uncertainty markers when explaining that her son passed away from kidney failure but cannot provide additional details. Evidence includes the filler word 'eh' and pause in line 103, together with the hedged claim 'I think' (line 107) and explicit confirmation 'I really don't know' (line 108). Hedged and mitigative turn designs in a conversation help participants delicately manage an interaction should they subsequently be challenged and or proved wrong by their claim (Caffi, 1999; Mondada and Peräkylä, 2023; Thomassen and Sarangi, 2012). The patient cautiously navigates this uneasy moment by attempting to maintain a positive image and relationship with the specialist (and possibly with her partner) despite her not having the information that is being sought be the specialist.

In Example 2:2 we show that the specialist remains uncomfortable about the lack of information about the patient's son's death and returns

to the topic in a second attempt to gain more information. The time elapsed between Example 2.1 (which occurs in the first 4 min of the consultation) and Example 2.2 (which occurs after 8 min into the consultation) is over 4 min.

Example 2:2 S = Specialist; P = Patient; F = patient's partner.

1	S:	So Bongiwe**, on your side of the family is there anyone else with
2		kidney problems?
3	P:	°No°
4	S:	No↑?
5	P:	°No°
6	S:	Okay (0.3) hhh. uhm
7		(1.0)
8	S:	Mhmm (0.4) and (0.3) when he (.) when your son was [diagnosed
9		with kidney problems (.)] did the doctors ever tell you WHY he
10	P:	[((frowning))]
11	S:	had the kidney problems?
12	P:	No:o (0.2) because I wasn't with him (.) he was in Eastern Cape
13		and I was here.
14-27		((Patient explains that she received a call that her son had died and that he had been sick for approximately 1 week))
28	S:	Hhh ja:a (0.3) because then we (.) we're just not sure what that
29	S:	means [(.) or] how its relevant [(.) or] IF it's relevant (.) so.
30	F:	[Mmm]
31	P:	[Mmm]
32	S:	that's just why I'm asking about it
33	P:	Mmm Mmm I understand.

**Pseudonym.

In Example 2:2, the specialist's sustained uncertainty about the relevance of kidney disease in the family becomes apparent. In lines 1–2 the specialist requests confirmation from the patient that there are no other individuals in the family with a history of kidney disease. When the patient replies 'no' in line 3, the specialist in line 4 repeats the word 'no' with a rising intonation, as a request for clarification. Previous interactional research has shown that the purpose of 'other repetition after an informing statement' (Svennevig, 2004, p. 489) is dependent on the tone in which the repetition is produced, or whether there are other accompanying particles. If accompanied by a falling intonation, or a final response particle such as 'yes', the repetition may indicate hearing or understanding. However, if designed using a high-tone response or a rising intonation, the repeat may display an emotional stance such as surprise or interest, which may warrant further clarification from the initial speaker (Svennevig, 2004). The patient again responds with 'No' in the third pair part (line 5).

In lines 6–11, the specialist's uncertainty continues to be evident through filler words ('uhm'), outbreaths, restarts, pauses and requests for additional information. This persistent questioning, even after the patient's prior indication of not knowing (Example 2:1), and indicating that she was not in the same province (the Eastern Cape)(lines 12–13) when her son died, reflects discomfort from the specialist with their epistemic position. In lines 28–33 the specialist's statement *'because we're just not sure what that means and how it's relevant'* provides explicit evidence for the interactional trouble caused by their position of having no further access to information. The patient's awkward communication with both the specialist and her partner makes it unclear if she genuinely lacks this information, or whether she is uncomfortable discussing the topic.

Example 3. When a patient claims to know, but this knowledge is challenged

The last example demonstrates how uncertainty can arise when a patient claims to know the cause of death of a family member, but the specialist challenges the legitimacy of the information provided. The case involved a 21-week pregnant, 42-year-old Mixed Ancestry woman who was referred due to her older age and the identification of a foetal soft marker for aneuploidy. The consultation was conducted in Afrikaans, the patient's home language. The individuals present in the consultation included the patient, the genetic specialist, and a GC student who observed the consultation. The research site forms part of a teaching hospital, thus students observing medical consultations is not uncommon.

Example 3:1 S = Specialist; P = Patient.

1	S:	en jou ouers↑? (0.2) leef hulle nog?
		and your parents↑? (0.2) are they still alive?
2	P:	Nee (.) altwee al (0.2) dood
		No (.) both are already (0.2) dead
3	S:	Albei al oorlede
		Both passed already
4	P:	((head nod))
5	S:	En waarvan is hulle oorlede?
		And what did they pass from?
6		(2.0)
7	P:	Asma
		Asthma
8		(0.5)
9	P:	((head nod))
10	S:	Asma↑ albei?
		Asthma↑ both?
11		(0.5)
12	P:	((head nod))
12	S:	Okay (.) Jonk? Oud?
		Okay (.) Young? Old?
14		(1.5)
15	P:	My pa was fourty three uh fourty=
		My father was fourty three uh fourty=
16	S:	=Dis maar jonk?
		=but that is young?
17-21		((specialist continues to ask about various family members))
22		Wat het gebeur? Weet jy?
		What happened? (.) Do you know?
23	P:	(0.4) Ek sal nou nie weet nie maar ek weet hy het asma gehad.
		(0.4) I won't now know but I know that he had asthma
24	S:	°Okay (0.4) en Jamil*** se kant van die familie↑
		°*Okay (0.4) and Jamil***'s side of the familie*↑
25-79		((specialist continues to ask about various family members))
80	S:	En waarvan is sy↑ oorlede? Weet jy?
		And what did she↑ pass from? Do you know?
81	P:	Asma
		Asthma
82	S:	Ook asma?
		((writing down notes in patient file))
		Also asthma?
		((writing down notes in patient file))
83		(0.5)
84	S:	En sy pa↑? Leef sy pa nog?
		And his father↑? Is his father still alive?
85	P:	Sy pa is ook oorlede
		His dad has also passed
86	S:	En weet jy wat het met hom gebeur↑?
		And do you know what happened↑ to him?
87	P:	(0.3) Hy't ook asma gehad
		(shifts in chair and tucks in lower lip))
		(0.3) He also had asthma
		((shifts in chair and tucks in lower lip))
89		(0.5)

***Pseudonym.

In example 3:1, uncertainty arises when the patient mentions that both their deceased parents died from asthma in lines 1–9. The specialist repeats the patient's claim in line 10 using a rising intonation. Similarly to example 2.2, we argue that the rising intonation used by the specialist is designed to indicate surprise or interest, as shown by Svennevig (2004), prompting the patient to confirm their initial claim. When the patient reveals that her father was 43 when he died (line 15), the specialist expresses further surprise at his young age of death by producing their turn in line 16 with a second rising intonation and probing further in line 22 as to what happened. The specialist goes on to enquire about the patient's partner's (Jamil***) family, the patient mentions several family members also died from asthma (lines 25–79, not shown), including his parents (Lines 80–81 and 86–87). The patient's increasing use of pauses (lines 83, 87, and 89) and uneasy body language suggest an awareness that her responses are problematic, given the specialist's surprised and confused reactions.

In example 3:2 below, we show that the patient's claims of 'asthma'

become the main cause of uncertainty in the interaction.

Example 3:2 S = Specialist; P = Patient; St = Student.

90	S:	Oka:ay
91		(1.0)
92	S:	Klink vir my vreemd↑↑ 'n bietjie almal met hierdie asma [hhh. hhh.
93		(0.3) uhm] maar in elk geval hhh. hhh. oka:ay↑
		((turns shoulders, gazes towards genetic counseling student, raises eyebrows and smiles))
		Sounds strange to me↑↑ a bit everyone with this asthma hhh. hhh.
		(0.3) uhm but anyway hhh. Hhh. oka:ay↑]
		((turns shoulders, gazes towards student, raises eyebrows and smiles))
94	St:	((gazing at genetic specialist and grins))
95	P:	[hhh. Hhhh.
96		hhhh.]
		((rocking in chair, smiling, and gazing at genetic specialist, and then at student))
98	S:	Goed (.) so (0.3) uhm
		Good (.) So (0.3) uhm
99		(1.5)
100	S:	Ons was besig om te praat <o:or di:ie> (0.3) oor die neus
101		beentjie
		We were busy talking <abo:out th:he> (0.3) about the nose bone

In example 3:2 above, lines 92–95 the specialist provides explicit evidence for their uncertainty through verbal and non-verbal gestures. This includes the statement: *"Sounds strange to me a bit everyone with this asthma",* accompanied by unprompted laughter. The specialist further reinforces the patient's problematic claim by turning towards the GC student, raising their eyebrow and smiling in line 93. The specialist's actions suggest a lack of trust in the information provided by the patient. Laughter in medical discussions without prompted jest may indicate interactional trouble or misalignment between participants (Haakana, 2001). This uncertainty is further reinforced by a grin from the student in line 94, as well as laughter and uneasy shifting in their chair from the patient in lines 95–96. Non-verbal gestures provide important cues on the emotional and relational state within an interaction (Heath et al., 2010).

We argue that these turn designs by the specialist in examples 3.1 and 3.2 indicate interactional trouble and uncertainty because the patient's information doesn't align with typical familial risk patterns for asthma. Although asthma may have some familial association, it does not typically result in multiple deaths of young family members (D'Amato et al., 2016). The specialist may also find it perplexing that both the patient and her partner have several family members who all died from asthma. The specialist may thus not understand the cause of death and subsequently doubts the patient's claims. This example differs from the other two examples since the patient is assertive in their claim of knowing the cause of death of her family members. In the other two examples, the patients are themselves uncertain of the information. Despite the patient's confidence in Example 3, uncertainty persists interactionally in what we contend is the specialist's difficulty in trusting the patient's claim to knowledge.

4. Discussion

In the context of prenatal GC consultations in South Africa, this paper highlights how interactional uncertainty can impact the communication process of gathering family history information. During this phase, uncertainty arises when patients are unable to provide clear family histories, or when the information provided does not make sense to the specialist. The requested family information may also be unrelated to the patient's reason for referral, thus patients may be unprepared for this type of questioning. Unlike the information-giving or decision-making phase in GC where medical reports and resources may be available, a genetic specialist relies heavily on a patient's verbal reports of family health information, making it a challenge when these details are unavailable. We demonstrate that uncertainty can be introduced during family history taking in three different ways. First, when a patient claims to not know a family member's cause of death, second, when a patient has some knowledge but lacks additional details; and third, when a patient claims to know the cause of death, but the specialist challenges the legitimacy of the provided information.

Patients may lack access to family history information due to limited medical literacy or cultural norms. This issue may be particularly relevant in a multicultural contexts. Previous South African research has shown that patient health literacy (Penn and Watermeyer, 2018; Swartz and Kilian, 2014) and comprehension of English-based genetic and scientific terminology (Shingwenyana, 2020) can be challenging in health interactions. Patients may also choose to conceal or may lack access to family medical information due to stigmatization or family conflict as shown in previous local haemophilia (Solomon et al., 2012) as well as TB and HIV (Murray et al., 2013) research. In instances where a child passed away suddenly under unknown circumstances (as in example 1), where there are new partners and children from previous relationships (as in example 2), or perhaps a family-based condition that a patient may not want to talk about (potentially example 3), patients may not feel comfortable discussing these topics in detail. The decision to disclose information to a healthcare professional can be difficult for patients, especially potentially emotive topics as shown in studies on intimate partner violence (Penti et al., 2018), parental grief after the loss of a child (Rosenblatt, 2016) and familial risks for Huntington's disease (Forrest Keenan et al., 2015). This social and emotional complexity may exacerbate the uncertainty that patients and genetic specialists must navigate when gathering relevant family risk information.

In the South African public healthcare context, detailed written medical records, especially about a patient's family member's health, are typically lacking. A shift in epistemic authority subsequently occurs during family history-gathering where, despite their potentially limited knowledge, patients become the primary source of information (Fritz and Holton, 2019). This shift in expertise can create uncertainty for specialists, as patients' claims of knowledge and understanding may be met with scepticism. Our argument is based on similar findings of reversals in epistemic authority in health (Antaki and Finlay, 2013) and teacher-student (Koole, 2010) interactions. Genetic specialists, who typically possess greater medical expertise, may question patients' understanding of family medical issues, leading to further interactional trouble.

In risk discussions that naturally involve elements of uncertainty, trust is crucial (Calnan and Rowe, 2007). The importance of developing a trusting relationship in GC interactions is previously described (Smets et al., 2007; Veach et al., 2007; Weil, 2001). We argue that genetic specialist needs to trust the patient's claims of family information to accurately determine their genetic risk. If trusting the patient's claim, it would be expected that a specialist would not pursue further interrogative questioning, but rather accept the patient's claim at the first utterance. The results of the study show that when trust is threatened genetic specialists continue to seek additional information and verbally express their discomfort when this is not granted (example 2) or when the provided information seems unusual (example 3). While research has focused on patients' trust in information from healthcare providers (Armstrong, 2018; Brown et al., 2012) this study takes on a different analytical angle that explores what happens when a healthcare provider's trust in the patient's information is undermined.

4.1. Implications for practice

The study's findings can be examined through the lens of uncertainty management theory (UMT) (Brashers, 2001, 2007) and uncertainty tolerance (Strout et al., 2018). These approaches focus on how other individuals respond to uncertainty, to understand and manage it interactionally. In addition, they can also offer insight into genetic specialists' emotional responses towards uncertainty and how to regulate feelings of discomfort. By using these approaches, genetic specialists

may be better equipped to identify layers and sources of uncertainty, be cognisant of its communicative and emotional impact, and navigate difficult conversations. Part of this training should include flexibility in gathering information, an awareness of contextual factors that contribute to uncertainty, and an acceptance that uncertainty may be inherent.

Establishing trust through verbal and non-verbal cues and teaching genetic specialists what trust 'looks' like in practice is important. Trust is influenced by socioeconomic and ethnocultural factors. Although obtaining accurate family history information can be challenging due to patients' knowledge limitations or reluctance to disclose information, genetic specialists can help patients feel more at ease by carefully framing questions, providing sensitive verbal responses, and using appropriate body language (Brown et al., 2012; Calnan and Rowe, 2007). Skills including active listening, recognizing subtle patient cues, and being attuned to the overall atmosphere of the interaction (Biesecker et al., 2019; Cragun and Zierhut, 2018; Langewitz, 2022; Watermeyer et al., 2020) are essential. Asking specific questions for genetic risk assessments, explaining the purpose of obtaining a family history, and giving examples of relevant familial medical concerns at the start of family history taking can facilitate patient engagement and targeted feedback. Considering sociocultural nuances and tailoring communication approaches can further enhance patient understanding and involvement (Watermeyer et al., 2020).

While these skills can be practised in classroom settings via simulated role-play exercises, real-life experiences are necessary to fully appreciate and master what Browning et al. (2007, p. 905) refers to as the "hidden curriculum". These competencies may take years to develop and become comfortable with. Research and professional communication training approaches like video-reflexive ethnography (VRE), exnovation (Iedema et al., 2013, 2018) and conversational analytic role-play method (CARM) (Stokoe, 2011) can be valuable for genetic specialists for uncertainty management training. These approaches use video recordings of professional services within particular contexts to highlight the construction, minutiae, and features of talk to encourage reflective practice and communication skills development (Iedema et al., 2013, 2018; Mesman et al., 2019; Sikveland and Stokoe, 2016; Stokoe et al., 2016).

4.2. Limitations

The study focuses on public prenatal GC consultations in Cape Town, South Africa, using a small sample size. While some findings may have relevance to other contexts, some of the conclusions made by the researchers may be specific to the research setting. Additionally, the analysis of family history taking for other types of GC consultations may differ.

5. Conclusion

Uncertainty is inherently part of GC due to the complexity of the type of information gathered and conveyed as well as the focus on the health of an individual, and that of their family. The paper highlights three ways in which uncertainty is introduced and maintained during family history taking in South African GC prenatal consultations and the communicative consequences thereof. Uncertainty about patient-reported family information creates asymmetries in knowledge, a reversal in epistemic authority and challenges in providing accurate risk assessments. These moments bring about trouble in the interaction which must be navigated delicately. The paper provides suggestions for training and practice, particularly regarding the management and tolerance of uncertainty using tailored communication approaches and video-based research methods. This study aims to enhance South African GC training and practice, but it may also have relevance to other global GC services in diverse settings.

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Ethics

The study was reviewed and approved by two tertiary academic ethics committees, namely the University of the Witwatersrand Human Research Ethics Committee (Medical) (Ref: M160318) and the University of Cape Town Human Research Ethics Committee (Ref 440/2016). Permission to conduct the study was received from the research sites, as well as written informed consent from all participants included in the study.

CRediT authorship contribution statement

Megan Scott: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Writing - original draft, Writing - review & editing. **Jennifer Watermeyer:** Conceptualization, Formal analysis, Supervision, Writing - review & editing. **Tina-Marie Wessels:** Conceptualization, Formal analysis, Supervision, Writing - review & editing.

Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this work, the authors used Grammarly and QuillBot to help with grammar, punctuation and reduction of word count. Reference management software, Zotero, was also used to manage bibliographic material. After using these tools, the authors reviewed and edited the content as needed and took full responsibility for the content of the publication.

Declaration of competing interest

Dr Megan Scott, Professor Jennifer Watermeyer and Professor Tina-Marie Wessels declare no conflicts of interest.

Data availability

Data will be made available on request.

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Appendix

Jeffersonian conversation analytic transcription symbols.

Symbol	Name	Use
[text] [text]	Brackets below each other in separate lines	Start and end points of overlapping speech between participants
(__)	Parenthesis with a line in between	Unclear speech
((italic text))	Double parenthesis	Non-verbal activity. E.g., eye gaze, pointing, writing, facial gestures.
(.)	Micropause	A very short pause. Usually less than a tenth of a second.
(# of seconds) e.g. (0.2)	Timed pause	Number of seconds in a pause. Measured to the nearest tenth of a second.
=	Equal sign	Represents latching between speech production, where there is no audible pause heard.
↑	Up arrow	Words produced with a rising intonation
↓	Down arrow	Words produced with a rising intonation
°	Degree symbol	Words spoken are whispered or spoken in a quiet tone
:::	Colon(s)	Uttered word is extended
TEXT	Capitals	Words are produced loudly
text	Underlined	Words are emphasized
		Enclosed speech delivered more slowly
>text<		Enclosed speech delivered more rapidly
.hhh	.h	Audible inhalation
hhh.	h.	Audible exhalation, laughter particles

(Hepburn and Bolden, 2012; Jefferson, 2004).

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