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CASE STUDY

A balancing act: Non-directive communication, risk perceptions, and meeting patient needs in genetic counseling: A South African case study

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Abstract

Genetic counseling (GC) traditionally follows a non-directive counseling approach. Although a cornerstone of GC teaching and theory, there has been debate on whether GC is, can be, or should be a patient-led service due to challenges in practice, as well as the advancement and complexity of genetic testing. Personal risk perceptions and patient expectations within particular contexts may further affect how genetic counselors discuss risk information, even while attempting to remain neutral. Less is known about the process of GC communication in non-Western settings. This paper presents empirical evidence from a South African prenatal GC consultation where tensions become apparent due to differing risk perceptions and expectations between a genetic counselor and a patient, which ultimately impacts non-directive communication practice. The case study forms part of a larger qualitative study focusing on risk and uncertainty communication within GC consultations in Cape Town, South Africa. A blended sociolinguistic approach drawing on principles of conversation analysis (CA) and theme-orientated discourse analysis (TODA) provides evidence of the complexity of imparting risk information and challenging patients to reflect on their decision-making, whilst refraining from sharing personal risk perceptions during everyday practice. The case study demonstrates how a genetic counselor may become implicitly and explicitly directive in their communication approach within the same consult which may reveal their personal risk perceptions on the matter discussed. In addition, the case study reveals how a genetic counselor may grapple with the dilemma of honoring the non-directive guidelines of the profession, whilst simultaneously supporting a patient who requests advice. The ongoing debate on non-directive counseling, decision-making, and patient care in GC is important for the reflection and development of the profession to understand how to assist and support patients facing sensitive and difficult decisions, in a meaningful, and contextually-tailored manner.

KEYWORDS
advice, communication, context, decision-making, non-directive counseling, risk perception

1 | INTRODUCTION

Non-directive counseling has been a long-debated topic in genetic counseling (GC). Traditionally introduced into GC practice as a means of moving away from prescriptive messaging, paternalistic practice, and power imbalances between healthcare professionals and patients (Biesecker et al., 2019; Pilnick, 2022; Weil, 2003), non-directive counseling aims to inform and educate individuals in an unbiased manner, whilst promoting self-reflection ultimately allowing for autonomous, patient-led decision-making (Biesecker et al., 2019; Resta, 1997). In contrast, directive communication tends to be influential, offers advice, and guides an individual towards a preferred decision (Kessler, 1997; Sandman & Munthe, 2010).

Non-directive communication has assisted genetic counselors and medical geneticists to navigate ethically contentious topics which focus on genetic disease, disability and termination (Rantanen et al., 2008; Walker, 2009), providing opportunities to distance themselves from patients' decisions (Biesecker et al., 2019). Although historically promoted in GC practice and theory, arguments have been made that complete neutrality in GC may not be possible, may not necessarily be helpful for patients, and that active engagement from GC practitioners is required to assist patients in meaningful ways (Arribas-Ayllon & Sarangi, 2014; Biesecker et al., 2019; Chańska, 2022; Clarke, 2017; Pilnick & Zayts, 2012; Sarangi, 2010; Schupmann et al., 2020; van der Steen et al., 2019; Weil et al., 2006; Wessels & Koole, 2019; Wessels et al., 2015). Non-directive counseling and patient-centered care in GC remains poorly defined, largely conceptual, and have created dilemmas about what is considered acceptable practice (Arribas-Ayllon & Sarangi, 2014; Chańska, 2022; Kessler, 1992; Pilnick, 2022; Schupmann et al., 2020; van der Steen et al., 2019). Advancements in genetic research, testing and interpretation of complex genetic results have also brought about more candid forms of communication, rather than the provision of abstract statements and passive counselor positions (Jamal et al., 2020; Riddle et al., 2021; Schupmann et al., 2020). These approaches have been particularly promoted in medical fields such as cardiology (Clarke, 2017); cancer (Riddle et al., 2021) and genomic medicine (Schupmann et al., 2020). The promotion of personalized communication strategies for differing patients (Biesecker et al., 2019; Pilnick, 2022) has also created further debate on how information should be provided in GC, and what is considered appropriate.

South Africa offers an interesting context to study GC communication practices. The country has a complex socio-economic and historic context, with several languages, religions and ethnic groups present among the local population of 60 million people (Coovadia et al., 2009; Mayosi et al., 2012; Statistics South Africa, 2019, 2022). Due to the country's burden of infectious and chronic diseases, genetic conditions and genetic clinical services remain relatively unknown and unprioritized by the government, the general public, and other healthcare practitioners (Greenberg et al., 2012; Kromberg et al., 2013; Malherbe et al., 2016; Morris et al., 2015; Ormond et al., 2018; Van Wyk et al., 2016). Illiteracy, poverty, unemployment and challenges in accessing basic public services are also common among patients using South African health facilities. Almost all patients using public health services, including genetic clinics, do so through a referral system from other healthcare facilities or professionals, rather than being self-managed (Morris et al., 2015; Wessels & Koole, 2019). Local patients also tend to defer to the authority of the healthcare provider (Adam & Lindeque, 2017; Day et al., 2003; Penn & Watermeyer, 2018; Wessels et al., 2015) and may not be actively involved in shared health decision-making or appropriately

What is known about this topic

How information is perceived is dependent on who is providing the information, how they provide the information, whom the information is being provided to, what their concern is, and the setting in which the conversation occurs. Non-directive counseling has been a long-debated topic within GC stemming from ethical concerns, the lack of clear theoretical definitions, various interpretations in practice, as well as new advances in genetic testing and service offerings in different medical fields. Most research on GC has occurred in Western settings, with little real-world evidence from diverse settings, such as the global South. Few studies have focused on interactional communication processes within GC practice, including the notion of non-directive counseling and being asked for advice. Understanding the process of GC communication in various settings is important for reflection on practice and enhancing patient care.

What this paper adds to the topic

The case study adds to the discourse on patient care and non-directive approaches in GC by providing insight from a diverse, non-Western context, namely South Africa. The case study highlights empirical evidence from a prenatal GC consultation that demonstrates how a genetic counselor may struggle to conceal their personal risk perceptions through the use of both implicit and explicit directive communication approaches, as well as how a genetic counselor may respond when a patient seeks advice. These communication approaches may ultimately impact patient decision-making. We argue that GC practice is a multidimensional, and complex process. Levels of neutrality in a GC interaction may be impacted by both genetic counselor and patient expectations and risk perceptions. Context may also play a role, especially in settings where patients may be accustomed to more directive healthcare communicative approaches. We use the case study as a springboard for further discussion on non-directive counseling in GC within various global settings, and the challenges of translating theoretical principles into practice.

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informed of their healthcare options (Hastings-Tolsma et al., 2018; Moore & Nöthling Slabbert, 2013; Patel & Dowse, 2015; Penn & Watermeyer, 2018; Watermeyer et al., 2020).

Non-directive GC approaches are encouraged in South Africa (Kromberg et al., 2013; Ormond et al., 2018) with regulating bodies such as the Health Professionals Council of South Africa (HPCSA) and Genetic Counselors South Africa (GCSA) being clear in their guiding policies that local GC should follow a 'non-direct[ive] counseling' approach (HPCSA, 2013, p.4). Despite these theoretical ideals, empirical evidence from a local prenatal GC study (Wessels et al., 2015, Wessels & Koole, 2019) suggest however that South African GC practice may include more directive counseling in terms of skills used, and that non-directive counseling may be poorly understood and perceived by patients in a local context.

In this paper, we use qualitative sociolinguistic methods to present an interesting case study focusing on a South African prenatal GC consultation where tension in non-directive and directive communication occurs within the same interaction. Qualitative sociolinguistic methods, such as conversation analysis (CA) and theme-orientated discourse analysis (TODA) are useful to understand the process of communication and what happens during real-time interactions and practice. CA focuses on how individuals achieve particular communicative goals, and how understanding/misunderstandings are dealt with on a fine interactional level (Ten Have, 2007). Similarly, theme-orientated discourse analysis (TODA) focuses on how individuals talk to one another, especially within professional medical settings where certain normative communicative actions and behaviors occur and where topics such as uncertainty, decision-making and risk management are commonplace (Roberts & Sarangi, 2005). The methods used in this case study highlight the complexity of GC communication in practice, and how different risk perceptions, communication expectations, verbal utterances, and contexts may create dilemmas in attempting to remain within the ideals of GC theoretical guidelines.

2 | CASE DESCRIPTION

The case forms part of a broader qualitative study that explored how genetic risk is communicated and uncertainty managed in South African GC consultations. Data was collected via video-recorded GC consultations, as well as genetic counselor and medical geneticist interviews. All consultations and staff were based at public GC clinics in Cape Town, South Africa, which provide services to patients from mainly middle-lower socioeconomic backgrounds, with Afrikaans and isiXhosa being the most commonly spoken languages.

The case was a follow-up GC consultation involving a 43-year-old Mixed Ancestry, first-language Afrikaans–speaking woman who was 20 weeks pregnant. The patient was referred for advanced maternal age (AMA) GC. She had also had a baby with trisomy 21 (Down syndrome) in a previous pregnancy, which was detected prenatally. She subsequently had a termination of pregnancy and genetic testing revealed trisomy 21 as a result of non-disjunction. Non–disjunction typically infers a low recurrence risk compared to the risk associated with Down syndrome caused by a chromosomal translocation error. The risk of having a baby with Down syndrome in her current pregnancy was thus largely age-related. AMA places women at higher risk for having a baby with a chromosome abnormality, especially trisomy 13, 18 and 21. Globally, and in South Africa, AMA has been one of the main motivations for invasive prenatal testing to detect related fetal aneuploidies (Carbone et al., 2020). Definitions of AMA vary globally but are generally regarded as 35 years or older. In the Western Cape province, where Cape Town is situated, AMA is considered from 40 years of age. The patient also happened to be a qualified and practising healthcare professional. During her initial GC consultation a few weeks earlier, the patient accepted the offer of invasive prenatal testing based on her age risk of 1 in 50 for trisomy 21 (Palomaki & Haddow, 1987), and an amniocentesis was performed. The patient also had a detailed fetal ultrasound before the first GC consultation and no soft markers were noted. During her follow-up GC consultation she was expecting to receive her genetic test results from her amniocentesis. The patient had also had a second detailed fetal anatomy scan before her follow-up GC consultation, where again no fetal anomalies or markers were noted, and her risk for a chromosomal aneuploidy was further reduced. During the follow-up GC consultation, the genetic counselor conveys the news to the patient that the testing at the laboratory has been unsuccessful owing to a poor-quality sample. The patient had already been made aware of the failed amniocentesis by the fetal medicine specialist who performed her second fetal anatomy scan, and is aware that a second amniocentesis can be offered to her should she want it. In the GC consultation, the genetic counselor discusses the patient's adjusted risk for trisomy 21, indicating it has been reduced to 1 in 5000 based on the findings from the second fetal anatomy scan.

Through sociolinguistic methods, we reveal how interactional tension is created during the consult when the patient chooses to have a second amniocentesis, and the genetic counselor challenges this decision-making. We argue that the reason these actions are taken during the consultation is due to differences in risk perception and preferred choice between the patient and the counselor. We further highlight that the patient may have had certain expectations from the genetic counselor when she asks for advice during her decision-making regarding invasive testing, deferring to the health practitioner's authority and guidance which is often a normative, culturally mediated practice in South Africa. We demonstrate how the genetic counselor and the patient use perspective display sequences (PDSs) during the consultation to produce both explicit and implicit directive communicative displays that may reveal their perceptions and possibly preferred actions towards the spoken-about risk, namely the risk of having a baby with Down syndrome, and the procedural-related miscarriage risk linked to invasive prenatal testing. PDSs form part of CA sociolinguistic analysis. During a conversation when a speaker offers an upfront opinion, it may have potential relational consequences if the listener disagrees with the speaker's assessment. Thus, rather than stating an upfront opinion from the start, individuals may

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first gauge a listener's receptiveness through particular conversational actions such as a PDS (Maynard, 1989). A PDS involves three conversational parts (parts 1, 2, and 3), with the final part (3) performed in two separate ways (i & ii):

A PDS:

1. The speaker invites the listener's opinion;
2. The listener responds to the request by producing their own opinion;
3. The initial speaker then produces their own opinion about the topic in 2 possible ways:
   (i) *Explicitly* via extreme case formulations (Pomerantz, 1986) and contra-indicative statements (Candlin & Lucas, 1986). These two strategies are used simultaneously to introduce consideration and to emphasize the positive or negative outcomes of a particular decision. Although this could be seen as information giving and reflection, Sarangi and Clarke (2002) argue that it could also be used as a rhetorical device to display and negotiate a preferred choice.
   (ii) *Implicitly*, where the initial speaker provides their own opinion through subtle displays such as using 'yeah' or 'mm' tokens. The speaker may not necessarily agree with or accept the listener's opinion or assessment but avoids overt conflict, especially when preferred responses are at odds (Maynard, 1989).

The data for the case study is provided in two conversational excerpts (1 and 2) from the consultation below, which are broken into smaller analytical segments. For readers unfamiliar with CA, please refer to the paper's Table S1 for a description of the Jefferson (Jefferson, 1985), annotations used in the transcripts below.

2.1 | Excerpt 1

Excerpt 1:1

G = Genetic counselor; P = Patient

1	G:	… because they didn't see anything↑ (.) has made
2		your risk very very very small (0.2) to have a baby with
3	P:	°mm°
4	G:	Down syndrome. So it's about one in five thousand now.
5		(2.5)
6	P:	Yes I understand
7	G:	You understand?
8	P:	Yes

Focusing on Excerpt 1:1 above, in lines 1 and 2, the genetic counselor frames the new given risk figure as *'very very very small'* increasing the certainty of the situation that a diagnosis of Down syndrome is extremely unlikely in the current pregnancy (and by extension that a second amniocentesis is not necessary). This overt assessment of the risk also indicates the genetic counselor's perception, supported by the repetition of the word 'very'. Repetition of a word or phrase e.g. 'no, no, no', or 'right now, right now', in a single turn constructional unit can be viewed as a strong suggestion for the broader course of action proposed by a speaker (Sacks, 1984; Stivers, 2004). This manner of presenting the information is directive, rather than neutral, and may be a strategy from the genetic counselor to challenge the patient to consider the low risk of having a baby with trisomy 21, and the comparatively high risk for miscarriage if she were to go ahead with invasive testing.

Excerpt 1:2

G = Genetic counselor; P = Patient

9	G:	How does that make you feel?
10	P:	More positive.
11	G:	↑MORE positive?
12	P:	More positive °yes°
13	G:	You seem like a very positive person [(.) you definitely] seeing
14	P:	[Hhhh hhh yes]
15	G:	the positive in this
16	P:	Yes, I uh am
17	G:	Ok so I mean the question now is whether then you still want
18		to go (.) ahead and do another amnio↑ (0.2) or if you'd like
19		to leave it?
20		(0.5)
21	P:	No:o I will do the amnio
22	G:	You want↑ to do the amnio↑?=
23	P:	= yes:s
24		(0.5)

We now consider the interaction in Excerept 1:2. In line 9 the genetic counselor initiates a PDS by asking the patient how the presented risk makes them *'feel'*. The patient replies in line 10 that they feel *'more positive'* to which the genetic counselor responds by exaggeratedly repeating the patient's answer using a rising intonation in line 11. Although the patient seems to refer to feeling more positive about the risk situation specifically, the genetic counselor goes on to extrapolate the patient's positivity to her general disposition and personality in lines 13 and 15. By stating *'You seem like a very positive person. You definitively seeing the positive in this'* and using extreme case formulations *'very'* and *'definitely'*, the genetic counselor may be displaying her preferred course of action and personal risk perception, in that the risk for trisomy 21 is low and a second amniocentesis unwarranted. After highlighting that the patient is a positive person, the genetic counselor enquires whether the patient wishes to undergo a second amniocentesis procedure in lines 17–19. The patient responds in line 21 that she does. The genetic counselor requests clarification by repeating the patient's response in line 22. The genetic counselor's repetition of the patient's response in line 22 is accompanied by two rising intonations. Repetition of a patient's

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statement by healthcare practitioners is thought to display the receipt of information and to encourage elaboration of the information supplied (Beckman & Frankel, 1984). The intonation in which the other speaker responds to a statement becomes particularly important in understanding the purpose of the repetition. A study by Svennevig (2004) of Norwegian conversations found three different forms of repetition, each having different sequential implications depending on how the repetition was presented. If produced with falling intonation, the repetition typically displays hearing, whilst a repeat accompanied by a response particle such as '*ja*' ('yes') indicates understanding. If repetition is produced with a rising intonation it indicates emotion such as surprise or interest in the claim or utterance made by the previous speaker. In this instance, the genetic counselor's repetition of the patient's utterance that she wants to proceed with the amniocentesis may indicate surprise, and potential concern as to whether the patient had understood the lower risk for trisomy 21 in this pregnancy versus the higher risk for procedural-related miscarriage if choosing to go ahead with the amniocentesis.

In lines 25–66 of the interaction (not shown in the transcript), the patient justifies her reasons for wanting to pursue the procedure by providing an account that she is concerned about the baby's growth and wants to confirm that there are not any genetic problems due to the previous amniocentesis failing. This justification could be understandable from the patient's risk perspective and experience, given that she has previously had a baby with Down syndrome. She uses a discussion with the fetal medicine specialist (displayed in Excerpt 1:3) who performed her most recent ultrasound as a further justification for a second amniocentesis.

Excerpt 1:3

G = Genetic counselor; P = Patient

67	P:	So I AM↑ going to do it (0.3) cos (.) the only thing that they
68		going to check is for Down syndrome again↓?
69	G:	Ja (yes)
70	P:	And then they will see if there's still any abnormalities
71	G:	Ja (yes)
72	P:	Ne? Hey?
73	G:	Mhmm
74	P:	>That's is how I understand it< (0.3). So that is the only
75		reason why (.) I will still just (0.2)
76	G:	You want to do it? (0.3)
77	P:	Yes I will do it.
78		(0.5)

In line 67 above, the patient indicates that she wants to go ahead with the amniocentesis by stating: '*So I AM↑ going to do it*' and again repeats her reasoning (67–75). During this explanation, the genetic counselor provides subtle replies of "Ja" (the Afrikaans term for '*yes*') in lines 69 and 71, and 'Mhmm' in line 73. These tokens may implicitly demonstrate that the genetic counselor does not accept the patient's risk assessment, nor their justification for wanting a second amniocentesis. Evidence for this is provided in their next turn part in line 76 when the counselor again requests clarification on whether the patient wants to go ahead with an amniocentesis. This repeated questioning by the counselor after the patient has already indicated that they want to go ahead with the test may demonstrate misalignment between the patient's and counselor's preferred outcomes and the counselor's potential rejection of the patient's choice through their continuous challenging of the patient's decision.

Excerpt 1:4

G = Genetic counselor; P = Patient

79	G:	.hhh And the fact that your risk is very very low now↑?
80		(3.0)
81	G:	That doesn't <change anything> for your (.) in your mind?
82	P:	No
83	G:	About the chances?
84		(0.5)
85	P:	°No°
86	G:	Do you think your chances are still high↑ to have a [baby with]
87		Down syndrome?
88	P:	[No I'm not]
99		(1.5)
100	G:	So (0.3) with the amnio (.) comes the miscarriage risk

When considering the final lines of this segment (Excerpt 1:4), the genetic counselor tries again to use a PDS in lines 79, 81, 83, and 86–87 to challenge and potentially dissuade the patient by emphasizing and framing the risk as '*very very low now*' and asks whether this changes the patient's perception. The patient rejects the counselor's statement by giving short '*no*' responses on lines 82, 85 and 88. The positioning of the 0.5 second pause in line 84 before the softly-spoken 'no' response from the patient in line 85 may indicate that the patient realizes that this is a response that the genetic counselor does not want to hear. In misaligned responses, a pause often occurs between a speaker's turn in the first pair-turn part of a question-answer adjacency pair and a recipient's response in the second pair part (Schegloff, 2007). Furthermore, the pause in line 99 may indicate trouble for the genetic counselor, who in lines 100 and onwards (not shown in the transcript) goes on to discuss the potential negative consequences of going ahead with the procedure, namely the risk for procedural-related miscarriage. The discussion of the miscarriage risk, although seen as part of standard reflective and information-sharing practice, could also be an example of the genetic counselor's use of an extreme case formulation to dissuade the patient from a particular course of action. Although this action could be considered as the counselor adhering to the GC principles of ensuring informed decision-making for the patient and challenging

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them to consider all the associated risks and subsequent outcomes of their decision; the action also demonstrates the complexity of doing this in practice. When analyzing this activity on a fine interactional level, we demonstrate that the persistent challenging from the genetic counselor could also be seen as the goal of subtly directing a patient towards a particular decision.

2.2 | Excerpt 2

The second segment of the interaction, taken from further along in the consult, shows a salient moment in the interaction in which the patient requests advice from the counselor. The patient's explicit action sets off a sudden and deliberate shift in the genetic counselor's communication style from being directive to displaying an overtly neutral position.

Excerpt 2:1

G = Genetic counselor; P = Patient

1	G:	to think about what would happen then (0.2) how you would feel
2		about it and how Ben* would feel about it if (.) you did have
3		(.) you were that one in five hundred
4	P:	Ja
5	G:	You did have this miscarriage (0.2) I mean your risk is (.) is
6		very low in terms of (.) to have a baby with Down syndrome.
7	P:	Mm
8		(0.5)

Focusing on Excerpt 2:1 above, after several attempts of challenging the patient from going ahead with a second amniocentesis, the genetic counselor encourages further patient reflection. They do this via hypothetical framing in lines 1-6, by pointing out the potential psychosocial consequences for the patient and her partner, Ben* if the patient was that *'one in five hundred'* (line 3) to have a miscarriage. The genetic counselor's risk perception and more directive stance are further highlighted in lines 5–6 when they state: *'I mean your risk is very low in terms of to have a baby with Down syndrome'*. The genetic counselor's phrase in lines 5–6 creates uncertainty for the patient and displays possible disagreement with the patient's choice. The patient's '*mm*' response in line 7 and 0.5-s pause in line 8 may indicate that she is considering the genetic counselor's prior utterance in lines 5–6, but that she may not necessarily agree with it.

Excerpt 2:2

G = Genetic counselor; P = Patient

9	P:	So if I can ask you↑↑ a question (0.2) If you were in
10		my↑↑ shoes no:ow (0.4) wha:at would you↑ do now? i

The genetic counselor's successful goal of challenging the patient's decision and attempting to re-consider her choice becomes apparent in Excerpt 2.2 above. The patient's uncertainty and doubt on whether she is making the right decision is s explicitly demonstrated in lines 9–10 when she decides to seek advice from the counselor. The patient starts her turn in line 9 with the discourse marker '*So*'. The marker 'so' indicates a speaker's agenda for the next turn of phrase, and that there may be an expected course of action after a statement or request is made (Bolden, 2009; Raymond, 2004). The purpose of the patient's use of the marker *'so'* may be to get the genetic counselor to provide a directive and transparent opinion on whether she should perform an amniocentesis or not.

Excerpt 2:3

G = Genetic counselor; P = Patient

11	G:	It's a very difficult thing to say. Because [I'm not in your
12	P:	[hhhh hhhh
13	G:	shoes. (0.3) I know it (.) that sometimes we want↑ to ask
14		for advice (0.2) and to ask for (.) for help (.) [hey?]
15	P:	[Ja:a] [Ye:es]
16	G:	These decisions are very difficult to make (.) It's not fair
17		that you have to make these decisions.
18	P:	Ja:a Ye:es
19	G:	But (0.2) but I think you can make this decision (.) what's
20		best for you.
21		(2.0)

With the explicit request for directive advice in Excerpt 2.2., we demonstrate in Excerpt 2:3 that rather than stating their personal risk perception and preferred choice, the genetic counselor immediately reverts to their professional boundary and displays an overt non-directive communicative approach in lines 11, 13–14, 16–17 and 19–20. The genetic counselor acknowledges the patient's difficult decision but indicates they cannot decide for them. This neutral response from the genetic counselor after the patient's request for advice is reacted to by laughter from the patient in line 12 (shown with hhhh hhhh out breath tokens), indicating that the counselor's response is problematic. Unprompted and unreciprocated laughter is thought to be a sign of trouble in an interaction (Haakana, 2001; Jefferson et al., 1987). The genetic counselor's sudden overtly non-directive stance may be confusing for the patient since the counselor, even though never openly stating that the patient should not have an amniocentesis, has repeatedly challenged the patient's decision-making and risk perception during several moments in the preceding sections of the consultation. However, when asked for advice, the counselor does not offer it. After the genetic counselor re-enforces her

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neutral position in lines 19–20 by expressing that the patient has autonomy and the ability to make the best decision for herself, the patient responds with a lengthy two-second silence in line 21. Schegloff (2006) and Sacks et al. (1974) have shown the timing and length of pauses between turn-taking among individuals in a conversation provide evidence for harmony or tension in an interaction. Pauses of less than 0.5 s are considered brief placeholders where one speaker's turn ends and provide an invitation for the next speaker to begin their turn. However, pauses longer than 0.5 s indicate disengagement, disagreement, or hesitance from the next speaker to take their turn and respond to the previous speaker's utterance (Pomerantz, 1984; Sacks et al., 1974; Schegloff, 2006). The long pause in line 21 potentially shows disagreement and disappointment by the patient from the genetic counselor's uncommitted response in the preceding lines.

Excerpt 2:4

G = Genetic counselor; P = Patient; Ben = Patient's partner*

22	G:	What do you think it best?
23		(0.5)
24	G:	And perhaps Ben* also (0.2) What does he think about all this?
25		(3.0)
26	G:	Is he meant to help you make these decisions?
27		(2.0)

When considering the remaining lines of the interactional segment (shown in Excerpt 2:4 above), the genetic counselor goes on to pose a question, asking the patient what she thinks is best for herself (line 22) and her partner (lines 24) and whether her partner should help in the decision-making of invasive testing (line 26). The genetic counselor's question is met with further prolonged silence from the patient in line 23 (0.5 s), line 25 (3 s) and line 27 (2 s) again indicating that the genetic counselor's overtly neutral stance may be problematic to the patient. Although conversational styles may differ among cultures where silence mid-conversation may be considered acceptable or appropriate (Eades, 2007; Mushin & Gardner, 2009; Scollon & Scollon, 1981), these lengthy silences in the context of this interaction provides evidence for communicative trouble. The neutral response provided by the genetic counselor is considered unhelpful to the patient and may not be accepted. We argue that the reasons for this may be that before this moment in the interaction, the genetic counselor has displayed several moments of directive communication during their challenge of the patient's decision to go ahead with invasive testing, however on a more subtle level. However, when openly asked for advice by the patient, the counselor suddenly reverts to an extremely neutral stance and does not offer a professional opinion, which may be perplexing for the patient, given the counselor's prior communication style.

The consultation ends with the patient deciding to go ahead with a second amniocentesis and the decision being granted by the genetic counselor.

3 | DISCUSSION

Despite numerous theoretical debates and guidelines, little evidence exists on how non-directive communication is established and maintained in GC practice. Findings from this case study provides real–time data that shows oscillations between directive and non-directive forms of communication within the same interaction from a genetic counselor when discussing risk information and facilitating decision-making for a patient during a sensitive discussion on prenatal invasive testing. The findings point to the tension between the ideals and the realities of practice. Even though a genetic counselor may attempt to remain neutral, close analysis of the communicative and interactive process within practice, as in this case study, may suggest otherwise.

South African GC guidelines for training and practice indicate that genetic counselors are expected to have an awareness of personal, contextual and cultural nuances, and should be able to modify a GC consult in an appropriate 'client-centered' manner (HPCSA, 2013, p.4), whilst also following non-directive forms of communication (HPCSA, 2013; Ormond et al., 2018). We argue that the multi-dimensional role and activities that a genetic counselor has to play during an interaction may contribute to an unrealistic ability to live up to the idea of a complete non-directive approach during an interaction with a patient. These roles and activities include managing their professional and ethical boundaries, an awareness of their own and the patient's risk perceptions, meeting a patient's expectations, being gate-keepers to genetic testing, playing a supportive role to the patient, encouraging autonomy and empowering the patient, as well as tailoring information according to a patient's needs, culture, and context.

The findings in this case study support more contemporary research which suggests that the act of non-directive counseling in GC, and patient-focused care is a complex, multidimensional and contextually embedded activity (Arribas-Ayllon & Sarangi, 2014; Biesecker et al., 2019; Chańska, 2022; Clarke, 2017; Pilnick, 2022; Pilnick & Zayts, 2012; Wessels & Koole, 2019; Wessels et al., 2015). We demonstrate that the oscillation between directive and non-directive communication within the same interaction occurs during the provision of information as well as during the decision-making phase. During patient decision-making, active patient reflection from a genetic counselor is considered acceptable, even expected, in a consultation. However, van der Steen et al. (2019) highlight that a healthcare professional's communication style, internal feelings and external actions (even if subtle) may steer patients towards a preferred decision. As the case study demonstrates, spending more time discussing one test over another, a genetic counselor's use and choice of language e.g., "*The risk is only 1/5000*", *or* repeatedly challenging a patient's decision, may unintentionally encourage patients into a particular decision-making pathway when seemingly encouraging patient reflection, meaning-making, and informed consent. Self-awareness is thus vital on the counselor's part when communicating information and facilitating decision–making in a patient consultation.

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Being openly asked for advice from a patient may further place a genetic counselor in a particular dilemma on how best to support a patient, yet adhere to the principles and ethical boundaries of GC. When considering the South African context, patients attending public South African genetic clinics may either have limited, or no knowledge of what to expect in a GC consult, and may be unaccustomed to the neutral, patient-led, communicative approaches used by the GC profession during healthcare decision-making. Rather, local patients may expect, or seek advice from healthcare professionals, including genetic counselors and medical geneticists, trusting that the healthcare professional will use their expertise to decide for them. The National Society of Genetic Counselors (2018) indicates that genetic counselors have a responsibility towards a patient to provide and explain the facts of their situation, as well as the outcomes of the different options and decisions that they have available to them. This definition, as Chańska (2022) highlights, although considered part of patient reflection, may be further interpreted by some GC professionals as a stance that genetic counselors should not have an influence on the decisions of patients, and if asked for advice, should refrain from providing it, since genetic testing are personal matters that a patient should have full autonomy over regardless of the genetic counselor's risk perceptions or views. However, as seen in the case study, avoiding patient requests for advice may be particularly difficult when certain societies view healthcare professionals as experts in their fields (Cockerham, 1992; Pilnick, 2022), or when patients assume or want healthcare services and professionals to be more directive (Levinson et al., 2005; Marton et al., 2021; Russo et al., 2019). The continuous challenge of a patient's autonomous decision during a GC may also create doubt for a patient on whether they have made the right choice.

The patient in the described case study was a healthcare professional who had previously had an amniocentesis, making this consultation somewhat of an outlier in the South African context, where asymmetries in medical literacy, power and position often occur between medical professionals and patients. The patient also had previous personal experience of having a baby with trisomy 21. Despite these assumed professional alignments and shared knowledge between the genetic counselor and the patient, micro-interactional analysis of the case study reveals communicative tension. The tension is created through several sequences in the consult, including the continuous challenging of the patient's decision by the genetic counselor, the apparent success of the genetic counselor to get the patient to carefully consider her decision, the patient's subsequent uncertainty about her decision, and then the denial of the request for advice by the genetic counselor. In these moments we see that rather than the genetic counselor empowering the patient by making her feel certain and capable of making her own decision, the opposite has occurred. Rather, the patient is left feeling unsure of her decision, with decision-making left solely to the patient. Despite the patient's professional status in this case study analysis reveals how the issue of non-directive communication places her in a disempowered position. The assumed professional alignment may have also created different expectations from this particular patient who may have wanted the genetic counselor to be more directive and potentially supportive as a colleague, even if she knew that professionally, the genetic counselor is not obliged to do so. Previous studies have revealed that some patients may want assistance from healthcare professionals in their decision-making, either by making a decision for them or being jointly involved (Barnett et al., 2008; Chańska, 2022; Ford et al., 2003; Toerien et al., 2018). Receiving no advice from a healthcare professional when openly requested to do so by a patient may threaten the therapeutic and trust relationship (Wyatt, 2001; Yip, 2020). This tension is demonstrated in this case study. For South African patients, particularly in the public health sector who may be less inclined to be provided with choice over their health management, experiencing greater patient autonomy and being asked to be an active participant in their health decision-making may be somewhat perplexing. Explaining and re-iterating the value of non-directive communication in GC, and highlighting the purpose of a 'partnership' where equal power and expertise are recognized (Wolf et al., 2017) between a counselor and a patient, may be helpful for some patients, especially those accustomed to, or expecting advice.

Little is known about how local patients and genetic counselors respond to and navigate communication practices in a South African context. This case study highlights some of the complexities of GC communication in a local setting. Genetic counselors and medical geneticists have both a responsibility as experts and gatekeepers to genetic testing to ensure that a patient's individual needs and wishes are respected, but also ensure those patient decisions are not made alone in potentially highly emotive situations. Carefully honed skills such as active listening, reflective practice and awareness of utterances and word choice are critical in these moments of practice. Enhancing genetic counselors' psychosocial skills as well as giving them the confidence (and permission) to be flexible in their directive and non-directive forms of communication with patients may be one way to work towards enhancing patient care and ensuring personalized and tailored consultations in various settings. As Kessler (1992, 1997) reminds us, non-directive counseling is not the absence of persuasion nor the opposite of being directive. Rather it is a task of *engaged* neutrality where counseling skills are used to ensure patient self-actualisation. Further debate and research on the function and impact of non-directive and directive communication in everyday GC practice are needed, especially within diverse contexts. Reviewing current healthcare policies and recommendations, including those in GC, and embedding them within a firm understanding of actual practice within various settings is vital to ensure that genetic counselors are not placed within intractable and difficult dilemmas that however they approach the situation will be deemed unsatisfactory, either to the patient, or to their professional community (Pilnick, 2022). Further insights on the practical challenges of implementing GC guidelines may have implications for local GC training and practice, as well as the development of more nuanced and descriptive South African regulatory policies for GC communication approaches.

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AUTHOR CONTRIBUTIONS

Dr Megan Scott is responsible for the manuscript conception, design, data analysis and write-up. She takes responsibility for the integrity of the data and the accuracy of the data analysis, as she had full access to the data in the study. Professor Jennifer Watermeyer was the supervisor for Dr Scott's PhD and assisted with the conception, data analysis, write-up and review of the manuscript. Professor Tina-Marie Wessels was the co-supervisor for Dr Scott's PhD and assisted with reviewing the data analysis and editing the manuscript draft. All authors had access to the study's data. Analysis was conducted independently by Dr Scott and cross-checked and validated by Professor Watermeyer and Professor Wessels to ensure data integrity and accuracy. All authors have approved the final manuscript and take responsibility for its content.

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CONFLICT OF INTEREST STATEMENT

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

DATA AVAILABILITY STATEMENT

Anonymised transcripts of the video-recorded consultations and audio-recorded interviews are available on request.

ETHICS STATEMENT

Human Studies and Informed Consent: 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.

Animal Studies: The article did not involve any animal studies.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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