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"There is a chance for me" – Risk communication in advanced maternal age genetic counseling sessions in South Africa

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ABSTRACT 350

Providing risk information is central to genetic counseling. Many studies have examined risk communication, but the focus has been on professional and patient perspectives. Less information is available on risk communication in interactions. This study aimed to examine genetic counselors' (GCs) risks communication in multicultural genetic counseling sessions with women of advanced maternal age (AMA). Six GCs (2–20 years' experience) conducted AMA sessions in English (women's second language). The sessions were video and voice recorded and transcribed verbatim. Data were analysed using conversation analysis (CA). CA examines discourse as a topic, i.e. describing the turns, its functions and how these functions are accomplished. Analysis revealed that the GCs presented the risk of having a baby with a chromosome abnormality in several ways and that they invite the women to reflect on the risk information. This discussion was found to be a five step process and showed that the women responded to the invitation to reflect rather than the risk information itself by providing additional information. The counselors in the majority of the sessions responded to this additional information the women provided. It therefore seems that the way in which risks are presented are less important than the meaning of the risks for the women. The research showed the power of interactional research such as CA methodology to gain new insights into old problems. Importantly, the study revealed some on the nuances of risk communication in genetic counseling and has implications for practice.

1. Introduction

Providing risk information is central to genetic counseling and it is known that risk communication, risk perception, and its use in decision-making is a complex process (Baty, 2009; Weil, 2000). Especially in the prenatal setting where patients have to consider the risk of having a baby with a fetal abnormality versus the risk of spontaneous abortion if they have an invasive prenatal procedure.

Research on risk communication has concentrated on professional and patient perspectives on how risk should be communicated and great diversity was found in the way professionals communicate risk information (Fransen et al., 2006; Henneman et al., 2008; Abby Lippman-Hand and Fraser, 1979a,b; Michie et al., 2005). Risks are communicated as percentages, odds, numerical and descriptive phrases in some instances, while in others both the positive and negative risk is provided (O'Doherty and Suthers, 2007). The words 'risk' and/or 'chance' is used when communicating genetic risks. The preferred format also seemed to vary depending on the counsellor's training, experience, abilities and counsellor's assessments of their patients' verbal and non-verbal responses and needs (Henneman et al., 2008).

As with the counselors, there is no consensus as to what patients prefer in terms of risk formats (Baty, 1998; Lobb et al., 2004). Some patients reported they prefer numerical figures, others prefer qualitative probabilities while others had no preference (Baty, 1998). Research findings is inconsistent and no clear conclusions can be drawn (Hallowell, 1999; Hallowell et al., 1997; Hopwood et al., 2003).

It is known that patient's perception of risk varies according to context, their previous perception of the risk, the desirability of the outcome, emotions associated with risk, personality, cognitive ability, beliefs, values, culture and experience (Baty, 1998; A. Lippman-Hand and Fraser, 1979a,b; McAllister, 2003; Pilnick, 2004; Sivell et al., 2007; Weil, 2000). Patients find it difficult to understand and quantify risk and they have a tendency to overestimate their risks, which might adversely affect their health and lead to inappropriate uptake of medical services (Sivell et al.,

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Table 1
Participant's characteristics.

Session	YOB	First language	Marital Status	Employment	Education	Child	Pregnancy	Gest	Amnio
P01	1968	Sotho	Married	Unemployed	Gr 12	1	Unplanned	21w	No
P02	1969	No Info	Married	Employed	No info	1	Unplanned	16w	No
P03	1967	Tswana	Traditional	Unemployed	Gr 10	2	Unplanned	17w	No
01	1969	Zulu	Single	Employed	Gr 12	1	Planned	23w	No
02	1972	Tswana	Single	Unemployed	Gr 12	2	Unplanned	22w	Yes[b]
05	1973	Sotho	Married	Employed	Gr 7	1	Planned	23w	No
06	1972	Afrikaans	Single	Unemployed	Gr 10	3	Unplanned	32w	Not offered
07	1972	Ibo	Married	Employed	Tech	2	Planned	22w	Yes*
08	1965	Xhosa	Married	Employed	Gr 11	3	Unplanned	12w	No
09	1970	Zulu	Single	Employed	Gr 8	3	Planned	20w	Yes*
10	1968	Xhosa	Married	Employed	Gr 10	3	Planned	16w	No[a]
11	1972	Tswana	Single	Employed	Gr 12	0	Planned	18w	Yes[b]
13	1966	Xhosa	Traditional	Unemployed	Gr 12	1	Planned	16 w	No
14	1969	No Info	Single	Employed	No Info	3	Planned	15 w	No
16	1969	No Info	Single	Employed	No Info	1	Unplanned	26 w	Not offered

* Initially requested an amniocentesis but did not have the test.
[a] Had an infant with Down Syndrome – passed away.
[b] Amniocentesis outcome: normal infant.

2007). For women at risk of breast/ovarian cancer it results in emotional responses and anxiety and depression are often associated with cancer risk assessment (Bennett et al., 2008). Loewenstein et al., (2001) distinguished between anticipated (immediate feelings) and anticipatory (feelings expected to be experienced in the future) emotions. They state that the "consequentialist perspective" which is based on a cognitive evaluation of the risk and a consideration of the chances that it may happen in the future is not sufficient in understanding risk evaluation and its use in the decision-making process. They suggest, "Gut feelings experienced at the moment of making a decision, which are often quite independent of the consequences of the decision, can play a critical role in the choice one eventually makes" p281. Similarly Chen et al. (2017) found that women make their decision of undergoing prenatal screening based on their values and if the test can be performed on the day of counseling rather than risk figures.

Based on the research findings and models or conceptual frameworks, an extensive list of recommendations is available (O'Doherty and Suthers, 2007; Smerecnik et al., 2009; Veach et al., 2003; Weil, 2000). But as Henneman et al. (2008) reported, the counsellors in their survey rarely drew on the recommendations from risk communication literature. Austin (2010) commented that risk communication in genetic counseling seems to be "ineffective" and that we don't understand the nuances of this process.

Examining risk communication in interactions has aided our understanding beyond individual perspectives. A study in cancer, for example have revealed that the meaning of the risk differed depending on the discursive context and that only very clear explanations would result in patients understanding of the given risk or probability (O'Doherty, 2006). A study on Huntington disease and cancer predictive sessions showed that the different types of risks, the risk of inheriting (genetic risk) and the risk of knowing you are at risk could become merged (Sarangi et al., 2003). Sarangi (2002) also showed that professionals' risk communication is affected by their attempts to maintain a non-directive stance. Interactional research also showed several strategies (abstraction, reformulation, externalisation, localisation, temporalisation and agentivisation) that both patients and professionals use to escalate or de-escalate the risks (Sarangi et al., 2003). Interactional research in the prenatal setting is available, but these studies have not specifically focussed on risk communication (Benkendorf et al., 2001; Hodgson et al., 2010; Kessler, 1981; Kessler and Jacopini, 1982; Pilnick, 2004), therefore leaving this area under-investigated.

This paper's focus is on this area and examines, from a process perspective, how genetic counselors communicate risks in genetic counseling sessions with woman of advanced maternal age (AMA) in one centre in South Africa.

2. Study setting

The setting is one of cultural and linguistic diversity. South Africa has 11 official languages, patients have diverse religious and cultural believes and many patients access traditional health care services (Greenberg et al., 2012). South Africa has a private and state health care sector. Individuals who pay out of their pocket or who belong to a medical aid (medical insurance) can access private health care. This is expensive and only a select few can afford. The majority of the population access the state funded services that is based on an "income classification system". In the prenatal service, screening for chromosome abnormalities is based on age (over 35 years in the research site). High-risk women are identified at their primary clinics and are then referred to tertiary centres where there are fetal medicine clinics where they are offered first or second trimester ultrasound and an amniocentesis to exclude a chromosomal abnormality. Maternal serum screening and non-invasive prenatal screening is not available in the state service. The counseling at the fetal medicine centres is done by Masters trained Genetic Counselors. The data was collected at two large state tertiary level hospitals in Johannesburg, South Africa. The staff of the Division of Human Genetics of the University of the Witwatersrand and the National Health Laboratory Service runs weekly genetic counseling clinics at these (and other) hospitals. Women who are less than 22 weeks gestation and over 35 years of age are referred by other health care providers for counseling and invasive testing.

3. Methods

The study participants were women referred for AMA genetic counseling and offer of amniocentesis. Table 1 is a summary of the participants' characteristics. All the women could speak English and all the sessions were conducted in English by six genetic counselors who each conducted between two and four sessions. At the time of data collection, the counselors were between 25 and 51 years of age and they had between one and 20 years' experience in genetic counseling. The data consist of 15 genetic counseling session recordings. The sessions were between 45 and 60 min long, they were voice and video recorded and was transcribed verbatim.

The data were analysed using principles of conversation analysis (CA). CA was developed in the early 1960's by Harvey Sacks, Emanuel Schegloff and Gail Jefferson (Ten Have, 2007). The focus of CA is on the detail of the conversation which allows the researcher to analyse the structure and order of the conversation and how the participants understand and relate to each other (Wood and Kroger, 2000). CA reveals information regarding turn-taking (who speaks first) and turn-design

(how speakers design the turn), the sequence organization (how one thing leads to another) and repair organization (how miss-hearing or misunderstandings are dealt with (Schegloff et al., 2007)). The first author, who is the primary researcher identified the focus of the paper, identified the collection of pertinent conversations and performed the initial analysis. Both authors further analysed and discussed the findings before producing the final results. The analyses in this paper focus on how the age specific risk of having a baby with Down syndrome is managed by the women and the counselors during the genetic counseling sessions.

Ethical clearance was obtained for the research from the University of the Witwatersrand Research Ethics Committee (M070222). Informed consent and study information documents were designed for the study. It is acknowledged that video recording a session is invasive and that this may have an impact on the consultation and great care was taken to ensure voluntary consent. A research assistant, not part of the service and proficient in several languages approached the women and counsellors to ask them to participate. All the counsellors in the service were given a choice before data collection commenced whether or not they want to be part of the study. All but one had agreed. All the women were approached by the research assistant on the day and the process were discussed with them in her home language. About half of the women approached declined to participate. All women who met the study criteria who presented at the clinic (first to arrive, only women attended clinic (no partners except one session), up to six on a day) were asked to participate. Data collection took place over a period of 18 months. The long period was due to suitable participants not available, only able to record one session on the day and about half of participant' declining to participate.

4. Results

Risk communication sequences, where the counselors explain the age related risk of having a baby with Down syndrome, are identified in the transcripts. The counselors present this risk in the different formats that have been reported in the literature and include odds, analogies and comparisons (A. Lippman-Hand and Fraser, 1979a,b; McAllister, 2003; Pilnick, 2004; Sivell et al., 2007; Baty, 2009; Weil, 2000). Our analysis of these risk communication sequence show that counselors and women engage in a patterned interactional activity that consist of five steps:

i. Counsellor presents the risks of having a baby with Down syndrome in terms of a "chance" (two sessions used both risk and chance).
ii. Counsellor reformulates the chance in terms of a dichotomy: something that will or will not happen.
iii. Counsellor invites the woman to share her perspective
iv. Woman shares her perspective
v. Counsellor responds.

We will illustrate these five steps and show that the women's responses to the risk presentations (step iv) show a stronger orientation to the design (the choice of words) of the immediately preceding invitation (step iii) than to the risk presentation in terms of chances or dichotomies from steps (i) and (ii). Excerpt 1 contains instances of steps (i) and (ii).

Excerpt 1:		Session 16, Couns F - Both positive and negative format and an analogy
1259	**C:**	At 39 is one in eighty-three
1260	**W:**	uhm
1261	**C:**	Okay so what that means is that if we can find 83
1262		ladies exactly your age
1263	**W:**	uhm
1264	**C:**	And who are pregnant and if we imagine them all in the
1265		room together
1266	**W:**	Uhmhm
1267	**C:**	83 and you one of them
1268	**W:**	Uhmhm
1269	**C:**	One of those ladies in the room
1270	**W:**	uhm
1271	**C:**	Is gonna have a baby where the chromosomes aren't right
1272	**W:**	uhm
1273	**C:**	And the other 82 ladies
1274	**W:**	Uhm hmm
1275	**C:**	Who gonna have babies with the chromosomes are fine

C is counsellor, W is counsellor.

In line 1259 the counsellor presents the risk in terms of a one-in-eighty-three chance (step i) and then in step (ii) reformulates this in lines 1261–1275 in terms of a dichotomy between "one" (lines 1267, 1269) who "is gonna have a baby where the chromosomes aren't right" (line 1271) and the "other ladies" (line 1273).

Also in excerpt 2, the counsellor first speaks of a "one in eighty chance" (line 702) and then in step (ii) she reformulates this chance into a dichotomy of "one" who "would have one of the problems" (line 708–709) versus the others "79". The counsellor uses the image of "women in a room" (line 706) and subsequently she compares the risk of a younger woman to that of an older woman.

Excerpt 2:		Session P01, Couns C – Analogy and comparison of young vs. old
702	**C:**	Is 1 in 80, 1 in 80 chance, so I'll write that down for you, 1
703		over 80 so that's for someone who's 39 years old. So if we
704		took 80 women who are your age
705	**P:**	Mmm
706	**W:**	And pregnant and we put them in a room
707		((nods))
708	**C:**	we say 1 out of those 80 women, the baby would have one
709		of these problems
710	**W:**	((nods))
711	**C:**	okay but what if you're younger, probably younger than 35?
712		The chance is about 1 in 600

After the risks are communicated the counsellors invite the women in step (iii) to reflect on the provided risk in what Maynard (1991) called a "perspective display sequence" (PDS). The different perspective display invitations in the sessions included; "How does it sound?" (in seven sessions), "How do you feel?" (in two sessions), "What do you think?" (two sessions), "What do you understand?" (one session), "Does that make sense?" (one session), and two sessions had no specific question.

Excerpt 3 shows the counsellor's risk communication with the perspective display invitation in line 695.

Excerpt 3:		Session P02 Counsellor B Perspective display sequence
685	**C:**	°Okay ° the chance you would a baby with <u>any</u> chromosome
686		problem (.) is 1 (.) in 102 okay so if we took a 102 women > the
687		same age as you < also pregnant one of those women will have a
688		baby that have a chromosome problem.
689	**W:**	uhm
690	**C:**	the other 101 women their baby will not have a chromosome
691		problem.
692	**W:**	°okay°
693	**C:**	°okay°
694		(0.2)
695		how does this chance (.) sound (.) to you
696		(0.3)
697	**W:**	Aih↑ to me > it it < I sound silly for now (.) I don't know I I feel if it's
698		1 in 102 I feel that there <u>is</u> a chance for me

In the excerpt, after having presented the risks in terms of a "1 in 102" chance (line 686; step i) and having reformulated this in step (ii) as a dichotomy between "one" who "will have" (line 687) a baby with a

chromosome problem and others who “will not” (line 690), the counselor's step (iii) invites the woman to share her perspective on this with “how does this chance sound to you” (line 695).

Note that the woman's step (iv) response in lines 697-8 is strongly aligned to the design of the invitation. It adopts both the words “sound” (l. 697) and “chance” (l. 698) from the counsellor's invitation and further uses “silly” (l.697) as an answer to the how-format of the invitation.

When the initial PDS invitation does not elicit a response, the counsellors follow up with providing more information or clarifying potential misunderstandings before producing another invitation. This second invitation is a different format in that it is produced as an alternative question that gives the women options to choose from. Excerpt 4 shows a perspective invitation containing two alternative questions in lines 1014 and 1015.

Excerpt 4:		Session 6, Couns A Second invitation
1012	**C:**	Okay (.) How? does the risk sound for you?
1013		(0.4)
1014		Does it sound (.) Lo:w? hi:gh?
1015		> does it not really make you worried <u>does</u> it make you < worried?
1016	**W:**	°It doesn't make me worried°

The counsellor produces this question after the first invitation in line 1012 did not elicit a response from the woman. Note the 4 second gap before the counsellor produce the second invitation. Note also the interactional preference organization that makes the woman respond not in terms of the first pair of alternative answers (low of high) but in terms of the latter pair: not worried or worried.

In excerpts 3 and 4 we have seen how the normative organization of social interaction places pressure on the women to answer within the terms of the question. In some instances the women only produce responses within these terms while in some cases they add additional information. The following two excerpts, 5 and 6, illustrate responses in which the women's response to the perspective display invitation first remain within the terms of the question but then add additional information.

Excerpt 5:		Session 01 Couns C – Woman respond to both terms and add additional information
1119	C:	Okay (.) how↑ do you feel about these risks at 38, what do you (.)
1120		think about them
1121		(0.5)
1122	W:	it's really? bad but what? Can we do
1123		(0.2)
1124	C:	when you say it's really bad,↑ what do you mean?
1125	W:	It's bad, but now there's nothing you can do > if you've got a
1126		child like that you have? to accept, < I mean I think it's a child it
1127		is a gi:ft from Go:d
1128	C:	Okay so (.) when you say to me it is really bad, do you think they
1129		High? risks?
1130		(0.2)
1131	W:	there i:s high risks.
1132	C:	You think it's high
1133	W:	°uhm°
1134	C:	> for you you think its high <
1135	W:	(nod)
1136	C:	Okay (.) So (.)
1137		when you say to me what can you do, we can
1138		offer a women a test to check if the baby's got a chromosome
1139		problem
1140	W:	Okay

In line 1119 the invitation is designed as “what do you think about them (i.e. the risks]” and the woman responds in line 1122 with a two-part reply. The first part (”it's really bad”) accepts the terms of the question while the latter part (“but what can we do”) moves beyond these terms. We see a similar phenomenon in excerpt 6.

Excerpt 6:		Session 10 Couns C - Woman respond to both terms and add additional information
1220	C:	How? do you fe:el. about these ri:sks I've given you at your age of
1221		40 (.) what? do you <u>think</u> of these risks.
1222		(0.5)
1223	W:	ahh it <u>is</u> risky but? (0.2) with me I don't (want to remind) at all
1224	C:	okay (.) no that's <u>fine</u> you > as I said < it's your decision as to
1225		[what]
1226	W	[yes]
1227	C:	> what you want to do < but when you look at those risks do you
1228		say they are risky? What do you mean by that.
1229	W:	<u>like</u> I'm trying to say hmmmn it shows that it <u>is</u> (.) <u>high</u> like the
1230		risk are <u>higher</u> at for people like my age
1231	C:	[uhm hum]
1232	W:	[you see] ja
1233	C:	okay so you? feel
1234	W:	but everything is in God's hands
1235	C:	okay so when YOU look at those risks you say they ARE? high
1236		you feel they high
1237	W:	hmmn
1238	C:	but for you (.) you not gonna worry about them
1239	W:	°it's the chance I'm gonna take
1240	C:	it's a °chance you gonna take okay, all right so those are the
1241		<u>risks</u> we would say at your age this is your chance of having a
1242		> baby with Down syndrome < or any chromosome problem okay
1243	W:	okay

Here the counsellor's invitation in lines 1220–1221 is phrased in terms of “risks”. This invitation receives a response of which the first part (line 1223) “ah it is risky” is also phrased in terms of risks while the second part goes beyond the normative boundaries that are set by the question.

A second commonality between excerpts five and six lies in the ways in which the counsellors respond to these two-part perspective displays. The counselors’ uptake of the two-part response can be to continue the conversation by focusing either on part one, thus remaining within the terms of the question or they can focus on the additional and deviant information in part two.

In excerpt 5 the counsellor's response refers back to the first part of the woman's prior turn that was concerned with ‘risks’ by directly asking if “really bad” means the risk is high. This allows the counsellor to sustain a focus on risks until she introduces the test in lines 1137–1139. Similarly in excerpt six. The counsellor first responds by accepting the second part of the woman's perspective display turn (lines 1224–1227: “it's your decision as to what you want to do”) and then returns to the terms of her original question when she says “but when you look at those risks do you say they are risky, what do you mean by that”.

In contrast to these examples, counsellors can only respond to the additional information the women give in their response to the perspective display invitation. Excerpt 7 is a case in point.

Excerpt 7:		Session 16, Couns F – Counsellor responds to additional information
1309	C:	That means that we got to find eighty three ladies?
1310	P:	uhm
1311	C:	like you to find one who's gonna have the baby with the
1312		problem and the other eighty two ladies like you
1313	P:	Uhmhm
1314	C:	Are gonna have babies that are fine.
1315	P:	uhm
1316	C:	What does that does that worry? You (.) or if
1317	P:	Hu uh I'm not?
1318	C:	°You not worried°
1319	P:	Hu uh I'm not worried but
1320	C:	°okay°
1321	P:	If this <u>one</u> is > for the last <u>one</u> <

1322	C:	This one's the last one.
1323	P:	uhm
1324	C:	okay so you not worried about this pregnancy
1325	P:	uhm
1326	C:	Everything seems to be going fi:ne in this pregnancy
1327	P:	uhm
1328	C:	but you > not wanting to have another <
1329	P:	No but you no because now the stuff is to:o expensive
1330	C:	Oka:y
1331	P:	uhm
1332	C:	Oka:y the baby stuff
1333	P:	Uhm the baby stuff is too expensive
1334	C:	okay
1335	P:	uhm
1336	C:	Okay so is that the reason that this is
1337	P:	uhm
1338	C:	The last one
1339	P:	uhm
1340	C:	Okay have you already started buying? baby stuff
1341	P:	Uhm I'm? I'm busy (.) buying (.) now
1342	C:	°Okay°

The woman's response to the perspective displays invitation is first directed at the terms “not being worried” but then she talks about this baby being the last one. The counsellor in contrast to excerpts 5 and 6 responds to this part of the woman's answer and a discussion ensues about this being her last baby and preparing for the baby.

5. Discussion

Analysing the data from a CA perspective showed how the counsellors and the women engaged in a discussion about the risk of having a baby with Down syndrome. This conversation is a five step process where the counsellors provide the risk information and invite the woman to respond. The counsellor's invitation to the women to reflect on what the risks mean for her, actually results in the woman not reflecting on the risks provided but rather on what they feel about these risks. It therefore seems that the format of the risk information and the numerical meaning of the risk does not influence the women's' responses. Instead, the women respond to the design of the counsellor's perspective display invitation. The significance of this perspective display invitation is further echoed by the fact that in the majority of the sessions, the counselors continue the discussion based on the additional information the women provide. This focus on the second part of the women's responses suggests that the risk format and numbers provided are less important than the meaning of having a baby with Down syndrome. This was also found in Chen et al. (2017) study that show that the women in their study's decision to undergo prenatal screening was not based on the risk of having a baby with a chromosome abnormality but rather the woman's values and convenience factors.

As a profession, the goal of genetic counseling is to follow a mutually agreed upon agenda and help the patient to adjust to the implications of being at risk (Resta et al., 2006). As a result, a large focus of the session is advocated to be on the psychosocial aspects of the case and the emotional issues that being at risk bring. Kessler has written about the counseling and education models of genetic counseling (Kessler, 1997). The counseling model takes the psychosocial aspects into consideration and with the current study's results it is helpful to see when and how additional information beyond the terms of the question, in this case the risk of having a baby with Down syndrome, is incorporated in the sessions.

What CA has been able to reveal, is the moment in the session when the woman and the counsellor could respond to the terms of the question or provide additional information.

This could align with Kessler's analysis of a transcript where he suggests that there is a pivotal moment in the session where the counsellor can pursue the medical or the psychosocial agenda (Kessler, 1981; Kessler and Jacopini, 1982). Whether this information can link to measure of success in genetic counseling is unclear, but it certainly provides some insight into conversations about genetics and in this case how the risk of having a baby with Down syndrome is provided and dealt with in the session.

6. Practice implications

The tension of the roles of the genetic counsellor as a counsellor and as an educator in these sessions is evident as the counsellor try to balance the two. On the one hand the counsellors attempt to educate about risk figures as is evident by the Genetic counsellor's effort to present risks in many formats and to check understanding. However, the checking of understanding goes beyond risks and the woman shares additional information about their concerns or worries. The preference organization shows that the women's' response is not to the risk information but rather the psychosocial aspects associated with being at risk of having a baby with Down syndrome. The counsellor's have to go back and forth between these roles as they navigate the session to ultimately assist the woman to make an autonomous informed decision.

It is also possible that the counsellor's actions could be linked to the setting which is complicated by language and institutional barriers. The repetition and invitation to reflect could be attempts to ensure the woman understand the risk information communicated. This repetition and checking of understanding have also been found in the decision-making sequence of these sessions (Wessels et al., 2015). The authors suggest that, because the counselors and women do not speak the same language and the women are referred and in most instances unaware of why they have to attend the clinic, the counselors may use such strategies to engage the women because they do not perceive or expect the women to actively participate unless they are directly asked. However, as discussed the women's response does not show that risk figures and numbers are important to them. Their responses show that their focus is on the implications for them and their baby.

7. Limitations

The study was done in one setting and it is likely that different features will be evident in other setting as Zayts and Sarangi, (2013) has shown. This study was further restricted to one unit and only examined AMA sessions. Research is ongoing in South Africa, which includes counseling sessions conducted by Medical Geneticists and Genetic Counselors in paediatric and adult counseling sessions with a focus on risk communication and managing uncertainty. It is expected that further insights will be gained from this work.

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Appendix A. Transcription conventions

Wo[rd	Overlap onset
[word	
Word]	Overlap end
Wo]rd	
word	Verbal utterance
(2.0)	Pause of 2 s
–	Cut-off or self-interruption
( )	Verbal utterance not heard/understood
(word)	Guess of verbal utterance
((laughs))	Description of events
.	Falling intonation
?	Rising intonation
,	Continuing intonation
↑word	Rising syllable intonation
↓word	Falling syllable intonation
word	Stress or emphasis
°word°	Softly spoken
word°	Decreasing volume
WORD	Loudly spoken
Wo:rd	Lengthened sound preceding colon
⟨word⟩	Pronounced at slower speed than surrounding talk
> Word <	Pronounced at higher speed than surrounding talk
Word >	Decreasing speed
Word <	Increasing speed
hhh	Hearable aspiration
·hh	Inhalation aspiration

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