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ORIGINAL RESEARCH

Explaining Mendelian Inheritance in Genetic Consultations: An IPR Study of Counselor and Counselee Experiences

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Abstract The explanation of Mendelian inheritance is a key component of most genetic counselling consultations, yet no evidence base exists for this area of practice. This qualitative study used Interpersonal Process Recall (IPR) to explore how information about X-linked inheritance is provided and received in genetic counseling. Twelve consultations involving two senior genetic counselors and 21 counselees were videotaped. Section(s) of videotape featuring the explanation were subsequently played back separately to both counselees and counselors and their responses and reflections recorded. All interviews were fully transcribed and analysed using the constant comparison method. A personalised diagram, drawn "live" by the counselor during the consultation was recalled by counselees as being central to their understanding of the "bottom line". This helped bridge the gap between scientific information and their family experience and did not appear to require a baseline understanding of genetic concepts such as genes or chromosomes. Counselors reflected on the diagram's positive impact on the way they sequenced, paced and tailored the explanation. A positive counselor-counselee relationship was vital even during this educative exchange: for counselees to feel at ease discussing complex genetic information and to help gauge counselee understanding.

Keywords X-linked · Interpersonal Process Recall · Patient education · Genetic counselling · Process research · Reflective practice · Observation

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Introduction

Education is one of the primary aims of genetic counselling (Fraser 1974; Resta et al. 2006) and is an expectation and valued outcome for patients (Bernhardt et al. 2000; McAllister et al. 2008a; McCarthy Veach et al. 1999; Wang et al. 2004). However, this is just one of several aims and Kessler (1997) described the tension between educative and psychodynamic approaches to practice. Others have argued for a model which incorporates these competing aims and suggest that counseling skills can be effectively employed in the diagnostic and educative, as well as the more explicitly psychosocial, elements, of the consultation (Biesecker and Peters 2001; Ellington et al. 2006; McCarthy Veach et al. 2007).

There is evidence from observational process studies that, unsurprisingly, information provision constitutes a substantial proportion of the genetic consultation (Armstrong et al. 1998; Ellington et al. 2006; Lippman-Hand and Fraser 1979; Pieterse et al. 2005; Smith et al. 2000). Research into the effectiveness of information provision has focused primarily on the *outcome* of patient knowledge and the *process* of communicating risk figures. Early findings suggested that patients' knowledge improved after genetic counseling (Kessler 1989; McCarthy Veach et al. 1999; Sorenson et al.

1981) however subsequent work has highlighted significant gaps in recall of key risk related information (Benjamin et al. 2003; Hallowell et al. 1997; Skirton and Eiser 2003). More recently the value of information recall as an outcome in itself has been challenged, and contemporary definitions of genetic counseling describe the information goal as the counselee's ability to use information in a personally meaningful way, for example to help with decision-making and to increase personal control (Biesecker and Peters 2001; Resta et al. 2006; Shiloh et al. 2006). Risk communication has been studied extensively, mostly in the cancer and prenatal genetic setting (reviewed in Julian-Reynier et al. 2003; Meiser and Halliday 2002; Smerecnik et al. 2009). This has led to recommendations for *how* risk should be communicated in these settings. The authors of a recent review of the impact of genetic counselling on risk perception accuracy (Smerecnik et al. 2009) recommend using both verbal and visual presentation of numerical risk estimates as the basis for discussion about the personal meaning of this information. This supports previous recommendations by Julian-Reynier et al. (2003) who suggested a 3 stage approach to providing risk information. These involve assessing prior beliefs and expectations, the tailoring of information to the counselee's needs and provision of an information resource following the consultation. The authors suggest that the latter could be achieved through both standardised tools such as videos and leaflets as well as a personal letter summarising the consultation.

Factors other than the teaching skills of the counselor are likely to impact on how information is assimilated. Several authors have described the influence of patients' beliefs about inheritance on their understanding of the biologically based information discussed in genetic counseling; for example using the pattern of disease manifestation in their own family rather than Mendelian based risks to predict who will be affected in their family (Chapple et al. 1995; Kay and Kingston 2002; McAllister 2003; Richards and Ponder 1996; Skirton and Eiser 2003; Walter et al. 2004).

The personal meaning of the information discussed in genetic counseling (including threat to health of self or family) is also likely to impact on understanding and recall. Genetic counselors are aware that the potentially serious nature of the information imparted may engender strong emotions which are likely to affect the patient's ability to hear and process the information (Djurdjinovic 1998). However, it is of interest that this personal and social contextualising of information is also central to theories of learning in non- healthcare settings, as discussed in the science education literature where factors such as students' prior knowledge, attitudes and goals are acknowledged to have an important role in the learning process (Ross et al. 2000; Wellington 2000).

The role of written information has also been studied. Written information as an alternative to a consultation has been investigated in the prenatal screening and cancer genetic settings. No particular standard method has emerged as superior in randomised control trials (O'Cathain et al. 2002; Thornton et al. 1995) although clarity of information and comprehensiveness have been highlighted as important to patients (Murray et al. 2001). Personalised written information in the form of a summary letter post consultation has been shown to lessen anxiety and increase information recall (Lobb et al. 2004; Meiser et al. 2008). Further, there is evidence that patients value having a summary letter to refer to at home and to share with family members (Hallowell and Murton 1998; Stayner and Kerzin-Storrar 2004).

The explanation of Mendelian inheritance is often the centrepiece of information provision in genetic counseling, however to date there has been no research looking at specifically at this area of practice. A desired outcome for counselees at risk of Mendelian conditions extends beyond an understanding of their own individual risk to a wider appreciation of the genetic implications within the family context. In contrast to communication of empiric risk information, such as that provided in cancer and prenatal genetic counselling (Smerecnik et al. 2009), the explanation of the mechanism of Mendelian inheritance opens up additional research questions including: Do counselees need to understand the mechanism of inheritance in order to assimilate the key points necessary for reproductive and other decision-making? What is the role of visual aids in explaining inheritance? Should the explanation include describing the relationship of genes to chromosomes and cells?

The aim of this qualitative study was to initiate an evidence base for this area of practice by exploring how X-linked inheritance is explained by counselors and received by counselees in genetic counseling consultations. X-linked inheritance was chosen as it is the most complicated mode of Mendelian inheritance to communicate to patients. The study adopts the techniques of Interpersonal Process Recall (IPR) (McLeod 1994), an approach more commonly associated with psychotherapeutic counseling.

Methods

Study Design

Interpersonal Process Recall (IPR) is an approach that has been used in the training and continuing professional education of psychotherapists to facilitate reflective practice (West and Clarke 2004). Interpersonal Process Recall involves videotaping a clinical session and a facilitator playing back specific sections of the videotape (for example

to focus on helpful and hindering events in the session). The facilitator and participant will also look at what was happening immediately before and after the actual event that is under review. Whilst the original aim of IPR was to help educate counselors and improve their therapeutic skills, at an early stage it was noted that the client frequently gained insight as well (Kagan and Schauble 1969). Interpersonal Process Recall has subsequently been adopted by a number of psychotherapy researchers to explore important elements of therapeutic practice (Elliott 1986; Wiseman 1992). More recently it has been suggested that this method could be usefully applied to process studies of genetic counseling (Biesecker and Peters 2001; MacLeod et al. 2002). In the research setting, the researcher, together with the participant (e.g. counselee), watch sections of the videotape of the clinical session, and the dialogue between researcher and participant is audiotaped. The role of the researcher conducting the IPR interview is to help facilitate participants' insights to thoughts and feelings at the time of the original consultation. The audiotaped IPR interview is then transcribed and subjected to qualitative analysis.

The study design is shown in Fig. 1.

Ethics Approval

Ethical approval for the project was granted by the Local Research Ethics Committee.

Participants

All participants were recruited through a Regional Genetics Service, in the north of England. Thirteen counselees referred for genetic counseling in connection with a family history of an X-linked condition were invited, and all agreed to participate. Additional family members for whom the explanation of inheritance was relevant, were also invited to participate. A total of 21 (17 female, 4 male) counselees ranging in age from 14 to 66 years were interviewed. Counselees were referred for genetic counseling for a number of different X-linked conditions: Duchenne and Becker Muscular Dystrophy (DMD, BMD), Fragile X, Norrie Disease, Congenital Adrenal Hypoplasia (AHC) and Retinitis Pigmentosa (RP). The two participating genetic counselors were both experienced clinicians (>10 years) and each held an MSc qualification in genetic counseling and UK professional registration.

Interpersonal Process Recall Interviews

Consultations were filmed in the clinic setting. All IPR interviews with counselees were conducted in their homes by one of the researchers (TG) before receipt of the consultation summary letter (median time 5 days). The recording of the consultation was viewed on a DVD player or laptop. Counselors were interviewed by another researcher (SP) in a private studio room at the hospital.

In each case (counselee or counselor) the interview began with the researcher playing back the section(s) of the consultation in which inheritance was explained, usually 10–15 min in total. Participants were asked to try to cast their mind back to their experience during the consultation, and to stop the DVD whenever they wanted to make a comment or discuss their thoughts. This process was facilitated by the researcher, who had watched this part of the recording prior to the research interview, by prompting the participant at transition points in the explanation or in response to counselee/counselor non-verbal cues. For example: "What did it mean to you when the counselor used the word

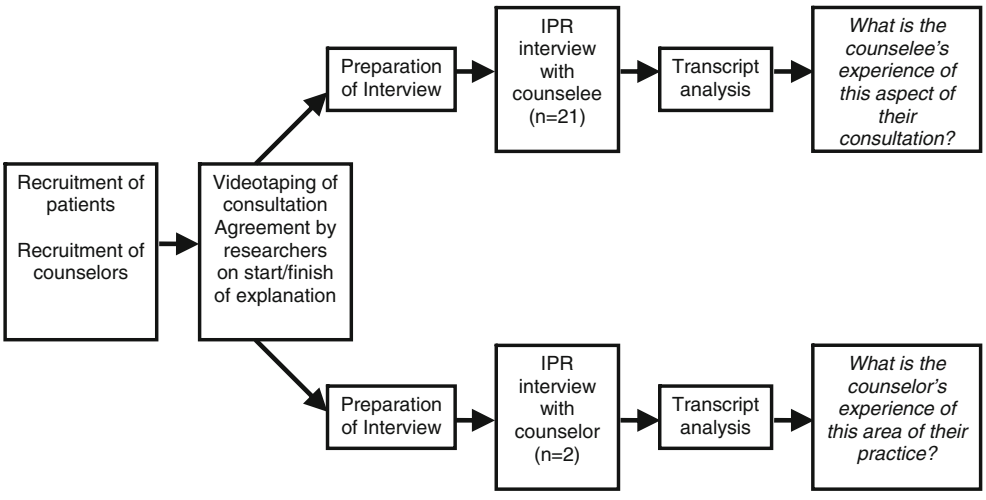

Fig. 1 Flowchart Outlining the Two Arms of the Study.

'chromosome'?" [when the counselor used the word 'chromosome' for the first time] or: "In this section, the counselor was explaining how your son inherited the condition — can you remember what was going through your mind at this stage?" [after counselor had completed a diagram of X-linked inheritance] or "Were you [counselor] aware when the partner moved closer to you at this point in the explanation?". Interviews lasted between 30 min and 1 h and were audio-recorded.

Data Analysis

The audiotapes of the IPR interviews were transcribed in full, and a thematic analysis was conducted in accordance with the approach outlined for analysing dialogue by Mason (2002) and Silverman (2006). Counselee interviews were analyzed by the researcher who had conducted these (TG) and the senior author (RM). Counselor interviews were analyzed by the researcher who had conducted these (SP) and the senior author (RM).

An inductive coding approach was used, with different segments of the data being grouped into preliminary emerging categories. All categories were continually re-examined against the original transcripts to try to ensure that alternative interpretations had been considered and meanings clearly described. The analysis was an iterative process and was ongoing throughout the data collection process such that important emerging categories and themes — for example the importance of the personal diagram — could potentially be explored more thoroughly during subsequent interviews. Ongoing comparison of differences and similarities within and between codes allowed for further clarification of meanings, for example "helpful: personal drawing" which emerged as important early on, became subdivided into sub-codes including both descriptive aspects such as "helpful: step-wise construction" and "helpful: using names on drawing" and more interpretative aspects such as "personal meaning of drawing". Codes were also re-examined in the context of their original transcript to try to fully understand all subtleties of meaning. Towards the end of the study (counselees only), several main overarching themes had been identified, and no new themes were emerging, suggesting that data saturation had been achieved for the counselee sample.

The data were managed using the qualitative software package ATLAS.ti version 5.0.66.

Results

Counselees were overall very positive about the explanation of inheritance which they had received. Two major themes emerged from the interviews with both the counselees and counselors: the importance of 1) the counselor-counselee relationship, and of 2) the "live" personal drawing. Table 1 outlines the themes.

Counselor-Counselee Relationship

Counselees

Counselees appreciated both the time taken over the explanation and the counselor's focussed attention; these were taken as evidence of the counselor's commitment to their care.

> *"She was really into explaining it and just making sure that we got it…I wasn't just a patient…I wasn't just someone that she had to see."*
>
> (19 year old woman, family history of DMD; attended for carrier testing with her partner)

Counselees had confidence in the counselor's expertise and ability to communicate and reframe complicated information in a simple way. Several counselees expressed

Table 1 Major Themes and Sub-themes which Emerged from IPR Interviews with Counselees and Counselors

Major Themes	Sub-themes
Counselor-Counselee relationship	From counselees:
	• Valued counselor commitment to ensuring understanding
	• Confidence in counselor expertise
	• Not made to feel foolish
	• Validation of own understanding
	• Counselor avoided making assumptions about prior knowledge
	From counselors:
	• Counselee non-verbal cues aid ease of explanation
	• Rapport with counselees seen previously impacts on counselor explanation
"Live" personal drawing	From counselees:
	• Personalised to their situation
	• Step-wise drawing
	• Taking the drawing home
	• Accessible to visually impaired
	• Understanding "the bottom line"
	From counselors:
	• Slowed pace of explanation
	• Helped sequence explanation
	• Used to personalise to counselee's situation

trust in the counselor not to make them feel foolish should they not understand something:

"You know that if you don't understand you can just turn round and say 'well I don't get that' and she'll explain it different…but with teachers you're like 'Oh, they're gonna shout at me.'"

(14 year old girl, brother affected with DMD; attended for carrier testing with her mother and stepfather)

This also allowed them to validate their own understanding of the explanation, and to positively reinforce a sense of their own capability:

"… a lot of the time you want confirmation of what you think you already know … so it was just very helpful to hear somebody else with a lot more knowledge and understanding than me saying things and explaining things in the way that I had interpreted them."

(32 year old female biology teacher, family history of AHC; attended with husband for carrier testing in pregnancy)

"I was really worried that I wouldn't get it but … I was feeling a whole lot better about it cos I was understanding and it wasn't anywhere near as complex as I thought it was going to be."

(19 year old woman, family history of DMD; attended for carrier testing with her partner)

It was important that the counselor had avoided making assumptions about their prior level of knowledge, either too much, or too little. Sometimes a question such as "did you do much biology at school?" was helpful in this respect:

"She didn't assume that I knew it, or I knew anything in particular which again was good."

(32 year old female biology teacher, family history of AHC; attended with husband for carrier testing in pregnancy)

It was appreciated by some counselees that the explanation had also been pitched towards those family members present at the consultation. Interestingly, however, a couple of accompanying family members recalled feeling unable to ask questions, because they perceived the consultation was intended for another family member:

"I'm thinking: 'well, perhaps they'll ask because they've got the condition' … I just felt that, I don't know, I thought 'no it's not me, it's them that needs the asking.'"

(59 year old carrier of RP; attended with affected son and brother for results of gene testing)

Counselors

For genetic counselors the importance of a good rapport went beyond the relationship per se; it helped them to gauge counselee understanding. They spoke of the importance of a good rapport and reliance on visual cues from the counselee(s) to indicate whether (s)he was following the information and engaged in the consultation.

"She is listening and watching my explanation….I guess that is why I am pausing, to see what sort of feedback I get."

"I thought at the time they were engaged, their eye contact was good, they seemed to be watching and wanting to hear what I was saying. I didn't feel at any time that they were not interested or that it was too complicated, they were with me."

This type of monitoring went on throughout the consultation with both participating genetic counselors looking for shifts in affect or understanding:

"When you are giving information you are constantly aware that there might be emotional reactions to it, so shifting from information to emotions happens normally quite comfortably and easily."

"I like people asking questions and wondering things as it gives me an idea of their understanding."

Whilst the genetic counselors appeared comfortable with counselee cues signalling confusion or distress, by way of contrast they recalled *lack* of emotion as more problematic. The genetic counselors found a perceived lack of patients' cues was harder to interpret and worried that it could be a reflection on the relationship and a difficulty in establishing rapport.

"My work with her in previous consultations is that she has been very, very quiet and I had absolutely no idea of what she knew or she understood but she had not really engaged with me in the past, and this is the first time that she is engaging with me and I am feeling really good about how that's going in this session."

Counselors commented that watching the tape during the research interview provided an opportunity to reflect on their counseling practice, which they felt was similar to the process of counseling supervision, a requirement of professional practice. Counselors reported that they might not have been aware during the consultation that they were checking for understanding or reassurance but realised immediately when watching the video that this had occurred:

"Watching it now he is actually responding to me but in the session I didn't get that feeling."

"I think her body language is different today from how she has been before. She is giving me a lot more eye contact, she was participating, the fact that she joined in occasionally during inheritance was giving me a lot of reassurance that she was understanding."

Meeting an individual on more than one occasion was perceived by both counselors as helpful in facilitating rapport. They believed this came about through counselees feeling more at ease in advance of discussions around complex information or decisions.

"I often find that meeting people more than once, particularly teenagers, gives an opportunity for them to get to know me, and me to feel more comfortable"

"Live" Personal Drawing

Counselees

One particular aspect of the explanation of inheritance - a hand drawn visual diagram demonstrating how X-linked conditions are passed on in families — was recalled with particular enthusiasm by participants. Counselees spoke with little prompting about how the diagram had facilitated their understanding. All participants, with the exception of a man with severe visual impairment, had had a diagram similar to Fig. 2 drawn for them by their counselor. Most counselees recalled the drawing vividly, with several becoming animated, and prior to being shown that particular section of the tape in the research interview. All counselees felt that the diagram helped them not only to understand the mechanism of inheritance, but also to retain the information after the consultation.

"When she drew like this diagram at the end, showing like how it's passed on, and how it's not passed on. That was what made me understand it."

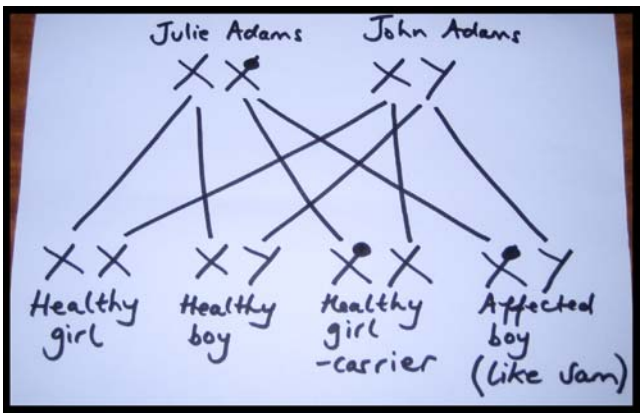

Fig. 2 Example of the Counselor's Hand-drawn Diagram Showing the Four Possible Outcomes in Pregnancy for A Carrier Female.

(18 year old woman, brother affected with DMD; attended for carrier testing with her mother, father, sister and brother)

Personalised diagram Regardless of the X-linked condition or reason for referral, the personalised nature of the diagram, drawn to reflect their individual circumstances, was important to counselees. Not only did this help to contextualise the key message or 'bottom line' for that particular consultation — e.g. what is the chance I am a carrier? What is the chance I will have a second affected child? — it personalised the information in the context of their own family thus providing a link between counselees' experience of the X-linked condition and the medical explanation. It also provided further evidence of the counselor's investment in their relationship:

"... rather than sort of 'here's one I prepared earlier' flipchart for 'this is bog-standard' sort of thing, it made it more like 'this is to your specific situation', and just made it a bit more comfortable, in that way."

(35 year old woman, family history of BMD, 2 daughters; attended with husband for carrier testing)

The personalised drawing helped counselees to make sense of various different aspects of their personal and family circumstances. For example, by depicting visually why a boy with a 'faulty' gene on his sole 'X' chromosome will be affected with the condition, while a girl who has 2 'X' chromosomes will (usually) not, counselees were provided with an explanation of the presence of the condition in their family:

"... cos it helped me understand like how me brother ended up with it."

(18 year old woman, brother affected with DMD; attended for carrier testing with her mother, father, sister and brother)

One woman enthused that annotating the diagram to differentiate the male and female 'parents' with the initials of herself and her partner: "Mr A and Mrs A" had served to clarify that it was in fact herself that was a carrier of the condition, and also to reinforce the personal nature of the explanation:

"You know, to have that particular person who it involves instead of different people like, getting all mixed up. Putting Mr A and Mrs A, you know who's who and what's what, you're not getting anything mixed up ... It was brilliant what she done there with that ... if she does it to another family, and they're called James or something like that...Mrs J and Mr J. You know whose family it is who don't you?"

(52 year old DMD carrier with one affected son; attended with daughter for her carrier testing)

By demonstrating exactly how the various genotypes of the second generation are created from the genotypes of the first parental generation, and thereby showing how the condition may be passed from one carrier to another, without any signs of the condition manifesting, the drawing provided a basis upon which to link the present to the past family history, or absence of this:

"Because you look for a disabled child or something going back, you look as far as where you can see in the family can't you? Apparently though if you go back in the generations and generations ... probably [my partner's] great-great-grandmother may have been a carrier, well obviously someone's been a carrier and passed it through to this and where it's come down through the line now to [her son]."

(50 year old man; attended for counseling with partner whose son has Fragile X)

Giving an explanation of the clinical outcome or phenotype of each genotype in the second generation helped counselees to understand all the possible outcomes of a pregnancy in a future generation, and also the equal likelihood of each of these options occurring:

"That was really useful the way she did that, again I think helping you to visualise how it's passed on and the chances of it being passed on if I am a carrier, no it was really helpful that"

*(*32 year old female biology teacher, family history of AHC; attended with husband for carrier testing in pregnancy)

Furthermore, for those women considering carrier testing, the diagram helped to underpin the basis for the quoted risk figure.

"So you want to see if I've got that X and that X, or that X and that X."

(16 year old girl, with brother affected with DMD; attended with mother for carrier testing)

"Cos then she could actually see it's 50:50, and how it had actually come about."

(47 year old carrier of DMD, attended with her daughter for her carrier test result)

It was important for participants that the counselor had fully articulated the clinical implications for each resulting phenotype, as it was drawn, rather than assuming counselees themselves would make this connection. Similarly, annotating the diagram with both gender and clinical status beneath each outcome e.g. "carrier female", or "affected boy", was also helpful in being able to follow what was being drawn and being able to recall the outcomes.

"... she explains each 4 options what each of the options are and how it's going to turn out, so you remembered."

(56 year old woman; attended with husband and nephew (both affected with RP) and sister in law for genetic test results)

"To see it building up, and explained through it, each part, I think it registers better."

(46 year old woman, carrier of Norrie Disease with 3 affected sons; attended with daughter for results of carrier testing)

Step-wise drawing Since the diagram emerged as a key theme in the early interviews, subsequent participants were asked to consider whether they would have felt differently had they been shown a ready-completed version of the diagram, either pre-drawn by the counselor, or a standard one such as might be found in a genetic counseling aid or leaflet. Although 2 counselees had no preference, the majority who were asked (13/15) felt that "building up" the diagram at the time of consultation was better:

"I preferred it that way I think, for her to draw it stage by stage and sitting in front of her while she drew it."

(30 year old Fragile X carrier, one affected son; attended with new partner)

"Building it up was much better, than just pulling out, you know this is the final version, much better."

(32 year old female biology teacher, family history of AHC; attended with husband for carrier testing in pregnancy)

"Building up" the diagram with counselees was helpful because of the dual impact of the counselor's verbal explanation combined with her drawing:

"No, it was as she was drawing it, as she was explaining, that was really good ... you were seeing it progress ... she was like putting pictures to words ... the way that she did it was good."

(19 year old woman, family history of DMD; attended for carrier testing with her partner)

A step-by-step drawing also slowed down the pace at which counselees needed to assimilate information, which made them feel under less pressure to keep up with the

explanation, and hence made them feel more at ease. Similarly, the slower pace also allowed for questions:

> *"I think it also gives you a chance if you want to, to ask the question about each option, yeah, when she's drawn it, you know rather than seeing it all and thinking 'right, where do I start here with all this business here?'"*
>
> (30 year old Fragile X carrier, one affected son; attended with new partner)

Taking the drawing home In some of the consultations counselees were invited to take the personalised diagram home with them. One participant described how it had been helpful to have this to refer to again when talking through the possible outcomes of pregnancy with her partner:

> *"I was glad she's done that cos we were able to take that sheet away ... because you come out and you talk about it and so on, and it was nice to have that to refer to again"*
>
> (30 year old Fragile X carrier, one affected son; attended with new partner)

Seven participants who were not offered the diagram were asked directly if they would have wanted this. Although some (3/7) felt that they understood it adequately and wouldn't have taken it, others (4/7) strongly felt they would have appreciated the offer to take the diagram home.

> *"I would have kept that. In every case I would have kept the actual drawing ... because you've got the mental picture you see and you remember the words that go with it."*
>
> (56 year old woman; attended with husband and nephew (both affected with RP) and sister in law for genetic test results)

Accessible to visually impaired Three of the 21 participants in the study were men with visual impairment due to X-linked Retinitis Pigmentosa. One man, counselled alone, commented frequently about his inability to "see" genes and chromosomes and felt that this impeded his understanding of these concepts, and hence the mechanism of inheritance. He did not have a diagram drawn in his consultation:

> *"I still don't understand the genes and the chromosomes ... I still get back to that I'm afraid ... If I could see it in a bottle or something then…say 'that's it floating around' ... I can't picture it!"*
>
> (66 year old man with visual impairment due to RP; counselled alone)

The two other men attended one consultation together with two sighted family members. It was interesting to note that despite the diagram being either unclear or, for the other counselee, completely non-visible, both appeared to be able to follow the verbal description that had accompanied it:

> *"Well, even though I can't see it, I mean it would be a lot clearer still if I could see ... I do take on board 100% what she's saying ... I just see it as 1 lucky person with the 2Xs and then 1 unfortunate person with the 2 Xs and I just sort of imagine that, same with the XYs."*
>
> (62 year old man with visual impairment due to RP; attended with wife, sister and nephew for genetic test results)

Understanding "the bottom line" None of the counselees interviewed felt that they had struggled to understand the explanation of X-linked inheritance, and many enthused about how pleased they were that they *had* understood. Although the aim of the research was manifestly *not* to assess accuracy of understanding, the participants' descriptions of the explanation given by the counselor often revealed that it was the essence of the explanation that had been interpreted within their own framework of understanding rather than the precise details recalled directly. For example, it was apparent that many participants conceptualised X-linked inheritance in the simple terms of the diagram — "X"s and "Y"s — rather than an accurate understanding of the biological link between genes, chromosomes, cells etc:

> *"To me all I need to know is that I've got this makeup within my body that's slightly wrong and I just look at it as an X, that's gone wrong, you know ... it's got information on it and it's gone a bit faulty, and I think if she'd gone into how this gene's — I think it might have been a bit mind-boggling for me."*
>
> (46 year old woman, carrier of Norrie Disease with 3 affected sons; attended with daughter for results of carrier testing)

Strikingly one participant, who had stated at the outset that the diagram had been critical to her understanding, openly described that she had struggled with the concept of chromosomes:

> *"From that bit where she mentioned the chromosomes, I were sat there going 'what are them?' ... I didn't understand one bit of it."*
>
> (18 year old woman, with brother affected with DMD; attended for carrier testing with her mother, father, sister and brother)

It seemed, in this study, that an accurate understanding of genetic concepts such as genes, chromosomes and cells was *not* necessarily a pre-requisite for counselees' ability to follow the personal diagram, or to take from the explanation the answers to the questions which constituted their personal 'bottom line'.

Counselors

Both counselors reflected on their use of a personalised diagram as part of the explanation of X-linked inheritance. They, too, noticed when watching themselves on tape that it helped to slow down their explanation:

> *"Drawing makes you slow down because you have to actually do it so it is quite a good thing to learn that maybe when you are just talking with your hands you can maybe do it too fast."*

> *"Drawing slows me down. I think if they are already drawn out I can see myself rushing through them quite quickly and not taking much time in assessing how the information is going."*

Counselors also reflected that the drawing was part of a typical sequence which they preferred to follow when explaining X-linked inheritance:

> *"I generally do the genes and chromosomes without drawing anything just trying to get a few concepts across and then I start talking about the X and the Y showing pictures."*

> *"I am starting out with the real pictures of the chromosomes and then I move on to symbols with my own drawings and hopefully that would make sense having shown them [counselees] pictures."*

Despite having a preferred sequence however, counselors were aware that they made efforts to 'tailor' an explanation for a particular counselee or situation, by varying the personal diagram, for example, and/or by altering the emphasis of the verbal explanation that accompanied it:

> *"I clearly have a picture in my head as to whom these drawings relate to and how I describe it would be different depending on the situation."*

> *"I think my pictures probably look the same but the way that I describe it is probably different…. I had emphasised 50/50 in the past [risk of counselee being a carrier] … and this time I am emphasising 75% chance of having a healthy baby … I am presenting the data to them in a slightly different way using different numbers."*

Counselors also observed that the diagram could be drawn to convey the important messages without a prior detailed explanation of the function of genes and chromosomes:

> *"… perhaps I don't use the chromosome book with younger people…. I think I am happier just using diagrams and explanations in a more basic situation with younger girls that haven't come across the word chromosome."*

Participants' Response to IPR Methodology: Interviewer Impressions

Participants appeared to differ widely in terms of their metacognitive abilities, i.e. in their ability to think about their own comprehension or thought processes. Some could recall easily what they were thinking at certain points and describe — with little prompting — for example, changes in their perception of inheritance in response to what was happening in the consultation. Others seemed to find it harder to recall their own thought processes, often initially using more basic descriptors such as "that was good"; "that was fine", thereby requiring additional prompting from the interviewer, which usually served well to expand their answers. Although many participants were very open during the research interviews, a few participants appeared somewhat nervous and this may have influenced their ability to engage as thoroughly with the process. One participant appeared quite defensive during her interview, as though she were being tested on her knowledge, although it had been stated explicitly that this was not the case. Most counselees relied on the interviewer to stop the tape at regular intervals rather than initiating this themselves, which the interviewer perceived to be due to a number of factors such as: unfamiliarity with the IPR process, difficulty in recall without prompting, or possibly for a few participants a general reticence relating to concern that their own understanding was being assessed.

Discussion

This is the first study to investigate how Mendelian inheritance is explained in the course of genetic counseling. A novel approach was adopted using the techniques of IPR to explore both genetic counselor and counselees' perceptions of what transpired during this part of the consultation. Most genetic counseling process studies have asked counselors and/or counselees about their experiences of genetic counseling (Bernhardt et al. 2000; McAllister et al. 2008a; Skirton 2001). Kessler (1992) has argued for observation studies looking at what actually goes on in the interior or 'black box' of genetic consultations. This gap has begun to be addressed by studies which have analysed

taped consultations (Ellington et al. 2006; Ellington et al. 2005; Lobb et al. 2005; Michie et al. 1997; Michie and Marteau 1996; Sarangi et al. 2004). Some of these studies have included both analysis of consultation content and interviews with counselors and/or counselees (Chapple et al. 1995; Hallowell et al. 1997; Lippman-Hand and Fraser 1979). In this study the approach differed through the use of IPR which linked "live" observation of the consultation tape with counselor and counselee interviews.

Counselor-Counselee Relationship

Although the research focussed on an aspect of the consultation where information was being relayed, counselees and counselors frequently made comments about the rapport established during this educative exchange and perceived that a good rapport led to a better outcome. The counseling relationship has been reported elsewhere as an important outcome of genetic counseling (Bernhardt et al. 2000; McAllister et al. 2008b; McCarthy Veach et al. 2007; Skirton 2001), but this study differs as the finding relates specifically to information provision. A positive relationship with the counselor was felt to help counselees feel at ease discussing complex genetic information. Counselees recalled two particular concerns prior to the consultation: whether they would be able to understand what they expected would be complex information and whether they would be made to feel foolish. In fact, they recalled the actual experience as affirmative which they related to their belief in the counselor's commitment to helping them understand the information as well as having the expertise to go over the information using a different approach if necessary.

Counselors' commitment was also evident in their IPR interviews where they recalled using a variety of monitoring strategies to check counselee understanding. Bernhardt et al. (2000) also reported that counselees recognise the genetic counselor commitment to patient understanding. Interestingly for some counselees in the current study, a sense of mastering the information (whether or not they actually had) seemed to boost feelings of self worth. Information provision has previously been reported to have psychosocial benefits including raising patients' perception of personal control (Berkenstadt et al. 1999) and alleviating feelings of guilt (Chapple et al. 1995).

Live Personal Drawing

A striking finding from this research was that counselees often perceived that their understanding of inheritance had been achieved at the point when the counselor had drawn a diagram depicting X and Y chromosomes which was personalised to the family's situation.

Previously, observation studies of genetic counseling process have largely focused on the verbal content of the consultation, in particular analysis of genetic counselor dialogue (e.g. Ellington et al. 2006; Lobb et al. 2005; Sarangi et al. 2004). Meiser et al (2008), in their review of observational process studies, note that a consistent finding is the variability in therapeutic skills and effectiveness between individual counselors. A gap in the literature has remained, however, with regard to how genetic counselors incorporate educational aids and diagrams into their verbal explanations of inheritance, and to what extent these are associated with a good outcome from the patient's perspective. The limited existing literature on the use of educational tools compares standardised tools (e.g. computer program, video or slide show) with a personal verbal explanation by a counselor (e.g. Cull et al. 1998; Green et al. 2001). In this study looking specifically at counselor-delivered explanations of inheritance, it was the "live" diagram combining a visual depiction together with a verbal explanation, which was recalled with particular enthusiasm.

The two helpful components which facilitated the explanation for the counselors and expedited understanding from the counselee's perspective were the diagram's stepwise nature and the labelling which was personalised to the family situation. The time taken to build up the drawing in the course of the consultation was observed by both counselees and genetic counselors during the IPR interviews to slow the pace of the consultation, allowing for questions and slower assimilation. The importance of counselees' personal beliefs have been highlighted in relation to assimilating new genetic information (Chapple et al. 1995; McAllister 2003; Richards 1998; Richards and Ponder 1996). Here, personalising the diagram (for example, labelling pairs of chromosomes with the known status of named family members) helped counselees integrate their own experience of what had happened in the family with the Mendelian explanation.

Previous studies involving members of the general public have shown a poor understanding of 'basic' genetic concepts such as genes and chromosomes and it has been suggested that complex mechanisms such as X-linked inheritance, would be more difficult to grasp (e.g. Lanie et al. 2004; Richards 1998). It has also been suggested that counselees assimilate new scientific information into existing frameworks (including both taught concepts and family experience), by a process of anchoring unfamiliar concepts to more familiar ones, and by turning concepts that are abstract into those that are more concrete (Michie and Marteau 1996). From the IPR interviews it was observed that counselees appeared more familiar with the construct of sex chromosome pairs and the use of the X and Y symbols, compared with the counselor's introductory verbal

description of genes and chromosomes; in fact understanding of these more 'basic' genetic concepts did *not* appear to be a prerequisite for following the rest of the explanation.

Kessler (1989) argued that counselees store new genetic information as "personally meaningful units" which can then be used for decision-making. It was interesting in this study that for counselees a positive outcome of the consultation was to gain a 'good enough' understanding of X-linked inheritance which would enable them to make sense of their family history and to make personally relevant testing decisions. They did not *expect* to understand all aspects of the explanations, and neither did this matter to them. As long as they understood what was for them the 'bottom line' for example: "what is the chance I am a carrier?" or "what is the chance I will have an unaffected son?" then a positive sense of having understood prevailed.

Because three of the counselees interviewed had visual impairment due to RP, we were able to ascertain valuable information about the process of explaining inheritance in this situation. One man attributed his lack of understanding to his inability to see but, interestingly, the other two participants recalled being able to follow the verbal commentary which had accompanied the counselor's stepwise diagram, which she had drawn for the sighted family members present. This limited data suggests that people with visual impairment may still benefit from a 'live' drawing particularly where it helps the counselor structure and pace the explanation or through more imaginative verbal describers. Further research with this patient group including the use of graphic verbal descriptions and alternative formats is needed.

Methodological Issues

Interpersonal Process Recall was found to be an effective method for capturing both counselee and counselor experiences in the genetic counseling setting. Future studies using IPR to investigate the genetic counseling process could explore how different types of inheritance are explained in consultations. Additional areas of study would be to explore language in genetic consultations such as metaphors used by both counselees and counselors. Other specific aspects of genetic counseling would also appear suited to this approach, for example presenting genetic test options or giving test results.

An early IPR paper discusses how the method facilitates client disclosure of discomfort, ultimately leading to personal growth (Kagan and Schauble 1969). Whilst these counselees overall recalled feeling comfortable at the time of the consultation, the IPR interview enabled a few to reflect on what was inhibiting them from sharing with the counselor when they were feeling lost or unable to ask a question.

In IPR, participant interviews normally take place immediately after the consultation but this was not possible for this study. It could be argued therefore that the short time lapse could have affected recall, for example participants might have misattributed their thoughts or feelings from another segment of the consultation to the one in question. This possibility cannot be ruled out, but most participants did, however, appear to engage easily with what they were observing on screen and to recall what was going on for them at the time. We suggest that for studies such as this one, where participants are directed to one specific section of the consultation, a short time lapse may not be problematic and may even be preferable, to allow some processing of the consultation overall before the research interview.

The study looked at the practice of two very experienced genetic counselors; in order to learn about effective elements of practice it was felt appropriate to begin by involving clinicians whose practice is recognised and respected by their peers. For the purposes of the current investigation it was important that the participating genetic counselors had built up experience of counseling for X-linked disorders. It is highly likely that skilled genetic counselors work intuitively and IPR provides a method of helping to unpick contextual decisions and counseling behaviour as it transpires. What appears to be 'intuitive practice' may actually draw on a range of theory and experience. Indeed as a profession genetic counseling has been influenced by a number of disciplines including science, psychology, nursing and the social sciences. However as this exploratory study involved just two genetic counselors, we would welcome further studies to seek to replicate these findings amongst a larger and more heterogeneous of genetic counselors with a broader range of experience.

A potential concern about investigating specifically the information aspect of the consultation was for 'performance anxiety', both for the counselors with respect to the quality of their explanation and for the participants in terms of the 'correctness' of their understanding. We attempted to minimise this by carefully explaining the aims of the study (which did not include trying to measure information recall) to both counselors and participants.

All the IPR interviews in this study were audio taped but video taping the interviews may allow more in-depth study of transitions. This would however be technically more difficult and may interfere more with the interview process.

Conclusions

Established educational aids such as those published by the Greenwood Genetic Center (*Genetic Counseling Aids* 2007)

are invaluable tools for genetic counselors including chromosome karyotypes and diagrammatic illustrations of prenatal diagnostic procedures. However, the findings of this study raise the possibility that drawing step-wise personalised diagrams when explaining Mendelian inheritance may be preferable to using pre-prepared material.

Patients' own views about the extent to which they have 'mastered' information may prove to be a useful measure of outcome post consultation. Perceptions of 'mastery' appear to be contingent on the individual's needs for information and how they choose to use information e.g. to help with decision-making. Finally the techniques of IPR have been shown to be effective in helping counselees reflect on their experience of genetic counseling and counselors reflect on their practice. Further use of IPR promises to yield more information about the 'black box' of what takes place in genetic consultations than would be achieved through observation or interviews alone.

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References

Armstrong, D., Michie, S., & Marteau, T. (1998). Revealed identity: a study of the process of genetic counselling. *Social Science & Medicine, 47*(11), 1653–1658.

Benjamin, C. M., Colley, A., Donnai, D., Kingston, H., Harris, R., & Kerzin-Storrar, L. (2003). Neurofibromatosis type 1 (NF1): knowledge, experience, and reproductive decisions of affected patients and families. *Journal of Medical Genetics, 30*(7), 567–574.

Berkenstadt, M., Shiloh, S., Barkai, G., Katznelson, M. M., & Goldman, B. (1999). Perceived personal control (PPC): a new concept in measuring outcome of genetic counseling. *American Journal of Medical Genetics, 82*, 53–59.

Bernhardt, B. A., Biesecker, B. B., & Mastromarino, C. L. (2000). Goals, benefits and outcomes of genetic counseling: client and counselor assessment. *American Journal of Medical Genetics, 94*, 189–197.

Biesecker, B. B., & Peters, K. F. (2001). Process studies in genetic counseling: peering into the black box. *American Journal of Medical Genetics, 106*(3), 191–198.

Chapple, A., May, C., & Campion, P. (1995). Lay understanding of genetic disease: a British study of families attending a genetic counseling service. *Journal of Genetic Counseling, 4*(4), 281–300.

Cull, A., Miller, H., Porterfield, T., Mackay, J., Anderson, E. D. C., Steel, C. M., et al. (1998). The use of videotaped information in cancer genetic counselling: a randomised evaluation study. *British Journal of Cancer, 77*, 830–837.

Djurdjinovic, L. (1998). Psychosocial counseling. In D. L. Baker, J. L. Schuette & W. R. Uhlmann (Eds.), *Guide to genetic counseling*. New York: WileyBlackwell.

Ellington, L., Baty, B., McDonald, J., Venne, V., Musters, A., Roter, D., et al. (2006). Exploring genetic counseling communication patterns: the role of teaching and counseling approaches. *Journal of Genetic Counseling, 15*(3), 179–189.

Ellington, L., Roter, D., Dudley, W. N., Baty, B. J., Upchurch, R., Larson, S., et al. (2005). Communication analysis of BRCA1 genetic counseling. *Journal of Genetic Counseling, 14*(5), 377–386.

Elliott, R. (1986). Interpersonal Process Recall (IPR) as a psychotherapy process research method. In L. S. Greenberg & W. M. Pinsof (Eds.), *The psychotherapeutic process: A research handbook* (pp. 503–527). New York: The Guildford.

Fraser, F. C. (1974). Genetic counselling. *American Journal of Human Genetics, 26*, 636–659.

Genetic Counseling Aids. (5th ed.)(2007). South Carolina: Greenwood Genetic Centre.

Green, M. J., McInerney, A. M., Biesecker, B. B., & Fost, N. (2001). Education about genetic testing for breast cancer susceptibility: patient preferences for a computer program or genetic counselor. *American Journal of Medical Genetics, 103*(1), 24–31.

Hallowell, N., Green, J. M., Statham, H., Murton, F., & Richards, M. P. M. (1997). Recall of numerical risk estimates and counsellees' perceptions of the importance of risk information following genetic counselling for breast and ovarian cancer. *Psychology, Health and Medicine, 2*(2), 149–159.

Hallowell, N., & Murton, F. (1998). The value of written summaries of genetic consultations. *Patient Education and Counseling, 35*(1), 27–34.

Julian-Reynier, C., Welkenhuysen, M., Hagoel, L., Decruyenaere, M., & Hopwood, P. (2003). Risk communication strategies: state of the art and effectiveness in the context of cancer genetic services. *European Journal of Human Genetics, 11*(10), 725–736.

Kagan, N., & Schauble, P. G. (1969). Affect stimulation in interpersonal process recall. *Journal of Counseling Psychology, 16*(4), 309–313.

Kay, E., & Kingston, H. (2002). Feelings associated with being a carrier and characteristics of reproductive decision making in women known to be carriers of X-linked conditions. *Journal of Health Psychology, 7*(2), 169–181.

Kessler, S. (1989). Psychological aspects of genetic counselling VI. A critical review of the literature dealing with education and reproduction. *American Journal of Medical Genetics, 34*, 340–353.

Kessler, S. (1992). Process issues in genetic counseling. *Birth Defects, 28*, 1–10.

Kessler, S. (1997). Psychological aspects of genetic counselling IX: teaching and counselling. *Journal of Genetic Counseling, 6*(3), 287–295.

Lanie, A. D., Jayaratne, T. E., Sheldon, J. P., Kardia, S. L., Anderson, E. S., Feldbaum, M., et al. (2004). Exploring the public understanding of basic genetic concepts. *Journal of Genetic Counseling, 13*(4), 305–320.

Lippman-Hand, A., & Fraser, C. (1979). Genetic counselling: provision and reception of information. *American Journal of Medical Genetics, 3*, 113–127.

Lobb, E. A., Butow, P. N., Barratt, A., Meiser, B., Gaff, C., Young, M. A., et al. (2004). Communication and information-giving in high-risk breast cancer consultations: influence on patient outcomes. *British Journal of Cancer, 90*(2), 321–327.

Lobb, E. A., Butow, P., Barratt, A., Meiser, B., & Tucker, K. (2005). Differences in individual approaches: communication in the familial breast cancer consultation and the effect on patient outcomes. *Journal of Genetic Counseling, 14*(1), 43–53.

MacLeod, R., Booth, K., & Craufurd, D. (2002). Patients' perceptions of what makes genetic counselling effective: an interpretative phenomenological analysis. *Journal of Health Psychology, 7*(2), 145–156.

Mason, J. (2002). *Qualitative researching* (2nd ed.). London: SAGE Publications Ltd.

McAllister, M. (2003). Personal theories of inheritance, coping strategies, risk perception and engagement in hereditary non-polyposis colon cancer families offered genetic testing. *Clinical Genetics, 64*(3), 179–189.

McAllister, M., Payne, K., Macleod, R., Nicholls, S., Donnai, D., & Davies, L. (2008a). Patient empowerment in clinical genetics services. *Journal of Health Psychology, 13*(7), 895–905.

McAllister, M., Payne, K., MacLeod, R., Nicholls, S., Donnai, D., & Davies, L. (2008b). What process attributes of clinical genetics services could maximise patient benefits? *European Journal of Human Genetics, 16*(12), 1467–1476.

McCarthy Veach, P., Bartels, D. M., & LeRoy, B. S. (2007). Coming full circle: a reciprocal-engagement model of genetic counseling practice. *Journal of Genetic Counseling, 16*(6), 713–728.

McCarthy Veach, P., Truesdell, S. E., LeRoy, B. S., & Bartels, D. M. (1999). Client perceptions of the impact of genetic counselling: an exploratory study. *Journal of Genetic Counseling, 8*(4), 191–216.

McLeod, J. (1994). *Doing counselling research*. London: Sage.

Meiser, B., & Halliday, J. L. (2002). What is the impact of genetic counselling in women at increased risk of developing hereditary breast cancer? A meta-analytic review. *Social Science and Medicine, 54*(10), 1463–1470.

Meiser, B., Irle, J., Lobb, E., & Barlow-Stewart, K. (2008). Assessment of the content and process of genetic counseling: a critical review of empirical studies. *Journal of Genetic Counseling, 17*(5), 434–451.

Michie, S., Bron, F., Bobrow, M., & Marteau, T. (1997). Non-directiveness in genetic counseling: an empirical study. *American Journal of Human Genetics, 60*(1), 40–47.

Michie, S., & Marteau, T. (1996). Genetic Counselling: some issues of theory and practice. In T. Marteau & M. Richards (Eds.), *The troubled helix: Social and psychological implications of the new human genetics* (pp. 104–122). Cambridge: Cambridge University Press.

Murray, J., Cuckle, H., Sehmi, I., Wilson, C., & Ellis, A. (2001). Quality of written information used in down syndrome screening. *Prenatal Diagnosis, 21*(2), 138–142.

O'Cathain, A., Walters, S. J., Nicholl, J. P., Thomas, K. J., & Kirkham, M. (2002). Use of evidence based leaflets to promote informed choice in maternity care: randomised controlled trial in everyday practice. *British Medical Journal, 324*(7338), 643–646.

Pieterse, A. H., Van Dulmen, A. M., Ausems, M. G. E. M., Beemer, F. A., & Bensing, J. M. (2005). Communication in cancer genetic counselling: does it reflect counselees' previsit needs and preferences? *British Journal of Cancer, 92*(9), 1671–1678.

Resta, R., Biesecker, B. B., Bennett, R. L., Blum, S., Hahn, S. E., Strecker, M. N., et al. (2006). A new definition of genetic counseling: National Society of Genetic Counselors' Task Force Report. *Journal of Genetic Counseling, 15*(2), 77–83.

Richards, M. (1998). Lay understanding of Mendelian genetics. *Endeavour, 22*(3), 93–94.

Richards, M., & Ponder, M. (1996). Lay understanding of genetics: a test of a hypothesis. *Journal of Medical Genetics, 33*(12), 1032–1036.

Ross, K., Lakin, L., & Callaghan, P. (2000). *Teaching secondary science: Constructing meaning and developing understanding*. London: David Fulton.

Sarangi, S., Bennert, K., Howell, L., Clarke, A., Harper, P., & Gray, J. (2004). Initiation of reflective frames in counseling for Huntingtons Disease predictive testing. *Journal of Genetic Counseling, 13*(2), 135–155.

Shiloh, S., Gerad, L., & Goldman, B. (2006). Patients' information needs and decision-making processes: what can be learned from genetic counselees? *Health Psychology, 25*(2), 211–219.

Silverman, D. (2006). *Interpreting qualitative data: Methods for analysing talk, text and interaction* (3rd ed.). London: Sage.

Skirton, H. (2001). The client's perspective of genetic counseling: a grounded theory study. *Journal of Genetic Counseling, 10*(4), 311–329.

Skirton, H., & Eiser, C. (2003). Discovering and addressing the client's lay construct of genetic disease: an important aspect of genetic healthcare? *Research and Theory for Nursing Practice, 17*(4), 339–352.

Smerecnik, C. M. R., Mesters, I., Verweij, E., de Vries, N. K., & de Vries, H. (2009). A systematic review of the impact of genetic counseling on risk perception accuracy. *Journal of Genetic Counseling, 18*, 217–228.

Smith, J. A., Michie, S., Allanson, A., & Elwy, R. (2000). Certainty and uncertainty in genetic counselling: a qualitative case study. *Psychology and Health, 15*(1), 1–12.

Sorenson, J. R., Swazey, J. P., & Scotch, N. A. (1981). Reproductive pasts reproductive futures. Genetic counseling and its effectiveness. *Birth defects original article series, 17*(4), 1–192.

Stayner, B. L., & Kerzin-Storrar, L. (2004). *Genetic counselling summary letters: Patients' views and uses.* Paper presented at the European Meeting on the Psychosocial Aspects of Genetics, Munich, Germany.

Thornton, J. G., Hewison, J., Lilford, R. J., & Vail, A. (1995). A randomised trial of three methods of giving information about prenatal testing. *British Medical Journal, 311*(7013), 1127–1130.

Walter, F. M., Emery, J., Braithwaite, D., & Marteau, T. M. (2004). Lay understanding of familial risk of common chronic diseases: a systematic review and synthesis of qualitative research. *Annals of Family Medicine, 2*(6), 583–594.

Wang, C., Gonzalez, R., & Merajver, S. (2004). Assessment of genetic testing and related counselling services: current research and future directions. *Social Science and Medicine, 58*, 1427–1442.

Wellington, J. (2000). *Teaching and learning secondary science: Contemporary issues and practical approaches*. London: Routledge.

West, W., & Clark, V. (2004). Learnings from a qualitative study into counselling supervision: Listening to supervisor and supervisee. *Counselling and Psychotherapy Research, 4*(2), 20–26.

Wiseman, H. (1992). Conceptually-Based Interpersonal Process Recall (IPR) of change events — what clients tell us about our micro theory of change. In S. G. Toukmanian & D. L. Rennie (Eds.), *Psychotherapy process research: Paradigmatic and narrative approaches*. Newbury Park: Sage.