

**MEDICAL WORK OR COUNSELLING WORK? A
QUALITATIVE STUDY OF GENETIC COUNSELLING**

By

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Abstract

This thesis presents a qualitative study of genetic counselling. Using a combination of semi-structured interviews and conversation analysis, it focuses on the role, function and structure of genetic counselling and on its status as medical or counselling work. Semi-structured interviews are used to ascertain genetic counsellors' accounts or perceptions of the nature of their role, their views on client expectations, and genetic counselling clients' perceptions and expectations of the same. Conversation analytic study of recorded genetic counselling consultations is used to identify whether or not they possess an overall shape and whether they appear conversationally as a counselling or a medical interaction. Rose's (1998, 1999) sociological work on the growth of the therapeutic community and the techne of 'psy' provides a framework for a discussion on the strength of the genetic counselling profession's association with a Rogerian counselling philosophy and on the potential difficulties this may bring. The questions are raised; does genetic counselling have many similarities to "personal, emotional or psychological" 'counselling' at all? And is this alliance with the counselling community either fair or possible for the professionals involved? The results were as follows. First, that the genetic counselling consultations in this corpus do not present with one unique overall shape that can encompass all interactions. Second, that the accounts of the genetic counsellors and clients in this sample, and the conversation analytic study of the recorded consultations, suggest that genetic counselling is primarily a medical-based activity and that this is what clients want. Third, that genetic counselling has a number of dissimilarities to psychotherapeutic counselling that suggest it is not so much 'counselling' as using counselling skills, and finally, that the tensions incurred in fulfilling medical-type tasks within what is ostensibly a 'counselling' role are neither fair nor practical for the professionals involved.

Contents

Chapter	Title	Page
	Introduction	1
1	Review of Genetic Counselling Literature	8
2	Review of Conversation Analytic Literature	41
3	Selection to Conclusion: Methodology and Research Process	57
4	Genetic Counselling and the Therapeutic Community – Role and Expectations	85
5	“It’s what I wanted anyway” – Client Accounts of the Genetic Counselling role and Encounter	126
6	The Genetic Counselling Interaction	146
7	Genetic Counselling as a Therapeutic Encounter: Tensions and Dilemmas	216
	Conclusion	250
	Bibliography	268
	Appendices	283

Introduction

The term “genetic counselling” was adopted by Sheldon Reed in 1947 to represent the practice of “unbiased presentation of information without guidance” (Wertz 1997:1) by those involved in the medical practice of human genetics. It was to replace the 1930s eugenic approaches and previous terms “genetic hygiene” or “genetic advice” (Wertz 1997:1). As the century progressed it became extended and further clarified into a public and professional association with the theories of Rogers’ client-centred counselling and particularly the Rogerian principle of non-directiveness (Resta 1997: 257). This is generally acknowledged to be primarily in response to the need to dissociate the human genetic profession from the abuses perpetuated by the eugenics movements in Europe and North America in the first half of this century (Clarke 1997:182). Today “genetic counsellor” is the term commonly used to represent the practitioners involved in the transmission of genetic information to families and individuals affected by genetic disorder.

This association with what Rose (1998, 1999) called the “therapeutic culture” is not, however, unique to genetic counselling. There are many health-care – and other - professions that have taken this stance and ‘counsellors’ are becoming ever more common. As Feltham declared it is indeed “a fast growing field” (1995:1). With the proliferation of ‘counselling’ into areas as diverse as hospitals, education and personnel the question might be raised in an overall sense, or for each, what does ‘counselling’ actually mean? Silverman (1997) in his work on HIV counselling suggests that, among other things, this will be influenced by the institutional context in which the activity occurs. Different institutional contexts will give counselling different meanings (1997:5). Nevertheless, he believed that definitions such as those of Feltham (1995) or the British Association for Counselling indicate that there are some defining principles that should remain, with non-directiveness and the development of self-knowledge foremost among them (1997:8). In medical settings such as HIV counselling, however, the prevalence of information-giving, health-promotion and effective advice raised for him the question whether or not this could be called ‘counselling’ at all (1997:10).

It also means that in their dealing with clients, “HIV professionals”, he states, “are pulled in two potentially different directions: health promotion... and non-directive counselling” (1997:10). This leaves practical and ethical conflicts within their role. Silverman’s work provides a template for some of the questions that are raised in this thesis. Genetic counselling frequently takes place in a medical setting, facilitated mostly by medical personnel. Genetic disorder may require medical information, diagnosis, testing or medical management. Its institutional context will have implications for its meaning and practice as a ‘counselling’ profession. Is it therefore primarily a counselling or a medical role? Is it predominantly a counselling or a medical interaction? Can it be identified with what Feltham described as “the personal, emotional or psychological kind” of counselling at all (1995: 5)? These are issues that have not so far generated much research. Central among the questions that are raised by this project therefore are the following: a) Does genetic counselling have many similarities to “personal, emotional or psychological” ‘counselling’ at all? and b) do its tasks and institutional context mean genetic counselling is primarily a counselling or a medical activity? Sub-questions within this might include what does ‘counselling’ mean in genetic counselling health-care terms and, if genetic counselling has little similarity to psychotherapeutic counselling, is it justifiable to label it ‘counselling’ at all?

Silverman’s (1997) finding that HIV counsellors are pulled in two directions may also have relevance for genetic counsellors. Non-directiveness, or the eschewing of giving clients advice or leading in the making of decisions, is central to both Rogerian counselling and to the proclaimed ethos of the genetic counselling profession. Nevertheless there is much internal controversy about its possibility or its use. The letters by Clarke (1991, 1993), for example, on the viability of non-directiveness in practice, have stimulated much debate. There are serious doubts for some about the difficulties that it causes the practitioners involved. Work by Michie, Marteau and Bobrow (1997), among others, has also raised questions about whether it is what clients want. This leads to another of the central topics of my research: what are the potential implications for the genetic counselling

profession of this association with the counselling community? What might be the practical and ethical complications that result? Given the debates about non-directiveness, this is a legitimate concern. As this thesis will demonstrate, other areas of difficulty will also be revealed. Michie, Marteau and Bobrow's (1997) study also highlights another area of potential concern, what is it that clients are wanting from their genetic counselling consultations? This is a subject around which it is acknowledged that too little is known (Michie, Marteau and Bobrow 1997: 237). Although the difficulties I encountered in accessing clients mean my information base on this is smaller than I would have liked this is another question that is raised in this research.

Before I can begin to look at these areas, however, there is another question which must be explored. That is what is the nature and function of the genetic counsellor role? It is not possible to consider whether it can be described as primarily medical or realistically defined as 'counselling' without some understanding of what the role entails. Here again this enters another area of some contention within the genetic counselling world. There is no one universally accepted definition and no clearly agreed consensus on what genetic counselling should involve. For professionals such as Clarke (1993, 1997) and Chadwick (1993) this has been an ongoing debate. As Clarke (1991, 1993) discussed its resolution has implications for service evaluation, for public policy and for what might be described as 'success'. The effectiveness of a service cannot be assessed without a corresponding understanding of what it hopes to achieve. Although an assessment of the impact and effectiveness of genetic counselling is not an achievable aim of this research in what became its final form, the information gained on the role and structure of genetic counselling, and on client expectations, might make some contribution to this debate.

To summarise therefore, major research questions of this thesis include:

1. Is genetic counselling primarily a medical or a counselling activity?
 - What is the structure and function of the genetic counsellor role?

- What is that clients are expecting and wanting from their genetic counselling consultation?
2. Does genetic counselling have many similarities to “personal, emotional or psychological” ‘counselling’ at all?
 3. What are the practical and ethical implications for genetic counselling practitioners of the genetic counselling profession’s alliance with the counselling community?

To give some broader societal context to this proliferation of counselling into so many fields I will also be considering Rose’s (1998 1999) theories of the development of the “therapeutic culture” and the techne of ‘psy’.

To achieve these goals this study approaches the area from a sociological viewpoint, using a combination of semi-structured interviews and conversation analysis. Conversation analysis has been criticised for being reluctant to move beyond the minutiae of the interaction data, qualitative methods such as interviews for being dependent on subjective views and memories. This work is methodologically innovative in combining details of actual interactions with interviews aimed at eliciting client and counsellor accounts of their expectations and perceptions. This paves the way for enhanced understanding of how expectations, role perceptions and contextual constraints are reflected in consultation behaviour. The conversation analytic study of recorded consultations allows genetic counselling to be studied as a dynamic two-way communication or interactional process. When, as Pilnick, Dingwall et al (2001: 103) suggested, “genetic counselling is defined as a communication process (Lindhout et al, 1991), and can only be fully understood when considered as such” , this is an appropriate method to use. It also goes some way to filling an acknowledged gap in genetic counselling research. As Kessler states the existing concentration on outcome studies means “the genetic counselling session remains largely a mysterious black box” and until more process research occurs “our understanding of the strengths and limitations of genetic counselling will remain truncated and fragmentary”

(1992: 6). The semi-structured interviews with genetic counsellors and clients again go some way to meeting acknowledged limitations in existing research. As Michie and Marteau state “There is little research documenting what counsellors describe themselves as doing, or what they actually do, during the counselling process” (1996: 105). This, they claim, leads to a lack of understanding of how the counselling process relates to outcome and a lack of awareness among counsellors of the things that clients would like to discuss. The study by Michie, Marteau and Bobrow (1997) indicating little is known about client expectations or the extent to which these are met also supports a need to explore what clients want.

The unique contribution of this research in its analysis of genetic counselling as a counselling or a medical interaction is also served by the combination of interviews and conversation analytic study. Existing conversation analytic studies into medical interactions give a comparative research base on which to build, and the accounts of the genetic counsellors a contextual insight into their perceptions of the ethical obligations associated with their counselling role. The interview reports on the dilemmas attached to this contribute information on the interactional tensions evident within the consultations. The differences and, at times contradictions, between what is said and what is done illuminate the level of difficulty in fulfilling their medical tasks within what is purported to be a counselling role. The ways in which the clients represent themselves in interview also gives information on the possible medical or counselling functions they are requiring of the genetic counselling staff. Finally the conversation analytic study can contribute to the debate on non-directiveness as it reveals how it is played out in the everyday practice of the genetic counsellors role.

The format of this thesis then is laid out as follows.

- Chapter one: a review of the existing genetic counselling and counselling literature that is relevant to a discussion of the research questions.
- Chapter two: a review of relevant existing conversation analytic research.

- Chapter three: a discussion of the methodology and research process as it applies to the planning and execution of this research.
- Chapters four and five: an analysis of the results of the genetic counsellor and client interviews. Looking at both types of interviews as moral accounts they are considered in terms of what the respondents are actually doing with their talk. Understanding the constructs that they present in interview will give insight into the moral framework that both genetic counsellors and clients bring to their genetic counselling and the corresponding context within which the work will take place. Chapter four considers the roles that the genetic counsellors construct for themselves in interview and how they demonstrate their moral allegiance to the Rogerian philosophy their profession professes to espouse. It also discusses how they call on conflicting responsibilities to illustrate the ensuing tensions that are characteristic of their work. Information is gained on the structure and function of the genetic counselling encounter and on the potential consequences of the association with the therapeutic community. Chapter five considers how the genetic counselling clients present themselves as responsible parents and, in line with neo-liberal discourse, autonomous agents able and wanting to make rational health decisions and to seek information for themselves. It gives information on their expectations and their perceptions of the type of encounter (medical or counselling) they believed – or wanted - their consultations to be.
- Chapters six and seven: conversation analytic study of recorded consultations. Chapter six includes a review of the structure or overall shape of the genetic counselling consultation and a discussion of whether genetic counselling is a counselling or a medical interaction. Chapter seven focuses on areas of particular relevance or difficulty for genetic counselling. These include non-directiveness, the presence of multiple clients, agenda-setting, the need to ensure informed consent, advice and uncertainty.
- Finally the thesis concludes with a conclusion covering the implications for genetic counselling practice, contributions to conversation analytic research

and a brief discussion of the implications for society of the spread of counselling and the therapeutic culture.

Chapter 1

Review of Genetic Counselling Literature

Introduction

In the introduction I outlined the need for clarification on the structure and function of the role of the genetic counsellor, whether genetic counselling is a medical or a counselling interaction and the potential consequences of being allied to the therapeutic community. I also discussed the centrality of debates around the ethos of non-directiveness within the profession itself. In this chapter I consider these topics in the light of existing literature, looking at the issues involved, the research and discussion already carried out and the questions left unanswered. I begin with the debates around the definition and role of genetic counselling and with the associated issue of client expectations. I then move on to research that is relevant for a consideration of whether genetic counselling is or is not a counselling interaction and what being called ‘counselling’ might imply. Finally I discuss the debates about non-directiveness and its possibility within the genetic counselling consultation. In view of the fact that this research involves a conversation analytic study of recorded consultations, I then go on in the following chapter to review the relevant conversation analytic literature.

The role of the genetic counsellor

One of the central aims of this thesis is to identify whether genetic counselling is primarily a counselling or a medical interaction. In order to address this it is necessary first to clarify the structure and function of the genetic counselling role. This is a subject of some debate within the profession itself. There is no universally accepted definition, and contention around some of the clinical aims and goals. This latter is reflected in the debates and arguments about how to evaluate effectiveness and measure what counts as “success”. Much existing research into genetic counselling has concentrated on outcome measures and been carried out from a social psychological standpoint. Major areas assessed include educational aspects such as knowledge acquired and information recalled (eg Rowley, Fisher et al (1981, 1983), Michie, McDonald et al (1997)), reproductive

intent and decision-making (eg Hildes et al (1993), Frets et al (1991)) and risk perception (eg Wertz et al (1986)). These are indicative of what many consider to be among the primary genetic counselling tasks, the giving of information and education about genetic disorder, discussion about testing and decisions that may effect reproductive intent and the delivery of information on heredity and risk. The use of such functions as central goals and therefore as a means of evaluating effectiveness, however, has not been without challenge. Clarke (1990, 1991) in particular has been active in promoting the view that there are real dangers to measuring 'success' by outcomes such as reproductive decisions or numbers of terminations of affected pregnancies. They lead, he believes, to the possibility of a system of "eugenics by default" (Clarke: 1990) or the abandonment of "the non-directive nature of genetic counselling in favour of a genetic public health policy" (1991: 999). Genetic counselling, he argues, needs an alternative qualitative assessment of process incorporated into the evaluation of services, and the clear separation of practice "from public health policies and goals aimed at a whole population" (1997: 175 and 181). This would then allow a focus on quality and the comparison of different models or methods of service.

His views are not shared by all, however, and his letters in the *Lancet* caused considerable dissent. Chadwick (1993), for example, while agreeing that numbers of terminations is not an acceptable outcome goal, argues that to some degree the geneticist's involvement in the incidence of genetic disease and therefore public health genetics is unavoidable. She believes that this is acceptable providing the public has the information to understand this and to make free choices (1993: 45). She described genetic counselling as including the following kinds of activity. "(a) advising adults pre-conception, of the probability of their conceiving a child suffering from genetic disorder; (b) advising adults, post-conception, and as a result of some method of fetal screening, as to whether or not a fetus is suffering from some genetic disorder; (c) alerting them to the options open to them" (1993: 43). Although she added the disclaimer that this list was not exhaustive, Clarke (1993), in his response to this article presents a significantly wider angle to the

genetic counsellor's role. He argues that Chadwick's portrayal of genetic counselling as *necessarily* being involved with the incidence of genetic disorders in the population is inaccurate because reducing the suffering caused by genetic disorders does not have to equate with reducing the births of affected individuals. He highlights a number of other genetic counselling activities including the pursuit of children's diagnoses, the development of specific therapies for genetic disorders (ie gene therapy), screening for complications, and the provision of social and practical support for affected individuals and their families. All these activities he sees as being part of the genetic counselling remit in terms of diminishing "the burden of inherited disease". (1993: 48) This accords with his declaration in his 1991 article that the primary aims of clinical genetics are to care for all those with genetic disorders both medically and socially, to support them in all their decisions and to contribute to their general welfare. (1991: 999) These aims he sees as incompatible with genetic public health policies, believing an emphasis on the eradication of genetic disease, particularly through abortion, can be deeply detrimental to the self-esteem and welfare of existing affected individuals. (1991: 999).

If we turn at this point to the question of definition Clarke's aims here are also broader than those in the comprehensive definition held by the Association of Genetic Nurses and Counsellors. This appears very similar to the definition provided by Fraser (1974) and quoted in Michie & Richards (1996: 104). The AGNC definition is as follows: genetic counselling is

"a communication process which deals with human problems associated with the occurrence, or the risk of occurrence, of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained persons to help the individual or family to [1] comprehend the medical facts, including the diagnosis, probable course of the disorder, and the available management; [2] appreciate the way heredity contributes to the disorder, and the risk of recurrence in specified relatives; [3] understand the alternatives for dealing with the risk of recurrence; [4] choose the course of action which seems to them appropriate in view of their risk, their family goals and their ethical and religious standards, and to act in accordance with that decision; and [5] make the best possible adjustment to the disorder in an affected family member and/or the risk of recurrence of that

disorder” (Ad Hoc Committee on Genetic Counseling, American Society of Human Genetics, 1975, *Am J Hum Genet.* 27:240-42).

This definition supports an image of a service committed to providing medical information on the facts and management of genetic disorder and on the heredity and risk associated with these. It also stresses the client’s choice in the making of appropriate decisions in accordance with that risk and with their ethical and family beliefs. It basically aligns with and enlarges upon the most commonly accepted definition in the genetic counselling world, that of Lindhout et al (1991), where genetic counselling is described as a communication process that deals with the occurrence, or the risk of recurrence of genetic disorder in a family.

There are a number of issues emerging from these definitions that are of relevance for the questions posed by this thesis. The first is that there is a definite emphasis on medical information, on medical tasks such as diagnosis and clinical management of genetic disorder and on the communication of risk. These are all functions associated with a medical-type role. Second, there is also an emphasis on family. This is because, as Wertz (1997) says, genetic decisions are different from other kinds of medical decisions because they involve families and not just individuals. This represents a difference to most counselling encounters where the individual client is the sole concern. Third, genetic counselling is described as a communication process. This suggests, as already stated in the introduction, that it requires a method that is able to study it as such. This has been recognised within the profession itself. There has been a call for process studies from a number of prominent practitioners including Clarke (1991, 1997), and Kessler (1992, 1997). There is an awareness that the concentration on outcome has resulted in limited knowledge on what goes on within the genetic counselling sessions and a limited understanding of the relationship between process and outcome. Having argued the case for more process research for the study of risk, agenda-setting and non-directiveness in 1992 Kessler went on to state that “unlocking the black box of genetic counselling” and revealing the actual contents of sessions is essential “if

genetic counsellors are to have a realistic basis for evaluating their work and for improving their counselling and communication skills” (1997: 467). Few studies, however, have taken up his advice so far.

Client expectations

When discussing the nature and function of the genetic counsellor’s role it is perhaps also necessary to consider what it is that clients might be wanting or expecting when they attend for their genetic counselling appointments. Taking on board client wishes and expectations is obviously of relevance if the service is to fulfil a public need. This is not an area on which a great deal of research has been done. As Michie, Marteau and Bobrow comment in the introduction to their study on the psychological impact of meeting patients’ expectations “We know little about patients’ expectations of genetic counselling, the extent to which these are met, and whether meeting expectations is associated with improved patient outcomes” (1997: 237). They also make a salient point on the genetic counselling role when they observe that what little process research has been done has found the most frequent type of interaction is the giving of factual information and that “the amount of time dealing with psychological or social issues appears to be minimal” (1997: 237). This suggests that ascertaining client’s wishes in this area would be beneficial. It also suggests that this might be another potential difference with a therapeutic counselling role.

Michie, Marteau and Bobrow used a combination of questionnaires and interviews to assess client expectations, the extent to which these are met and if meeting expectations affected client outcome. They also recorded the consultations. In a brief questionnaire/interview before the consultation they asked 131 clients what they were hoping for using a number of pre-selected categories. They then contacted them by telephone or questionnaire one to two weeks and six months later to ascertain how these hopes were met. Levels of anxiety were also measured. They found a sizeable minority did not get their expectations met in information (26%), explanation (44%), reassurance (40%), advice (39%) and help with making

decisions (27%). Reporting receiving reassurance if it was expected was associated with greater reduction in anxiety than if it was not. The same was true of receiving advice. Expecting and receiving information was associated with satisfaction -although this was not straightforward. They conclude that identifying and meeting expectations may lead to better outcomes and satisfaction levels and that if patient expectations are deemed unrealistic altering them may be more successful than simply not meeting them. Their results also add to the debate on the question of giving advice that will be considered later in this chapter. The authors believe that if 50% of the clients in this survey wanted and reported receiving advice, and this is associated with a reduction in anxiety, then more process and outcome research into this whole area is needed.

Other studies that have gained information on client expectations have included Hallowell, Murton et al (1997) and Skirton (2001). Hallowell, Murton et al used semi-structured telephone interviews pre-counselling and postal questionnaires and face-to-face interviews post-counselling to assess the information needs of women attending for familial breast or ovarian cancer. Sessions were also recorded and observed. It is noticeable that this study is confined to *information* needs rather than a free-standing agenda. Their findings indicated that although all women expected to discuss their risk of developing cancer and risk management options, 37% of women did not really know what to expect beyond this. They also found that 65% felt they would have gained more benefit if they had been adequately prepared for the amount of family history required. This lack of preparation and uncertainty over what was going to happen also meant they had been unable to formulate questions in advance. 15% however felt the consultation did not match their expectations because they thought they were going to have some sort of test or examination. This might suggest there is a need to provide more preparatory information before the counselling sessions or that expectations may, as Michie, Marteau and Bobrow found, be unrealistic. The design of Hallowell, Murton et al's study did allow analysis of what expectations were, whether they remained the same and whether they were met. However, a method

allowing analysis of the interaction in addition to the ethnographic material could have given much more information on *how* things were said. For example, it could have considered in detail the way(s) in which clients try to get their expressed expectations met or any ways in which the counsellor might encourage or prevent this. It could also have investigated any discrepancies between counsellor/client versions of what was discussed.

Skirton's (2001) study used semi-structured interviews with forty-three families to ascertain client needs and expectations of the service both before and after counselling. Using a grounded theory approach to data analysis a primary finding was that the need to find certainty for present or future was a major motivation for clients to seek counselling. This might include diagnosis or confirmation of genetic disorder and represented a means of gaining some form of perceived control. As certainty is not always something that genetic counselling can offer this may be another area where expectations might not be fulfilled.

Is genetic counselling 'counselling' at all?

In this section I move on to consider whether, given the literature discussed above on the definition and role of genetic counselling, it is appropriate to call genetic counselling 'counselling' at all. Before we can look at this it is necessary first to define what 'counselling' means. This is not necessarily simple. As Feltham (1995), a respected counsellor and author in the counselling field, states, because of the myriad uses of the term

“it is extremely difficult to define counselling in a way that fairly, unambiguously and accurately places it beyond misunderstanding and which reasonably distinguishes it from other similar activities” (1995: 6).

The following definition is to be found in the 1996 BAC Code of Ethics and Practice for Counsellors - it is perhaps not insignificant that the *new* BACP Ethical Framework for Good Practice in Counselling and Psychotherapy (2002) does not attempt to provide one. The British Association for Counselling and

Psychotherapy – the BACP - (formerly the British Association for Counselling. BAC) is Britain's leading professional counselling body.

“The overall aim of counselling is to provide an opportunity for the client to work towards living in a more satisfying and resourceful way. The term ‘counselling’ includes work with individuals, pairs or groups of people often, but not always referred to as ‘clients’. The objectives of particular counselling relationships will vary according to the client's needs. Counselling may be concerned with developmental issues, addressing and resolving specific problems, making decisions, coping with crisis, developing personal insight and knowledge, working through feelings of inner conflict or improving relationships with others. The counsellor's role is to facilitate the client's work in ways which respect the client's values, personal resources and capacity for self-determination.” (BAC Code, 3.1)

This differs somewhat from Feltham's eventual definition, taken from an earlier work by Feltham and Dryden (1993). Here counselling is defined as;

“a principled relationship characterised by the application of one or more psychological theories and a recognised set of communication skills, modified by experience, intuition and other interpersonal factors, to clients' intimate concerns, problems or aspirations. Its predominant ethos is one of facilitation rather than of advice-giving or coercion. It may be of very brief or long duration, take place in an organisational or private practice setting and may or may not overlap with practical, medical and other matters of personal welfare” (1995: 8). He goes on to clarify this further emphasising that it is a contractual relationship, sought by people in distress, that “there are many schools of counselling but all share respect for the client's autonomy” and that “counselling aims to promote healthy functioning as well as having a problem-solving focus” (1995: 9).

Although the definitions do vary there are some common themes, first that the counsellor's role is that of a *facilitator* for the client to move towards “healthy” or “more satisfying” living. Second that the client's autonomy or capacity for self-determination be respected and third, advice is not involved. Advice is directly contraindicated at a later point in the BAC code. Finally there is also a stress on counselling being a mutually defined relationship between counsellor and client.

At first glance there is not a great deal here that would automatically differentiate therapeutic counselling from genetic counselling as we have seen it described – although overall whether it is facilitating “more satisfying and resourceful” living

might be questionable. However, it might be pertinent here to note that it is specifically *Rogerian* counselling theory which genetic counselling professes to espouse. Rogers was one of the founding fathers of the Humanistic school of counselling theory and it is his person-centred approach that genetic counsellors in Britain have adopted as the basic philosophy that underpins their counselling work. The term ‘non-directiveness’ originates from his writings. Briefly Rogers believed that, for many clients, the conditions of worth with which they have been brought up lead them to have little faith in their own judgement, low self-esteem and a self-concept which may “run quite counter to its own organismic response to experience” (Thorne 1993: 32). He saw three core conditions as being central to the therapeutic relationship – empathy, congruence and unconditional positive regard. As the counsellor creates an atmosphere characterised by a warm empathy or understanding, a genuine here-and-now involvement, and an open unconditional acceptance, the client can begin to get in touch with their capacity for growth, change their self-concept and take over the direction of their lives. Humans, he believed, have an innate self-actualising tendency that can be released by the counselling relationship and it is the nature of this relationship that is the central element to the work. Rogers describes his ideas on client-centred therapy as presenting “a distinct and definable approach to the process of facilitating constructive change in the troubled person” and goes on to emphasise that the “phenomenal world” of the client was to be an essential counselling focus (in Kirschenbaum and Henderson 1990: 10). He also laid out on a practical level that it was the client who was to be responsible for setting the agenda and, as already mentioned, that non-directiveness was to be at the centre of the counsellor’s role.

This choice of theoretical base is not insignificant. Of alternative approaches to counselling the cognitive-behavioural approach is more directive and the psychoanalytic more focused around the expertise of the counsellor. Neither is as compatible with the specific need of genetic counselling for a non-directive approach that leaves the responsibility for decisions, particularly reproductive decisions, with the client. Nevertheless this choice of professional alliance is not

without implications for the genetic counselling role; not only are they to be 'counsellors' rather than solely medical personnel, there are also the above theoretical beliefs to take on board. Whether or not genetic counselling is compatible with the person-centred approach therefore is another question. The exercise of the core conditions of empathy, congruence and positive regard as an aspect of service provision can be a positive aid to enabling individuals to feel free to find and make their own conclusions. Similarly the alleged growth in psychosocial content (Spijker and ten Krood (1997)) and the supportive work highlighted particularly by Clarke, also lend themselves to the possibility of relationship-based work. However, the emphasis in person-centred counselling is strongly on client self-development and inner growth and, usually, on the establishment of a relationship over at least a number of weeks. This is not the case for a sizeable number of genetic counselling appointments. It is not uncommon for there to be only one or two sessions and quality of relationship and personal growth are rarely prioritised. In these instances it might be more appropriate, as Silverman (1997) suggested for HIV counselling, to recognise that they are using Rogerian counselling *skills*, rather than counselling as such.

Silverman (1997) compared the BAC definition of counselling with an accepted definition of HIV counselling in his consideration of whether HIV counselling can indeed be called 'counselling'. Many of his arguments can be related to genetic counselling also. He discovered two main differences that he believed distinguish HIV counselling from general counselling. First, HIV counselling is compulsory before taking an HIV test. This lack of positive choice may result in clients adopting a passive rather than an active role. Second, the blood test is a medical procedure and therefore requires informed consent to avoid legal accusations of assault. This creates a medical and legal environment where the transfer of information is usually essential. Both factors are present to some degree in genetic counselling. Clients may be obliged to come for counselling if they want tests or screening. Consultations often take place with medical staff or in a medical environment. There may be tests or procedures that require informed consent. For

these reasons the giving of information is still often an important function of the genetic counselling encounter. This clearly takes the focus from the client's "phenomenal world" (Rogers in Kirschenbaum and Henderson, 1990).

Silverman's discussion subsequently turns to the role in HIV counselling of advice and Health Promotion. He sees the slant towards education and a change in behaviour as incompatible with the counselling goals of non-directive facilitation of client decisions and believes there will always be a tension between the two. This leads him to conclude that it is more appropriate to describe HIV counsellors as using 'counselling skills' rather than 'counselling' per se. There is a parallel in this with the debates in genetic counselling on the role of 'guidance' or 'advice-giving' by medically skilled staff in a complex technological area and Clarke's anxieties about genetic public health policies. However, although there is some internal dispute on the nature of the latter, the public face of human genetic science comes down heavily on the necessity for non-directive counselling and the facilitating of clients to make their own informed decisions from their own perspective. Michie et al (1997c) quote Wertz & Fletcher (1988: 40) as recording that more than 90% of geneticists surveyed in 18 nations believed a non-directive approach was appropriate in genetic counselling. It remains to be seen how this is played out in the actual interactions.

There are arguments then both for and against the claim that genetic counselling is deserving of the term 'counselling' in its wider sense. Its public embracing of non-directiveness and the facilitating of clients to make their own decisions are consistent with the BAC and the Rogerian counselling ethic. Helping families to come to terms with genetic disease, the growing emphasis on psychosocial content and on ongoing support for those affected by genetic disorder are also compatible with person-centred style counselling work. Short-term information based genetic counselling with a heavy medical slant, however, may not be and may be more consistent with merely using counselling skills. The analysis in this thesis will provide some indication of where the balance in this corpus of data lies.

Whether genetic counselling is deserving of the term 'counselling' or not, however, a further question remains - are there other potential consequences allied with its use? Calling the service 'counselling' could have implications for both counsellors and clients in terms of their expectations and interactional behaviour. Situated as it is within a medical environment, do clients expect a 'medical' or a 'counselling' interaction? Would this make any difference? Does calling it 'counselling' influence clients' initial affective and cognitive response or make any difference to how they actually behave? Given overall commitment to non-directiveness and a Rogerian approach, do genetic counsellors see themselves as conducting primarily a counselling or a medical appointment? Are there any known interactional differences between the two? These questions are important because the expectations, content and structure of the counselling interaction may influence the impact, development and effectiveness of the counselling procedure.

In terms of client expectations not a great deal of research has been done in this area. As already discussed, Michie, Marteau and Bobrow (1997) suggest that patients do not necessarily have much idea what to expect from a genetic counselling appointment. Williams (1993), having agreed that counselling as applied to genetics implies non-directiveness and a non-judgmental approach, goes on to suggest that this does not imply psychotherapeutic counselling. She wonders whether clients may associate this with the psychiatric services and then be put off the genetic counselling process. This is therefore a question that might profit from more research.

Whether or not there are interactional differences between a counselling or a medical encounter highlights another point which it is pertinent to explore here. As well as looking at definitions of what is meant by 'counselling' it is also necessary to consider what is meant in this context by a 'medical' interaction. There is a wealth of literature which might be relevant to this point, ranging from the early work of sociologists such as Talcott Parsons (1951) to the more recent work of

conversation analysts such as Perakyla and Silverman (1995), Heath (1992) and ten Have (1991). Much of the early work “treated doctor-patient interaction as a site where doctors exercised power over patients” (Murphy and Dingwall (2003: 134)), emphasising the asymmetrical nature of the physician/patient relationship and attributing this to “an effect of institutional structures, rules or resources” (ten Have, 1991: 138). Other studies critiqued this power imbalance and made suggestions on how the perceived “doctor-centred” model of practising might be improved or made more “patient-centred” (ie Balint, 1964, Mishler 1984). This reflects an ongoing debate and indicates that, in the same way as counselling may take varied forms, there are different types of medical interaction. (I return to this point later in this section). Classical work of the early 70s concentrated on the format of the consultation as a series of tasks and stages (eg Byrne and Long, 1976), a theme which was continued with the work of later researchers such as Heath (1992). More recent work has also moved to consider how these asymmetries are collaboratively co-constructed “in and through the details of ... situated interactions” (ten Have, 1991: 138) by both doctors and patients (ten Have, 1991, Heath, 1992), acknowledging the continued presence of asymmetry but highlighting a potentially different construction. These brief summaries point to a number of the main areas on which research into what characterises medical interaction has concentrated. They are not all-inclusive but the extensive nature of existing research means it is beyond the scope of this chapter to present a more comprehensive review. I have addressed the question of what is meant here by a ‘medical’ interaction, therefore, in two ways. First by focusing on aspects of particular models that are representative of major research areas and second, by identifying a number of significant factors that have been highlighted by key studies as characteristic of medical consultations.

Two seminal works on doctor-patient interaction were conducted by Strong (1979) and Byrne and Long (1976). Strong (1979) identified a role format dominant across varied medical consultations which he called the “bureaucratic format” and Byrne and Long (1976) a six phase process around which the verbal behaviours of

2000 GP consultations were organised. Strong found his “bureaucratic format” was overwhelmingly dominant in the consultations he studied and was collaboratively created by doctors and patients. Doctors were assumed to be competent ‘experts’, committed to the individual case, and set the agenda. Patients were assumed to have no technical competence, challenged the doctor rarely and brought topics for solution not discussion. Conflict was generally avoided and both sides were usually polite. A ‘medical’ consultation for Strong then would be recognisable by asymmetry of knowledge with the doctor in the ‘expert’ role, an agenda dictated by the practitioner, a lack of conflict and topics brought by the patient for the doctor to resolve. All these factors would be collaboratively created by both parties with no dissent as to their existence. Byrne and Long (1976: 21) identified six phases that characterised GP consultations. I. The doctor establishes a relationship with the patient. II. The doctor attempts to discover the reason for the patient’s attendance. III. The doctor conducts a verbal or physical examination or both. IV. The doctor, or the doctor and the patient, consider the condition – this phase includes any diagnostic information that the doctor gives and, they found, may often be brief or absent altogether. V. Detailing of future treatment or investigation and VI termination, usually by the doctor. In 95% of the consultations they found the doctor to be in charge of the “how” as well as the “what” of the consultation. This kind of tight organisation in terms of phases devoted to specific consecutive tasks (ten Have 1991:139) has also been identified in later studies (ie Heath, 1992). The tasks involved often include what Byrne and Long describe as the “medical procedures” from the “standard medical model”, history taking, examination, diagnosis and treatment (ibid: 21). What this might suggest in terms of what might constitute a ‘medical’ encounter, therefore, is an encounter characterised by recognisable phases organised by the practitioner and perhaps centred on such “standard” medical procedures as those described above.

Another influential study into the style and format of medical interactions is that by Mishler (1984). Mishler drew attention to the fact that a recurrent feature of what he called “unremarkable interviews” was the presence of a “unit of discourse

consisting of a three-part utterance sequence: physician question- patient response- physician (assessment) next question” (1984:90). He found this unit occurred repeatedly in the form of strings of questions and answers with an asymmetrical distribution in favour of the professional. Further, the practitioner’s questions were often closed, thereby restricting the patients response. Accompanied by a disattendance to the life-contexts or situations of patients’ symptoms or problems, and pauses before the patient responds to doctor-initiated changes in topic, Mishler described this unit as representative of what he calls the “voice of medicine”. “Borrowing” from Silverman and Torode’ “notion of “voices”” (1984: 63) – where a ‘voice’ represents “the realisation in speech of underlying normative orders” (ibid: 103) - the “voice of medicine” reflects the “scientific attitude” (ibid: 104) or the biomedical model where “events are decontextualised by an appeal to abstract rules” (Silverman, 1987: 197). It is contrasted with the “voice of the lifeworld” - “dependent on the patient’s biographical situation and contextually grounded experiences” (ibid: 197). Both participants can use either voice, but Mishler’s overall finding was that doctors stay predominantly in the voice of medicine, drawing the patient into the voice of medicine in return and interrupting his/her attempts to tell their story in the voice of the lifeworld. The suggestion is that “the net effect of the physicians interruptions” is to strip away attention from the “contexts of the patient’s experience of her problems”, focusing on and isolating her “objective symptom” (Mishler, 1984: 120), and keeping their discussion within the impersonalised and decontextualised world of biomedicine. In the closing chapters of his book Mishler reveals his moral position when he goes on to discuss this reliance on the biomedical model as one that results in a practice that is both “not humane” and “ineffective” (p192). He critiques the “asymmetric power relationship” of forms of clinical practice which emphasise the voice of medicine and suggests alternative practices which enhance the voice of the lifeworld. In this way he was to become a powerful voice in the campaign for “patient empowerment” (p193) and patient-centred medicine.

The presence or predominance of strings of Question/Answer sequences with the

doctor in the Questioner role has also been a feature identified by conversation analytic studies of medical interactions. These are discussed in more detail in the following chapter. Work by Frankel (1990) and Maynard (1991), among others, has demonstrated that practitioners have privileged access to first position in such sequences. Along with the asymmetries of task and topic highlighted by ten Have (1991), this operates as a major tool for interactional control and results in a dispreference for patient-initiated questions or patient-initiated utterances in general. Although this body of work challenges the notion that interactional asymmetry in favour of the practitioner is imposed by external forces and demonstrates its co-construction by both parties, the practical effect is that sequence organisations that influence agenda control or topic initiation are generally controlled by the professional and dispreferred by the patient. Similarly work such as that by Perakyla and Silverman (1995) has demonstrated that medical settings are often characterised by a restriction in communication format or conversational role options for participants. Perakyla and Silverman's Interview Format (IW) has been shown in a number of studies to be dominant in many medical interactions and they found their HIV counselling sessions were dominated almost exclusively by this and what they described as the Information Delivery (ID) format. Both of these formats allocate to the professional the role of initiator and of "knowledgeable identity", maintaining asymmetry in terms of differential states of knowledge. The medical practitioner occupies some form of 'expert' role. As the role options of these formats are often associated with the initiation of sequences this again restricts patient's options for agenda or topic selection.

If we add, therefore, the above factors to those highlighted by Strong and Byrne and Long, we might suggest that for the purposes of this study a 'medical' encounter might be defined as one that possesses some or all of the following characteristics.

- Restrictions in the communication formats and role options present with a possible predominance of Question/Answer/Evaluation sequences with the professional in the questioner role.
- An associated asymmetry in topic and agenda initiation with control in the hands of the practitioner.
- The practitioner in the role of ‘expert’ or “knowledgeable identity”, resulting in asymmetry of tasks as well as an acknowledged superiority of professional as opposed to lay knowledge.
- The practitioner potentially controlling the “how” as well as the “what” of the consultation, instigating phases associated with specific tasks and controlling such factors as when the consultation begins and ends.
- Medical procedures such as diagnosis, treatment and examination possibly central and a phase format with some similarities to those identified by Byrne and Long.
- The ‘medical voice’ may predominate with little attention paid by the professional to aspects of the patient’s lifeworld or contextual factors.

And finally;

- An overall asymmetry in favour of the professional that is collaboratively constructed by both practitioner and patient “in and through the details of the situated interaction”. Questions are likely to be dispreferred by patients and the professional’s expertise rarely challenged.

One significant factor, however, that should be recognised in these characteristics, and indeed in all the studies described, is that they all highlight an asymmetry between doctor and patient that attributes power to the professional. They then go on to concentrate on the ways in which this has occurred. Ainsworth-Vaughn (1998), in her studies of doctor-patient communication, raises a salient point when she questions this focus and adjusts her own research to also concentrate on the ways *patients* claim power through their talk. She argues that this, and the study of medical interaction in private practice, are “understudied” topics, leaving the body of research not representative of the spectrum of medical encounters or of the

ways in which power is negotiated within the consultation. She also argues that most studies concentrate on encounters where patient and doctor do not know one another and neglect the sequential meetings of long-term relationships. Although she addresses all of these points in her studies she believes her major contribution to existing research is the focus on patient's actions and the demonstration "that patients can and do take an active part in the medical encounter" (1998: 175). She suggests that studies such as Byrne and Long emphasise the "ritualised" phases of medical interaction and neglect the conversational, and concludes that her studies indicate that medical interactions exist on "a continuum between interrogation, as described in Mishler (1984), and friendly conversation with a small amount of time devoted to satisfying medical goals" (ibid: 179). She found patients claimed power in seven ways, using linguistic devices to, for example, control topic and choose speakers or co-construct diagnoses, and physicians co-operated with them in achieving this – although she did not deny that there were also instances of physician domination. She suggests that facilitating ways of helping patients *share* power is a way forward for medical professionals. Although some aspects of her research are not directly applicable to this study in its current form – for example, the late discovery of her work means the conversation analytic study of the consultations does not include an analysis of whether patients are indeed claiming power in the ways she suggests – she does highlight some relevant points that it is worthwhile mentioning here. First, as was raised earlier in this section, there is no *one* form of medical encounter but rather a spectrum of encounters that are influenced by a mix of variables. They take place in different settings with different emphases, different participants and different relational situations. Medical consultations with long-term professional/patient relationships, for example, may have significantly different interactional characteristics to single meetings. It is not, therefore, possible to provide one definition, theme, or set of characteristics that encompasses all types of medical interaction. Second, concentrating on *physician* activities or how physician power is maintained is one-sided and neglects how patients also may be active in taking control and third, research and training which facilitates a more equal distribution of power - if this

is indeed what patients want - may be a positive way forward for the future. All these factors are informative in setting challenges and pointers for future research.

Before I conclude this section let us return to one of the questions with which we began, will the type of interaction clients or counsellors expect make any difference to how they might proceed? The collaborative and repetitive nature of the findings of many of the studies into medical interactions would suggest that it might. If they are believing it to be a medical encounter both counsellors and clients may bring strong expectations of what will happen and how to behave. Research, therefore, into client and counsellor expectations in this area would seem potentially advantageous and might be constructively used alongside process research to establish whether expectations influence behaviour within the genetic counselling session.

Non-directiveness

Non-directiveness - the refusal to lead clients in ways that might influence their decision-making in a particular direction (Clarke, 1997) - is a central ethic of Rogerian counselling and of genetic counselling as already discussed. It is a goal towards which most genetic counsellors profess to aspire. As such it is integral to definitions of their role. Its widespread espousal is generally attributed to the following factors. The contemporary dominance of the medical ethic of autonomy, and the need for protection from;

- a) Association with the abuses perpetrated by the eugenics movement
- b) Over-involvement with clients and
- c) Litigation

(Elwyn, Gray & Clarke, 2000).

It has played a crucial part in the discipline's attempt to distance itself from its eugenic past – and the strong place of the concept of autonomy in the past twenty years, particularly in medicine, has added to its prominence. Despite this, however, little research into this area has been done and as Michie, Drake and Bobrow (1994) state “The extent to which health professionals agree with or follow these

guidelines is not known” (1994: 864). Given this lack of knowledge and the fact that is such a central concept to modern genetics, considering the nature of the genetic counselling interaction without its inclusion would be an obvious omission. It is also one of the major ethical obligations of a Rogerian counselling role and as such one of the major implications of the alliance with the counselling world.

Despite the overt public support non-directiveness is currently a highly contentious subject within the profession itself. Dispute centres on three interrelated issues.

- i. Are the concepts of autonomy and non-directiveness always compatible?
- ii. Is non-directiveness possible?
- iii. Is it what clients want?

The following sections provide a brief summary of each area.

Autonomy

The principle of autonomy, say Huubers and van t'Spijker (1998), takes its underlying meaning from the work of Mill and Kant. Combining these two approaches results in the moral duty to respect the choices that people make and means both making these choices possible and at times having “a duty to support these choices directly”. (1998: 3) They believe the core position of this principle relates to the strengthening of the patient’s place in the doctor - patient relationship and the increasing awareness of patient rights. Dingwall (2002) however believes that the situation is more complex than this. He suggests that autonomy also owes some of its pre-eminence in the US and, progressively, in the UK, to its place as an ideology that is “supportive against the claims of justice and community”, does not need “an apparatus of regulation and quality assurance to guide purchasing decisions” and challenges the concept of “managed care” (20002: 168-169). It and the rise of bioethics as a whole are useful for resisting litigation and deflecting concerns with “the lack of accountability for its (*US medicine’s*) practice” (2002: 171). The most significant expression of autonomy is found in the patient’s stated right to informed consent, a right which leaves the obligation on the professional

to ensure that information is understood, believed and related to in a meaningful way. (Williams 1993: 46) Failure to achieve informed consent in a situation that requires it could be said to represent ineffective counselling.

In his discussion of the spread of what he calls the “therapeutic culture” Rose (1998, 1999) suggests the backdrop to the importance of autonomy is more subtle and pervasive. His work also indicates potential reasons why genetic counselling, along with so many health-care professions, is allying itself with the counselling community. Rose believes that the therapeutic culture and its vocabulary have expanded into “every practice addressed to human problems” (1999: 218), including hospitals, doctor’s surgeries, personnel offices, education and all types of counselling. Through the mass media the language and the underlying ethic of the ‘autonomous self’ has been spread into every home and has come to dominate the ways in which we in Western Europe and North America see and understand ourselves. The themes of collective provision, social solidarity and communal obligation have been replaced by the rationale of free choice with the self “obliged to construe a life in terms of its choices, its powers and its values”(1998: 231). Psychotherapeutic values and techniques, as already seen, are themselves geared to the pursuit of autonomy and self-growth and are therefore the ideal option for those struggling with or unable to attain these goals. They are compatible with the post-war ideals of democracy and what he calls the “advanced liberalism” of the Western world. ‘Psy’ professionals then become the obvious ones to consult when there are ‘problems’ for the individual in reaching these goals. In this way, Rose argues, politics, power and psychotherapy are inextricably linked, with therapeutic technologies of knowledge and the governing of the self serving as effective means of social control.

Transferring this ethos across to genetic counselling, clients are encouraged to order their own lives through the choices that they individually make. Their autonomy is then protected and both the state and professionals are freed from the responsibility of these choices and from making ethical decisions as to which

genetic technologies should or should not be allowed, at least in many grey areas. The values of communal and collective responsibility are then replaced by an individual philosophy resulting in an acceptance of inadequate state funding and the avoidance of suggestions of state eugenics. Clarke believes that to some extent this is opting out, arguing that a refusal to set up some criteria and a blanket adherence to the “purportedly non-directive, consumer-choice counselling”, certainly in the area of prenatal diagnosis and termination, amounts to the abdication of professional responsibility. (1991: 1000) The debate implicit in the phrase “*purportedly* non-directive” will be taken up shortly.

Wertz (1997) describes how Kessler (1997) and White (1997) challenged the assumption that non-directiveness always supports autonomy. Kessler believes that “Some practices at the core of today’s non-directiveness are actually insults to client autonomy” (1997: 1). He believes that telling clients you will support their decisions and co-opting the moral high ground does not allow them to exercise autonomy and can be highly directive. Elwyn, Gray and Clarke (2000) quote Kessler as suggesting a moderated definition of non-directiveness for genetic counselling -

“Non-directiveness describes procedures aimed at promoting the autonomy and self-directedness of the client” (2000: 3).

This retains the concept of non-directiveness but allows for the fact that informative, prescriptive or confrontational interventions made by the counsellor *can* sometimes be directive. It is what he calls ‘persuasive coercion’, a deliberate attempt to undermine autonomy by deception, threat or coercion, that remains unacceptable. (Kessler, 1997) This modified definition is necessary because the genetic counsellor cannot delegate all the counselling agenda to the client as in Rogerian psychotherapy. There is an inherent dilemma between the counsellor’s need to pass on the information needed for informed consent and Rogerian non-directiveness in terms of letting the client lead the way.

White (in Wertz, 1997) states that autonomy is not just a negative withholding but “a positive right to maximally enhanced decision-making capacity” with counsellor and client equal in the decision-making process. Individual choice should be exercised only with consideration of social consequences. Genetic decisions are different as they involve families not just individuals (Wertz 1997: 2). This view is compatible with the suggestions of Elwyn, Gray and Clarke (2000) that genetic counsellors should follow an approach called “shared decision-making”. Here the client and counsellor share information on which a decision is to be made, discuss their views and come to a joint decision, for which responsibility is to be shared. This, they claim, allows non-directiveness to be retained where appropriate but also allows the professional to give his professional opinion.

Genetic counselling in these terms becomes an activity that positively enhances client autonomy and choice by the exercise of joint negotiation, judicious use of professional knowledge and shared responsibility. Scholz (1992) believes that decision-making in genetic counselling is a complex interactional process. To assess its operation in practice then requires a means of analysing both the content and process of non-directiveness in genetic counselling as a two-way collaborative interaction. Conversation analysis is ideally suited to do this.

The possibility of non-directiveness in genetic counselling

The debates into the *possibility* of non-directiveness in genetic counselling take two main forms: is non-directiveness possible in practice; and does the structure of the genetic counselling encounter make non-directiveness unrealisable? Related back to the central topics of this thesis, if these propositions hold some truth, are the consequences of the obligation of non-directiveness imposing upon the genetic counsellors an unrealistic task?

Very few studies have attempted to study non-directiveness in practice. Michie et al's (1997) work is an exception. They asked 131 counsellees to complete a brief

pre-session questionnaire, recorded and transcribed their consultations and conducted telephone interviews one to two weeks later. Using pre-defined options counselees were asked before counselling what their hopes were, how anxious they were and their concern about each issue. After counselling they were asked to rate their satisfaction with the information they had received, how well their hopes had been met and again how anxious they were. Counsellors were asked to rate their own directiveness and the counsellee's level of concern on their specified issues. 'Directiveness' was rated by volunteer students using an adapted version of Hill's 'direct guidance' response-category item on the transcripts. Three categories were identified, advice, evaluation and reinforcement. The results showed that all sessions contained at least two 'directive' statements, there was a mean of 5.8 'advice' statements per consultation, and 75% of those who made decisions felt the counsellor had an opinion. There were no significant associations between directiveness and client satisfaction, anxiety reduction, met expectations and concern. Directiveness was related to client socio-economic status and to the *counsellor* rating the client as more concerned. The authors comment that this final point accords with a number of studies that document a mismatch between counsellor and counsellee concerns and expectations.

This study has been used by a number of writers to make different points. Bernhardt (1997) states unequivocally

“At last, here are observational data to substantiate the long-held impression that non- directive genetic counselling is impossible to achieve” (1997: 17).

She commends the use of the consultation itself as a source for studying directiveness although she points out that it is not only how things are said in the counselling session that may influence clients. What information is given or not given is also important as are the context of the discussion and the counsellor's assessment of an individual client's requirements. Along with Clarke (1991, 1997) she also believes that the offer of testing itself can be influential. Finally, she sees as especially significant the reported lack of associations between client satisfaction, met expectations and reduced anxiety with rated directiveness. This,

she says, begs the question, if non-directiveness is unimportant to clients should it be of central concern to genetic counsellors? Again this is an issue that would benefit from research.

Kessler (1997), however, disagrees and says Bernhardt misrepresents the implications of Michie et al's study. As already discussed he believes definition is the key and non-directiveness is not impossible to achieve when coercion is recognised as the core issue. Without this recognition almost every utterance could be seen as directive. Clarke (1997) differs again, criticising the method of rating directiveness and the use of predetermined expectation lists and claiming the operational definition may be misleading and may lead away from relevant issues. With Elwyn and Gray (2000: 3) he sees this approach as unable to respond to the clinical context and therefore as unable to contribute to discussions on non-directiveness with practitioners. This, however, is a vital function given its professed importance. He recommends "a more sophisticated framework of analysis" focusing on the process of genetic counselling (1997: 191). This again highlights the need for new and innovative process research such as conversation analysis (1997: 195) that can study non-directiveness as it occurs within the genetic counselling interaction.

Structural influences

Berhardt's (1997) comments on the influence of context and the offering of testing introduce the second major debate about the possibility of non-directiveness in genetic counselling. Does the structure of the genetic counselling encounter make non-directiveness unrealisable? This contention has a number of implications with regards to the capacity for individual free choice, informed consent, 'strong' or 'weak' eugenics and the possibility of eugenic outcomes.

Clarke again is a key contributor to this debate. Like Bernhardt he believes strongly that the "very context of genetic counselling" (1997: 181) influences and puts pressure on the client in relation to their reproductive decisions. The offer of

testing in itself implies a recommendation to accept it and, if abnormality is shown, to terminate the pregnancy. So, irrespective of an individual counsellor's wishes, "the Holy Grail of non-directive counselling is unattainable" (1991: 1000). Clarke argues that the existence of the tests leaves a burden of responsibility on couples that may push them to take them and then, if the fetus is abnormal, to act. This is problematic, as Shakespeare points out, because the state of technology is such that, in many disorders, "the only possible 'action' to be taken on diagnosis is.... termination of pregnancy". The alternative is *inaction* (1998: 676). This suggests a conflict with the ethic of autonomy as defined by Huubers and van't Spijker (1998); an autonomous choice requires voluntariness, alternativity and competence. If there is no real alternative option there is no autonomy. There is a paradox here as Clarke points out as *not* offering testing is also limiting choice.

Clarke (1997) also believes, with Bernhardt, that directiveness in genetic counselling is related to what information is given and the context it is given in. Information given on a condition like Down's Syndrome can be significantly different in a pre-natal than in a post-natal interview. For example, 'positive' aspects are less likely to be given prenatally than after an affected birth. There is frequently a lack of preparation for the probable guilt and depression that can follow termination or for the possibility of confusing or incidental other results from testing. Clarke acknowledges that providing information that, say, puts Down's Syndrome in a positive light may be distressing for some but claims that omitting this and therefore giving an unbalanced view in fact 'nudges' parents towards screening and termination. He argues there is no clear distinction between facts and values or between providing information and making decisions in genetic counselling. As the choice of what counts as 'fact' and what information to give is made by the counsellor, it is not therefore 'neutral' and so cannot be non-directive (1996: 185).

Both Clarke and Shakespeare also emphasise the influence of broader societal factors on decision-making within genetic counselling and the effect of genetic

technology and medical science on collective and individual social expectations. Two main societal factors are highlighted as being significant pressures on clients to select prenatal testing and termination of affected fetuses. These are inadequate welfare services and financial benefits, and social attitudes to disability. The “patent inadequacies of health and social services provision” may lead families to choose termination against their own wishes and beliefs through a fear of financial difficulties and of there being no-one to care for their offspring when they are gone (Clarke 1990: 1146). Unless services and benefits are improved this will continue to be a restrictive element on individual choice.

Social attitudes to disability are also influential. Shakespeare (1998) speaks of the difficulties of living as a disabled person in our society due to social barriers, prejudice and discrimination. He also highlights the lack of representative voice for disabled people in many political, governmental and public arenas, including genetics, and strongly advocates the need for disabled people to be involved in discussions on prenatal testing. He agrees with Clarke that these attitudes, combined with parental fears of the “supermarket syndrome” (public shunning or hostility towards obvious disability) and society’s demand for the “perfect child” “may also be a potent influence on decisions about termination” (Clarke 1990: 1146).

Both writers, however, also point out the corollary, that medical science has contributed to these attitudes through the expectation that “medical expertise will deliver a baby free from impairment or illness” and the ‘geneticisation’ of social experience (Shakespeare 1998: 666-7). Geneticists have created a ‘discourse’ that portrays “disability as personal medical tragedy”, the birth of a disabled child as “a problem best prevented” and prenatal screening as a procedure for eliminating human suffering from genetic disease - by eliminating the potential human (Shakespeare 1999: 674-5). This, coupled with the increasing availability of prenatal testing and its consequent dilemmas, has resulted in what Rothman (1986) calls ‘tentative pregnancy’ and a belief that people are ‘selfish’ if they choose to

continue with an affected gestation. This is supported by Marteau and Drake's (1995) study which found that refusing screening for Down's Syndrome was likely to lead to more 'blame' if an affected child was born, particularly among the general public, than if testing had not been offered. These factors present an implicit influence towards a culture that sees disability "as a major problem, which should be removed by almost any means necessary" (Shakespeare 1999: 673). This might indicate that genetic counselling is having a perhaps unanticipated impact on public attributing of guilt and blame that provides another push towards testing and termination of affected pregnancies. This suggests it is an area that requires further interactional research into how counsellors deal with the introduction of the different options available and how clients receive them.

If both structural and societal factors mediate against non-directiveness and influence individuals towards selective termination then there are considerable implications for the possibility of individual free choice and the concept of informed consent. Shakespeare (1998) and Clark's (1997) arguments present a strong case for suggesting that the medical ideal of individuals making free informed choices for or against testing and termination is not happening – and indeed cannot happen - in practice. Many pressures undermine the capacity for free choice and push women towards one particular option – termination of affected pregnancies. The lack of unbiased, non-directive or balanced information – or in some cases much information at all – brings into doubt the notion of *informed* consent. To be properly informed the client must receive balanced information across all options. The current shortage of resources for prenatal and genetic counselling suggests that, as prenatal genetic testing increases, this doubt can only grow. If a fundamental aim of genetic counselling is to facilitate autonomous individual choice and informed consent then, certainly for Clarke and Shakespeare, it is failing. Research into this area is therefore essential and more information is needed.

There are also implications for the question of eugenics. British genetic science uses its policies of free individual choice and informed consent as a central part of its defence against unwanted accusations of eugenics. These distinguish it from what Shakespeare calls “strong eugenics” – “population-level improvement by control of reproduction via state intervention”. Strong eugenics typified genetic practice in the 1920s and 1930s and is motivated by a social judgement that disabled people’s lives are unworthy of life and society should not have to support them (1998: 669). He suggests that current British genetic practices might fit a definition of “weak eugenics” - “promoting technologies of reproductive selection via non-coercive individual choices” and motivated by medical judgements around unacceptable suffering in disabled people’s lives (1998: 669). This suggestion in itself causes discomfort and controversy for many genetic professionals. He goes on to cite the opinion that the collective effects of many individual decisions to terminate affected pregnancies, “in a context where social and professional pressures strongly determine this outcome” (1998: 669) could well result in eugenic outcomes or the eradication of disabled people through reproductive technology. With the current trend towards more prenatal testing and cost-benefit audit, if free choice and informed consent are not happening then Shakespeare believes “weak eugenics” might have the same practical result as “strong eugenics”. If genetic science wishes to avoid accusations of ‘strong eugenics’ this is an issue and potential impact that it cannot afford to ignore.

What do clients want?

The final question around the area of non-directiveness is “is it what clients want?”. As Bernhardt points out the lack of association between rated directiveness and client satisfaction, met expectations and reduced anxiety in Michie et al’s (1997) study would suggest not. Shiloh and Saxe (1989), however, found that the more neutral the counsellor was perceived to be the higher the client thought their reproductive risk was. They suggest this may be linked to the fact that clients associate neutrality with concealing bad news. Michie, Marteau and Bobrow (1997) reported 50% of their sample wanted advice and those that got it

experienced decreased anxiety. Similarly Michie, Drake and Bobrow (1994) conclude that the evidence from other studies suggests that when facing serious threats to health patients often want guidance. They quote Somer, Mustonen and Norio's (1988) study indicating that 42% of genetic counselling clients want the counsellor's opinion about what they should do. In their conclusion they argue finding out what counselees want is a necessary first step towards "the development and evaluation of systematic approaches to counselling following detection of a fetal abnormality" (1997: 867). These studies show the inherent tension between the non-directiveness advocated by the counsellors and the tendency of clients to view them as medical 'experts' whose opinion they want. There is a need for ethnographic work that investigates client wants and expectations to be combined with research that can follow how this tension is dealt with in the interactional process.

Process Research

It has been apparent overall that there is a need – and a call - for process research to be able to adequately tackle both the questions set by this thesis and the underlying issues of current genetic counselling debates. In concluding this chapter, therefore, I consider the limited process research that has already been done. Most uses either a quantitative base or a psychological framework and only the work of Chapple, Campion and May (1997) and Chapple and May (1995) is able to use the process of communication as a topic in itself.

Interaction Analysis

Interaction Analysis Systems are a common form of process research that have been used to study consultations between patients and family doctors. These systems allocate segments or units of speech into categories. Bales for example separated speech into "12 mutually exclusive categories" including "Shows solidarity" or "Gives opinion" and Stiles coded speech into Verbal Response Modes such as disclosures or questions. Along with Roter's classification system they are summarised in Inui et al, (1982, p538-542). Kessler and Jacopini (1982)

used Bales' system to analyse a genetic counselling transcript, applying scores and categories to small sections of it. They concluded the counsellor treated the male and female clients differently and focused on giving information rather than exploring feelings and meanings. Michie and Marteau (1996) criticise this study for being unable to evaluate directiveness and for being too time consuming to generate enough data to test hypotheses (p114) but are supportive of the idea of creating a rating to measure directiveness as already seen (Michie et al,1997c). It might also be suggested that these forms of analysis draw attention away from the actual form and content of the communication process and fail to treat it as a two-way dynamic exchange.

Other process research

Kessler has also conducted process studies of a different type underpinned with a psychological framework. Kessler (1981) uses the evaluations of two separate readers to analyse one genetic counselling session in terms of illustrating 'psychological issues' (p138). He concentrates on the process rather than the content of the session, looking at style, procedure and type of interaction. He concludes that the counsellor evades affective issues and is sometimes directive. This is interesting but limited as a single study. It does illustrate how process studies may be used for training purposes. Kessler, Kessler and Ward (1984) use transcripts to discuss guilt and shame, giving suggestions as to how they might be identified and dealt with. However, again they deal predominantly with psychological issues, moving away from the actual process of interaction and leaving social and contextual issues unexplored.

The final two studies I am going to consider are by Chapple and May (1995) and Chapple, Campion and May (1997). The former used two case studies to look at the impact of genetic counselling on knowledge and family relationships and Chapple, Campion and May looked at the effect of clinical terminology. Both are useful and informative ethnographic studies involving the recording of interviews with counsellors and clients, the recording of the genetic counselling consultations.

and conversation analytic study of the data. The same data corpus is used for both, showing the advantage of the conversation analytic approach to no a-priori restricting of data collection. This allows further research to be developed into whatever is carried within the data and does not define in advance what is to be discovered nor restrict client responses to researcher selected categories.

Chapple, Campion and May's study revealed how clinical terminology could cause anxiety and confusion for clients. Client's interview comments on the language used were combined with the consultation text to map their thoughts and feelings. The use of complex medical terminology and its effect on clients can thus be monitored through the whole series of consultations and the practical implications considered. Constructive information is gained on both content and the communication process and a link formed between outcome in terms of emotion and process. In addition their work contains a good example of how a counsellor/client discrepancy in opinion can be followed through. A client expresses in interview that the diagnosis has not been explained to her. Reference to the consultation transcript shows that the consultant had in fact attempted to do so extensively. The earlier interview can then be used to track how the confusion might have begun and the consultation transcript to show how the process continued. This demonstrates how the ability to analyse the detail of what has actually occurred can add to client/counsellor ethnographic data on understanding, expectation and satisfaction.

The earlier study by Chapple and May (1995) followed similar procedures and used two particular case studies to demonstrate that genetic counselling does have an affect on family relationships in terms of guilt and blame. The transcripts showed however that these types of areas were rarely discussed in the consultation. This reveals a potential impact or effect that perhaps needs to be included by the counsellor. Their results show how a combination of interviews and CA can be used to gain information on the process and context of communication in genetic counselling. This can then serve as a training resource.

as additional information on how knowledge is given and perceived, or as an indication of the psychosocial issues raised for clients for which counsellors should be prepared.

Chapple, Campion and May's (1997) and Chapple and May's (1995) work shows the potential contribution of process and outcome studies of this type for an evaluation of the genetic counselling interaction. They highlight the advantages of using ethnographic data in combination with a means of analysing the interactional process, in this case conversation analysis, rather than using each method alone. Their work is influential in providing pointers for further research. In the following chapter I pursue the review of available literature further to illustrate how conversation analytic institutional studies can also be utilised to identify contextual aspects to the data and to provide additional constructive information to answer the central questions set by this research.

Chapter 2

Review of Conversation Analytic Literature

Introduction

The previous chapter has indicated that there are a number of acknowledged shortcomings in existing research into genetic counselling. Much existing research in this area has concentrated on outcome measures and is from a fairly simplistic, predominantly quantitative social psychological standpoint. This has been criticised for being methodologically inadequate alone (Kessler 1997) and, at least where reproductive decisions are involved, potentially eugenic (Clarke 1990 1991). It also yields little information for service development, training and refinement. Little research has been done on the ways in which the counselling *process* relates to outcomes and there is an acknowledged gap in information on what occurs within actual genetic counselling sessions (Michie and Marteau 1996). This leaves many issues unexplored and others only partially investigated. Information may be gathered, for example, on *what* is learned but not on *how*. There is also little research that is able to consider genetic counselling as a two-way communication or interactional process. This is a significant omission as “genetic counselling is defined as a communication process (Lindhout, Frets et al. 1991), and can only be fully understood when considered as such” (Pilnick, Dingwall et al. 2000). More specifically, there is indication that there is need for more information on agenda setting, topic initiation, interactional asymmetry, non-directiveness in practice, and decision-making. There is also uncertainty about what understanding clients have of the structure of the genetic counselling appointment and whether they view it as a ‘counselling’ or a ‘medical’ consultation.

Many of these criticisms can be responded to by a method that is able to take account of and analyse the *process* of genetic counselling and that is able to utilize the interaction as a resource in itself. As the studies of Chapple and May (1995) and Chapple, Campion and May (1997) indicate, the sociological method of Conversation Analysis (CA) is ideally suited for these ends. Offering the ability to consider genetic counselling as a two-way communication process and to show how the functions of genetic counselling

are achieved through the talk that occurs, analysis of the consultations used with existing CA research into both ‘ordinary’ and ‘institutional’ conversation can provide detail on most of the areas discussed. The existing body of research into the format and structure of a variety of medical encounters can also be used to facilitate analysis of whether genetic counselling is a counselling or a medical interaction.

This chapter, therefore, will use a review of existing CA literature to provide an introduction to conversation analysis as a whole and to the work on institutional data that has already been done. Beginning with a brief consideration of what CA is, it will move on to outline a number of key conclusions about ‘ordinary’ conversation before proceeding to context and to information on institutional research into medical and counselling arenas which are more specifically relevant to the topic of genetic counselling. More detail on the history and position of CA as a sociological methodology will be located in the Methodology chapter of this thesis.

What is CA?

Conversation Analysis originated in the 1960s with the work of Harvey Sacks and his compatriots Emmanuel Schegloff and (later) Gail Jefferson. Summarised in Sacks’ own words in its broadest sense, CA “is about talk. It is about the details of talk. In some sense it is about how conversation works” (Sacks 1984). Further than this however, it is about the analysis of talk as social action or as a vehicle for social action - a principle means of pursuing individual or institutional activities or goals (Drew and Heritage, 1992: 3). Schegloff defined the field of CA as follows:

“The target of its inquiries stands where talk amounts to action, where action projects consequences in a structure and texture of interaction which the talk is itself progressively embodying and realising, and where the particulars of talk inform what actions are being done and what sort of social scene is being constructed” (quoted in Peräkylä, 1995: 17)

This quotation is described by Peräkylä as encapsulating three central tenets of CA research. Talk amounts to action, the actions accomplished through talk are structurally organised and within the minutiae of the talk itself participants create an intersubjective understanding of what it is attempting to achieve.

CA then is looking at how social action is accomplished in and through talk-in-interaction and at how these actions are organised through ‘utterances’ – units of talk – and sequences of utterances which proceed in a commonly understood and orderly pattern. A pattern that is clearly but implicitly understood and shared in by all the participants involved. Sacks was intensely interested in the existence of this “order at all points” (Sacks, 1984: 22) and held it to be so pervasive that “it would be extremely hard *not* to find it, no matter how or where we looked”. (Sacks quoted Silverman, 1998: 59). He believed all naturally occurring conversation to be a rich resource for locating the social organisation through which people communicate and an excellent subject for sociological study. For CA this has meant a prime focus on this orderliness and on how this orderliness is locally produced by the interactants themselves. In summary, therefore, CA can be described, to quote Heritage, (1988) as

“..an approach to investigating the normative structures of reasoning which are involved in understanding and producing courses of intelligible interaction. The objective is to describe the procedures by which speakers produce their own behaviour and understand and deal with the behaviour of others” (1988: 128).

Key features of the structural organisation of interaction

Conversation analytic studies have demonstrated many practices or ‘rules’ that govern ‘ordinary conversation’ and are common to almost all talk. Amongst the most fundamental and essential to a basic understanding of CA’s analytic structure are Sack’s features of turn-taking and sequence organisation. These are summarised below.

1. Participants talk in turn, one at a time and speaker change recurs with minimal gap and minimal overlap at transition-relevance places – points in the conversation where a turn or its ‘action’ may be judged to be complete. This is locally managed and achieved on a turn-by-turn basis by the interactants themselves (ten Have, 1999: 111-112).
2. Talk is sequentially organised where each utterance may be expected to both refer back to the one before and forward to the next one. This can be particularly seen in adjacency pairs where given a first part, a second is required, for example a question requires an answer (although there are ‘acceptable’ ways such as ‘insertion sequences’ in which this can be delayed) (ten Have, 1999: 113-114). Questions and answers may at times

be given one after another in 'chains'. Control is retained by one party through the requirement for a second 'pair' response and the completed answer then giving the floor back to the questioner.

3. These two conversational features are 'normative'- deviation from them is usually met with some kind of sanction or requirement to account for why they have not been adhered to (Heritage, 1997: 162, Peräkylä, 1995: 20). Some kind of 'repair' is then necessary (ten Have, 1999: 116).

Heritage (1997) discusses how these core facts about sequences of actions are linked with context and meaning as a major underlying part of conversation analytic theory. Social context, he says, "is a dynamically created thing that is expressed in and through the sequential organisation of interaction" (p162). He goes on to describe how this is illustrated as follows. First the addressing of participants to preceding talk shows that talk is "context-shaped". Second, the projection into the next utterances with its potential requirement for a next action creates (or renews) "a context for the next person's talk" and third, participants' orientation to this in their next action and through the use of repair demonstrates mutual understanding of a "sequential architecture of intersubjectivity". He also discusses how these same assumptions on context can be extended to the study of institutions. Starting from the view that 'context' is both a project and a product of participants' actions CA then moves on to assume that

"it is fundamentally through interaction that context is built, invoked and managed, and that it is through interaction that institutional imperatives originating from outside the interaction are evidenced and made real and enforceable for the participants." (Heritage, 1997: 163).

So, the task of CA is to show how this happens – how, for my research, the counsellors and counsellees build the context of genetic counselling in and through their talk and how they construct their interaction together as a genetic counselling consultation.

It is CA's body of work into the study of institutions that is of particular relevance for research into medical or counselling arenas. Using the information gained from 'ordinary' talk-in-interaction as its baseline or 'benchmark' there is a steadily growing body of research into how "particular

institutions are enacted and lived through as accountable patterns of meaning, inference and action” (Drew and Heritage, 1992: 5). In other words the institutional talk programme involves research into how talk and forms of talk can be seen to be instrumental in creating and supporting the specific contextual character of any particular institutional setting. Three main features have been identified that characterise institutional talk (Drew and Heritage, 1992: 22). i) Institutional interaction often involves an orientation to specific goals that are tied to the particular institutional identities (ie doctor and patient). ii) There are often special constraints on what participants are allowed to say or discuss linked with these roles and goals. And iii) Institutional talk may be associated with inferential frameworks and procedures that are specific to that institution - so some words/phrases/actions etc may be interpreted or understood in a particular way because of the setting in which they occur. These features create a unique ‘fingerprint’ for each institutional setting consisting of “a set of interactional practices differentiating each form both from other institutional forms and from the baseline of mundane conversational interaction itself”(Heritage and Greatbatch, 1991: 95-6). These differences often take the form of *reductions* of the range of conversational options and *specializations* and *respecifications* of the practices that remain. Identifying and describing this ‘fingerprint’ can provide an in-depth understanding of how a particular institution, in our case a genetic counselling unit, operates in and through the interactional processes of those involved.

Many of the earlier institutional studies were into formal settings such as courtrooms and classrooms where turn-taking is rigidly ordered and departures from this order overtly sanctioned, (eg Atkinson and Drew 1979), but it is the work into less formal interactional settings that is more pertinent for this research. The turn-taking procedures characteristic of these settings – described by Heritage and Greatbatch (1991) as conversational or quasi-conversational – have been found to be less inflexible and not as easy to map out. Nevertheless much useful work has been done. Relevant studies have been conducted in doctor/patient interactions (eg Frankel 1990, Heath 1992) in HIV and AIDS counselling (Peräkylä 1995, Silverman 1997), in health visitor/mother dyads (Heritage and Sefi 1992), in pharmacy interactions (Pilnick 1998), in

psychiatric work (Bergmann 1992) and in a number of other medical or counselling type settings. Their conclusions and observations have been wide-ranging and encompass a variety of interactional procedures such as the use of turn design or sequential organisation like adjacency pairs (in particular questions and answers). A number of these studies have suggested that two key interrelated areas in which medical or counselling data differ from ‘ordinary’ conversation is in aspects of interactional asymmetry and in what Peräkylä and Silverman (1991) call ‘communication format’ – types of conversational role. These are effectively displayed in restrictions or reductions in the interactional turn-taking or role options available to the participants, particularly to the patient or client. As these aspects may be of significant importance for areas such as agenda setting or topic initiation which have already been highlighted as of potential relevance to genetic counselling, they will be summarised here.

Interactional Asymmetry

“Traditionally”, states ten Have, “the asymmetry of doctor-patient interaction was considered as an effect of institutional structures, rules or resources” (1991: 138). The acknowledged difference in power status in favour of the doctor has been posited as being effectively “imposed” on participants by external structural forces (Maynard 1991). Communication was only considered “as a by-product of these overarching societal structures of power and authority” (Pilnick, 1998: 30). In recent years however, CA studies into how asymmetry is locally produced in and through the details of the interaction have challenged these assumptions and shown them to be essentially flawed. The prevailing evidence from CA research into doctor (or other practitioner/patient interaction suggests that asymmetry is co-constructed and *interactionally achieved* by *both* parties (cf Maynard 1991, ten Have 1991, Pilnick 1998). Rather than being structurally imposed or the “automatic effect of institutional forms” (ten Have, 1991: 149) it is locally produced and collaboratively constituted by both doctor and patient throughout the consultation. Although the resulting asymmetry gives interactional dominance to practitioners, in the ways in which they conduct and orient themselves patients “reveal a deep sensitivity” (Heath, 1992: 261) to preserving this asymmetry and towards not challenging the notion of the superiority of

professional as opposed to lay knowledge. Even in the face of conflicting opinions the practitioner's status as 'medical expert' is maintained.

However, despite this co-construction, this interactional asymmetry nevertheless means practitioners effectively dominate turn-taking design and sequential organisation in medical settings. Ten Have (1991) suggests that there are two kinds of asymmetry in doctor/patient interaction – asymmetry of topic in that it is the patient's and not the doctor's health that is under investigation and, associated with this, a corresponding asymmetry of tasks in the encounter. It is this asymmetry of *tasks* that he believes “involves quite “natural” interactional dominance by the physician” (p140) as he/she finds out the problem, investigates and provides diagnosis or treatment. Much of the work into doctor/patient asymmetry has highlighted the practitioner's privileged access to first position in sequences, particularly question/answer sequences, as being a major tool for interactional control. Maynard 1991, Frankel 1990 and ten Have 1991 have all produced detailed accounts of how practitioners' control in this way is a dominant feature in medical interviews and leads to a dispreference for patient-initiated questions and patient initiated utterances in general. Where patients *do* initiate questions (less than 1% of the time in Frankel's study), they are usually marked by some kind of sequential modification or preceding condition such as 'announcements' on the part of the practitioner (Frankel 1990). Maynard suggests these are all ways in which patients are demonstrating their sensitivity

“to the interactional constraints of the encounter, namely, the distribution of speaker rights and obligations (physicians initiate sequences and topics) and utterance type in relation to the speaker (physicians ask questions – patients respond)” (Maynard 1991:232).

Although all three authors stress again the voluntary and co-constructed nature of this 'sensitivity', these constraints have the practical effect that sequence organisations like questions and answers that influence agenda control are usually initiated by the medical practitioner and 'disprefered' by the patient (Frankel 1990). To quote Maynard once more, doctors ask more questions than patients, interrupt patients more often and control topical development (p456).

These examples give an indication of how CA's work into the creation of asymmetry can be of practical use in the assessment of topic initiation or agenda selection. They also demonstrate how the institutional identity of medical interviews can be seen in the restriction of turn-taking and sequence organisation options available to patients. Further work such as that by Pilnick (1998) has gone on to develop and refine this theme by illustrating how factors such as long-term relationship and enhanced patient knowledge can alter the nature of this asymmetry, although its basic direction and co-constructed existence still remains.

Communication Format

Peräkylä and Silverman (1995) in their studies of HIV counselling sessions concluded that these sessions differed from 'ordinary' conversation in that they were almost totally restricted to two sets of "locally managed conversational roles" (p629) – Questioner and Answerer, Speaker and Recipient. They labelled these persistent sets of roles the Interview format (IW) and the Information Delivery format (ID), with the counsellor predominantly functioning as Questioner and Speaker and the client as Answerer and Recipient. The Interview format basically consists of a chain of questions directed by the counsellor and answered by the patient - following the obligations of 'adjacency pairs' as described earlier. Peräkylä and Silverman are at pains to point out, however, that these are not formally determined and either party could terminate the chain at the end of each pair. Once again both parties locally and collaboratively produce its continuation. The same is true of the Information Delivery format where the counsellor produces 'multi-unit' turns of talk giving information or sometimes advice. They observe that these long turns appear far less 'problematic' in counselling sessions than in ordinary conversation – they do not need as much 'floor-holding' activity in order to maintain or justify them. Both of these formats give the counsellor the role of initiator and of 'knowledgeable identity'- holding asymmetry in terms of differential states of knowledge. There are deviations from these formats during the sessions but where they occur they are usually brief, 'marked' in some way as exceptional and still orient to the counsellor as knowledgeable.

These conclusions are consistent with the other studies into medical consultations already discussed, where the interview-type interaction has been seen to be the dominant format. They indicate that the institutional identity of medical settings can be demonstrated in a reduction of role options as well as in turn-taking or sequence organisation. The association of these role options with the initiation of sequences again has the effect of restricting the patient's opportunities for influencing agenda selection and topic initiation.

Although the IW format is one of the major formats found by Peräkylä and Silverman, the equal dominance of the ID format in the counselling sessions might perhaps suggest that there could be some structural distinction between HIV counselling and doctor/patient interactions such as the GP consultations studied by Heath (1992). (Heath's results showed that the giving of diagnostic information is often very brief). This may be linked to the need to accomplish the specific tasks of each interaction – HIV counsellors, as Silverman (1997) points out, are legally required to ensure informed consent before testing. Or it could be an indication that *counselling* interactions have a different structure to *medical* interactions. As already discussed in chapter one, understanding whether clients view genetic counselling as a medical or a counselling interaction is potentially a very significant topic. Identifying the nature of its interactional structure could well be an important resource in its investigation.

In addition to the work on asymmetry and communication format there are a number of other areas of CA research which are relevant for an analysis of the process of genetic counselling. Their significance lies either in terms of their potential similarity of function or of format. These include how advice and information are given and received, how professionals deal with the giving of 'bad news' and professional caution or neutralism. To give an indication of their connection the following section will briefly summarise one or two major texts or findings in each area.

The Giving of Bad News

Two key texts in this area are those by Maynard (1991, 1992) on the perspective-display series (pds) in the delivery of diagnostic news. Maynard

illustrates how in delivering bad news clinicians use different forms of interactional structuring to “maximise the possibility for presenting clinical findings as in agreement with recipient’s views” (1991: 165). By avoiding “direct pronouncing” and co-implicating the recipient’s perspective in an “interactionally organised manner”, the clinician is able to make the diagnosis “a joint activity” on which both parties’ views converge. They do point out, however, that this is usually based on the clinical position (1992: 332-337). The pds is a common device used in medical dialogue to preserve this unity. Maynard describes it as schematically taking three turns: First, the clinician’s opinion query or perspective-display invitation. Here the clinician elicits the client or parent’s perspective on their child. Second, the recipients reply or assessment. The parent delivers their view. Third, the clinician’s report and assessment. The clinician draws in the parent’s perspective and formulates or reformulates his diagnosis in order to present it as a jointly arrived at decision. This can be simple in format where the parent’s views converge with his own or more complicated where the clinician has to work to confirm then upgrade and elaborate the parent’s views to achieve a new diagnosis as compatible with his own as possible. If serious disparity exists this may involve engaging in “persuasive devices” such as converting and identifying (1992: 334).

The Giving and Receiving of Advice and Information

Two major works in this area are Jefferson and Lee’s (1992) study on the rejection of advice in “troubles talk” and Heritage and Sefi’s (1992) account of the delivery of advice by Health Visitors. Jefferson and Lee began by looking at how ‘troubles’ are talked about in ordinary interaction. Their study resulted in the following findings. Although not strictly regulated there was some overall shape to many of the conversations which could constitute a “Troubles-telling”. There were also two categories to which the participants were orienting – a Troubles Teller and a “properly aligned” Troubles Recipient (1992: 522). Found together in the appropriate positions these might constitute a Troubles-Telling Sequence. Departures from the sequence occur when the two participants are misaligned, for example, the recipient does not take up the ‘role’ of Troubles Recipient (interactional asynchrony), when it is another activity such as an absence from work excuse rather than a Troubles-telling, or

when the trouble becomes a source of dispute. This latter frequently occurs after the giving of advice especially if this is placed early in the telling. Advice given later after a troubles-receipt is more likely to be accepted. Their conclusion, confirmed by further study of what they call service encounters, is that if advice is given too early this puts the recipient into the role of Advice giver and the Teller into the role of Advice Recipient – not what they wanted. The advice will then be rejected and dispute may occur. If the initiatory participant requires a service encounter the reverse may be true – a lack of advice or recipient behaviour as Advice Giver may lead to confusion or dispute. So, when wanting advice, ‘affiliation’ or troubles recipient interaction is rejected and when wanting to tell of a trouble early advice or a lack of emotional reciprocity is rejected. This information is potentially very useful in indicating what service users may require in circumstances such as emergency calls, social services or maybe counselling of various kinds. It also indicates that ‘mistakes’, disputes or the rejection of advice may occur when the respective role requirements are not correctly read or taken up.

Garcia and Parmer (1999) discuss one such set of ‘mistakes’ in a 911 call which was to lead to the failure to dispatch urgently needed assistance for two fatally wounded police officers. They use findings from previous CA studies into emergency calls to shed light on how this occurred and to illustrate the importance of both the social, physical and temporal contexts and of the immediate *sequential* context in the construction of this particular call. They discuss how doubt and disbelief is an integral part of a call-takers role and “how the credibility of a caller’s claims is a) due to the interactional context within which it occurs and is b) collaboratively created by the actions of both participants” (1999: 298). Media reports of the event allocated blame largely with the call-taker but their representations of the content of the call ignored the sequential order of many of the utterances and the lack of understanding by the call-taker at the time. Garcia and Parmer show how, although the call-taker does make ‘mistakes’, the caller also fails to fulfil the interactional ‘activities’ described by Zimmerman as being required of a caller within a 911 call. In this way, they argue, he contributes to the miscommunication and mistrust that results in the failure to send help. They go on to conclude that this conversation

analytic study of the interaction has been of use in demonstrating how both participants failed to use the procedures available from ordinary conversation to establish the trust necessary to correctly action the call.

Heritage and Sefi's (1992) study into the acceptance or rejection of advice in health visiting is also illuminating. Their findings indicate that health visitors give advice "explicitly, authoritatively and in so decided a fashion as to project their relative expertise" (1992: 369). They initiate the vast majority of advice giving sequences without clear indication of their requirement by the mother (mothers initiate only 10% of advice sequences). This is not necessarily surprising as advice-giving is seen as part of their role. However, as Health Visitors are perceived as potentially standing in judgement over the first-time mother's role as competent carers, the mothers' responses often reflect a reluctance to openly accept this advice. They receive the advice in three ways. With marked acknowledgements, acknowledging the information specifically as informative advice. With unmarked acknowledgements, avoiding openly acknowledging the information as informative or overtly accepting it. Typical of such responses are continuers such as "mmhm, yeh, that's right". With assertions of knowledge or competence, resisting its receipt by asserting they already know or are acting on the information given. The predominant format of advice reception comes in the form of unmarked acknowledgements, defined by Heritage and Sefi as 'passive resistance'. They claim that as much as three-quarters of all HV advice is passively resisted. This avoids overt rejection and disagreement but also avoids the possibility of the mother appearing incompetent. This might be said, however, to be an external interpretation of the meaning and purpose of unmarked acknowledgements rather than being directly observable from the interactional data.

The findings of Silverman (1997) are broadly in line with those of Heritage and Sefi (1992). He found the majority of advice sequences were initiated by the counsellors without being preceded by a "problem-indicative response" (Silverman, 1997: 125), and received mostly unmarked acknowledgement and little client uptake. In those sequences where advice emerges from a client request or where a step-by-step approach was used, however, obvious client

uptake predominates. Where advice is resisted, it is mostly through silence or unmarked acknowledgement with little overt rejection. The outright rejections that do exist are marked as interactionally dispreferred. In these ways, suggests Silverman, social solidarity is maintained and both participants collaboratively construct the talk to minimise disagreement and manage any conflicts that do emerge (1997: 136-139). In his final chapter on advice-giving Silverman moves on from Heritage and Sefi's work to analyse how HIV counsellors overcome some of the difficulties of delivering personalised advice by 'concealing' it as non-personalised Information Delivery. He notes that their encounters differ from health visiting encounters in two ways. First, although advice based on clients' questions is more likely to generate marked acknowledgement, the strength of uptake varies, and second, HIV counsellors may create ambiguity by using an 'institutional' or 'passive' voice in advice-giving sequences (ie "we" rather than "I" or "The preference is.." rather than "I would recommend"). He goes on to describe how this ambiguity can be utilised to interactionally stabilise the advice-giving sequence by packaging the advice as information delivery. This then requires only minimal response tokens to allow continuation and avoids interactional misalignment and personalising the delicate issues involved in discussing sexual behaviour (ibid, 1997: 154-181).

All of these studies indicate how CA research can yield information on the process of giving and receiving advice or information. Silverman also points out that even where advice is *not* considered part of the counselling remit, this work is of relevance in terms of invoking client involvement and enabling client-centred counselling. The studies also suggest how important it is in the delivery of an interactional 'service', whether it is in health visiting, counselling, emergency call department or whatever, that the professional is clear on the role and function required by the *client* if the service is to be given effectively. The rejection of advice when given in interactionally inappropriate places or when unsought is also significant. It highlights the relevance of work into the expectations and requirements of genetic counselling clients in terms of advice, information and the outworking of non-directiveness in practice.

Professional Caution and Neutralism

The CA work on professional caution and neutralism may have significant relevance for a study of non-directiveness in genetic counselling. Neutrality is a cause of concern for a number of professionals including doctors, court officials, news interviewers and divorce mediators. It has been studied specifically by Clayman (1992) or Heritage and Greatbatch (1991) or more indirectly in studies like Maynard's (1991, 1992) on the perspective-display series. Greatbatch (1992) discusses how the turn-taking system in news interviews allows interviewers to meet the legal requirement to maintain impartiality in news coverage. If interviewers act in accordance with this system they will "automatically maintain a formally neutral or neutralistic stance" (1992: 270). By only asking questions they avoid expressing opinion, and interviewees in confining themselves to answering them "avoid challenging or commenting on the presuppositions or character of their questions and, in so doing, collaborate in preserving the IRs' neutralistic stance" (1992: 270). The formal pre-allocated requirements of the turn-taking system then support the maintenance of professional caution in this setting.

Greatbatch's comments are typical of the findings in settings such as news interviews or broadcasts. They demonstrate how restrictions in the turn-taking system and in role obligations can be used to support an ethos of neutrality. He then goes on to illustrate how disagreements are managed within the same structure. Maynard's study shows how in more subtle ways an 'expressive caution' can be facilitated through interactional devices. A CA study of the interactional structure of genetic counselling can potentially reveal how issues of advice and non-directiveness are practically handled within this less formal setting. It is also possible that it might uncover the opposite – where or how directiveness *does* happen in spite of the prevailing norms *or* what is taken practically to count as directive or non-directive in this setting. Such a situation was revealed within Greatbatch and Dingwall's (1989) study of divorce mediation. Following a single case study by Dingwall (1988) in which the mediator was shown not to be neutral - using the 'negative power' of a veto to influence the result – further research found this was not an exceptional case. Many cases were demonstrably not neutral although it was more often the "positive power of encouraging discussion in specific directions that was used"

(1989: 617). They do point out, however, that there is some contradiction between the ethos of neutrality for facilitating client decision-making and the commitment to the protection of equality in the eventual settlement. This might go some way to 'explaining' this. This might have relevance for genetic counselling in that there is some conflict between the ethos of non-directiveness on the one hand and the need for informed consent for testing on the other. There is also a suggestion that some clients expect or *want* directiveness or advice within the genetic counselling consultation (Michie, Marteau & Bobrow's (1997). Greatbatch and Dingwall go on to illustrate by detailed reference to the interactional text how through what they call "selective facilitation" the mediator selectively chooses to pursue opportunities for talk on one option and avoids discussion of another. This has the practical result of favouring one outcome over another and "calls her substantive neutrality into question" (1989: 638). It can also influence or reduce client control over decision-making. The potential of a method to identify such issues as the selective encouragement of certain forms of discussion or information is very relevant to the study of non-directiveness. As Harper and Clarke (1997) in particular have pointed out selectivity in the subjects discussed within the consultation – 'substantive neutrality' as opposed to 'formal neutrality', phrases such as 'it's ok for you to decide' - has considerable implications for the ability of genetic counselling to call itself non-directive.

Overall structure and form of the consultation

Finally, before I conclude this section, another study of potential significance is that by Pilnick (2001) on the interactional organisation of pharmacy consultations in a hospital setting. Following earlier CA work on the "explications of loose, 'overall structures' of particular types of encounter" (2001: 1931) such as Jefferson's (1988) description of the Troubles-telling sequence or Zimmerman's (1992) sequence for emergency calls, Pilnick analyses the pharmacy consultation in a similar manner. Using a detailed discussion of a single case, she suggests that pharmacy consultations exhibit an amalgamation of Jefferson and Zimmerman's features and appear to take the following loose shape. As in Jefferson's sequence not all the segments are present in every encounter and at times the order is disrupted. The consultation

opens with an *opening, identification, recognition or acknowledgement* sequence and a *greeting* or '*how are you*' sequence. This sets the scene for the business of the consultation. This is followed by *approach* and *arrival* to advice or information-giving sequences by the pharmacist, signalling his intention. Dependent on the *acceptance or rejection* of this intention by the client the pharmacist then moves into either a negotiated *rearrival* or into *delivery* of the advice or information. This then leaves the client with the decision of type of *response* to this. Finally the consultation then moves into *close implicature*, possible *questions* and *reclose implicature* and *exit*.

Pilnick describes this "template" as "a tool to begin the analysis of 'what pharmacists do' in this setting" (2001: 1943) and suggests that it is only by identifying the interactional work that is done that appropriate training programmes can be defined and developed. She also uses the sequence to discuss the potential interactional difficulties that pharmacists may encounter in delivering advice to long-term oncology clinic clients. Both these functions are of potential relevance to genetic counselling. In addition, with the acknowledged uncertainty about what goes on in the genetic counselling process and the focus of this research on the structure of the genetic counselling consultation, identifying whether genetic counselling possesses a loose 'shape' that is uniquely its own is likely to be constructive.

Conclusion

This chapter then has contained an introduction to the Conversation Analytic approach to the study of talk-in-interaction, both to some very basic features of 'ordinary' conversation and to some of the relevant institutional work that has been done. It gives an indication of the ways in which CA might be used to facilitate discussion on the topics raised in this thesis. It illustrates how the studies conducted into communication format, asymmetry, topic initiation and advice-giving might be used to consider how these areas are dealt with in the genetic counselling interaction. Finally it demonstrates how the studies into medical settings as a whole might be used in the search to identify whether genetic counselling is a counselling or a medical interaction and to uncover what actually goes on within the genetic counselling role.

Chapter 3

Methodology & Research Process

Introduction

The purpose of this chapter is to provide an understanding and description of the methods and methodology used in this research. As part of this it will also detail the research process that was to result in significant changes to both the research questions and the research design. I will begin with a discussion of the methodology selected, move on to its application as it worked out in practice, including the issues of ethics, access, sampling and analysis, and conclude with the actual progress of the final research. I will also broaden the debate within this chapter to include the implications of the difficulties I experienced in gaining ethical clearance for the overall topic of the ethical review of health-related social research.

Methodology

“Knowing what you want to find out leads inexorably to the question of *how* you will get that information.”

This quotation by Miles and Huberman (1984: 42), reproduced in Silverman (2000: 88), suggests a particular sequence to the selection of a methodology. As Silverman states as part of his case for the rejection of a rigid quantitative/qualitative divide, “the choice of research methods should depend on what you are trying to find out” (2000: 1). The method chosen should be appropriate to the nature of the questions being asked (2000: 12). When research is adding to an existing body of work it is also appropriate to consider where there are acknowledged limitations or highlighted gaps. With these points in mind, therefore, the methods chosen for this research were a combination of conversation analysis and semi-structured interviews – a conversation analytic study of recorded genetic counselling consultations and semi-structured interviews with genetic counsellors and clients.

Conversation analysis and ethnomethodology

The main reasons for the selection of the sociological approach of conversation analysis were summarised in the introduction to chapter two (see pages 41-42).

Briefly recapped these include: a) A demand for process research that can unlock the “black box” of genetic counselling and reveal what goes on within the sessions b) A need for a method that can consider genetic counselling as a two-way communication process and identify whether genetic counselling is a counselling or a medical interaction and, c) A means of analysing the process of decision-making, agenda-setting and non-directiveness in practice. Conversation analysis as an ethnomethodological approach to the study of talk-in-interaction is a method appropriate to these needs.

Ethnomethodology originated in the 1960s with the work of Harold Garfinkel and is described by Bryman as

“an approach to the study of social reality which takes people’s practical reasoning and the ways in which they make the social world sensible to them as the central focus (1992: 53).

Located in mainstream sociology as a qualitative methodology Bryman also believes it is one of the main routes by which the phenomenological ideas of Schutz made inroads into social science (1992: 53). He describes Schutz, writing after the Second World War, as wanting to utilise Husserl’s phenomenology to build on Weber’s notion of *verstehen*, to reject the positivist position that there is no difference in the subject matter of the social and natural sciences and to emphasise that any attempt at understanding social reality must be grounded in people’s experience of that reality (1992: 51-53). His influence is apparent in many of Garfinkel’s ideas and, as there is widespread acknowledgement that conversation analysis owes much of its methodological heritage to Garfinkel’s work (Heritage 1984, 1988; ten Have 1999; Clayman and Maynard 1995), in the later works of Sacks and conversation analysts.

Ethnomethodology arose out of Garfinkel’s response to the work of Talcott Parsons (1937) on the ‘Structure of Social Action’. Although an admirer and PhD student of Parsons, Garfinkel disagreed with his theories on a number of fundamental levels. First he rejected the concept that social organisation can be studied from a ‘top-down’ perspective that stands outside or leaves out the common-sense judgements and everyday choices of the individual societal

actor. Instead he believed social organisation should be studied from a ‘bottom-up’ perspective “as an emergent achievement that results from the concerted efforts of societal members acting within local situations” (Clayman and Maynard, 1995: 2). Discovering this “common-sense reasoning and practical theorising in everyday activities” (ten Have, 1999: 6) should be the central aim of sociological research. Members’ common sense knowledge should not be treated simply as a *resource* by sociologists but as a *topic* in its own right.

Second and inter-linked with this Garfinkel believed that actors – or individual societal members – are both reflexive and rational. They are not “judgmental dopes” acting only by reference to institutionalised internalised norms (Heritage, 1984: 27). Rather than action being *determined* by these norms or rules, as Parson’s theory implied, actors use common-sense and accommodative interpretation of the local situation to decide how to apply these rules in ways that make sense of their activities. They are aware that there are options open to them, aware that their actions and responses will be *interpreted* and understood by others and capable of reflexive judgement as to how to behave. They are also aware that their actions will be treated as morally *accountable*, that breaches of normative conduct will be treated as a matter of choice and that other members will respond to them accordingly. It is this reflexive understanding of the normative accountability of actions, therefore, that governs their choice – usually, states Heritage, in the pursuit of order as actors “find that their interests are well served by normatively organised appropriate conduct” (1984: 117). As Clayman and Maynard describe

“It is this situated accounting work that particularises and reconciles abstract rules with the details of actual conduct and thus provides for the maintenance of accountable patterns of social life” (1995: 17).

Third, Garfinkel believed that time is a relevant concept to the understanding of social order and that action must be considered as part of a temporal sequence. He believed that Parsons’ theory treated time as a “fat moment” where actors’ circumstances are unchanged by their courses of action (Heritage, 1984: 109). For Garfinkel, however, actors’ actions “reflexively contribute to the sense of the scene which is undergoing development as a temporal sequence of actions” (Heritage, 1984: 104). As they act they

unavoidably influence the local situation as it unfolds. This means that norms, therefore, “rather than regulating conduct in pre-defined scenes of action, are instead reflexively constitutive of the activities and unfolding circumstances to which they are applied” (Heritage, 1984: 109). Integral to this, and to the notion that actors reflexively take into account the normative accountability of their actions in any local situation, is the concept of *context*. The choice of action the actor may make in any given situation is inextricably related to the “particulars of the actions, persons, places and circumstances of their occurrence” (Heritage, 1984: 108). Action may be variously interpreted according to the situation in which it occurs. So where the activity takes place, the circumstances under which it takes place and what comes before and potentially after, all play their part in determining the choices that are made.

Finally, before we move on to consider how these theoretical assumptions are reflected in the conversation analytic approach, there is one further aspect of Garfinkel’s theory that merits a mention here. That is his emphasis on the role of language in the construction of social reality. Although it is Goffman who is credited with establishing interaction as a legitimate topic for sociological study, it was Garfinkel who first treated descriptive accounts and the “mastery of natural language” as crucial to an understanding of how actors “encounter and manage a social world-in-common” (Heritage, 1984: 139). Understanding language, he believed, involved understanding utterances as *actions* which, in the same way as other social actions, are interpreted in relation to the context in which they occur. Utterances and descriptive accounts are ‘indexical’, “understood by reference to a mass of unstated assumptions” and made sense of in the context of the situation in which they are produced (Heritage, 1984: 140-141). They are also “‘reflexive’ in maintaining or altering the sense of the unfolding circumstances in which they occur” (Heritage, 1984: 140). Although this may be a problem for those interested in “semantic clarity” Garfinkel and Sacks argued that the properties of indexical expressions are in fact orderly and socially organised and “far from being a problem ... can be a resource for broadly social ends” (Clayman and Maynard, 1995: 11). Through utterances and their indexical properties actors “produce mutually intelligible courses of

talk, and achieve all manner of relationship, interdependence and commitment” (Rawls, 1989 quoted Clayman and Maynard, 1995: 13).

Conversation analysis

Although the work of Sacks and Garfinkel were eventually to part company the reflection of Garfinkel’s ethnomethodological assumptions are evident in the descriptions of CA in chapter two (pages 42-45). They will be briefly summarised and enlarged on here. Broadly like other forms of ethnomethodology CA “is concerned with the analysis of the *competences* which underlie ordinary social activities”, specifically those “which ordinary speakers use and rely on when they engage in intelligible, conversational interaction” (Heritage, 1984: 241). There is a belief that talk amounts to action, that order can be found within it and, in accord with Garfinkel’s ‘symmetry’ proposal, that “both the *production* of conduct and its *interpretation* are the accountable products of a common set of methods and procedures” (Heritage, 1984: 241). Talk-in-interaction therefore is considered as a local achievement in which members reflexively use their common-sense knowledge to work out appropriate means of response. In a similar way to other forms of social action it is also morally accountable.

Methodologically CA concentrates on description and the study of naturally occurring interaction, working inductively and rejecting the concept of explanation and experimentation. Ideas are formed from out of the data and without *a priori* assumptions. To quote ten Have it attempts to

“explicate the inherent theories-in-use of member’s practices as *lived orders*, rather than trying to order the world externally by applying a set of traditionally available concepts, or invented variation thereof” (1999: 32).

Its data are recordings of natural interactions and its aim is to describe *how* common-sense reasoning and social organisation work rather than to develop theories and explanations of why. Transcripts of recorded data are used as a method of making “*what* was said and *how* it was said available for analytic consideration” (ten Have, 1999: 33, original italic). Talk is indexical and sequentially organised with context dynamically created and both a project and a product of participants’ actions (Heritage 1997: 162-163). Actors choose

what they say according to the context in which the conversation is taking place and in line with preceding talk. Their actions then create or renew the context for the next contributor. It is through this reflexive reference to the context of interaction that “institutional imperatives originating from outside the interaction are made real and enforceable for the participants” and the characteristics of specific institutional settings can be made visible through a study of their talk (Heritage, 1997: 163). For the purposes of this thesis therefore CA can be used to consider how genetic counsellors and clients build the context of genetic counselling in and through their talk and how they use common-sense knowledge of its sequential organisation to collaboratively construct the interaction that is a genetic counselling consultation.

Interviews

Returning to the methodology selected, although later events were to render some of these - particularly in point two - difficult to achieve, the decision to include semi-structured interviews with genetic counsellors and clients alongside the conversation analytic study was taken with the following objectives in mind.

1. To ascertain information on client and counsellor expectations, wishes and perceptions of the genetic counselling encounter. This was discussed in chapter one as being an acknowledged gap in genetic counselling research. Areas of particular relevance included advice, non-directiveness, agenda-setting and the structure or nature of the genetic counselling consultation.
2. To allow a historical and sequential study of how participants' expectations and perceptions first affect the interaction and then how the interaction itself impacts on perception, understanding and satisfaction. This could then provide a means of identifying what clients and counsellors want and therefore might class as effective, of examining how process relates to outcome - eg satisfaction – and of assessing how internally held beliefs and perceptions relate to what actually happens in the actual interaction.

Interview style

Burgess (1984) describes interview style as running along a continuum from structured interviews to ‘semi-structured’ or ‘interviews-as-conversation’. He defined a structured interview as one in which “the interviewer poses questions and records answers in a set pattern.” (1984: 101) and a semi-structured interview as one which “employs a set of themes and topics to form questions in the course of conversation” (1984: 102). The informal or semi-structured interview is conducted along a continuum from mostly pre-set questions to totally unplanned time and, with its greater flexibility, was more appropriate for my needs and more compatible with my overall qualitative methodology and the inductive nature of my research.

Field Method

Having selected my overall methodology my next task was to decide on the *details* of my method and to negotiate the issues of ethics and access. In this section I outline my intentions at the outset of my research.

Interviews and consultations

I planned to conduct twenty pre- and post-counselling semi-structured interviews with haemochromatosis clients and to tape-record their actual genetic counselling consultations for the conversation analytic study. The interviews were to be between thirty to sixty minutes in length and held in the client’s home. I intended to construct an interview guide of the type described by Maykut and Morehouse (1994: 84), using a number of planned themes while leaving some elasticity for the interviewee to have some control over what might be discussed. Again this was compatible with the qualitative and inductive nature of my research. Themes to be explored pre-counselling included the expectations, desires and needs the client had of the session in terms of content, information, advice and decision-making and in any other areas the client might introduce. They also included his/her understanding of the nature of the counselling encounter. Themes to be explored post-counselling included information on client satisfaction or dissatisfaction, the meeting of client expectations, feelings on advice and decision-making and again their beliefs on the structure of the genetic counselling interaction. These interview plans are reproduced in Appendix A.

I planned to conduct nine genetic counsellor interviews in advance of any counselling. Again these were to be thirty to sixty minutes in length. This comprised the four geneticists and five nurse-counsellors within the department. I also left open the possibility of conducting some post-counselling interviews dependent on the emerging data. Themes to be explored included their understanding of the structure of the consultation, of the role of the genetic counsellor and of what they expect to be covering within the session. I also intended to ascertain their ideas of what the *clients* are expecting and wanting in terms of content, agenda and advice, and their own professional views on non-directiveness in practice.

Sampling

The intended sample was to be the first twenty haemochromatosis clients attending the department for the first time for genetic counselling after the research commenced and willing to participate. The selection of the disorder haemochromatosis was made at the specific request of the staff in the Clinical Genetics Department with whom access had been negotiated. It had been decided that selecting one disorder would minimise one source of variability in the research data and enable potentially useful information to be collected on this disorder for the Department.

Ethics and Access

Access had already been negotiated before the research proposal was submitted to the ESRC for funding and it had been agreed that the study was to take place within the Clinical Genetics Department of a local hospital. The project also needed to be submitted for ethical approval to the Local Research Ethics Committee of this hospital before fieldwork could commence.

Confidentiality and Anonymity

Both clients and counsellors were entitled to confidentiality and anonymity respectively. All identifying features were to be removed from the transcripts, and consultation and interview tapes held in a secure location (ie locked containers). The length of time for them to be held is governed by university policy. Computerised data was to be password protected. The tapes and

transcripts were to be used only for research and training purposes and any personal details in sections reproduced in my thesis or in research articles were to be similarly removed.

Informed consent

Informed consent is another ethical responsibility and a priority in any research. It was planned to send a concise and informal information letter detailing the study to prospective clients with the initial appointment sent by the genetic counselling department. This was to contain a brief explanation of the study and its purpose, explanations of confidentiality and anonymity, assurance that not wishing to take part would not affect their genetic counselling and an opt-in form to return to me if they wished to participate. The genetic counsellors were opposed to the idea of telephoning clients without them having sent back a form. Written consent was to be gained at interview and opportunity for questions given. Consent forms were also to be prepared for the genetic counsellors. A copy of this letter and the consent forms are included in Appendix A.

Avoidance of Harm

Avoidance of harm is another important principle. As I was not to be present in the counselling sessions counselling care was not directly affected. It is generally believed that audio recording does not have undue influence beyond an initial awareness. Burgess (1981: 8) suggests that resulting inhibitions usually recede fairly quickly and the advantages outweigh the risk. Recording was the only realistic way of reproducing the consultation. The same applied for the interviews. Note taking can destroy continuity and misses much of the information. Permission was to be sought both in the consent letter and at the time of recording. My counselling training meant that I would be well-equipped to handle the interviews, and clients' anxieties, with sensitivity and it was to be made clear in the letter that I am not medically trained and could not therefore offer medical information. I also intended to reassure counsellors that I was not setting out to judge or criticise their work.

Data Analysis

The data analysis was to take place in two parts in accord with the two methods used. It was to be ongoing and evolving as the research progressed and each was to be used to inform the other. Both methods are primarily inductive, working from the ‘bottom-up’, studying the research material collected in order to look for regularities, themes and patterns, and generating theory from out of the data. Although some overall themes were identified in advance in accord with the research questions there were to be no *a priori* assumptions, particularly in the conversation analytic study, that it was possible to predict what in the data was going to be significant. In line with Coffey and Atkinson (1996) the process of analysis was viewed as cyclical, a ‘reflexive activity’ that should inform all the research stages. The reading around the issues present in genetic counselling were to guide the initial questions and themes, and the findings revealed in the data to prompt further questions, research and theory. Further details of the process of analysis are located later in this chapter.

Methodological issues

The particular methods or methodologies selected for this study raise two issues that need to be addressed before I move on to describe the process of the research as it was eventually to evolve. These involve the way I treat the status of my interview data and the potential problems incurred in using multiple methods.

Multiple methods

A combining of research methods, sometimes known as ‘triangulation’, is not without contention. As Silverman (2000) points out it may raise “complicated issues about how to ‘map’ one set of data upon another” (2000: 49). This is particularly relevant if the methods used treat “social reality as constructed in different ways” (Silverman, 2000: 99). To some extent this could be said to be true of the combination selected here. Both are qualitative and primarily inductive in approach (although ten Have (1999: 36-38)) suggests that some aspects of CA might be described as *deductive*), but some of their underlying epistemological and ontological assumptions are commonly held to differ. Interviews (or at least semi- or unstructured interviews) have commonly been

associated with attempts to understand social phenomena by gaining access to members' 'authentic' inner experience or meaning. In Burgess's words

"The focus is upon the way in which participants interpret their experience and construct reality (Berger and Luckman, 1967). The ultimate aim is to study situations from the participants' point of view" (1984: 3).

This, he goes on to say, owes much to symbolic interactionism,

"an interpretative view of sociology which puts emphasis on understanding the actions of participants on the basis of their active experience of the world and the ways in which their actions arise from and reflect back on experience"(p3)

The assumption for many researchers has been that interview accounts therefore can represent 'truth', be informative about the underlying constructs that motivate social action and, to quote West in his discussion of Moerman's definition of ethnography, provide explanation of "how people make sense of their lives" (1996: 327)).

CA however, as we have seen, has traditionally rejected this emphasis on meaning and the 'content' of talk, preferring to concentrate on the 'form' and 'machinery' that is used "in the *production* of particular regular features of social reality" (Silverman, 1998:69, original italic). It treats talk as a locally achieved accomplishment. In terms of interviews particularly there is a rejection of the use of subjects' verbal reports as a substitute for the observation of actual behaviour (Heritage, 1984: 236). There is also a rejection of their role as "primary data on the interactions accounted for" (ten Have, 1999: 33). As ten Have continues "Such explanations may be interesting in their own right as 'accounting practices', but are not accorded any privileged status in the analysis of the original interaction" (ibid: 33). The emphasis overall is not on improving sociological understanding by appeals to concepts like 'culture' or 'social structure' but on working out how people accomplish whatever they do by studying the social organisation found in everyday mundane activities (Silverman, 2000a: 58).

In some ways, therefore, my selected combination of methods might be criticised by some as mutually incompatible. Indeed a similar call by Moerman (1988) to "marry" the tools of ethnography and conversation analysis raised

many protests from conversation analysts themselves (West, 1996: 327-328). However, although I recognise the difficulties involved and would not claim that by combining methods I can therefore produce a complete picture or one overall truth, I would concur with Silverman's eventual conclusion that the potential problems do not necessarily "exclude the possibility of using multiple means of gathering data" (2000: 51). Rather I would contend that for the specific questions addressed by this thesis they provide a combination that is well-suited for their different aspects. The client and counsellor interviews provide access to accounts of perceptions and expectations that might not be framed in the actual interaction and the genetic counsellor accounts or conceptualisations of their role can add context to the interactional analysis. Similarly, as already stated, they offered the possibility of a historical and sequential study of how perceptions and expectations influence the consultation interaction and how the interaction influences perceptions and understanding. Although context is already an integral feature of CA (see page 44), insight into how the counsellors account for what they do and into the conflicts they are already aware of between their medical and their counselling roles can illuminate what the analysis is revealing.

Status of the interview data

My approach to the status of my interview data is also less problematic to a dual methodology than some of the attributes highlighted in the preceding paragraphs. Silverman described the most popular approach to the status of interview data as treating respondents' answers as describing some external reality (for example facts or events), or internal experience (for example feelings or meanings). He termed this the 'realist' approach (2000: 122). He contrasts this with the alternative 'narrative' approach in which respondents' answers can be seen "as accessing various stories or narratives through which people describe their world" (Silverman 2000: 122). Here the claim to 'reality' is surrendered allowing analysis of the "culturally rich methods" through which interview participants together "generate plausible accounts of the world" (Silverman, 2000: 123). The locally produced nature of accounts is therefore to the fore. In an earlier work he also discusses Baruch's seminal discussion of the production of interviews as "moral tales" or accounts that can be treated as

revealing relevant narratives created for a particular function or audience. The mothers involved in his research interviews created 'morally adequate' accounts of their roles as parents of handicapped children as they told their stories (1993: 108-114). He uses this work to illustrate that a simple dichotomy between interview as 'truth' or as 'situated narrative' is not necessarily inevitable, cultural particulars and locally accomplished practices can be studied together. Dingwall (1997) also discusses Baruch's work in his discussion of interviews as accounts. He rejects the concept that interviews can be treated as offering "literal descriptions of the respondent's realities", describing them rather as "artefacts" or social encounters that are a joint accomplishment of interviewer and respondent (Dingwall, 1997: 60). He goes on however to say that they can instead be analysed "for what they can say about the kind of accounts that are treated as legitimate in a particular setting" (1997: 60). So in Baruch's study they were able to offer information about "the work of doing being a normal family" (Dingwall, 1997: 60).

Transferring Dingwall and Silverman's views across to my research this means that rather than treating the genetic counsellor accounts as either solely 'narrative' or 'truth' the interviews can be used to offer information on the ways genetic counsellors construct moral accounts of 'the work of doing being' a genetic counsellor. This then gives insight into the professional narrative that underpins their genetic counselling role. The interview information can then be used alongside the conversation analytic study to consider how their stated perceptions of the ways in which their actions will be locally understood or judged as accountable are reflected within their actual practice and, as was to be revealed, the interactional difficulties that ensue. In acknowledging the existence of the interview as an artefact and a locally produced accomplishment therefore, and not attempting to give it 'privileged status' as 'truth' in analysing the genetic counselling interaction, the underlying methodological or conceptual differences between this and a conversation analytic approach are not as great as they might have been.

Research Process

In my introduction I detail the research questions that form the basis of this

research in its final form. To recap briefly these include:

1. Is genetic counselling primarily a medical or a counselling activity, incorporating a consideration of client expectations and the structure and function of the genetic counsellor role?
2. Does genetic counselling have many similarities to “personal, emotional or psychological” ‘counselling’ at all?
3. What are the practical and ethical implications for genetic counselling practitioners of the genetic counselling profession’s alliance with the counselling community?

This was not however the format with which it began. In this section I discuss the process that was to change this project from what were its initial aims into the study it is now. The initial research questions concerned an assessment of the impact of genetic counselling on a group of clients receiving counselling for the genetic disorder haemochromatosis. This was moderated prior to the internal process of upgrading from MPhil to PhD status to focus primarily on impact with a view to promoting practitioner dialogue on the *meaning* of efficacy. Access had been negotiated prior to seeking ESRC funding, the research methodology was selected as has been described and, following successful upgrading from MPhil to PhD status at the end of my first year, the project was ready to seek LREC approval. It was in this process that I was to begin to encounter the problems which were to be influential in changing the final format and aims of my research. Submitting a qualitative proposal within a pre-dominantly quantitatively based system was to prove very difficult. The process was to take five months in total, to undermine the qualitative tenets of my research and to cause delay to my research schedule. In the following sections I detail my experiences and the effects they had on the progress of my research. I also include a discussion on the questions raised and on whether modifications in procedures and principles are necessary to provide effective ethical review of health related social research. Much of this discussion is extracted from a paper I had accepted for publication as a book chapter, scheduled to be published around November this year. I conclude this chapter with a summary of the methodological details of my research in its final form.

Before I begin however I would like to state that the discussion here is not intended as criticism of the local hospital Ethics Board. There are many pressures on LRECS and resources are often limited. They are seen as protection against the fear of litigation but may have only general guidance at local level. The hospital involved, which is not the main research hospital in the area, is less immersed in the research culture and has less experience to draw on. Their Ethics Committee has, as yet, dealt with very few qualitative projects and it is likely, therefore, that their system will be less flexible and able to cope better with quantitative studies. I do not see the difficulties I experienced as intentionally obstructive but rather as a reflection of the problems facing a local committee in finding its way under challenging circumstances. The dilemmas raised are not about individual liability, nor about an LREC organisational bias against qualitative research, but about elements of an overall research review system that would benefit from discussion.

LREC application

I began the process of ethical review near the beginning of July 2000. It was to take five months in total, with the official letter of approval arriving in the New Year. Although perhaps three weeks must be accounted for by delays in my returning amendments due to illness or conference attendance this still leaves a waiting period of around four months during a time-limited research period. This was a substantial chunk of my three-year PhD schedule. It was a frustrating period in which potential field research time was lost and limited relevant work could be achieved. As I discuss in more detail later the difficulty in defining a qualitative proposal according to quantitative-type parameters and the resulting requests for difficult-to-provide amendments may well have been contributory factors to the extended delay. The following areas were to prove particularly difficult.

1. Quantitative parameters with qualitative research

A major difficulty I encountered lay in the clinical emphasis and in the incompatibility between some quantitative and qualitative parameters. The application form is designed specifically with clinical Randomised Control

Trials in mind. It was difficult to define my research with the precision required by some of the criteria. Terms such as hypothesis, rationale, investigator and scientific background are more typical of an experimental model than a qualitative one and I found myself confused as to what information was required where. It would also have been less restrictive to the practicalities of my final research plan to structure my proposal using the more familiar format of research question, methodology, method, researcher, etc. The most significant difficulty of the leaning towards quantitative requirements, however, lay in the modifications or amendments requested by the Committee. These were to add to the length of time the process was to take and I was to find it hard to satisfy the level of detail asked for in some areas.

The most obvious example of this was the repeated request for a list of clearly defined questions or themes for the interviews. As already stated, I had decided that, with their greater flexibility, semi-structured interviews were more appropriate for my needs. This meant, however, that it was impossible to produce a precisely defined set of interview questions in the research proposal. This was to prove problematic. The first set of amendments requested me to provide details of the format of the semi-structured interview. I took this to mean some idea of the composition of the interview and of the general areas to be dealt with within it so, for example, included the following on the pre-counselling interviews:

“Client interviews will take place in their homes unless an alternative location is preferred. They are expected to be between 30 and sixty minutes in length. Themes for discussion will include the expectations, needs and wants that the clients have of their counselling session in terms of content, information, advice and any other areas the client might introduce, and their understanding of what genetic counselling involves.”

As the interviews were discussed within the research protocol I enclosed an amended version of this along with the other amendments requested on the information and consent sheets and returned it to the Committee. This summarised the state of progress at this time and I felt it was sufficient to cover the LREC review requirements. However, when the second response was received the same request was included again. I was then forced to create a

more detailed list of questions on a separate sheet, including the examples below.

What do you expect is going to happen when the genetic counsellor comes to your home?

What kinds of things would you *like* to be discussed?

This was accepted and approval was given. However, the precision required seemed excessive and the nature of my method was transformed from an informal semi-structured to a closely structured interview that approximated a questionnaire. There is also a question whether this exceeds the remit that LREC's are expected to fulfil. The 1990 Report of the Royal College of Physicians states that

"The objectives of Research Ethics Committees are to maintain ethical standards of practice in research, to protect subjects of research from harm, to preserve the subjects' rights and to provide reassurance to the public that this is being done." (RCOP, 1990: 3)

The Department of Health specifies that this should cover areas such as the provision of adequate procedures and information to ensure informed consent, voluntary participation, the preservation of confidentiality, scientific merit, sufficient qualified supervision of researchers and consideration of hazards to health (DOH, 1991). Safety procedures and financial considerations should also be monitored. This suggests therefore that the amendments required by the Committee would not be included within this. It is *methodological* material not ethical - and to a level of detail not realistically compatible with my research ethos. It was also practically redundant in that the nature of the interviews meant some of the questions were answered within others and some were not relevant in every interview.

2. *Amendments with implications for progress of research*

There were some amendments, however, which were both very specific in detail *and* carried the potential to be detrimental to the research process itself. These related mostly to the patient information and consent material. Informed consent is of essential importance and is a vital part of the LREC recommendations. The DOH and Royal College recommendations for committees include ensuring the voluntary nature of participation with clear

indication that no difference to treatment will ensue from refusal or withdrawal at any stage, adequate information, written consent and assurance of confidentiality of patient identification data. Patients should also be told if the trial is non-therapeutic. The local hospital has assembled its own comprehensive guidelines which detail under headings how information should be displayed. I had constructed a patient information sheet in the form of a one-page letter covering most of the above recommendations (see Appendix B) – although I had omitted a specific statement on the study involving no direct benefit to patients. It was designed to be easy to read, friendly and not too long. An “opt-in” form was also included for the client to return to me if they were willing to take part. Both had been checked, commented on and altered where they felt necessary by the genetic counselling team.

The first letter requesting amendments made the important point that I must state that the study is of no direct benefit to patients. They also requested that the structure of the letter should be changed to include all the section headings contained within their guidelines. Tape storage and destruction details were to be mentioned and more included on confidentiality. This change was to have a big effect on the nature of the sheet I produced. Including all the sections extended the letter to nearly two full pages and writing under headings resulted in a much more formal presentation than originally intended. Instead of an informal and friendly “invitation” patients received a complex set of formal explanatory guidelines. Again this can be found in Appendix B. In addition, the second amendments required a covering letter from the counsellors to accompany the information letter. This meant that, along with their appointment, the patients received a detailed two-page letter, an opt-in sheet and another “covering” or explanatory letter from the counsellor. Feedback from one of the genetic counsellors suggested these changes might have resulted in patients being intimidated by the formality of the presentation of research material and/or put-off by the excessive amount of paperwork to read. This was to have deleterious effects on recruitment and the response rate over several months was zero. At this point another request was put into the committee to reverse these changes so that the letter again became more user friendly and less documentation was required. This was another long procedure

that took months to complete, with yet more research time lost. After this point I was able to recruit two patients to the study in the form it was planned. However, due to the late stage of the research, I felt if I wanted to attempt to gain significant client participation it was necessary to amend my search to include *past* clients. Forty patient names were extracted from the records by one of the genetic counsellors and letters sent asking if they would attend for a post-counselling interview only. This resulted in a further six clients being interviewed. Two more response letters were received too late to include in the study.

The consequences overall for my research was that the focus was to change from the impact of genetic counselling on a group of clients receiving counselling for the genetic disorder haemochromatosis into the form it is now, centring on the structure and function of the genetic counselling interaction and on its position as part of the therapeutic community. The lack of recruitment left me at Christmas of my third year with nine genetic counsellor interviews completed and only nine months to go. It was decided at this point therefore to utilise the fifteen genetic counselling consultation tapes already held within the School of Sociology and Social Policy as the main data for the conversation analytic study. This was not ideal as, although they were recorded within the same Genetics department (with LREC approval for a previous study), they were four years old and some of the genetic counsellors had moved on and been replaced. It also meant that the specific focus on haemochromatosis was removed as the existing tapes covered a variety of conditions. I had, fortunately, already taken a general as well as a haemochromatosis specific approach to the genetic counsellor interviews. Although I was able to add two new tapes to the corpus this also meant that overall I could not pursue the sequential progression from pre-counselling interviews through the consultations to post-counselling interviews. I was unable therefore to combine the two methods in quite the way I had hoped. Nevertheless I was still able to consider the genetic counsellor interviews as providing insight into the professional narrative that they used to provide an account of their role and to consider the conversation analytic study in the light of this. I was also able – belatedly, as by the time the revised letter had been passed by the committee

and I had been given the past client names it was May 2002 – to gain a limited amount of information on client expectations and perceptions.

These direct and specific influences on the research material again raise some of the questions already mentioned. Is this level of methodological detail part of a committee's review role and is it appropriate for qualitative as opposed to quantitative-type research? Are all the areas included relevant and how far, however unintentionally, do they result in impediments to the process and progress of research? Again this is not intended to directly highlight the hospital's work as individually liable for criticism, but to raise significant questions that merit overall discussion.

3. *Delay*

All of the areas mentioned contribute to the significant problem of the lengthy application process. The long gaps in between sending material and response, the producing of two sets of amendments, and the amount of work and detail required all resulted in a five month procedure. Several more months were also taken later on trying to rectify the difficulties caused. It could be said that, if attention had been paid to purely ethical issues, only one set of amendments would have been necessary, the delay could have been lessened and recruitment might have been improved. The length of delay seriously affected my research timetable and put back the potential start to my fieldwork by a number of months. With a financial time-limit and ESRC departmental quotas and deadlines for research completion this *could* have had significant consequences for my – and the university's - research career.

4. *Effects on Researcher Morale*

A final difficulty that this whole ethics application procedure was to bring was a more personal one but not, I imagine, unique to me. The long periods of waiting, the disappointment at a second set of amendments and the feeling of time-wasting, all contributed to an overall sense of frustration as time progressed. Lack of motivation became a problem as I wanted to be getting to a point where fieldwork was a possibility and anxiety crept in as I could see my schedule being eroded. I felt that I had little control and that some things I was

required to do were either unprofitable or detrimental to my research. Overall it was a procedure that, although essential, I would not look forward to repeating.

Issues raised for the ethical review of qualitative social research.

The difficulties I encountered with my application raised a number of practical and ideological questions for the ethical review of qualitative social research within the NHS. In this section I briefly discuss what these questions are and the potential areas that need to be addressed if the review procedure is to fulfil its functions of maintaining ethical standards of practice, protecting subject's rights and, in The Royal College of Physicians words, encouraging rather than hindering "good medical research" (RCOP, 1990: 3). The majority of this discussion is taken from my book chapter.

Perhaps the most significant practical question concerns the need for reducing the delay. This has additional consequences beyond the disruption to research schedules. The time taken, says Nicholl (2000: 1217) "has become a barrier to our research" and also adds up "to the impossibility of doing practical research in the NHS to help decisions which must be made promptly." It may discourage some research altogether, can be prohibitive to some kinds of potentially informative student projects (Jenkins, 1995) and dissipates resources. For qualitative social research this delay may often be linked to the additional question of whether or not there should be a separate system and/or form for assessing this type of research. As my experience has shown the difficulty of fitting qualitative research into a quantitative-type format and satisfying the subsequent demands can add to the length of time taken. Alberti (1995: 639) reinforces this when he suggests "social protocols seem to create the biggest uncertainty for ethics committees" and describes "sociological studies" as a "difficult area" for them to deal with. One solution he proposes is that there should be more consistent central guidance available for local committees. Oddens and De Wied (1995) support this when they observe that many of the problems associated with "social medical research" are related to the fact that no clear guidelines about ethical aspects of this type of study exists. Sociological studies will often have different priorities for ethical review – less emphasis is required, for example, on the protection of patients

from physical harm – and different information may be required. From their position on the board of trustees of the International Health Foundation in Brussels Oddens and De Wied also go on to advise that research ethics committees design special application forms for social medical studies. This would seem a sensible proposition in the light of the disparity between clinical and social research parameters – indeed in the light of pressure from within the School and from a senior member of the Clinical Genetics department this has now been implemented at the local hospital. Other suggestions on dealing with forms of research unusual to committees have included the extended use of expert help and in particular expert external peer review (Report of the review into the research framework in North Staffordshire (2000)). All of these ideas might speed the review process up by reducing the need for local committees to ‘reinvent the wheel’ each time they deal with non-clinical research and give them confidence to approve applications without excessive interference. They might also shift the emphasis from the clinical scenario to a rethink of what might be significant principles relevant to the more social forms of medical research.

An additional, though closely associated, question that merits discussion concerns the overall scope and purpose of ethics committees. Nicholl (2000: 1217) comments that in his department’s experience the frustration at delay and interference is made worse by the fact that committees have been concentrating on “scientific, legal, and confidentiality issues instead of ethical issues.” My own experience supports this – although in my case much of the material requested by the committee concerned *methodological* rather than ethical detail. Committees need greater clarity as to what counts as “ethical review” in sociological studies and involvement should perhaps be restricted to these areas. Again this relates to the lack of existing guidelines for social research. The North Staffordshire Report quoted above stresses the need for clarification of “the roles and accountabilities of the different bodies involved in research and its management” (2000: 21) and again emphasises the importance and expertise of external peer review. They point out that before allocating funding the vast majority of funding bodies will have carried out rigorous checking. This highlights another relevant point. Since it was funded

by the ESRC my research had already been subject to thorough review. ESRC studentships are very competitive and comprehensive detail is required on research questions, purpose, method and methodology with an increasing amount of space being dedicated to issues of ethical significance. The ESRC is skilled at assessing social research. This raises two further questions, first, whether full LREC review of the whole protocol is necessary after prior expert peer review and second, whether LRECs are effectively qualified to challenge the status of such review in requiring multiple changes? It may be, as the North Staffordshire Report suggests, that “In order to avoid overwhelming bureaucratic obstruction to legitimate medical research different levels of research activity need to be subjected to a greater or lesser degree of control” (2000: 21). This might include more limited review – or even the delegation of review - of projects already passed as methodologically and legally sound by other expert social research bodies.

The LREC system fulfils an important role in maintaining ethical standards and protecting the rights and interests of NHS patients involved in research. However, its current organisation and the principles on which this is based may not be appropriate for all types of research. For some kinds of social research it may be, as I have found, not only a hindrance but also detrimental. There is a mismatch between the ethical review that is needed and the system in place to supply it. As the amount of health related social research is increasing there is a definite need for change. Clearer guidelines and more suitable parameters are required and consideration of alternate forms of review might be beneficial. The scope of LREC review in social research needs to be clarified. There are some overall developments of the ethical review of medical research already underway. These include the introduction of a Central Office for Ethical Review and operational changes announced in November 1999 which mean a substantial number of large-scale studies of non-therapeutic research will be considered by MRECs alone. Perhaps alongside of these developments a rethink of the principles and procedures that underlie the ethical review of social medical research in the NHS might be constructive.

Final field method details

I conclude this chapter with a description of the details of my field method as it reached its final form. As issues of ethics and access have already been discussed in previous sections I do not repeat them here.

Interviews

I was eventually able to conduct two pre-counselling interviews and two post-counselling interviews with new haemochromatosis clients, and four post-counselling interviews with past clients. Two of these included two participants with separate stories. The questions used for both types of interviews are reproduced in appendix B. I conducted nine genetic counsellor interviews, four with geneticists and five with nurse-counsellors. All the interviews were between thirty minutes to an hour in length and tape-recorded. Written consent was gained at each interview and information delivered as already described. Opportunity for further questioning was given.

Consultation tapes

The tapes used for the conversation analytic study were divided between two new tapes recorded during this research and fifteen already stored in the department. These were collected over several months in 1997. One of these was found to be largely impossible to hear and transcribe. As a sample they covered a wide variety of disorders. These are listed in Appendix C. At least six different counsellors appear to be involved, two male and four female although two of these are nurse-counsellors in a largely supportive or secondary role. The number of clients in each consultation varied from one to three. Again the number of persons present is reproduced in Appendix C.

Data Analysis

Guidelines for working through the interview data can be found within the works of Coffey and Atkinson (1996) and Huberman and Miles (1994). Huberman and Miles (1994) see qualitative data analysis as consisting of “three concurrent flows of activity: data reduction, data display, and conclusion drawing or verification” (p10). Data reduction begins with the selection of the

research questions and conceptual framework and continues throughout the research process. The unwieldy bulk of the interview transcripts is 'reduced' by 'coding' and sorting the data into patterns or themes reflecting the research objectives. This coding "enables the researcher to identify meaningful data and set the stage for interpreting and drawing conclusions" (Huberman and Miles, 1994: 56). So in my data the respondents' accounts were 'sorted' into information related to the main research themes identified in the research questions – the role of the genetic counsellor, expectations or wishes of the genetic counselling process, beliefs around advice and non-directiveness, agenda-setting, decision-making and the structure of genetic counselling as a counselling or medical interaction. Similar themes were also identified in the conversation analytic study. The themed material was then collected together using the cut and paste function on the computer – part of what Huberman and Miles call 'data display'. Data display involves representing the coded transcript material in "an immediately accessible, compact form" which allows the analyst to see what is happening and "permits conclusion drawing and action". (1994: 11) The displayed material was then studied "in order to find commonalities, differences, patterns and structures" (Seidel & Kelle, 1995, quoted Coffey & Atkinson: 29) and used alongside relevant literature to address the research questions and construct an analysis of the narrative that underpins the genetic counselling role.

Guidelines for the conversation analytic study can be found in ten Have (1999). The analysis began with the process of transcription using the system devised by Gail Jefferson (1972). This system is designed to reveal the sequential features of talk and the transcripts to make what was said and how it was said accessible both for the analyst and to a wider audience (ten Have, 1999: 76). Words as spoken, pauses, silences, sounds as uttered, incomprehensible words or noises, overlapping speech, emphasises, volume, pace etc are all made available in a viewable form (ten Have, 1999: 79). Although previous researchers had already transcribed a few of the existing tapes, I transcribed the majority personally. One tape was virtually inaudible and the last recorded tape was listened to but not transcribed in detail as it arrived so late in the research schedule. Although certain themes had already been noted as potentially

significant with reference to the research questions and genetic counselling literature the analysis continued with what ten Have describes as “a tentative, open-minded approach to the data at hand, using just a few basic concepts from the CA tradition to structure one’s looking” (ten Have, 1999: 102). This included concepts such as turn design, sequential organisation, adjacency pairs, repair etc. Once this initial scan had been completed previously established concepts and findings from both ‘ordinary’ and ‘institutional’ interaction were used alongside the searching to further the research goals of identifying whether genetic counselling is a counselling or a medical interaction and whether it has an identity uniquely its own. These included the more specific concepts of topic initiation, asymmetry and communication format. ‘Deviant case analysis’ – the intensive study of normative orientations in isolated exceptions – was also utilised at points to deepen the analysis. Other overall aims were to identify the organisation of any interactional structures that participants may be using to create and sustain the ‘institution’ of genetic counselling and to establish any ‘patterns’ in how the broad themes listed in the research questions are conversationally handled.

Generalisability

The question of generalisability is one that has raised considerable debate amongst qualitative researchers. Although some have argued that it is not necessary to generalise beyond the single case, others believe that “qualitative research should produce explanations which are generalisable in some way, or which have a wider resonance” (Mason (1996) cited Silverman (2000: 103)). This gives rise, however, to a separate problem, in a small scale qualitative study, given that statistical sampling procedures (the common solution to the problem of generalisability in quantitative studies) are often not available, how is the question of ‘representativeness’ to be addressed?

Silverman (2000) suggests that there are a number of ways in which this might be done. These are 1) “combining qualitative research with quantitative measures of populations”, 2) “purposive sampling guided by time and resources”, 3) “theoretical sampling” and 4) “using an analytic model which assumes that generalisability is present in the existence of *any* case”

(Silverman, 2000: 103). These are pursued within this research in the following ways. First, “in obtaining information about relevant aspects of the population of cases and comparing our case with them” (Hammersley, 1992, cited Silverman (2000: 104)). In practical terms this simply involved using the literature review to locate other relevant studies and comparing their results with mine. In this way the question of generalisability is tackled by “demonstrating the similarities and differences across a number of settings” (Perakyla, 1997: 214, cited Silverman, 2000: 104). Second, the research site was selected as a well-known and specialised department where genetic counselling occurred. All the genetic counsellors in that department at that point in time were interviewed and clients selected on the basis of their disorder – although it should be acknowledged that the unfortunately small number of clients prevents generalisability in this area beyond the parameters of this thesis. The consultation data, although not largely purposively selected for this research, were accepted as providing a cross-section of cases seen. This was not ideal but was influenced by the research process as described. Finally, and encompassing Silverman’s third and fourth suggestions, the conversation analytic method was chosen as a theoretical approach most appropriate to address the research questions set. It also provides a method that sees generalisability or order as present in every single case. Perakyla applies this logic to institutional research in terms of ‘possibilities’. He argues, using his HIV research as an example, that, even if the practices described are not “actualised in similar ways across different settings”, they are still generalisable “as descriptions of what any counsellor or other professional, with his or her clients, can do, given that he or she has the same array of interactional competencies as the participants of the AIDS counselling sessions have” (1997: 215-216, cited Silverman, 2000: 109). In this sense therefore the practices outlined in the conversation analytic section of my research can be generalised as describing possibilities that might exist in any genetic counselling setting.

Dissemination of Research Findings

I conclude this chapter with a brief consideration of the means in which I hope to disseminate my findings. The bulk of the total work will be reproduced and

submitted in this PhD thesis. I would also anticipate producing other reports in line with clinical requests for information on specific areas such as client satisfaction, expectations etc. The most accessible or most useful form in which to communicate my findings to them can be negotiated with the supporting centre. I have also already made presentations of findings to relevant conferences and intend to submit articles for possible publication in relevant journals.

Chapter 4

Genetic counselling and the therapeutic Community

Introduction

This chapter presents my analysis of the genetic counsellor descriptions of the structure and function of the genetic counselling role. Treating the interview responses as situated accounts I consider the concepts and terminology that the counsellors draw on as they construct their stories of what their work entails. I look at the similarity of these concepts to those of the Rogerian counselling community and reflect on how this might be influenced by the socio-political background in which they are found. I consider their reported views on whether genetic counselling is a counselling or a medical interaction and discuss how this might be seen to differ according to the medical or nursing profession in which they are trained. I look at how nurses and doctors are careful, in their capacity as genetic counsellors, to define for themselves a separate role. Finally I discuss the difficulties with conflicting responsibilities that the genetic counsellors raise and show how they call on alternative ethics to defend their moral competence when they fail to meet the Rogerian ethos on which their profession claims to be based.

Treating the genetic counsellor interviews as ‘situated accounts’, as already introduced in the previous chapter, implies certain assumptions and presuppositions about the nature, status and function of the interview data. Scott and Lyman define an account as “a linguistic device employed whenever an action is subjected to valuative inquiry” and state that such accounts “are “situated” according to the statuses of the interactants” (1963: 46). Dingwall (1997:58-59) discusses how the interview is a social situation where “the interviewer defines what the parties are going to talk about”, where “order is deliberately put under stress”, and where “the respondent is.. concerned to bring the occasion off in a way that demonstrates his or her competence as a member of whatever community is invoked by the interview topic”. This, he states, “is an inescapable constraint on face-to-face interaction” (p59). In my genetic counsellor interviews, therefore, the situation of the respondents is subject to the following influences. First, the status of myself as the researcher

and interviewer and themselves as professionals and interviewees. Second, the additional complication of my separate status as a practising counsellor, which may in itself carry the potential to influence their responses. Third, they are likely to view themselves or their role as potentially under evaluation and fourth, to be concerned to “demonstrate their moral adequacy” (Seale, 1995: 388) as members of the genetic counselling community. Consequently I am not treating the status of the data as “reports on external realities” (Silverman, 1993:106) or as “reproductions of the mental states” (Murphy, 1999: 192) which motivate the genetic counsellors as they pursue the activities that make up their role. I am treating them rather as “displays of perspectives or moral forms” (Silverman, 1993:106). To quote Silverman again, the focus is on what the genetic counsellors “are *doing* through their talk” (ibid:106). I am not concerned so much with truth or falsity but with what they are trying to achieve with their accounts and with why this might be so. Understanding this will give insight into the particular moral constructs and pressures that underlie their role, potentially shaping and constraining their consultation behaviour.

Functions and Structure of the Genetic counselling Role

The focus of this chapter as a whole centres around the ways in which the genetic counsellors present the main functions and structure of their role. This is of relevance to the questions set by this thesis in considering both what their role entails and the consequent nature (ie medical or counselling) of the genetic counselling interaction. The constructs that the genetic counsellors invoke when presenting their accounts are likely to be representations of the kinds of factors that will be influential as they pursue their daily tasks. As the later parts of the chapter indicate they are also reflective of the dilemmas that accompany the potentially conflicting functions that their professional association with the counselling community leaves them attempting to fulfil.

On a scan through the data two themes were immediately apparent. First, that there was a differentiation between the nurse-counsellors and the doctors in a) their positioning of themselves as participating in a counselling or a medical interaction and in b) their definitions of what their role entails. Second that, regardless of this role differentiation, the genetic counsellors’ talk was threaded

through with a strong undercurrent of concepts and themes that could be identified as consistent with a Rogerian counselling philosophy. I will deal with each of these in turn.

A counselling or a medical interaction?

In response to my question on how they perceived the structure of the genetic counselling interaction, there was a marked difference in the views of the doctors and the nurse-counsellors. The nurse-counsellors all stated that they recognised that there was a difference between a counselling or a medical interaction and predominantly presented it as both counselling *and* medical. As counsellor VII declared:

“Oh I think there’s a difference, I think how I see my contact is that obviously I think it’s a mixture of the two” (VII NC)

They were also keen to identify themselves more strongly with a counselling position than a medical one, stating for example,

“It’s medical end of counselling I would say rather than counselling end of medicine” (VI NC).

“If I had to say either/or I would say the counselling rather than medical” (VII NC).

The recognition that this might be different to how the doctors perceive themselves was also overtly declared:-

“the medics would probably say medical and we’d probably say counselling” (VIII NC).

This openly acknowledges that, although both doctors and nurse-counsellors in this unit share the label ‘genetic counsellor’, their roles may not be, or they may not perceive them to be, the same.

We can see the nurse-counsellors, therefore, being clear to identify themselves as associated with both the counselling and the medical professions but also to locate themselves as working *predominantly* within a counselling framework. They differentiate this from the position that the doctors might take, claiming that they might consider themselves as more ‘medical’. This forms a key part

of the ways in which throughout the interviews nurse-counsellors define their job as different to that of the doctors. In a sense jostling in the same occupational arena as the doctors, but without a doctor's medical background to fall back on, their accounts stress instead their counselling skills and their involvement in more counselling-type functions. Indeed there was at times a suggestion that they needed to be there to protect the clients from the doctors' possible lack of counselling skills. In the words of respondent VI;

“...throughout the process kind of you know picking up on the kind of social and emotional dimensions of what's going on like you know when they come to the clinic um you know the doctors vary in the amount of kind of counselling in inverted commas involvement that they want to have so like some are extremely competent counsellors and you just sit there basically and let them get on with it but some there's well I feel more of a need to kind of - not acting as an advocate ..but kind of watching out for the kind of emotional dimensions of what's going on” (VI NC).

There was an overall sense, as here, that the doctors might not see 'counselling' as their role and that the nurse-counsellors were both there to take this position *and* to see that the client's emotional needs were picked up on.

What the nurse-counsellors do within this process is to carve out for themselves interactionally a professional role that is separate and distinct from the doctors. This is reflected many times at different points within the interview data, both by the nurse-counsellors and by the doctors themselves. The nurse-counsellors do not wish to relinquish their association with the medical community so they do not describe themselves exclusively as having a counselling role, but, equally, they are keen to establish a professional position that is uniquely their own. This may be associated with the comparative difference that still to some extent exists between the doctor's and the nurse's status within the medical hierarchy. It may also be associated with the need for non-medical health service practitioners to establish and consolidate their roles as unique and essential. Identifying themselves wholly with medical roles may leave the potential for them to be seen as replicating the work of doctors but without the doctor's level of qualification. Similarly in an under-resourced and over-stretched health service there is continual awareness that, if health professionals cannot justify their time and their specific functions as necessary

and cost-effective, their role may be eradicated or subsumed into others. The nurse-counsellors attempt to do this in these interviews by identifying themselves more strongly than the doctors with the counselling community as seen above, and by claiming primarily for themselves functions such as psycho-social support, information or family-tree gathering and preparing clients for, and supporting them in, their consultations with the doctors at the clinic. This is illustrated quite clearly in the following quotation (which includes but extends the one reproduced above).

“..my role is to kind of manage the psycho-social processes around the genetic information so on the ground that’s extremely broad ranging I would say going from ... where people are at emotionally and particularly where they are at emotionally in a way that might kind of make it difficult for them to make good use of the information... throughout the process you know picking up on the kind of social and emotional dimensions of what’s going on so like you know when they come to the clinic um you know the doctors vary in the amount of kind of counselling in inverted commas involvement that they want to have so like some are extremely competent counsellors and you just sit there basically and let them get on with it but some there’s well I feel more of a need to kind of -not acting as an advocate ..kind of watching out for the kind of emotional dimensions of what’s going on and sort of making my contributions on the lines of if I think somebody is not listening I might sort of intervene and say you know I notice you’re getting upset and .. call a halt to the information giving process for a while until we’ve dealt with that kind of thing” (VI NC).

Here nurse-counsellor VI is locating psycho-social support as central to her role and explaining how she carries this through into her actions and contributions in the clinic consultations. She translates the potentially vague concept of ‘psycho-social processes’ into specific tasks and terms. In this way she is defining an active and separate role for herself both in the home visits and in the clinic consultation. This is perhaps particularly important when the evidence of the recorded consultations used in this study suggests that the contributions of the nurse-counsellors to actual consultations in the clinic are both marginal and minimal. The same respondent does acknowledge this inequality to some extent when she describes the clinic visit as “the doctor’s party” but is quick to suggest that “if the doctor came on a home visit I would expect to be taking the lead” (thereby defining the boundaries as spatial as well as professional). She is also quick to rise to her own defence when I suggest I am hearing her role in the clinic as “facilitative to the doctor’s role in

information-giving”, responding “ooh I could bristle about that couldn’t I” and going on to describe her role rather as “facilitative to the *family* rather than the doctor” (VII NC). By appealing to the family, the proper subject of a genetic counselling interaction, she then justifies her presence as significant in its own right.

Her ascribing of psycho-social support as of major importance is typical of the nurse-counsellor interviews as a whole. Their accounts are consistent in stressing this as a major function that is more specifically their own. It is seen as being part of the counselling side of their role. In this they are supported by the doctors who, while they claim to be sensitive to the need to deal with emotions as they arise, were equally consistent in defining further emotional support as primarily the nurse-counsellors’ role. The following quotations are representative of their responses.

“... a lot of that is actually addressed by the nurse-counsellors who sit in on most consultations with us and in fact have visited the family before and have tried to work through the emotional problems with the family by having a chat with them even before they have come to us” (III Dr).

“I saw my role, if someone was distressed or there was something that they were finding difficult, drawing them out so they were able to discuss that and suggesting that they might find it helpful to have a word with someone else” (IV Dr). (‘Someone else’ was later clarified as the nurse-counsellors).

The doctors then are constructing an account that specifically *dissociates* their primary role from the need to provide psycho-social support or to deal in any depth with client “emotional problems”. This they state quite clearly is *not* part of their remit. Their accounts do not suggest that they will totally ignore client distress but rather that it is the *nurse-counsellors’* role to explore or get to the bottom of it. Working through client “emotional problems” is considered to be equivalent to “having a chat with them”. Respondent V – who, as will be seen later, is much more counselling oriented than his doctor colleagues - was of the opinion that this view is typical of doctors’ undervaluing of counselling as a whole. Using the example of conversations with a fertility counsellor he described a very similar response to that made by respondent III.

Co “...and just the same way as counselling is let’s face it undervalued

and I mean just to quote from Y's own colleagues who are of the opinion you have a very nice chat with people.... And er you know we know you do a very nice little counselling as though it was just you know... (pause)
I'viewr "Tea and biscuits?".
Co "Yeh *absolutely*" (V Dr).

Given that the interviewees were unaware of course of the comments voiced by their colleagues, the similarity between this description and the words used by respondent III would support the idea that there is a belief among medics that counselling work is of relatively little value or maybe requires less professional expertise. It is perceived to be of lesser value than the 'real', potentially more important work of being a doctor. It would not be surprising therefore to find them working within the interviews to minimise their involvement in counselling and to stress their identity and role as medical doctors. Being seen as a counsellor might diminish their moral adequacy as medics. It would also not be surprising, as indeed we have seen, to find them allocating this work as more appropriate for the nurse-counsellors.

The views of the majority of the doctors on the structure of the genetic counselling interaction support this and reflect an allegiance to their medical role. This can be seen in the following examples.

"I see them as medical appointments... I don't like the word genetic counselling I prefer genetic advice it's less restrictive" (III Dr).

"I've never done sort of counselling or any form of psychotherapy so I would see it as a medical appointment" (IV Dr).

"There's certainly a difference but they're sort of intertwined I think in our job But I think you know from the medical clinic session point of view most of its information-giving, a lot of people won't need any in-depth counselling" (II Dr).

In these extracts the doctors are positioning themselves as predominantly medical in orientation. Although they are being interviewed here in their capacity as genetic counsellors they are also aligning themselves as medics and suggesting that they are not there primarily to 'counsel'. Respondent III in fact overtly denounces the counselling aspect as he states (controversially given the genetic counselling profession's rejection of advice-giving) he doesn't like it

being called genetic counselling because it's "too restrictive" and he would prefer it to be called "genetic advice". This, presumably, would give him the leeway to retain his role as medical expert and allow him to offer opinions based on this. Unlike the nurse-counsellors, who to some degree may feel the need to create a role that is uniquely theirs, the doctors are confident in the status, training and, probably, the job security of their medical role. They are concerned within the interviews as a whole to retain their identity as 'medical doctors'. They call upon both the function of the role – medical or genetic information-giving, diagnosis etc - and on issues such as their professional background or training to justify this. Interestingly respondent II presents the moral justification that this is what the clients need:- not getting involved in counselling is acceptable because it is not why clients are there. Respondent IV justifies her view by declaring it can only be a medical appointment because she has no counselling or psychotherapy experience. She expresses this even more explicitly elsewhere when discussing counselling support -

"I never saw it as my role to offer that kind of support because that's not what I'm *trained* to do" (IV Dr).

Whereas the nurse-counsellors in the genetic counselling role are currently struggling to establish a professional base with the creation of new formalised counselling entrance paths, Masters degrees and training programmes, the medics have an already accredited and high status training and background on which to both call and stand. Like the nurse-counsellors they are keen to stress the differentiation between the two roles, but for them this includes an emphasis on their *medical* background and on the medical rather than the counselling aspects of their genetic counselling role.

Only one of the doctors appeared to reject this differentiation, stating:

"I don't like to think of it as a medical interaction if we're talking of a medical model of symptoms, signs, diagnosis, treatment cos that medical model has so much for the doctor to do and the poor patient is just a passive recipient" (V Dr).

The story that he was keen to portray was of himself primarily as a genetic *counsellor*. He saw a primarily medical interaction as one that is characterised by a doctor-led one-sided discussion and which results in a family that is not

going to be “well-counselled”. The patient is passive and plays little part in decisions about what is to be done or what is to be talked about. This was a role, or at least a particular method of fulfilling that role, that verbally he explicitly rejected. He asserted in opposition to this that the genetic counselling process should be “dynamic” and firmly “a counselling based thing” oriented to client thoughts, ideas and discussion. “Its most important aim” was to

“have people first going out with understanding and secondly with a feeling that they are able to make that decision themselves, empowering them to make the decision” (V Dr).

What is particularly interesting in this is that this respondent, although there is a time-gap between the recorded consultations and the interviews, is present in both parts of the study. Despite his strong declaration and adherence to counselling principles in the interview, however, a number of his recorded consultations have a communication format and style very similar to that found in other medical interactions. Possible philosophical or broader societal or professional reasons why this espoused belief in the importance of dynamic interaction does not translate into practice differences are discussed at the end of this chapter.

This clear differentiation on the part of both nurse-counsellors and doctors in their accounts of the structure and function of what their job includes, suggests that it may represent a significant factor in the day-to-day operation of their respective roles. Although, as will be seen, many of their tasks are described as similar there may be differences in the emphases or contextual contexts that they bring. Nurse-counsellor/doctor boundaries could, therefore, be potentially relevant in any assessment of what genetic counselling involves. The work of Allen (1997), however, indicates that professional boundary claims in interview are not always representative of how they may behave. Further research would be necessary to see whether this differentiation could be seen to be reflected in their actual professional practice.

Genetic counselling and a Rogerian counselling philosophy

In spite of this role differentiation and the propensity of the doctors in general to identify themselves as functioning predominantly as medics, concepts reflecting a Rogerian counselling ethos were prominent in both doctors' and nurse-counsellors' accounts of their role. Intermingled with the more pragmatic information that the genetic counsellors used to describe the practical functions that make up their role, there was an underlying rhetoric of counselling-type terms and ideals. For the doctors this, and indeed the evidence of the recorded consultations, might be seen as contradictory. Despite all the genetic counsellor accounts, there were a number of areas within the consultations where the proffered concepts and the real interaction data did not concur. This gives rise to two issues which it might be pertinent to mention here. The first is, as Whyte (1980) observed, that ambivalence is characteristic in the mind of individuals. Individuals "can and do", he states, "hold conflicting sentiments at any given time" and "varying sentiments according to the situations in which they find themselves" (1980: 117). It is not necessarily inconsistent for the medics to hold two positions according to the context of the question that is being addressed. Accepting this is compatible with the decision not to view the interview data as giving access to one stable meaning or internal or external realities. It also prevents the necessity to enter into discussions around truth or falsehood. The second is that the question is also raised, *why* do the accounts of the genetic counsellors at times not match the consultation patterns that are revealed? Again the answer to this can be sought within the selected approach to the interview data. If the interview responses are treated as moral perspectives or morally adequate accounts then, in addition to asking what the genetic counsellors are doing with the tales they tell, we also need to consider the moral or philosophical background against which these tales must be set. In Scott and Lyman's terms, we must ask what is the framework against which their actions are subject to valuative inquiry? I will consider both the interview data and these questions within the following sections.

An analysis of the data on the functions and role of the genetic counsellor revealed a number of recurrent themes. As already stated these included both practical tasks and a broader rhetoric around them. Tasks which were

highlighted as significant and central functions for both nurse-counsellors and doctors included genetic information-delivery, education, and ensuring informed decision-making and consent. Tasks which were highlighted as part of specifically the doctors' role included diagnosis, examination and treatment, and tasks that were highlighted as part of the nurse-counsellors' role were psycho-social support and information-gathering. Genetic testing was also described as significant although it was not specified who might do this. The broader rhetoric apparent within the data involved the manner in which these tasks should be achieved. Counsellor accounts stressed that information-delivery should always be set in the context of clients' lives, that allowing the client to set the agenda should be a primary goal, that non-directiveness is vitally important and across all areas that the genetic counsellors should be seen not just as informing, and particularly not as guiding or advising, but rather as facilitating, enabling, communicating and empowering.

Looking at these themes two factors are immediately apparent. First that the practical tasks, genetic information delivery, ensuring informed consent, testing, diagnosis, examination and treatment are primarily medical activities. This has significance when considering both whether genetic counselling is primarily a counselling or a medical activity or indeed whether it is 'counselling' in the traditional sense of the word. It also has implications for what 'counselling' may mean in genetic health-care terms. Second, that the accounts of *how* these tasks are to be achieved reflect an essentially counselling ethos. Before I go on to discuss these factors further let us look in more detail at the data from which these conclusions are drawn.

The following quotations have been selected to encapsulate many of the points I have highlighted.

"I think the important thing is to give the clients or the patients the information ... in a form that they can understand and use for their own benefit and help them sort of assimilate that information and ... being the bridge between the science and what's actually available to people and helping them decide. or a discussion of options, facilitating the decision-making too which is very often hard because there are no rights and wrongs in the decisions people make" (II Dr).

“In a general way I see it as a sort of facilitator enabler role but I see that to have many sorts of aspects to it so it might be around information, education, sharing of information, explaining information in a way that people can understand. It might be around helping people unpick emotional barriers so that they are in a frame of mind where they can access the information... but I would class all these things as being an enabler and empowering people to take control of this lump of information and help them some way towards doing something with it if that’s what they feel they need to do” (IX NC).

“I think as a facilitator for the families concerned, you know, make sure they get the best from the material and see things from their point of view as well as the medical point of view. Giving accurate information certainly, to support the family all the way through their journey” (VIII NC)

“It’s about giving information in a way that people can understand and also use... can put that information in the context of their lives” (IV Dr).

“..for diagnostic reasons.. to try and reach some unifying diagnosis...to discuss the genetics of the condition and to talk with the family about things like what are the chances of this happening again if maybe they have another pregnancy, what are the pre-natal tests they can have, then talk about the condition itself, what the long-term implications are” (III).

First, then, what is apparent across all these quotations is the centrality of information delivery to the role of the genetic counsellor. This is an inescapable part of their job and one which occupies a large proportion of their time. Respondent III’s assessment goes some way towards identifying what the *content* of this may be. He highlights genetic information, the chances of recurrence, testing and the long-term implications of the condition itself. These issues were common throughout the interviews as a whole. The data revealed that the facts on inheritance, the meaning of the condition for the family or the individual, the options for reproduction and the tests available according to the disorder involved were repeatedly raised. Other areas raised by the counsellors included ensuring the client has all the information needed to make an informed decision on testing, treatment and reproduction, and accompanying this with “a discussion of options” as respondent II suggests. Respondent III also discusses diagnosis. Diagnosis might in itself be classed as information for both family and practitioner, although it might also fill a deeper role in dictating treatment, prognosis and future options.

The mention of education by respondent IX is also significant. A number of the counsellors expressed the belief that their role was educational - “there is a straight educative side to what I do” (VI NC) – they saw themselves as not only informing but also educating clients or, as above, “being the bridge between the science and what’s available to them” (II Dr). Genetic information was seen as complex and the genetic counsellors job “to really find the key to make them understand” (V Dr). We can begin to pick up an image of a service, therefore, being portrayed as heavily involved in transmitting, communicating and interpreting genetic information to the client.

Most of these functions are consistent with the AGNC (2001) definition reproduced on page 10 in chapter one. Their emphasis of these functions, then, might suggest that the genetic counsellors are aware of the definitions relevant to their profession and, to portray competence, are keen to describe themselves as adhering to them. The recorded consultations, however, also indicate that their reports are consistent with this particular body of data. The consultations contain large amounts of genetic information-delivery, many sequences on options for testing and reproduction and episodes of diagnosis. They also contains sequences of explanation or interpretation of genetic data using a variety of educational means such as diagrams, simplifications etc. What is apparent is that, whatever else may occur, genetic counselling for this department – or ‘counselling’ in genetic health-care terms - frequently involves the transmission of significant amounts of complex medical information. If this is so, therefore, then there is a strong suggestion that genetic counselling must hold some dissimilarities to forms of psychotherapeutic counselling. Information-delivery and education do not generally occupy a significant role in Feltham’s “personal, emotional or psychological kind” of counselling (1995: 5). Questions must also be raised, in Silverman’s (1997) terms, as to whether an activity with such a major emphasis on medical information – and other medical tasks - can indeed be accurately identified as ‘counselling’ at all.

Facilitating, empowering and enabling

In the quotations reported on page 95-96, however, the genetic counsellors can be seen to be doing far more than simply reporting that their role involves

information-delivery, education, diagnosis and the discussion of options necessary for informed consent. They are also situating themselves as working from within an overall counselling framework. If we consider this data in more detail this is revealed in a number of key counselling concepts and terminology. First the descriptors 'facilitate' (or facilitator), 'empowering' and 'enabler' occur frequently within these statements. These terms are not insignificant as part of the discourse around their role, they are not neutral but have significance as concepts commonly found in psychotherapeutic discourse. They are consistent with the Rogerian philosophy that genetic counselling professes to espouse. Bond (1993: 62) highlights the term 'facilitator' as being one of a number of metaphors used to describe the counsellor's role. Along with others not relevant here, he sees it as serving the purpose "of maintaining an emphasis on the client's responsibility for his contributions in counselling and for its outcome" (1993: 62). It contributes to a division of responsibility which overall sees counsellors responsible for the counselling *method* and clients for its *outcome*. Facilitate, facilitator and facilitating occur frequently in definitive works on the definition on counselling, including the BAC definition quoted in chapter one. (See for example Feltham & Dryden 1993, Feltham 1995: 8, 17, 21). Strawbridge (1999: 295) says of the word 'empowering', "It is a buzz-word widely used in the helping professions and has a moral flavour" and the term "enabler" has similar connotations.

All these terms support the idea that the professional does not take control but rather provides the conditions for the client to do so. They can also be tied into the prevailing ethos of self-governance described by Rose (1998, 1999), and the current dominance of autonomy and self-determination in medical and psychotherapeutic arenas. Feltham (1995) describes the ethic of autonomy as often having "the flavour of a sacred right" and of being "intimately associated with the concept of authenticity and our right, if not duty, to be authentic". Counsellors, he states "are expected to respect and safeguard the autonomy of the client and no other concept is quite so central to counselling and psychotherapy". It is "inviolable" within our culture (1995: 130). In an account illustrating the moral competence of any counselling professional, therefore, it might be expected to be paramount and its absence potentially accountable.

So, the genetic counsellors here can be seen to invoke these concepts repeatedly. Respondent IX places them as central to all aspects of the genetic counselling role – “in a general way I see it as a sort of facilitator enabler role”. She specifies that this role might include information, education, and “emotional barriers”. She reinforces this concept by calling on the term “empowering” also, “empowering people to take control of this lump of information and help them somehow towards doing something with it if that’s what they need to do”. The “doing something with it if that’s what they need to do” places responsibility for any action, or decision for action, strongly in the hands of the individual. In this way she is positioning herself firmly in the centre of a counselling based ethos and her role as solidly counselling oriented. Her role as she is defining it, is not solely to transmit factual information or to make any attempt to guide, control or advise but rather the much more politically powerful one of empowerment and enabling of self-governance. In this way she is linking her professional role into a much wider social and political discourse that reifies autonomy and the rationale of free choice. She is also very much locating herself within the genetic counselling professional discourse which, as has already been stated, declares itself as espousing a Rogerian counselling philosophy.

Respondent II can also be seen to invoke the concept of facilitation, although less broadly. Here it is applied specifically to decision-making - “facilitating the decision-making too” –, which is in itself significant. Perhaps the most sensitive of areas for genetic counselling or for human genetics is the area of choice around decisions involving reproduction. It is here where the spectre of eugenics looms most large. The genetic counselling profession, therefore, is keen to dissociate from any suggestion that clients might be influenced by the genetic counsellors towards any particular decisions. This sensitivity is reflected in these interviews. Respondent II’s response was typical of the interviews as a whole. Decision-making by the client was referred to frequently as an important part of genetic counselling. Areas involved might include whether or not to have testing, children or treatment or what to do in pregnancy when the presence of genetic disorder is indicated. In accord with Shiloh and

Saxe's claim that one of the main functions of genetic counselling is "the provision of 'objective' information from the counsellor and its interpretation by a patient" in order to help the patient understand the facts about his condition and make informed decisions (1989, in Michie et al, 1997: 101), there was a recognition that this was a major part of their role. Again this is also consistent with the AGNC definition reproduced in chapter 1.

Virtually always, however, the respondents presented this function in terms of *facilitating* clients to make their own informed decisions, with a corresponding emphasis on ensuring informed consent. Overall there was an explicit renunciation of any counsellor role in the decision itself – although as will be seen later this was not always without contention or difficulty. As respondent VII replied emphatically when asked if she had a role in client decision-making, "not in making the decision, no" (VII NC). Similarly, in line with Clarke's 1991 declaration that one of the primary aims of clinical genetics is to *support* clients in all their decisions, there was also an explicit emphasis on supporting the client in whatever they decide to do – "we'd be supporting them with whatever they decide and just be there if they wanted" (III Dr). What can be seen, therefore, is that in Bond's (1993) terms, the genetic counsellors are drawing on the counselling metaphor of being a facilitator in order to define a particular role for themselves in the process of client decision-making. As Bond describes, this places the responsibility for the decision outcome solely on the client. It also positions the counsellors once more in the wider socio-political discourse on the ethic of the free autonomous self and the belief that the professional is there to encourage the client to improve his/her own quality of life by making individual choices and exercising authority over themselves (Rose, 1998). This is accompanied by frequent reference to the associated concept of non-directiveness, which might also be said to fulfil a similar function. I will be discussing this further later in this chapter.

Client lives and a client-led agenda

To return to the discussion on the underlying counselling concepts present within the counsellors' talk, we have seen that prominent within this data is the recurrence of the terms 'facilitator', 'empowering' and 'enabler' in the genetic

counsellors' descriptions of their role. The use of these terms is the first of a number of ways in which they are potentially identifying themselves with a psychotherapeutic and Rogerian discourse and representing their moral adequacy as counsellors. A second recognisable concept lies in the use of such phrases as "in the context of their lives" (IV Dr), "use for their own benefit" (II Dr) and "see things from their own point of view as well as the medical point of view" (VIII NC). Here the genetic counsellors are suggesting that the clients' needs and the relevance of the information for the clients' life-worlds should be central to the consultation goals. Concentrating on the delivery of medical information alone is limited and potentially useless, it must be tailored to the context of their individual 'real-world' lives. Respondent VIII might be said to make this explicit when she contrasts the clients' "own point of view" with "the medical point of view". This presupposes that there is a difference between the two. It reflects perhaps the influence of work such as Mishler's (1984), who highlighted what he called "the voice of medicine" and "the voice of the lifeworld" as two contrasting discourses that can be identified within medical interactions (see page 21-22). The medics use predominantly the voice of medicine and the patients the voice of the lifeworld. Mishler's criticism of the medical practitioners in his study was that they excluded and often ignored the voice of the lifeworld when introduced by the patients, keeping the consultation within a medical model and maintaining the focus on doctor defined concerns. Although his model can be criticised as difficult to define with any precision, his work was nevertheless central to a major push among critics of the traditional medical model of practising medicine towards a more patient-centred model that prioritises listening and awareness of the patient's broader concerns. This is of course very much at the centre of the Rogerian client-centred philosophy also. What the genetic counsellors are doing here, therefore, is showing themselves to be aware of the broader debates around their role. They are demonstrating their understanding that there are different ways of dealing with patients/clients, and medical information, and are situating themselves within a client-centred model of working. Their reported emphasis in these statements, and throughout the interviews as a whole, is on gearing the counselling sessions to the needs of the client rather than the

doctor. They are telling us that to be competent genetic counsellors requires them to be committed to a client-centred role.

This is supported by a corresponding emphasis that is also very prevalent in the genetic counsellor accounts, the need for the client to set the agenda. Virtually all the respondents reported the importance of the need to concentrate on the information that the clients want to know, rather than ploughing on with a pre-set counsellor-led information agenda. Finding out the clients' agenda early in the session was presented as paramount, with only one counsellor noticeable by an omission to mention either of these areas. This opening statement by counsellor V reflects the centrality of pausing and finding out first what the clients' needs really are. He is rejecting the idea that the purpose of the genetic counselling consultation is only "to talk about genetics" and advocating a client-centred approach. It is significant, however, that he is still suggesting that their 'needs' from the session might be question-based. This is common within the recorded consultations discussed in chapters 6 and 7.

"I think the most important thing, it is to answer the questions the patients have. Sometimes you get referrals from a doctor to say "please can you talk to this man about genetics" and when we say "what do you want to know?", the man doesn't want to know a thing about genetics and in fact it was alien to him... so the first thing I want to do is to establish what are their needs..." (V Dr).

The question of who sets the agenda in genetic counselling has been highlighted by a number of studies. Michie, McDonald et al (1997), Sorenson et al (1981) and Wertz et al (1986) all picked up discrepancies between what clients and counsellors saw as important in genetic counselling. This led Michie, McDonald et al to question who prioritises outcomes and whether concentration on one may be at the expense of another. (1997, p105). If genetic counselling is for the *clients* then setting an agenda and prioritising outcomes to meet their needs is obviously of central importance. The genetic counsellors in this study, often at the very beginning of the interview, were strong in propounding the view that finding out and pursuing the client's agenda is of *primary* importance. The emphasis throughout their accounts is on the client's needs being put first, in agenda, questions, information-giving, decision-making and emotional aspects. There was a declared resistance to the idea of

“churning” information out and an emphasis on “tuning in” to where clients were coming from, with information-giving described as “secondary” in comparison. The following examples were typical of the statements made.

“We do, or at least most of us do, try very hard to operate on the basis of what's their agenda and relating to their agenda um rather than just churning it all out”
(VI NC).

“Yeh tuning in to where they're coming from first is very important rather than launching into a monologue Their agenda is the most important thing. I think as doctors we get quite defensive oh I must tell them a b c you know, I've got to cover myself but erm.. I think in genetics that's.... it's a, secondary thing you need to cover things but you need to be... to make sure that they're actually receptive” (II Dr).

In these examples we can see the respondents highlighting the importance of ascertaining what the client's agenda is in preference to pursuing their own. Respondent II is clear that it is “the most important thing”. She goes on in fact to refer to the need that doctors may feel to make sure certain information is given in order to “cover” themselves, presumably against litigation or allegations that they have not ensured informed consent. The need to ensure informed consent, therefore, is subordinated here to finding out and following the client's agenda. Although she is claiming to establish an order of priority in favour of client agenda-setting this is interesting as it raises one of the dilemmas that central tenets of the Rogerian counselling philosophy – as client agenda-setting is - can cause. Part of the genetic counselling role, as already stated, includes the need to ensure informed consent. Of necessity this often involves the transmission of specific medical or genetic information. As the conversation analytic study of the recorded consultations will illustrate, the two functions are not always compatible. Giving relevant information may sometimes only be achieved at the cost of moving outside of the client's agenda. More broadly it is not always possible to follow a counselling ethos in the process of achieving medical tasks. This will be illustrated further in the following section on non-directiveness.

What can be seen here, then, is the genetic counsellors giving precedence, and indeed primary position, in their narrative to what is, as already stated, one of

the central tenets of Rogerian counselling theory. Rogers was very clear that part of his client-centred ethos included the premise that the client should be responsible for setting the session agenda and that the counsellor should only go where the client led. This is an essential part of the *client*-centred emphasis that gave the approach its name. It is significantly different to “the bureaucratic format” to medical consultations identified by Strong (1979) as dominant and collaboratively created by doctor and patient across varied medical settings. Here doctors were assumed to be responsible for setting the agenda and patients brought topics for solution not discussion. More recent conversation analytic studies (ie ten Have 1991, Pilnick 1999) have confirmed this, showing that medical interactions are predominantly co-constructed by patient and doctor to be asymmetrical in form, with topic and agenda initiation dominated by the practitioner but, importantly, actively ‘dispreferred’ by the patient. What the genetic counsellors are doing, therefore, is accessing a discourse that dissociates themselves once more from a traditional medical model and identifies them with a client-centred Rogerian ethos. They are presenting an account of themselves as functioning as competent members of a client-centred profession. Coupled with the already discussed counselling rhetoric this might suggest their genetic counselling would hold a significant leaning towards, or similarity to, a psychotherapeutic type interaction. What is perhaps of particular interest in this study, however, is that this prioritising of the client’s agenda does not work out so clearly in genetic counselling practice. The evidence of the recorded consultations illustrates that although there *is* often an agenda-setting segment to the consultation, it is often limited or guided by the practitioner. It is rare that the client is offered the opportunity to have an open choice as to what they want to do. Similarly many of the interactions possess communication formats that resemble those found in studies of other medical interactions and show little indication of being client- rather than professional-led. The question is raised once more, therefore, if there is a mismatch between discourse and practice, what is motivating the counsellors to produce a counselling rhetoric in response to a situation where they are called upon to give an account of the nature of their role?

This question is heightened by the fact that the genetic counsellors themselves are aware that the concept of client agenda-setting does not always sit comfortably with the particular circumstances of their role. A number of the interviewees raised the point that multiple clients, or the concern of genetic counselling with the family rather than the individual, could make following the client's agenda problematic. As respondent IV explained

“We can get tied up in absolute knots where different people have entirely different agendas for the consultation and you have somebody hijacking somebody else's consultation” (IV Dr).

So although expressing their moral commitment to client agenda-setting, they were also letting me know that multiple clients made their position difficult. If different clients had different aims then they were facing an impossible task. Significantly they were not questioning the aim but highlighting the difference between theory and practice. Goals and reality are not always compatible. This is a dilemma that becomes even more obvious in the following section.

Non-directiveness

A third recognisable Rogerian counselling concept within the genetic counsellor interviews is the theme of non-directiveness. Although it is implied in the suggestions of facilitation, particularly within the realm of decision-making, it should be pointed out that this was not a theme that always occurred spontaneously, but rather as a response to specific questions on my part. Nevertheless the depth and similarity of the interviewee responses suggested that this is an area of significance within their professional discourse and within their role. Given its prominence in the genetic counselling professional literature this is not surprising.

As stated in chapter one, the term non-directiveness originates from the work of Carl Rogers. Rogers' overall belief was that it is the client who knows best what is wrong in his/her life and that, in the final analysis, it is also the client who knows best how to move forward. The counsellor's task, therefore, is “to enable the client to make contact with his own inner resources rather than to guide, advise or in some other way influence the direction the client should

take” (Mearns and Thorne, 1988: 1). He was very clear that the counsellor was not to be seen in the role of ‘expert’, believing that “such an ethos has the effect of reducing human beings to the level of objects and of placing disproportionate power in the hands of the few” (Mearns and Thorne, 1988: 5). Human beings, to Rogers, were more than capable of taking responsibility for their own lives and should be encouraged to do so. Non-directiveness, therefore, and a corresponding rejection of the role of ‘expert’, was central to his ethics and practice, and central to his client-centred role.

Throughout the interview responses there was no overt challenge to the *importance* of non-directiveness within the genetic counselling role. Many examples were produced that were in accord with this and there was an overall consensus that they should “try to be as non-directive as possible” (III Dr). The picture presented was that it was a goal towards which they were expected to aspire, and with which they were in agreement. Respondent III summarised this, and gave an indication of its institutional origins when he said:

“Well I mean it is traditional teaching, that’s the way we’re kind of trained, to be non-directive and we try to be as non-directive as possible” (III Dr).

Here he is reflecting the centrality of the ethos of non-directiveness to the genetic counselling profession as a whole. As discussed in chapter one it is widely proclaimed as a core tenet on which genetic counselling practice is based. Again it is also in accord with the Rogerian philosophy they profess to espouse. As respondent III is indicating it is firmly embedded in both its professional ethics and in its professional training. In declaring their allegiance to it, therefore, the genetic counsellors are displaying themselves to be morally committed to a central part of their professional code, and to working in ways consistent with their training. Its importance is such that, as has already been suggested, the absence of such a commitment would have been a significant, and potentially accountable, omission.

Its significance as part of their training is also indicated perhaps in the similarities in the ways in which the genetic counsellors understood the term non-directiveness. The following three definitions of the concept recurred

repeatedly. Non-directiveness was seen as putting or giving information in a neutral manner, not giving cues which indicate your or society's views or opinions; and not attempting to influence clients in any particular direction. These are summed up in the following examples;

“I understand non-directiveness as putting information in a way that is neutral so you're not putting any weight either positive or negative to influence them making their choice, you're just giving them the information” (IV Dr).

“Well non-directiveness hopefully is....sort of the information giving side of genetic counselling, that you're actually going to have to provide information that's not going to indicate your bias one way or the other or what society's bias is one way or the other” (VII NC).

“Not directing them towards any direction in terms of not influencing any of their decisions personally because of your own experiences or whatever or your own thinking” (III Dr).

As the respondents report it, then, the *focus* of non-directiveness is associated with the provision of information to be used by clients for making choices, and the *function* of non-directiveness with ensuring that this information is given in such a way that these eventual choices are autonomous and uninfluenced by counsellor or society opinions. “It's trying to put the information in a neutral way so that person can make the best choices for themselves” (IV Dr). Many of the counsellors expanded this to include the concept of enabling clients to make the best use of this information in the context of their lives and thus to make the best decisions for themselves. This ties in with the moral perspective already discussed that a central part of the genetic counselling role is to facilitate clients in making their own informed decisions on life-choices related to genetic disorder. It also ties in with the wider encouragement of individual autonomy and the autonomous self.

The emphasis, therefore, is on neutrality and on not attempting to influence client decisions by giving information in a way that reveals the counsellor (or society's) opinion. It is also strongly focused on the task of decision-making. There are marked similarities with Clarke's definition of non-directiveness as quoted in Williams, Alderson and Farsides (2002). Clarke defined the purpose of non-directiveness as

“....not to lead clients to make particular decisions or choices (those preferred or recommended by the clinician, the health service or by society) but to help them to make the best decisions for themselves and their families as judged from their own perspectives” (1997: 180).

In giving accounts of themselves as supporting non-directiveness in this form, therefore, the genetic counsellors are a) showing their awareness of the meanings ascribed to non-directiveness within their profession, b) as already stated, showing their adherence to their professional code and c) once more allying with a wider socio-political rhetoric on the role of the professional as facilitating the autonomous self and individual choice. In addition to being a core value of the counselling community, this latter is a reflection of what Rose (1998) describes as one of the central tenets of Western liberalism. The reification of autonomy, coupled with the growth of the concern with democracy and what he calls ‘advanced’ forms of liberalism, has resulted in the construction of a notion of the ‘self’ as a subjective autonomous being and of destiny as a matter of individual responsibility (Rose, 1998: 151). Regardless of external circumstances, the responsibility for ‘governing the soul’ and improving personal quality of life has been removed from the political government to become the ostensible outcome of individual choice. The values of autonomy and self-realisation are celebrated to such an extent that the constructed ‘self’, claims Rose, is in the psychological sense “‘obliged to be free’” (1999: ii). The role of the ‘psy’, or therapeutic, professionals within this ideology then becomes to offer their expertise to facilitate this goal. So what the genetic counsellors are doing as they describe the necessity of presenting information in a neutral, non-directive way in order to encourage autonomous decisions, is both tying themselves into, and reiterating the rhetoric of, this broader societal and psychotherapeutic/psychological theme. In the realm of genetic choices they are presenting themselves as professionals offering options that maximise individuals’ “capacity... to exercise authority over themselves” (Rose, 1998: 63).

There was, however, another facet to the respondents’ views on non-directiveness. This is suggested in respondent III’s quotation on page 106. In using the words “we try to be as non-directive as *possible*” he is highlighting a

dilemma raised by many of the interviewees, that non-directiveness is not always easy to achieve. A range of opinions were presented, crossing the spectrum of belief from the overall possibility to the overall *impossibility* of being totally non-directive within the genetic counselling setting. In this they were reflecting the range of beliefs expressed in the genetic counselling literature, following Clarke's provocative letters challenging the possibility of non-directiveness in the early 1990s (see page 9). The responses of authors such as Super (1991), Harris and Hopkins 1991) and later, following Michie et al's (1997) study, Bernhardt (1997) and Kessler (1997), varied from "yes it's possible all or most of the time" to "no it's not possible at all". As the following quotations show this was very similar to the responses in this study.

"I've read a lot by Angus Clarke on directiveness and his argument is that it is not really possible and I don't agree with him.....I really do go for non-directiveness" (V Dr).

"I think it's almost impossible to be non-directive, I think it's very nice in theory but we all probably do put information in a particular way" (IV Dr).

"I don't think I could hand on heart say I am never directive, however hard I try" (VIII NC).

"I would hope that at least 99% of the time I could actually look back and think this was totally non-directive but yeh I think I would be living in cloud-cuckoo land if I said that *all* genetic counselling was entirely non-directive" (VII NC).

What is common to all these responses (and many others), with the exception of that by respondent V, is the representation that no matter how much they may try, non-directiveness can be hard to achieve in practice. Respondent V was the only counsellor who did not express reservations about the possibility of non-directiveness, although even he acknowledged "there are lots of traps around". They were very willing to be open on this subject, perhaps reflecting the liveliness of the debate within the profession as a whole. Again though, in the majority of their responses, there is still a public declaration that it is right to try. In reporting to me their difficulties they are situating themselves as morally correct in doing their best, but also representing themselves as engaged in a battle that is at times impossible to win.

The fundamental nature of this battle was highlighted by their claim that non-directiveness might exist in even the most basic of their tasks. There were a number of suggestions that in simply offering information, particularly around options for testing, they might be accused of being directive. As respondents VIII and I report:

“You can’t be totally non-directive, sometimes it’s very unintentional, you go expecting them to want something, a test for example, you might think that’s what they want, ... you realise you’re going down that track and they’re not. Because the fact is there’s directiveness in offering” (VIII NC).

“I wonder though if we are being directive just by offering options that they may not have even known were there” (I NC).

What they are suggesting here, therefore, is a conflict between their basic role as information-givers – or as those responsible for ensuring informed consent – and the non-directiveness they are expected to espouse. By simply giving information on testing they might be implying that these are options that *should* be considered or putting them into the field of debate when clients may not have known they exist. They are not *intending* to be directive, so morally they remain unblemished, but sometimes it might happen anyway. Respondent VII believed that even the *order* in which information is given could be perceived as directive –

“I think in whatever order you put things you’re somewhat being.. people perceive as being directive, I mean if you’re saying well there’s you know options, this, this or this, I mean I think many people would latch onto the first one” (VII NC).

As information has to be put in some order to be transmitted this again suggests that non-directiveness is very difficult to avoid. In using these examples then the genetic counsellors are communicating the extremity of their dilemma. However innocent their interventions, they are still at risk of being defined as directive.

A number of other factors were also called upon to justify or explain why it was sometimes very difficult to be non-directive. Some are reminiscent of Clarke (1991, 1993) and Bernhardt’s (1997) beliefs that “the very context of genetic counselling” contributes to the structural and practical impossibility of

non-directiveness (as indeed are those described above). One of the major factors highlighted concerned the medical setting and the difficulties involved when a particular course of action might be medically recommended. Respondent III described the ensuing dilemma in the following example.

- “ C “If somebody is taking vitamin C and they are at genetic risk of the C282Y homozygote, I think in that situation you might have to be a little directive.... I think because if you're non-directive about the situation you're.. You could be held negligent even you know, you have that information which could potentially reduce the risk of haemochromatosis in somebody and you're not telling them what to do so you know that's the flipside of the coin, that you've been negligent.”
- I “If you don't...”
- C “I would suggest...knowing about that information and haven't explained that it would be a good idea to stop” (III Dr).

Here respondent III is making the case that he believes there may be occasions, as in the example above, where it might be *negligent* to withhold information which might influence decision-making. He is explaining that he might feel the need to indicate to patients that taking vitamin C enhances the absorption of iron and is therefore not recommended for those at risk of haemochromatosis. (The damage caused by haemochromatosis is directly related to the body retaining too much iron). This might be said to be an example of what Elwyn, Gray and Clarke (2000: 136) call “clinical recommendation”, a situation in which the genetic counsellor in his or her clinical capacity believes some treatment or investigation to be in the client's best interest (and therefore one might say beneficent). What respondent III is presenting, therefore, is the moral dilemma between his role as a medic, with knowledge that could influence his patient's future health, and his ethical requirement as a genetic counsellor to maintain non-directiveness. His account calls upon the ethics of his medical profession, in which he is committed to beneficence, or to act positively for the patient's well-being, to justify occasions when he might need to contravene the ethic of non-directiveness. In this way his behaviour, though potentially accountable in terms of genetic counselling philosophy, can still be defined as morally adequate.

A similar example, which might be considered equivalent to Elwyn, Gray and Clarke's (2000: 136) definition of an “ethical recommendation”, a situation

where the genetic counsellor may feel that a course of action should be recommended for an ethical reason, is described by respondent VI. Here she is presenting a case where the suggestion is that it may be for a *relative* of the client's good that pure non-directiveness might not be appropriate.

"Say... somebody's discovered to be a carrier of cystic fibrosis and they've got a pregnant sister. You would want to be saying to that person maybe you want to do something with this information in a way that would actually be saying I think your sister *ought* to have this information." (VI NC).

She goes on to discuss how this is linked to another specific dilemma for genetic counselling, that responsibility is to the family rather than just the individual.

"I think that's also another example of why I'm certainly not non-directive... because we're dealing with family rather than an individual, that we have a responsibility to the whole family so there are certain situations where we actively want people to actively do something or the family needs that person to do something" (VI).

Again what is happening, therefore, is that respondent VI is appealing to an alternative frame of reference that prioritises a different moral need, this time the fact that being non-directive in the treatment of one client may neglect the needs of another. Genetic counselling's responsibility, unlike most forms of psychotherapeutic counselling, is broader than to just the individual. The ethic of beneficence, (or non-maleficence perhaps, in that not giving the information might constitute harm), extends to other members of the family also. So non-directiveness, although ethically a necessary and desirable goal, must be balanced against the need to work for the good of the whole family. In both these examples, then, in a similar way to the mothers in Murphy's study on infant feeding, the genetic counsellors might be said to be "drawing on a range of socially available legitimisations" to "defend their practices by redefining their behaviors in a positive light" (2000:304). They are aware that directive behaviour might be construed as morally accountable within the ethos of their profession, so they are calling on other equally valid aspects of their professional ethics to defend their actions and still assert themselves as morally competent practitioners.

Although they are careful to do this, however, the counsellors are, as has already been suggested, also involved with a more pragmatic concern. In asking them to describe for me their views on the structure and function of their role and on non-directiveness, I am also providing them with a potential forum for airing their problems and raising the profile of the dilemmas they face on a daily basis. The tensions between the medical and counselling aspects of their role appear to come to a head where the issue of non-directiveness is concerned, and the counsellors were keen to highlight this. They describe a multitude of areas where it may cause them problems, explaining how difficult it was from their own perspectives. They also, however, presented it as a moral dilemma not only for themselves but also for the clients. For many clients, they declared, “are coming along expecting to be given advice by somebody they are going to trust” (V Dr). So in addition to facing potential difficulties with conflicting ethics in the circumstances already described, they are also facing difficulties with client expectations.

They associated this specifically with the medical setting and the concomitant assumption that they – and particularly the doctors – were experts in their field and would naturally tell them what to do. As respondent VI reports;

“It’s part of sort of the whole thing about being part of the medical setting that people have expectations of being told what to do even if they have no intention of taking this advice... they will expect that the doctors will know what they should do and advise them accordingly” (VI NC).

They described this causing them considerable problems with a frequent recourse by clients to the specific question “what would you do if you were me”, or the similar “what would you do if you were in my shoes”? This was presented as being very difficult to handle and “the hardest thing to fend off” (VI NC), the latter once more invoking images of it being a battle into which the counsellors were being involuntarily drawn. Their potential reported responses to this were variable, although in general they gave accounts of themselves as supportively acknowledging clients’ difficulties in making potentially traumatic decisions while still refuting the invitation to help them decide. So in the words of respondent I:

“You can appreciate that they are having a hard time deciding and that it is a difficult situation for them though you don’t know what they might do then encourage them to consider the options available” (I NC).

In this way they are portraying themselves as maintaining a supportive client-centred role and morally adhering to the non-directive ethos in spite of pressure to the contrary.

What might be classed as non-directive, however, varied between counsellors, with some respondents explaining they might give other people’s experience – “just give them some examples what people may have done in a similar situation, ” (II Dr), - while others would view this as directive. There was also some uncertainty and confusion as to whether indeed it *was* totally desirable not to respond to the question “what would you do if ...” positively. This was reflected in the contradictory nature of some of their responses. Respondent one, for example, seen above explaining how to deflect the question, also stated that, as clients come expecting expert information, “It can be an opt-out not to respond at all” (I NC). Respondent II variously reported

“Sometimes they will actually throw it back at you and say well what would you do and of course you can’t put yourself in that position so you just appreciate that you know it’s difficult but until you’re in a situation you can’t make a decision and you might make a different one anyway. So it’s not appropriate to answer that because you can’t it’s obviously just an expression of their difficulty” (II Dr) .

And shortly afterwards

“You’ve got to take into account that they’re regarding you as a kind of expert or a resource of information and advice so you can’t completely say oh well it’s up to you ... you’ve got to actually have much more of a dialogue with them and um but be careful not to influence them too much and give them the time they need um but as I say it’s more *appropriate* to be more directive.” (II Dr).

So she would seem to be saying both that it was important *not* to be drawn into responding with any kind of opinion *and* that the fact that the client is expecting expert help should be addressed and responded to with direction. These examples were not unique, a scan through the data on non-directiveness revealed that similar contradictions occurred in most of the interviews. It might be easy to suggest that this means the counsellors are merely adhering to the

‘party line’ in proclaiming support for non-directiveness. This would be an over-simplification, however. It is probable that what the contradictions are actually revealing is the confusion that exists within genetic counselling as to how possible, or even desirable, it is to maintain non-directiveness in the face of client needs and expectations for advice, and the tension between their medical and their counselling roles. Being seen as, and responding as, an ‘expert’ and giving advice is not, as Strong’s (1979) work indicates, considered unethical in traditional medical roles. This is supported by the fact that the confusion occurs within discussion on what the genetic counsellors have, as already stated, themselves raised as a source of difficulty in their practice. It is also supported by their references to the fact that it is a source of confusion for clients that genetic *counselling* is located in a medical setting. There might also be an echo of another dilemma between conflicting ethical responsibilities. Michie, Marteau and Bobrow (1997) reported that 50% of genetic counselling clients in their study wanted advice, and that advice could be related to a reduction in anxiety. This would suggest that if the counsellors are to fulfil client agendas, to promote satisfaction and to pursue beneficence (improving client well-being), then they would once again need to violate non-directiveness. What the confusion is reflecting, therefore, is one of the dilemmas that are faced by the practitioners as they pursue the everyday tasks of “doing being a genetic counsellor”.

A final difficulty that was raised by the counsellors in responding to requests for advice, concerned the sensitive and time-limited situation that might be faced in situations such as pre-natal testing. Here it was the pressure of time and the anguish and responsibility of such a traumatic decision that was presented as problematic. It was described as being so stressful that this was one of the situations where clients were most likely to ask for advice, and therefore, one of the hardest to remain impartial in. As respondent VII described;

“I think that you’re not able to be as non-directive as you would like to be because you’re partly directed in ..there’s this length of time to make this decision in... I think particularly for things like during a pregnancy that maybe non-directiveness is perhaps more difficult to achieve” (VII).

It was also considered to be such a sensitive area that it would be impossible to refrain from introducing some elements of direction – “there’s no neutral language really to be talking about those kinds of things” (VI NC). So again the counsellors are explaining how difficult non-directiveness can be and presenting their role as a battle they struggle to win. It might be suggested that there is perhaps a tension and a paradox here, in that where accusations of eugenics are most likely to occur and non-directiveness might therefore be considered most vital, the genetic counsellors are reporting this to be one of the most difficult areas in which to practise it. The overall theme was once more, that there was a conflict between their medical roles as experts and their non-directive role as counsellors. Again there was also the suggestion of conflicts between different principles of biomedical ethics - in following non-directiveness they might be causing clients harm by leaving them to struggle alone with very difficult and emotionally laden decisions.

Before I conclude my analysis of the genetic counsellor interviews there is one more theme which I would like to explore. It concerns nurse-counsellor reports on the similarities and differences between genetic and psychotherapeutic counselling and on whether they are ‘counselling’ or using counselling skills. Despite the nurse-counsellor’s declaration that their work was primarily counselling oriented and their extensive use of a counselling rhetoric in their descriptions of their role, the nurse-counsellors specifically stated that they felt they were using counselling skills or techniques rather than counselling per se and all emphasised that they believed generic and genetic counselling were substantively different. The following examples illustrate this.

“We’re not sitting here contemplating people’s navels we’re sitting here putting people through what is essentially an educative process so in that sense I think our role is very different from like say a straightforward psychotherapy type counsellor, it’s completely different. So what we’re doing is using counselling skills in what is essentially an educative process” (VII NC).

“I think genetic counselling’s different from counselling... generic counselling. I’m sure it is because you have to have some knowledge of the condition that you’re working with, part of the counselling’s giving them information and making sure that people understand it” (VIII NC).

“I think it’s about using some counselling skills in delivering medical information” (IX NC).

“It is not counselling in the general sense of the word. Before I did counselling training I used to think I did counselling but now I know I don’t I think I use counselling skills in my work but there is too much information involved to call it counselling. Counselling is the building of a relationship with boundaries and contracts etc” (I).

These statements are in accord with Silverman’s (1997) conclusions about the differences between HIV and therapeutic counselling, and perhaps highlight the similarities between the two arenas. The overall feeling presented was that the medical component and the amount of information-giving and gathering involved in genetic counselling both made it dissimilar to therapeutic counselling and left them more utilising counselling skills to fulfil what is at times an educative process. Given that the nurse-counsellors were keen to associate their role with a counselling framework it is interesting that they also spontaneously offered comments that marked it out as significantly different to a psychotherapeutic counselling one. They appear here to emphasise an educative above a counselling function *and* to dissociate themselves from being seen as involved in counselling per se. They are not so much *counsellors* as medical professionals using counselling *skills*. Although, as already discussed, they had presented information-delivery and education as a part of their role this specific dissociation would appear to me to be to some extent contradictory with their earlier expressions of allegiance with a counselling function. Why, if they wish to be seen as counselling oriented are they at another point in the interview actively involved in demonstrating that they are *not* like therapeutic counsellors? Perhaps what is happening once more is that they are engaged in defining for me a role that they can claim to be unique – in the same way as declaring themselves more counselling than medically oriented differentiated their role from that of the doctors, so the dissociation with a “straightforward psychotherapy-type” counselling differentiates them from a psychotherapeutic counsellor. Their educational and medical function means they have a role that cannot be filled by a non-genetic generic counsellor. Their function therefore remains defined as both necessary and unique.

Their highlighting of the issue as to whether or not they are in fact counselling or using counselling skills is in itself of interest for the questions raised by this thesis. If their stated belief is that they are *not* counselling per se this has relevance when considering both whether genetic counselling can in truth be called a counselling interaction and what 'counselling' means in genetic health-care terms. Does it in fact amount to using counselling type skills to facilitate primarily medical tasks? This is a subject to which I return in the conclusion to this thesis.

Summary and Discussion

In summary then, the following themes were recognisable in the genetic counsellor accounts on the structure and function of their role. First the genetic counsellors described a role dominated on a practical level by tasks such as genetic information-delivery, education, testing and ensuring informed decision-making and consent. For the doctors diagnosis, treatment and examination were also included, and for the nurse-counsellors psycho-social support and information-gathering. It was noted that the majority of these tasks reflect a predominantly medically oriented role, presenting a picture of genetic counselling as an activity and interaction strongly influenced by medical goals. In terms of the questions raised by this thesis this might suggest both that it is primarily an encounter dominated by medical activities and that it has some marked dissimilarities to a traditional psychotherapeutic counselling role.

Second this division reflects a further theme, all the respondents, as they presented their accounts, were consistent in constructing separate roles for the doctors and the nurse-counsellors. The nurse-counsellors were keen to describe themselves as more counselling-oriented and the doctors to draw upon their medical background to present themselves as genetic counsellors but also medics. It was suggested this might relate to a need on the nurse-counsellors' part to carve out for themselves a unique professional role, and to a desire on the doctors' part to retain their status and security by representing themselves as part of the medical community. It might have implications for the emphasis that each may place on either the counselling or medical aspects of their work – and potentially on the conflicting ethical dilemmas that might then ensue.

Further research would be necessary to see how this differentiation might work out in actual counselling practice.

Third, notwithstanding this division, counselling concepts and counselling terminology recurred frequently within *all* of their talk. The genetic counsellors drew on a range of Rogerian and psychotherapeutic constructs to construct an image of themselves as operating on a client-centred basis. These included prioritising finding out and working on the basis of the client's agenda, not just presenting information from the doctor's perspective but situating it in the context of the clients' lives, and a proclaimed adherence to and support of, non-directiveness. They also referred to themselves as facilitators, empowerers and enablers, particularly in the region of client decision-making, thereby drawing on typical metaphors associated with a counselling framework and with the encouragement of autonomy and individual responsibility. In this way they were presenting themselves as competent moral members of the 'psy' community, and, in the process, allying themselves with the broader socio-political rhetoric of advanced liberalism, the autonomous self and self-actualisation through acts of individual choice. Similarly their accounts work to dissociate themselves from responsibility for client decisions, to protect themselves from accusations of eugenics and to separate themselves from a more traditional doctor-centred medical role. In terms of genetic counselling specifically they were demonstrating themselves to be in tune with current genetic counselling philosophy, up-to-date with current debates and, therefore, working as morally adequate members of their profession.

This declared association with the therapeutic community and with client-centred practice, however, was revealed to be not always straightforward. Their accounts suggest that it has problematic ethical and practical consequences for the professionals concerned. As will be seen in chapter 6 and 7 these claims were supported by the evidence of the recorded consultations. The conversation analytic study of the recorded data shows that the alleged commitment to allowing the client to set the agenda does not always occur and that there can be conflicts between session goals. Ensuring informed consent and staying within the client's agenda, for example, are not always compatible.

Similarly, despite the spoken commitment to client-centred practice, many of the consultations are very similar in format to studies of other medical interactions. Areas such as topic initiation are dominated by the practitioner and the clients are often restricted to answerer and information-recipient roles. Non-directiveness was equally problematic with many examples of recommendations, suggestions or even advice. The counsellors were keen to raise some of these areas themselves. Multiple clients were highlighted as causing problems with pursuing agendas and non-directiveness was acknowledged as difficult to achieve. The conflict between their medical and non-directive functions was specifically mentioned as was the expectation of clients to receive advice. Although preserving their morality through recourse to alternative ethics, the genetic counsellors used the interviews as a forum to discuss the difficulties that their profession's adherence to non-directiveness frequently caused. The contradictions in their arguments were perhaps indicative of the problems involved.

The fact remains, however, that despite these difficulties the genetic counsellors continue to give accounts of themselves as functioning primarily in a client-centred role and continue to profess a moral commitment to many aspects of a Rogerian philosophy. Their talk continues to be peppered with the rhetoric of autonomy and Rose's 'advanced liberal' ideals. What this suggests, therefore, is that such a rhetoric is considered essential in response to "valuative inquiry" on the nature of their role. The question is raised, then, what is the social and political background against which these claims are made? Why do the genetic counsellors, when subject to "valuative inquiry", produce accounts that are largely consistent with Rogerian beliefs? Why, in essence, when they describe themselves as functioning primarily in what are often medical tasks, do they need to define themselves as 'counsellors' at all? And why, if we take these to be moral perspectives reflecting the professional expectations of their role, does the genetic counselling *profession*, in the face of acknowledged difficulties and public debates, nurture this strong allegiance to these therapeutic links?

The history of genetic counselling and the techne of 'psy'

To begin to answer these questions we need to look at the history of human genetics and the wider socio-political context in which the profession exists. The history of human genetics has been chequered, “linked with controversy and potential misuse since its earliest years” (Clarke, 1997: 219). It has been scarred by the abuses perpetuated in the name of eugenics. ‘Eugenics’ was the term coined by Francis Galton who, according to the following quotation from Ferreira (1999), used Suzuki and Knudtson to define it as

“the science of improving the human condition “through judicious mating.. to give the more suitable races or strains of blood a better chance of prevailing over the less suitable” (Suzuki and Knudtson, 1988)... (positive eugenics)”.

This was not considered in any way unethical by the scientists and medical professionals of the time and in the 1930s it was extended to include ‘negative eugenics’, the prevention of reproduction by those considered “less suitable”. The extent to which it could be misused, however, was to reach a peak in Nazi Germany before and during the Second World War. Compulsory sterilisation was enacted for many conditions including congenital mental illnesses or disabilities, severe alcoholism and epilepsy. Euthanasia for infants and young children with congenital defects was in place at the end of the 1930s and by the 1940s the addition of the concept of “racial purity” was to result in the genocide of Jews and gypsies in the Holocaust (Ferreira, 1999). Germany was not alone, however, compulsory sterilisation laws for the mentally handicapped and for “sexual perverts, drug fiends, drunkards, epileptics and diseased degenerate persons” (Garver & Garver, 1991, in Ferreira, 1999: 1) were enacted in many states of the USA, and in Scandinavian countries such as Sweden, with some not repealed until as late as the 1970s.

These abuses of genetic practice in both Europe and North America have left human genetics a legacy it has been difficult to overcome. As Resta (1998) reports “Eugenics is the albatross that hangs around the collective neck of genetic counsellors”. Its “shared heritage” with genetic counselling “has led many geneticists to “apologize” for medical genetics and to try to extricate themselves from the eugenics quagmire” (1998: 431). “Horrors such as the Nazi programme of racial hygiene, which in turn led to compulsory

sterilisation and subsequently to medicalised murder” (Clarke, 1997: 183), have led to good reasons for the genetic counselling profession to want to dissociate itself from its recent past and any association with potentially eugenic political regimes. The scene was set, therefore, for an association with a completely different and more liberal regime.

On a more general societal level the aftermath of the Second World War was also to coincide with the work of Carl Rogers and the growth of counselling in the 1950s and 1960s. This was part of a wider growth of what Rose (1998, 1999) called the ‘therapeutic culture’ and the ‘psy’ disciplines, psychology, psychiatry, psychotherapy and psychoanalysis. These disciplines have gained enormous influence in the Western world, a process that Rose associates with the post-war development of the concern with democracy and what he describes as ‘advanced’ forms of liberalism. By this he means not just a political philosophy but “a family of ways of thinking about how government is to be exercised” (1999: pxxii). ‘Advanced’ liberalism is more than a single political program, it is a more general response which has as one of its most salient features a rejection of the notion of the ‘social state’. In the ‘social state’ it is the “political apparatus and its functionaries” that carry the responsibility for actively governing and controlling employment, security, organizations etc. In the advanced liberal state, governing occurs without direct action on society by “acting on the choices and self-steering properties of individuals, families, communities, organizations”. This, he says, opens “free space for the choices of individual actors whilst enwrapping these autonomized actors within new forms of control” (1999: xxiv). He believes that the psy disciplines and psy expertise provide a language, knowledge, means of practice and claim to truth that are fundamentally compatible with and useful to such contemporary forms of political power. They have had a key role in constructing “governable subjects” and made it possible to govern them in ways that are compatible with the principles of liberalism and democracy (1999: i).

Perhaps the most significant tenet of the ‘psy’ disciplines is, as we have seen, the ethic of the free autonomous self. This ‘regime of the self’ and its ‘regulative ideal’ (1998: 2) is reflected in our politics, our ethical dilemmas and

debates, our life-styles and our ways of dealing with a variety of national and international disputes (Rose, 1998: 1). The ‘psy’ disciplines, Rose believes, have “played a rather fundamental part in ‘making up’ the kinds of persons that we take ourselves to be” (1998: 10). Not as a body of abstract theories but as “an ‘intellectual technology’, a way of making visible and intelligible certain features of persons, their conducts, and their relations with one another” (1998: 10-11). The ‘techne’ of psychology – its characteristics as skill, art, practice and set of devices – has transformed the stewardship of human conduct into “an intrinsically psychological activity” (1998: 81). Psychological experts, vocabularies and techniques have become indispensable in governing and understanding conduct in all aspects of our lives.

Rose attributes the reasons for this potency of psychology “in lending its coloration to so many of the practices, locales and forms of judgment in the societies of the West” (1998: 86) to its ‘expertise’. By this he means its

“particular kind of social *authority*, characteristically deployed around *problems*, exercising a certain *diagnostic* gaze, grounded in a claim to *truth*, asserting technical *efficacy*, and avowing *humane* ethical virtues” (1998: 86). (Original italic)

The key to psychology’s widespread ‘social penetration’, therefore, lies in its ‘generosity’, its capacity to “lend itself freely to others who will ‘borrow’ it because of what it offers them in the way of a justification and guide to action” (1998: 87). So it has allied itself with agents of social authority and its ways of thinking and acting have become an integral part of the practices of “other social actors such as doctors, social workers, managers, nurses, even accountants” (1998: 87). Its claims to ground itself in scientific truth and effective ways of working then adds to social authority an ethical basis to justify its actions.

If we consider this as both the socio-political background and the philosophy with which the genetic counselling profession has chosen to associate, we can see why, despite the difficulties it causes, it is an attractive option. For a profession in need of a specific dissociation with potentially eugenic regimes, the language and techne of ‘psy’ provides a positive alternative. It is

ideologically and politically compatible with both liberalism and democracy and embraces ethics that are of practical use in the mechanics of genetic counselling practice. The ethic of the free autonomous self and the encouragement of self-government and individual choice are directly relevant to the genetic counselling role. Clients do not choose genetic disorder in the family but once its presence is known the advancing technology means decisions and choices can now be made. This places the genetic counselling practitioner at the centre of a potentially sensitive process. Reproductive choices are common in genetic dilemmas while the spectre of eugenics renders these particularly politically delicate. Choices around genetic testing may also affect not just individuals but whole families. Allying themselves with the ethic of the autonomous self and the facilitation of the self-governing subject allows them to offer their professional expertise while abstaining from responsibility. They offer options but do not make decisions. The therapeutic ethos, grounded in claims to scientific 'truth' then supports their role, allowing them (largely) to remain separate from accusations of eugenic influence or interference in their client's individual or family lives. Its claim to "humane ethical virtues" adds to this, giving a positive ethical justification that reinforces and supports the essential morality of their work. Calling themselves 'counsellors', therefore, provides them with a theoretical and philosophical framework compatible with contemporary socially approved and 'virtuous' goals.

The combination of the genetic counselling history and the current socio-political climate, then, provides a major incentive for the genetic counselling profession to ally itself with the counselling community. Rogers' person-centred counselling, with its commitment to autonomy, non-directiveness and client-centred practice, makes a perfect choice. It not only provides protection from accusations of eugenics but also supports the most ethically and politically valued professional goals. It renders the most sensitive reproductive areas potentially less vulnerable to political attack. It is not surprising, therefore, that it forms a key part in the genetic counsellor descriptions of the nature and function of their role. Its absence would not reflect the public and professional face of the genetic counselling world. Its presence tells us of the ethos that surrounds the work of 'doing being a genetic counsellor' and the

allegiances required to produce a morally adequate account. The responses of the genetic counsellors, and indeed the evidence of the recorded consultations, suggest, however, that it is a political rhetoric that is not always easily compatible with the reality of the genetic counsellor *tasks*. It can cause conflicts with the medical nature of much of their work. This suggests that the other side of ‘doing being a genetic counsellor’ evidenced by these interviews, is the daily facing of the tension between theory and practice and between the philosophical requirements of a traditional medical and Rogerian person-centred counselling role. In Meyer and Rowan’s (1977) terms there is a gap between their formal structures, policies, practices and “institutional myths” and their ongoing work activities. Although they ensure their “legitimization”, and avoid their conduct being questioned, it can make the genetic counsellors role impossible to fulfil.

Chapter 5

“It’s what I wanted anyway” – Client accounts of the genetic counselling role and encounter

Introduction

This chapter follows chapter four in continuing my analysis of the interview data. Focusing primarily on the genetic counselling client interviews I continue to treat them not as reports on objective realities but as “displays of perspectives or moral forms” (Silverman, 1993: 106), concentrating once more on what they “are doing through their talk” (ibid: 106). Although the genetic counselling clients may not experience the same pressure as the genetic counsellors to present themselves as morally adequate members of a specific profession they will, nevertheless, still be constrained by broader socio-political discourses that influence what may or may not be defined as a moral or responsible genetic counselling client. In Rose’s terms, as we have already seen, such discourses may include their individual responsibility to control their own destiny and shape their lives through acts of choice (1998: 151) and to seek expert assistance if they cannot do this alone. As the very nature of genetic disorder generally involves not just individuals but wider family networks it may also include their potential moral status as responsible and caring family members. They are required within their genetic counselling to demonstrate their answerability not just for ensuring their own health but also that of their wider kin. As Murphy states, the neoliberal “prudentialism” discussed by Rose combines with the current emphasis on individual management of risk in the pursuit of health, to devolve “responsibility for securing health for oneself and for those to whom one owes allegiance” onto the “the individual actor who is required to exercise prudence in the light of expert assessments of risk” (2000:293). As she goes on to say this also brings with it notions of accountability as health becomes something which can be chosen and, therefore, “an objective witness to his or her suitability as a free and rational agent” (Greco cited Murphy, 2000: 294). The genetic counselling clients in these interviews then are presenting their responses and choices around their genetic disorder (in this case haemochromatosis) against a

backdrop of concepts of accountability and responsibility both for themselves and for their family members. How they demonstrate their health choices has implications for their status as responsible free actors and rational beings. This may influence the wants and expectations that they allow themselves to bring. Understanding the constructs that they present in interview will give insight into the moral framework that they bring to their genetic counselling and the corresponding context within which the genetic counsellors' work must then be performed. It gives information on the underlying rhetoric that will exercise constraints on what may or may not be seen to be done. It will also give information on the kinds of expectations that the genetic counsellors are likely to be required to fulfil - potentially useful as an area on which limited research has as yet been done. Finally in terms of the specific questions posited by this research this might be particularly relevant with respect to their perspectives on the type or orientation of interaction (either counselling or medical) which might best address their needs.

Themes

Although it should be cautioned that the small number of genetic counselling client interviews I was able to gain mean that conclusions must be taken as tentative and not necessarily widely generalisable, a number of recurring themes were immediately apparent. These were a reported emphasis on concern for family or children rather than themselves, a majority rejection of the notion that "counselling" was either what was needed or received, a stressing that they were making, and wanting to make, their own autonomous choices alongside of taking professional advice and a declared commitment to actively seeking information for themselves. An overall picture was created, much as has been discussed above, of genetic counselling clients as active participants in making autonomous choices for their own health while taking on board expert advice, taking responsibility for their health and for the health of their families in line with predictions of the risk of future behaviours, and responsible caring parents who prioritised their children's health above their own. Perhaps in contrast to Rose's theories on the 'psychologising' of society, however, a majority were also active in presenting themselves as emotionally and psychologically robust and *not* in need of counselling or psychotherapeutic

help. Indeed, of interest to some of the broader aims of this PhD, they were emphatic in describing the genetic counselling consultation as primarily medical in nature, and highlighting this as very much in line with their desires. I look in more detail at each of these areas along with the actual data in the following sections.

“My primary concern was for the kids”

A recurrent construct in the client accounts was the assertion that their primary concern was always for their children. The following comments were typical of their responses.

“My primary concern was for the kids, I have three children... it’s almost like I can deal with it but I want to ameliorate any problems that they’re going to have at a very early stage rather than it get ahead of themselves... I don’t matter” (G)

“I was afraid for my family, I wasn’t afraid for me I was afraid for my children. I was absolutely terrified that they would have to go through what I’ve been through” (B)

“I’m not so bothered for myself ...but I am concerned ..I’ve got two sons and it doesn’t manifest from what I’ve read until about 40 or 50 so I want to know they’re alright .. I really am very much thinking about them and their lives.... I think *every* mother would say you would put up with anything to protect your children, given the choice I would have it ten times over rather than one of those two have it” (A)

“Obviously my main concern really which she explained about how it could be carried on to the children and that was my main concern for their sort of life really, that was more important than my own” (E).

Murphy (2000) discusses how the ideology of motherhood in advanced liberal societies proposes that a “good mother” is one who “maximises physical and psychological outcomes for her child, regardless of personal cost” (p293) and we have already mentioned the need for individuals to take responsibility for securing both their own health and the health of those close to them. Both these ideals can be seen reflected here. What the interviewees are constructing with their talk is an account of themselves as moral and responsible mothers (these clients are all women - although a similar response was also made by one of the men in the study) who put the health and well-being of their children above themselves. The imagery used is powerful in that they not only claim to be

most worried for their children but significantly reduce the status of their own health in comparison – “I don’t matter”, says respondent G, “I would have it ten times over rather than one of those two have it”, says respondent A, “I’m not afraid for me”, says respondent B. Each is proclaiming in some way that compared to the lives and health of their children their own is insignificant. Similarly strong language is used to indicate the depth of their concern and, perhaps, their consequent love for their children – “I was absolutely terrified” (B) or “I would have it ten times over” (A). Respondent B also talks elsewhere of her “agony” as she waited for news on her children’s testing. They are also using terminology that suggests this frame of reference is to be taken as the norm, it is how they as loving and caring parents might be *expected* to respond. Respondent E prefaces her discussion with the word “obviously” and respondent A explicitly calls on what she believes to be an accepted more to support her case – “I think *every* mother would say you would put up with anything to protect your children”. They are portraying themselves as doing what all ‘good’ parents would do. They are also attributing much of their motivation for attending genetic counselling in the first place to their natural sense of responsibility to ensure the health of their children is properly taken care of. They want the information and the medical care not primarily to look after their own health but to safeguard the future of their children. They want to “ameliorate any problems they’re going to have at an early stage” (G) or “to know that they’re alright” (A). Again what they are concerned to convey to me is their appropriate and positive taking up of an active and responsible role in maximising their children’s chances of good future physical health. They may also be forestalling any potential claims to selfishness – they are doing everything they can for their children while selflessly brushing aside any significance of the disorder for themselves.

A number of the respondents widened this representation of a sense of responsibility for “those to whom one owes allegiance” to include their siblings or extended family circles. Respondent B reported feeling, in the absence of action by the genetic services, that there was no choice but for her to contact all family members to tell them about the implications of her haemochromatosis diagnosis and to suggest that they be tested themselves. Indeed she took this

responsibility further into actively pressurising them into doing so when they appeared to take it less seriously than she felt it deserved. Respondent C, her daughter, (also diagnosed as having genetic haemochromatosis), heightened this image of her mother dedicatedly fulfilling an onerous obligation as she described how this was “extra stress .. she shouldn’t have to have had”. Here the image is put across of the interviewee as a responsible family member who is fulfilling her moral duty despite the fact that it was an inconvenience and a burden at a time when she was reeling from the diagnosis and not well herself. Respondent A, on the other hand, represents herself as taking it up willingly, telling her siblings “I’ll go to the doctor, I’ll have the test and then I’ll come back to you and tell you what it all involves”. If it has been worthwhile she will contact them all so that they can have it too. Respondents D and E also reported voluntarily contacting siblings and other family members because they felt it was their role to make sure that all were informed. Again all were painting a picture of themselves as moral family members actively participating in doing their best to safeguard the wider family health.

A final point which might be made from these quotations is that the respondents are also portraying themselves as relatively courageous in the face of their own actual or potential suffering or ill-health. While expressing concern for their children, in addition to minimising their own health in comparison, they are also denying fear or concern for themselves. Respondent G talks of being able “to deal with it”, respondent B of not being afraid for herself and respondent A that she would be “able to put up with anything” and at another point in the interviews “I’ve got other problems so ... it’s not as disastrous for me if I did have it”. Respondent H also talks within the interviews about “not being a flapper” in terms of the potential implications for himself once he was reassured his daughter was not in danger. What they appear to be doing is representing themselves to me as courageous, strong and capable individuals who are not defeated or fearful when faced with personal adversity. Their decision to have testing and to seek information on potential lifestyle modifications (revealed at other points in the interviews) demonstrates their active role in choosing health as far as possible but, where choices end, they seek to be seen as facing their fate with bravery and without complaint.

No need for ‘counselling’

Perhaps to some extent associated with this stress on competence and lack of concern or fear for themselves, a majority of the clients were also keen to dissociate themselves from any need for, or receipt of, ‘counselling’ in the emotional or psychotherapeutic sense of the word. This was interesting both in its implications for how the respondents wished to be seen and, in terms of one of the questions raised by my PhD, for the content and structure of the genetic counselling encounter. The following quotations illustrate some of the views of this sample on what they wanted from their session.

“I think what I wanted was a medical-led appointment rather than it being – when you imagine a counselling session you imagine talking through your feelings I don’t think I talked through the emotions of it at all with her so maybe she picked up from me that that door’s closed by the way my body language was” (G)

“I didn’t at any point look on it as counselling exercise ... it was a fact finding mission” (H)

and later

“ My agenda was asking her what do I need to do here and asking her whatever I felt was relevant” (H)

“I don’t think it’s necessary to have counselling at all, I have no need for counselling... I felt it was making more of it than is actually necessary” (I)

Despite Rose’s beliefs that the therapeutic culture has expanded into “every practice addressed to human problems” (1999: 218) and that ‘psy’ professionals are the obvious ones to consult when problems arise, the above statements indicate that these respondents were clear in their avowal that they did *not* need counselling-type help or what they perceive counselling-type help to be. This was to some extent consistent with the views expressed by the genetic counsellors that some clients were concerned about the term ‘counselling’. As counsellor IX reported

“The word counselling often bothers them even in the context of genetic counselling because I’m not mad, I’m not not coping, I’m not any of those things so why do I need counselling” (IX NC)

Client I's response was in fact very similar to nurse-counsellor I's statement that she often got the response "I don't want counselling, I don't need counselling.. I just want to have the test" (I NC). She felt that the requirement to have genetic counselling before testing was an over-reaction, making a simple clear-cut decision on her part into something more. She believed that her wish to have a test was one which she could make on her own, that she wasn't worried about it and that she didn't need any kind of professional help at the moment beyond the actual physical provision of the test and the interpretation of the result. She described seeking for information for herself from both her extended family and the Internet and professed herself satisfied with the result. As will be seen later she was also strong in her denial of any need of advice from the counsellor. What she was doing in effect was clearly defining for herself the status of a competent autonomous individual independent of the need for any kind of outside intervention – particularly, as she felt "no concern", counselling intervention. She appeared to be wanting to represent herself as taking on the mantle of autonomy and responsibility for her own health without any corresponding need for 'expertise'. In association with taking active responsibility for her own health, however, she did make the exception that she might require professional guidance on potential lifestyle modifications should the test be positive.

Respondents G and H were also clear that what they needed was different to how they perceived counselling-type help. Both constructed an image of themselves as requiring medical facts and medical guidance as to the best way to proceed but not 'counselling' in the sense of talking through emotions or psycho-social support. They were informative in offering some kind of definitions as to what they thought 'counselling' might imply. Both were clear it was not what they considered they received. Respondent G associated counselling with psycho-social support, talking through feelings and "a two-way relationship rather than someone coming to give you advice" (what she meant by advice will be discussed later). Respondent H explained

"the word counselling to me is somebody that needs some form of help and I didn't look on it as that I just looked on it as this lady wanting to come and talk to me about my family history to get to the nuts and bolts if you like of

whether we're carriers so I never looked upon it at any point as counselling and still don't, I wouldn't have said she counselled me".

He went on later to enlarge on this by explaining that if he had been stressed or "flapping about it" then he might have wanted counselling but he was not and therefore did not. Again he was emphatic in declaring "I'm not sure that anybody would have called what I've been involved in counselling". What these interviewees are doing with their talk, therefore, is clearly dissociating themselves from the kind of people or situations that might need counselling, those who "worry", "flap", "need help", need "to talk through feelings", are "concerned", or who "make more of it than necessary". Although part of a society where, as Burnard remarks, "It is difficult to avoid counselling these days" (1999: 1), they are presenting themselves as separate and independent from the counselling culture. They do not need and deny any suggestion of receiving anything that might resemble emotional or psychotherapeutic help.

Respondents G and H's views on whether or not their genetic counselling did constitute counselling per se have relevance when looking at whether genetic counselling is primarily a medical or a counselling interaction. Along with respondents A, B and C, indeed all who expressed an opinion, there was a clear consensus that not only did it not constitute what they would call counselling, but that it was definitely a medical encounter. For respondents B and C, in contrast to those interviewees already discussed this was *not* a welcome outcome. Their representation of themselves was very different, the emphasis of their stories as a whole was of people who had had a bad experience with both haemochromatosis and with the genetic counselling service. Their claim was that they wanted counselling but did not get it. I discuss their case in more detail later. However, what was common to all was both a declaration that it was a medical encounter and a description of an interaction that was dominated by medical information giving, discussion and history taking and with an absence of talking through feelings, psycho-social support and the formation of a two-way relationship. Given that the nurse-counsellors put considerable emphasis on their role in offering psycho-social support (and these clients had all received counselling from the nurse-counsellors) this is an interesting anomaly, both in terms of the fact that this was not what they reported

receiving and, for the majority of cases, not what they required. If the implications for client expectations are that most clients do not wish for much psycho-social support or for a counselling as opposed to a medical-type service then it raises additional questions for genetic counselling about their adherence to and association with the therapeutic culture. When the clients are reporting that they are not *receiving* psycho-social support or a counselling interaction it also raises questions about the nurse-counsellors self-ascribed role. Similarly, when what the clients are describing are primarily medical-type tasks there is a strong suggestion that from the client viewpoint genetic counselling is primarily a medical function. I will return to this and to the question of client expectations later in this chapter.

It's what I wanted anyway

Another picture that emerged from the client interviews was of individuals who were willing to listen to expert information but wanting and competent to make decisions for themselves. Most of the clients interviewed had had decisions to make about having genetic testing for the haemochromatosis gene and the genetic counselling was part of the procedure that they had to go through to get this. When asked about whether they wanted advice from the genetic counsellors their responses were varied. A number, perhaps the majority, reported that they did not want advice in terms of anybody to tell them what to do, so for example -

“I don't particularly want advice I'm quite independent I want to be given all the facts and then I'll decide what I want to do” (A)

“I don't want to be told what I should do, I'm a militant person” (G)

“I've already made up my mind I don't need the service for advice” (I)

However, this was qualified by a willingness to accept information, as with respondent A above, or with respondents G, H and I, some kind of professional guidance or opinion as to what might be the best way to proceed. Respondent G went on to say that she might want “a kind of guided information, it's that you can take from it recommendations rather than being told what to do” (G). Respondent H said he wanted an opinion – “that would have suited me cos I

would have said what do I need to do here” and respondent I that she might want guided information as to potential lifestyle modifications if she were tested positive (though *not* about testing). Only respondents B and C did not query or dispute the term advice, taking more the view that it was necessary because “obviously I didn’t know anything about it I mean I know what genetic is but when she says you’ve got a genetic disease you don’t know what to think after that” (D). What was very noticeable though across all the respondents, whether they acknowledged wanting or receiving any kind of guidance or not, was an avowal that having testing was their decision and what they “wanted to do anyway”. The following examples were typical of the responses:-

“I don’t think she really left it for me to decide, well she did obviously she can’t make me but I think she encouraged me to have it done ... but then I wanted to anyway so... it was my own decision if I’d said no there’s nothing they could have done about it” (D)

“I don’t think I ever thought about not having the test I just assumed that we were going to have it done...
I’ve viewer Do you think the counsellor had an opinion about the test?
Yeh I think she did but it was hard to differentiate between what she thought and what I thought because I wanted to have it done” (G)

“Why not have the test? What would you achieve by not doing it... I’ve already made up my mind” (I)

“I didn’t see the harm in having the test I couldn’t see the point in not having the test....” (H)
and later

“ It (the counselling) didn’t influence my decision no” (H)

What the respondents are doing overall, therefore, is constructing an image of themselves as actively deciding what to do. Again they are portraying themselves as responsible individuals who are willing to gain expert information in a positive pursuit of the best health choices to ensure their and their families future health. Their reports that it was pretty much a foregone conclusion that they should have the test appears to indicate that they have accepted the concept of taking responsibility for their future by learning what their risks were. On top of this, however, they are carving out a role for themselves as autonomous individuals, active health consumers who choose

their path for themselves rather than passively accept professional advice or allow themselves to be told what to do. In their accounts to me they are effectively dissociating themselves from a traditional medical model which allowed the professional to dictate future progress and allying themselves with an autonomy discourse where, as Rose states, “the self is to style its life through acts of choice” (1998:158). Even where professional advice has been solicited or it is perceived that a counsellor opinion has been expressed (as was reported by a number of cases), they are still demonstrating their autonomy by telling me theirs was the final decision or that, regardless of what the professional might have said, it was what they wanted to do all along. Some, as has been seen, explicitly declared the counselling had not influenced them at all, again because it was what they had already decided they wanted to do. The picture they are building is of competent individuals weighing up information and making independent choices for their future lives. They are maximising their chances for future health by making autonomous choices in the now.

The fact that a number of respondents express a wish for at least some degree of guidance or knowledge of the counsellor’s opinion, albeit they want to make the decisions for themselves, does have some implications for the non-directive ethos so central to genetic counselling. Similar desires were picked up by Somer, Mustonen and Norio (1988) and by Michie, Marteau and Bobrow (1997). Although the numbers in this study were too small to be significant alone, once again they suggest that if the genetic counsellors wish to fulfil client desires and expectations then there is considerable potential for conflict with Rogerian counselling goals. The fact that a number of respondents also believed that they *knew* what the genetic counsellor’s opinion was (see for example D and G above) is also interesting in that it suggests that, whatever their professional ideals, the clients were picking up some degree of preference, in some cases strong ones, from their genetic counselling service.

Expectations

Accompanying and building on this image of competence and responsible health consumers the respondents also constructed a role for themselves as

searchers after information and the facts about their disorder (or possible disorder). When asked about their expectations and their wishes from their genetic counselling appointments the majority highlighted a need for medical information about the condition and the potential ways it might affect them. They also sought knowledge on potential lifestyle modifications. The following examples illustrate typical responses.

“Well somebody to explain it, that’s what I wanted as well someone to explain it ... the genetic side of it ... the cause of it, where it was from.... other than just wanting the test and wanting to know about the disease that’s all I wanted from her” (D)

“A bit more (information) about the disease.. bit more about the aetiology of it and I guess the genetics of it” (A)

“I want to know about side-effects, carrier effects...lifestyle information, is there something I should avoid?” (I)

“A fact-finding mission.... My agenda was asking her what do I need to do here and anything else that was relevant” (H)

“I did not look upon it as counselling I just thought she’d come to explain what it was all about and get some family history to take back to wherever it was which was then followed up by me having tests” (H)

“I wanted to know how it would affect me because this had come at me as a completely new disease.... What this disease was and how it was likely to affect me.. worst case scenario, how much of a burden am I going to be on other people and I think the big one was how is it going to affect my kids” (G)

Overall all the interviewees reported wanting information and testing as primary goals and all expected that, along with family history gathering, this was what was most likely to occur. As the examples in the earlier section on the family indicate they were also concerned about the mechanics of inheritance and how it would affect their children. Largely it was these things that they felt they received and a majority expressed themselves satisfied by this. There is a strong suggestion here that, having largely rejected the need for a counselling service, what the clients are saying they *do* want is a service oriented to the giving of medical information and the provision of medical technology such as genetic testing. This supported their image of being responsible enough to gain expert information about their condition and created

a picture of serious consumers being interested enough to become educated about how and why it happened, and what to do. However, many of them were also keen to be seen as both capable of and interested in conducting independent research, reporting that they had sought out information for themselves outside of their sessions. Over half claimed to have researched extensively on the internet, using particularly the extensive (and more advanced) Australian and Canadian sites, and others to have used books or the British Haemochromatosis society. Interestingly, in contrast to the genetic counsellors who viewed the internet as problematic –

“The Internet is a growing problem with people looking up things before you see them. The trouble is this information can come from anywhere and they don’t know how to tell the difference” (I)

- the client interviewees viewed it as very informative, more informative at times than the genetic counselling itself. Respondents B and C in particular were adamant in insisting that without it they would not have had enough knowledge to make choices on what they should and should not do. This may be an experiential finding that links to the quality of their genetic counselling but it is also possible that it may be linked to the differences between oral and ‘written’ information. Ley’s (1988) review of work into the recall of information after GP and hospital consultations established that levels of recall were mostly between 50 and 65% in GP consultations and 40 to 70% in hospital consultations (p31 and 33). One or two studies recorded higher figures but the majority fell within this range. As these consultations were a lot shorter than the genetic counselling consultations the implications for their recall are considerable. Ley also reported that giving *written* information resulted in improved recall levels. It may be, therefore, that what the clients are reporting reflects the ability of the internet to allow clients to gather, read and print information at their own pace and to return them at their leisure. This may then be more effective for them in terms of retention and comprehension, and result in a level of recall which suggests to them that the Internet is more productive.

However, whether this is the case or not, what they were portraying to me What they were portraying to me again was an image of themselves as involved consumers who took the responsibility for looking after their own

health seriously, diligently researching information about the condition, its effects and, significantly, potential ways in which it might be constructive to modify their lifestyles or behaviour (“what do I need to do here?” (H)). It was considered very important to learn what actions they might be able to take to protect themselves from harm. Again they wished to be seen as pro-active, not passively accepting what fate might throw at them – or indeed what the medical professionals chose to tell them - but taking steps for themselves to assert control. By seeking information 1) about their future risks of developing the health problems associated with haemochromatosis through testing (carrying two genes is the major risk factor) and 2) about what lifestyle or behaviour modifications might lessen or improve the development of symptoms they are showing themselves as choosing health. Their commitment to private research demonstrates their entrepreneurial competence and autonomy in line with the discourse of the autonomous self. Their reported willingness to make appropriate lifestyle changes (as defined by expert assessments of what constitutes safe or risky behaviour) demonstrates their capacity for self-care in line with what Peterson describes as the associated neo-liberal ideology that it is on individuals that responsibility falls to take care of themselves and “protect themselves from risk” (1997: 194).

Although the majority of the respondents reported that their expectations were broadly met and professed themselves satisfied (while still researching and gaining extra information for themselves) respondents B and C, in accord with Michie, Marteau and Bobrow’s (1997) findings that a sizeable minority did *not* get their expectations met, were profoundly *dissatisfied* with the service they received. They felt they did not get adequate information or explanation, that without the internet they would have been left without adequate guidance as to what they should do to help themselves, and that there was a “blasé attitude” (C) towards their disorder. Both (a mother and daughter interviewed together at their own request) had been diagnosed with genetic haemochromatosis and respondent B was seriously affected, more so than any other interviewee within the sample. This may lend support to Clarke’s (1997) argument that unwelcome news may lead to “blaming the messenger” and make global measures of satisfaction as a means of evaluating genetic counselling

unreliable. Both were also distinct within the sample as the only interviewees who would have positively wanted therapeutic type counselling or psycho-social support – although they were adamant this was not what they received. Still keen, as other respondents, to assert themselves as autonomous individuals who were pro-active and responsible in searching for information and making health promoting behavioural choices, they differed in presenting themselves as wanting access to ‘psy’ assistance and expertise. When considering the significance of this, however, what needs to be taken account of is the wider context of which this report is part. This whole interview has some strong similarities to the atrocity stories described by Stimson and Webb (1975) and Dingwall (1977). The respondents used the occasion to present a succession of ‘stories’ or criticisms about the genetic counselling service and other medical professionals. They introduce derogatory language – the genetic counsellor “was dismissive and blasé”, using “all technical jargon” (C) (Stimson and Webb, 1975: 106) – and they present themselves as active participants in both discussions with their GP and in getting things done that the genetic counselling service should have done for them (ibid: 97) So:-

“She had to tell her GP what to do because he didn’t know anything” (B)

“I’ve got all the information on haemochromatosis and how it affects your blood and where we’re going but I’ve had to find that information myself, no-one’s told me what I’m looking at, no-one” (B)

Similarly much of the daughter’s story serves to justify a continued pursuit of professional care in the face of the genetic counsellor’s prescription that no current medical input is needed and that she should “not worry” because her iron count is low. She goes on to explain “I’ve seen what it’s done to my mother and they’re saying don’t worry about it ... if it’s going to happen to me it would be nice to know more not just don’t worry about it” (C). She is drawing on her personal experience in seeing her mother suffer in order to reject the genetic counsellors advice and instruction as invalid and, along with her mother, to make a case for further tests and intervention. Indeed a great deal of the case which is being made in the interview as a whole is a moral justification of the need for more action for themselves and wider family members in the face of *inaction* by the genetic counselling (and GP) services.

As respondent B explained with some distress “They don’t take it *seriously*, they don’t recognise it’s a serious problem”. They utilise the interview situation to tell me how bad things have been for them, how hard they have had to work to secure their own health in the absence of sufficient professional support and how much they still need further professional action to maximise their and their family’s chances for good health in the future. Perhaps the stories are also part, as Stimson and Webb suggest, of a process by which they are making sense of past events and trying to redress some of the inequalities of power they have experienced in their relationships with GP and genetic counselling professionals (1975: 90).

In their tone and emphasis they do stand alone within the client sample. Given that this is the case and that they appear to have a desire to present *all* aspects of their genetic counselling experience as not what they wanted, it might be that their expression of a desire for counselling type help could be taken as reflecting an individual need for expressing dissatisfaction and not necessarily as significant for a wider population. This might, however, be neglecting other aspects of their story. Firstly the mother, respondent B, is the most severely affected of all the interviewees by the disorder. Only respondent E has symptoms in any way comparable. Secondly many other members of their family have also been found to be homozygote for the disorder. Again this is unique within the sample. It may be that their expressed desire for counselling type help is a reflection of these factors and that other clients with the same variables would express the same desires. Further research with a larger sample and comparable clients would be needed to clarify this.

Summary

Rose (1998, 1999), as we have already discussed, writes about how the discourses and beliefs of the psy technologies have become enshrined in the ways that we as individuals see and understand ourselves. The ethic of the free autonomous self has come to dominate our thinking and there is widespread acceptance of the pursuit of self-actualisation and the shaping of one’s own destiny through acts of choice. Community or welfare systems and the “social state” have been replaced by individual responsibility and neo-liberal

government occurs without direct action and overt political control. Entrepreneurship, freedom and autonomy are the new personal life projects and goals. As Peterson (1997) states “neo-liberalism calls upon the individual to enter into the process of his or her own self-governance through processes of endless self-examination, self-care and self-improvement” (1997: 194). Peterson goes on to discuss how this burden of self-care is also reflected in attitudes to health promotion and to public health. Individuals rather than the state are seen and promoted as responsible for preserving health and protecting themselves from risk. Self-help is paramount, the individual is required to adopt and demonstrate prudence with regard to risk and “healthism” proposes he/she has choice in protecting their own health from disease (ibid: 198). As Nettleton describes “Health is something which lies within the control of the individual. All active citizens have a right and a duty to maintain, contribute to and ensure (or should that be insure?) their health status” (1997: 208). In addition they are endowed with an accountability that calls on each person “to continuously demonstrate one’s competency to take care of the self and other” (Peterson, 1997: 199) and to utilise their health choices as evidence of their “suitability as a free and rational agent” (Greco cited Murphy, 2000: 294).

What appears to be happening in these interviews is that these respondents are demonstrating their adherence to these widely proclaimed and accepted discourses. They are presenting themselves as autonomous individuals capable, free and willing to take responsibility for making health choices or decisions for themselves. They will seek expert knowledge but not delegate their freedom to decide. They are showing themselves diligent in maintaining and contributing to their health status by seeking information on their and their family’s risks from their genetic haemochromatosis heredity and by actively searching for ways in which they may take behavioural control. By declaring their commitment to such risk-reducing actions they are choosing to protect their own health and acting prudently with regard to risk. They are demonstrating their competence “to take care of the self and other” and, in their concern for ‘other’, demonstrating their commitment to their children and their wider kin. Respondent G, in her claim (with regard to psycho-social support) to “think more along the lines of a support group than contacting a medically

qualified person” is overtly allying herself to what Peterson describes as the self-help trend (1997: 199). In addition, in their claimed primary concern and in their diminishing of their own health they are declaring themselves as ‘good mothers’ (or fathers) who prioritise their children’s lives and health above their own. What the majority are *not* doing, however, in their rejection of the need for ‘counselling’ per se, is lending support to Rose’s suggestion that, for these respondents at least, ‘psy’ professionals are taking control of “every practice addressed to human problems” (1999: 218). They have taken on board the ethic of autonomy and the subjective self but not the need to seek ‘psy’ expertise. They are swift in their disavowal of the wish for psychotherapeutic style help and keen instead to proclaim only a desire for *medical* ‘expert’ aid. Aside from information their reported emphasis is on self-help and committed self-improvement. They are using their health behaviours to demonstrate their accountability as “free and rational agents”.

In terms of the specific aims of this thesis, however, what are the implications for genetic counselling practice of the ways in which these clients present their genetic counselling choices? What do they tell us of the expectations that they may hold and the constructs which are likely to constrain or influence their genetic counselling behaviour? What are their implications for genetic counselling’s allegiance to the therapeutic culture and what do they say about the structure of the genetic counselling encounter? Firstly their accounts of themselves as not needing counselling suggests that the majority of this group of clients is coming to genetic counselling with a preconceived perception that ‘counselling’ is for people with the kind of problems with which they do not wish to be associated. When this is coupled with the assertion that what they want is a medical appointment the suggestion is that they will not respond positively to a counselling orientated style or agenda. Indeed the resistance of client I to the fact that she had to attend any kind of ‘counselling’ appointment before she could be tested, supported by the genetic counsellors’ claim to have met client opposition to the notion of ‘counselling’, gives a strong hint that the association with the therapeutic culture might lead to negative reactions to the genetic counselling service. It certainly suggests that some clients may be uncomfortable with psychotherapeutic counselling-type interventions.

Secondly the presentation of themselves as competent autonomous individuals actively seeking expert information to help maximise their and their family's chances for future health, suggests that accessing information will be a major consultation need. Seeking testing to ascertain their genetic status and therefore their comparative risks is also likely to be prominent. This is supported by their prioritisation of both testing and medical information when asked to describe their expectations and by the evidence of client agenda requirements in the recorded consultations. (Although, as has already been discussed, this may be influenced by the ways in which the counsellors offer the agenda). The desire to present themselves as committed parents and family members also suggests that information on inheritance will be a big part of this and that the genetic counsellors may expect to face considerable concern for family issues within the clients' agenda. Neither emphasis would normally form a central part of a Rogerian counselling role. Thirdly, although they are emphatic in declaring themselves as autonomous individuals capable and willing to make choices for themselves (and therefore rejecting being told what to do), the declared commitment to protecting and maximising their health includes the wish for some form of guided information from the genetic counsellors. This lends weight to the genetic counsellor accounts that the emphasis on strict non-directiveness can be impossible to achieve. There is a suggested conflict between the Rogerian ethos and potential client needs.

The combined content of these constructs suggests that what clients are bringing to and wanting from their consultations is more compatible with a medical-type encounter than with a Rogerian counselling one. Medical information-delivery, some form of guidance and genetic testing predominate over emotional or psycho-social support and exploration as primary needs. Meeting client expectations, therefore, might mean surrendering some of the Rogerian counselling goals. It might also challenge the nurse-counsellors' construction of psycho-social support as a major part of their role. Client descriptions of the actual structure and content of their sessions, not inconsistent with some of the genetic counsellor accounts, suggest that, in their perception, they are dominated by medical information-delivery, information gathering and talk and decisions around genetic testing. This, as will be seen, is

consistent with the majority of the consultation data examined in the following chapters. Again this is not easily compatible with a psychotherapeutic role. Overall there is a strong suggestion that, for these clients, if asking the question what does counselling mean in genetic counselling health-care terms then the answers are to be found more in medical information-delivery and in medical tasks rather than in traditional psychotherapeutic realms.

Chapter 6

The Genetic Counselling Interaction

Introduction

In this and the following chapter I will be discussing the results of the conversation analytic study of the genetic counselling consultations. This is designed to complement, inform and be informed by the data collected on the genetic counsellors' accounts of their role. I begin with a consideration of whether or not the genetic counselling consultation has an overall structure which might tentatively identify it as a unique form of institutional interaction. To accomplish this I utilise first Levinson's notion of an "activity type" and Jefferson and Lee's suggestion that a range of conversations such as their corpus on "talk about a trouble" may be seen to have an overall "shape" that is manifested in the talk. In the course of this exploration, using where relevant some comparative data from recorded psychotherapeutic counselling sessions, I also consider whether the data in this corpus suggests that genetic counselling is a counselling or a medical interaction.

Activity Types and Vague Shapes

Levinson defined an "activity type" as referring to "a fuzzy category whose focal members are goal-defined, socially constituted, bounded, events with constraints on participants, setting and so on, but above all on the allowable contributions" (1992: 69). He uses as examples a job interview, a dinner party, a lecture or a court case. Levinson bases his notion on Hymes' ethnography of speaking but refines or "divides the pie a little differently" by "making a first distinction between the structure of the event in question, and the style in which it is conducted" (1992: 70). Within this chapter his basic concern is with the *structure* of the activity - its "subparts" (ie a seminar often consists of presentation and discussion), "any prestructured sequences that may be required by convention, the norms governing the allocation of turns at speaking, and so on" within these and elements such as constraints on the roles personnel can take (Levinson, 1992: 71). He also felt it was important to see these structural elements as "rationally and functionally adapted" to the goal of the activity, "the function or functions that members see the activity as having"

(p71). Many of the apparent 'ad-hoc' arrangements and constraints therefore can then be seen as logically related to this goal. This would seem to fit in well with the aim of my research in seeking to relate information gained from both the locally organised consultation talk-as-action and the genetic counsellor accounts of the construction, aims and context of their role.

Jefferson and Lee (1992: 521-523) describe how in their corpus of data on troubles-talk they began to get a sense that "although many of the conversations were long and multi-faceted, they were not amorphous." They seemed to possess a shape which "recurred across the range of conversations" and "which could be sensed to be rather well formed in some of the conversations and distorted or incomplete in others" (1992: 521-522). They also felt there was a series of utterance types which recurred often within the corpus and which seemed to belong in certain places. Using these and the category types they had already identified they developed a "candidate Troubles Telling Sequence" comprising roughly "(A) Approach, (B) Arrival, (C) Delivery, (D) Work-up, (E) Close-implicature and (F) Exit " (Pilnick 2001: 1931), which they then went on to search for within a detailed scan of the data. They did not find it. There were no instances where the sequence was present element by element in order. However, what they did find was that the proposed elements of the sequence did recur repeatedly in a disordered fashion and that there was some "gross sort of observable order", some elements seemed to belong to early parts of the sequence and others to parts towards closure. From this they concluded that there was a vague shape that was dimly manifested in the talk. Further study then persuaded them that it was "a potentially strict sequence that is encountering problems, and is thus becoming disordered" (Jefferson and Lee, 1992: 523), a formulation they suggested was methodologically similar to Weber's 'ideal type'. Similar shapes have been proposed in Zimmerman's (1992) configuration of sequences in emergency calls and Pilnick's (2001) "putative structure" for the interactional organization of pharmacist consultations. The idea that medical consultations can have some kind of basic overall structure is not limited to CA research and was a central focus of Bryne and Long's (1976) classic work on doctor-patient interaction.

I commenced my analysis, therefore, with a comprehensive scan of the data to see whether there was evidence to suggest that the seventeen genetic counselling consultations possessed an overall interactional structure which contained features similar to Levinson’s activity type or Jefferson and Lee’s “vague shape”. Those present at the consultations were usually one of a number of geneticists and nurse-counsellors and one or more clients. A nurse-counsellor alone was present on two occasions. Perhaps the first thing that was immediately obvious was that, in accord with the genetic counsellors’ accounts of their role, the consultations contained within them a broad range of functions for the counsellors. These included diagnosis, the giving of information, education, revealing test results, facilitating decision-making, information-gathering and some degree of psycho-social support. There were also a number of practical medical activities such as taking blood for testing, physical examination and health assessment. It was not surprising therefore that there appeared to be a wide range of interactional features or potential elements to the consultation formats. It was difficult initially to discern much similarity between them. In addition the consultations varied in length from just under half an hour to an hour. This is considerably longer than many interactions that have been studied in this way and enhances the possibility for multiple elements or communication formats. However, as my analysis progressed I began to feel that there were some elements that were recurring within the majority of the consultations and that could often be found in broadly similar places in the interaction.

Introduction or Greeting

With the exception of the four consultations where it would appear the tape is switched on after the initial preliminaries, all the consultations begin with some form of introduction or greeting. This varies according to whether or not the participants had met before.

Typical introductory sequences proceed as follows;

N = Nurse counsellor, D = Doctor/geneticist, C = Client, F = Researcher

Extract 1. Tape 6

- 1. N This is Dr X
- 2 D Hello [it’s nice to meet you

3	C	[Hi (.) hi
4	N.	G. this is F F
5	C	[Hello
6	F	[Hello
7	D	Would you like to come and sit [over (.) there
8	N	[Have a seat
9		(0.8)
10	D	Great

1	N	Come on in
2	D	Hello there [(.) Good to see [you
3	C1	[()
4	N	[Dr X you know
5	D	Pleased to see you again
6	N	This is [F
7	D	[pleased to see [you again
8	C2	[([)
9	D	[thank you for letting Sarah 10
10		join us.

genetic counselling consultations, small talk, initiated by either professional, may also be present as part of this introductory sequence but, with one exception, it is always the doctor who goes on to introduce the reason for the visit. In the exception it is the doctor's initial "how are you?" enquiry that elicits from the client one of her reasons for being there. This variation is probably due to the subtle differences in position in which the professionals find themselves. In GP consultations the doctor is unlikely in the majority of cases to know the precise reason for the visit. He has therefore to either wait to be told or be active in eliciting the story. In genetic counselling consultations, however, the doctor has some information but is often unsure how much the *client* knows. Information gained from the genetic counsellor in the genetic counsellor interviews indicated that it is not uncommon for some clients to have little understanding of the reason for their referral – if they were aware they were to be referred at all. This is supported by comments in two of the consultations in this corpus where clients either did not understand why, or were surprised they had been, referred to the genetics department. Similarly the possible lack of knowledge might be significant if the reason for the visit involves the potential for bad news. Ascertaining how much is already known might be important before information is given.

Reasons for visit and agenda-check

In all the consultations, although in one this is very minimal, there is some sequence of utterances that establish the reason or agenda for the visit. This usually occurs immediately following the introductory segment and, as already stated, is initiated by the doctor. This element generally has two components; a summary of why the doctor believes the consultation is taking place, in roughly half the cases citing a GP referral letter, and an 'agenda check' to see if this coincides with what the client wants or if they have anything extra they wish to add. A typical example of this can be seen in extract four on page 152. Where both occur they are generally fairly close within the interaction, often within the same or consecutive turns. Where there are some utterances in between these usually concern some clarification or follow-up questions/explanations arising from the summary. In nine cases both are present to some degree, in

three cases only a summary takes place and in one the consultation proceeds as follows.

Extract 3. Tape 3. C1 is the mother, C2 the father, Hilary their 2 year old daughter

- 27 D When we met a year ago (.)
28 C1 Mm
29 D =there was a question mark about Hilary as to whether she'd
30 got this thing () is that right?
31 C1 Yeh
32 C2 That's right yeh.
33 D How do you think she's doing? Any any developments?

In extract 3 the doctor does not formally summarise the reasons for the consultation but begins in lines 1, 3 and 4 by making the assumption that the primary function for the visit is to establish whether or not the child has Neurofibromatosis. He then uses the question “is that right?” in line 4 to ascertain if the clients agree. On their assent in lines 5 and 6 he moves straight into beginning his assessment in line 7. In consultations where the genetic counsellor does not explicitly ask or check with the clients what it is they are expecting or wanting from the consultation, the formulation ‘is that right?’ or the alternative “is that alright?”, is often used as a way of gaining client agreement for the doctor to proceed.

The question of agenda-setting is of relevance in a number of ways. First, as already discussed, a central tenet of Rogerian counselling is that the client sets the agenda. All bar one of the genetic counsellors interviewed specifically stated that a *primary* function of their role is to follow the client's agenda. Second the ethos of non-directiveness is essential to both Rogerian counselling and to the field of human genetics. It could be argued that this in itself requires the client to set the agenda. Structuring the information that is given can in itself be a form of directiveness (Clarke 1997). Third, topic initiation and control of the agenda can be important indicators of asymmetry in the interaction. Studies dealing with medical and counselling settings have suggested that one way in which these data differ from ‘ordinary’ conversation is in aspects of interactional asymmetry. Although not strictly pre-allocated as in courtrooms (Atkinson & Drew, 1979) or news interviews (Heritage & Greatbach, 1989) turn-taking organisation in medical arenas has been shown to

be asymmetrically dominated by the practitioner. Although recent research demonstrates this is co-constructed and interactionally achieved by *both* parties (Maynard 1991, Pilnick 1998) it has the practical effect that sequence organisations (for example questions and answers) that influence topic control are usually initiated by the medical practitioner and ‘dispreferred’ by the patient (Frankel, 1990). “Doctors”, states Maynard “ask more questions than patients, interrupt patients more often and control topical development” (1991: 456). Fourth, agenda setting within genetic counselling is a topic that is currently under review. A number of studies have indicated that there is a divergence between the views of counsellors and clients as to what it might be profitable to be looking at or discussing within the counselling sessions (eg Wertz et al (1986), Michie et al (1997). If genetic counselling is to meet the needs and expectations of its clientele, therefore, detailed consideration of this issue is essential.

A typical sequence in which both summary and agenda check are offered in the same turn can be seen in the following extract. The client is attending the clinic for the first time after a home visit by Sally, the nurse-counsellor.

Extract 4 Tape 1

- | | | |
|----|---|--|
| 1 | D | Grand (.) E::r (.) Sally (.) told me the gist of (.) a couple of |
| 2 | | things you discussed and of course Dr Bloggs (.) said in the |
| 3 | | letter that (0.2) erm (.) (.) y-your late father had Huntington's |
| 4 | | Disease and [that |
| 5 | C | [mmm (.) |
| 6 | D | you'd <u>thought</u> things through and I think he prompted things a |
| 7 | | little when he asked you some leading (hhh) questions |
| 8 | C | yeah [and |
| 9 | D | =[and you thought things through and you wanted to find |
| 10 | | out a little bit more and (.) look ahead t- e::r an' an' and |
| 11 | | consider the (0.2) pros and cons of, sort of (.) er (.) what the |
| 12 | | next step <u>might be</u> (0.3) Can you just ask? (.) Have you got any |
| 13 | | extra questions that (.) if you want to add to the obvious list (.) |
| 14 | | that |
| 15 | C | U::m (.) °not, not (that ah fink of the moment) (.)° |
| 16 | D | °Okay° (.) So the um you you know a <u>bit</u> about Huntington's |
| 17 | | Disease but you really want to go into where things are at and |
| 18 | | (.) what might be the list of possibilities |
| 19 | C | Mmhmm |
| 20 | D | =°for your good self°. |

In lines 1 to 10 the doctor summarises the information he has received so far from both the nurse-counsellor and the GP. In lines 11 and 12 he checks if the client has anything to add and, having received a negative answer “of the moment”, goes on to confirm again in lines 14 to 16 that this is what he “really wants”. Having received the client’s minimal assent in line 17 he then proceeds. Perhaps an important point to make that is repeated in most of the agenda checks, both alongside the summary or later, is that the agenda is offered to the client in terms of extra or other “questions” or even “genetic type questions” (ie transcript 4). It may also be offered in terms of information, ie Transcript 8: “do you want me to describe to you what sort of tests (0.6) are available?” The following extract, where the client has previously been estimated as having a 96% chance of carrying the Huntington’s gene, is the only one in which the offer is openly phrased.

Extract 5 Transcript 12

- 51 D We met about 4 and a half years ago in this room (
 52 concern around) and you knew you didn’t particularly
 53 want to ask and you’ve come back, I assume you want to go
 54 into that a bit more and also your concerns are in the context of
 55 the next generation.
 56 C Yes we’d like another baby
 57 D Right. So what... what exactly would you like us to do for you?

In this consultation the doctor begins in lines 51 to 54 by citing previous meetings between them and summarising why he believes they are there. The client agrees and adds that they’d like another baby. The doctor acknowledges this with “right” and goes on in line 56 to clarify exactly what it is they want the counsellors to do for them - without in this case restricting them to questions or information. Theoretically therefore the clients have free range to ask for whatever they want. This however, as already stated, is the only time this occurs. More commonly in examples such as extract 4, although the genetic counsellors are offering clients a chance to add things to the agenda it might be argued that interactionally they are subtly directing them towards an assumption that this must consist primarily of information. The offer is not phrased in open terms - for example how would you like to use your time today? – but, as described above, limited to questions or offers of information.

In some senses therefore, while the genetic counsellors describe their role in terms of fulfilling the clients' agenda, it is an agenda that is already partially pre-defined. The use of phrases such as "consider the pros and cons" in line 10 of extract 4 also contributes towards a suggestion that discussion about factual advantages and disadvantages is the way to proceed. A scan of the summaries given reveals that a stress on information is consistent throughout many of the consultations and that it is either information or practical medical tasks such as testing, diagnosis or health assessment checks that are put forward as the reasons for being there. There is little emphasis on psycho-social or 'feeling' content. This would appear to be consistent certainly with the majority of the doctors' accounts of their perceptions of their role as mostly concerning testing, decision-making and the transmission of information. It is also consistent with the nurse-counsellors perception of the clinic consultation. In most of the consultations there is little client disagreement with the initial summary, where questions are given these again usually concern information or requests for testing and assent to proceed usually takes the form of "yeh", "mm" or "mmhmm". Any information given by the client is almost always in the 'answerer' role of Silverman and Perakyla's Interview Format (IW) (see page 48). Interactionally therefore the clients at this early point appear to be demonstrating a co-construction of asymmetry in topic initiation and confirming that *their* expectations are that the doctors set the agenda, and that this agenda *largely* centres around information or medical procedures. This is largely in accord then with other studies of asymmetry in medical interaction such as Frankel (1990), ten Have (1991) and Pilnick (1998). There is one noticeable exception to this in consultation five where the client interrupts the doctor to introduce a topic of her own. This is discussed after extract 6 on page 156.

This kind of agenda-setting would not appear to conform to what I would recognise as typical of a 'counselling-type' encounter, certainly not in Rogerian terms. Here the agenda would be much more open and the consultation would be likely to include some exploration or emphasis on client feelings. The exchange of information would perhaps at times be part of the session but not the major emphasis. Frequently it would not occur at all. In

addition, even where the counsellor has some knowledge of the client in advance of an initial session it is considered good practice to encourage him/her to reveal in their own words why they think they are there and what they want from the session or from the counselling. Both these points are illustrated in the following examples. Extract A is taken from a demonstration counselling session by Carl Rogers with a volunteer client and live material and extract B is from a family therapy consultation. Both are transcripts from recorded interactions.

Psychotherapeutic counselling extract A

Carl: Now I feel more ready. I don't know what you want to talk with me about, because we haven't done more than say hello to each other. But whatever you would like to bring up, I'd be very ready to hear.

Jan: I have two problems. The first one is the fear of marriage and children. And the other one is the age process, aging. It's very difficult to look into the future and I find it very frightening (Kirschenbaum & Henderson Ed, 1990: 139).

Psychotherapeutic counselling extract B

Therapist: When you and I first talked on the phone you told me that Karen was having problems in school and that's why you wanted family therapy. Will you tell me more about that? (Erskine, 1997: 196)

In example A the counsellor has no prior information and offers the client an open space to explore whatever she wants to. This leads to the client describing two areas that are problems for her. It is noticeable that even in this initial statement she feels free to introduce a statement that expresses her feelings and establishes them as a legitimate part of the agenda. In example B the therapist has had a small amount of information already but he uses an open-ended introductory question to encourage the client to tell him more about what she wants from the session in her own words. Both examples of opening exchanges are much more open in what they offer than those typical of agenda-setting sequences in the genetic counselling consultations.

The exception to the agenda-setting pattern in the genetic counselling corpus, consultation five, is unusual from the start and is unique in its development as a whole. It is the only consultation in which a significant amount of emotion occurs. It has broadly medical goals and includes health assessment and examinations and the provision of opportunities for questions on the genetic

condition. It also involves the giving of a test result on another child (not present) in the family. Extract 6 gives the initial ‘why-we-are-here’ element and its immediate follow-up.

- Extract 6 tape 5 C1 is the mother, C2, Susy, the daughter
 Sally the Nurse-counsellor, Gordon the son
- 33 D Ri:ght (.) no:w (0.3) I think a follow-up visit for yourself to
 34 come along and talk to us
- 35 C1 Uh- huh
- 36 D =and just check out that there are no (.) other genetic questions
 37 or any other queries that you want to ask about (.) myotonic
 38 dystrophy but this was just going through the err the process
 39 anyway and and that was the main reason that we had this slot
 40 available but (.) just a few days ago the test on (.) Gordon
- 41 C1 Yeah
- 42 D =came back and it shows that he does not have the (.) gene
 43 [which is to do with-
- 44 C1 [And and he’ll be okay for the rest of his life?
- 45 D So that means that the err issue of muscle disease
- 46 C1 Yeah
- 47 D =due to myotonic dystrophy is just not one that is is a bother for
 48 him
- 49 C1 °Mm°
- 50 D Wh- and that, obviously that’s super news
- 51 C1 °Yeah°
- 52 D But-
- 53 C1 I was wondering um you know Susy got a biopsy (ago)
 54 °because she er°
- 55 D The uh Sally Sally told me that
- 56 C1 Yeah
- 57 D And what I can do is summarise (.) what was found
- 58 C1 Yeah
- 59 D =in the overall research. Some of it is still not finished because
 60 although (.) the test was done (.) two years ago the (.) overall
 61 work from all the samples was °too difficult to be° ((continues))

In lines 36 to 39 of this extract the doctor summarises what he sees as the reasons why they are there, receiving only minimal acknowledgement from the client in line 35. He then moves straight on in lines 40-43 with both the news of the arrival and the result of the genetic test on the client’s son, again with only a “yeah” from the client. This is unusual in two aspects. First, there is *no* check at this point as to whether this matches the clients’ understanding of why they are present - no agenda-check *or* confirmatory “is that alright?” - and second, the genetic result is then given immediately with no preparation at all. To represent the counsellor fairly, he does ask if there are any items the clients

wish to add to the “list” on two occasions a little later in the consultation. The client marks her reception of the news with an overlapping question in line 44 to check that this means her son will “be ok for the rest of his life”. The doctor does not answer directly with a yes or no but continues with a confirmatory statement that this is so and the claim that “*obviously* that’s super news” (italics mine). The “but” in line 52 indicates that he intends to continue further until the client’s interruptive change of topic in lines 53-54 takes away his speaker rights at this point. This result-giving is untypical of a counselling encounter in that no attempt is made to gain the client’s perspective or feelings about the result – indeed the counsellor assumes them as “obvious” in line 50. Given the unexpected emotional responses to negative genetic tests for Huntington’s Disease this is perhaps an unsafe assumption (eg Spijker & ten Krood 1997).

The client’s response is interesting, apart from her brief information-seeking question in line 44 she makes no comment at all on the result, giving only continuers and acknowledgements in lines 46, 49 and 51. Her interruption in line 53 perhaps reveals one of the reasons for this and for the deviation from the assenting pattern seen in the other consultations. In not making even a cursory check as to whether his ideas of why they are there conform with the client’s, the doctor has not given her opportunity to voice what is one of her main concerns – she does not understand why her daughter has had to have a biopsy elsewhere and wants the doctor to explain. Later we see she is worried because her sister had the same condition and she died so she is afraid for her daughter. The result, which it is fair to say might be expected to be important, appears almost a minor diversion to her – although it should be acknowledged that she had not come expecting it to be a part of the agenda. She does, however, potentially mark her interruption as “accountable” with the phrase “I was wondering” thereby acknowledging she may be moving out of her expected interactional role. The perturbations in the doctor’s speech in line 55 suggest he may be taken aback by the interruption and he attempts to regain control by offering to summarise what was found and explain the research is not yet finished. As will be seen later this does not satisfy the client who minimally acknowledges his statements with an “hmm” but goes on, again in overlapping speech, to explain her concern further. Here then we see a client

who does not appear to fit the pattern seen in the other consultations, she does not confine her role to that of answerer and she interrupts the doctor to introduce a topic of her own. Nevertheless, it can also be seen that the doctor himself deviates from the usual pattern and that she marks her intervention with “I was wondering” suggesting some conformity with a co-constructed asymmetry. She also at this stage is still basically asking for information. As the consultation proceeds, however, the content is so markedly different from the rest that it does suggest that for this client at least, her expectations of genetic counselling are not of an asymmetrically controlled medical encounter marked largely by information-giving. I examine this consultation further later in this chapter.

In a number of the consultations the agenda-check component of the “reasons for the visit” element are lacking altogether as in the example below. In extract 7 the doctor simply states “what I want to do” in lines 21 to 25 and asks for ‘permission’ with “is that alright?” in line 27. The client is attending after having been identified as carrying the Fragile X gene.

Extract 7 Tape 6

- | | | |
|----|---|---|
| 21 | D | What I (.) what I want to do today, and I'll probably do this (.) |
| 22 | | quite near the beginning is actually (.) to examine you (.) and |
| 23 | | measure your (heart and your heart) and things (.) Erm and |
| 24 | | then (.) I'll sort of explain the chromosome (.) result for you |
| 25 | | <u>and</u> put it into context for you. |
| 26 | C | °Mm° |
| 27 | D | Is that alright? |
| 28 | C | yeah (°yes°). |

There is no attempt to establish whether the client has any other ideas of what she would like to do with the appointment and in this session no check is made at any point if there is more the client wishes to add, indeed there is no real attempt to ascertain if the client wants most of the information she is given. (This raises significant questions around the right not-to-know.) It should be stated, however, that this is not common to most of the consultations.

In this and in the other consultations where an agenda-check is not offered the genetic counsellors' emphasis on catering for the clients agenda as a *primary* function of their role might perhaps be seen as somewhat contradictory,

particularly as when it *is* offered it is often in a subtly restricted form. However to make such a statement would be to ignore the institutional context of their role. Ten Have (1991) discusses how asymmetry of task is an integral part of a medical practitioner's role and Levinson, as we have already stated, how structural elements of institutional interaction may often be seen to be geared towards achieving the *goal* of the activity type. In many of the consultations the genetic counsellors have a medical type goal and medical or informational tasks to achieve. It is logical therefore that the interaction so far reflects that. The apparent contradiction may also reflect one of the inherent tensions in the genetic counselling role. They represent themselves as a *counselling* profession while being required to fulfil these alternative *medical* goals. Examination, testing, physical health assessment and diagnosis are not counselling goals. Neither primarily are the giving of information on physical or genetic conditions and their treatment. Similarly it needs to be taken into account that in the majority of these interviews these are secondary to some other kind of medical or nurse-counsellor interviews where some degree of finding out what the client wants has already taken place and been reported to the doctor. This may mean that, for the clients, their *GP's* understanding of what genetic counselling consists of has already influenced their expectations and for the geneticists, that they already have some idea what the client is allegedly wanting.

As the consultations progress the unfolding of the agendas can be problematic. In a number there are multiple clients, and different or conflicting client agendas cause the doctor some difficulty. There may even at times be disagreements between clients both about what is being asked and over issues discussed. This raises a question highlighted both by the literature and by the genetic counsellor interviews, is genetic counselling oriented towards the individual or to the family? Is it the individual who is 'the client' or is it 'the family'? Where does their primary responsibility lie? At least one of the nurse-counsellors who mentioned it believed it to be the family. This highlights as well a major difference between genetic counselling and most forms of psychotherapeutic counselling where the focus is on one client alone. Similarly at times there is obvious difficulty in the interaction for the genetic counsellors

difficulties genetic counsellors face with multiple clients and potentially competing agendas. Throughout this consultation the daughter says relatively little although the appointment is as much for her as for her mother. The mother interrupts often and dominates the client part of the interaction. The counsellor is aware that he has two clients to consider and at times, as in this example, deliberately turns to include Susy. However, as can be seen in lines 126 and 129 the mother gives her little chance to answer and takes over the interactional floor again from 129 onwards. She overlaps her daughter's turns in the same way as she does the doctor's elsewhere. This is typical throughout the consultation. The doctor has little success in allocating any equality of time and attention to the agendas of both clients and it is the mother's which dominates.

Health or development assessments.

In the majority – nine - of the consultations, usually somewhere in the early stages there is some kind of health or development check or assessment. It may concern the health of individuals or the development of a child. It may be brief or it may go on for many turns. In most cases it is directly relevant to a stated goal of the consultation. In only one is it difficult to see where it fits. The example below gives the start of one of these segments and in this case is related to ascertaining whether or not the child has neurofibromatosis. It follows straight on from extract 3 on page 151.

Extract 9 Tape 3. C1 is the mother C2 the father

- | | | |
|----|----|---|
| 34 | D | How do you think she's doing? Any any developments? |
| 35 | C1 | Mmm no not really erm I've noticed another birthmark |
| 36 | D | Another one? |
| 37 | C1 | Yeh |
| 38 | D | In fact she's obviously- I was going to say is she well but of |
| 39 | | course she's well. She's two? |
| 40 | C1 | [yeh |
| 41 | C2 | [yes |
| 42 | D | Almost two |
| 43 | N | I'm just going to lock that and then no-one will push that door |
| 44 | | open when she's standing behind it. |
| 45 | D | Hilary is almost two |
| 46 | N | I know but that's meant you can't get out. ((to child)) |
| 47 | D | Do you have any problems? |
| 48 | C1 | Not that I've noticed |
| 49 | D | No problems (0.8) She's now walking and talking? |

As can be seen in this example the format of this element is a sequence of questions and answers with the doctor as Questioner and the clients as Answerers - Silverman and Perakyla's IW format. It again maintains the asymmetry of the interaction in terms of topic initiation, task initiation and retaining the doctor as medical 'expert' (Frankel 1990, ten Have 1991). In some consultations it forms a significant percentage of the interaction. Where this assessment does not occur at all it has no real relevance to the particular goal(s) of the consultation - for example in consultation sixteen where the session aims are to discuss carrier testing for haemochromatosis. This is significant when considering whether genetic counselling consultations can possess a specific institutional identity or shape. The goals and role of genetic counselling, as highlighted by the literature review (page 9) and the genetic counsellor interviews, are both multi-faceted and in some aspects poorly or not clearly defined. Although the transfer of information is often a primary goal some of the specific issues are dissimilar enough for one overall 'shape' to be unlikely to suit all. A consultation that has as a major function a physical or health assessment is unlikely to be directly comparable to one in which the client's physical health is not relevant – again as in tape 16 where the concern is carrier testing on a healthy person. It became apparent as my analysis progressed that some of the specifically medical goals (ie examination, diagnosis, giving test results or almost entirely genetic or 'medical' information) in particular were likely to be associated with particular elements and types of communication format. Those consultations with the most 'medical' goals were most likely to be similar in asymmetry, roles that participants could occupy and communication format to those identified in previous studies of medical and HIV counselling interactions (Frankel 1990, Maynard 1991, Silverman and Perakyla 1991). They were predominantly (though not exclusively) seen to be using the IW and ID (Information Delivery) formats. Those with less easily identifiable 'medical' goals were likely to have a more varied presentation. I explore this further later in this chapter.

A further element associated with a specifically medical role, found in six of the consultations, was a physical examination sequence. Apart from not being found in the closing phases this is not located at any specific point in the consultation. In general it comprised three components: preparatory phrases indicating it is to take place at that point and often asking for permission, the examination itself (performed outside of the taping room) and delivery of the examination results. In one of the six this final component was absent and it is noticeable that this is the only one where the examination does not appear to be implied from the stated consultation goal goal. Examples of the preparatory sequence include:

Extract 10 Tape 6

50 D Is it alright if we go next door and (.)
51 C Yeah
52 D And [examine you?
53 C [Yeah that's fine

Extract 11 Tape 2

345 D Right (0.2) I wonder if we could take you along and (.) I'd like
346 to examine you and just (.) check things over.

Perhaps the interactional significance of these sequences is twofold. First that the doctor/geneticist in his role as genetic counsellor has to perform a task – examination - naturally associated with the medical arena and therefore perhaps, for clients particularly, the interactional 'rules' that accompany this. And second that the doctor in all cases but extract 8 seeks some kind of permission to do so, "is it alright if" in line 50 of extract 10 and "I wonder if we could" in extract 11.

Component three of this examination sequence can cover a varied number of turns, depending on the findings and significance of the findings for the goals of both the examination and the consultation. Information-delivery is often a big part of this and may precede other related sections of information-delivery or question/answer sequences from doctor or client. It can, therefore, in some consultations directly or indirectly influence a large section of the main body of the interaction. The findings may also lead to some form of diagnosis and into 'suggestions' for referral, further checks or behaviour to maintain health. I mark my use of the word suggestions as their presentation at different points

varies in strength, ranging across what might be interpreted as suggestion to recommendation to effective advice. Take for example, extract 12 below.

Extract 12 Tape 1 June is the nurse-counsellor

302 D We we we think it's worthwhile (0.2) taking a little bit of time
303 and some planning to (0.2) e::r (.) t to do the test (0.2). One of
304 the first things that we like to suggest after this initial discussion
305 with (.) people like June and myself (0.3) is that (0.3) you get
306 seen by a neurologist (0.2) who would examine (0.2) all the
307 neurological (.) aspects (.) and the reason for doing that is that
308 (0.3) in the great the very very great majority of cases that's
309 showing that the (.) neurological examination is quite normal
.....((continues))

Here the doctor is talking with the client about the test for Huntington's Disease and at this point is introducing the procedure that the counsellors like clients to follow before a decision to test is taken. In line 304 he states to the client "one of the first things we like to suggest" and goes on in the rest of the sequence to say what and why – a visit to the neurologist that shows most people they're currently "normal" (showing no visible neurological signs of the disease). It might be argued that to use a phrase like "we like to suggest", with "we" representing doctors or a form of institutional authority, could be construed as directive and a form of advice - although the perturbations in line 1 and the many pauses throughout perhaps suggest the counsellor is uncomfortable with this. These 'suggestions' also occur in some consultations without examinations. They can be the cause of perturbation in the smooth flow of the interaction and can result in dissent or some level of disagreement from the client(s). I will be considering them in more detail in the following chapter in relation to non-directiveness and the giving and receiving of advice. There is some inherent tension between these diagnostic, health assessment type functions with their potential associated responsibilities and the strong emphasis on non-directiveness in the genetic counselling ethos. As will be seen this is reflected in the way these 'suggestions' are sometimes presented. They lack the assumption that exists in 'normal' medical interactions that making referrals and recommendations about treatment is an expected part of the role.

To summarise what I have said so far, the genetic counselling consultations in this collection have elements which appear to be common to many of them

early on in the interaction. These are a greetings or introduction segment often begun by the nurse-counsellor and taken on by the doctor, and an agenda-setting segment initiated by the doctor. This comprises one or both of a summary of why the doctor perceives they are there and a check whether the client is in agreement with this or wishes to add anything else to the agenda. Later in many of the consultations, where this is goal relevant, there is a health or development check or assessment, largely in IW format controlled by the doctor, and in six of the consultations, again where goal relevant, there is an examination sequence. These latter two elements can take up large portions of some consultations and lead into diagnosis, information-giving or health suggestions. These components might be said to resemble Byrne and Long's (1976) first four consultation phases. Their presence gives some 'vague shape' to the early parts of many of the more 'medically' oriented agendas and interactions. Where 'medical' goals make up the majority of the agenda the interaction is more likely to have similarities to other forms of medical interaction studied by authors such as Frankel (1990) and ten Have (1991), in areas such as asymmetry of topic initiation and task. In types of communication format these interactions may be *predominantly* made-up of the IW and ID formats identified by Perakly and Silverman (1991). However, although this may be seen to be an overall trend it is not exclusively so and the asymmetrical control, as will be discussed more later, is not as rigid as in some forms of interaction. There are also features such as the presentation of 'suggestions' that may be atypical to most medical interaction.

Towards Closure

A number of elements can be seen to be recurrent within many consultations towards the closing end of the interaction. These are a summary of "what is to be done", a form of agenda-check or 'final/any questions' offer and moves towards closure or goodbyes. A summary of what is to be done occurs in all the consultations apart from consultation five and the absence here is probably significant. Consultation five, as already mentioned, took a somewhat unusual path and its absence may mark both the long length of the session and the counsellor's perturbation at how it developed. In most of the remaining consultations the summary appears close to, either before or after, the final/any

questions sequence. Both are usually initiated by the counsellor and appear to be part of a closing ‘pattern’ moving towards ending the encounter. Tape two presents an exception to this as follows. The client is there for information about a muscular disorder and an assessment of his health.

Extract 13 Tape 2

- 601 D They would probably be out of your body by about (.) three
602 weeks but (.) I would far (.) rather that a longer period of time
603 had gone before you got back to (0.2) serious work (.) e::r
604 training. (0.5)
605 C Right. But what do you do now, I mean do you write to me GP
606 and [say
607 D [Well (.) I’ll write back to your GP .((continues))

This example is very interesting in that it follows a sequence where the doctor has delivered the client some unwelcome advice not to return to competitive sport too soon. The client has twice refused to accept it and this move in line 605 represents a third - effective – effort at curtailing this and strongly implicating moves towards closure himself. It is relevant to a consideration of both non-directiveness and the giving and receiving of advice and will be considered again in the next chapter. It is noticeable that he also uses the word “right” as an indicator of an ‘announcement’ (Frankel 1990) in a way more usually typical of the professional. ‘Right’, ‘Well’, ‘Ok’ are commonly used by the genetic counsellors to introduce either topic closures, initiations or summaries of what is to be done.

The moves towards closure may include the checking of address-type details, small talk, thanks and goodbyes. Sometimes during this pattern, as observed by Pilnick (2001) in hospital pharmacist interactions, as closure is implicated the client may suddenly bring up some other point or story that is bothering them. The following extract illustrates this.

Extract 14 Tape 11 C1 is the mother of Jenny who is there for a check on neurofibromatosis

- 439 D I mean as I say there’s an open door if you want to come and
440 see me again in three or four years we can do that or if you just
441 want to leave it until you’ve got particular questions or () back
442 at some stage
443 C1 Yeh yes
444 D =because you know by that time (Jenny might be thinking about
445 having a baby as well)
446 C1 Yes quite

447 D = and it might be useful to discuss it
 448 C1 We heard about a case it was about a year ago in the paper and
 449 it was I don't know if you read it there was a little girl who was
 450 having her leg removed that had had the same problem as Jenny
 451 there was quite an article wasn't there about it?
 452 ? Yeh
 453 C1 Yeh well actually I think I did write and send a photograph and
 454 ()but apparently it didn't work out for her and she had to
 455 have her leg removed
 456 D Mm right so she'd got the condition?

In lines 439 – 447 we see the doctor repeating to the clients that there is an open door policy at the centre. Prior to this she has summarised what she is going to do and the clients have thanked the geneticist for her time. Moves are being made, therefore, towards closure. However, in line 448 the client suddenly introduces a story that she has seen in the media about a child who has lost her leg. The story bears no direct relevance to what has gone before. The resulting sequence lasts for several minutes and may be an indication of some anxiety on the mother's part although the link to her daughter's condition appears tenuous. The counsellor subsequently reassures the client that this is unlike Jenny's condition and the consultation moves into closure.

Extract 15 illustrates an example of a summary and final questions component that occur together. June is the nurse-counsellor.

Extract 15 Tape 1

843 D In fact (.) what we (0.2) suggest (.) what I've just suggested here
 844 for your (.) °good self° is (.) very much something which has
 845 been looked at both (.) nationally and internationally and (.) hhh
 846 (.) the received wisdom of (.) lots and lots of doctors and
 847 neurologists and (.) e::r (.) geneticists has has been (that) (.) it it
 848 (.) it's good to approach it this way
 849 C °mmhmm°
 850 D And e::r (0.3) °I have to say this (.) most people (.) e::r feel that,
 851 that's right ° whatever happens when the test is done (1.1) °Any
 852 final questions? °
 853 C °No° ((laughing))
 854 D Well (.) what I'll do is (0.3) write you a letter to summarise
 855 things
 856 C mmhmm
 857 D E::r I'll write to Dr Bloggs and (.) do likewise but (.) ask if (.) he
 858 could give us advice about the (.) particular psychiatric
 859 colleague that °he° feels would be most helpful and either he or I
 860 will (.) fix that up(0.2) and (.) we'll ask Joe L, Joe Long to (0.2)
 861 e::r (.) to see you at his clinic °which is in our department in

862 Newtown so you may bump into° June and myself when you're
863 there or you may not.

Here in line 851 the doctor concludes what he has been discussing, pauses and then asks the client if he wishes to add any final questions. On the client's quiet "no" he uses the word "well" as an announcement in Frankel's terms and goes on to summarise what he will do. The consultation then moves into an invitation to contact them if the client has other questions, some small talk and goodbyes. I include the utterances preceding the "any final questions" because again they raise interesting questions around non-directiveness. This sequence occurs later on in the same consultation as extract 12. Part of "what I've suggested here" in line one is the visit to the neurologist originally proposed there. The counsellor has then gone on to suggest other referrals and checks that the "received wisdom" of national and international doctors (line 845-846) recommends as advisable before a test for Huntington's Disease. Adhering to a strict ethos of non-directiveness, again phrases such as "what I've just suggested here" (line 843) might indicate a form of directiveness or advice. The comment "most people feel that's right" in lines 850 – 851 is also suggestive of pressure towards making a particular decision. In fact it should be noted that the presentation of this sequence of checks and visits as 'suggestions' or options is in itself somewhat misleading, in many cases if the clients wish to have the test on the NHS they *have* to follow the procedure through. It is not really an option at all. On the other hand this perhaps highlights the dilemma raised by Clarke (1997) and by some of the genetic counsellors in my research between professional responsibility and non-directiveness and between the obligation to ensure informed consent and non-directiveness. As a dominant condition, if the test is positive, HD will develop at some time but it is not known when. The referrals are, as already stated, to a neurologist to check if there are any signs at present – if not the development of the disease is many years away – and to a psychiatrist specialising in analysing the potential reactions to a negative or positive result at this point in the client's life. They are part of a sequence apparently recognised as the most constructive way to proceed. To not give this information might be considered an abdication of professional responsibility or less than informed consent. Elwyn, Gray and Clarke's (2000) notion of shared decision-making could

therefore be relevant here. The tension may be evident interactionally in the marking of the potential directiveness by the quietly spoken phrase “I have to say this” in line 850 and the e::r type perturbations – although this may also be related to an awareness that many people feel this process is too complicated and they would rather proceed quickly with the test. The use of the authority of an external ‘expert authority’ and of other families is also of interest. I will be again considering these points in more depth in the following chapter.

The “any final questions” offers the floor to the client to add any questions he/she would like to add to the agenda but retains interactional control by the doctor. As Perakyla and Silverman (1991) state, although this sets up the capacity for a mirror-image of the IW format, the offer in itself suggests it is a departure from the norm. It marks the client’s questions “as an exceptional phase in the consultation, thus orienting to and reproducing an expectation that outside the ‘question time’ questions usually do not appear” (1991: 635). They believe its position near the end of the session confirms this. In some of the genetic counselling consultations, however, this demarcation is not as rigid as in Perakyla and Silverman’s study. The offer for clients to ask questions is repeated in different forms a number of times throughout, perhaps illustrating the stress on meeting the client’s agenda and on information-giving and the complex nature of the information given. Again, though, it is usually restricted to “questions” and may be more limited, even the final time it is offered, taking the form “is there anything you don’t understand” or “Anything I’ve said that’s new or worrying to you?” (tape 11). In many instances, certainly towards the end, this time in accord with Perakyla and Silverman’s findings, there is a negative or sparse client response. This may reflect the complexity of the information or it may again suggest that the clients are conforming to an interactional asymmetry that largely allocates the genetic counsellor the Questioner role.

In some cases, the “any final questions” may be phrased in terms of understanding or worry – “is there anything you haven’t understood?” or “Have we said anything that has worried you?” (tape 3). The common factor, however, is that with the exception of consultation 2 or extract 13, it and the

summary are usually initiated by the doctor and precede closure. As Pilnick (2001: 1941) commented on pharmacist interactions genetic counselling consultations do not always “present a natural or specific endpoint which is clear to both parties” and some kind of close-implicature is necessary. It is significant that, as with the early stages of the consultation, it is accepted by both parties that interactional control is taken by the professional.

The Body of the Consultation

In this section I look at the middle, or main body of the consultations. As the longest segment of many of the interactions, it is also the most varied.

Nevertheless some common recurring elements can be identified. These are:

1. Long sections of information-delivery
2. Decision-making sequences consisting of discussion or information on how to make decisions
3. What one counsellor describes as “nuts and bolts” – the procedure that must be followed before testing or the decision to test occurs
4. A limited number of what might be called ‘troubles-telling’ sequences.

I explore each of these individually in the following sections. The main body of the consultations also yields much relevant data on the differences and similarities between genetic and psychotherapeutic counselling. This will also be explored in the following pages.

Expression of emotion

I begin with a consideration of what I would see as one of the major differences between genetic and psychotherapeutic counselling within this data corpus. That is the lack of encouragement of the expression or exploration of emotion across virtually all of the consultations. Apart from a limited number of consultations in which feelings on decision-making were explored this was an area that was noticeably absent. As this is a function that would be prioritised in many forms of psychotherapeutic counselling, particularly in the person-centred approach, this is not without significance. A typical example is found in consultation three after the diagnosis of neurofibromatosis has been made in the couple’s daughter.

- 192 D I think (.) she probably does have (0.2) neurofibromatosis.
 193 C1 Uh
 194 D It's very likely that she does (0.2) she probably still doesn't
 195 fulfil the criteria according to the text book but she's very likely
 196 to have this soon given you have it the text book (0.2) whoever
 197 draws the rules decided that you should have at least six of these
 198 brown marks and that they all have to be at least half a
 199 centimetre wide or something but (.)given that (.) you've got
 200 this um and that you're sort of gradually starting to see more of
 201 these develop
 202 C2 Mm
 203 D It's very likely that she has it
 204 C1 Mm
 205 D Um now
 206 N () ((to child))
 207 D =the first thing to say is she's a lovely child um I think I've
 208 indicated to you before that *most* people with neurofibromatosis
 209 or NF () so most people live very normal lives and are
 210 very happy
 211 N () ((to child))
 212 D And many never go anywhere near a doctor (0.2) so when you
 213 go to books and you read about problems (0.4) it's well it's the
 214 exception that's proving the rule you know it's like hearing the
 215 news they tell all the bad things but they forget to tell you that
 216 most people have quite good days so
 ((chat to child over several utterances))
 222 D So the likelihood is that your daughter's going to be a very
 223 normal happy lass
 224 C2 Yes
 225 C1 Yeh
 226 D There is a general recommendation that children with NF should
 227 perhaps see a paediatrician once a year just to check that they're
 228 growing ok and that there are no problems (.) ((continues)).

The most obvious thing that I would note as a counsellor is that at no point during this sequence does the doctor ask the clients for their reaction to this diagnosis. Equally neither do they offer it. Their response to the news is minimal, 'uh' and 'mm', not even acknowledging it as 'newsworthy' or informative. They respond slightly more positively with 'yes' and 'yeh' to suggestions that she will be "normal". Later interaction shows that the mother is upset by the confirmation of the disorder but expression of this is not specifically encouraged anywhere. The doctor moves immediately from the diagnosis in lines 192 –203 into a mixture of reassurance and information-delivery and in lines 226 onwards into recommendations for management of

the condition. This pattern is similar to that identified by Heath (1992) in GP consultations. He found that there was often little patient response to the GP's diagnoses, even where interactional space was provided. He also found that diagnosis was often followed quickly by a move into management. His suggestion was that this relates to the asymmetry of the interaction and "in particular the relative distribution of expertise between the participants" (1991: 246). This failure to ask for an affective response, however, would be most unusual in a psychotherapeutic counselling session where the clients' emotional and thinking responses would be encouraged and explored. The following example demonstrates this.

Psychotherapeutic extract C

- 1 Karen: I think about them having fun playing together and laughing at
 - 2 me for not being like them.
 - 3 Therapist: What do you feel inside then?
 - 4 Karen: I feel hurt.
 - 5 Therapist: And then? (long pause)
 - 6 Karen: Roberta pushes me out of her room too. (Begins to tear but no
 - 7 audible cry)
 - 8 Therapist: And what do you feel?
 - 9 Karen: I don't belong with her either.
 - 10 Therapist: Is that like with the other kids?
 - 11 Karen: I don't know.
 - 12 Therapist: (softly) Well your tears look like they know. What do you
 - 13 feel?
 - 14 Karen: I just don't belong – I just go away from them."
- (Erskine, 1997: 196)

Although the language is kept simple as Karen is a child, the therapist takes the client's initial statement in line 1 into an examination of how she feels in lines 3, 5, 8 and 12 and into thinking about how that fits with her other experience in line 10. Although Karen responds only with "I don't know" in line 11 it can be seen that the gentle probing throughout this sequence results in Karen revealing her distress, her central feeling that she doesn't belong and her habitual behavioural response to this – "I just go away from them".

Although it is perhaps the most extreme example, the lack of encouragement of emotional expression in extract 16 is not untypical in the consultation data. The fact that the clients don't offer any feelings suggests that they don't *expect* to talk much about them in this setting or that they are deferring to the

interactional constraints of an asymmetrical encounter. Throughout most of this interaction they introduce few questions and those that they do offer result from doctor-initiated topics. With the exception of one or two sequences such as extract 17 below, only small talk about the child produces spontaneous information. Consultation three, therefore, is, to me, clearly a medical rather than a counselling encounter. It contains little expression or exploration of the clients' feelings or agenda and not a great deal of what would be identified as counselling-type skills or interventions.

Troubles-telling

Another type of sequence that might be expected to occur naturally alongside the exploration of feelings in psychotherapeutic counselling would be the unveiling of 'troubles' which might at least partially resemble Jefferson and Lee's (1988) troubles-telling sequence. Assuming that they are voluntary participants in the counselling process clients are often there because they are in need of sharing their 'troubles' and will have been informed early on that the counsellor is not there to tell them what to do. In all counselling, but perhaps in person-centred counselling in particular, there is a strong emphasis on the importance and power of active listening by the counsellor (see for example Nelson-Jones discussion of "rewarding listening" (1993: 85-86)) and this might be expected to occupy a majority of the session. Some of this is likely to take the form of Jefferson and Lee's 'troubles-receiving'. In the genetic counselling consultations there are a number of instances where 'troubles-telling' takes place but these are not usually extended or a dominant part of the interaction. Extract 17 taken from earlier in the same consultation as extract 16 above demonstrates this.

Extract 17	Tape 3
901	D She sleeps alright
902	C1 Mm I wouldn't say she sleeps alright just lately. She gets very
903	na- she gets very nasty when we tell her she's got to go to bed
904	N Ooh ((to child))
905	C1 =she stands up in cot and kicks cot and rattles it, tries to climb
906	out.
907	D Oh dear hahaha
908	C1 We used to have her so good in bed at night I mean she used to
909	go at 7till 7 now it's going 11-o-clock and she's getting up at 6
910	D Oh dear that's exhausting for you

911 N () Daddy
 912 C1 And so – she won't even get down for an hour in the afternoon
 913 no more – want to come to mummy? ((to child))
 914 D What about (mummy health-wise)?

This extract is part of a sequence in which the doctor is checking on the child's progress so is introduced in line 901 with the doctor's question on the child's sleeping. It follows not long after the sequence reproduced in extract 9 earlier in this chapter. As extract 9 shows previous questions have produced only short or yes and no answers.

In extract 17 the mother uses this question to take the opportunity to tell a 'trouble', marking her potential disagreement with "mm" before she goes on to say "I wouldn't say she sleeps alright just lately" – a form of Jefferson and Lee's (1988) first element the "Approach". Through lines 902-913 she goes on to tell her 'trouble'- Jefferson and Lee's Arrival and Delivery segments - and receives sympathetic statements from the doctor and nurse in lines 904, 907 and 910. These align the professionals as appropriate "troubles-recipients" and the mother is then willing to relinquish the role of troubles-teller in line 913 and allow control of the interaction to pass back to the doctor and his next question in line 914. Jefferson and Lee's Close-implicature and Exit are effectively accomplished in line 11 with the phrase "and so" and the invitation to the child in line 913. This is typical of the troubles-telling sequences that do occur in the genetic counselling consultations. It is not extended, it arises from a counsellor's question and it makes up only a small percentage of the interaction. In one or two consultations there are longer troubles-tellings but these still tend to match the other two criteria. Again the exception to this is consultation five where the mother engages in a number of long 'troubles-telling' sequences. In the following extracts I show how the genetic counsellor works to deal with these within the interaction.

Extract 18 Tape 5 C1 is the mother who with her daughter (C2) is there for a health-check and information session on myotonic dystrophy. Sally is the nurse-counsellor.

937 C1 She won't let me see them. But she she's got it all cut'n'dry. It's
 938 all so straight-forward to her
 939 D °yeah°
 940 C1 =But it's not. I know myself there's more to finding a cure than
 941 she seems to think and it's trying to get through to her (0.1) she

942 just won't listen to no-one else, you know. It gets me so angry at
 943 times=
 944 D =Yeah yeah. I can understand (.) because all of you in the
 945 family feel (0.3) upset about this [condition
 946 C1 [her upset
 947 D =and each of you has got a different way=
 948 C1 =my brother was upset, [my sister and I er
 949 D [yeah
 950 C1 =accepted it and when my brother and my father found out they
 951 had it they wouldn't talk about it [but my sister an' I accepted
 952 ? [yeah yeah
 953 C1 =it, we could talk about it cos we accepted it more, I mean we
 954 C2 Mmm
 955 C1 =we knew there was something wrong =
 956 D =yeah
 957 C1 =And and we thought w-well all we could do was to get on with
 958 it=
 959 D yeah
 960 C1 =not let it bother us, you know
 961 (.)
 962 D If anyone in the family (.) wants particular questions [about the
 963 genetic
 964 C1 [mmhmm
 965 D =bit answered then
 966 C1 Yeah
 967 D I-in the first instance having a word with Sally is, is a way, and
 968 it might be (.) that other people in the family besides yourself
 969 would (.) want to see Sally if they've not already [seen her
 970 C1 [yeah
 971 D that's possible (.) But of course if there are (.) medical type
 972 questions like, I think, when you get into proteins etc [that Sally
 973 could explain
 974 C1 [yeah
 975 D =quite [a bit of it but (.) er there might er be occasions when you
 976 C1 [yeah I will
 977 D = want to come up to the clinic and that'd be ok [too
 978 C1 [yeah, I mean
 979 as I say, I know there's more involved than my mother seems to
 980 think, [it just
 981 D [yes
 982 C1 makes me angry to think that it's so easily solved I mean it's not
 983 [but
 984 D [no
 985 C1 =she just don't don't understand [that
 986 D [But she's not deliberately
 987 wanting to make you angry I'm sure, it's her own [(.) turmoil
 988 C1 [mmm
 989 D =trying to (.) sort it [out
 990 C1 [I think she's worrying because me dad's..
 ((continues with trouble))

This extract is part way through a long sequence where the client gets very upset discussing her sister's death and moves into a long and emotional 'troubles-telling' describing problems and grievances in her relationship with her mother. At this point she has already taken up several minutes complaining about her mother's "ignorance" in believing that replacing the protein missing in the muscles in myotonic dystrophy is simple. She has introduced the topic herself after some information-delivery by the doctor on the daughter's condition - although her hesitance in starting (see extract 19 below) suggests she is acknowledging the fact that initiating a new topic is accountable in this situation.

Extract 19	Tape 5
856	C1 "Um (.) this thing about (.) I know (0.2) lots of problems to do
857	with protein not getting to the muscles..... ((continues)).

The doctor's contribution to the sequence so far has been to acknowledge the client's understanding, give some information and attempt to suggest that it may be the mother's way of finding an explanation that suits her. Extract 18 begins with a continuation of the complaint. The "them" in the first line are papers from America on myotonic dystrophy. Prior to this point she has concentrated on her mother's knowledge assumptions but in line 942 she moves on to state how it makes her "so angry". She speaks quickly though the majority of this sequence with few pauses, and this is reflected in the doctor's jumping in in line 944 with a rapid "Yeah yeah" in acknowledgement of her turn. He then goes on to attempt to understand and suggest a reason for her anger. It is noticeable that he doesn't reflect the emotion back to her or encourage her to explore it, as might be usual in a psychotherapeutic counselling session when an emotion is expressed for the first time. He acknowledges it but appears not to want to take it further. Example D below is more typical of psychotherapeutic counselling where it can be seen in lines 5 and 7 that the counsellor encourages the client to explore her feeling of hopelessness further.

Psychotherapeutic counselling extract D.

- 1 Counsellor: It feels that you've been avoiding looking at me today ...
- 2 and you seem much quieter ... how are you feeling?

- 3 Joan: [bursts into tears] It's so hopeless – I'm hopeless – I can't do it – I
4 just can't leave him [Roger]
5 Counsellor: Is there any other feeling there as well?
6 Joan: I'm hopeless ... [pause] I feel that I'm letting you down.
7 Counsellor: Letting me down because you're not as strong as you have
8 been?
9 Joan: Yes I'm so embarrassed. (Mearns and Thorne, 1988: 120)

In line 946 of extract 18 the client responds to the genetic counsellor's suggestion quite explosively with an interruptive "Her upset" and does not allow the doctor to complete his turn before she goes on in lines 948 - 960 to state that she and her sister had accepted and talked about the illness. The doctor surrenders the speaker position and responds with frequent "yeahs". The client pauses briefly in line 961 and he enters the conversation again with what could be an attempt to change or conclude the topic as he offers any of the family help with "genetic questions". Again this turns the consultation away from encouraging any expression of emotion and from Jefferson and Lee's role of "troubles-recipient" rather than "service provider". Follow-up is once more offered in terms of information. "Troubles-receiving" in Jefferson and Lee's terms is not really offered. Instead the professionals go into more what they describe as a "bland attention to a "problem and its properties"" (1992: 537) typical of a service encounter rather than the focus on "the troubled person" (1992: 541) that they identify with troubles-recipient. This is consistent with the goals of the consultation – information - as stated by the doctor in lines 1 – 7 of extract 6, but perhaps not with the client's wants or needs.

Although she acknowledges the doctor's statements with "yeah" and "yeah I will" the client is still not ready to give up the role of troubles-teller. In line 978 she overlaps the end of the doctor's speech with a "yeah" that recognises the interactional need for contextual relation to the previous utterance but then returns to her anger. She does, however, signal the recognition that she is terminating his attempt at problem-solving with her prefatory statement "I mean, as I say" thereby relating the utterances back to a previous part of the conversation. The speed and continuity of her speech is illustrated in line 986 as the doctor interrupts in overlapping speech with perhaps another attempt to circumvent the emotion and excuse the mother. Again, however, this does not

halt the client, she minimally acknowledges the interruption and then interrupts him to carry on. The statement in line 986 would *not* be recommended in a counselling session in that it directly interprets another individual's motives and affect. Such a suggestion might be made in a more cautious fashion ie "it might be that she's not..." but not as a categoric statement. It perhaps indicates the counsellor's need or wish to move on.

Later in this sequence we see the counsellor move more into what I would recognise as 'counselling-type' responses as his offers of information and more pragmatic offerings fail to halt the sequence and the client gets visibly upset and begins to cry. As this happens he moderates his approach, using the skills of empathising, summarising and clarifying to stay with her for a while before suggesting that some form of additional counselling might be helpful. Phrases such as "obviously talking here has brought back a lot of those feelings" and, as she gets very upset, "J-just say a little bit, I don't know all the details", do encourage her to express and explore her distress. Clarifications such as the following in extract 20 also have the same result.

Extract 20 Tape 5

1116 D So so am I understanding right that what you're saying is that (.)
1117 from time to time over the years (.) y-you've asked your mum
1118 not to bring too many problems?

It is interesting, however, to note that there are perturbations in the counsellor's speech in extract 20 with "so so" and "y-you've" and in the "j-just say" that might indicate he is not altogether at ease with this extended emotional sequence. After several more minutes of talk he brings up the suggestion that the family might benefit from some form of extra counselling "after such a sad bereavement". Eventually, though not without more troubles-telling, the sequence is concluded after an offer for the nurse-counsellor and himself to look into the question of further counselling with the GP or with CRUSE, a specific bereavement counselling organisation.

This avoidance of emotional material and concentration on the "problem and its properties" seen in extract 18 is typical of much, although not all, of the interaction in these consultations. The "problem" is the genetic disorder and its

“properties” the consequences, diagnosis, potential courses of action, tests etc that follow on from it and for which information or assessment is required. This is consistent with the genetic counsellors’ accounts of the clinic consultations as not concentrating on psycho-social issues unless they are immediately present - although even when they *are* immediately presented they tend to be curtailed as soon as possible. This is not dissimilar to ten Have’s account that personal concerns or comments are often glossed over by GPs (1991: 141). It is, however, very untypical particularly of person-centred counselling where the “troubled person” is very much the focus of the sessions and of the counselling process itself. Rogers describes his ideas on client-centred therapy as presenting “a distinct and definable approach to the process of facilitating constructive change in the troubled person” and highlights as one of these “the continuing focus on the phenomenal world of the client” (in Kirschenbaum and Henderson, 1990: 10). Extract D on page 177 shows how this emphasis might be demonstrated in the counselling process itself. The counsellor has initiated the sequence because he felt that Joan was – unusually - avoiding eye-contact with him and he follows the concentration on Joan’s immediate presentation in the counselling relationship in line 5 with a continued focus on her *feelings* rather than being drawn into discussing or offering solutions to her “problem”. The emphasis is on her current experience, her internal distress and on Joan as a person as she is relating to the counsellor. Again this differentiation between what happens in the genetic counselling consultations and in psychotherapeutic consultations seems to mark a clear indication that genetic counselling is more a medical than a counselling encounter in both its orientation and its goals.

If we return to Levinson’s (1992) theory on the structure of an activity being “rationally and functionally adapted” to its goals then it is logical to assume that this might be operative here. The medical goals of genetic counselling consultations, particularly those of information-giving and assessment, account in many cases for a large percentage of the time available. Although the genetic counsellors are encouraged to account for themselves as ‘counsellors’ and part of the ‘therapeutic culture’, the dominance of their medical functions do not allow much scope to explore or follow a counselling-type agenda. In many

cases it would appear that the clients concur with this in their lack of offering much emotional content, and in their acceptance of the interactional asymmetry and dominance of the medical agenda. The mother in consultation five is unusual in that she does not. She persistently brings in her 'troubles' and initiates new topics. Her expectation appears to be that genetic counselling *is* an appropriate environment for extended troubles-telling and she is reluctant to accept an alternative 'service-encounter' response.

In summary then, sequences resembling Jefferson and Lee's (1988) troubles-telling sequence do occur at times within the body of the genetic counselling consultations. However, unlike in psychotherapeutic counselling, they do not generally occupy more than a small proportion of the interaction, they are usually brief and linked to a doctor-initiated topic. In the one major exception to this we see the counsellor using the same offering of information and assistance via information as in other types of sequences. We also see him failing to pick up on or at explore in any depth the emotional content that is revealed. He appears to want to curtail the sequences where possible, perhaps to fulfil the information and medical agenda already laid out – although that it not to say he is insensitive or abrupt in his responses. When the client is not distracted and becomes visibly upset he moderates his approach to use more counselling-type responses although at times he appears uneasy in this role. With the exception of this client most clients appear to conform to the expectation that extended troubles-telling sequences and the expression and exploration of emotion are not part of the genetic counselling agenda and accept the counsellor's curtailing of such. Again I would see this as a marked difference between genetic and psychotherapeutic counselling.

Decision-making Sequences

Another type of sequence usually found within the main body of the consultations, is one that deals with the making of client decisions and the role of the genetic counsellors in these. This is an issue of great significance in genetic counselling. The spectre of eugenics means that any process potentially relating to decisions concerning reproduction is very sensitive. In many cases,

as Shakespeare pointed out, where pre-natal testing is involved “the only possible ‘action’ to be taken on diagnosis is.... termination of pregnancy” (1998: 676). As already discussed in chapter one this raises social issues such as attitudes towards the place of the disabled in our society (Clarke 1990, Shakespeare 1999), the potential elimination of disabled people and expectations of a perfect baby. Non-directiveness is considered essential as pressure on clients towards termination or testing might be construed as contributing to a eugenic outcome. Genetic counsellors are expected to give sufficient information to ensure informed consent but not to influence or advise client decisions in any way.

As decision-making is such a central issue to genetic counselling I explore it in some depth in the following chapter. In this section, therefore, I highlight only some of the more general features of the decision-making sequences. Decision-making is of relevance for clients in just over 50% of the consultations. The structure, length and positioning of these sequences varies considerably. They may be as brief as one statement or cover a number of turns, they may occur in a form similar to a discussion or to a type of information-giving, and they may be in one place only or scattered in several sections throughout the consultation. With the exception of consultations nine and thirteen, the sequences are initiated by the doctor. These consultations, as will be seen shortly, differ in a number of ways to the majority. Extract 22 below gives an example of one of the decision-making sequences. The sequence is taken later in consultation three some time after the diagnosis of neurofibromatosis explored in extract 17. ‘It’ in line 453 is the decision the couple might make prior to re-contacting the clinic to have another child and the sequence proceeds on the supposition that, after testing, the baby is shown to be carrying the Neurofibromatosis gene.

Extract 22	Tape 3
453 D	If you decide that you really would like to go for it and that you
454	want tests in the pregnancy then if you let us know in advance
455	we will <u>try</u> to arrange for blood samples to be taken from all of
456	you
457 C1	Yeah
458 D	=sent off to a reference lab in Manchester so that we can offer
459	you a test in the pregnancy to see if the baby’s got your good

460 gene or your NF gene (1.0). That does raise this awful dilemma
 461 that you might then face at 12 weeks of the pregnancy just as
 462 you stop having morning sickness
 463 C1 Yeh
 464 D Of deciding do you really want to end the pregnancy (
 465)
 466 C1 Yeh
 467 D And I think that needs a bit of thought
 468 C1 Mm
 469 D Because that's one hell of a decision
 470 C1 Scarey int'it?
 471 D And that sort of decision only you can make (.2) and you have
 472 to be happy with it
 473 C1 Mm
 474 D Now we'll be able to help in that we'll give you as much
 475 information and guidance as we can but we can't tell you what
 476 to do () you've got to both be comfortable living
 477 with it (0.2) () As a general rule in life you'll never really
 478 be happy with yourself if you don't give it a shot (.) but so what
 479 I'm saying is don't rush out and get sterilised until you're really
 480 sure

Although the decision-making sequences cannot be said to hold any standard structural format extract 22 contains a number of characteristics that recur in many of them. First the idea that a major 'decision' is necessary is raised by the doctor in line 464 as he delivers a summary of the information-delivery and discussion that has taken place in the consultation so far. (It should perhaps be mentioned here that this is not the first time the question of a decision about termination after a positive test has occurred, although the earlier sequence holds virtually all of the characteristics found here). Second, in line 460, the doctor describes this decision – “do you really want to end the pregnancy” (line 464) as an “awful dilemma”. This is a phrase that occurs in more than one of the consultations and was also used by the genetic counsellors when discussing pre-natal testing in my genetic counsellor interviews. It is interesting in that it might at once be considered both empathic in the sense that for most clients it *is* an ‘awful dilemma’ and almost directive in the introduction of a suggestion that perhaps it *should* be. One of the genetic counsellors commented in her interview that on one notable occasion in particular a consultation had proceeded on this assumption only to get into difficult waters when it was realised that for the couple concerned it might be more a relief than an ‘awful dilemma’. Third in line 467 the counsellor states “I think that needs a bit of

thought”. This is a concept that recurs, often in a stronger form, in nearly all discussion on client decisions. Extract 23 illustrates this. The need for sustained “thought” or consideration by the client is portrayed as an essential part of the decision-making process and firmly establishes their cognitive contribution as central. The client must think because the counsellor is not going to make the decision for them and it is the client who has to live with it – so “we can’t tell you what to do” and “you’ve got to be comfortable living with it” (lines 476 and 477).

Extract 23 Tape 10 C is attending with a history of colon cancer in the family

- 1128 D And some people only want the blood test um ()
 1129 But it’s something you would need to think about very very
 1130 carefully because it you know with it being one where you’ll
 1131 know
 1132 C Yeh no I have thought about it (.) and I I do want the test.
 1133 D Yes
 1134 C Yeh I have thought about it
 1135 D And I can’t – I won’t do it today cos I think you need to think
 1136 about things, the details you know and just make sure that there
 1137 are certain things
 1138 C Yeah
 1139 D =you know in place because sometimes I don’t know whether
 1140 you’ve thought about things like life insurance
 ((Continues))

Here in line 1129 the counsellor puts the emphasis on the need for thought much more strongly – “it’s something you would need to think about very very carefully” - and when the client indicates she has already thought and definitely wants the test, she goes on to say in line 1135 “I think you need to think about things, the details you know”. The “I” is significant. As already stated it occurs in many of the sequences, often with the concurrent refusal, as in line 1135, to act or take tests immediately. It is significant that the counsellor changes her initial ‘I can’t’ to ‘I won’t’ making the statement interactionally non-negotiable. It perhaps reflects the doctor’s commitment to ensuring informed consent, part of which appears to be a need on his/her part to either cover all the information that is felt necessary, in this case insurance etc and part of which appears to include the client taking *time* to think. It might also reveal it to be a priority that primarily meets the *doctor’s* need rather than the clients, particularly as in this case the client has repeated twice that she *has* thought

things through. This, however, is inconsistent with person-centred counselling and might be classed as telling the client what to do. As “I” in this case is the doctor it also subtly influences the power dynamic by invoking the concept of professional authority. Again it reveals a potential tension between the two roles. If in this extract the doctor did not ensure the client had considered the social implications such as insurance she may not have met her medical goal of informed consent, but in over-riding the clients response and imposing her own information-agenda she has perhaps failed to meet her counselling goals of non-directiveness and a client-centred agenda.

All of these characteristics are interactionally significant in that they are doctor initiated, it is the doctor who suggests a major decision is involved, it is the doctor who identifies it as an ‘awful dilemma’ and it is the doctor who states that thorough and extended thought is required. It is also the doctor who insists that only the client can make it. It could perhaps be argued therefore that the counsellor is constructing or defining within the interaction decision-making within genetic counselling as a particular type of entity - major, potentially ‘awful’, needing a lot of thought and the client’s sole responsibility with which they must “be happy”.

Returning to extract 22 a fourth common characteristic in decision-making sequences, as already highlighted above, is the affirmation in line 471 that it is a decision only the client can make and one with which the client must be happy. Other ways of phrasing it have included “but it’s your business and we’ll support you in whatever you decide” (Tape 12). This firm putting of the decision onto the client, backed up by the “we can’t tell you what to do” in line 476 is consistent with the ethos of genetic counselling as non-directive. It puts the responsibility for the decision and its consequences onto the client and away from the counsellor - although in this case the use of the word “guidance” in line 475 is interesting in that “guidance” might be said to suggest more than information-giving. It is then even more interesting in that the counsellor appears almost to contradict his own words as he finishes the sequence with what could be described as a form of “telling them what to do” – “what I’m saying is don’t rush out and get sterilised until you’re really sure”. Clarke

(1997) believes that the blanket refusal to be involved in the decision-making process can amount to an abdication of professional responsibility and, with Elwyn, and Gray (2000), has suggested that shared decision-making might at times be more appropriate (see page 30). Perhaps in a sense this is what this counsellor, while putting forward the non-directive ‘party line’, is actually doing. The phrase “as a general rule in life” depersonalises what he is saying, allowing it to be heard as not necessarily specifically for them. The final phrase, though, “so what I’m saying is”, is more direct. However, C1, the mother, has first stated that she does not want more children because of the fear that they might be affected with neurofibromatosis, gone on to say she might have more if they could be tested (see extract 40) and then said that she really would like four. In the context of the prior discussion therefore the counsellor’s “guidance” reflects and is consistent with what she has expressed. He is in effect taking her opinions as they have been worked out within the context of the information she is given and, in the light of these, presenting his own as to the course of action that might be appropriate. I will be looking further at how much non-directiveness in decision-making takes place within the interaction in more depth in the following chapter.

The phrase from tape 12 quoted above, “we’ll support you in whatever you decide” is consistent with the genetic counsellors’ accounts of their roles in the counsellor interviews. As well as being important in terms of non-directiveness and in refuting suggestions of eugenics, it is also a part of the declared person-centred emphasis on being present for the client in a supportive and empathic way. The phrase “what they mean for you” reproduced in line 237 of the extract below is also consistent with the genetic counsellors’ equally person-centred emphasis on centring the counselling within the context of the clients individual lives.

Finally, in terms of sequences relating to decision-making, there is often an emphasis on there being no “correct” decision or “no rights and wrongs” as in extract 24 below.

Extract 24 Tape 13 The couple have a Downs Syndrome child and are considering whether or not to have more children.

236 D "So it's a case of weighing up the pros and cons of the different
 237 options, what they mean for you and what you will do about
 238 them anyway as you were saying earlier on
 239 C Yeah
 240 D And there's no rights and wrongs, for everyone really it's an
 241 individual choice..

Again this is an interactional manifestation of a commitment to being seen not to be influencing the client's choice. It is also another means of reflecting the decision back on to the client and relating it to his/her individual life circumstances. The phrase in line 237 "what they mean for you" acknowledges that different clients may have different priorities and different structures of beliefs and meanings about what the decisions might represent. In this extract the clients involved have strong individual beliefs about termination.

Nuts and Bolts

Inter-linked with point three in the preceding section, another type of sequence that occurs usually within the main body of the consultation is what one of the genetic counsellors describes as "nuts and bolts". "Nuts and bolts" within the genetic counselling interactions is a process involving the discussion of a set of questions or procedures that must be followed before certain tests or medical procedures can be done. The procedure preceding the test for establishing whether or not a client is carrying the gene for Huntington's Disease is perhaps the most formal of these.

In consultation 12 C1, the female client who has been established as having Huntington's Disease through genetic markers, has stated that what she would like from the genetic counsellors, as they want another child, is "to have the baby without the Huntington's hanging over its head". The counsellor responds as follows.

66 D "(I'm confident) we should be able to arrange this for you.
 67 There's quite a few er nuts and bolts we have to sort out along
 68 the way".

Later these nuts and bolts were to be clarified in lines 97 –99 (highlighted) of extract 25 and lines 14-16 and 255-261 of extract 26 as follows.

Extract 25 Tape 12

94 D Over the last few years a specific test has been developed
 95 extending that whereby you can take someone's blood and show
 96 with close on one hundred per cent confidence whether they're
 97 going to get this or not and that should be (). *So there are a*
 98 *number of questions that raises and we need to make sure that*
 99 *they're all thought through, well thought through.* The first is if
 100 you were to have such a test and get one hundred per cent
 101 confirmation instead of 96% would that be devastating for you?

Part of the “nuts and bolts” then were a number of questions that needed to be “well thought through” in a similar format to the decision-making sequences described above. In lines 98-101 he introduces the first of these and over the following few minutes a further selection that included:

- a) The possibility of testing baby if mum tested positive and the “awful decision” this would raise if the baby's test was positive for the gene.
- b) The fact that if they then decide not to terminate they have in fact already tested the baby without its consent.
- c) Whether a *negative* test result on C1 would lead to any adverse effects.
- d) Whether it was absolutely certain the disorder in the family was Huntington's.

When these had been discussed to the doctor's satisfaction – indicated by line 224 below - he went on with the following sequence. Note the sequence is concluded when all the things are covered that *he* rather than the client wished to talk about.

Extract 26 Tape 12 C2 is the father, Mary the nurse-counsellor

224 D (2.0) Um (1.0) I think we've probably covered all the things I
 225 wanted to talk about () um What um I think we should do
 226 overall um is offer you the option of having your blood taken
 227 today, you went through a whole lot of I presume um um careful
 228 examinations and assessments before. Some places think that
 229 people who have this test you should do all that again um (.4)
 230 um my experience in the past is () (to start again
 231 what we've covered once). Do you see anybody at all ever or do
 232 you just stay away from doctors?
 233 C1 What what do you mean?
 234 D In the context of this kind of () do you ever see anyone
 235 now?
 236 C1 No not really, there's been nothing recently or anything no
 237 D Right that's [fine
 238 C1 [It's very rare I ever need anybody no
 239 D (that's good) We we have one (.) of two suggestions. the
 240 first is that we will ask you to sign the form which I've probably
 241 lost if I can find it again

242 C1 Hee hee
 243 D Mary gave it to me half an hour ago so .
 244 NC I did ()
 245 D One is to sign the form to say that you agree to all this,
 246 C1 Yeh
 247 D =the other is a suggestion, it's only a suggestion that you might
 248 just once go and see an extremely nice neurologist who works
 249 with us here (1.4) He he would er have a gentle look at you in
 250 the way that possibly that Dr Andrews did ()
 251 C1 To look to see if I'm sane ((laughs loudly))
 252 D ((seriously)) Not so much sane, no it's not so much sane no as to
 253 reassure you that you haven't got any signs of it at the moment
 254 (.2)
 255 C1 Yeh alright
 256 D =um and have and give you a second chance to discuss it with
 257 somebody who really is (an expert in the area)
 258 C2 Um How would it help?
 259 D It might.. it would be if we found out it maybe showed nothing
 260 wrong, it's reassuring that you haven't any evidence now
 261 C1 That's right
 262 D So you're not going to get it for several years
 263 C1 That's right
 264 D If they if you do find signs that you show any features which
 265 demonstrate that you've got a slight tremor or something
 266 C1 Right
 267 D (.) it might influence your decision about having children
 268 C1 That's right cos I don't think (it's right)to bring a
 269 child into the world knowing that you're going to be (as you
 270 would)
 271 C2 (no that's true?)
 272 D It's only optional as I say but it's there as an option (your
 273 business) when you've thought all this through but it's an
 274 option which sort of tends to be recommended

In lines 224-231 the doctor indicates that as they have covered all the things he wished to talk about and as the client has previously gone through examinations and assessments, the blood for the test can now be taken – the first stage of his “nuts and bolts” has been completed. He goes on to state, however, that “some people” would still have wanted a series of examinations and assessments to be done but that “in his experience” it wasn't necessary. This demonstrates the formalised routine that has developed around the testing for Huntington's Disease. As has been discussed on page 168 it is also expected that assessments and examinations take place before the blood test can be performed. Despite his assertion that the client needs no further

assessments, the doctor goes on in lines 247 – 250 to make a “suggestion” that she “might just once” go to see “an extremely nice neurologist” to see whether any signs of the disorder are currently noticeable. The stressing and repetition of the fact that it’s “only a suggestion” or “only optional” (line 272) is typical of the presentation of suggestions for referral or further treatment in the genetic counselling consultations. Interactionally they tend to be voiced with hesitation and an emphasis that it is the patient’s choice. They also often contain an element of praise of the other professional – “an extremely nice neurologist” (above) or an “absolutely lovely” co-ordinator (tape 3). This is somewhat different to the more directive statements more typical of a medical interaction such as “I want you to take one of these tablets four times a day for the next five days” or “If you not alright then: come back and see me again then” (Heath 1992: 244). Again this may be the interactional manifestation of the tension between the medical ethos that allows the ‘expert’ to instruct the patient what to do and the counselling ethos that eschews the role of expert and bids the counsellor defer to the client’s choice. The following utterances, however, might be said to bring this tension to the fore in a more obvious way and I will be returning to this and the following extract on page 235 in chapter 7.

At the client’s partner’s question in line 258 the doctor explains that the *absence* of signs would indicate that the disease was unlikely to show for many years and that the *presence* of signs might influence their decision about children – to which the client is quick to agree (line 268-269). The “suggestion” as a whole is defined as an “option” (line 272) for this client, but is usually part of the pre-testing routine. This is evident in consultation one where the client has had no prior experience of genetic counselling or of any kind of testing for the Huntington’s. Here the conversation goes as follows;

Extract 27 tape 1 June is the nurse-counsellor

- 296 D I- it- it (.) if I just go on a little bit and tell you (.) what (0.2) w:e
 297 offer e::r ah to people who want to go ahead and have (.) °
 298 testing ° (.) hh I think the first thing to say as (.) I’ve already
 299 implied is that (0.3) ° we we’re ° certainly not (.) enthusiastic
 300 about (.) somebody coming along and saying just take a blood
 301 test and send it away
 302 C ° Mmm °
 303 We we we think it’s worthwhile taking a little bit of time and
 304 some planning to (0.2) e::r (.) t- t- ° do the test ° (0.2). one of the

305 first things that we (0.2) like to suggest after this initial
 306 discussion with June and myself (0.3) is that (0.3) you get seen
 307 by (.) a neurologist (0.2) who would examine (0.2) all the
 308 neurological aspects (.) and (.) the reason for doing that (.) is
 309 that (0.3) °in the great° the very very great majority of cases
 310 that's showing that the (.) neurological examination is quite
 311 normal. ((continues))

The counsellor begins in lines 296 – 301 by introducing what is offered to 'people' who want to be tested with the emphasised explanation that “we're certainly not enthusiastic” about taking a blood test straightaway. This is minimally acknowledged by the client in line 302 before the counsellor goes on to explain what is on “offer”. The term “offer” is somewhat euphemistic in that, as already discussed above there is, in reality, little alternative. He later goes on to explain in a similar fashion to extract 27 above that the absence of symptoms would indicate a long period before the disorder would appear *if* the test were positive. This reassurance is given as another reason for getting the check done. Suggestions are also made for a visit to a psychiatrist and a further chat with the genetic counsellors before the testing would proceed. The perturbations, stammers and repetitions, seen also in extract 29, may again be a reflection of the counsellor's awareness of the conflict between the “suggestions” he is making and the requirement for non-directiveness in genetic counselling. The whole sequence is repeatedly presented as an established process that has been ascertained by medical experts as the best way to ensure an informed and “best” decision is taken by the client. Extract 28 is one of a number of places where this is explained.

Extract 28 Tape 1

237 D There's been a huge amount of discussion (.) over the (.) °over
 238 the° last ten years about (.) what's the best way to (0.3) carry
 239 out these tests and (.) what is the way to make sure that people
 240 don't rush into doing tests (0.2) without stopping and thinking
 241 (.) what's the best way to do the tests at the best time in a
 242 person's life ° when it's ° (.) the uh I-it's going to suit them best

In the current context in which we are considering these extracts – in terms of the “nuts and bolts” that must be processed before any other agenda can proceed – it can be seen that for Huntington's Disease this is an extended sequence that occupies a large percentage of the consultation time. Although perhaps the most organised and non-optional sequence of checks and discussions this is not unique to Huntington's.

similar processes are followed for most decisions regarding testing or termination. Interactionally, certainly for Huntington's Disease, they can come to follow a routinised pattern that has a significant influence on the way the consultation proceeds.

Information-Delivery

Finally, as already stated, large portions of the main body of the consultations are taken up with some form of information-delivery and the ID format. The content, amount and structure of these sequences vary, however, often according to the main consultation goals. In some consultations few sequences exist which don't conform to the ID or the IW communication formats. In others there is a greater variety with clients apparently more free to introduce new topics or enter into client-initiated discussion. The consultations might be said to form a continuum, with those consisting almost exclusively of counsellor-led ID and IW formats at one end and those with a more flexible and less asymmetrical structure at the other. In general, the more medically oriented the goals, the more asymmetrical the communication formats. The dominance of information-delivery as an activity within the interactions is variable also, in some it occupies most of the consultation, in others it may share equal time with question and answer or discussion sequences. Consistent with the emphasis put on information-delivery and education both by the genetic counsellors and by the literature, however, it is rare for it not to play a significant role. In this data it is only in tape two, where the major goal of the consultation centres on establishing the client's state of health and desire to return to competitive sport, that it is comparatively unimportant. In an aside after this consultation the counsellor comments that this was a very untypical session. It is not possible to cover comprehensively all aspects of the information-delivery sequences but I will endeavour to provide a brief introduction to some of the more recurrent features.

At the far end of the continuum lie interactions such as consultation 6. Consultation 6 begins with the introduction reproduced in extract 7 where the doctor informs the client what is going to happen. The interaction then continues much as she has described. The client plays little active part, she is

Further along the continuum are interactions that are composed *almost* exclusively of the ID and IW formats with large sections of information - delivery by the genetic counsellor. Consultation one is typical. There are many long sections of information-delivery, some turns as long as a page in length, with minimal “mmm” or “yeah” responses from the client. There are also a number of sequences of information-gathering in the IW format by the counsellor. However, it is important to note that, if we return to extract 4 earlier in this chapter, this client has indicated that what he *wants* is to find out more about Huntington’s and the options for testing or other possibilities for himself in the future. The large amount of information-delivery therefore is consistent with the consultation goals – although as already discussed on page 152 the doctor in line 11 might be said to subtly gear the interaction towards information with his comment “any extra questions that (.) if you want to add to the obvious list”. For the majority of the consultation the client conforms to the IR and the Answerer role. There are just a few instances where he makes comments, enlarges on his opinions or raises questions, although these are always linked to doctor-initiated topics. Again, overall, consultations like tape one conform to an asymmetrical medical interaction.

Consultations such as tape 10, where the client is attending because of colon cancer in the family, are similarly geared towards information-delivery and the vast majority of the interaction takes place in the ID and IW formats with the doctor in the speaker role. However, the interactional asymmetry is considerably less rigid than that found in tapes 1 and 6. In the consultation as a whole there were forty occasions where the client initiated questions, offered unasked-for information to the doctor or made comments. Although greatly exceeded by the doctor-initiated ones this is still a significant number. Many of them, however, on closer inspection, hold within them features that conform to Peräkylä and Silverman’s (1991) “knowledgeable identity”, or Frankel’s (1990) four identified ‘conditions’. Extract 30 follows a piece of information-delivery by the doctor with the client having applied the information to her family. Although it does contain a client-initiated topic change, a number of factors suggest it is still conforming to the expected interactional structure of a medical encounter.

indicate the patient's awareness that this is a dispreferred option in the setting. Frankel's argument is that this and his other three conditions continue to defer as Maynard states to the

"interactional constraints of the encounter, namely, the distribution of speaker rights and obligations (physicians initiate sequences and topics) and utterance type in relation to the speaker (physicians ask questions – patients respond)" (1991: 232).

In the same way, although in line 271 the client is initiating a question and reversing the questioner/answerer roles she is still maintaining the geneticist's role as a "knowledgeable identity", a second characteristic of Peräkylä and Silverman's Information Delivery format (1991: 638). This then collaboratively continues to preserve both the ID format and the asymmetry of the interaction in terms of the acknowledgement of differential states of knowledge (Drew & Heritage, 1992: 50). Extract 31 gives an even clearer example of this.

Extract 31 tape 10

- 351 D This gene and misprint is actually dominating over the normal
352 copy so if you have this
353 P Is that - is that just a factor of this that if there's a default as it
354 were it dominates?
355 D Yes for this particular inherited pattern.
356 P Right
357 D Not all conditions.
358. P But for this one yeh
359 D For this one () ((ID continues for another 1 ½ minutes))

This example occurs during a long section of information delivery given by the doctor and in line 352 she is still in the process of talking. There is no real pause before the client comes in in line 353 to ask a question, although the speech is not overlapping. She then temporarily becomes a questioner and the doctor an answerer before the information delivery continues smoothly in line 359. Like the other questions of this type the client's question arises from the technical information she is being given about her own genetic history. They appear to emerge as spontaneous parts of the process and preserve the counsellor's position as the expert. As Peräkylä and Silverman predict, the sequences are often short and Information Delivery is quickly "re-instituted as the basic format" (1991: 636). In addition, although the client initiates these

sequences they do not represent a change of topic or agenda, they follow on from issues the geneticist has introduced. The same is true of a number of other instances where a “conversational contribution” (a spontaneously offered comment or piece of information) is given rather than a question.

Line 282 marks another interesting point in this example. The client does not immediately accept the change to the role of Recipient but interrupts with a comment of her own. However, in this case we can see the doctor in line 285 virtually ignores the interruption giving it a token “Mm” and carrying on with the information delivery. In this way she preserves the asymmetry of the interaction in one of the ways ten Have suggests - ignoring the client’s reported experience (1991: 141). In line 287 we see the client quickly subsides and goes on over a number of utterances to take up the Recipient role. The same is true in a number of other instances where the client offers information without directly being asked for it, sometimes in overlapping speech. The counsellor either ignores her altogether or moves on very quickly.

Extract 32 gives an example of another of Frankel’s ‘types’ of patient-initiated questions or comments, after ‘solicits’ or ‘announcements’.

Extract 32 tape 10

- | | | |
|-----|---|---|
| 136 | D | I’ll summarise it all in a letter for you as well and let your GP |
| 137 | | know as well |
| 138 | P | Yeh |
| 139 | D | =What we’ve discussed |
| 140 | P | What are the time scales on this then on the er on the testing. |
| 141 | | What was the second er the first procedure called the er colon |
| 142 | | something? |
| 143 | D | The colonoscopy (1.4) So it’s colon and oscopy means scope |

Here the doctor in lines 136-139 makes what Frankel calls an ‘announcement’ of what she is going to do. This, he says, marks a sequential boundary point or a potential action or ‘solution’ to what they’ve been talking about and allows for a patient response to confirm closure of the topic or initiate new information or questions. (1990: 244-248). Lines 138 and 140 give both, the client’s yeh agrees to the doctor’s statement of action and she then goes on to ask a new question. Solicits such as “okay” or “is that alright”, according to Frankel, perform similar functions.

To some extent then it could be said that these extracts, although appearing to be client-initiated, are not really disrupting the counsellor's control or seriously challenging her asymmetrical speaker rights and obligations. However, they are also illustrating that the interactional structure locally created between them is flexible enough to allow the client to ask information-seeking questions when she needs to or to make contributory comments at other times. There are no rigid rules or sanctions to prevent her. She is not passive and the interaction is not so dominated by institutional constraints that she is unable to discuss what she wants or raise her own concerns. Unlike in Frankel's (1990) data it is not true to state here that there were "no free-standing" patient-initiated questions" (p240) but rather as ten Have says the asymmetry is changeable and locally "produced" to a "variable extent" (1991: 139). Possibilities do exist for the client to "extend (her) chances to bring in materials on (her) own". (1991: 145). As it might also be said that the asymmetry of knowledge represents one of the reasons the client is there – she wants to know more about her condition and the counsellor is the one who can inform her – then this flexibility is a key factor. It may represent a significant difference between a traditional asymmetrical medical encounter as portrayed in some of the other consultations and a more varied form of communicational structure that might be characteristic of a genetic counselling encounter.

There are also a number of sequences that do not conform with Frankel's conditions or Silverman and Perakyla's knowledgeable identity. There are points where the client either expresses her concerns with some persistence or simply makes humorous comments and is listened to or laughed with by both professionals. It is interesting that these are mostly times when all three participants are active within the interaction (for the majority of the consultation the nurse-counsellor is very much in the background). Extract 33 is a sequence that illustrates this, it comes at the end of a geneticist information monologue describing the colonoscopy procedure.

Extract 33 tape 10

- 831 D ...and examines very closely the whole area of the colon (.8)
- 832 C Sounds very unpleasant hee hee hee
- 833 D Well it's not pleasant ((small laugh))

834 N (?) No
 835 D It's not painful it's just (.2) ooh you just don't want it to happen
 836 (.)
 837 C Yeh, yeh
 838 D (.2) and I think it's a little bit uncomfortable and (.2) I mean (.4)
 839 I will arrange this for you. What happens is
 840 C Yeh
 841 D =you'll get a package through the post telling you what's going
 842 to happen and (.6) you have to pre- prepare your bowels, get rid
 843 of all the faeces from it before you can have it done (2.0)
 844 C Right
 845 D It's it's important it's done
 846 C Yeh hee hee
 847 N People talk about it as being undignified rather than [painful
 848 C [Yeh
 849 D [Yes I mean it isn't painful
 850 C I've worked this bit about emptying your bowel out actually.
 851 I've been thinking about it sometimes, well they will have to
 852 empty the whole thing won't they? ((hint of laughter here))
 853 N And it's particularly (joyful) you perhaps need the day before
 854 off work.

In this sequence the client uses a remark made laughingly in line 832 to interject and to introduce the question of how pleasant or unpleasant the experience is going to be. In this case the accompanying laughter from the professionals is limited, perhaps because they recognise that laughter used in this way often masks emotions such as fear. In other examples all three participants laugh loudly and spontaneously together in a very equal way, very much as you might find in an unstructured social setting. In lines 833 to 845 both the doctor and the counsellor pick up the new topic and quickly provide reassurance and information. In line 846 the client laughs again although her only word is the continuer "yeh" and again both professionals respond quickly in a similar fashion. In this way she has very effectively changed the slant if not the total topic and gained some control of the interaction at this point. Again this demonstrates a flexibility that suggests not all genetic counselling consultations are restricted to the communication formats typically found in a medical consultation.

At the far end of the continuum however are a small number of other consultations that are marked by a greater input of what might be described as

counselling-type interventions, and it is in these particularly that the increased variety of communication format, activity and utterance types take place. One is a discussion of the value of the procedure for testing an adult for Hurler's Syndrome and another on testing a foetus prenatally for Downs. Neither involves physical procedures or health assessments apart from the taking of blood for the Hurler's test which is done after the session by the nurse. Both do however involve some information-delivery from the doctor, but this is presented overall in a much less structured way.

Perhaps the first thing that is obvious in these consultations is the altered balance of counsellor/client utterance input. In the more medically oriented consultations this is heavily weighted in favour of the counsellor. In consultation nine on Hurler's Syndrome there are a few short phases of information-delivery by the counsellor but overall the balance is much more equal. Consultation 13 on Downs has more information-delivery but there are still a number of sections of the interaction that possess either equal or more input on the part of the clients. A contributory factor to this is the use of what I would judge to be more open 'counselling-type' utterances on the part of the counsellor(s). The following extract from consultation thirteen illustrates this.

Extract 34 Tape 13

- 59 D Um I mean what what d'you think you might have (.2) how
60 would you have felt if it had been picked up during the
61 pregnancy?
62 C1 Um well this this is one of the (.) the things that I I don't think
63 (.) well we're both agreed aren't we that we couldn't (.) and
64 we're glad the way it's worked out
65 D Right
66 C1 [Because I wouldn't have wanted to
67 C2 [We We discussed it we didn't discuss it when we were
69 (.)pregnant with Sam but we did with our (.) other son if there
70 was any disability or whatever
71 C1 Because we knew we [didn't have the test didn't we?
72 C2 [()
73 D Right yeh
74 C2 ()
75 C1 And then we just went ahead this time and had the test just
76 because (.8) more of a matter of course we didn't actually
77 discuss it as much did we? [Which was you know strange
78 C2 [No
79 C1 =But erm (.4) but this is the one of the problems because (.6)

80 um (.4) I I don't know whether I want to be put into the
 81 situation where (.) if I do want another child (.6) where we have
 82 the test and it it shows something up (.)
 83 D °Mm°
 84 C1 =um cos I don't think I could go through ha- with you know
 85 with having an abortion
 86 D °Right°
 87 C1 =so I don't know this is one of the reasons what we want to
 88 know you know (.)
 89 D Yeh
 90 C1 what would be the particular need to have it.
 91 D Right (.) um well your act- much of the difficulty would concern
 92 you say you don't know whether you want the the
 93 foreknowledge because
 94 C1 Yeh
 95 D = you don't know what you whether you want to act on it
 96 C1 but but[
 97 D [There's no obligation to have any test [at the moment
 98 C1 [No no
 99 D = but erm I think it's sensible to think it through thoroughly
 100 well in advance
 101 C1 But then (.2) I don't know (.) perhaps it would have been better
 102 to have just been- just to have known mightn't it? (.6)
 103 C2 But you you'll never know
 104 C1 Well no but
 105 C2 You don't know what it would feel like given plenty of time so
 106 it's only
 107 C1 I mean I had a wonderful pregnancy really enjoyed it whereas if
 108 I'd been told um [I might not have enjoyed the pregnancy
 109 C2 [it would have spoilt your pregnancy
 110 D Yeh
 111 C1 But then it came as a really big shock
 112 D Yeh
 113 C1 So (.)
 114 D Yeh was it very soon after um Sam was born (.) that you were
 115 first told?

I reproduce the sequence in its entirety because it contains a number of interesting factors. The first is that the sequence itself begins in lines 59 and 60 with one of the rare examples of a specific open question by the doctor to elicit client feelings – “how would you have felt if it had been picked up during the pregnancy?” “It” in this case is the fact that the couple’s baby has Down’s Syndrome. The question results in a set of turns largely dominated by client input. Apart from lines 91-100 the counsellor’s main input consists of continuers or acknowledgements. In fact, following the counsellor’s question in lines 114-115, there are several minutes of interaction where the clients discuss and air different concerns and the counsellors largely respond either with continuers, summaries or answers. The initial question in line 59 also results in the clients saying in line 62 they were glad they didn’t know during

this pregnancy and in lines 75 –90 revealing one of their central concerns. This is summarised neatly by the doctor in lines 91-94 -

- 91 D Right (.) um well your act- much of the difficulty would concern
92 you say you don't know whether you want the the
93 foreknowledge because
94 C1 Yeh
95 D = you don't know what you whether you want to act on it.

The female client then goes on to elaborate her dilemma in lines 101-103 “But then (.2) I don't know (.) perhaps it would have been better to have just been- just to have known mightn't it? (.6).” As the consultation proceeds this turns out to be a major source of turmoil for them and *not* one that had been identified by the initial summary of why they were there in the opening stages. There it was the risks of another pregnancy having Downs that was highlighted as the main purpose of the consultation. Extract 34 indicates they didn't know and were glad they didn't know in one sense *but* would the shock of finding out have been less if they had known. The use of the standard counselling tools of open-ended questions (see Nelson-Jones, 1993: 98) and summarising (p125), clarifying (p123) or reflecting back (p99) the clients' statements, therefore, has resulted in an introduction and exploration of their major concerns and in a sequence not restricted to the IW and ID communication formats with the clients purely in answerer or recipient roles. This is continued over the next few turns. The clients begin by answering the counsellor's question but their responses are not limited to short answers and they move on to other issues. This use of the counselling skills of summarising, clarifying and reflecting back is also instrumental in the development of consultation nine with a more equal balance of client input and in a more ‘counselling-type’ manner. The following examples illustrate this.

Extract 35 Tape 9

- 107 D .. I may be wrong but I'm picking up from what you are saying
108 that if you were tested and you found that you were a carrier
109 that you would feel uncomfortable about it because it has that
110 extra dilemma
111 C1 Um I think I'd feel uncomfortable for the children really
112 D Ok
113 C1 = I wouldn't be um I wouldn't think it were – it isn't really a
114 worry because I'm almost 90% sure that Steven's not a carrier
115 so it wouldn't concern me that I would have an affected child
116 really (.) it concerns me for um my children really that (.) I
117 would like them to have the knowledge really that should they

result in much greater client input and more in-depth revealing of client concerns. The clients generally respond interactionally with longer answers and the introduction of new areas of information about their feelings and needs. Although to some extent the genetic counsellors may open these sequences with questions or comments the clients are not restricted to short answers, question/answer chains occur less and the sequence structures do not really conform either to the IW or the ID formats. More discussion takes place and the clients interject, explore, ask questions, make suggestions and offer their own opinions. The pattern of asymmetry in turn allocation, speaker rights and interactional role is less rigid than that observed by Maynard (1991), Frankel (1990) or Perakyla and Silverman (1991). In addition, in both of these consultations there are also segments where the clients argue quite strongly for their own opinions, even when these might be at odds with those of the counsellors. The extract below is one of a number of such sequences from consultation 13.

Extract 37 Tape 13

567 D Well quite often people you know do um (.2) request sort of
568 extra detailed scanning () identify (that)
569 that no risk's bad enough ()

570 C2 The problem is though (you've got to decide on that risk, it
571 opens) a decision up I mean that's ultimately if you're going to
572 get information you've got to make a decision on the
573 information

574 ? Yeh mm

574
575 C2 You know you've got to decide then if you're going to carry on
576 with it

577 C1 It's a balance though isn't it if there's too much balancing one
578 way

579 C2 () it's a moral issue

580 C1 Well yeh

580 C1 Wen-yeu
581 C2 () got to decide if you're going to want to terminate
582 or not if you aren't going to terminate then

((All at this point are talking at once there is a lot of overlapping speech))

583 C1 [Well this is it

584 C2 Then [what's what's the point in ()]

584 CZ Then [what = surprise and
585 [take your =surprise and

585 C1 [A lot of this is moral principle for us ()]

585 CI [A lot of this is moral principles] ()
586 NC [some people do it for reassurance as well as for (

586 NC
587)

587)
588 D [There's a lot of point in ()]

588 D [There's a lot of people
589 C1 Yeh you said that before

589 CI Tell you said that before
590 NC =(other people)

590 NC ≡(other people
591 D (and things and) for reassurance or um even

591 D

592 just fore- warning sometimes you know people want to do it.
 593 ? Yes mm
 594 D The other tests I'll talk about briefly are ((continues))

In line 567 the doctor offers the information that “people” quite often request a more detailed scan than the norm when a previous abnormality has occurred. The utterance is quite difficult to hear but the significance of the sequence lies in the clients’ immediate responses. C2 enters swiftly to present what he sees as a problem raised by this even when no risk is involved –information may mean a decision about termination. In line 577 C1 also joins in offering similar opinions. Both believe it is a “moral issue”, termination is not what they would want so a scan might not be useful. From lines 582 to 588 the speech is difficult to pick out as all the participants are speaking in overlap, the clients persisting with their moral objections and the counsellors explaining why the information has been offered or the scan might be done. Even the basic rule of conversation that one person speaks at a time is over-ridden here. Line 589 is interesting in that C1 appears to dismiss the doctor’s explanation with “yeah you said that before”. The sequence ends in line 594 with the doctor retaking the Speaker role with more information and the clients realigning to the Recipient role.

In terms of the interactional structure the clients are demonstrating that they do not feel constrained by their role in the contributions they might make. They are not reluctant to initiate new ideas, topics or comments and they are not expressing a dispreference for disagreement with the professionals. The smooth flow of the interaction is disturbed with overlapping speech from all participants as the clients react and the counsellors respond. Although the disturbance is not prolonged it is not an isolated incident. In both consultations 9 and 13 there are a number of occasions where the clients are able to express their opinions fairly forcibly or discuss openly with the counsellors whether or not they agree with or want to follow the options available. In consultation 13 there are several points where overlapping speech occurs in this type of sequence and in both there are points where the information-delivery is not confined to a doctor-led Speaker/Recipient format and the clients feel able to initiate information questions of their own.

To summarise then, in consultations 9 and 13 although information-delivery occurs the interactional structure is not confined to the ID and IW formats with the doctor in the Speaker and Questioner roles. The asymmetry typically found in conversational analytic studies of medical interactions does not exist to the same extent. Client questions are not “dispreferred”, clients initiate topics, make “free-standing” comments and are not afraid to voice their own opinions. Sections of more conversational-type format or discussion are present, with more equal distribution of speaker rights and roles. Ten Have’s suggestion that the asymmetry is changeable and locally “produced” to a “variable extent” (1991: 139) is obvious to a greater degree than that found in those consultations further down the continuum such as consultation 10. Information-delivery is still a part of the consultation agenda but the evidence from these examples is that the structure of the genetic counselling consultation is not *uniformly* asymmetrical or representative of a typical medical encounter.

Few conversation analytic studies of counselling or therapeutic interactions exist so it is difficult to establish if these genetic counselling consultations have a format similar to other counselling situations. As already stated, the findings appear *dissimilar* in communication format or conversational style to Perakyla and Silverman’s work on HIV counselling. Czyzewski’s chapter in ten Have and Psathas (1995), however, contains information that is potentially relevant. Briefly Czyzewski proposed that in his provisional research results on psychotherapeutic in-take interviews he had “located four different interactional devices based on a systematically different use of “mm hm” tokens” (1995: 75). He gives examples of each, detailing the difference between them, and describes two, the “conversation-oriented “mm hm”” and the “analytical “mm hm”” as “therapeutic” interactional devices specifically connected to the structure of the interviews as therapeutic work (1995: 82). The analytical ‘mm-hm’ is particularly significant in “that after the subsequent pause (which can be quite long, up to several seconds) it is the patient who takes the floor again” (1995: 78). Both are interactional devices that contribute to maintaining the fluency of the talk. The significance here lies not only in the detail of his “interactional devices” but in the association of the prevalence and variety of “mm hm” response tokens in therapeutic work. This would be

consistent with recommendations from well-known counselling training texts such as Nelson-Jones who recommends the use of “small rewards” like “uh hmm” as a means of developing the helping relationship and encouraging clients to continue speaking (1993: 97). He sees them as an important tool in the repertoire of “good listening skills” so essential for effective counselling (1993: 85). It is also consistent with my personal experience as both counsellor and client, the two-syllabled tokens “mm hm” or “uh hmm” – so similar phonetically that “uh hmm” may be Nelson-Jones translation of the same sound – are commonly and frequently used in the ways Czyzewski describes. What is noticeable in the genetic counselling consultations is their relative absence. Even in consultations 9 and 13 “mm hm” or “uh hmm” are comparatively rare, the continuers used by the counsellors to maintain the flow of the consultation are generally the single syllabled “yeh”, “right” and “mm” as illustrated in extract 34. The subtle differences that Czyzewski highlights between types of “mm hm” suggest this might be interactionally and functionally significant. The shorter continuers recognise that the speaker has not yet finished his/her turn, acknowledge or receive what is being said and give permission or encouragement to keep talking, but they may not carry the same conversational or therapeutic implications as “mm hm” or “uh hmm”. The absence of these responses may be an important indicator that the format of even the less recognisably ‘medical’ genetic counselling consultations may not be typical or representative of psychotherapeutic counselling sessions.

If we return to the discussion with which we began this chapter it may be relevant to consider consultations 9 and 13 in the light of Levinson’s ‘activity types’. The goals in these consultations are not as medically oriented as the goals in some of the other consultations. There are no examinations, no medical procedures and no need to establish developmental or health assessments. No diagnosis is made and no test results are given. If the structural elements of an activity are “rationally and functionally adapted” to its goals and the arrangements and constraints logically related to these goals then it is likely that the less formal medical functions allow for a different set of roles and constraints. The time available can be utilised differently with more space for a counselling-type emphasis and agenda that bears some

relation to the genetic counsellors' account of genetic counselling as part of the therapeutic community. The use of standard counselling skills and techniques are interactionally much more evident to me in these consultations than in the majority of the rest. Although there are small sections in others they remain brief and discourage exploration of feelings or, in many cases, client points of view. The interventions used in consultations 9 and 13 are *more* reflective of a psychotherapeutic counselling session and result in a greater knowledge and concentration on what the clients would like to look at. The consultations as a whole are more "client-centred" in their content and structure. However, as already indicated they lack some features common to psychotherapeutic counselling and still have an emphasis on information-delivery not usually found in psychotherapeutic sessions. It may be that in accord with Silverman's assessment of HIV counselling (1997) and with the genetic counsellor's accounts of their own role in my genetic counsellor interviews, they are using Rogerian counselling *skills* in the course of their work rather than counselling *per se*.

Conclusion

In conclusion therefore, this suggests to me that genetic counselling cannot be defined interactionally as uniquely a counselling **or** a medical interaction. The conversational structure is variable in accord with the goals of the sessions and some interactions are more asymmetrical and typical of medical encounters than others. The conversational format and speaker roles, rights and obligations are not always restricted to those usually found in medical interactions. The presence of counselling-type interventions, skills and techniques and a more client-centred interactional format suggests a counselling element to some consultations and there is more flexibility for clients to initiate topics and questions than that described by Frankel (1990) and Maynard (1991). The institutional location of genetic counselling does not confine the genetic counselling consultation to a specifically medical set of conversational rights and obligations. However, information-delivery is still a significant function. Although transmitted in a more flexible manner it has a dominance not consistent with person-centred psychotherapeutic counselling. The focus of much of the discussion necessarily remains around specific medical issues such

as carrier and ante-natal testing. If this is compared to the emphasis on inner growth and on the development of a relationship characterised by the core conditions so central to person-centred theory then there is little similarity. In addition the number of consultations - two out of seventeen - in which the counselling element is evident comprises only a small proportion of the data corpus. This leaves a large majority with little interactional resemblance to a counselling encounter. Of these at least nine have health or development assessments of some form and nine include physical examinations or blood tests. These are functions strongly associated with a medical agenda, placing the genetic counsellor in a medical role. Many of those with an examination included have an interactional asymmetry very similar to that typical of a medical encounter, suggesting that the medical activities are accompanied by the conversational expectations associated with this. Overall my conclusion would be that, although the interactional structure of genetic counselling consultations is not rigidly or necessarily asymmetrical or confined to the ID or IW formats, the genetic counselling consultation as it appears in this data is *primarily* a medical rather than a counselling interaction. A majority of the consultations have strong similarities to medical interactions and few counselling-type features. There may be more flexibility for client contributions than that typically found but only a small minority of the consultations have conversational structures, rights and roles easily identifiable as significantly different to those associated with a medical setting.

Returning to Jefferson and Lee's (1992) concept of a "vague shape", however, does genetic counselling have a recognisable shape or structure and do the consultations possess any "gross sort of observable order"? Although the detail of the interactional structure is dependent on the particular goals of the consultation there are some common elements that appear in broadly similar parts in most of them. Virtually all the consultations have some elements that generally occur either early on or towards the end of the interaction. In the early stages there is a Greetings or Introduction segment and an Agenda-setting segment comprising a Summary and/or Agenda-check. In the later stages there are segments containing a summary of What-is-to-be-done, a form of Agenda-check or Any Final Questions sequence and moves towards Closure and

Goodbyes. These are common to most of the conversations. In consultations with more medically oriented goals, usually in the earlier stages, there is a Health or Development Assessment and, where relevant, an Examination Sequence. This comprises a majority of the interactions but not all, and can have significant implications for the pattern of information-delivery, recommendations and discussion in the rest of the session. For some consultations these functions are not necessary. This can make a fundamental difference to the conversational structure and style, with more flexibility in communication formats, speaker rights, roles and obligations and less similarity to the asymmetrical pattern typically found in studies of medical interactions (eg ten Have 1991). There is also less restriction on the distribution of the consultation time. This renders the proposition that one ‘shape’ can completely encompass *all* genetic counselling sessions unviable. In Levinson’s (1992) terms genetic counselling cannot be defined as one “activity type” because its “sub-parts” may differ according to the individual consultation goals. Where these goals are less easily associated with a traditional “medical” role, ie examination, diagnosis, treatment etc, then the interactions are not as rigidly bound by the same constraints or “allowable contributions” (Levinson, 1992: 69). Before considering the content of the main body of the consultations therefore it might be suggested that genetic counselling can take one of two “shapes” or structural forms dependent on how medically oriented the goals or tasks of the particular interaction are. Where these do not include health or development checks, examinations, physical procedures or diagnosis then some elements are absent and the shape may be more flexible and possess more conversational-type communication styles.

In the main body of the consultations information-delivery plays a major role. It may be more or less asymmetrically organised, as already discussed, according to the particular consultation goals. In the more medical-type consultations the information-delivery often consists of information monologues with the counsellor in the Speaker role, interspersed with question and answer sequences. For the majority of the time the genetic counsellor is likely to be the questioner, although in some consultations a number of client-initiated questions do occur. The medical or health implications often result in

information sequences which include recommendations for tests, referrals or future treatment. Where the genetic counsellor's medical role is less prominent then the information-delivery is less professional-led. There are some monologues but these tend to be shorter and the consultations progress more in the form of a discussion with more client input, topics, questions and opinions. Counsellor's questions are more open-ended and more likely to lead to longer client responses. There is less need for suggestions for further checks or preventative health care. Although the consultations do move along a continuum from more to less rigidly asymmetrical, as a general rule the more medically oriented the activities the more asymmetrical the format.

Also found in the body of the consultations are sequences centring on decision-making. These might include what the decisions are, how they can be made, what part the genetic counsellors will play and the "nuts and bolts" or procedures that have to be gone through before a decision can be acted on (eg a genetic test performed). More than fifty per cent of the consultations involve decisions or decision-making material. Its presence or absence can make a significant difference to the content of the consultations. In some interactions information and discussion relevant to the decision occupy a large proportion of the agenda. In general, however, it is the presence or absence of other medical activities such as the examination sequences that define the conversational structure. Decision-making sequences are distributed across the consultations regardless of their asymmetry or similarity to medical interactions.

Finally there are a few sequences resembling Jefferson and Lee's (1992) Troubles-Telling Sequence. With the exception of one consultation their relative infrequency perhaps indicates the heavy role of information-delivery, decision-making and medical functions in genetic counselling. Clients do not in general treat the consultation as a place to tell their troubles or share their feelings, their and the genetic counsellors' expectations of the interaction appear to be that it is largely for information or for activities requiring the counsellor's medical expertise. Again the presence of troubles-telling appears

unrelated to the stated consultation goals or to the asymmetry of the interaction.

I would suggest then that in this corpus genetic counselling consultations appear to take one of two broadly recognisable “shapes” (Jefferson and Lee 1991) or “activity types” (Levinson 1992). The particular interaction elements and interaction structure present vary according to the individual goals of the consultation. Where these can be associated with more traditional medical activities such as diagnosis or examination then the genetic counselling interaction takes what I will call shape A, where these are absent shape B. Similar to Jefferson and Lee’s (1992) findings the elements are not necessarily in the same order in each consultation. Rather they can be “understood as recurrently present, but occurring in a disordered fashion”. They do possess, however, “a very gross sort of observable order”, beginning with elements which seem to belong to early stages of the shape and closing with elements that seem to belong to the latter stages (Jefferson and Lee, 1992: 522). The shapes can be broadly defined as follows;

Shape A. (Medically-oriented goals)

- A. Greetings or Introduction Sequence
- B. Agenda-Setting Sequence; Summary of why-there and/or agenda check
- C. Health or Development Assessment
- D. Physical Examination Sequence
- E. Information-Delivery. Asymmetrical format, information + one or more of the following; Test Results, Diagnosis, recommendations/ suggestions for referrals, tests, future care or treatment
- F. Decision-making Sequences
- G. “What-is-to-be-done” (Action to follow session) Sequences
- H. Agenda-check/Any Final Questions
- I. Closure and Goodbyes

Shape B (Less identifiably “medical” goals)

- A. Greetings or Introduction Sequence
- B. Agenda-Setting Sequence; Summary of Why-there and/or Agenda-check
- C. Information-delivery; Flexible format, information in discussion form
- D. Decision-making sequences
- E. “What-is-to-be-done” Sequences
- F. Agenda-check/Any Final Questions
- G. Closure and Goodbyes

“Troubles-Telling” type sequences may occur in either shape but their presence is not frequent enough to be included as a typical recurring element.

Again similar to Jefferson and Lee’s findings these shapes can be seen to be “rather well formed in some of the conversations and distorted or incomplete in others” (1992: 522). That is, not all the elements are present in every consultation – for example the Agenda-check/Any Final Questions Sequence does not occur in five of them and the decision-making or examination sequences depend on the relevance of these activities for each case. The diversity of the genetic counselling role is reflected first in the need for two “shapes”, second in the potential for differing combinations of these elements to be present and third, in the variety of activities that might be located within them. Element E of shape A for example may contain diagnosis, test results, referrals etc. This can result in interactions whose content is very variable although the interactional *structure* in terms of Levinson’s “allowable contributions” (1992: 69) remains the same. Nevertheless the activities can be broadly banded into rough encompassing elements and some pattern of progression can be identified in the majority. Consultation five forms an exception. The extended client “troubles-telling” significantly disrupts the pattern at Element E of Shape A. The counsellor has assessed the client’s health and made some suggestions but the information-delivery is then effectively halted by the long and untypical conversational segment that follows. The client gets distressed and the story of her ‘trouble’ takes up a considerable proportion of the consultation time. The abnormality of this kind of sequence in a genetic counselling consultation is reflected in the genetic

counsellor's responses within the interaction (see page 176) and by the subsequent stages. The move to end the consultation comes without both the "What-is-to-be-done" and Agenda-check/Any Final Questions sequences. The counsellor jumps abruptly from the conclusion of this segment to closure-implicative statements and a brief Closure and Goodbye. The absence of both sequences G and H is unique to this encounter.

An analysis of this departure from the commonly found sequence suggests that this might be due to what Jefferson and Lee call "Interactional Asynchrony". This is defined as involving "roughly, that co-participants can be characterised as improperly aligned by reference to the categories provided for, and crucial to, the orderly progression of the sequence" (1992: 524). So in consultation five client one does not align as co-participant in the ID format by taking up the "Information-Recipient" role (Perakyla and Silverman 1991). She moves instead into telling her 'trouble' eventually causing the genetic counsellor to take up a form of "Troubles-Recipency". This appears then to cause problems for the progression of the overall shape or genetic counselling sequence. A similar but smaller example is seen in consultation two where it is the *client* rather than the counsellor who initiates the "what is to be done" sequence. Here as seen in extract 13 this follows an attempt by the counsellor to offer a form of advice that is rejected as the client refuses to align as Advice –Recipient.

The pattern described in Shape A suggests that in a majority of cases the interactional format of genetic counselling has many similarities to Byrne and Long's (1976) six consultation phases (in Heath 1992: 237). Element A can be likened to phase I "relating to the patient", element B to phase II "discovering the reason for the visit", elements C and D to phase III "conducting a verbal or physical examination" and phase IV "consideration of the patient's condition", element E to phase V "detailing treatment or further investigation" and elements F to I phase VI "terminating". Perhaps the most significant differences are located in the amount of information-delivery and in the importance of decision-making. The communication formats of Shape A also bear many similarities to the conversational structures found to be typical of medical encounters by ten Have (1991), Frankel (1990) and Maynard (1991).

This might be said to indicate that in many ways, where medical goals predominate, genetic counselling cannot be said to possess a unique interactional identity. Its information-delivery may be more extensive and its content specifically genetic but its form and communication formats bear a strong resemblance to other medical interactions. However, the presence of the consultations identified as possessing Shape B suggests that *some* interactions do have a unique form and a structure dissimilar to medical appointments. Although these are in the minority, this flexibility or variation in format does therefore give genetic counselling some claim to a unique identity or to an institution that can be differentiated from other types of professional consultation.

Chapter 7

Genetic Counselling as a Therapeutic Encounter – Tensions and Dilemmas

Introduction

This chapter follows and builds on chapter 6 with a more concentrated analysis of the interactional format and significance of a number of key issues for genetic counselling; agenda-setting, non-directiveness and decision-making. These are all of central import in the genetic counsellors' accounts of their roles and form an essential part of the profession's identification with the counselling or therapeutic community and defence against accusations of eugenics. Using key extracts from the consultations I illustrate their problematic nature and how they are handled in practice by the genetic counsellors and by their clients. Within these broad subject areas I will be looking separately at the problems raised by multiple clients, different client goals, the counsellor's need to ensure informed consent or to facilitate informed decision-making, referrals, and the giving and receiving of 'suggestions' and advice. I begin with the potential conflict between the counsellors need to facilitate informed decision-making and their central 'counselling' requirement to follow the client's agenda.

Agenda-setting and the need for informed consent

The following extract from consultation 3 follows the giving of the diagnosis of neurofibromatosis in the couple's child reproduced in extract 16. The mother has already been diagnosed with the disorder previously. The doctor has examined the child, given the diagnosis, told them that most children with neurofibromatosis have "normal happy" lives and informed them of the recommendations for future medical care. In a brief discussion with the father while the mother was getting the child undressed the father has said that the mother wants another child although he himself is unsure. In extract 38 the doctor now moves on to introduce the subject of more children with the assumption that "you've gathered by now that this runs in families obviously".

Extract 38	Tape 3	C1 is the mother, C2 the father
278	D	Now the last time we met we discussed genetics um because you've

279 gathered by now that this runs in families obviously
 280 C1 Yeh
 281 D And there's a suggestion that one of your parents had this (0.2) Are
 282 you thinking of extending your family?
 283 C1 No
 284 D No?
 285 C1 Not going to risk it
 286 D You're not going to risk it
 287 C1 No
 288 D Because of the worry that you might have a baby with more
 289 [serious problems
 290 C1 [Well with me finding out she's got it it's put me off having any
 291 more now (0.8) I mean I'm just happy with her now cos knowing
 292 she's (.) perfectly healthy
 293 ? ()
 294 C1 Yeh you know the next one might not be so (0.4) lucky so I don't
 295 want to risk it
 296 D I understand. The risk is one in two.
 .
 .
 .
 316 D Um have you sort of made an irreversible decision? I mean you
 317 don't have to answer that () I'd just like to think that
 318 you're happy with whatever decision you've made because
 319 sometimes people change their minds a few years later
 320 C1 What about another baby?
 321 D About more babies yeh
 322 C1 Oh definitely not
 323 D ()
 324 C1 Definitely not
 325 (0.8)
 326 D If you change your mind ever and you want to talk about it, we're
 327 very happy to see you again um that's our main job to talk about
 328 risks.
 329 C1 Yeh
 330 (0.6)
 331 D If there was a test in pregnancy (0.6) um that could show whether a
 332 baby was likely to be affected or not, is that something you've
 333 thought about?
 334 C1 If I got if I got caught pregnant again and I had the tests and there
 335 could be a test running and it was said that Sarah had got – that
 336 another baby had got it I wouldn't have it
 337 D You'd end the pregnancy?
 338 C1 I'd end the pregnancy yeh (1.2)
 339 D And that [()
 340 C1 [cos there's some people – we had to discuss it before
 341 when we found out she might have had it and me and me husband

342 kept saying like what shall we do about it?
343 C2 I personally don't think it's that much to worry about I don't, that's
344 my opinion anyway
345 D You've obviously got a difference of opinion
346 C2 Yeh
347 C1 Yeh
348 D That's tricky
349 C1 It's with me seeing my mum die from it you see ()
350 C2 [She
351 didn't die from it
352 C1 Well
353 C2 ()
354 C1 It didn't help though did it?
355 D I'm sure you're correct
356 C1 Yeh
357 D Um (0.6) if if you did catch by accident um and you decided you
358 really did want to have a test in pregnancy then (0.3) it might be
359 possible to arrange for that it might
360 C1 Mm
361 D () what would happen is ((child very noisy here)) ()
362 of pregnancy would be to obtain a sample of blood for you and
363 from dad and from the little one.
364 C1 Mm
365 D Which would be () could be done and we send those samples
366 off ((continues))

Having introduced the ‘obvious’ fact that the disorder is hereditary the doctor continues in line 281 by asking the clients whether they are thinking of extending their family. The mother responds in line 283 immediately and categorically “no”, enlarging on this in line 285 as something she’s not going to “risk”. Her voice tone on the tape is emphatic. In lines 288-289 the doctor questions if this might be due to the possibility of another baby having “more serious problems”. She does not answer directly but declares in line 290 that finding out “she’s got it” (the daughter) has “put her off”. This is the first indication since the diagnosis was given that the client has been deeply affected by it. As already discussed on page 171 client reactions to the diagnosis were not explored at the time. In line 294 she confirms the doctor’s assumption – she’s afraid “the next one might not be so lucky”. Over the next 20 lines of dialogue the doctor then goes on to discuss the risk and suggest again that most people with the disorder live “normal lives”. Once again he does not encourage the client to go further into her feelings but responds

with information. Similarly in lines 288-289 he does not use an open-ended question to explore the reasons for her response but offers instead a closed question and an explanation which she takes up. It is possible that a more open 'counselling-type' approach at this point might have facilitated the client to explore her reasons and her feelings in more detail and allowed the counsellor to introduce information naturally, therefore avoiding the ensuing dilemma. However, interactionally both participants appear to combine in preserving formal asymmetrical ID and IW formats with the doctor in the Questioner and Speaker roles. The doctor asks a series of questions and gives information and the client confines herself to the typically brief answers described by ten Have (1991) as characteristic of medical interviews.

In line 316 however the doctor returns to the subject of more children with the enquiry "um have you sort of made an irreversible decision?" His hesitance, indicated in the "um" and hurried "I mean you don't have to answer that", probably reflect his tension in re-introducing the topic when the client has effectively closed it. He then goes on to produce a form of explanation as to why he is doing so – sometimes people can change their minds. Again in lines 322 and 324 the client's response is unequivocal, "definitely not". This presents the genetic counsellor with a moral and conversational dilemma. The client has twice now firmly refuted the suggestion that she might want more babies. Interactionally therefore she has not given him permission to pursue this as a subject and, if he is to remain firmly person-centred as a counsellor following only what the client is wanting to talk about, then the topic is closed. In lines 326 and 327 he appears to accept that, offering the chance to talk about it another time. However, as a geneticist he knows he has information that the clients do not yet have that may influence or be relevant to their decision. If he is to fulfil his *medical* obligation to facilitate an informed decision then this information needs to be transferred. There is a potential conflict therefore between his role as a person-centred genetic counsellor, committed to allowing the client to dictate the agenda, and his role as a medical expert with information he needs to impart. After a pause he begins in line

331 “If there was a test in pregnancy (0.6) um that could show whether a baby was likely to be affected or not, is that something you’ve thought about?” This is both cautious and diplomatic, offering the information to the client as an option she may have thought about and giving her the opportunity to take on the topic as something *she* wants to discuss. Again his hesitation is revealed interactionally with another pause and the perturbation “um”. The client does not take him up on this directly but in lines 334-336 discusses what she would want if she “got caught” and the baby was shown to have the gene – termination. This promotes a disagreement of opinion between the clients which I consider on page 222 in the following section. In line 357, the doctor again returns to his topic and, still without any direct interactional request from the client, uses her suggestion of “being caught” to deliver his information from lines 366 onwards. In this way he manages the conversation smoothly and relates his information contextually to prior talk. A few turns later the client goes on to state “If I knew that they definitely would do a test then I think we’d have another one wouldn’t we? Cos it’s just the risk.”

Extract 38 then provides an example of the potential dilemma and conflict that can arise when the client’s local interactional response and the doctor’s need or wishes to deliver particular information are not easily compatible. If the client’s agenda is to be pursued in accord with his *counselling* goals then the doctor’s *medical* goal of facilitating an informed decision will be incomplete. If he gives the information on the possibility of testing in pregnancy when she has categorically stated she does not want more children then he is not staying with his client’s agenda. He might also be leaving himself open to accusations of directiveness or eugenics in introducing the concepts of pre-natal testing and termination when the client is saying she has already made a decision not to get pregnant at all. It could be suggested he is trying to influence her decision and guide her in a different direction. The reversal of the client’s decision not many utterances further on is illustrative of the level of dilemma the doctor may face. In his role and experience as a geneticist or medical expert he is aware from prior experience, as he states in

lines 317 – 319, that individual's decisions may change and that in future years what seemed sure at the time may come to be regretted. This is particularly so with such an emotive issue as childbirth. He also knows that the information he has *may* change their minds now. In this case this is exactly what happens, once she knows there may be a way of testing for the gene in any future pregnancies she does in fact go back on her stated decision and say she thinks she “would have another one”.

There is also perhaps a conflict between the ethics of autonomy, beneficence and non-maleficence. The doctor's overall commitment, suggested by his phrase in line 317 “I'd just like to think you're happy with whatever decision you've made”, is for the client's well-being, to ‘do good’, to work positively for her health. This might suggest she needs all the relevant information he can give to make her decision in an informed way. The ever-present emphasis on autonomy, however, might suggest that it is the client's decision and he should respect it without attempting to change it. In addition, could he be accused of maleficence if he withholds information that may help her? Or, without knowing the client well, could he be causing harm by giving her information that might lead to extra anxiety before or after decisions on termination? These are all issues the genetic counsellor has to weigh up and make an interactional decision on in a relatively short space of time. They are not unique however to genetic counselling or to medical interviews alone, even in psychotherapeutic counselling where the amount of information-giving is less, there are times when this kind of dilemma occurs. In my own work with women who have been raped or sexually abused women may, for example, make a sudden decision that they want to report a rape or abuse that perhaps occurred a long time before. They may make this decision stating they anticipate justice and declare firmly within the interaction that this is their intention. If there is no concrete ‘evidence’, however, I am aware that they are unlikely to ‘succeed’ in the justice system and may face considerable trauma and distress. As a counsellor I have to find a way to balance the ethic of non-directiveness that bids me support her autonomy and the ethic of non-maleficence

which might suggest that allowing her to proceed without all the relevant information may lead to her experiencing harm.

Multiple Clients

As is evidenced in extract 38 genetic counselling consultations often contain multiple clients or participants. This can lead to difficulties with multiple agendas or diverse goals. The counsellor may find it hard to satisfy the needs of each participant equally and at times their goals may conflict. Meeting the requirements of one client may mean going against or neglecting the wishes of another. Ensuring that each client has the information they need to make an informed decision may be problematic, as may ensuring each client makes an *autonomous* decision when other family members may be exerting influence or pressure or simply dominating the interaction. It may be difficult to remain non-directive in such circumstances. Client disagreements as in lines 343-354 of extract 38 above may also occur. Again the counsellor’s neutrality may be difficult to maintain. In this extract the counsellor is relatively successful in remaining impartial. He highlights the fact that there is a conflict and comments that this is “tricky” but refrains from getting involved. To some extent it might be said in line 355 that he aligns with the mother but his tone on the tape is even, the interaction proceeds smoothly and the disagreement is not pursued. Extract 39 below is more problematic, the counsellor in essence has to select between clients to proceed.

Extract 39	Tape 12	C1 is the client C2 her partner
403	D	You look bored
404	C1	It’s <u>him</u> that’s making me bored, I can see that he looked ()
405	D	There’s - what else have you got have you got a new list of
406		questions with you?
407	C2	Not necessarily obviously I would say as() conversation
408		transpires I was taking on board what you’re saying.

This extract follows a fairly long sequence in which the counsellor has been answering questions posed by the client’s partner. The partner has been asking questions and exchanging ideas and information-delivery has taken place. Here the counsellor turns to include client 1, commenting to her that she looks “bored”. She responds with some irritation that “it’s him that’s making me bored” and although

the end of the sentence is inaudible her overall message is clear – she doesn't want the questioning to continue. Later, following another sequence of questions by the partner, it becomes evident that she does not want to keep being told by friends and family about new research but just wants people to “leave me alone”. She gets quite voluble about this, speaking quickly and when her partner intervenes to say it's because they care, almost shouts, “YEH I'm SURE I'm SURE” then overshadows him as she goes on to explain;- “Of course yes same thing but like I haven't I don't feel that I have I don't really feel that there's anything wrong with me at the moment and I'm sure there's going to be something wrong with me but I you know I wish everybody'd just like (laughs) treat me like a normal person”. In line 405 of extract 39 the counsellor turns from the mother back to the partner saying “have you got a new list of questions with you”? Although he answers “not necessarily” the counsellor has to some extent made the choice to attend to *his* agenda requirements at this point of time. The mother – the actual client – is in a sense not catered for, if the partner has more questions, as he in fact does later, she has to remain ‘bored’ or become frustrated or distressed as indeed we have seen she does. The counsellor cannot meet both parties' needs, both in the moment and in the wider interaction. The later emotional outburst from the client indicates that by offering the partner the time and space to follow his need for information the counsellor has in fact moved directly against *her* wishes in giving information she did not want.

Establishing the agendas of all the clients at the outset may also be problematic, particularly where parents and children are involved. In both consultations 5 and 8 for example the daughters contribute little. In consultation 5 it is solely the mother who responds to the doctor's questions on what they would like to “cover” (see extract 40 below) and at later stages she also, as in extract 43 answers for her daughter (Megan) on other areas.

Extract 40	Tape 5
115 D	Are there any other things you want me to put on the list that you
116	want to cover (°just to add°)?
117 C1	I don't know (.) I mean at the moment Megan's been having
118	problems ... ((continues)).

Extract 41	Tape 5
197	D Do you enjoy school? (0.4)
198	C2 °Some[times°
199	C1 [No
200	D [Ha ha ha
201	C1 Ha ha ha (can I miss school ()home) don't want to go to
202	school ha ha
203	D Ok well I've got those things on the checklist about (.) er (.) Megan
204	what about yourself in anyway are there any queries you've got?

Here in line 197 of extract 41 the doctor asks the daughter if she enjoys school. After a pause she answers quietly “sometimes”. However, in overlapping speech in line 199 the mother contradicts this with her answer “no” and goes on, laughing, to imitate her daughter complaining about going to school. In line 200 the doctor laughs also before he goes on to change the subject by asking if the mother has any questions about her own health as both mother and daughter are the subjects/patients of this consultation. Both these extracts illustrates how difficult it can be interactionally when dealing with families rather than individuals. It is not easy for the counsellor to elicit each client’s goals or opinions separately when one participant is interactionally dominant and answers for another. How does the doctor here attend to the needs of both participants clearly and how, in a situation where there is an unequal power dynamic between the clients, can he ascertain the wishes and feelings of the less dominant party? He laughs with the parent but it is not obvious if the daughter is laughing too. By joining in laughter with the mother he is not strictly remaining neutral. It could be that the daughter might feel isolated or marginalised within the interaction and her participation or autonomy be compromised. Consultation 8 illustrates this and the difficulties of dealing with multiple clients more starkly as the following extract shows.

Extract 42	Tape 8
60	D Erm right. Well obviously today ((coughs)) () is really to
61	give you the result of the test and erm (0.2) it's that the test <i>did</i>
62	show (.) that the change (.) is there in in your X chromosome (.)
63	E:rm (.) is that what you were expecting((goes up)) or – ?
64	C1 °no °
65	D You didn't so it's come as a bit of a (.) surprise has it? (0.4)
66	C1 °uhhhh°

67 C2 It shouldn't do [if you read the letter on Thursday Molly
 68 C1? [mm
 69 D? Mm
 70 (0.4)
 71 D You knew [there was kind of a fif[ty % of a chance
 72 C2 [y-knew [bi -bigger chance
 73 D =of that [didn't you? [()]
 74 C2 [mm [didn't you] really
 75 D Yeah. I mean I don't think (.) that doesn't change you as a person
 76 overnight or anything like that or (.) it doesn't mean anything for
 77 your physical health or anything you know, so- but it is something
 78 that (0.8) you know you may want to think a bit more about and
 79 have some sort of (0.4) discussions about. E:rm (1.2). Were you
 80 thinking it – it was just going to be negative or just (.) did you just
 81 not know?
 82 (0.6)
 83 C1 Mmhmm ((this sounds almost like an embarrassed laugh))
 84 D Mm
 85 (1.6)
 86 C2 You just hadn't thought about it had you?
 87 C1 Ahmm[((similar sound))
 88 C2 [No
 89 D Just put it to the back of your mind?
 90 C2 Ye:ah

In this consultation it is the daughter C1 (Molly) who is the client. Her father, C2, and her mother are present with her. As the doctor says in line 60 the appointment has been made to give the results of a blood test to see if she is carrying the Fragile X gene and in lines 61-62, with no lead-up or preliminaries, she reveals that the test is positive. In line 65 she then asks the client if that is what she was expecting. Again it is noticeable that this is not an open-ended “how do you feel about that” question but a closed question to which the client is almost invited to answer yes or no. At the client's very softly spoken “no” she then asks another closed question, “so it's come as a bit of a surprise has it?” After a pause the daughter answers with a quiet assenting-type “uhh” and is almost overlapped by the father saying that it “shouldn't have” if she'd read the letter. Molly responds minimally again. At this point the doctor also says “mm” and goes on in lines 71 and 73 to agree with the father, saying the client knew there was “kind of a fifty per cent chance”. The father in lines 72 and 74 provides overlapping agreement and after a brief explanation that “it doesn't change you now” the two of them then

collaborate interactionally in lines 79-86 to suggest why she is surprised. The daughter in lines 83 and 87 responds minimally to their explanations – she did not know or had not thought about it – with a quiet embarrassed sounding assent. Eventually doctor and father decide together in lines 89 and 90 that she had “just put it to the back of (her) mind”.

At first sight this extract appears to be an excellent example by the counsellor of how not to remain impartial in the presence of multiple clients and how not to exercise Roger’s core conditions of empathy and unconditional positive regard! The counsellor’s responses to the daughter appear judgemental, she agrees she “shouldn’t have” been surprised and reminds her really she “knew”. The client’s feelings are not explored openly or empathically and the doctor appears to ally interactionally with the father in speaking for the daughter. Both combine to define what Molly was feeling and why she has acted as she did. However, making such a judgement would ignore its conversational context and fail to acknowledge some of the institutional or interactional difficulties the counsellor faces. Firstly although the daughter is the client in this instance the family is known to the counsellor, she has been tested for the Fragile X gene because her brother has been identified as suffering with the disorder. Although he is now a teenager, later discussion in the consultation suggests that there had been many years of uncertainty before the diagnosis was made. The father and the family have experienced considerable difficulties, anxiety and distress through the disorder. They can therefore lay claim to personal experience and insider knowledge that gives them a type of ‘authority’ within the consultation. As ten Have (1991) and Pilnick (1998) have pointed out such patient knowledge can influence some of the interactional asymmetry normally found in medical interactions. The relationship between the counsellor and the father therefore may be less asymmetrical than usual and the counsellor may find it harder not to assent to the father’s “knowledge”. Second the daughter in this consultation is nineteen but she sounds and responds interactionally in what seems like a much younger manner. She says very little throughout the consultation and it is impossible to know whether this is because the father is so

dominant or because she has little commitment to the counselling process. She may be there only because the parents think she should. The counsellor may be aware from prior experience that attempting to draw her out will be unproductive. She may also have spent some time and effort already explaining things to Molly yet her responses appear to indicate that little has been taken on board. In person-centred terms this does not justify the lack of empathy nor the failure to attempt to establish the reasons for Molly's apparent reluctance to look at the possibility of a positive result, but it does illustrate both the complexity of dealing with a family unit rather than a single client and the ease with which participant marginalisation might occur.

The interactional difficulties of dealing with multiple family clients become yet more apparent as the sequence unfolds.

In part two of this extract the doctor, perhaps aware of the marginalising of the daughter in the previous turns, makes a concentrated attempt to address the interaction to her. In lines 90 – 91 she concludes the previous sequence with “Right ok”, then pauses and offers Molly the chance to ask questions. Again it is noticeable that what is on offer is “anything you want to *ask*” rather than an opportunity for Molly to explore her feelings. She also again uses a closed rather than an open question. There is a significant pause where Molly does not respond and it is only when the counsellor concludes her sentence with “do you think it will take a while to sink in?” that she very quietly echoes that it will. Again the counsellor has effectively provided an answer for her. In line 94 after acknowledging Molly's response with “mm” the counsellor pauses once more, giving her chance to say more. When no further response is forthcoming she moves into saying first that it's “no-one's fault” and then into some information-delivery. At this point she is still speaking directly to Molly and in line 100 starts to ask if they had discussed the testing before, perhaps to see what Molly knows. However, in line 101 the father interrupts in overlapping speech asking about the timing of the testing the doctor has mentioned. The doctor appears taken aback.

saying “Right” and pausing for two seconds before she starts to ask a question. C2 interrupts again in line 104 and from lines 105 to 109 there is a series of overlapping utterances between the two of them. The doctor attempts to intervene in line 106 and again in line 108 but the father retains control of this sequence of the interaction until he concludes in line 109 with the same question. The doctor’s struggle to deal with the interruptions and still direct her attention to C1 is apparent over the next turns. Once again she says “right ok” and in lines 110-111 re-addresses Molly, asking *her* if she wants the tests described. Having received a minimal assenting response she then asks her if she is considering pregnancy “in the near future” promoting an embarrassed-sounding “no” with a short laugh and subsequent laughter from all. It is significant that the humour from the nurse-counsellor’s comment in line 118 is about the *father’s* potential response to this question. Laughter notwithstanding, this indicates another potential difficulty for the doctor in dealing with multiple participants – how honest or comfortable is a teenage daughter going to be answering a question on pregnancy in front of her (dominant) father? The doctor’s awareness of this difficulty is perhaps indicated by the perturbations in her speech in both lines 124 and 126 where she stammers with “I-I” and “b-but” and hesitates with “e:rr” as she explains or justifies why it is “useful” to discuss these things well in advance – although they may also be an indication that she is needing to justify her information-delivery in the face of Molly’s lack of response in line 93 as I discuss below. It is noticeable again in lines 128 and 131 that it is the father rather than the daughter who is responding but the words “James your brother” in line 135 demonstrate that it is to *Molly* once more that the doctor addresses the information that follows.

Again this whole section illustrates how difficult it can be for the genetic counsellor to fulfil the counselling goal of catering primarily for the client’s agenda in an interaction with multiple clients, particularly a family unit. The doctor consistently attempts to address herself to the daughter but is repeatedly interrupted by the father. Nevertheless she pursues her efforts to centre on Molly, checking with her that she wants the information given and offering her the

opportunity to ask questions. Ascertaining the daughter's perspective, however, is very difficult. Molly gives little in the way of information. Her responses are minimal and she does not pursue the chance to ask questions. This is a pattern that continues throughout the consultation and, combined with the father's dominance, is later to cause the doctor great difficulty in maintaining neutrality within the information-delivery. I will be pursuing this in the following section. Molly's reticence also presents the doctor with a dilemma around her own information-delivery agenda. As already discussed part of the genetic counsellor's role is to ensure that enough information is given to make informed decisions. Although Molly does not need to make a decision now, she is of an age when she could become pregnant, planned or not, at any time. The doctor's raising of the issue of testing prior to the father's questions in lines 99 – 100 indicates that she has information she wishes to impart but Molly's lack of response in line 93 has not given her a clear interactional permission to proceed. With the father's interruptions in lines 101, 104, 107 and 109 it takes her several attempts to get a minimal-type permission from Molly to go on to deliver what she wants to say. As mentioned above the perturbations and the justification in lines 126 – 129 that "sometimes it's useful to have you know (.) a discussion well ahead of that" perhaps reflect her awareness that she is almost forcing the interaction towards the information-delivery she wishes to give (and finally does from lines 133 onwards) without much interactional support from Molly.

Multiple Clients and Neutrality

Later in consultation 8 the presence of the family unit leaves the counsellor in an interactional situation where the need to be neutral and non-directive and to ensure autonomous decision-making become very difficult to fulfil. Extract 43 follows a description by the counsellor of the tests that are available in early pregnancy to establish whether or not a foetus carries the affected gene. Apart from minimal acknowledgements Molly has remained silent and again it is the *father* who has been asking questions about the timing and routine.

Extract 43 Tape 8

331 D [Each of these tests (0.4) does carry a small risk

332 C1 [°mm°
 333 D =of of miscarriage because obviously it's taking tissue from the
 334 developing pregnancy so there is a small risk associated (.) e:rm
 335 and with the amniocentesis later on it's around 2 per cent (0.6) and
 336 with the CVS earlier on it's around one per cent (0.4) E:rm so you
 337 know it's – unfortunately there isn't a (.) test that (.) doesn't
 338 C2 Huhh
 339 D =hold any risks at all but e:rm
 340 C2 I think one or two per cent risk [is er
 341 D [°mm mm°
 342 (0.8)
 343 D mm
 344 (1.4)
 345 C2 =[small enough I say as just a (0.4) child's blood
 346 D [yeah
 347 C2 =isn't it? (.)
 348 D Well you weigh that up against the risk of there being a problem
 349 and [decide
 350 C2 [that's it
 351 D Obviously it's for Molly and her partner to decide if that – if they
 352 want to to do that. There's a lot of experience with both techniques
 353 certainly and you know e:rm the earlier they're [done
 354 C2 [it's a tiny amount
 355
 356 of risk (.) weighed up [against trying to
 357 D [mm
 358 C2 =raise a [handicapped child [for the rest of
 359 D [mm [mm
 360 C2 =their lives
 361 D mm
 362 C2 I mean I [think one outweighs the other a great deal
 363 D [I
 364 C2 But
 365 C3 huhh that's right
 366 D Well there's – there are no rights and wrongs in these situations
 367 [some people (0.4) [are dead against (.)
 368 C2 [that's it [yeah
 369 D =testing things at all other people (.) really want to know an-and (.)
 370 this what you whatever you (.) wanted to do [you know what I
 371 mean yeah
 372 C2 [yeah (0.4)

In lines 331 - 337 here the counsellor states that each of the pregnancy tests carries an unavoidable small risk of miscarriage, about two per cent with amniocentesis and one per cent with CVS. She then hesitates, leaving enough space for the father

in lines 340 –347 to intervene and air his opinion that this risk is “small enough”, requesting her to collaborate in supporting this with “isn’t it?” in line 347. The counsellor does not accede to this but opens in line 348 with “well” and offers the neutral “you weigh that up against the risk of there being a problem and decide”. The generic “you” serves to keep the conversation general and her personal position ambiguous. However, in line 350 the father comes in with overlapping speech and attempts to use what she is saying to support his viewpoint. If she wishes to enforce Molly’s right to an autonomous choice and maintain the neutrality of the interaction the counsellor then needs to strengthen her position. She does this by personalising her statement and emphasising that it is “obviously” for Molly and her partner to decide. In lines 351-353 she begins to offer more information but is interrupted again by the father saying “it’s a tiny amount of risk weighed against trying to raise a handicapped child for the rest of their lives”. In line 362 he furthers this with the statement “I think one outweighs the other a great deal” and is supported by the mother – hitherto a non-contributor – saying “that’s right”. These utterances are made flatly and on the basis of the couple’s experience in raising their handicapped son. As already mentioned (see page 226) this experience gives them a degree of knowledgeable authority within the interaction that is potentially difficult for the counsellor to contradict. At this point, having made only minimal acknowledgements, she tries to intervene but is talked down until in line 366 she enters the interaction again and states firmly “there are no rights and wrongs in this situation, some people are dead against testing things at all, other people really want to know ”. In this way she then aligns herself in opposition to both parents in expressing a viewpoint contrary to their own – it is not a clear-cut decision with only one ‘right’ answer. Molly, as has been seen in prior sequences, continues to remain silent and passive. As Pilnick (2002) states, in her analysis of the same sequence, “the father’s expression of his views potentially threatens not only the choices of his daughter in relation to testing, but also the professional neutrality of the counsellor. As a result the counsellor’s steering of the father away from his expression of these viewpoints becomes progressively more forceful” (p84). Although her statement is non-directive in that it is advocating a

free choice for Molly she is forced to overtly voice her opposition to the parent's view that there is no choice to make. If she were to remain specifically neutral the balance of the consultation information-delivery or discussion would lean heavily towards testing and termination and Molly's potential viewpoint or decision might be left similarly influenced. The counsellor later reinforces her viewpoint and Molly's individual rights to decide by stressing again that it will be up to her and any future partner to decide and that "at the end of the day it's up – it's up to you and you'll weigh up the pros and cons". She also offers to see her again alone to "have another chat". It is noticeable once more that Molly continues to do no more than offer minimal responses and when asked if she wants the counsellor to say more replies quietly "no" and after a one second pause "not really". Whether she wanted any of this information in the first place is dubitable.

Williams, Alderson and Farsides (2002) quote Clarke describing the non-directive approach as

"....not to lead clients to make particular decisions or choices (those preferred or recommended by the clinician, the health service or by society) but to help them to make the best decisions for themselves and their families as judged from their own perspectives (1997: 180)"

In the presence of multiple clients with the potential for differing perspectives, however, this is not always simple. In extract 43 the father's view is so dominant that it is not possible to know what the daughter's are. How then does the counsellor lead her to make the best decision from her own perspective - certainly without revealing something of her own viewpoint?

Non-directiveness in decision-making and the medical role

The presence of multiple clients however is not the only circumstance in which non-directiveness appears difficult to maintain. In some consultations it is the medical nature of the subject under discussion that leads to tension. The definition above suggests that being non-directive means that the client should not be "led" to make choices that are recommended by the counsellor, the health service or

society. We have already seen, however, that “suggestions” and “recommendations” do occur and that in some of these the “leading” is stronger than in others. In consultation ten the client is attending to discuss the tests and checks available for colon cancer. The following extracts are taken at different points during the interaction.

Extract 44 Tape 10

- 813 D As we’re sitting here I can’t tell one way or another but you have a
814 high chance actually of developing
815 C Yeh
816 D =this problem (0.4) about 40% which is ()
817 C Right
818 D And it’s for that reason we need to offer you screening
819 C Right
820 D Um because there are two things we can offer. I’ll go through them
821 both
822 C Right
823 D We’ll have to think carefully about what’s right for you
824 C Yeh
825 D The first thing we can offer is what is called um -
826 C Yeh
827 D or what we would recommend is called colonoscopy
828 C Mm
829 D =which is a telescope up the back passage to look all the way round
830 the bowel ((continues with information))

Extract 45 Tape 10

- 150 D But when we start seeing a family like this (0.4) we work out who
151 are the people we should be offering appropriate counselling
152 appropriate screening. We’re looking at a condition where if
153 something is found it can be picked up early and treated very early
154 which is () than later on life.

Sacks noted that when speaking as a member of an organisation speakers often refer to themselves as “we” rather than “I”, indicating, state Drew and Heritage, that they are invoking their institutional identity over a personal one and “speaking as representatives, or on behalf of, an organisation” (1992: 30). The counsellor in these extracts uses “we” repeatedly as she lists what can be offered and what is “needed” or “recommended”. Silverman, in his work on decision-making discourse in a Paediatric Cardiology Unit, describes the use of the “we” and the “I” voice together as a “persuasive format” that invokes the “collegial authority” of

the medical team (1987: 57-58). The “I” presents the thinking and the “we” describes the action. So, states Silverman, “The “I” voice receives support from its institutional base but also reveals its authority in being able to formulate its proper action – exactly *what* ‘we should do’. This combination of authoritative reflection and collective action reveals the power of the persuasive mode” p57). The use of this format, aided by the voice of reason that provides a rational explanation *why* the course of action is necessary can make it difficult for the patient, excluded from the authority, to challenge. In extract 44 the counsellor appears to present her information as Silverman describes. She gives her thinking in line 813 as she declares the client has a “high” chance of getting colon cancer but “as we’re sitting here I can’t tell one way or another” and presents this as a logical “reason” why “we need to offer you screening” in line 818. She then goes on in line 826 to state “what we would recommend is called colonoscopy”. The client acquiesces with “yehs” and “rights” throughout. The presence of Silverman’s “I – We persuasive format” and the terms “need” and “recommend” would not appear to correspond with the definition of non-directiveness described above. The counsellor in this case uses her medical authority to present a case for screening which she later goes on to justify further with the explanation – again using “we” – given in extract 45, the condition is treatable if caught early. In effect she could be said to be “leading” the client towards a particular decision or course of action and violating her Rogerian ethic of non-directiveness. Again, however this simplistic judgement would be ignoring the complexities of her role. She is a geneticist with the medical knowledge that indeed she presents here, the screening she is recommending saves lives, its’ absence may lead to undiscovered and fatal bowel tumours. Not to present this information may, as one of the doctors in the genetic counsellor interviews believed, amount to medical negligence. Although it might be argued that the counsellor could have presented the information in a less overtly directive form – less use of the term “we” and a more neutral presentation of the facts – these extracts nevertheless again highlight a tension between the medical and the counselling roles. Screening is a course of action that is *medically* recommended but to suggest this violates the *counselling* edict of non-directiveness. Sarangi and

Clarke (2002) suggest that in situations such as this – “promoting surveillance for complications of a genetic disorder (eg surveillance for tumours in a family with high risk of bowel cancer” (p296) - Elwyn, Gray and Clarke’s (2000) concepts of shared decision-making may be more appropriate.

There are a number of sequences within the genetic counselling corpus where the counsellors make “suggestions” as to further courses of treatment or referrals. In the extract above the counsellor presents her information in a format identified as typical of medical interactions without apparent interactional hesitation. In other examples within the corpus this is not the case. Extract 26 on page 187 includes an example of suggestions for referrals marked by considerable hesitation on the part of the counsellor. It is part of the “nuts and bolts” worked though before testing for Huntington’s Disease, in this case with the client who has already been though assessment using genetic markers. Extract 46 reproduces a section of extract 26 for consideration here. For further context and analysis see page 188.

Extract 46 Tape 12

- 20 D One is to sign the form to say that you agree to all this,
21 C1 Yeh
22 D =the other is a suggestion, it’s only a suggestion that you might just
23 once go and see an extremely nice neurologist who works with us
24 here (1.4) He he would er have a gentle look at you in the way that
25 possibly that Dr Andrews did ()
26 C1 To look to see if I’m sane ((laughs loudly))
27 D ((seriously)) Not so much sane, no it’s not so much sane no as to
28 reassure you that you haven’t got any signs of it at the moment (.2)
29 C1 Yeh alright
30 D =um and have and give you a second chance to discuss it with
31 somebody who really is (an expert in the area)
32 C2 Um How would it help?
33 D It might.. it would be if we found out it maybe showed nothing
34 wrong, it’s reassuring that you haven’t any evidence now
35 C1 That’s right
36 D So you’re not going to get it for several years
37 C1 That’s right
38 D If they if you do find signs that you show any features which
39 demonstrate that you’ve got a slight tremor or something
40 C1 Right
41 D (.) it might influence your decision about having children
42 C1 That’s right cos I don’t think (it’s right/I could)to bring a child

43		into the world knowing that you're going to be (as you would)
44	C2	(no that's true?)
45	D	It's only optional as I say but it's there as an option (your business)
46		when you've thought all this through but it's an option which sort
47		of tends to be recommended

As already stated in the previous discussion the “suggestion” here is presented very hesitantly, with perturbations and with the emphasis that “it’s only a suggestion” (line 22) and “only optional” and “your business when you’ve thought all this through” (line 45) (although this is difficult to hear). There is none of the “persuasive format” identified above. This may be indicative of the counsellor’s awareness that “recommendations” are likely to violate the non-directive ethos. Nevertheless in lines 46 – 47 he goes on, still somewhat hesitantly to state that it is “an option which sort of tends to be recommended”. Again the dilemma is evident for the practitioner, he is caught between informing the clients that this is an option which has been found by medics to be useful and the non-directive ethos that states he should not use his position of authority to influence client decisions. His compromise appears to be that he stresses the fact that it is optional and couches his recommendation in terms of “sort of tends”. Nevertheless such a description by a professional in a position of authority is unlikely not to be defined as directive by those who advocate a strict policy of non-directiveness.

Decision-making, non-directiveness and advice

Throughout the genetic counsellor interviews the interviewees gave an account of their role in decision-making as strictly in terms of providing the client with the information they need to make their own informed decisions. Consistent with the strong ethos of non-directiveness already discussed, when asked if she had a role in client’s decision-making, counsellor seven encapsulated the views of the majority when she declared firmly “Not in making the decision, no”. In extract 22 in the preceding chapter (page 182) we have seen how the genetic counsellors discuss this in practice as they describe to clients what – allegedly - the process of decision-making in genetic counselling involves. Decision-making is a dilemma, it requires much thought, it is the client’s ultimate responsibility and the genetic

counsellors can “help” but they can’t “tell you what to do”. This abdication of ultimate responsibility is repeated elsewhere in this interaction with the declaration “it’s a very very difficult personal decision and only you can make it but we’re here to help you if you want us.” Again the stress is on the client’s role in making the decision and the counsellor’s in providing help if required.

In the previous section we have seen how non-directiveness can be problematic in genetic counselling where certain courses of action such as referral or screening are believed to be beneficial. We have also seen how at times this is reflected in the hesitation or perturbations with which “suggestions” or “recommendations” are made. In some interactions, however, the non-directive nature of some “suggestions” is further eroded and they move into what Silverman (1997) defined as advice. Drawing upon the definition proposed by Heritage and Sefi (1992: 368), he identified as advice “those sequences in which the professional ‘describes, recommends or forwards a preferred course of action’ to the client” (1997: 111). Extract 47, taken from a consultation discussing testing for haemochromatosis, gives one such example. The counsellor is concluding a section of information-delivery on the condition and how it can be treated.

Extract 47 Tape 15

- 465 C So it’s an extremely easily treatable condition
466 P Oh that’s good
467 C Yeh so it’s only if you don’t know about it (.)
468 P That you can have problems
469 C That you have problems
470 P So it’s a good job my ((relative)) pushed me into (.) isn’t it really?
471 C Absolutely
472 P Cos I didn’t know about that ((identifying text removed)) That’s
473 very good that’s a good explanation about why I need to pursue it
474 C Yes as I say I mean normally I I I would always say to people you
475 know I wouldn’t want to advise people to have genetic testing but
476 with haemochromatosis (.)
477 P yeh
478 C =I would advise people to have it because I think it’s daft not to
479 really
480 P You’ve got nothing to lose have you? If I’m alright fine if I’m not
481 alright We can we can plan we can treat it and you know stop

The counsellor concludes her information-delivery then with the comment that the condition is easily treatable. On the client's "that's good" she goes on to point out that there is only a problem when the presence of haemochromatosis is unknown. The client's response in line 470 refers to the fact that it was a relative's dying wish that she be tested. The counsellor's confirmatory "absolutely" could in itself be described as directive - she is effectively expressing a personal viewpoint even if it is in accord with the client's own. Her following utterances, however, are *explicitly* directive as she states that although "normally" she would not want to be advising "people to have genetic testing", "with haemochromatosis I would advise people to have it because I think it's daft not to really". The client then reinforces this position with her statement "You've got nothing to lose have you?" This small sequence therefore is a long way from the genetic counselling and Rogerian edict of non-directiveness. It is explicitly directive, it reveals clearly the counsellor's own viewpoint, it attempts to lead the client towards a particular decision and it recommends a preferred course of action. Interactional emphasis is put on the word "advise" and a value-judgement on *not* having the test with the stated belief that "it's daft not to". All of these factors, given by a professional 'expert', put a strong pressure on the client towards compliance.

Again taken at face value and presented alone this extract could be given as a classic example of directiveness in practice. This would not, however, take into account some of the local conversational features or the wider context of the counsellor's role. Within the interaction sequence itself we can see again that the counsellor is not altogether at ease with the advice she is giving and that she is aware of the potential violation of the non-directive ethic underlying her role. First in line xx there are a number of perturbations - "as I say", "I mean", "I I I". Second her use of the word "normally" and her decision to state this, openly acknowledges that this is a deviation from 'normal' or expected practice and her repeated use of the term "people" globalizes and slightly distances her advice from the individual client before her. This, says Silverman, allows the client to hear the advice as to

“people in general” rather than to them specifically (1997: 114). She is not explicitly saying “ I would advise *you* to have the test and I think *you* would be daft not to”. Similarly it would be unfair not to acknowledge other local features of the conversation. The client is herself a health professional and has already indicated fairly directly, in line 470, and at earlier points of the interaction, that she has more or less decided to have the test. Her use of the question “isn’t it really?” has also invited the counsellor to agree that testing will be a positive decision. The advice is delivered therefore in the context of prior conversational collaboration. To quote Silverman again, the client’s perspective has been elicited and “the participants have established an alignment in their perception of the problem at hand” (1997: 148). In terms of the wider context of her role the factors highlighted in the previous section are again relevant. Haemochromatosis is treatable once its existence is known, regular venesection, or blood-taking, prevents iron accumulating and damage to the organs occurring. The counsellor therefore possesses information that indicates there are strong medical reasons why the client should be tested and it might be considered negligent not to report this. Again the tension between medical and counseling responsibilities is evident.

It would be true to state, however, that this information could have been delivered in a less overtly directive fashion. Explicit “advice” is unnecessary and the judgment “it’s daft not to” might almost be considered a form of Kessler’s “persuasive coercion” (see page 29). It might also be pointed out that the counsellor also falls into the more subtle form of directiveness highlighted by Clarke (1996) and Bernhardt (1997). She presents only the positive aspect of the treatment for haemochromatosis. She does not make any reference to the potential negative lifestyle implications of venesection highlighted by Seamark and Hutchinson (2000). It might be that in this case the counsellor would have been wiser to follow Elwyn, Gray and Clarke’s (2000) shared decision-making, perhaps offering collaborative discussion and professional opinions but refraining from personal and potentially judgmental views.

Non-directiveness and the rejection of advice

In extract 47 the counsellor’s advice - although not in accord with the ethos of non-directiveness - is received positively and the interaction proceeds smoothly. Where advice or suggestions are given in the genetic counselling corpus this is generally the case. In common with Heritage and Sefi’s (1992) findings in Health Visitor interactions the overt rejection of advice is rare. There are some instances where it is received with what Heritage and Sefi called ‘unmarked acknowledgments’ (1992: 395), as in extract 48 below, but only one consultation where overt rejection could be said to occur. Nevertheless, given its potential for disruption to the smooth progress of the interaction and particularly as in this case it eventually results in the uncommon occurrence of a client initiating termination of the consultation, it will be beneficial to consider why it happens.

Extract 48	Tape 3
235 D	Um the only recommendation for children and for grown-ups
236	who’ve got NF is that if you get a sort of apparently trivial medical
237	problem (0.4) that is a bit slow to go away then you should take it
238	more seriously than most so if you get headaches everybody gets
239	headaches but if you get a lot of headaches and they don’t go away
240	for a month then you should go and see your doctor and you should
241	do something about it cos once in a blue moon um you can get very
242	high blood pressure and () measures for it
243 C1	Mm
244 D	Um and that applies to yourself as well if you get some medical
245	problem that you might think is trivial but it doesn’t go away after a
246	week or two then you should go to your doctor (0.4) and you should
247	probably have your blood pressure measured once a year
248 C1	°Mhmm°

In this extract the genetic counsellor is giving medical recommendations for “children and grown-ups” with neurofibromatosis following the diagnosis made on the child (see extract 16). As such they form part of the standard medical consultation/diagnosis interactional pattern described by Heath (1992) – diagnosis followed by management of the condition. There has been no request for this advice from the clients. C1, the mother, does not respond with active agreement, or utterances that mark the information as newsworthy (such as “oh” or “right”), but gives only the “receipt objects” “mm” and a quiet “mhmm”. This, claim Heritage

and Sefi, receipts the talk but does not “acknowledge or accept that talk as advice” or constitute an undertaking to follow it (1992: 395). It should be noted, however, in the context of the genetic counselling consultations that neither do they make any protest nor express any surprise at being given it. This is suggestive again of the fact that interactionally these clients are expecting – or at the least are not surprised to experience – a medical-type appointment. It is interesting also that in this extract there is no hesitance in the counsellor’s speech to suggest that he is interactionally uncomfortable with the advice he is giving. This is also true in his first attempt to offer advice in consultation two, reproduced in extract 49 on the following page. This is significantly different from the same counsellor’s “suggestions” in extract 46 or extract 27 and with the care he takes in introducing information on pre-natal testing in extract 38 later in this same consultation. Perhaps the substantial difference lies in the nature of the advice or suggestions that are being given. The sequences marked by hesitation and perturbations are in the context of discussions on genetic testing. Extracts 27 and 46 concern the procedure followed before pre-symptomatic testing for Huntington’s and extract 38 pre-natal testing for neurofibromatosis. Extract 48 here, as already stated, forms part of a *physical* diagnosis sequence and extract 49 below follows a verbal health assessment, a physical examination and a conclusion that the client is not showing any signs of the muscular disorder in the family. Again therefore this reproduces Heath’s (1992) sequence of diagnosis and management. Perhaps it might be tentatively suggested that for this doctor it is ‘permissible’, or he is comfortable in offering advice around ‘ordinary’ medical tasks or information but where genetic *testing* is involved then the ethos of non-directiveness and need for avoidance of suggestions of eugenics comes to the fore.

In extract 49, however, the doctor’s advice is not received either positively or passively but with rejection. The client has come with physical complaints for a health assessment and a brief discussion of the muscular spinal disorder that is in his family. He is disturbed about the fact that his physical health – in fact unrelated to the genetic disorder – is preventing him taking part in competitive sport. The

541 back to winning
542 D Mmmm

In his work on HIV counselling, Silverman (1997) found that in his work with colleagues examining three centres in the USA and the UK out of fifty advice sequences there were no instances of outright rejection of advice. Heritage and Sefi (1992) found only one. Silverman uses these data to claim that “the demands of maintaining self-esteem and social solidarity support a preference for the acceptance of advice” (p134). Drawing on Goffman’s (1955) theory that “a persistent consideration of interactants is to protect one another’s public self-esteem or ‘face’” (p135) he states: “Rejecting advice is an action that potentially threatens the face of the speakers, and thereby undermines local social solidarity” (p137). He then goes on to support this with his initially apparently contradictory findings from one counsellor’s work in a British clinic. Here in only three interviews there were four outright rejections out of eighteen advice sequences. Although the data are might appear contradictory in that they feature an unusual number of outright rejections in a small corpus they are supportive, he claims, in that the utterances still manage to preserve the conversational preference for agreement.

In extracts 49 and 50 the counsellor delivers his advice in ways that both Silverman (1997) and Heritage and Sefi (1992) identify might lead to resistance. There is no attempt to access the client’s perspective, no request from the client and no lead-in. In lines 1 – 5 of extract 49 the counsellor is discussing what might be done about the client’s current chest problems. He then goes on in line 6 to suggest – or advise - that the client should build up his sport gradually towards the summer. In lines 10 – 14 the client rejects the advice but offers what Silverman describes as “mitigations” – presenting circumstances the counsellor wouldn’t know about (that his GP had already tried this), then uses this as the reason for saying “so I wanna get it right”. The counsellor exits the advice sequence at this point, giving non-committal continuers in lines 13 and 15. In this way Silverman would argue that both participants are exhibiting a preference for agreement even

though disagreement has occurred. In extract 50, after a couple of minutes further discussion of his physical condition and a suggestion that he should see a chest specialist the counsellor returns to the subject of the competitions, asking him when the next ones are “coming up”. The client indicates that they run all year round. The doctor acknowledges this with “°Yeah° (.)” then moves to offer further advice saying “I mean my (0.2) I’m not an expert on (.) sports medicine but my (.) feeling is that (0.2) it wouldn’t be (.) realistic to expect you to be able to get back to doing too much of that (0.3) for 6 months or 9”. He begins therefore with some mitigation using “I mean” and “I’m not an expert but”. Both of these indicate awareness that what he is going to offer is probably unwelcome and also perhaps contrary to his counsellor’s code. With the choice of the term ‘feeling’ they also have the effect of softening the advice from a statement of command to more of a suggestion. Nevertheless he emphasises the words ‘but’ and ‘feeling’ and goes on to give his professional opinion that it would not be realistic to attempt competition work at this time. Initially the client responds with Heritage and Sefi’s (1992) “unmarked acknowledgement”, “yeah”, neither rejecting the advice or committing himself to it but as the counsellor continues he then flatly states “I’m going to get right for those competitions”. On the counsellor’s intake of breath and acknowledging “ah” he moves away from the potential conflict and hurries on in overlapping speech to start talking about the competition history. The counsellor again exits the advice sequence quickly and offers instead to refer him to an expert in sports medicine for “any suggestion he would have to advise you”. Both participants therefore again organise their talk in a way that Silverman would say preserves the preference for agreement, the client by delaying the rejection by a turn and the counsellor by exiting quickly.

The conversation then continues for a couple more minutes before the counsellor returns once more to a repetition of his advice to wait with the sequence reproduced in extract 13 on page 166. The client’s response at this point is to acknowledge the opinion with “Right” and in a move more usually the counsellor’s (see page 166) initiates closure of the interaction. Again the

counsellor has offered some mitigating words with the cautionary “*I would far rather* that a longer period had gone” (italics mine). The client, however, has perhaps had enough of an opinion he does not want to hear and, without overtly rejecting the advice here, exits the disagreement and the interaction.

These rejections of the counsellor’s advice, therefore, do in fact exhibit the interactional preference for agreement that prevents outright conflict or argument. This preserves ‘face’ and social solidarity. Nevertheless the advice does result in the client ending the interaction and in a sense in a challenge to Strong’s (1979) “bureaucratic format” (see page 20) in which the patient does not challenge the doctor. This might suggest that this client does not accept that genetic counselling is a straightforward medical encounter. The overall interactional format of the consultation, however, does not support this. The majority of the time is spent in the ID or IW communication formats with the doctor in the Questioner and Speaker roles. It may be that the doctor would have benefited from utilising a form of Maynard’s (1991) perspective-display sequence, eliciting the client’s perspective before giving his advice in an overt form. By the end of extract 49 the client has expressed his desire to return to competitive sport and his intention to do so. In *repeating* his advice in extract 50 and in extract 13 the counsellor is not only violating the ethos of non-directiveness he is also risking another overt rejection. Again it may be that he would have benefited from heeding the ‘unmarked acknowledgement’ in line 527 before he continued. Although it is apparent that the counsellor felt that *medically* his advice was sound it may be that, after two rejections it might have been better not to repeat it. Once more however it does illustrate the dilemma for genetic counsellors between their medical role as ‘experts’ and their counselling role in which advice of any kind should not be given.

Decision-making, non-directiveness and uncertainty

In the previous sections we have discussed the presence of ‘suggestions’, ‘recommendations’ and ‘advice’ within the genetic counselling consultations and

438 (1.2)
 439 D But we can't guarantee we can't tell you anything as to if the baby
 440 were to inherit the gene whether it will be mild or severe
 441 C1 Yeh
 442 D It could well be like Hilary it's likely the baby will be mildly
 441 affected
 442 C1 Yeh

Both the genetic counsellors in their interviews and the genetic counselling literature highlight the difficulty for clients of dealing with uncertainty in their genetic results. As van Zuuren states;

“genetic knowledge is fragmentary and incomplete. Definitive answers can seldom be given..... instead of offering the certainty longed for, the information provided during genetic counselling will often be full of uncertainties.” (1997: 130)

He describes how, as in extract 51, unpredictability about the severity of a disorder may be a significant factor, potentially leaving a client with considerable distress. As “what clients want mostis certainty”, he concludes, “there is a bad match between client needs and purposes, and the actual genetic services provided” (p136). This need for certainty was confirmed by Skirton (2001). In her study of 43 families referred to a UK clinical genetic service she found that the need for certainty was a powerful factor that motivated clients to pursue genetic counselling and that ‘peace of mind’ as an outcome was “directly connected with the extent to which the genetic counseling process is able to address the client’s concern for certainty with regard to the genetic condition in the family” (p325). Being given certainty, she concluded, gave clients a greater sense of control (p326).

In extract 51 it is possible to be certain as to whether or not a fetus carries the neurofibromatosis gene but, as the counsellor states in lines 389 – 390, not to gain any indication how severe the disorder might be. In lines 392 –398 he goes on to describe the likelihood of a new baby being more affected than their existing child – about five percent or one in twenty, a chance he defines qualitatively as “small”. He acknowledges this is a worry to them but goes on to emphasize that the test cannot tell them. After a short extract of conversation (not reproduced) where the

client discusses the fact that, were it not for her anxiety around the disorder, she would definitely like more children, he goes on in lines 426-429 to state “It’ll be a pity then to sort of close the door completely so don’t rush off and have operations to tie tubes until you’re really sure”. This is not phrased as a ‘suggestion’ and could be defined as overtly directive. To make this judgement however would once again ignore the interactional context in which the utterance is placed. The client has expressed a desire to have more children but is anxious not to have a child severely affected with the disorder. The counsellor has been able to offer the possibility of finding out whether or not a child carries the gene but not to give her the reassurance or certainty that she desires. He is aware, as revealed in extract 38, that people can change their minds and that sterilisation would render this impossible. His apparent directiveness therefore reflects his medical knowledge in the face of the uncertainty that is all the genetic testing can so far provide.

This type of uncertainty is not uncommon within the corpus of consultations studied. It is often possible to reveal the presence of a gene but not the severity or the time of onset of a disorder. Although the client might be disturbed by this the counsellor can only offer the genetic technology as it stands. It is noticeable however that in this instance the client responds only minimally throughout this description with mm, yeh or no, again giving no indication of her feelings on receiving the news. Once more it is also noticeable that the counsellor does not ask her for them. This is repeated in lines 439 – 442 when the counsellor returns to the uncertainty and reiterates the same message. Given the difficulties reported by van Zuuren (1997) and Skirton (2001) for clients in dealing with uncertainty, the chance to explore their responses to this within the genetic counselling consultation might seem a positive move.

Conclusion

To summarise therefore, the nature and function of their role leave the genetic counsellors facing specific difficulties with maintaining non-directiveness and a client-led agenda. If they delegate all responsibility for the setting of the agenda to

the client this may lead to an absence of relevant information-delivery or the invalidation of informed consent. If they remain strictly non-directive the client may not receive important information or recommendations that may save their lives. Their medical knowledge and the client's expressed wishes to receive their medical knowledge mean the role of expert – eschewed by the person-centred counsellor - is, in many consultations, impossible to avoid. Suggestions, recommendations or even segments of advice are not infrequently given. The presence of multiple clients in many consultations leads to further complications. Following the agenda of one may mean ignoring the agenda of another and maintaining the neutrality of the interaction may be problematic when one or more family members is vociferous in voicing a particular point of view. The counsellor's role in decision-making is described as being confined to providing the information that clients need to make an informed decision. They must play no part in the making up of the client's mind. The medical nature of many decisions and the uncertainty often present contribute to situations that render this problematic to sustain. The presence of perturbations such as “um” or “er”, repetitions such as “ I I I” and the frequent repeating of phrases such as “it's only optional”, “it's only a suggestion” or “it's your business when you've thought this through” perhaps indicate the counsellor's awareness of the tensions inherent within their role. They account themselves as ‘counsellors’ but are often required to pursue medical tasks within this counselling role. In fulfilling their medical obligations they must frequently contravene the underlying ethos of their person-centred counselling role. The tensions that this creates frequently leave them with conflicting philosophical positions that are impossible to sustain.

Conclusion

Introduction

The preceding chapters and this thesis as a whole have focussed on the role, ethos and function of genetic counselling as it locates itself within both the counselling and the medical worlds. There has been a focus on the tensions that belonging to two at times conflicting philosophical and practical arenas can bring. I have asked the genetic counsellors how they perceive and account for their role as they perform their task of dealing with those affected by genetic disorder, and followed this accounting through into conversation analytic study of actual interaction. I have posed the questions: why does genetic counselling ally itself with the therapeutic culture and what does '*genetic* counselling' actually mean? Is it a counselling or a medical interaction? What are the problems that this alliance with, and description of, themselves as 'counsellors' can bring? I have also looked at the opinions and expectations of genetic counselling clients and the practical and ethical tensions these can cause. Finally I have looked at the structure of the interaction itself and considered whether genetic counselling has a recognisable format and an identity uniquely its own.

In the conclusion to this project I briefly summarise some of the major conclusions I have drawn and explore their contributions to a number of areas. First the implications for genetic counselling practice, second to the existing body of conversation analytic research into medical and counselling interactions, and third to wider society in line with Rose's (1998, 1999) concerns. Finally, alongside of these, I also consider the issues revealed for potential further research.

The role of the genetic counsellor and the structure of the genetic counselling consultation

Two of the major inter-related areas on which this research has concentrated are the role and function of the genetic counsellor and the consequent structure of the genetic counselling consultation. As stated in chapter one (page 8) these form a subject of some contention within the profession itself. There is no

universal agreement on a definition of genetic counselling, and conflicting views on what the role of the genetic counsellor should entail. The information gained here from the genetic counsellor and client interviews, and the recorded consultations, presents a picture of a role often dominated by information-delivery, education, testing for genetic disorders, decisions about testing and other medical tasks. Health assessment, physical examinations, blood tests and diagnosis were prominent in the recorded consultations. The genetic counsellors assess, diagnose, take and explain tests, and deliver information on all aspects of genetic disorder. They also give recommendations, suggestions and, at times, overt advice. The interview accounts of client wishes and expectations and the interactional evidence from the consultations suggest that most of these functions are compatible with what clients expect and want. Clients look to the genetic counsellors as medical 'experts' whose role is to inform them and at times to guide them so that they can make rational choices when difficult genetic decisions or lifestyle modifications may be required.

The conversation analytic study of the recorded conversations indicates that the overall structure or shape of many of the consultations bore marked similarities to Byrne and Long's (1976) six consultation phases, and to features highlighted in standard medical interactions by conversation analysts such as Maynard (1991) and Frankel (1990). Interactional asymmetry, with topic and agenda initiation dominated by the practitioner, was often evident, and Peräkylä and Silverman's (1991) Interview and Information Delivery communication formats with the genetic counsellor in the Questioner and Speaker roles were prominent in a majority of consultations. Compatible with ten Have's (1991) study of GPs and Pilnick's (1998) work on hospital pharmacists, there is also interactional evidence that this asymmetry is co-constructed by both counsellors and clients. The genetic counsellors lead the agenda, initiate many question/answer sequences and deliver information, and the clients actively allow them to do so. Although there is a little more flexibility than studies of standard medical interactions have revealed, consultations that are markedly different from this general format are in a minority. In all but a small number of the consultations there are also noticeable *dissimilarities* to aspects of a therapeutic counselling role. The exploration of emotion is rare and troubles-

telling or client-dominated discussion unusual. The balance of counsellor/client input falls heavily in favour of the professional and, as already mentioned, setting of the agenda is nearly always their domain.

The overall picture presented, therefore is that, although there are a few exceptions, in task and interactional structure genetic counselling appears primarily as a medical role. Both counsellors and clients hold expectations consistent with this, and in this corpus behave interactionally in a manner similar to that found in other medical arenas. Given their 'counselling' label and public espousal of Rogerian counselling ideals, however, this has major implications for genetic counselling practice. The genetic counsellors are expected to pursue medical tasks in a medical setting while also espousing the philosophical assumptions of a person-centred counselling role. This means they are obliged to be non-directive, allow the client to lead and set the agenda and to relinquish the 'expert' role (Rogers in Mearns and Thorne, 1988: 3). They are expected (and give accounts of themselves as doing) to conduct their sessions as equals in an 'enabling' or 'empowering' way, to facilitate their clients to make autonomous decisions, and not to give recommendations or advice. The evidence of this research suggests that this is leaving them pursuing an unreachable goal. Counsellor and client opinions and the interactional evidence indicate that these twin roles are impossible to simultaneously fulfil. They cannot function as Rogerian counsellors *and* fulfil what is often primarily a medical role. The underlying assumptions and tasks are too far apart.

Genetic counselling and the therapeutic culture: dilemmas and conflicts

Foremost amongst the conclusions I have reached, therefore, is that allying itself to the therapeutic culture, to Rogerian theory and to the techne of 'psy' is essentially problematic for the human genetic profession. Although allowing them to dissociate themselves to some extent from the controversial history of eugenics (Clarke 1997), and to claim allegiance to Rose's (1998, 1999) 'advanced' liberal democratic ideals, it leaves the genetic counselling practitioner with a difficult task. They face many ethical and practical dilemmas as they attempt to act as both counsellors *and* medical personnel.

Both the interview material and the conversation analytic study of the recorded consultations reveal the extent of the tensions and conflicts that are involved. Strict non-directiveness in particular is very difficult to adhere to. There are many consultation segments that contain recommendations or even advice. The presence of interactional perturbations, or repeated comments such as “it’s only an option”, “it’s only a suggestion” - unusual in medical interactions - as well as genetic counsellor accounts of difficulties or conflicts, illustrate the tension that the counsellors often feel. They are aware of the conflicts between their roles and often struggle to find a way to fulfil them both. Reported client expectations of guided information or recommendations on what to do compound this difficulty. If they follow the client’s desired medical-type agenda they violate the ethos of non-directiveness and the person-centred eschewing of the ‘expert’ role. The medical nature of the majority of the information is also problematic when future health or management of the client’s condition is at stake. The counsellors may be left with the choice of refraining from recommendation to pursue non-directiveness or risking negligence or an accusation of maleficence if they do not give information that may protect the client from future harm. Recommending surveillance tests for colon cancer or haemochromatosis may be examples of this; if the client is at risk and testing is not done then potentially devastating – or indeed fatal - health consequences may ensue.

Other specific dilemmas for genetic counselling practice in following Rogerian counselling ideals are also revealed. Pursuing a client-led agenda may be problematic while simultaneously ensuring informed consent to genetic testing. It may at times be necessary to deviate from the client’s expressed agenda to ensure they have all the information to make an informed decision. The frequent presence of multiple clients leads to further complications. Establishing and following the client’s agenda can be difficult when different clients have conflicting goals. This can also add to the difficulties in maintaining non-directiveness when one client is vociferous in voicing a particular point of view. Finally, the presence of many medical-type tasks such as assessment, examination and diagnosis mean the basic function of the genetic counselling role is often at odds with a counselling-type role. Time

limitations mean it is not possible to allow the client to set much of the agenda and there may be consequent limited opportunity for the development of open discussion or the exploration of emotional response. Such medical tasks also mean that client expectations of a medical-type appointment are often confirmed, with the subsequent influence on their interactional response. They expect and receive medical care and assessment and then behave interactionally in a way they perceive as appropriate to a medical situation. The medical tasks also position the professional conversationally in an expert medical role and it might be fair to suggest that this might be difficult then to exit or avoid.

The question might be raised, therefore, in its association with the therapeutic culture, is the human genetic profession imposing upon their practising personnel an unreasonable as well as an impossible task? There may be public and political advantages to this alliance, but is it either realistic or fair on the practitioners involved? Is jumping on the therapeutic bandwagon the only option? Similarly, is its overt proclamation preventing a more open and realistic discussion of the ways to manage the tensions and difficulties that are raised? Or to tackle the sensitive reproductive and public health issues that the new and rapidly evolving genetic technologies are creating? Given the level of practical and ethical difficulties that arise these are questions that might benefit from further debate.

Genetic counselling: ‘counselling’ or using counselling skills?

In addition is there an element of deception in calling genetic counselling ‘counselling’ at all? The evidence collected from both the conversation analytic study and the genetic counsellor and client interviews would suggest that in practical reality it bears little similarity to therapeutic counselling as it is professionally and popularly perceived. It may have some counselling-type elements but others such as exploration of emotional responses and of personal problems and troubles were noticeably absent. The pursuit of self-actualisation and internal conflict resolution were not part of the stated genetic counsellor goals. As already stated, in a majority of consultations conversational features such as interactional asymmetry and communication format bore marked

similarities to previous studies of medical interactions (ie Strong 1979 Frankel 1990 Maynard 1990 ten Have 1991). Are they then 'counselling' or rather, as Silverman suggests for HIV counselling, using counselling skills? A number of the nurse-counsellors spontaneously raised this question themselves. Despite their declared commitment to a counselling role they suggested that the differences between genetic and psychotherapeutic counselling meant that they were not so much counselling as using counselling skills to perform an educative function (see pages 116-117). They cite the amount of medical information-delivery required as a central part of this. The closing comment in the quotation by counsellor I (who has recently completed lengthy therapeutic counselling training outside of her genetic counselling role) – "Counselling is the building of a relationship with boundaries and contracts etc" - raises two further points which might be relevant here. The BACP ethical code is clear that counselling involves an overtly contracted relationship with definitive boundaries, and Rogerian counselling usually involves the building of a relationship over a period of time. Genetic counselling does not involve either the development of a client/counsellor contracted relationship with specific boundaries, working contracts and aims or, in general, the building of a therapeutic relationship over time. The latter *may* happen in genetic counselling, families are given long-term access to the department, but more usually clients see the genetic counsellors a limited number of times for specific purposes (ie the preparation for or taking of tests). If these factors are absent can 'counselling' per se be said to be occurring? As well as highlighting the importance of a contracted relationship Bond (1993) discusses the difference between counselling and using counselling skills by citing the following questions from the BAC Code of Ethics and Practice.

1. Are you using counselling skills to enhance your communications with someone without taking on the role of the counsellor?
2. Does the recipient perceive you as acting within your professional caring role (which is not that of being their counsellor)?

If answers to both questions are yes then counselling skills are being used to fulfil a role and if no then it is counselling. In these terms then genetic counsellors are using counselling skills, genetic counselling is not a specifically 'contracted' role, the clinicians are seen primarily as doctors and

the emphasis is, for the majority of the clients, on the genetic and medical rather than the counsellor part of the role. Taken with the already discussed dissimilarities to psychotherapeutic counselling it might be feasible to suggest, therefore, that genetic counsellors are not engaged in 'counselling' per se but rather, as they themselves perceived, using counselling skills in the pursuit of primarily medical goals.

Practical applications

Despite the controversy and difficulties of this alliance with the counselling world, however, the conversation analytic study of the recorded consultations revealed that there were positive lessons that could be learned where practical counselling *techniques* were applied. Skills such as open rather than closed questioning, paraphrasing, clarifying and reflecting back (Nelson-Jones 1992) could be seen to encourage greater client participation and freer exploration of their information agendas and genetic concerns. They also resulted in a greater percentage of client-initiated questions, longer segments of mutual discussion and, within consultations nine and eleven, a possible increased willingness to be seen to disagree. As the genetic counsellors on the whole expressed a desire to pursue a client-led agenda, and to be able to orient the sessions towards the context of the individual client lives, these might seem desirable session goals. Similarly in the broader context of today's trend towards patient-centred medicine and autonomy (Schneider 1998: 2-5), if this is to be accepted as an overall goal, such characteristics in the session would seem beneficial as part of facilitating these ends. Although counselling skills do form a part of genetic counselling training today the absence of some of the most basic of these techniques in a majority of consultations would suggest that there is further progress to be made.

Non-directiveness and decision-making

Other areas of implications for genetic counselling practice raised by my research include issues around non-directiveness and decision-making, evaluation and client satisfaction.

The evidence of this research on both client expectations and the tensions and difficulties around the practice of non-directiveness, suggests that the work by Kessler (1997) and Elwyn, Gray and Clarke (2000) recommending moderated definitions of non-directiveness for genetic counselling and a process of shared decision-making may have validity. Counsellors' expectations of client wishes for advice and the limited feedback from haemochromatosis clients in this corpus suggest that clients do very often wish for some kind of professional guidance, if not overt advice, on what would be the best choices to make. In accord with Schneider's (1998) views it would appear that they do not necessarily wish to make difficult medical – or in this case genetic - decisions entirely alone. The health implications of choices around testing, screening or lifestyle management when genetic disorders such as haemochromatosis or colon cancer are involved means that for the professionals some degree of medical recommendation is also often seen as necessary or desirable if their clients are to be adequately informed. Elwyn, Gray and Clarke (2000) believed that a process whereby responsibility for decision-making was seen as a shared process between professional and patient would allow for situations where clinical recommendations could be incorporated. This would then allow the genetic counsellors freedom to offer a professional opinion where it was judged beneficial. Although it might be argued that this would mean an overt acknowledgement that pure non-directiveness in genetic counselling is impossible to attain - with its consequent political implications - it might ease the frequent dilemmas that this research has revealed.

Client expectations, evaluation and satisfaction

The suggestion from both counsellor and client interviews that clients do in fact have some wishes and expectations for guidance within their consultations also has implications for client satisfaction or for the evaluation of genetic counselling. There is a conflict between the ethos of non-directiveness and the potential to meet these expectations. If Michie, Marteau and Bobrow's (1997: 237) conclusion that it is "the interaction between expectations and subsequent experience that leads to satisfaction or dissatisfaction" is correct for genetic counselling, then this may by definition lead to dissatisfaction. Skirton's (2001) research on the importance for clients of finding some kind of certainty poses

similar problems. If this is an expectation or hope that the genetic counsellors cannot fulfil then a negative impact on satisfaction might be a possible result. Although the numbers of client interviews were limited, however, the results in all but two suggested that client satisfaction with the service was generally high. This may have some relation to what the clients are meaning when they use the term 'advice', they may as a number of the genetic counsellors suggested, be referring as much to information as to giving clients an opinion on what to do. There was a suggestion from those clients who expressed a viewpoint on this, however, that although information is a big part of what they need and they didn't want to be told what to do, they did in fact want something more than information alone. This is an area where further research would be beneficial.

Contribution to Conversation Analytic Research

The conversation analytic study of the recorded consultations adds to the body of CA research in a number of areas. On a broad level it contributes to the growing amount of CA research into institutional interactions or "talk-at-work" (Drew and Heritage, 1992). It adds a comprehensive study of a data corpus consisting of sixteen consultations to a small but significant body of research into genetic counselling. It analyses how genetic counsellors and clients build the context of genetic counselling in and through their talk and how they construct their interaction together as a specific genetic counselling consultation. It can be used alongside the existing papers by Pilnick (2002), Chapple and May (1995) and Chapple, Campion and May (1997) to offer insight into particular areas or interactional processes that are relevant to the institution of genetic counselling. Similarly, in the sense that genetic counselling takes place in a medical setting, is usually facilitated by medical personnel and is shown here to bear marked similarities to other medical interactions, it also takes its place in the growing range of conversation analytic research into different medical arenas.

On a more specific level this research also contributes to the body of CA work concerned with Levinson's (1992) concept of interactions as "activity types" – "goal-defined, socially constituted, bounded, events with constraints on

participants, setting ...and allowable contributions” (p69) - and Jefferson and Lee’s (1992) concept that certain sequences or types of interaction might possess an overall ‘shape’ that identifies them for what they are. Jefferson and Lee suggested that their corpus of data on “talk-about-troubles” possessed a shape that, although vague, appeared to recur across a variety of conversations (1992: 521-523). Some elements seemed to appear repeatedly with some sort of gross observable order. On the basis of this they constructed a set of utterance types that they felt broadly comprised a Troubles Telling Sequence (see page 50 this thesis). Similar “shapes” were identified by Zimmerman (1992) in emergency calls and Pilnick (2001) in oncology pharmacist consultations. This research contributes to this discussion as it asks the question does genetic counselling have a recognisable shape or structure and does it have an interactional identity that is uniquely its own? Given the debates over the role and definition of genetic counselling and the acknowledgement that there is a lack of knowledge as to what goes on in the actual consultations these are questions that have research validity for the profession itself. As Pilnick (2001) declared of her “putative structure” for pharmacist consultations, it is only when it is identified what it is the genetic counsellors are interactionally required to do that “it will be possible to define and develop appropriate training programmes” (2001: 1943).

The findings were that in this corpus no one shape was sufficient to cover all the consultations, suggesting that there is no *single* goal-oriented set of elements or activity that can be said to constitute a genetic counselling interaction. In Levinson’s terms it does not represent one “activity type”. A number of elements were common to the majority but there was a diversity that prevented one shape being recognisable in all. Further investigation, however, suggested that it was possible to allocate the consultation elements into what was essentially *two* broad shapes, one resembling a medical consultation with medical type tasks, goals and communication formats and a second that was more flexible and less representative of a medical encounter. The shapes identified can be summarised as follows:

Shape A. (Medically-oriented goals)

A. Greetings or Introduction Sequence

- B. Agenda-Setting Sequence; Summary of why-there and/or agenda check
- C. Health or Development Assessment
- D. Physical Examination Sequence
- E. Information-Delivery. Asymmetrical format, information + one or more of the following; Test Results, Diagnosis, recommendations/ suggestions for referrals, tests, future care or treatment
- F. Decision-making Sequences
- G. “What-is-to-be-done” (Action to follow session) Sequences
- H. Agenda-check/Any Final Questions
- I. Closure and Goodbyes

Shape B (Less identifiably “medical” goals)

- A. Greetings or Introduction Sequence
- B. Agenda-Setting Sequence; Summary of Why-there and/or Agenda-check
- C. Information-delivery; Flexible format, information in discussion form
- D. Decision-making sequences
- E. “What-is-to-be-done” Sequences
- F. Agenda-check/Any Final Questions
- G. Closure and Goodbyes

(“Troubles-Telling” type sequences may occur in either shape but their presence is not frequent enough to be included as a typical recurring element.)

The fundamental difference between them appeared to be associated with the presence or absence of medical activities such as examination, health or development assessment, diagnosis or disease management (covered under Elements C, D and E in Shape A). Where these were present the conversational format and speaker roles, rights and obligations were similar to those identified by Frankel (1990), Maynard (1991) and Peräkylä and Silverman (1991) in other medical interactions and the broad overall shape resembled Byrne and

Long's (1976) (non-conversation analytic) six consultation phases (see page 21). Where these were not present there is more interactional flexibility and the shape may possess more conversational-type communication styles. The overall conclusion therefore was that genetic counselling can take one of two shapes or structural forms dependent on how medically oriented the goals or tasks of the particular interaction are.

What was also apparent however was that *within* these shapes there was considerable diversity as well. The number of elements identified in shape A amounted to nine and there could be a variety of activities within them. The Information-Delivery Element, for example, could cover a number of different functions – referrals, condition management, test results etc. This can result in interactions whose *content* is very variable though the interactional structure in terms of speaker rights and obligations remains the same. The conversation analytic study therefore was informative in making transparent the diversity of the genetic counselling role and the multiple functions that can take place within it. The allocation of Shape A to a large majority of the consultations was also informative in its strong indication that genetic counselling *is* predominantly a medical role with marked conversational similarities to other medical interactions. This has been discussed more fully in earlier sections of this conclusion.

The results of my study are also supportive of the work by ten Have (1991), Pilnick (1998) and other conversation analysts which suggest that asymmetry in medical interactions is interactionally achieved rather than imposed by the professional. Although in the majority of consultations the genetic counsellors do dominate topic and agenda initiation and much of the time is spent in Peräkylä and Silverman's (1991) ID and IW communication formats with the professional in the Questioner and the Speaker roles, this is rarely challenged by the clients. When offered the opportunity to ask questions or add to the consultation agenda they often do not do so. After diagnosis or condition management information, as Heath (1992) observed in GP interactions, they again often make little response. Their answers in question-answer sequences are frequently relatively short and on the occasions when they take the

initiative, as Frankel (1990) observed, they tend to relinquish this fairly quickly. The asymmetries of task and topic highlighted by ten Have (1991) and the deference to the professional as “knowledgeable identity” described by Peräkylä and Silverman (1991) were also very apparent. Again these factors appeared to be accepted and supported by the clients rather than challenged. The presence within a number of the consultations of a greater flexibility than that which has been found in some studies of medical interactions, suggesting that the institutional constraints of the genetic counselling do not *dictate* an asymmetry as rigid as that identified by Frankel (1990), might also be said to indicate a co-constructed asymmetry. The fact that possibilities do exist for free-standing contributions or client-initiated topics and yet clients frequently choose rather to defer to, and support, the professional’s interactional dominance and expertise, is in accord with ten Have’s (1991) findings that the asymmetry is changeable and locally “produced” to a variable extent. It is also consistent with Heath’s (1992) GP practice findings that patients consistently make a deliberate effort to preserve the practitioner’s expert status (1992: 261-262).

In considering the construction of asymmetry, however, the work of Ainsworth-Vaughn (1998) highlights an area that is omitted within this study. While analysing the presence of asymmetries of topic and task and observing their co-constructed nature I have not pursued alternative ways in which clients may claim power within their talk. Analysis of whether or not the seven methods that Ainsworth-Vaughn identifies can be recognised within this body of data might be a constructive template for future research.

Where this research has something more original to add to the field of conversation analytic research is in its contribution to an analysis of genetic counselling as a ‘counselling’ interaction. Although the majority of the consultations were observably medical in nature the existence of a minority of consultations with a different interactional structure gives scope for significant additional information. The presence in these encounters of more counselling-type interventions, skills and techniques and the consequent effect on client responses and interactional format contributes to an understanding of the

process of counselling and to the impact of subtle changes in practitioner approach. This might be of use both in the education of genetic counsellors in the pursuit of their proffered client-centred genetic counselling goals, and in the informing and educating of counsellors in a therapeutic counselling role. Similarly if there is a wish on the part of practitioners to lessen the asymmetry of their professional consultations, to encourage more client exploration and focus on client rather than counsellor goals then the analysis of these consultations gives some pointers on where to begin. The significant differences in communication format, speaker rights and obligations in consultations where medical type goals were absent also gives information on where the move into calling a service 'counselling' in a therapeutic sense – if that is what is to be desired - may realistically be made. The body of conversation analytic work into therapeutic counselling is noticeably thin. The small number of consultations indicative of a more counselling-type interaction may give a little further information on the process of counselling per se but they also highlight an area where much more research is needed.

What it might also be true to state is that the analysis of the consultations as a counselling or a medical interaction contributes to an understanding of the factors that are preventing some counselling-type functions occurring. The encouragement of the expression of clients' agenda requests in terms of information or questions that they might want to ask and the lack of any pursuit or facilitation of clients emotional responses both gear the pattern of the consultations towards medical 'facts' and information-delivery rather than an exploration of the clients thoughts, feelings or 'troubles' more characteristic of a therapeutic counselling encounter. Given that the genetic counsellors are expressing a desire to offer at least a degree of psycho-social support and are wishing to locate the information in the context of the clients lives this might suggest a process that needs amendment.

Finally, in terms of specific processes relevant to genetic counselling the conversation analytic section of this study has also yielded information on client agenda-setting and on non-directiveness as they are worked out in practice. This has already been discussed on page 257 of this conclusion. The

conflicts at times between the need to allow the client to set the agenda, and the counsellor's need to facilitate informed decision-making and to ensure informed consent, were highlighted as they developed within the interactional process. A similar pattern was seen for non-directiveness, particularly with multiple clients or issues involving recommended medical interventions or established procedures. The counsellors struggled interactionally as they attempted to follow non-directiveness and to give the professional recommendations that belonged to their medical role. The conversation analytic study has been able to illustrate *in process* the delicate pathway that the genetic counsellor has to tread in an attempt to fulfil both roles and raise pertinent questions for professional debate.

Wider Societal Implications

I conclude this thesis with a brief consideration of some of the wider implications to society of medical alliances with the therapeutic culture and the continual growth of counselling and the techne of 'psy'. These implications are threefold, first externally to the individual client or patient as they attend for their appointments, second internally for the professionals themselves and third for the general expectations and responsibilities of society at large.

For the individual patient or client the association with the therapeutic culture and the relentless pursuit of autonomy may lead to an effective *lessening* of choice in some areas. They may no longer have the option of asking a medical professional's advice and may in Rose's terms, as already discussed, be "obliged to be free" (1999: ii). Schneider (1998) questions whether this is actually what patients want. He uses his own research to present evidence that for some at least full responsibility for their medical decisions is unwelcome. Challenging the concept of patient empowerment, he states his research

"has led me to doubt what the conventional wisdom assumes – that patients want primarily to be "empowered" – and to believe that what patients want, what they reasonably want is complex, ambivalent and ambiguous"
(1998: 5).

He concludes that when they are sick people may have other priorities, they may want concern, competence and kindness. They may distrust their own ability to make complex medical decisions and they may want to be dissuaded

from choices they might otherwise make (1998: 4-5). Pursuing autonomy to the exclusion of anything else – what he calls ‘mandatory autonomism’ – may leave them reluctantly to make difficult and stressful medical decisions alone. It may, as Clarke (1991) also declares, amount to an abdication of professional responsibility that leaves the client/patient lacking the access to professional knowledge that evidence suggests they might wish to use as a support.

For the professionals themselves, across the variety of medical fields now allying with counselling or designating their functions with a ‘counselling’ label, the consequences are likely to bear similarities to those seen in the genetic counselling role. Tensions and dilemmas are likely to be manifest as they attempt to match the conflicting philosophical or ethical assumptions of the therapeutic culture with the traditional formats and responsibilities of the medical ‘expert’ role. The transition to counsellors is unlikely to be accomplished without causing the practitioner practical stress, or conflicts between therapeutic ‘rules’ and their day-to-day activities. Nevertheless, as the work of Rose (1998, 1999), Burnard (1999) and Feltham (1995) suggests, the burgeoning of ‘counselling’ amongst medical (and other) professions is ongoing and seems set to continue.

Meyer and Rowan (1977) might be said to put forward an additional perspective as to why this attachment to the tenets of the ‘psy’ community is continuing to gather strength. In their work on formal structure as myth and ceremony in institutionalized organisations, they suggest that many organisations, including hospitals and schools, are forced to take on formal organisational structures that possess highly institutionalised forms. Despite the fact that there may often be conflict between these structures and their everyday tasks, “organizations”, they state, “are driven to incorporate the practices and procedures defined by prevailing rationalized concepts of organizational work and institutionalised in society” (1977: 340). They go on to claim that their formal structures, practices, policies and procedures, therefore, “dramatically reflect the myths of their institutional environments instead of their work activities”, and that gaps are then maintained between these structures and their ongoing work activities (1977: 341). These

‘institutionalised’ rules reflect “classifications built into society as reciprocated typifications or interpretations” which may be “taken for granted or supported by public opinion or the force of law”. They “inevitably involve normative obligations but often enter into social life primarily as facts which must be taken into account by actors” (1977:341). They are “in some measure beyond the discretion of any individual participant or organization” (p344) and are forced upon organisations and institutionalised into professions because of the need for *legitimization*. That is the need to be seen as “proper, adequate, rational and necessary” (1977: 345) and ‘legitimate’ according to socially constructed and collective norms. As Meyer and Rowan describe:

“By designing a formal structure that adheres to the prescription of myths in the institutional environment, an organization demonstrates that it is acting on collectively valued purposes in a proper and adequate manner.... The incorporation of institutionalized elements provides an account (Scott and Lyman 1968) of its activities that protects the organization from having its conduct questioned. The organization becomes, in a word, legitimate, and it uses its legitimacy to strengthen its support and ensure its survival” (1977: 349).

For our purposes, therefore, the profession of genetic (and other forms of health-care) counselling take on the typifications or normative obligations of the concepts of the ‘psy’ community – for example, autonomy or non-directiveness - as institutionalised ‘rules’, policies or myths built into their formal structures in order to ensure their legitimacy as an organization and, consequently, their survival. In this way they avoid their conduct being questioned and are accepted as rational, socially acceptable organizations. The consequences for their practitioners, however, are that these institutionalised rules are, as Meyer and Rowan predicted, and as has been demonstrated in this thesis, often in conflict with their everyday work activities. This then leads to tension and the demonstrated gap between ethical intention and practice. Health-care professions such as genetic counselling, then, might be said to be in a double-bind situation. To be seen as legitimate they need to adhere to collective formal structures compatible with institutionalised ‘psy’ concepts or ‘rules’. However, this then actively creates conflict and a gap between myth, rule and everyday work activity. It also creates a situation for society where these particular rationalised myths become progressively more integrated and

widespread within our work, health and educational institutions, and within our overall community norms.

The propagation or acceptance of these myths or values, however, does not come without a cost to society as a whole. As Feltham (1995), Schneider (1998) and Rose (1999) all discuss, the growing emphasis on individual responsibility, on autonomy, on professional non-directiveness, and on personal self-actualisation are not achieved without loss elsewhere. This is seen both privately and in relation to state responsibilities and concerns. The values of communal responsibility, interdependency, of obligations to others and of mutual support are lessened as the cult of the free-choosing autonomous individual gains in strength. Governments and official bodies progressively step back from any notions of responsibility for the care of the vulnerable and towards a culture of individual responsibility, or even *blame*, if self-support and self-improvement do not occur. As Feltham states;

“Psychology’s, and counselling’s promotion of the individual may have led ironically to the enthronement of the individual and his or her rights, to the detriment of human connectedness and sense of social cohesion... overlooking the question of moral responsibility or obligations to others” (1995: 131).

It may also lead to a concentration on the self that ignores any spiritual or religious connotations, or concept of a being that transcends the individual, and a neglect of religious values such as duty or self-sacrifice. Although, as a practising therapeutic counsellor myself, I hold many values that are consistent with Rogerian counselling and the techne of ‘psy’, I find in these comments, and in my own spiritual beliefs, an ongoing challenge. Is there, as Rose (1999) declared, an “ethical paucity” in some of the therapeutic ideals if they are taken as a philosophy or an ideology on their own? To what extent do I want to emphasise self-actualisation and autonomy to the exclusion of a moral commitment to the welfare of others or the community at large? These are not questions to which, as yet, I fully have an answer, but as the therapeutic self-actualising ideals increasingly become part of the actual language or narrative of Western society they form an ever-growing public and private concern that would merit active debate.

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Appendix A

First set of interview themes sent to committee.

Semi-structured Interview Themes

Burgess (1984) described a structured interview as one in which “the interviewer poses questions and records answers in a set pattern.” (1984, p101) and a semi-structured interview as one which “employs a set of themes and topics to form questions in the course of conversation” (1984, p102). Designed along a continuum from mostly pre-planned questions to totally unstructured time, the semi-structured interview is more appropriate for the needs of this research. Its greater flexibility allows scope for access to interviewee-initiated topics and thoughts as well as researcher-initiated themes. As such, however, the provision of a list of pre-planned questions is not possible in advance of the interviews. The following themes are designed instead to act as an interview ‘guide’ (For more information see Maykut and Morehouse, 1994, p84).

Clients

Pre-counselling

Client hopes, needs and expectations from the genetic counselling.

Client’s understanding of what genetic counselling is.

What clients expect to talk about.

Client views on advice and guidance.

Who clients believe the genetic counsellor will be (ie doctor, nurse etc).

How clients learnt about their genetic counselling.

Client feelings about the counselling.

Client feelings about haemochromatosis in the family.

Post-counselling.

Whether client expectations were met. If not what expectations were not met?

Client satisfaction with genetic counselling.

Any areas of client dissatisfaction/particular satisfaction.

Was genetic counselling itself organised as was anticipated? If not in what ways was it different?

The impact of genetic counselling on client feelings.

The impact of genetic counselling on client’s life.

Client feelings about haemochromatosis in the family.

Was any decision made about testing?

If yes did the genetic counselling influence the decision?

Clients' feelings on advice and guidance during the session and what type of statements might represent 'advice' to them.

Client feelings after testing if testing occurred.

Counsellors.

Pre-counselling

Counsellor expectations of genetic counselling (generally).

What counsellors expect to cover in the session?

What counsellors think clients are expecting/wanting in terms of content, agenda, advice etc..

Counsellor views on non-directiveness.

Post-counselling

Counsellor views on how session has gone.

Counsellor understanding of client satisfaction.

Counsellor understanding of client needs.

Counsellor views on any decision-making.

Counsellor perception of client wishes around advice or guidance.

Amended interview themes

Interview Topics – Pre-Counselling

Expectations

What do you expect is going to happen when the genetic counsellor comes to your home?

What do you want to happen?

What do you expect will be talked about?

What kinds of things would you *like* to be discussed?

Is there anything else you want or need from your counsellor? If yes what?

How do you feel about whether or not you should be given advice or guidance by the genetic counsellor?

Do you want the counsellor to tell you what she thinks you should do?

Understanding

What do think is meant by genetic counselling? What does the description mean to you?

Who will your genetic counsellor be? Will she be a nurse? Doctor? Counsellor?

General

How did you get to know about haemochromatosis in your family?

How did you get to know about genetic counselling?

Did somebody else refer you? If so who?

Did you want to have contact with the genetic counselling department?

Feelings

How do you feel about your appointment?

?How do you feel about the haemochromatosis in your family? Ie Are you worried by it?

Interview Topics –Post-Counselling

Expectations

Were the expectations you had of the genetic counselling met? Did you get what you wanted from it?

Were there things that you wanted from your genetic counselling that you *didn't* get? If so what were they?

Was there anything that you feel should have happened that didn't?

Satisfaction

How satisfied were you with your genetic counselling?

Were there any things you weren't satisfied with?

Were there any things that you *were* particularly satisfied with?

Understanding

How did the way the genetic counselling was organised compare with the way you thought it would be?

If it was very different how?

Has it changed your ideas of what genetic counselling is?

Feelings

How do you feel now about the haemochromatosis in the family? How does this compare with how you felt before the counselling?

What impact has the genetic counselling had on your feelings?

General

What impact has the genetic counselling had on your life?

Testing and Decision-making

Did you have any decisions to make about genetic testing for haemochromatosis? If yes, did you decide to have a test done or not? Did the counselling influence your decision? Was the decision your own?

Did you feel the counsellor had an opinion about what you should do? Did she try and guide you in any way?

Did you ask for advice within your genetic counselling consultation? If yes did the counsellor give you advice? If not how did you feel about that?

If you had a test would you be willing to share the result with me? If yes, how did the test result leave you feeling?

Appendix B
Original Intended consent and Information Sheet (Pre-amendments)
Headed Paper

Dear x,

My name is Melanie Pearce and I am a PhD research student in the Genetics and Society Unit at the University of Nottingham. I am writing to ask if you would be willing to take part in a research project studying genetic counselling for people with haemochromatosis. The project is taking place with the co-operation of the Department of Clinical Genetics at Nottingham City Hospital. Before you decide it is important that you understand why the research is being done and what it will involve. Please would you take the time to read the following information carefully. If you would like more information please do not hesitate to ask.

Purpose of the Study

I am trying to find out six things from this study.

1. What do you understand by the term 'genetic counselling'?
2. Does genetic counselling have any impact on people with haemochromatosis?
3. Do people with haemochromatosis get what they expect or want from their genetic counselling?
4. How satisfied are people with the genetic counselling they receive?
5. How do the genetic counsellors talk about haemochromatosis in the session?
6. Are some of the ways in which genetic counsellors talk about haemochromatosis more effective than others at helping people to understand its implications for them?

This information will help the Department of Clinical Genetics to be sure if it is offering the best quality service and meeting the real needs of the people it is trying to serve. However, I am not a medical person or a member of this department and will not be able to give you medical information about haemochromatosis.

If you are willing to help with my research, I would like to come and talk to you at your home once before and once after your counselling – for about half an hour to an hour each time. I would also ask your permission for the counsellor to tape record the counselling session. The tapes and information from them will only be used for research purposes and when the research is written up there will be nothing to identify patients who have taken part or who has said what.

You do not have to take part in this project if you do not want to: saying no will make no difference to the counselling or other treatment you receive. If you do decide to help I will be very grateful and the information gained will be used to help other haemochromatosis clients. There is a stamped envelope addressed to me at the Genetics and Society Unit included with this letter. There is also a sheet with your name, telephone number and a box for you to tick saying you wish to take part. If you are willing to take part in the research please would you return these to me with the times of day when it might be convenient for me to ring you. I will then phone you at home to arrange a time to come and see you.

Thank you for taking the time to read this letter.

Yours sincerely, etc

Melanie Pearce

Amended Letter and Information Sheet for Committee

Headed Paper

Study Title:- The impact of genetic counselling on a group of clients receiving counselling for the genetic disorder haemochromatosis.

Dear

My name is Melanie Pearce and I am a PhD research student in the Genetics and Society Unit at the University of Nottingham. I am writing to ask if you would be willing to take part in a research project studying genetic counselling for people with haemochromatosis. The project is taking place with the co-operation of the Department of Clinical Genetics at Nottingham City Hospital. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please would you take the time to read the following information carefully. If you would like more information please do not hesitate to ask me. I can be contacted on telephone number 07979 836328.

Purpose of the study.

I am trying to find out six things from this study:

1. What do you understand by the term 'genetic counselling'?
2. Does genetic counselling have any impact on people with haemochromatosis?
3. Do people with haemochromatosis get what they expect or want from their genetic counselling?
4. How satisfied are people with the genetic counselling they have received?
5. How do the genetic counsellors talk about haemochromatosis in the sessions?
6. Are some of the ways in which genetic counsellors talk about haemochromatosis more effective than others at helping people to understand its implications for them?

This information will help the Department of Clinical Genetics to be sure that it is offering the best quality service and meeting the real needs of the people it is trying to serve. However, I am not a medical person or a member of this department and will not be able to give you medical information about haemochromatosis.

Why you have been asked to take part.

You have been asked to take part in the project because you are a new patient who is shortly to receive genetic counselling for haemochromatosis for the first time. The project is to run for twelve months from October 2000 and will involve twenty new genetic counselling patients with haemochromatosis in the family.

You do not have to take part in this project if you do not want to and if you do take part you may withdraw at any time. Saying no will not make any difference to the counselling or other treatment you receive. If you do decide to help, I will be very grateful.

What will happen if you decide to take part.

If you are willing to help with my research, I would like to come and talk to you at your home once before and once after your genetic counselling - for about half an hour to an hour each time. I would also ask your permission for the genetic counsellor to tape record the counselling session. The tapes and information from them will only be used for research purposes and will be kept in secure storage. University regulations state that the tapes must be stored for seven years. At the end of this time they will be considered for destruction. If you decide to withdraw from the study at any point, you may request that the tapes be destroyed.

Benefit of study.

The information gained will not be of direct benefit to you but it will be used to benefit people who are concerned about haemochromatosis in the future. The study is funded by the Economic and Social Research Council.

Confidentiality.

All information collected about you will be kept confidential. Your name and address will be removed from it so that you cannot be identified. When the research is written up there will be nothing to identify patients who have taken part or who has said what.

What to do.

There is a stamped envelope addressed to me at the Genetics and Society Unit included with this letter. There is also a sheet with your name, telephone number and a box for you to tick saying you wish to take part. If you are willing to take part in the research please would you return these to me with the times of day when it might be convenient for me to ring you. I will then phone you at home to arrange a time to come and see you.

Thank you for taking the time to read this letter.

Yours sincerely,

Melanie Pearce.

Final letter after request to reverse amendments late on in research period
Headed Paper

Dear

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your friends, relatives and your GP if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

My name is Melanie Pearce and I am a PhD research student at the University of Nottingham looking at genetic counselling for haemochromatosis. I am trying to find out six things from this study: 1) What do you understand by the term 'genetic counselling'? 2) Does genetic counselling have any impact on people with haemochromatosis? 3) Do people with haemochromatosis get what they expect or want from their counselling? 4) How satisfied are people with the counselling they have received? 5) How do the counsellors talk about haemochromatosis in the sessions? 6) Are some of the ways in which genetic counsellors talk about haemochromatosis more effective than others at helping people to understand its implications?

The project has the co-operation of the Department of Clinical Genetics. This information will help the Department of Clinical Genetics to be sure that it is offering the best quality service and meeting the real needs of the people it is trying to serve. However, I am not a medical person or a member of this department and will not be able to give you medical information about haemochromatosis.

If you are willing to help with my research, I would like to come and talk to you at your home once before and once after your counselling - for about half an hour to an hour each time. I would also ask your permission for the counsellor to tape record the counselling session. The tapes and information from them will only be used for research purposes and when the research is written up there will be nothing to identify patients who have taken part or who has said what.

You don't have to take part in this project if you don't want to. Saying no will make no difference to the counselling or other treatment you receive. You may withdraw at any time and any tapes already made can be destroyed. If you do decide to help I will be very grateful. Although you yourself will not gain any direct benefit from the research, the information gained will be used to benefit other haemochromatosis clients. There is a stamped envelope addressed to me at the Institute for the Study of Genetics, Biorisk and Society included with this letter. If you are willing to take part in the research please would you return this to me with a piece of paper giving your name, telephone number and times of day when it might be convenient for me to ring you. I will then phone you at home to arrange a time to come and see you.

Thank you for taking the time to read this letter.

Yours sincerely, etc

Melanie Pearce.

Opt-in Form

Name:

Telephone number:

I am willing to take part in this study:

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Convenient times of day to be contacted:

If you would like more information before returning this slip please feel free to contact me on 07979 836328.

Appendix C

Consultations

Consultation	Disorder	Present
One	Huntington's Disease	Geneticist, Nurse-Counsellor, Client
Two	Muscular Spinal	Geneticist, Nurse-Counsellor, Client
Three	Neurofibromatosis	Geneticist, Nurse-Counsellor, Mother and Child Clients, Client's Husband
Four	Muscular Spinal	Geneticist, Nurse-counsellor, Client, Client's Wife
Five	Myotonic Dystrophy	Geneticist, Nurse-counsellor, client and client 2 (daughter)
Six	Turners syndrome	Geneticist, client
Seven	Breast Cancer	Geneticist, Nurse-counsellor, Mother and daughter – both clients
Eight	Fragile X	Geneticist, Nurse-Counsellor, Teenage Client, Client's father and mother
Nine	Hurler's Syndrome	Geneticist, Nurse-Counsellor, Client and Client's Husband
Ten	Colon Cancer	Geneticist, Nurse-Counsellor, Client
Eleven	Neurofibromatosis	Geneticist, Nurse-Counsellor, Teenage client and Client's Mother
Twelve	Huntington's Disease	Geneticist, Nurse-Counsellor, Client and Client's Husband, Child
Thirteen	Down's Syndrome	Geneticist, Nurse-Counsellor, Clients 1 and 2, - mother, father & baby
Fourteen	Epilepsy	Geneticist, Nurse-Counsellor, Client
Fifteen	Haemochromatosis	Nurse-counsellor, Client
Sixteen	Haemochromatosis	Nurse-counsellor, Client

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