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Initiation of Reflective Frames in Counseling for Huntington's Disease Predictive Testing

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Genetic professionals and clients are likely to assign different meanings to the extended format of the counseling protocols for predictive testing. In order to facilitate informed, client-centered decisions about the possibility of predictive testing, counselors routinely use the question format to initiate what we call "reflective frames" that invite clients to discuss their feelings and encourage them to adopt introspective and self-reflective stances toward their own experience—spanning the past, the present, and the hypothetical future. We suggest that such initiations of reflective frames constitute a key element of counselors' nondirective stance, although the exact nature of their formulations can be complex and varied. Examining 24 Huntington's Disease (HD) clinic sessions involving 12 families in South Wales with the tools of discourse analysis, our focus in this paper is twofold: (i) to propose a classification of six types of reflective questions (e.g. nonspecific invites, awareness and anxiety, decision about testing, impact of result, dissemination, and other) and to examine their distribution across the various clinic appointments, and (ii) to investigate the scope of these questions in terms of temporal and social axes. We link our analysis to the current debate within the genetic-counseling profession about the merits of reflection-versus information-focused counseling styles and the need to abide by professionally warranted and institutionally embedded counseling protocols.

KEY WORDS: reflection; HD predictive testing; nondirectiveness; professional identity; genetic counseling; discourse analysis.

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INTRODUCTION

Genetic counseling is both an activity and a profession, although there are variations within and across countries. In the United Kingdom, generally speaking, genetic counselors have developed their own professional identity working alongside clinical geneticists, but both groups undertake the activity of “genetic counseling.” Discussions in clinic may address a range of related topics such as the way in which the family disorder came to attention, the possibilities for predictive genetic testing or prenatal diagnosis, surveillance to detect early signs of a disorder, or to avoid its complications, a couple’s desire to have (further) children, the type of support or treatment that can be provided for affected individuals or the responses of other family members to their genetic situation. Genetic counseling could therefore be expected to consist largely of technical information provided by the counselor and of family background and personal context provided by the client—but it is not so simple.

When examined closely, genetic counseling can be seen as a hybrid activity-type situated between mainstream medical consultation and other types of counseling or psychotherapy (Sarangi, 2000). This hybridity is manifest at the interactional level in terms of how sequences of information, explanation and advice are constantly managed between clients and counselors. Genetic counselors have to use a range of knowledge bases in their deliberations—clinical, scientific, probabilistic—while also taking into account their clients’ social and family concerns. If the client is confronting a decision about predictive testing, then the conversation is likely to address how he/she would respond to the various possible scenarios that may lie ahead. Genetic counseling thus incorporates reflective elements where counselors attempt to provide scaffolding for clients—and this typically includes the person considering the test as well as a partner or other family members—with which they can think aloud about their decision-making strategies and the possible implications associated with having a specific test result. The counseling process is thus a complex one, involving tensions of various kinds such as the balancing act genetic counselors have to undertake in giving ‘adequate’ information while assessing the consequences such information may have for future decisions—because what may appear on the surface as “information” provided by a professional can potentially be taken up by the client as direct “advice” (Peräkylä, 1995; Silverman, 1997). In addition, the professional will often be holding in their mind a conceptual model of their counseling role based on an understanding of the client’s decision-making process in the difficult context of risk for an incurable genetic disease (Soldan *et al.* 2000). The counselor may wish to assess the extent to which the client has explored the possible consequences of genetic testing, and perhaps to promote such explorations but without putting in jeopardy the client’s psychological defenses.

In this paper, we examine one aspect of the process of genetic counseling in relation to predictive genetic testing for Huntington’s Disease (HD). In this context,

it is customary for the professional to ask the client seeking a predictive test to reflect upon their likely feelings and responses, and the likely feelings and responses of others, to three possible outcomes of the counseling-plus-testing process—a favorable result, an unfavorable result, or a decision not to proceed with testing.

INTERACTIONAL MANIFESTATION OF REFLECTIVE FRAMES

A useful concept here is the notion of frame, borrowed from Goffman (1974, p. 21), to refer to the “schemata of interpretation” that enable participants to “locate, perceive, identify, and label” occurrences and events. In interaction, language functions at a metalevel to signal how what is being said should be interpreted. A related notion is “footing” which brings about changes in our framing of events: “a change in the alignment we take up to ourselves and the others present as expressed in the way we manage the production or reception of an utterance” (Goffman, 1981, p. 128). In the context of genetic counseling, counselors shift their footing—sometimes offering genetic explanations, sometimes eliciting information about family pedigree. One such footing shift constitutes the initiation of reflective frames—counselors move into the interactional role of active listener and relinquish the primary speaker slot to clients, inviting the latter to reflect on their decision-making process about predictive testing and about their mechanisms to cope with (un)favorable test results.

The reflective frame (defined as exploring the psychosocial dimension of decision making about predictive testing and its future implications) found in genetic counseling is similar to the therapeutic frame identified elsewhere, especially in psychotherapy. Client and counselor need to assume asymmetrical interactional roles with the counselor usually limiting herself to minimal back-channeling (e.g., mmh mmh, right, ok) during the client’s extended speakership. Ferrara (1994) points out that such flatly produced minimal responses allow the therapist to signal attentiveness, while withholding immediate assessments of the client’s talk, thereby creating a climate of unconditional acceptance for the client. Other interactional features of therapeutic talk are collaborative overlaps and joint turn-completions between counselor and client. Ferrara claims that these can be seen as the interactional expression of empathy. Therapeutic talk is also characterized by reflection in terms of explicit definitions of the situation or of participants’ role relationships. Turner (1972), in his study of group therapy, describes how there is a continued need to provide accounts for the question: what are we here for? All of these features can be seen in the ‘reflective frame’ discussed here (see Sarangi *et al.* 2003a, for a detailed account of our preference for adopting the term “reflective frame” in the context of genetic counseling).

Typically the clients’ framing of the question to counselors—“what would you do if it were you”—is often referred to as the “infamous question” in genetic counseling. It is very likely that whatever the counselor says in response to such a question may be heard as potential advice (Sarangi and Clarke, 2002a,b, see also

Silverman, 1997). This means that the counselor has to work hard—interactionally speaking—so as to avoid an advisory role if s/he did not want it. In our data corpus, however, we found that a much more frequent occurrence was for the counselor to pose the opposite question to clients—“What would you (the client) do in case of a particular test result?”. It is this range of questions initiated by counselors, which we refer to as “reflective frames” whereby clients are invited to offer a display of their understanding of the decision-making procedure as well as their readiness to adjust to favorable, unfavorable, or indeterminate results arising out of testing. From the genetic-counseling perspective, clients need to think through the intended and unintended consequences of having a test and do so in the clinical context of “here and now”. Questions of a reflective nature are crucial so as to ensure that the clients have gone through an informed process of reaching a decision—the counselor thus focuses on the process of the decision making rather than the decision reached (Shiloh, 1996).

METHODS

One common reason for referral for genetic counseling is a healthy client’s wish for information about their chance of developing a genetic disorder that affects other members of the family. In the pattern of service delivery provided by the Clinical Genetics service in Wales, most clients referred for genetic counseling—except for cancer genetic counseling—are visited at home by a genetic counselor or clinical nurse specialist in genetics. This enables background information about the reason for referral to be gathered as well as information about the family history and the client’s hopes and expectations of the referral. Following the home visit, there will be a preliminary discussion in clinic and then two more structured clinic appointments leading up to the test. After the test there will be a results session and then appropriate follow-up will be arranged (see Fig. 1).

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Following standard ethics committee approval, the procedure for recruitment of clients involved the genetic nurse specialist briefly introducing the background to the research project to the client at their home visit. If the client was interested in finding out more the nurse would give the client a letter of introduction (introducing the researchers and the research center), a letter of invitation (providing background on the project) and a consent form. Clients were then able to decide over a period of time whether or not they wished to participate in the project by giving written consent and thus allowing their clinic sessions to be audio-recorded. These were transcribed following standard procedure for anonymization (see Appendix for transcription conventions).

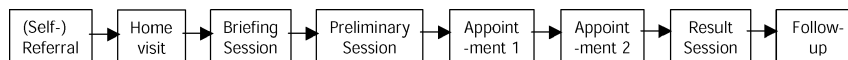


Fig. 1. Protocol of predictive testing for Huntington’s Disease.

The participants for this study were adults at risk of HD who had been referred to genetic-counseling services by their general practitioners, or in some cases self-referral. Our data consists of transcripts of audio-recordings of 50 counseling sessions for HD predictive testing. Our analysis in this paper is based on 24 sessions involving 12 clients, selected purposively to consist of 8 each of the preresult sessions (preliminary, appointment 1 and appointment 2 sessions). The clients (seven female, five male) represent different family circumstances and in most cases attended clinics with their partners (17 out of 24 sessions), or occasionally with their mothers or friends (4 out of 24 sessions). Only in three sessions the client attended alone. Two of the counselors were female and one male.

DATA ANALYSIS

We adopt a broad notion of discourse analysis, centered around the multifunctional, context-specific nature of language use both in written texts and in spoken interaction (Cameron, 2001; Drew and Heritage, 1992; Sarangi and Coulthard, 2000; Sarangi and Roberts, 1999; for a discourse analytic approach to genetic counseling, see Sarangi, 2000, 2002, in press; Sarangi *et al.*, 2003b; Sarangi and Clarke, 2002a,b). A central tenet of discourse analysis is the coding of transcripts along the lines of interactional and thematic maps (Roberts and Sarangi 2002). Whereas thematic maps are helpful in locating content areas such as risk, autonomy, nondirectiveness, etc., interactional maps are useful for identifying contextual features such as question–answer sequences, interruptions, overlaps etc. In the context of this paper, the interactional maps allowed us to identify the initiation of reflective frames accomplished through question–answer sequences.

The actual framing of the question can be varied, as can the scope of what might qualify as an adequate response. Also, the questions can be mapped onto an implicit/explicit cline in light of how specific the counselors sound in their formulation of the questions. This can be in a very explicit manner such as

G: You know that if you have the gene (.) that there will be a time when you can't *not* think about it. and really how you would—how you would cope with that.

This formulation is very much a binding one, similar to what Pomerantz (1984) calls an “extreme case formulation” whereby the client is coerced into producing self-reflection. A more implicit invitation would be the following:

G: How do you think you might feel if you definitely got the gene

It is possible that clients might see these reflective questions as unnecessary routines that are of a gatekeeping nature. This may be particularly so where clients have already made up their minds about the testing or have other things to worry about in addition to their situation of genetic risk.

FINDINGS

In what follows we offer an overview of the range of “reflective questions” asked by counselors in the three sessions leading up to the giving of the test result for HD. Table I is based on the coding of 24 HD counseling sessions—eight sessions each of preliminary interviews (PI), first appointments (A1), and second appointments (A2).

From our data corpus, a total of 286 reflective questions were coded. This included all counselor questions inviting clients to adopt reflective stances, regardless of whether a “reflective frame” was actually brought off successfully. (Occurrences of “reflective frames” brought off without counselor initiation have not been considered here.) No simple relationship between the number of questions coded and the amount of “reflective talk” produced by clients can thus be assumed. In fact, high numbers of the same type of reflective questions in one and the same session are likely to be indicative of counselors struggling to engage the client in reflection (see the extended example in Data Extract 2 section later for an illustration). It is therefore useful to consider the frequency of the six types of questions across sessions (Table II) in conjunction with the number of sessions in which a particular type of question occurred (Table III).

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As Table II shows the highest number of counselors’ questions in our data were devoted to exploring clients’ feelings of living at risk (a total of 100 questions or 35%). An equal number of counselors’ questions (a total of 59 and 60 questions, respectively, 21%) were about how the decision to have a test was reached and how a particular result might affect clients. The fact that a high amount of counselors’ questions revolves around issues of decision making—seven out of eight A1s and five out of eight A2s—suggests that counselors treat clients’ choice to proceed with testing as still in progress.

The number of reflective questions asked at each of the three stages of the counseling protocol (PI, A1, and A2) did not vary greatly (91, 106, and 89 questions, respectively). The slightly higher number of questions in A1s in our data might be accounted for by the fact that it was most often at this stage of the counseling protocol that a partner was brought to the clinic for the first time. Table II shows that the two most frequent types of questions to come up in PI were questions exploring clients’ awareness and anxiety (39) and their decision to have predictive testing (27). These two types of questions were asked in all eight Preliminary Interviews as can be seen from Table III, which shows the number of sessions in which a particular type of question occurred, regardless of how often it was asked.

In A1s, counselors continued to explore clients’ awareness and anxiety in all but one of the eight sessions coded, and with 39 questions this was the most frequent type in A1s. Questions exploring the likely impact of the test result were asked at least once in each session and altogether 26 such questions occurred in A1s. Questions regarding the decision to have testing were the third most frequent type

Table I. Six Categories of Counselors' Reflective Questions

Question type	Definition	Examples
Nonspecific invites	These are open-ended questions (mostly found at the outset or closing of a session) which invite clients to introduce their own agendas or bring up any issues that might concern them.	(a) when you came along this morning wh- what were (.) your sort of hopes or- (..) what were the issues that you wanted to raise (b) so since we last met the 6 weeks ago ehm (.) I mean I wondered if there where any issues that had come for (.) for you as a couple (.) in that time at all
Awareness and anxiety	This question type explores clients' and their families' living at risk: e.g. how aware are they of the condition in their everyday lives, how much do they worry, think and talk about it, what is their intuition about their genetic status, how do they experience the testing process, or how do they feel about experiencing the disease in other family members.	(a) um (..) so for both of you it (.) it doesn't seem an ever (.) present on the surface issue (.) or is there a conscious effort every morning that I will not think about it (b) AND AND DO YOU in yourself sort of have any idea do you think (..) yes I have got it or no I haven't or does it change or (.) do you just not think (c) so from your experience you've seen it in your Granddad and (.) and having it diagnosed in your Mum I mean (.) what- what do you think of it as a condition? do you- (.) when you think about Huntington's? (.) when you've grown [up with it]
Decision about testing	These questions explore how the decision to have testing was reached, what are the main motivations, and whether the time is right to have the test. Also, how other family members might feel about the person having the test.	(a) um? so can I ask you what's made you sort of (.) think about having the test now (b) okay (..) ::um so who who sort of have you sort of told about the sort of fact that you're coming here today or who knows about the test and that if anybody (.) your son
Impact of result	This question type is aimed at uncovering coping strategies and consequences for clients and their families if faced with a positive or negative (or indeterminate) test result.	(a) have you thought about how you would deal with the knowing "cause it's a- as you say you're not- you wouldn't expect to have any symptoms a for a long time (b) and and from the g- with regard to your father and your brother it- can you see any way that they would say if you had a bad news result they'd find that out or what impact it might have on them if they did (c) I guess in a sense what it does is, it changes- it changes the questions rather than (.) anything else. so that- (.) that instead of thinking have I got it haven't I got it (..) it's just a different set of questions you'll have to live with. (.) and I just wonder (..) for you what difference that would make

Table I. Continued

Question type	Definition	Examples
Dissemination	This question type asks about who the client might want to tell about their test result, when and how. (Note that questions asking who clients told that they were considering testing were coded under "decision about testing").	(a) right (..) .hhh one thing I- mentioned last time we talked about i::::s- is who you want to tell? (..) ehm (..) as and when you have a result. (..) .hhh it applies much more I think (..) if you got the gene than if not. but if you- have you given that any thought? (b) *yeah* (..) the last time we talked (..) I said that the two major issues for me (like) this one are issues of who you (..) would want to tell and- and had [you]- you thought about (yeah I mean) I'm- don't expect to hear the nitty-gritties of things but the practicalities of whether you .hhh want breathing space for yourselves (..) after the result or whether you would want to tell people straightaway (..) em and who (..) who you would want to know em (..) and those are the- one of the major issues for us at this stage really in terms of just thinking through
Other (residual category)	Questions coded under this category, unlike the nonspecific invites, tend to explore clients' personality and coping strategies as well as general family dynamics and future aspirations (e.g. wish to have children).	(a) so how do you deal with the stress do you cope by just sort of hitting it face on dealing with it or are you (..) bottle it up or do you talk about it (b) the other (..) issue talked that we talked a (..) a bit about last time (..) um (..) was (..) having children ((coughs)) (..) your feelings or both of your feelings about that has (..) has that still been something that you sort of been (..) talking about or something that you've been (..) thinking about

(23 questions across 7 A1 sessions)—suggesting that counselors were cautious in treating the decision to proceed with testing at this stage as still not irrevocable.

In A2s, counselors' questions continued to pursue the impact of a positive result (with 24 questions the most frequent type, occurring in seven out of eight sessions) but now also issues of dissemination (19 questions across seven out of eight A2 sessions). The other main focus of counselor questions in A2s was awareness and anxiety (22 questions in five out of eight sessions).

INTERACTIONAL MAPPING OF REFLECTIVE QUESTIONS

We recognize the limitations of the gross figures we have offered so far in the context of the complexity of the counseling process as discussed earlier.

Table II. Frequency of Types of Reflective Questions Across PI, A1, and A2

Types of questions	PI	A1	A2	All preresult questions	Percentage
Nonspecific invites	8	3	12	23	8
Awareness and anxiety	39	39	22	100	35
Decision about testing	27	23	10	60	21
Impact of result	9	26	24	59	21
Dissemination	2	8	19	29	10
Other	6	7	2	15	5
Total	91	106	89	286	100

In what follows we want to illustrate the application of this system of coding counselors' questions to an extended data extract taken from the very beginning of a second appointment (A2, i.e., the last meeting before the giving of the result). The client is a woman in her early 20s who attends the clinic with her partner and her mother-in-law. In addition to identifying the types of reflective questions (marked as =>), our analysis will focus on how counselors might formulate and reformulate reflective questions, for example, to pursue the impact of a positive test result and the awareness and anxiety of the client and family members.

DATA EXTRACT 1

01=>G: how have you been?
 02 AF: okay?
 03 ((gap 1.5 seconds silence))
 04 G: okay okay or sort of- (^^^^^^^^^^^^^^)?
 05 AF: =no I've been okay (fine)
 06=>G: is it ((having the test)) something that (.) you've chatted about just since we last met?
 07 ((gap 1 second silence))
 08 AF: [no]

Table III. Number of Sessions in Which Questions Were Asked

Types of questions	PIs (total = 8)	A1s (total = 8)	A2s (total = 8)	All preresult sessions (total = 24)
Nonspecific invites	7	3	8	18
Awareness and anxiety	8	7	5	20
Decision about testing	8	7	5	20
Impact of result	4	8	7	19
Dissemination	2	4	7	13
Other	4	4	2	10
Total	33	33	34	100

- 09 MP: [not (really)]
10 G: right
11 MP: ((starts to laugh))
12 ((everybody laughing for about 3 seconds))
13=>G: so it's not been much of an issue in the (.) [meantime] between
14 MP: [no]
15 AF: [no]
16=>G: ((quietly)) *right* (..) and in yourself how do you feel about [things]
17 AF: [okay?] I haven't really thought about this *you know*
18 (..)
19=>G: .hhh (..) we talked about a lot last time I talked about some of the (.)
the fears that you have specifically (..) ehm (..) and one of them was
the effect that the testing and having the gene would have on (..) your
relationship. (..) is that something that- that you had a chance to talk
about or has that gone (opaque)?
20 AF: .hhh we had (too much [going on])
21 MP: [what's that?]
22 ((gap 1 second silence))
23 AF: ((inbreath)).hhhh
24 ML: [how it will] affect your relationship
25 MP: well-
26 ((gap 2 seconds silence))
27 MP: hm
28 ((gap 1 second silence))
29 AF: no we haven't really talked about [it] did we?
30 MP: [no]
31 (..)
32=>G: 'cause it was a bit of a surprise to you wasn't it how strongly (..) ((name
AF)) felt that it would have an effect?
33 MP: =mmh
34 (..)
35 G: yeah
36 ((gap 1.5 seconds silence))
37=>G: .hhh and for you going into the test 'cause obviously we reach a point
where we move closer (..) is that still (..) one of the main issues for you
or have things moved inside (..) inside (of your thinking)
38 AF: I haven't thought about it (..) keep myself occupied so
39 G: mm
40 (..)
41 AF: it's the best way isn't it?
42 G: mm
43 ((gap 1.5 seconds silence))

Here we see the counselor (G) attempting to initiate the reflective frame at first with a “nonspecific invite” (turn 1). AF initially takes up the question as a conventional “how are you?” rather than as a serious inquiry about her emotional well-being since the last session. The 1.5-s pause leads G to qualify in turn 4 what “okay” means in this case, eliciting, however, only another minimal response. In turn 6, the counselor moves to an even more implicit and indirect strategy using an “awareness and anxiety” question to ask whether the test has been a topic of conversation rather than asking AF and MP directly about their current feelings and attitudes to testing. The general laughter arising in turn 12 after yet another minimal response cycle could be seen as a mutual acknowledgement by all present (client, partner, clinician, and the genetic nurse specialist) that agendas are in misalignment and the common ground to pursue the reflective frame is currently amiss. After the indirect line of questioning on how much of an issue the test has been for the couple has thus run dry, G returns to focus solely on AF (“and in *yourself*”) in turn 16, with another “awareness and anxiety” question about her feelings, but this doesn’t lead to fruition either. It is important to remember that the lack of uptake of these invitations to reflect aloud provides the counselor with much information about the client’s emotional state and sometimes about family relationships, so it would be inappropriate to regard these episodes as simply “failures”.

In turn 19 we see the counselor launching into a much longer, more elaborate turn, using a recycled discussion (about ‘what we talked about last time’) as a backdrop for a much more concrete “impact of result” question concerning how the test result might affect the clients’ relationship (see Sarangi and Clarke, 2002b, for a more in-depth discussion of how counselors use such recycling of previous, mutually known events to maintain a non-directive stance). Again, as we can see, G opts for a less confrontational and indirect line of questioning (“is that something you have had a chance to talk about?”) rather than putting the question directly (e.g. “how it will affect your relationship?”). The interactional risk/cost of this formulation is that clients respond to the indirect framing (“no we haven’t really talked about it”) rather than accomplishing the counselor’s aim to facilitate clients’ engagement with this issue. In turn 32, G asks an impact of result question, this time directed at AF’s partner (“‘cause it was a bit of a surprise to you, wasn’t it . . .?”) but this only elicits minimal confirmation from MP.

In turn 37, the counselor switches her footing back to AF, this time formulating a more direct “either–or” question (“is this still an issue for you or have things moved inside of your thinking”), to explore the client’s changing “awareness and anxiety” as she moves nearer to the time when the test result will be disclosed. However, AF’s retractive reply demonstrates that no question is escape-proof. Interestingly, AF follows G’s upgraded directness with a defensive move, inviting the counselor to agree that keeping herself occupied and avoiding reflection is “the best way,” at least for her (turn 41). It is also interesting to note that this flat-out

dismissal of reflective activity as useful is met by G with a minimal agreement token and silence, rather than being openly challenged. It seems that ultimately the preservation of interactional harmony/civility prevents the counselor, for now, from pursuing the reflective frame in a more forcefully direct fashion.

INTERACTIONAL MAPPING OF REFLECTIVE QUESTIONS ALONG TIME AND SOCIAL AXES

Further insight to the counseling process can be gained by examining the scope of counselors' reflective questions along a time axis (i.e., do questions focus exploring the past, present or future scenarios?) and a social axis (i.e., do they focus on the client requesting testing or do they aim to include the client's partner, family and wider social network?). As can be seen from the example in Data Extract 1 section, counselors may reformulate reflective questions shifting or specifying their timeframe (as in turn 37) or social orientation (as in turn 19) so as to be able to pursue the issue without appearing coercive. However, apart from such strategic shifts in footing, certain patterns in the timeframe and social orientation can be observed across the preresult sessions.

We found that in the PIs counselors' questions are predominantly aimed at exploring clients' past and present emotional situation, whereas in A1s, exploration of past and future are given near equal weight. In A2s (which is the final consultation before giving of the test result) questions about the future far outnumber those about the past. Questions orienting to the time frame of the counseling protocol itself occur three times more frequently in A2s than in PIs and A1s—an indication that A2s are highly recursive in their content (i.e., reference to what has already been talked about) serving to bring about closure to the issues raised in previous sessions.

In terms of social orientation, although the greatest number of questions in each session type focus on the person who is requesting the test, throughout the protocol the scope of counselors' questions also broadens beyond the individual client and his or her partner to include the immediate family (parents, siblings, and children). The client's wider social and family network is primarily oriented to in A2s when issues of dissemination are routinely discussed. A1s and A2s also show an increase in questions that ask clients to reflect on behalf of absent others, thinking through the feelings and possible reactions of those for whom the test result might bear relevance.

Our second extended data extract, taken from a AI, looks at attempts by a counselor to trigger reflection about the likely impact of a favorable test result indicating that such a result may not be as unproblematic in reality as it may have appeared in advance. Counselors are aware that a negative result and the resulting certainty of being free from the disease can create its own problems of identity for the client, uprooting established family dynamics and being associated with

feelings of survivor guilt. The client (AM) is middle-aged and attends the clinic with his female partner. One of AM's brothers has just been found to carry the gene mutation, and immediately prior to the start of the extract, AM has stated that if found to carry the genetic mutation he hopes that his reaction would be as positive as that of his brother. However, the counselor attempts to raise the issue of how a negative test result for AM might affect the relationship between the siblings.

DATA EXTRACT 2

- 01=>G: mm (..) SO IN A SENSE (..) it i- it's a hugely difficult question to answer in a sense very often there isn't an answer because people say well I (.) I don't know
- 02 AM: mm
- 03=>G: I don't know .hh (.) but it it's the crux of the whole issue is this (.) this point of moving from one area of uncertainty (.) to an area of certainty and moving from this (..) as you said you're a sitting on the fence sort of person (..) and (.) we're about to heave you off it in one direction or the other (.) and so it's living with (..) the side of the fence that you come down on
- 04 AM: mm
- 05=>G: and there are consequences and (.) you know I'll come to those in a minute of actually (living with a result that shows you're) clear?
- 06 AM: mm
- 07=>G: given that (..) for *you* (.) your immediate family (..) one one of them's in the aftermath of [(finding)] out he's got the gene (.) (another one) about to go =
- 08 AM: [mm]
- 09=>G: = through it (.) you know how would (they) respond if you (..) you have a clear result
- 10 AM: mm
- 11=>G: what what it means for them and how it [(might s^^^)] within the =
- 12 AM: [(^^^)]
- 13=>G: =family as well, so in a sense we're about to sort of .hhh (..) lift you off a state of of limbo?
- 14 AM: mm
- 15=>G: and er (.) you've got one foot in both camps in a sense (move you) (.) somewhere else and it is it is the crux of (.) why we () talk (..) it's just (.) I suppose beginning to try and think through (..) difference it makes (..) all the possible (..) ripples that come out from a result whichever way it goes
- 16 ((gap 2 seconds silence))

- 17 AM: yeah that's a (..) I suppose that's for the (.) fair fair point you know it it er (..) I mean f- for me I mean hh (..) if if I if if I was negative and ((brother 1's)) positive I (.) what happens with ((brother 2)) I don't know you know he starts the procedure (..) but er I mean again a question I can't really answer I mean (..) um (..) how will ((brother 1)) think about it (.) (^^^) just (.) (guess) he'll be saying 'well lucky so and so' I guess
- 18 G: mm
- 19 AM: and er (..)
- 20 G: mm
- 21 AM: I don't think I'll think any different to him
- 22 G: mm
- 23 AM: he he might just think I- I'm just you know lucky and you know I was on the right side of the fence or whatever (..) it's er (..) it's very difficult to answer (^^^^^) (..) (^^^ think so)
- 24 FP: I don't think it would alter things at all
- 25 AM: [mm
- 26 FP: [you know in y- you're quite close you you tend to think along the same lines (^^^^^^^^^) I don't think it would er (..) I would be very surprised if it did
- 27 ((gap 2 seconds silence))
- 28 AM: *mm*
- 29=>G: SO IN A SENSE I throw it in not not for an answer and not .hh (.) not as something to solve or necessarily even to go into depth but just (.) in a way for something to think about and actually go through this process

We can see here how the G uses a very extended turn in her attempt to bring off a reflective frame regarding the impact of a clear result for AM. She starts by acknowledging the difficulty of AM in general to find concrete answers to hypothetical scenarios (turn 1: "very often there isn't an answer because people say "I don't know"). In turn 3, she then takes up the image of sitting on the fence, introduced by the client at an earlier stage in the session (not shown here) to describe the move from uncertainty to certainty as one that will have an effect either way. Turn 4 presents a potential reflective response slot for AM who however chooses to give only minimal acknowledgment.

G thus continues, reformulating her point once more explicitly ("there are consequences," turn 5). Turn 9 presents another reflective "impact of result" question that is potentially there for the take up of AM, but in the absence of a contribution from him G continues to elaborate the question (turns 13 and 15). In turn 17, in her formulation of the impact of result question, G employs further images ("one foot in both camps," the ripples that come out") to reiterate the issue that any result

will bring about a change the consequences of which should be considered in advance. After a more lengthy silence (turn 16) AM starts to enter into the reflective frame, whereas at the same time asserting how difficult he finds it to offer clear answers (turns 9 and 15). FP, on the other hand, repeatedly states her conviction that a favorable or unfavorable result would not affect the relationship between AM and his brothers. In turn 29, G emphasizes more explicitly that the purpose of reflection is not so much finding answers but actually going through the process (Shiloh, 1996).

DISCUSSION

On the basis of our coded corpus and the discourse analysis of extended extracts earlier, it is possible to argue that counselors may be drawing on reflective frames to maintain their non-directive stance, which is usually taken to mean that genetic counselors should not guide clients to make specific decisions although they may—indeed, should—provide relevant information, and they may help clients to think through the possible implications of any decision they make (“scenario decision counseling”—Arnold and Winsor, 1984; Huys and Evers-Kiebcorns, 1992). Mainstream nondirectiveness literature has equated nondirectiveness with information and explanation while withholding advice. From a discourse analytic perspective, nondirectiveness can be realized through various linguistic means such as indirect speech acts (as opposed to use of imperative mood or use of modal verbs of obligation) and hedges and hypothetical formulations (often prefaced by, “if”), oblique references (e.g. “one,” “we,” “some people,” etc.). These can be realized by rhetorical means (such as repetition), and by interactional means of turn design such as active listening, the restricted use of continuers (“mmh,” “uh huh”) and the absence of agreement tokens (“that’s right,” “I agree”). As we have seen, these features which are characteristic of nondirectiveness are also features of the reflective framing of talk. Hence a reflective frame becomes a marker of non-directive counseling. In some ways this echoes Weil’s claim that the psychosocial dimension A5 should be central to non-directive genetic counseling (Weil, 2003).

Clients, however, may see such reflective frames as irrelevant to the business in hand if they have already reflected in this way elsewhere in their decision-making process. Although some clients may welcome the opportunity to engage in self-reflective talk, others may choose to resist or evade the invitation to self-reflection, usually realized in minimalist responses such as ‘I have done that’. Such resistance then could be seen as a challenge to the counselors’ understanding of their professional role. More generally, this leads us to discuss the implications such an analysis might have for professional identity and practice.

An interesting question here concerns the remit of genetic counseling sessions as an activity type, including the relevance of existing protocols and the emphasis given to genetic explanations and informed decision making. For the counselor to

“insist” upon client-reflections has the paradoxical connotations of “compulsory counseling,” and entails a rejection of the client-centered approach associated with the original, Rogerian style of non-directive counseling. Equally, it runs counter to the contemporary dominance of autonomy over beneficence in medical ethics—such practices often being labeled as paternalistic. There may be scope for an “appropriate” paternalism, but this would require a very clear justification in the context of today’s bioethics. Is it appropriately or inappropriately paternalistic for the genetic counselor to ensure to her satisfaction that her clients have thought through their decision about predictive testing?

A6

Genetic counseling is a young profession and its goals are still maturing. A landmark was achieved in 1975 with the publication of the American Society of Human Genetics’ definition of genetic counseling (ASHG 1975), but the understanding by practitioners of their role is not static. Such goals include, or have included, the population goal of reducing the burden of genetic disease, the educational goal of imparting information to clients, the affective goal of enhancing psychological adjustment, the cognitive goal of facilitating the making of decisions and the behavioral goal of promoting the uptake of recommended health care interventions. The formulation of such professional goals and their operationalization as outcome measures together give insight into professionals’ collective understanding of their roles.

This question is crucial to the professional identity of the genetic counselor. What, after all, is genetic counseling? Is it primarily an educational endeavor—the neutral provision of information? Or is it rather aimed at maintaining the client’s psychological adjustment? Or is genetic counseling intended to impose a specific method or approach on the client’s decision-making processes, or to ensure a high uptake for predictive testing? Or is it essentially defined by the client, being client-led, with a narrow sense of client satisfaction as its primary goal?

If the primary goal is educational, then the counselor will give information about the testing process and the interpretation of possible test results, but will not actively promote hypothetical–reflective talk on the part of the client. If genetic counseling sets out to be client-led, then the counselor will respect the client’s autonomy (in a narrow sense of “autonomy”); the counselor will refrain from paternalistic practices such as the active promotion of client reflection, and will only impart as much information as is actively sought by the client. On the other hand, if the primary goal is to promote the client’s psychological adjustment (Weil, 2003), then the counselor will encourage reflective talk. This may even lead the counselor to adopt a gate-keeping role, refusing or deferring a test if the client is not deemed to be sufficiently robust to cope with adverse results. One particular strategy counselors are likely to use is to seek clients’ perspectives, where possible, about the pros and cons of various decision scenarios. This is a regular practice in some genetic counseling contexts, occasionally being highly formalized (Arnold and Winsor, 1984; Huys *et al.*, 1992) but more usually being achieved discursively.

Seeking clients' perspective is a general feature of mainstream medical consultation, and Maynard (1991) draws our attention to what he calls the "perspective display series" in the assessment of children with developmental problems, at the stage of delivering a diagnosis and in the discussion of treatment options. One possible consequence, according to Maynard, is that by seeking the client's perspective early on the doctor's advice is more likely to be accepted. Another recent trend is toward the framework of shared decision making, where client participation is deemed desirable in the delivery of holistic medicine (Elwyn *et al.*, 2000).

Whether or not clients respond favourably to the genetic counselor's initiation, it is arguable that genetic counselors issue such initiations as an invitation to display an understanding of the decision-making process. The ethos of nondirectiveness works if and when clients are forthcoming with reflective talk. A particular issue for the genetic counselor, when a client evades or resists the invitation to self-reflective talk, is how to challenge the client when appropriate—addressing issues they had previously avoided or denied—but with sensitivity (Soldan *et al.*, 2000). How should the counselor respond to clients when the reasons underlying their reluctance to employ reflective talk may differ greatly? Nondirectiveness can be understood as the avoidance of systematic influence on the client leading them toward one particular decision rather than another, but this leaves great scope for influencing of their decision-making processes. This important distinction has been emphasised by Shiloh—the appropriate goal of genetic counseling being to help ensure that clients make a decision wisely rather than making a (particular) "wise" decision (Shiloh, 1996). In this spirit, the adoption of an experiential approach to genetic counseling can lead the counselor to challenge the client very directly without losing the ethos of nondirectiveness (Wolff and Jung, 1995). A challenge to the client can be forceful and direct and fully compatible with nondirectiveness; indeed, it can be argued that counselors should confront their clients with challenges in advance of predictive or other genetic tests—presenting them with relevant but unwelcome considerations, for example—so as to ensure that their decisions have been adequately thought through. And although counselors' insistence on reflection might cause clients distress, the experience of distress might be functional in that it anticipates distress at a later stage thus developing clients' coping mechanisms in advance. This means that reflective talk remains a facet of the psychosocial dimension which in turn contributes to nondirectiveness, although the initiating of reflective talk itself can be seen as being directive.

CONCLUSION

In this paper we have focused on the counselor's invitation to the client to engage in self-reflective talk about likely personal responses to possible outcomes of the counseling-plus-testing process. We have shown that in order to initiate

reflective frames, the counselors' questions might need to be formulated as rather lengthy turns to prepare the interactional ground for client introspection. Such turns are also characterized by a high amount of activity and role-defining statements that seek to locate the counselor role somewhere between educator and therapist. We have shown that the range of reflective questions within each of our six categories shows considerable variation in the degree of explicitness as well as their time and social orientation. We have illustrated the need to go beyond the mere counting of questions to gain an insight into the amount and quality of reflective talk within genetic counseling as counselors' initiation of reflective frames might not always be taken up by clients in the intended fashion.

We have shown that a clustering of particular types of reflective questions occurs at certain stages of the HD counseling protocol, indicating a professional utilization of the protocol stages to serve particular psychosocial functions (i.e., raising issues and focusing on the decision-making process in the first stages and focusing on the likely impact of the result and its dissemination in the final stages). However, in line with the principle of nondirectiveness, at the level of single sessions the manner in which the different types of questions are staged largely depends on the situation and concerns of the individual client.

The range of questions shows that the genetic counselor may encourage troubles-telling or the (re)formulation of problems, or may set a hypothetical scene, or may merely encourage the client to talk through active listening and withholding advice. If the client complies with such an invitation—if he or she enters the frame and produces reflective talk—then the genetic counselor can be satisfied. Otherwise, if the client does not adopt the reflective frame, the genetic counselor has a problem. This makes it more difficult for the counselor to achieve their goal of nondirectiveness, and can be understood as arising from a misalignment between the professional's understanding of genetic counseling and the client's expectations. The various ways in which clients might respond to counselors' hypothetical-reflective questions are explored in more detail in Sarangi et al (in preparation).

Initiation of the reflective frame by genetic counselors is tied up with genetic counseling protocols. If there are going to be two or more clinical appointments before clients are permitted to decide about predictive testing, then counselors have to orient the sessions for the production of clients' self-reflections. Even when clients have made up their minds about having the test, the counselors use reflective frames so that clients sufficiently reflect on the possible consequences, including the unintended consequences, and the disclosure of results, whether favorable or unfavorable. Clients may instead prefer to focus on such procedural matters as when and how rather than reflecting on hypothetical scenarios—thus displaying a rational mentality which is focused on the present.

There has recently been some discussion about different genetic counseling protocols (Brain *et al.*, 2003) based on different modalities of counseling: educational versus reflective. Is it more appropriate to regard these as different types of

counseling protocol or do they differ more fundamentally? Are they essentially different modes of discourse or different communicative styles? Exactly what it is that constitutes “educational” and what constitutes “reflective” at the interactional level is far from clear. Similarly, if one were to recognise the value of reflective talk in genetic counseling, it is not always clear whether mainstream genetic counselors are well equipped with therapeutic modes of communicating. In other words, a professional and analytical challenge would be to compare how a similar case (client, condition) is managed interactionally and topically by a counselor and by a therapist.

APPENDIX: TRANSCRIPTION CONVENTIONS

We have used the following simplified transcription conventions:

G: genetic counselor

N: genetic nurse

AF/M: adult female/male client

F/MP: female/male partner

MO: mother of client

ML: mother-in-law of client

(.): micropause;

(.): pauses up to one second;

(. . .): pause exceeding one second;

((gap)): indicates an interval of longer length between speaker turns and an approximation of length in seconds;

.hhh: inhalation;

CAPITAL LETTERS: indicate increased volume;

word: indicates decreased volume;

question mark [?]: rising intonation;

[text in square brackets]: overlapping speech;

((text in double round brackets)): description or anonymised information;

(text in round brackets): transcriber’s guess;

=: a continuous utterance and is used when a speaker’s lengthy utterance is broken up arbitrarily for purposes of presentation.

GLOSSARY

Back-channeling: back-channeling involves the use of minimal response tokens, such as “mm,” “yeah,” “okay,” which signals active listening on the part of the hearer without wanting to claim a speaking turn.

Collaborative overlaps: collaborative overlaps occur when two speakers talk simultaneously, often signalling mutual involvement and degrees of agreement.

Unlike interruptions, such overlaps are not normally disruptive to the smooth flow of interaction.

Footing: footing is a communicative resource available to participants to signal change in their interactional status (e.g. from primary speaker to active listener). For instance, the use of visual or verbal cues, such as gaze direction or change in voice quality can mark shifts in footing.

Frame: a frame is a way in which a speaker presents their message with cues that would assist the hearer in interpreting the message as intended in the context of the ongoing activity (e.g., joking, play-acting).

Joint turn-completions: joint turn-completions are situations where an utterance initiated by the current speaker is completed by a second speaker, often signaling shared perspectives.

Schemata of interpretation: schemata of interpretation are mental/cultural scripts that participants bring to an interaction in order to make sense of what is said.

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