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Professional ambivalence: Accounts of ethical practice in childhood genetic testing

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Abstract

Childhood genetic testing raises complex ethical and moral dilemmas for both families and professionals. In the family sphere, the role of communication is a key aspect in the transmission of 'genetic responsibility' between adults and children. In the professional sphere, genetic responsibility is an interactional accomplishment emerging from competing views over what constitutes the 'best interests' of the child in relation to parental preferences on the one hand, and professional codes of practice on the other. In the present paper we extend our previous research into parental accounts of childhood genetic testing and explore the ethical explanations/descriptions of professionals in research interviews. Interviews (n=20) were conducted with professional practitioners involved in the genetic diagnosis and management of children and their families. We first identify four inter-related themes – juxtaposition of parental rights vis-à-vis child's autonomy, elicitation of the child's autonomy, avoidance of parental responsibility and acknowledgement of uncertainty – and then, using Rhetorical Discourse Analysis, examine the range of devices through which ethical explanations are situationally illustrated: contrast, reported speech, constructed dialogue, character and event work. An important device for facilitating ethical explanations is the use of *extreme case scenarios* which reconstructs dilemmas as justifications of professional conduct. While acknowledging ambivalence, our analysis of professional accounts suggests that ethical practice is not a simple matter of implementing principles but managing the practical consequences of interactions with parents and children. We conclude that more attention is needed to understand the way professional practitioners construct and share cases as useful illustrations of evidence-based ethical practice.

Key words: professional ethics, accounts, genetic counselling, genetic testing of children, rhetorical discourse analysis

INTRODUCTION

Professional accounts of ethical practice

Advances in medical/molecular genetics have led to an increasing availability of accurate tests for a range of heritable disorders. This will place new and more numerous demands on the relationship between professionals, patients and family members. Genetic testing will continue to raise ethical dilemmas about informed consent, about who can legitimately ask for a test, and how to negotiate competing responsibilities between families and professionals. On the family side, people already face complex choices and obligations about knowing or not knowing their genetic status (Chadwick, 2004) as well as disclosing or not disclosing genetic information to relatives who may be equally ambivalent about their genetic future (Hallowell, 1999, 2003; Foster et al., 2003). The scenario becomes more complex when it involves genetic testing of children, which is our focus here. Genetic professionals are required to follow a set of ethical guidelines while facilitating alignments with parents and at the same time preserving the 'best interests' of the child (Clarke and Flinter, 1996; Arribas-Ayllon, Sarangi and Clarke, 2008). However, less is known about the practical ethical challenges that face genetic professionals.

In a different context to childhood genetic testing, Taylor and White (2000) argue that within social work, which is rooted in evidence-based practice, exclusive attention is given to how knowledge is *used* rather than how it is *made* or constructed. They discursively illustrate how social workers routinely categorise people as blameworthy or responsible and construct morally persuasive versions of events which lead to 'affective' judgements about cases. For them 'reflexivity' is a matter of understanding the practical-moral activity of social work, in which case professionals are urged to critically interrogate their own assumptions. In a similar vein, Hall, Slembrouck and Sarangi (2006) examine practices of accountability and

categorisation among social workers in policy review interviews. They show that narratives are important displays of professional competence, which seek to justify difficult actions such as placing children in residential care.

Despite the growing interest in professional accountability (Bernhardt et al., 2000), few studies have actually examined the construction of professional accounts within clinical genetics and genetic counselling. Recent studies have examined the complex and innovative ways in which professionals balance and reconcile morally contentious aspects of genetic technology such as stem cell research (Wainwright et al., 2006), in vitro fertilisation (IVF) (Ehrich et al., 2006) and preimplantation technologies (PGD) (Williams et al., 2007). For example, Ehrich et al. have shown how staff engage in 'ethical boundary work' as they reflexively justify and balance tensions between the medical legitimacy and social accountability of controversial clinical procedures.

In this paper we investigate the detailed accounts of genetics professionals – to include clinical geneticists, genetic counsellors and paediatricians – involved in childhood testing. By 'accounts' we mean the activity of reporting troubles or explaining problematic events (Antaki, 1994). As action-oriented performances, accounts seek to construct various strategic versions of reality, to morally position actors/speakers, and engage in perspective-taking. This has obvious implications for the communication of ethical dilemmas as illustrations of evidence-based practice. First, we review the case for why professional accounts increase awareness and understanding of bioethical dilemmas. Next, we identify the main themes of our interview data, and conduct a detailed rhetorical discourse analysis of key extracts. This is followed by a discussion of our findings: linking rhetorical aspects of ethical dilemmas to justifications of professional practice.

Professional ethics and genetics

Beauchamp and Childress (1984) are routinely credited with principle-based ethics, famously known as the Georgetown mantra of 'beneficence, non-maleficence, autonomy, and justice'. From the professional practitioners' perspective, as Campbell (1984: 4) points out, 'the more concerned the professions of medicine and nursing have become about the formulation of codes of ethics, the more they have become aware of the complexity of the moral problems facing them'. Since the adoption of ethical 'codes' and 'guidelines' in the US and in Europe¹, there have been parallel debates within sociology and philosophy about the prescriptive, and possibly unhelpful, nature of code-oriented professional ethics (Pill et al., 2004, Gert et al., 1996). Tadd (1994) has shown in the context of nursing that codes not only frustrate the moral climate of work and fail to raise standards of care, but systematically disempower nurses. In a similar vein, Edgar (1994) argues that professional codes of ethics within social work prevent and marginalize innovations at the local level. More generally, Wainwright and Pattison (2004: 121) observe that codes are 'problematic at best' and should not bring closure to confusion and debate, but enable professionals to dynamically foster a sense of virtue that 'become better reflections on values within professional practice'. Criticism of this kind has prompted other scholars to consider a more contextualist reading of professional ethics (Weisz, 1990; Taylor and White, 2000). Following this latter trend, we suggest that professional and ethical dilemmas are fabricated and communicated through complex discourse practices – narrative frameworks, rhetorical devices and interactional moves – to underscore the accountability of professional practice.

¹ The first Code of Ethics (COE) were developed by the National Society of Genetic Counsellors (NSGC) in the US and were officially inaugurated and published in 1992 (cf. Benkendorf et al., 1992). The UK Clinical Genetics Society (CGS) developed a similar (non-regulatory) framework of 'principles and guidelines' in 1994. This was followed by similar frameworks in Europe. A set of international guidelines for 'Ethical Issues in Medical Genetics' were prepared for the World Health Organization (WHO) in 1998.

There are very few studies that examine professional dilemmas in the context of genetic counselling services (Callahan et al., 1995; Maley, 1994). Callahan et al. (1995) derived case studies from professionals' experiences and conducted a review of the counselling literature. They concluded that professional understandings of ethical and social dilemmas were mostly general and derivative. A more thorough review was needed to identify, classify and resolve ethical cases within medical genetics. Responding to this call, McCarthy Veach et al. (2001) conducted focus groups with genetic counsellors, nurses and physicians, identifying 16 major categories and 63 subcategories of 'ethical and professional dilemmas'. In a follow-up study, Bower et al. (2002) developed these same categories into a survey (n=454) so as to devise ethical strategies for genetic counsellors. The frequency and variety of challenges (esp. informed consent and value conflicts) implied that respondents recommended a *more* directive approach towards the process of genetic counselling. The authors argued for more research (e.g. personal interviews) to explore the use of *dilemma-specific* strategies in different counselling situations, which aligns with the main aims of the present study. The present study aims to isolate some of the key dilemmas and illustrate how professionals go about accounting for them.

Before we turn our attention to the present focus, it is worth acknowledging how early studies of professionals' accounts of genetic counselling have concentrated on how risk information is conveyed to clients (Rapp, 1988). Bosk's (1993) study of a genetic counselling unit found that counsellors placed such a high premium on 'correct information' and 'non-directiveness' that they often ignored the personal considerations of the client. Accountability was explicitly framed in terms of the quality of information provided, not the outcome of the patient's decision. While patient autonomy is upheld as an ethical ideal for many professionals, the right to choose or decide may be personally experienced as a moral and

psychological burden (Hallowell, 1999). Many studies have noted that where abstract ethical principles contradict each other there is very little guidance as to how particular situations should be managed by counsellors² (Huibers and van 't Spijker, 1998; van Berkel and van der Weele, 1998; Wüstner, 2003). In her work on the interactional activity of genetic counselling, Pilnick (2002) also shows how principles of patient autonomy and non-directiveness are interactionally difficult to reconcile. She argues that ethical principles in their abstract form are unable to adequately engage in the practical and local contingencies of counselling.

Childhood genetic testing

Since the mid-80s, the professional community have recognised the potential for inappropriate testing of healthy children (Craufurd and Harris, 1986; Harper and Clarke, 1990). Ethical guidelines clearly stipulate that genetic testing is recommended only if there is clear medical or psychosocial benefit to the child (Clinical Genetics Society, 1994). Despite the profession's explicit ethical stand, some studies attest to regular parental demands for predictive or carrier testing of healthy children (Chapple et al., 1996; Campbell et al., 2003). While the ethics of predictive testing is less equivocal, recent European surveys on carrier testing of 'incompetent children' indicate geographical and cultural variations in professional attitudes (Borry et al., 2007). Some have stressed the need for wider empirical research into the views of relevant stakeholders (Borry et al., 2005).

As far as immediate stakeholders are concerned, dilemmas in childhood testing often reveal a three-party tension between parents, professionals, and children. On the parental side, professionals are cast as the means through genetic information about the child is accessed. On the professional side, genetic counsellors may frame parental uncertainty and

² This tension between codes of ethics and mundane professional practice has been also discussed in the 'Genethics Club', which is a national forum for the discussion of practical ethical problems amongst clinical genetic departments in the United Kingdom (cf. <http://www.ethox.org.uk/ethics-support/the-genethics-club>).

anxiety in terms of seeking psychological assurance or wanting to know their child's genetic status, and will include the child's autonomy for legal and ethical reasons (McConkie-Rosell et al., 1999; Hamann et al., 2000). Sarangi and Clarke (2002) have explored the subtle negotiation of decisions between clinicians and clients over childhood carrier testing within an ethos of non-directive counselling. They show how nondirective counselling seeks to facilitate interaction while discourage testing by contrasting the child's future autonomy against the parent's current rights. Such contrastive strategies allow the counsellor to offer 'recommended options' without explicitly countering the mother's concerns. In the family context, parental explanations and descriptions of family communication reveal a precarious, and not always convincing, balance between parental responsibility and the child's autonomy. Arribas-Ayllon, Sarangi and Clarke (2008) have shown how parental accounts strategically portray a dialogic family which foregrounds child autonomy with regard to issues of how and when to disclose genetic information to children, of deciding whether or not to test etc. In this paper we shift our attention to professional accounting practices which no doubt embed, as we will see, parents' and children's perspectives.

METHODS

Twenty participants were recruited from paediatric and genetic services in Cardiff (Wales) and London. Both convenience and snowball sampling were used to contact professionals who, by either academic reputation or clinical experience, had worked on cases involving children and genetic services. Semi-structured interviews were conducted with paediatricians (n=10), clinical geneticists (n=2), and genetic counsellors (n=8), asking specifically to provide retrospective accounts of difficult or challenging cases involving genetic testing of children. The interviewees were also asked to give explanations of their ethical orientation about matters relating to the competence and maturity of children, the

concept of autonomy, the ethical differences surrounding predictive and carrier testing, and the difficulties of practicing nondirective counselling.

A broad thematic analysis was conducted on the transcripts using an iterative technique of close reading, note-taking and coding. The coding criteria were based on the interactional aspects of 'reporting troubles' (Morris, 1994) vis-à-vis heritable risk and childhood testing. Accounts of professional and ethical dilemmas were also identified via categorisations of conduct and reported tensions between different participants (e.g. mothers, fathers, practitioners, children, etc.). After coding and checking, a total of (n=26) extracts were compiled into a sub-corpus for more detailed inspection and analysis. A total of four themes were identified that capture the range and variation of professional dilemmas:

Juxtaposition of parental rights vis-à-vis child's autonomy

Elicitation of the child's autonomy

Avoidance of parental responsibility

Acknowledgement of uncertainty

As separate themes within our sub-corpus, each places a different emphasis on the role and character of participants, of the particular circumstances of events, around which ethical dilemmas are constructed. Before presenting our more detailed rhetorical discourse analysis we should briefly explain each of these themes. Fig 1 represents a summary of our thematic analysis, accompanied by an 'exemplar' account of each professional/ethical dilemma.

Figure 1. Thematic categories of professional accounts

Theme	Exemplar account
<i>Juxtaposition of parental rights vis-à-vis child's autonomy</i>	And they have two children of, I don't know, let's say six and eight. And the father is adamant that these two children should be tested, have carrier testing performed. And in that he's a very aggressive, pushy, difficult man
<i>Elicitation of the child's autonomy</i>	You ask a twelve year old a question that you might ask normal adult ... You don't get a question-answer- but when you chat to them and talk to them stuff comes out, bits and pieces, dribs and drabs, very frustrating, as a counsellor, you're thinking it's taking so much time. And you don't know when it's going to come or how it's going to come.
<i>Avoidance of parental responsibility</i>	And I said look, you know, I'm feeling very uncomfortable about dealing with these issues with this girl because she came to the clinic on her own, these are big issues we've got to discuss, and I'm not clear why the family aren't supporting her.
<i>Acknowledgement of uncertainty</i>	And I don't know because it is a bit of a struggle, there's part of me that wants him to recognise that what he's doing actually is about control, it's about his own anxiety and it actually isn't about the benefit of the children, is my belief, now I might be wrong

`Juxtaposition of parental rights vis-à-vis child's autonomy' represented the most common dilemma in which parents were seeking or demanding a genetic test without considering the autonomy of the child. Parental rights were posed as a problem when the `aggressive' mother or the `pushy' father resisted or ignored the ethical, moral or psychological implications of childhood testing. `Elicitation of the child's autonomy' represented the professional difficulties of assessing the child's capacity or recruiting their consent in matters of testing and/or diagnosis. `Avoidance of parental responsibility' described the scenario in which parental rights or responsibilities were largely absent, which often posed difficulties for the child's autonomy. Lastly, `acknowledgement of uncertainty' represented those accounts in which professionals were clearly ambivalent about their own responsibility. They described both a personal and professional conflict of views, often weighing whether it was ethical to deny parental demands for testing, whether `counselling'

was in the best interests of the family, or whether it was actually possible to `facilitate' the child's autonomy.

From our sub-corpus, we selected for each theme the most illustrative and exemplary accounts for Rhetorical Discourse Analysis (Arribas-Ayllon, Sarangi and Clarke, 2008a; 2008b). This entailed identifying and explaining a range of devices through which ethical/moral explanations are constructed: contrast, reported speech, constructed dialogue, character and event work. Contrast structures (Smith, 1978) are effective ways of not only categorising behaviour and identity, but also establishing different versions of events. Constructed dialogue, or `reported speech', is one device widely used in accounts to recruit voices and authenticate different versions of events. Character work is strategically deployed as moral descriptions/categorisations of conduct which facilitate ethical perspective-taking. Similarly, event work offers a re-interpretation of temporal (past/future) events to suit the speaker's current concerns. Together, these devices reconstruct *extreme case scenarios* to facilitate explanations of dilemmas which justify professional conduct.

DATA ANALYSIS

A notable characteristic of professional accounts were the ways in which descriptions of characters and events created a `scenario' of ethical tensions between different parties. For example, the *three-party tension* (professional-parents-child) was the most common form of dilemma in which professional practice was contested or rendered uncertain. The *four-party tension* (professional-mother-father-child) were examples of more complex cases usually involving further troubles between the parents (e.g. when childhood testing was used as an instrument for attributing family blame or justifying divorce). In all these cases, professionals, parents, children and/or other family members were encoded as key

participants to endorse professional practice in strategic ways. Different kinds of accounts would place the emphasis of ethical or moral concern on different participants. For example, is it the child's autonomy that becomes grounds for ethical concern or the rights of the parent seeking testing?

Juxtaposition of parental rights vis-à-vis child's autonomy: the means-end rationale

As we mentioned earlier, the most common ethical dilemma among professional accounts involved the reconstruction of scenarios in which parental rights seem to supersede the 'best interests' of the child. Variations on this theme ranged from the number of participants encoded as well as descriptions of presumed motivations that 'drove' parental concerns/desires for childhood testing. In the simplest version of this dilemma, a single parent (usually the mother) becomes the principal figure of moral accounting. In the account below, for instance, a genetic counsellor (GC) is describing a 'second referral' case involving a woman with Familial Adenomatous Polyposis (FAP) who 'came in wanting all five of her children tested'.

Extract 1

GC: I was referred to them as a second referral, and the approach of the person who had seen them had been very much, no, we don't do that- sorry, so she had become very cemented in this, I've got to have this test (.) she was also, to her credit, she was quite upfront about the reasons for that, it was very much for herself (.) she has Desmoid Disease where they develop benign tumours that develop and they grow (.) they're pretty much untreatable, managed with chemotherapy to keep them at a reasonable size (.) but the outlook for her wasn't particularly good, and so she was saying, I want to know what my children have, so that I can die in peace basically (.) it was for her anxiety and her worries about the future and wanting to know what was going to happen to her children.

There are two important aspects of this account that are worth considering. Firstly, the framing of the case as one in which the mother was initially refused testing by another professional colleague. This follows from an earlier remark that counsellors should not explicitly refuse childhood testing, but apply more subtle strategies of persuasion. She stipulated that it was better to say 'why we don't normally offer it' in order to avoid the

scenario where parents might become adamant about testing. The account therefore serves as an exemplar for avoiding such scenarios in practice. This relates to the other purpose of the account. Secondly, it engages in the moral profiling of the mother who becomes 'cemented' on what she cannot have ('I've got to have this test'), which, as it transpires, is not so much to diagnose risk in her children, but to assuage her own fears. Counsellors often reported that families requesting a genetic test for their children rarely considered the prospect that testing may indeed identify risk which may or may not materialise. Additionally, the accounts of 'benefits of knowing' one's risk may suppress those of 'risks of knowing' (Sarangi et al., 2003). Parents often thought of testing as a means of eliminating risk, of neutralising their fears, not confirming them. On the surface, the mother's argument may seem compelling given her poor prognosis: 'I want to know what my children have, so that I can die in peace basically', but the counsellor's contrasting point is to show that she has evidently failed to consider the probability of her children's risk, an unintended consequence that would certainly undermine the prospect of 'dying in peace'.

Among the professionals we interviewed, the notion that childhood testing might be exploited as 'a means to an end' was rhetorically managed in a number of different ways. The counsellor above had, at one point, clearly stipulated that libertarian arguments supporting parental requests for testing (on the grounds that the child would benefit from testing because it would relieve parental anxiety) were explicitly countered through this means-end rationale. In the next extract, we show how other rhetorical means are used to illustrate the dangers that may arise when the child's best interests are apparently ignored. In this more complex scenario, the professional (P) has just contextualised her move from paediatrics to clinical genetics, and provides an account of an early case in her career. Just before narrating this account, she adds: 'I always tell this story in the lectures I give'.

Extract 2

- P: And I was completely not ready for this and they were sitting there (.) mother was a social worker and dad was a very uptight business man in a suit- or looked like a business man; very sort of uptight (.) and we were talking and this boy had got the help he needed in the school and he was needle phobic and they were sitting- and really a very sweet kid about – I don't know, thirteen, whatever (.) and- but young, very young (.) you know, because he was developmentally delayed (.) and the mother was saying look, you know, if these tests will do him good then you know, that's fine (.) but I really can't see- he's needle phobic, de-de-de-de (.) and what benefit will it be, de-de (.) anyway it transpired that they are actually getting divorced and the reason the father was there was that he'd been told by his sister who read a woman's magazine, that this is likely to be fragile X (.) if it was fragile X he could blame her, the soon-to-be-ex-wife, because it was carried by women and therefore he'd a) get custody of the child and b) get a better divorce settlement.
- R: Oh, what

Quite different to the scenario of the 'anxious mother' in extract 1, we have here the encoding of multiple participants as well as more explicit character work to index stronger moral inferences about parental motivation. The account begins by orienting the listener ('And I was completely not ready for this...') to an apparent breach of routine practice. The scenario we are about to hear is marked as somehow exceptional or unusual. She begins framing the account by assigning roles to the parents from which a particular estimation of character can be inferred: the mother who is 'a social worker', the father who is an 'uptight business man', which is nicely contrasted with the 'very sweet kid' who is cast at the centre of an adult dispute. However, the innocence of the child is not simply a rhetorical index ('but young, very young') – it also signifies a symptom of developmental delay. The counsellor recruits the voice of the mother who is ambivalent about testing ('but I really can't see -'), which is clearly framed in terms of the child's best interests ('if these tests will do him any good...'). The narrative marker 'anyway it transpired' subtly orients the account to information that emerges *after* the clinical consultation of which further motivations are learned. The 'divorce' proceeding and the lay diagnosis of 'fragile X' by the father's sister 'who read a women's magazine' is effective in illustrating the cautionary tale that childhood testing can be exploited as an instrument of familial blame. It also foregrounds the unsavoury scenario that establishing the biological culpability of one parent provides a means of attributing a

`personal' dereliction of duty to another. The researcher's reaction to the account is included here ('Oh what') to indicate its rhetorical success in eliciting both surprise and disapproval.

Elicitation of the child's autonomy

In the previous extracts of professional dilemmas we have seen how childhood testing is posed as a problem when parental rights threaten to supersede the best interests of the child. In this section, we consider examples in which the autonomy of the child presents certain clinical challenges for professionals. Some genetic counsellors described the difficulty of eliciting informed consent from children who fell somewhere between the category of `minor' and `adolescent'. Counselling at this grey zone of autonomy required novel techniques of extricating children from the influence of parents to assess whether they can make informed choices. One genetic counsellor (GC) described counselling twelve/thirteen-year-olds as `unbelievably difficult'; she was not convinced that they were `making informed decisions in the way that an adult would'. In the account below, she describes the uncommon example of a twelve-year-old who declines testing:

Extract 3

GC: I have had a twelve-year-old decline testing (.) his mother wanted him tested, went through the whole process, all assuming it was going to happen because it always goes ahead, this kid was deaf as well so it was really complicated counselling (.) and sitting in McDonalds I said, you're going to go ahead with the test? And he said, no (.) his mother looked at him and she was saying, oh, you do want the test, and he just was shaking his head, she said, oh it's because he's worried about needles, and I said, well (.) if you didn't have to have a needle would you have the test? Thinking we could do a cheek swab or something, he went, no, but he couldn't really tell us why he didn't want the test, but that was okay and thank goodness his mother was quite a reasonable person and she respected that and he came back three years later when he was ready, when his younger sister was coming in as well.

We should note that this theme bears a close resemblance to `juxtaposition of parental rights vis-à-vis child's autonomy' because the child's mother is requesting a test. The important difference, however, is that the child is old enough to be consulted independently of the mother. We are also expected to interpret `decline testing' as an unusual outcome of

counselling. The reference to 'all assuming it was going to happen because it always goes ahead' is suggestive that children *routinely* endorse parental decisions – i.e. children often replicate the parent's wishes. The twelve-year-old's disability adds further complications to communicating complex issues. The reference to 'sitting at McDonalds' is an index to the counsellor's previous remarks about techniques to facilitate communication outside the medical setting. Though she described this technique as a means of seeing children 'by themselves', the reported speech that follows would suggest that the mother was present during the counselling.

The combination of reported speech ('I said', 'he said') and constructed dialogue are successful in reproducing various tensions between the professional, the child and the mother. For instance, when the child initially declines the test ('he said no'), the mother can be heard searching for clarification ('oh, you do want the test') as if the child was mistaken. The misalignment between the mother and the child is repeated ('he just was shaking his head'), at which point the mother attempts to repair the interaction by suggesting that the child is 'worried about needles' as opposed to displaying informed consent. Here, the counsellor's use of constructed dialogue successfully orients to the mother's motivation who clearly wants the child to consent to testing. Next we hear the counsellor skilfully neutralising the mother's suggestion of phobia ('and I said, well (.) if you didn't have to have a needle ...'), which indicates that the test could be performed by other means ('cheek swab'). When the child declines again we assume the choice is a rational one. However, the suggestion of rationality is immediately countered when it is explained that the child was unable to justify his reason for declining. This illustrates the counsellor's earlier point that children below the age of majority do not perform convincing displays of informed consent about complex risk. The above scenario is couched as a counselling 'success story' not because of the child's

persistence in declining testing or even the complicated counselling involved, but because the mother 'respected' the child's decision. She is morally cast as a 'reasonable person' because she did not challenge the child's weak display of autonomy.

Professionals often raised the concern that minors who consent to testing may be doing so on the basis of their parent's wishes. One paediatrician (P) used the example of the 'eight year old' to illustrate the difficulty of knowing whether *the child* is speaking or whether parents are speaking *through* the child. He continued to explain that while measures such as Gillick competence are, albeit 'subjective', assessments of maturity, doctors have always employed such methods in 'a beneficial way'. The presumption that doctors are experts of who is or is not mature was accounted for defensively: he contrasted the implied paternalism of medical authority with the paediatrician's responsibility of preserving the 'best interests' of the child. In the account below, the same paediatrician is responding to the researcher's question about whether there is any benefit from disclosing genetic information to children when they are 'younger'.

Extract 4

P: I think there's (.) I think kids end up carrying a lot of baggage anyway and I think to be lumbering and cumbering them with additional baggage for (.) which isn't going to- why spoil their childhood? If it's going to be bad news why spoil their childhood if it's not going to help them at all? (...) I don't think- I honestly don't think there's a right or wrong answer for what you should be doing, I like the idea that you shouldn't be testing or giving that information until they are mature enough to understand it (.) and you can always make a- come up with an example, why don't we just do that? But, I think you either have that rule or you don't and I suppose if you decided on that rule you're then left with some of the consequences of the, at some stage there's going to be this jarring (.) and adolescence is- is a difficult period but it's a difficult period for a number of reasons, a lot of which are that they're actually coming to realise things that they weren't aware of when they were children. (.) so I think it- I think adolescence is the time to start going through those issues, and I think to be telling a child, a young child, who particularly doesn't have the maturity to fully understand some of these concepts is difficult (.) but I think you could argue that that's a paternalistic view.

The benefits of disclosure are offset by casting the child as somehow already overwhelmed or besieged by concerns that may compromise their autonomy: disclosing a genetic identity would simply add further anxiety ('additional baggage'). What is interesting is that by

accounting for nondisclosure, the paediatrician does not invoke ethical guidelines or biomedical principles. Instead, he proceeds with a subjective account ('I honestly think...') that absolute principles ('right or wrong answer') may not apply to professional decisions. This subjective formulation is extended ('I like the idea...') to argue that delaying testing and disclosure until the child is 'mature enough to understand it' is a *preferred* judgement.

The paediatrician continues to reflect on how judgements about maturity are formed. He orients to the possibility of making rules ('you can always make a-'), but then abruptly describes 'an example' which may serve as an illustration of how to apply professional judgements. The contrastive statement 'but I think you either have that rule or you don't' sets up an either/or scenario which facilitates further ethical accounting: if assessments of maturity were rule-governed then professionals will be faced with 'consequences' where cases may not fit the rule ('at some stage there's going to be this jarring'). The paediatrician explains that inevitably rules cannot account for all contingencies; in situated cases some kind of subjective, professional judgement is required. By orienting the account to a description of 'adolescence', the paediatrician is actually performing expertise by demonstrating an empathic awareness of this 'difficult period'. The adolescent's change in identity and increasing awareness of self is cast as an optimal period to disclose a 'previous' genetic identity (Armstrong, Michie and Marteau, 1998). The notion that a genetic identity might 'spoil' the child's autonomy resonates with Davis' (1997) ethical argument that children have a 'right to an open future'. This position also reflects the current ethical guidelines which discourage disclosure *if* there is no medical benefit, implying that medical grounds take precedence over the possibility that early disclosure may have some psychosocial benefit (Robertson and Savulescu, 2001; Duncan and Delatycki, 2006).

The paediatrician infers that disclosing genetic information while the child is psychologically autonomous (i.e. capable of understanding changes within the self) is more beneficial to the child, and more ethical, than disclosing such information to children who cannot understand the implications of complex risk. However, the case of the latter seems to require further accounting about the professional role. Admitting that some are less autonomous than others might be construed as 'paternalistic'. This defensive move seems to anticipate potential disagreement about whether medical professionals are well equipped to expertly assess autonomy.

Avoidance of parental responsibility

In contrast to scenarios where parents 'want to know' the genetic status of their child, some professionals cited cases where parents 'don't want to know'. In these accounts, affected parents, or parents aware of familial risk, were cast as avoiding responsibility for disclosing genetic information that may have important medical or social consequences for their children. The two cases we present here are very different, but they are linked in terms of the temporal (future) consequences of not-disclosing genetic information to children.

In Extract 5, a Paediatric Nephrologist (P) is explaining how families usually have to overcome 'some huge agenda' in relation to genetic responsibility. She describes 'a very interesting family' who were unable to engage in risk communication with their children. She begins describing the scenario by assigning character attributes to each of the parents: the father 'was a solicitor ... a professional man' who was diagnosed with polycystic kidneys 'late in the stage of the disease' and the 'wife was an accountant' who felt 'absolutely incapacitated with guilt'. As we will see, framing the parents' character in this way has important rhetorical implications for imputing responsibility.

Extract 5

- P: They didn't want correspondence, I can't remember all the things they didn't want but you know they were absolutely unable to broach the subject with the children.
- R: Yeah.
- P: And I think that, I mean the problem is it's never going to be right for them so really you know if you can't tell your children when you're 12 and, when they're 12 and when they're given an opportunity, they're not going to be able to do it, I think one was 15 and doing 'O' levels and you know.
- R: Right.
- P: I think we did see them twice.
- R: Yeah.
- P: And clearly the children are just going to find out themselves at some time, and I mean, one of the things is that you know say the children get married have babies and then they find that they've passed it on to their baby and nobody told them and they've got two intelligent parents who obviously knew.

The paediatrician frames the parents' denial through the reporting of events ('They didn't want correspondence') in order to establish their evasive conduct. Despite her gloss of events ('I can't remember all the things they didn't want'), we are oriented to hear this account as a *complete* failure to initiate risk communication (note the use of '*absolutely* unable to broach...'). By framing the circumstances in absolute terms ('it's *never* going to be right for them'), the paediatrician seems to suggest that self-initiated future disclosure is not likely to occur once they miss the 'opportunity' to disclose. Reference to the children's age ('I think one was 15') is suggestive that they are certainly autonomous enough to benefit from disclosure at the current time. Furthermore, the statement 'I think we did see them twice' infers that the parents were indeed provided opportunities but failed to reconcile their guilt. The rest of the interaction is taken up by a prospective account of the ethical and genetic implications of failed disclosure. Framed as a self-evident scenario ('*clearly* the children...'), the paediatrician describes the hypothetical situation that the children will only learn of their carrier status once the mutation is passed onto their own children. The last two statements ('and nobody told them', 'they've got two intelligent parents') succeed in framing the account as a cautionary tale. The blameworthiness of the parents is inferred but palpable: educated professionals are expected to engage in responsible risk communication.

In the above account, deferring responsibility is largely posed as an ethical dilemma for parents, though other professionals indicated difficulties of dealing with families 'who don't want to know'. In the next account, we consider a similar scenario where parents have not disclosed genetic information and the adolescent in question has come to the clinic on her own. Unlike the previous account, the ethical dilemma below is clearly posed as a clinical challenge for the Paediatric Endocrinologist (P) who has to explain to the '17-year-old girl' that she has male chromosomes:

Extract 6

P: One of the things that made me realise that parents don't necessarily want to engage with us was my involvement with a 17-year-old girl who was referred to me because she had no secondary sex development (.) and she was tall so she clearly didn't have Turner Syndrome (.) anyway we did the usual full work up at 17, found that she had a 46 XY karyotype, so, you know, quite a big issue to deal with, bright, intelligent girl, planning to go to university, very articulate, had come to the clinic on her own, and I thought, ah shit, how am I going to deal with this? So I rang the GP and the GP was- by pure chance happened to be an ex trainee of mine from (place), and I knew that she'd done psychology before she came into medicine, and I said, look, you know, I'm feeling very uncomfortable about dealing with these issues with this girl because she came to the clinic on her own, these are big issues we've got to discuss, and I'm not clear why the family aren't supporting her.

The Paediatrician frames the account in terms of his own realisation that some parents are unable or unwilling to come to the clinic in support of childhood testing, presumably for reasons of guilt (he later alludes to the mother's guilt as a possible explanation). The detection of a '46 XY karyotype' presents complex psychosocial issues about the girl's gender and identity. These issues are made all the more difficult by building the girl's character as an autonomous individual: 'bright, intelligent girl, planning to go to university, very articulate, had come to the clinic on her own'. The self-reflexive question 'how am I going to deal with this' is an effective rhetorical display of professional responsibility and uncertainty (we will examine these markers of uncertainty in more detail in the next section). The ethical dilemma is framed in terms of the following: how does the professional convey sensitive genetic information without undermining the adolescent's future autonomy? How does one tell a 17-year-old girl that she has male chromosomes?

The professional management of genetic disclosure is reported via contact with 'the GP'. Fortuitously ('by pure chance'), the GP is known to the Paediatrician as an 'ex-trainee' with a 'psychology' background. The use of reported speech recounts the scenario to the GP as a breach of routine practice ('she came to the clinic on her own'), therefore involving careful and sensitive disclosure ('these are big issues we've got to discuss'). The pronoun 'we' is also indicative that the professional burden of disclosure is now shared. There is also the issue of the parents' absence which warrants an account ('I'm not clear why the family aren't supporting her'). After 'a very constructive consultation', it transpires that the mother was originally tested during pregnancy: the results of amniocentesis revealed the 46 XY karyotype. The paediatrician engages in the reconstruction of past events in order to explain the parent's absence: the mother had 'known all along that she was meant to have a boy', but let the matter pass thinking 'they've made a mistake'. When the daughter does not develop normally she is 'completely unable to deal with it and unable to support her daughter in the appropriate way'. Thus, a psychosocial account of guilt and self-blame is produced to explain the parents' absence.

In this account of avoidance of parental responsibility, we detect the professional's apprehension to engage the child's autonomy without the support of parents. Furthermore, this absence usually requires some kind of accounting, that is, by casting a moral tale about the unfortunate consequences that occur when genetic disclosure is not performed within the family. So far, we have examined examples of ethical dilemmas which reconstruct the tensions between professionals, parents and children in matters of childhood testing. However, these cases also raise ambivalence about the professionals' role. Professional

ambivalence was often accounted for when denying parental demands for testing or when counselling seemed to be at odds with the kind of support that families were seeking.

Acknowledgement of uncertainty

In this section, we examine how professionals account for uncertainty via reconstructions of troubling events and cases. In Extract 6 we noted how ambivalence arises from being confronted by the autonomous adolescent. In the following example, a genetic counsellor (GC) is narrating a scenario (consistent with parental rights vis-à-vis child's autonomy) involving a 'very aggressive, pushy' father who 'presented himself at clinic demanding that [his] children have carrier testing' for cystic fibrosis. The researcher's opening question orients to GC's labelling of this particular case as a 'very difficult one':

Extract 7

R: Simply because he's demanding it, it makes it awkward for you or?

GC: I think not that he's demanding it so much, that's apparent (.) maybe it's because he's not doing what we think he should.

R: Right.

GC: Maybe it is as simple as that.

R: Right.

GC: But it's- I don't think he's taken time to recognise, looked at himself and his need for doing it.

R: Yes.

GC: It's a huge control issue.

R: I see.

GC: And why is that important to me? And I don't know because it is a bit of a struggle, there's part of me that wants him to recognise that what he's doing actually is about control, it's about his own anxiety and it actually isn't about the benefit of the children, is my belief (.) now I might be wrong.

R is probing whether the difficulty of consulting the 'demanding father' was a personal burden. The invitation to give a subjective account is denied in favour of a speculative explanation ('maybe...') of the father's non-compliance with professional goals (note the use of 'we' to index the professional voice in 'what we think he should do'). GC's account of the problem is professional rather than personal. The 'simple' explanation offered is the practical difficulty of counselling parents who place their own needs and concerns above the interests of their children. In GC's next turn, she proceeds to develop the father's character as having

failed to examine his own motivations for testing. GC infers that the father cannot distinguish his own needs from that of his children, thereby seeking to 'control' his fears via testing. In the last turn, GC actually performs self-examination by directing a (rhetorical) question to herself: 'And why is that important to me?'. In response to her own question she presents a professional self who is divided ('There's part of me...') and ambivalent ('I don't know'). The 'struggle' she refers to harks back to the practical difficulty of managing parental rights and responsibilities. The formulation 'and it *actually* isn't about the benefit of the children' subtly infers that the father would have argued this point: that it was precisely in the interests of the children that carrier testing should be performed. GC is claiming to know the father's *real* motivations (i.e. 'anxiety' and 'control') which are concealed by the child's best interests. There are, however, a number of devices which mitigate professional certainty about the father's actual or presumed internal states: the father's 'anxiety' is offered as an opinion ('my belief'), while her final remark ('now I might be wrong') is offered as a concession. Mitigating this psychological assessment of the father not only signals professional ambivalence, but displays humility about making absolute claims of character and motivation.

Professional uncertainty may also arise when professionals are sympathetic to the interests of parents. For instance, the same genetic counsellor (GC) explained a hypothetical case of a family requesting carrier testing under the circumstances where a child has 'died horribly' (from 'a metabolic problem') and the paediatrician 'has a close relationship with the family'. Uncertainty arises when two competing interests are at work: the professional wants to help the grieving family, but at the same time must refuse childhood testing on the grounds that children ought to decide for themselves. The dilemma of counselling a family who

request a test after losing a child is powerfully conveyed by contrasting family, professional and personal perspectives.

Extract 8

GC: Doing something is what you're trained to do, and then one has to say actually hang on a minute, not only have you lost a child and you feel you can give them this, we're actually going to say no, it's not a good idea because that's theirs to have for themselves, that's actually quite hard (.) you do- I do feel quite cruel sometimes

R: Why?

GC: Because- quite brutal even, because sometimes you can see that these people are- or where they are for probably the best possible reasons (.) and they- but they haven't thought it through and you have to-

R: And they don't know-

GC: Yeah, and they just want to do something.

R: Yeah.

GC: And you're saying well, actually I'm not going to let you because I'm going to make you sit and talk to me

Here, the counsellor is describing competing goals/intuitions of the professional role: the professional is 'trained' to help the grieving family by 'doing something', but is immediately checked by another voice ('and then one has to say actually hang on a minute'). The rhetorical purpose of this contrast is to signal that the right thing to do is sometimes counter-intuitive. The counsellor engages in effective contrast work to develop this tension: she sympathetically weighs the concerns of the grieving family ('not only have you lost a child') with her own power to grant such a test (note the personal '*you feel* you can give them this'), which is contrasted again with the professional voice ('*we're* actually going to say no'). The decision to deny testing requires an account by way of endorsing the child's autonomy ('because that's theirs to have for themselves'). And while, ethically speaking, this may be the right thing to do, the counsellor conveys ambivalence ('I do feel quite cruel sometimes') about – what may seem to the family – not 'doing something'. This tension between 'doing' and 'not doing' is developed in the remainder of the interaction. GC concedes that the family are requesting a test for 'the best possible reasons' (given the loss of their child), but explains that they have not considered the autonomy of their remaining children ('they haven't thought it through'). Not thinking it through is actually justification for counselling: a form of

doing something through talk and reflection. This is implicitly contrasted with the family's perspective, which views counselling as a form of 'non-action' or 'delaying' medical action. In the final turn, this tension is expressed more explicitly by preventing the family from 'doing something' (i.e. seeking a genetic test for their children), which is accounted for by the counselling perspective ('because I'm going to make you sit and talk to me').

So far, we have examined cases of professional uncertainty where parents seem to be making unreasonable demands or requests for childhood testing. In our final case below, we return to the scenario in Extract 1, where the dying mother has demanded that all five of her children be tested. Many of the practitioners we interviewed explained that parents often thought of testing as a means of eliminating, not confirming, genetic risk. Once this anomaly of judgement was pointed out most parents accepted arguments in favour of the child's autonomy. In rare cases, however, parents still persisted, in which case testing was a means of confirming parental fears that their children were indeed at risk. Here, the source of professional uncertainty is not the interpersonal difficulty of refusing a test, but how refusal may affect the children.

Extract 9

GC: This woman, in fact, she was fairly cluey, she knew that with FAP you can sometimes get bony changes in the face, and so she watched those kids and she'd feel their scalps to see if they had any bones, and she'd decided which children were already positive and which weren't and was treating them accordingly (.) she was also fairly upfront about behaving a bit differently towards the ones – and that was quite a dilemma for me, because I was thinking, well, she's already behaving differently on her basis of her assumptions about testing, are we actually doing harm by not testing because maybe it is better for her to treat the children appropriate to their genetic risk rather than this presupposition of what they had (.) on the other hand her assessment could have been quite accurate as well.

An important aspect of recounting this scenario is the framing of the mother's conduct towards her children. The characterisation of her perceptiveness ('she was fairly cluey') and her medical knowledge ('she knew ... you can sometimes get bony changes in the face') construct a moral profile of the anxious mother who has taken it upon herself to monitor and

diagnose her children. The potential harm of lay diagnosis is at first implied (and she decided which children were positive') and then developed more strongly when we are told that she 'was treating them accordingly' and 'behaving a bit differently towards the one's'. The genetic counsellor succeeds in orienting her concern to the children who may be needlessly subjected to the mother's medicalising behaviour. By the time GC signals 'a dilemma' we are urged to sympathise with her. In the account that follows, she takes us through her thinking: is it better to test knowing that the mother is treating (and possibly harming) the children on the basis of 'her assumptions about testing'? Note how she adopts the professional voice ('are *we* actually doing harm by not testing?') to display ethical reflection. Though GC does not talk about ethical principles as such, she is weighing up the lesser of two evils: balancing maleficence with the children's autonomy. Testing would mean that the mother could 'treat the children appropriate to their genetic risk'. As a display of balanced thinking, the counsellor also concedes that the mother might be 'accurate' given the testimony of her character.

In the overall accounting of this case, the counsellor foregrounds professional uncertainty by developing the character of the mother as a potential danger to the children, by adopting the perspective of the children, and by orienting to future (ethical) scenarios. All this facilitates a complex account which seeks to *justify* professional practice: 'That was a really difficult situation to deal with because really what she needed was counselling, and good counselling'. In the end the 'eldest child' tested negative as a carrier of FAP. Though delighted with the news, the mother is later heard to say 'Right, now I want the rest done'.

DISCUSSION/CONCLUSION

In the context of genetic services, it is true that an unusually high premium is placed on patient autonomy (Bosk, 1993) not simply as the right to choose but the *responsibility* to make complex choices about healthcare. These choices are further complicated when they involve the health and welfare of others for whom ‘rights’ (to know or not know) and ‘autonomy’ (the right or ability to choose) are ethical considerations. The genetic testing of children is one such area in which parental rights and responsibilities come into conflict over what constitutes the ‘best interests’ of the child. Another way of posing this dilemma is that professionals have a stake in protecting the child from the anxieties and curiosities of parents. There is, however, an additional problem which is particularly relevant to testing children: who should assess when and under what circumstances that children are endowed with the *capacity* to engage in autonomous decision-making (i.e. informed consent). Naturally, issues such as these are manifestly related to uncertainties and ambiguities of professional practice, leaving individual professionals to do ethical ‘boundary-work’ (Ehrich et al., 2006) in situated encounters.

We agree with Bower et al. (2002: 184) that interviews ‘yield more detailed descriptions of the types of ethical/professional situations encountered’ and our analytic themes certainly attest to the types of situations in which dilemmas over childhood testing emerge. For instance, the first three themes we uncovered – *juxtaposition of parental rights vis-à-vis child’s autonomy*, *elicitation of the child’s autonomy* and *avoidance of parental responsibility* – foreground the professional agenda concerned with the child’s right or ability to choose. In the first case, parents are critiqued for fulfilling their rights and wishes without properly considering the child’s point of view. This calls for professionals to adopt an advocacy position whereby the child’s voice is heard so that testing might be delayed until they are autonomous enough to decide for themselves. In the second case, when children are closer to

the age of majority, the issue becomes whether the professional can assess or elicit autonomy as the capacity to choose, given the extremely variable individual circumstances. Here, the professional must be satisfied that children can demonstrate capacity independently of parents. In the third case, the autonomous child is abandoned by the parents, which raises psychosocial concerns about guilt, failed risk communication, and familial support for complex decision-making.

While typologies are no doubt useful for categorising and anticipating professional dilemmas, we believe that analytic attention should also be given to the way that such categories are discursively communicated and constructed. In our analysis we have focussed on the rhetorical dimension of ethical/professional dilemmas: the way the professionals persuade and convince us that certain characters and events are problematic, and warrant reflection prior to intervention. The most significant device we found was the use of *contrast structures* to contest or endorse different states-of-affair. Contrast devices facilitate the moral positioning of actors to assign responsibility or blame. For instance, moral profiles of the 'pushy' mother, the 'aggressive' father, and the 'innocent' child are particularly effective in upgrading the seriousness of dilemmas and narrating cautionary tales: children should be treated as ends rather than means, parents have failed to 'think it through' the testing process and possible unintended consequences etc. Contrast devices are also constructed through the categorisation of events which justifies professional action. The counsellor's dilemma is more compelling, for instance, when parents are cast as 'demanding' rather than 'requesting' tests. Furthermore, contrast work is performed through the strategic recruitment of clients' voices, like the case of the 12-year-old child who declines testing despite the mother's coercive remarks (cf. Extract 3). Ethical explanations are more powerfully conveyed when the

contrastive nature of characters, voices and events are encoded to depict 'extreme case scenarios'. Such accounts, we believe, bolster the justificatory role of professional accounts.

The last of our four themes – *professional ambivalence* – must be treated separately from the others because it is not specifically a dilemma concerning parental rights or the child's autonomy, but a dilemma of professional conduct. As we have seen, professionals display ambivalence about the difficulties of counselling anxious parents ('And I don't know because it is a bit of a struggle'), denying testing to grieving families ('I do feel quite cruel sometimes'), or counselling the solitary teenager ('how am I going to deal with this?'). It is also worth noting that professionals were implicitly ambivalent about the application of ethical codes or principles on the one hand, while being explicitly ambivalent about counselling difficult or troubling cases on the other. This suggests that while the application of ethical codes is cited as a potential problem for professionals the codes themselves are not the main source of professional ambivalence. We believe that the unexpected contingencies and unintended consequences of clinical interactions with parents and children are the most troubling aspects of everyday professional practice. Even when professionals know what principle or code to implement, accomplishing it through talk is a practical, interactional difficulty.

This raises serious concerns about the utility of code-oriented ethics. As Edgar (1994) has remarked, ethical codes can lead to a situation which, over time, is detrimental to professional practice. For instance, most individuals apply codes to *justify* their actions as we have seen in the case of our thematic typologies (i.e. genetic professionals give accounts about deterring testing on the grounds of the child's autonomy). But codes also work to *restrict* how professionals account for their own behaviour. Conduct that falls outside these explanatory

frameworks are rendered unaccountable and therefore become silenced. This creates an institutional scenario where codes put the grounds of interpretation outside the scope of their own ethical criticism. In other words, codes of ethics tend to exclude or prohibit the innovatory potential of new interpretations about ethical/professional practice.

We suggest that accounts of professional ambivalence are a valuable source of interpretation because they go beyond mere justifications of ethical codes. They indicate that ethical dilemmas reside not in knowing *what* code to implement *when* but in *how* to accomplish professional ethics *through* interaction. In the context of childhood testing, professional ambivalence is symptomatic of the power relations that are manifest in difficult interactions with parents and children regarding access to genetic services. These dilemmas are suggestive that more attention is needed to facilitate 'interactional expertise' (Sarangi, 2005) as the basis of managing difficult and challenging encounters, including the competent performance of boundary-work. Future research should pay more attention to understand the way professional practitioners construct and share cases as useful illustrations of evidence-based, situated ethical practice.

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