

Title: Genetics professionals' experiences of facilitating parent/child communication through the Genetic Clinic

Running title: Facilitating parent/child communication through the Genetic Clinic

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Abstract

While guidelines advise genetic health professionals to support and encourage family communication about genetic risk, there can be professional uncertainty when advising parents about communication with children. We sought to explore genetic health professionals' views and experiences of facilitating parent/child communication in clinical practice, particularly in relation to adult-onset inherited conditions. Twenty three in-depth interviews were conducted with United Kingdom genetic health professionals. Thematic analysis identified four main themes: offer professional involvement, encourage early disclosure, take a limited role, and challenges. Overall, our findings demonstrate a wide variation in genetic health professionals approaches to the provision of disclosure advice to parents, ranging from professionals who offered their communication skills and expertise, to those who took a limited role and reflected they were struggling, or even felt stuck. Giving tailored advice to parents about the timing of disclosure i.e. when to tell children, was a particular challenge because of the variability in children's maturity and coping styles. Nevertheless, we identified a range of strategies which were drawn upon by participants to facilitate parent/child communication in the genetic clinic. In conclusion, study results indicate that this remains a challenging and sensitive area, in which genetics professionals express a need for more resources and the clinical time to undertake this work. Further research is needed to develop and evaluate interventions which assist parent/child communication about serious inherited conditions and to help develop professionals' confidence and skills in this area.

Key words: Genetic risk, family communication, inherited conditions, genetic clinic, genetic health professionals, adult-onset, communication, genetic counseling, parents

Introduction

While informing children about a genetic condition in the family is generally viewed as a parental responsibility (Forrest et al. 2007; McClellan et al. 2013; Riley et al. 2012), disclosure to children can be very difficult for parents (Forrest et al. 2003; Metcalfe et al. 2011). As a consequence, patients may seek support and assistance from genetic health professionals about how and when to tell their children (Eisler et al. 2016; Metcalfe et al. 2011). Given that a key aspect of genetics healthcare is to support and encourage family communication, it is expected that genetic health professionals will have these discussions with parents (McCarthy Veach et al. 2007; Mendes et al. 2016). However, there can be professional uncertainty about what disclosure advice to give parents, and concerns about the ethics of sharing genetic information with affected or at-risk children and young people (BMA 2007; Eisler et al. 2017; Ulph et al. 2010). Furthermore, there is little specific guidance about how professionals should support parents with such disclosure decisions (Forrest et al. 2007; Werner-Lin et al. 2018).

At present, genetic health professionals such as genetic counselors or clinical geneticists, can use a range of options to assist patients with family communication (e.g. psychoeducational guidance, discussion (and encouragement) about who to inform, sending letters to relatives, and written information). In relation to parent/child communication, Mendes et al. (2016) cite two specific strategies: (1) tailoring information to a child's age/developmental stage, and (2) eliciting parental views about how to tell children. However, there is a lack of evidence about how genetic health professionals actually implement these strategies in practice (Mendes et al. 2016), with recent studies demonstrating parents may even experience 'unsanctioned' disclosure in a genetics setting (i.e. feeling that health professionals have shared inappropriate information with their children) (Forrest Keenan et al. 2019). Furthermore, there are certain

circumstances which can raise particularly difficult and complex ethical questions, leading to ongoing debates about the extent to which genetic health professionals should be involved in alerting relatives of their risk (Clarke and Wallgren-Pettersson 2018). For example, what should professionals advise parents about communicating risk of adult-onset conditions such as Huntington's disease to children and young people, when no treatment is currently available (Clarke and Wallgren-Pettersson 2018; Dyer 2017).

In recent years, several studies have begun to develop interventions to help genetic health professionals facilitate parent/child communication about genetic information, within and outside of the genetic clinic setting (Eisler et al. 2016; Peshkin et al. 2010). In the United States, Peshkin et al.'s work (2010) describes the development of a Decision Support Intervention (or Decision Aid) to assist mothers telling adolescents about their risk of hereditary breast cancer. Their findings suggest that parents' knowledge and confidence were increased when this intervention was used in clinic with patients. More recently, the SPRinG collaborative (2016) has developed an intervention with families and genetic counselors, based on multi-family discussion groups (MFDGs) in psychiatric settings, to help parents talk with their children (<18 years) about living with an inherited condition. Initial results suggest participants found the groups "highly beneficial" and that the intervention had a positive impact on family functioning. The experiences of three genetic counselors who received training to deliver the intervention were also sought, and provided an illuminating account of their views about the institutional, logistical and professional barriers to implementation in the United Kingdom (UK) (Eisler et al. 2016). For example, financial constraints associated with the publically funded healthcare system in the UK were viewed as a key barrier to implementation given the difficulty to fund anything beyond standard clinical care. The logistical challenges of organising regular meetings with busy families who lived far away

from each other was also highlighted. In addition, the genetic counselors raised anxieties about managing families' emotions, describing their skills as focussed upon information giving "rather than therapy." However, the Reciprocal-Engagement Model of Genetic Counseling Practice acknowledges that both information giving and counseling models are integral to genetic counseling practice, with a key goal of practice being to understand a patient's family dynamics, communication and culture (Costa et al. 2018; McCarthy Veach et al. 2007).

Whilst a small body of work has begun to develop interventions to help facilitate parent/child communication about inherited conditions (Eisler et al. 2016; Peshkin et al. 2010; Werner-Lin et al. 2018), there is a need to understand more about how genetic health professionals actually support and assist parents in clinical genetics practice. This is important given ongoing debates about whose responsibility it is to disclose sensitive genetic risk information to relatives and a move in some countries towards increasing the responsibility and involvement of genetic health professionals (Derbez et al. 2017; Dheensa et al. 2016). For example, in France there have been recent changes to the law which may increase the obligation of professionals to ensure that genetic risk information has been passed on to family members (Clarke and Wallgren-Pettersson 2018). As such, the aim of the present study was to explore and describe genetic health professionals' views and experiences of facilitating parent/child communication through the genetic clinic, particularly in relation to adult-onset inherited conditions.

Methods

The qualitative data from this paper were generated from a CSO funded (Chief Scientist Office, Scotland) study which aimed to explore the 'sharing of information between parents and

children about genetic risk.’ The main aims of this larger study were to: (1) Explore the information needs of children, young people and young adults at risk of adult-onset hereditary disease; (2) Explore professional interactions with these young people and their parents and (3) Develop evidence based resources to help guide parents and professionals in sharing information with children and young people about genetic conditions. The study included: interviews with parents, children and genetic health professionals; clinic observations; and collaborations with patient groups to help develop resources for children and young people. Huntington’s disease and familial hypercholesterolaemia were the two main exemplars in the fieldwork with families and the resources developed by patient organisations, whilst genetic health professionals’ counseled patients affected by a range of serious inherited conditions. This paper reports the findings of interviews with genetic health professionals given that a secondary aim of the overall study was to gather the views and experiences of genetic health professionals about how they facilitate parent/child communication, particularly in relation to adult-onset inherited conditions. The study was approved by the North of Scotland Research Ethics Service (REC Ref: 11/AL/0146).

Inclusion and exclusion criteria

Professional participants were eligible for the study if they undertook genetic counseling with patients who attended a genetic clinic where cascade testing and/or disclosure to children was likely to be raised by the genetic health professional, or patient. Cascade testing uses index patients who have been diagnosed with the condition through genetic testing to alert at-risk relatives, in the hope that they too will also seek testing, especially when treatment is available (Finnie et al. 2012). We anticipated the clinicians to be mainly clinical geneticists or genetic counselors, but other health professionals working in a genetics service with specialist genetics training were also included. Similar to Clarke and Wallgren-Pettersson (2018), we refer to our

sample as genetic health professionals. We did not invite participants from all four genetic services in Scotland as we only had R&D permission to recruit from three.

Recruitment and sampling

Potential participants were recruited by ZM through staff lists at genetic services in Scotland between September 2011 and April 2013. The staff lists comprised genetic counselors, clinical geneticists and other health professionals working in the service with specialist training in genetics. Purposive sampling was used to generate as diverse a sample as possible (e.g. differences in length of experience and qualifications) (Clarke and Braun 2013), and to invite participants known to work with families affected by serious adult-onset conditions. Participants were sent an invitation letter and information leaflet asking them to contact the researcher (KFK) to participate. The information leaflet stated that the study was to explore the participant's background; views and experiences about facilitating family communication in clinical practice; experiences of supporting parents in sharing genetic information with their children and experiences of providing genetic information to children and young people at risk of inherited conditions. We also stated that any reports quoting their response would be anonymised. Twenty three participants who met the inclusion criteria were recruited. All participants had the opportunity to ask questions and gave signed written informed consent before participating.

Data collection

Semi-structured interviews were conducted face-to-face by KFK at participants' place of work (n= 21), except for two that were by phone. All interviews were recorded and fully transcribed with anonymity assured. The interviews lasted between 30-60 minutes and focussed on: views

of current guidance and the role of genetics health professionals in facilitating family communication about genetics; experiences of parent/child communication in clinic and being directive or non-directive; challenging cases; and any strategies or resources used to help parents. In addition, KFK asked all participants to describe any experiences of counseling patients affected by a serious adult-onset inherited condition but did not ask for specific disease examples.

Data analysis

Given the exploratory nature of this study, a qualitative inductive approach was chosen in order to explore the in-depth views and experiences of genetic health professionals. A thematic analysis was undertaken of the transcripts, using the constant comparison method (Guest et al. 2011; Strauss and Corbin 1990). The main themes and subthemes were identified by reading and re-reading the transcripts and coding the data according to the main approaches and strategies emerging from participant's accounts. Any differences or similarities between participant accounts were noted. KFK drew upon Strauss and Corbin's (1990) approach to the coding of qualitative data, using a system of open, axial and in-vivo coding. Open coding is the initial stage of analysis where each segment of the data is labelled interpretively, reflexively or literally (Mason 2002). In-vivo coding uses the words of a participant to name the code, giving participants a voice in the research process. Axial coding is a process of relating codes to each other using inductive and deductive reasoning (Strauss and Corbin 1990). This process was done manually on the transcripts using Microsoft Word. The different codes were grouped together to develop categories, along with a process of ongoing reflection about the main themes and subthemes within the data (Coffey and Atkinson 1996).

Data analysis was an iterative and ongoing process, which occurred throughout the fieldwork until it was felt that a point of data saturation was reached and no new major themes were identified (Strauss and Corbin 1990). Quotes were selected because they represented a typical response within a theme, or exemplified the theme particularly well. If only one person articulated a certain view, or experience, this is stated. We have chosen not to quantify the majority of the results because this is an exploratory descriptive study, although the number of participants in each main theme is given in order to indicate the extent of variability in the approaches, which were identified by the researchers.

Whilst there is much debate about the emergence versus forcing of data using a grounded inductive approach (Kelle 2005), the initial analysis was undertaken without referring to the literature and was presented at two conferences, although KFK was familiar with previous studies in this field. In the later stages of analysis and writing, the literature review was updated and the findings discussed in relation to studies on family communication about genetics (Atkinson et al. 2013, Forrest Keenen et al. 2009; Metcalfe et al. 2011; van den Nieuwenhoff et al. 2007) and the role of genetic health professionals in this area (Derbez et al., 2017; Eisler et al. 2017; Mendes et al. 2016; Ulph et al. 2010). In addition, KFK reread the whole dataset during the writing stage to review and readjust the initial presentation of results.

Results

The participants

In total, 23 interviews were conducted with genetic health professionals across Scotland, primarily genetic counselors (n= 10) and clinical geneticists (n=7), as well as six other health professionals with genetics training, e.g. nurse specialists and third sector workers (i.e. from

non-governmental and non-profit-making organizations). Nineteen participants were female and four male. All participants described their ethnicity as 'white'. The average length of the interviews was 40 minutes, with the minimum being 20 minutes and the maximum one hour. All participants had professional contact with parents and children affected by, or at risk of, a serious inherited condition. Two participants were excluded from further analysis because they worked for a charity in the third sector and did not see patients in a genetic clinic. The length of participants' experience in genetic counseling was also wide ranging, from those who were recently qualified (i.e. under two years) to those who had over 25 years of experience. In order to protect confidentiality, we refer to participants as either a clinical geneticist, genetic counselor or other health professional. All names have been withheld and identifiable details omitted or changed to protect confidentiality. We have also chosen not to present the clinician's speciality in a particular condition for this reason.

Overall, our analysis revealed four main themes from interviews with professionals about their views and experiences of facilitating parent/child communication in the genetic clinic. These were the following: (1) offer professional involvement; (2) encourage early disclosure; (3) take a limited role; and (4) challenges. The major themes and subthemes are summarized in Table 1. In some accounts, there was overlap between themes but we have categorized participants into the most prominent approach they described.

Offer professional involvement

A subgroup of participants (n=7) described using their professional communication skills and experience to reflect upon any disclosure issues with parents, and what may be best for them and their children. This approach could also involve offering to speak with children directly,

and in cases of nondisclosure or delayed disclosure, intervening through other routes or “chipping away.”

Professional help and advice with family communication

These participants presented themselves as highly confident in supporting parents with disclosure to children, offering their own communication skills and services to help with parent/child communication about genetics and wider family communication issues. These skills were viewed as a key aspect of their professional role, in contrast to patients who may not have the “same ability.” Participants described a sense of professional responsibility to offer patients help and advice with parent/child communication, but not in a forceful or “coercive” manner. For example:

“I think when we are referred parents... it’s up to us to make sure we try to help them to judge whether we could be helpful in their particular situation. And not coerce them or convince them, but just help them to make that judgement themselves. Because I don’t think it’s fair on us to assume that everyone has the same ability to actually have those communication skills that we - in theory - have.” (P7, Clinical Geneticist, 20+ years of experience)

“They would ask me how do I tell them? Do I say straight away you’re at 50% risk, or what’s wrong with grandpa, or how much do you know? Or how much should I tell them? You know they would ask me, should I say these things? And so, depending on the age of the child, I would give what I hoped was appropriate advice.” (P1, Clinical Geneticist, 20+ years of experience)

“Some of the information is very complex and parents sit back and say oh gosh what do I explain to my children?...I would discuss well what about your diagnosis, how did you discuss that? What do your children know about that? How did they react? What sort of information did you [give]...did they ask for? Did they ask for anything, was it simply that you were giving that information? What did the parents feel that the children’s level of understanding of it is? (P16, Genetic Counselor, 10+ years of experience)

Offer to help tell children

In a few cases, professionals stated that they also offer to inform a patient’s children about the family condition and risk of inheritance themselves, inviting parents to bring their child/children to the genetic clinic.

“And I say to parents ... if you feel when you get the letter that actually you wouldn’t feel comfortable explaining it, or trying to talk about it, my role is to support families not just individuals ... So I would always offer them the option - if you wanted to bring your children up we could sit and go over it.” (P16, Genetic Counselor, 10+ years of experience)

One participant acknowledged that offering to help tell a patient’s children had become a key part of their routine, developing this strategy after observing the detrimental impact of children not being told about the family disease until adulthood, and the “burden” they felt parents experienced around telling.

“I developed a routine of offering to help to tell their children ... because I was seeing in adults the results of children not being fully informed... Parents would come ... and want to let me

deal with it... and I decided I would lift that burden from them” (P1, Clinical Geneticist, 20+ years of experience).

This participant also went on to describe how difficult the offer to help tell a patient’s children could be in practice, and the strategies they devised:

“Some parents would say ‘I’m planning to tell Mary or John next week, can you have an appointment ready so that I can bring them that afternoon to see you here?’ The practicalities were difficult. So I ended up seeing them at the end of a clinic or the beginning of a clinic - end of a clinic is better because these went on for a time some times.” (P1, Clinical Geneticist, 20+ years of experience)

Another participant also asserted that the standard counseling tools were inappropriate for using with children and the need to present information in a simpler format:

“Obviously you can’t just use the normal counseling aids because they are too complicated, but just quickly thinking ahead, how to bring it down to the way an 11 year old would understand” (P4, Genetic Counselor, 15+ years of experience)

Chip away

If parents were reluctant to tell their children, some professionals described a strategy of “chipping away”, which involved asking parents at all follow-up appointments about whether they had informed their children, and potentially involving other professionals. In addition, participants stressed that this process could take months, or even years, of work with families.

“If they’re coming back recurrently...there is an opportunity every time they come back to say have you told these children yet?” (P20, Clinical Geneticist, 20+ years of experience)

“I think asking the neurologist - who may see them every six months - to kind of chip away at it... and often I think as a process... over a few years... you can work through these difficulties, and people are at a wee bit different place in their head.” (P15, Clinical Geneticist, 15+ years of experience)

Use the best route

One participant also acknowledged that there may be times when parents were not the best person in a family to speak with a child about the inherited condition. In these circumstances, other family members may have a closer relationship with a child and be a more appropriate informant. For example:

“We use relatives [to tell] ... So where I’ve had a parent saying I don’t think they’ll want to be seen, I’ve then seen a sibling and said now will you please check with your other sibling whether they want to be seen, just in case. Because you’ll even find uncles who say, ‘look I speak to Jimmy all the time because he doesn’t get on with his dad.’ And trying to do that sensitively without informing too much of the family ... You just have to use the best route that’s available.” (P7, Clinical Geneticist, 20+ years of experience)

Encourage early disclosure

A second group of participant's (n=7) described a more generic approach in their discussions with parents, encouraging them to tell their children about any family history and personal risk from an early age - albeit in an incremental and "non-alarmist" manner.

Advocate early disclosure to children

These participant's focussed upon experiences of advocating early disclosure to children and young people about their family history, stressing a belief in the benefits of early disclosure versus the harms of concealment. When speaking with parents, participants outlined the potential harms of nondisclosure, such as: children feeling excluded, guilt, blame, anger, fear, as well as the potential for misunderstanding and misinformation, probing parents about the family context.

"I say to them quite bluntly - in my experience most people will find that it's easier if they include their children from the word go. Because you have to think about how your children will react if you wait until they're adults, that children are much more accepting of these things than you might think, and they will know that they are being excluded from something, they won't know what it is and they will feel personally responsible and guilty and bad, whereas if you include them they'll realise it's not their fault, and they are important enough to be included in the family ... and they grow up with the knowledge, so it's not as scary when the time comes." (P8, other health professional, 20+ years of experience)

"I've found... if they don't tell children and they then find out [as adults] that can cause problems in their relationship, I'm quite clear about that, I stress that quite strongly to the parent." (P21, Genetic Counselor, 10+ years of experience)

Incremental approach

At the same time, participants also stressed the potential harm of giving children “all of the information” or “adult stuff” – still advocating early disclosure but using an incremental, phased approach, which avoids children being told too much, or too little.

“I’m a great believer in that children do not need more information, or they do not need to be told adult stuff before they need, before they’re adults. I think as a society that’s what we’re inclined to do now... You give them all of the information ... I don’t think you need to do that. But I equally don’t believe that you need to hide stuff either. You can inform them throughout their life.” (P9, Genetic Counselor, 15+ years of experience)

Alert but don’t alarm

In relation to adult-onset conditions such as hereditary breast/ovarian cancer, several participants advocated that parents should inform young people about their risk, but did not want to cause undue alarm. As a result, they discouraged the uptake of predictive testing when there was no imminent risk nor age appropriate treatment, and openly acknowledged how directive this may seem.

“The teenagers tend mostly not to come on their own, they tend to come with their mum ... I tend to be quite reassuring when they’re very young. You know, this isn’t something that you need to worry about now ... Because I worry about causing huge anxiety in teenagers. And I stress - my message is they need to come back... They need to be aware, but not to be anxious

at 17 about a family history of breast cancer... And I think my job is to get the message across without being over-alarmist.” (P6, Genetic Nurse Counselor, 15+ years of experience)

“I’ve seen youngsters about the age of 18 who wanted a gene test, and I suppose... I was extremely directive about trying to talk them out of it. Saying there’s no rush, you’ve got plenty of time, come back and see me.” (P8, other health professional, 20+ years of experience)

Limited role

A third subgroup (n=7) described a more limited role in facilitating parent/child communication. Some experienced difficulties in giving advice to parents, whereas others described a less interventionist approach, and/or a belief that it is a parent’s responsibility to inform their children.

Difficult to give advice to parents

Whilst it was acknowledged that patients often seek advice about parent/child communication during genetic clinic appointments, a few participants admitted that their professional response was limited. These participants described how difficult they found it to give advice to parents, and in contrast to the more probing questions described above, only gave general advice such as “be honest” and initiate discussions when a child asks. Some also advised parents to seek further information and guidance from the third sector e.g. disease specific charities.

“Well often parents ask ... and I always find that a very difficult question to answer because it’s a very individual thing... So I find it difficult to give advice to parents who ask ... I tend to

say things like 'oh well, just be honest when they start asking questions' ... There's a limit to what you can do... I mean the other place that I often suggest families can get support and advice is the patient support groups.” (P3, Clinical Geneticist, 5+ years of experience)

This participant went on to describe the “nebulous” nature of providing risk information about adult-onset conditions to children and parents, which he found more challenging to discuss than with a patient who had a definitive diagnosis, and also difficult to assess in terms of patient understanding:

“Somebody who is ill or has something, it's a bit different to somebody who is well and is coming for a test or to find out if they're a carrier ... that does lead to a different perspective for the consultation, because you're talking about risks for themselves in the future, or for future children, but at that point it's not directly impacting on them, it's a bit more nebulous and you don't know how much they really have taken it on board.” (P3, Clinical Geneticist, 5 + years of experience).

Parental responsibility

A few participants asserted that the “duty” to inform children was a parental role, in contrast to offering professional help to tell children directly, or using different routes. The process of managing disclosure was viewed as an aspect of parenting itself, with one participant advising parents to integrate discussions about their family history into “everyday conversations”.

“Well I’ve always left it in the parents’ hands and said you know it’s... it’s the sort of thing you do as you’re going along with your parenting and say ‘everybody’s a bit different ...and in our family there’s this, but when you’re older you can go and find out for yourself. I would say this is something to just discuss as they’re growing up you know? Like you talk about your family, and differences between people, just make it part of everyday conversations.” (P12, Clinical Geneticist, 5+ years of experience)

“Mostly the conversations that I have are with the parents and I tend to leave the...the duty if you like, of translating that into something that their child can understand to the parents, than try to open up a dialogue with the child themselves... My own inclination is not to get heavily involved.” (P17, Clinical Geneticist, 20+ years of experience)

Be guided by parents

Some participants also asserted that they would follow their patient’s views about disclosure to children, unless there were “extreme circumstances”. Several reasons were cited for being “guided by the parents” which included avoiding professional/patient conflict and a belief that children would usually find out through “the passage of time.”

“I’d be guided by the parents, the last thing I would want to do is have a conflict with the parents - except under extreme circumstances. Sometimes...it’s taken a wee while to get around it, and I think with the passage of time one does ... I think if you let things be usually it gets out.” (P17, Clinical Geneticist, 20+ years of experience).

“I mean I think parents know their children best and they know...they have a much better idea of how they are likely to react, so being guided by parents when they think the child is ready.”

(P2, other health professional, 20+ years of experience)

Challenges

All three groups of participants, i.e. clinical geneticists, genetic counselors and other health professionals with genetics training, described challenges in facilitating parent child/communication, irrespective of the different approaches outlined above.

Individual differences in children

Individual differences in children’s maturity and coping mechanisms were cited as two main reasons for there being difficulties in advising parents, as well as the uniqueness of each family’s circumstances. In addition, some participants felt they could not advise parents about a child whom they had not met. Given the potential to do harm, one experienced participant asserted a belief that “lots” of genetic health professionals avoid discussing disclosure issues with parents in any depth, asserting a need for more information to support professionals in this area.

“You go to meetings and you hear the child who is now the young adult standing up and saying ‘I’m so glad I knew about this condition and its impact on the family, it’s normalised’ but you also hear the young person who’s now a teenager, or early adult, and will say ‘I wish I’d never known! It’s ruined my life!’ So we don’t know the uniqueness of the situation and to then try and make judgments and decisions about trying to support each family, about informing young

people and children... that's part of the reason lots of professionals just don't go there!... And so we had one of our meetings ... and this big discussion about the need for information to support clinicians, nurses, allied health professionals... the need to give them more confidence and better understanding of how to better inform and support whole families with this information.” (P13, other health professional, 15+ years of experience).

When is the right time to tell children?

A few participants reflected that they struggled - and one even felt “stuck” - when giving parents advice about when to tell children about the risk of serious adult-onset conditions such as Huntington's disease or hereditary breast/ovarian cancer. This participant asserted that as an experienced genetics professional she felt she should “know all this” but admitted that the question of when to tell children was a difficult issue, and hard to give advice about:

“You say ‘we're there to support you, we're happy to discuss it with them’ but when is the right time? It's a very difficult question, when is the right time to tell my son and daughter? ... If I'm being honest I sometimes feel a wee bit stuck - and I know that I probably shouldn't be saying that, that's not the right answer but...sometimes you do feel very stuck and you think well I don't really know when is the right time ... And then I'm meant to...know all this!” (P18, Genetic Counselor, 10+ years of experience).

Parent versus child's needs

Participants also acknowledged that there could be tensions between the needs of parents versus those of children, and further challenges when parents preferred concealment and were actively choosing not to tell. In these circumstances, some participants advocated additional genetic

counseling and a period of ‘emotion work’ e.g. around grief and loss, giving parents time to “work through” a bereavement or test result, before they “involve the children.” One participant asserted that there are “no clear cut answers.”

“There’s lots of people who would rather hide it away until they *need* to know, or even refuse to tell them... We’ve had people in here who are grieving who just can’t bear to let them know... And it can take a few years for the parents to get to the point where they would involve the children ... [In one case] We had seen them several times, and it took, it literally took a few years to even bring them [the children] in. So there’s no clear cut answers.” (P4, Genetic Nurse Counselor, 15+ years of experience)

“The thing I find most difficult is parents who do not wish to tell their children. That’s the challenging one and how hard...how hard do you push?... If there’s nothing you can do then I don’t feel so inclined to push.” (P15, Clinical Geneticist, 15+ years of experience)

Difficult areas

Several participants asserted that there are ongoing ethical challenges in particular areas, e.g. adoption, or specific circumstances when they would choose to be directive, or may even need to consider breaking patient confidentiality to inform an unknowing family member of their risk. For example:

“Adoption ... is a very difficult area and it is far from resolved... What you do about risk of Huntington’s and an adopted child?” (P1, Clinical Geneticist, 20+ years of experience)

“Duchenne Muscular Dystrophy risks...that would be seen as a disorder where you really should try quite hard to make sure that the ladies in the family are informed.” (P17, Clinical Geneticist, 20+ years of experience).

“You really are unfortunate in those cases where there really is no way of making sure the family is informed. But there will be cases, there are people who are overseas who contact you and haven’t had a full chance to get to know their family. There are the adoption cases.” (P7, Clinical Geneticist, 20+ years of experience)

Discussion

This paper is the first to explore genetic health professionals’ in-depth views and experiences of facilitating parent/child communication through the genetic clinic, with a particular focus upon sharing information about serious adult-onset inherited conditions. A thematic analysis was undertaken which identified four main themes from professionals’ accounts: (1) offer professional intervention; (2) encourage early disclosure; (3) take a limited role; and (4) challenges.

Overall, our findings demonstrate a wide variation in genetic health professionals’ approaches to the provision of disclosure advice to parents, ranging from professionals who offered their communication skills and expertise, to those who took a limited role and reflected they were struggling or even felt stuck. Participants who offered their professional involvement and intervened in parent/child communication through the genetic clinic, drew upon a range of strategies similar to those outlined by Mendes et al (2016), with some explicitly offering to

help tell children directly, whereas others took a less interventionist approach. Nevertheless, this aspect of patient/professional communication was viewed as an integral part of the role of a genetics health professional, supporting current guidance and models of genetic counseling practice (McCarthy Veach et al. 2007; Riley et al. 2012). In particular, we found a subgroup of participants who advocated a discourse of early disclosure to children, citing the findings of empirical research on parent/child communication about inherited conditions, and their own clinical observations as reasons for this practice. In these circumstances, participants asserted that children “should know” about the family condition, stressing a belief that keeping secrets, or hiding information, would have a negative impact on parent/child relations and disempower young people.

Of particular interest were participants who offered to tell children themselves in the genetic clinic - with or without a parent present – in order to “lift the burden” of telling from parents and take the opportunity to provide accurate information directly to children and young people. Interestingly, this is in contrast to the findings of a recent study where one genetic counselor did not view “sitting down and telling children” as part of her role (Eisler et al. 2017). Other participants in our study held similar views, highlighting the range of attitudes about the role of genetic health professionals’ and the variability of clinical practice in this area. In addition, a few participants asserted that early disclosure may not always be appropriate, supporting data from studies where young people felt they had been told “too much” (Forrest Keenan et al. 2009) and sociological work on genetic risk questioning the reality of the “open family” (Atkinson et al. 2013). For some conditions, participants also made a distinction between parents making children aware i.e. “alerting” young people of any risk (van den Nieuwenhoff et al. 2007), versus seeking treatment or genetic testing at an early age when no imminent action was needed (e.g. Hereditary Breast/Ovarian Cancer).

Another key theme in participant's accounts was the use of professional communication skills to undertake family communication "work" with some participants being more directive than others. Those who adopted a more limited role, stressed that they would be "guided by the parents" and a belief that family communication issues would generally be resolved "through the passage of time," supporting a model of genetic counseling practice which prioritises patient autonomy, resilience, patient/counselor relationships (McCarthy Veach et al. 2007) and nondirectiveness, as well as other more theoretical work on families living with genetic risk (Atkinson et al. 2013). It was also acknowledged that some individuals or couples may need more time and additional genetic counseling, before they are "ready" to discuss or reflect upon telling their children, particularly parents experiencing grief and loss, or those who have received an unfavourable test result (Forrest et al. 2003; Frich et al. 2006; van den Nieuwenhoff 2007). Thus, participants asserted the need for specific clinic time to undertake family communication work and more child-friendly "counseling aids", which invariably has cost and resource implications (Eisler et al. 2017). Nevertheless, it was not uncommon for there to be a tension between supporting a patient's autonomy and empathising with parent's emotions, versus a child's right to know (e.g. to make key life decisions and aid their developing identity) (Forrest et al. 2003; Metcalfe et al. 2011).

For those who considered using "different routes" participants had experienced the complexity of family dynamics and interpersonal relationships between parents and children, leading them to assert that parents may not always be the "best" person to speak with their children about an inherited condition. However, it was acknowledged that this strategy may raise considerable ethical challenges when trying to balance the rights of patients (to confidentiality) with the

rights of (unknowing) relatives (Lucassen and Gilbar 2018). As a consequence, participants concluded that there would always be difficult areas and “extreme circumstances”, for example, adoption and Huntington’s disease, which engender ongoing debates and ethical tensions (Bombard et al. 2012). From a broader perspective, the passage of time was also highlighted as important in relation to changing family roles and levels of communication by those “chipping away” or taking a more limited role, supporting previous research which demonstrates the need for genetic health professionals to be aware of the changing nature of parent/child communication about genetic risk at different life stages, e.g. after a young person’s predictive test result (Brouwer-DudokdeWit, et al. 2002; Forrest Keenan et al. 2015).

Taken together, our findings suggest that many participants used their clinical judgement in individualised discussions with parents – and young people – accepting that there may be ambiguity and uncertainty in many cases, suggesting that best practice may occur when practitioners use the approach which is most congruent with their training and personal style (LeRoy et al. 2010). Furthermore, whilst we categorised professionals according to the approach which was most prominent in their account, some participants fitted into more than one theme, and also experienced changes over time. For example, those who advocated professional involvement and offered to tell children themselves may have begun their career taking a more limited approach, drawing attention to the importance of professional flexibility, trial and error, and the uncertainties inherent in this area.

Our findings also highlight participant accounts where the focus was upon professionals encouraging parents to tell their children, in contrast to offering the use of ones’ professional communication skills to help parents reflect upon family dynamics (Mendes et al. 2016), or professionals offering to tell children directly. As such, disclosure to children about inherited

conditions was viewed as an aspect of parenting in itself, similar to parents educating children about other sensitive issues such as sexual health (Walker 2007), with the implication that managing early disclosure to children, albeit in an incremental manner, demonstrates “good” parenting. One limitation of this approach is the potential to blame parents in cases of non-disclosure, or when disclosure is delayed, and inflict damage on patient/professional relationships. Thus, whilst family communication about genetic risk may be viewed by some professionals as a more personal and family affair (Hallowell et al. 2005; Rauscher, et al. 2015), it is nevertheless considered an integral aspect of genetic counseling and long term preventative genetic medicine (Riley 2012). In light of this, some countries have increased the responsibility of health professionals’ duty to inform at-risk relatives (Derbez et al. 2017) and others advocate the use of more direct clinic contact versus family contact methods, particularly when treatment and/or preventative options are available (Newson and Humphries 2005). In our study, genetic health professionals drew upon a range of approaches when facilitating parent/child communication, which at one end of the spectrum was overtly directive and at the other end less directive - working with parents to reflect upon what is best for them, and in the middle was a more encouraging/nudging approach.

Another important finding was a subgroup of professionals who reflected upon their difficulties in providing advice to parents about disclosure to children, but also acknowledged that parents do seek disclosure advice. Similar to previous studies (Ulph et al. 2010), parental requests for guidance about when to tell children was felt to be a particularly difficult issue, with some participants reflecting that they struggled and gave limited advice. We identified several barriers to providing parents with disclosure support, particularly when this related to adult-onset conditions, such as: difficulties in assessing children’s maturity, individual differences in children’s coping and the uncertainty of much predictive genetic risk

information, all of which were compounded when children were not known to the service. As a consequence, our findings suggest that there are missed opportunities to provide relevant advice and support to parents in the genetic clinic, with strategies for improvement discussed in the practice implications below.

In other sensitive client/professional areas the concept of being “stuck” is a well-known phenomenon (Pack 2014). Various mechanisms are available to support and guide genetic health professionals, for example counseling supervision, which is a mandatory requirement for registered genetic counselors in the United Kingdom (UK Genetic Counselor Registration Board) and the use of a psychologist in one-to-one and/or group counseling supervision, an initiative which is used in some UK genetic centres (personal communication with Dr Rhona Macleod, Manchester Centre for Genomic Medicine). Recent studies also demonstrate that family communication interventions such as multi-family discussion groups can be undertaken, bringing together family members affected by a range of conditions facilitated by genetic counselors outside of the genetic clinic in group settings, although specific training and working out of hours was required (Eisler et al. 2016). In addition, we identified multiple strategies which our participants drew upon to promote effective parent/child communication in clinic which we outline below.

Implications for practice

Our study draws attention to the importance of seeking parental views about how and when (and indeed whether) to tell children about an inherited genetic condition, and parents experiences of disclosure themselves. Genetic health professionals should consider offering to talk directly with a patient’s children about their risk (with or without a parent present),

providing they feel confident to do so. Importantly, genetic health professionals should consider the need for additional counseling with parents before disclosure to children, e.g. around grief or loss, the results of a predictive test and the parents' experience with these issues. After parental disclosure, we recommend that parents are offered access to a follow-up appointment as soon as possible for themselves - and their children - if desired. In any subsequent follow up appointments there is the opportunity to enquire if parents have alerted children of their risk, and to suggest opportunities for disclosure. In addition, whilst there may be benefits of early disclosure to children, we recommend that there is exploration and discussion of an individual child's maturity, developmental stage and coping strategies in order to assess readiness. In some family circumstances, it may be advisable to consider using different routes if necessary (e.g. other relatives or healthcare professionals), although this will depend upon confidentiality and the particular family context. It may also be helpful to liaise with third sector organisations about any family communication resources they publish for specific inherited conditions (e.g. the Huntington's Disease Youth Organisation). Lastly, we recommend considering the use of novel family communication interventions and psychotherapeutic approaches to working with families (e.g. Multi Family Discussion Groups; cf. Eisler et al. 2016, 2017), although this may be dependent upon time and financial resources.

Study limitations

A limit of the study is the small sample size recruited from three genetic services in Scotland, which may not be able to be extrapolated to the wider population of genetic health professionals. However, 23 participants is an acceptable number for an in depth qualitative study. In addition, we were able to promise anonymity to participants, some of whom may have been more guarded during the interviews if we had generated accounts from one single centre.

The use of phone interviews may also have restricted the data which was generated, as both of those interviews were noticeably shorter with participants giving less in-depth responses.

A further potential limitation is that the interviews were conducted from 2011-2013, and aspects of the counseling and research context may be different now, including the availability of disease and age specific literature for families, particularly from the third sector e.g. HDYO and Heart-UK. However, there is still little guidance for professionals about helping parents with these difficult conversations in the genetic clinic, and the fundamental issues that our research addressed remain (e.g. Eisler et al., 2017). In the absence of comparable research, our data and analysis remain highly relevant.

Research recommendations

Overall, there was a strong sense in participant accounts of each case being unique on the one hand, while on the other hand professionals were seeking some kind of minimal standard of procedures or guidance. In this context, it would be useful to undertake further research on the development, implementation and acceptability of decision aid tools, which encompass age appropriate disclosure guidance to facilitate parent/child communication about genetic risk. Future research should also explore the extent to which the variation in approaches used by genetic health professionals is influenced by different professional backgrounds and expertise, as well as what different specialities could bring to this area. Future research should also include genetic health professionals who work in the third sector.

Conclusions

Overall, our findings demonstrate a wide variation in genetic health professionals' approaches to the provision of disclosure advice to parents, ranging from professionals who offered their communication skills and expertise, to those who took a limited role and reflected they were struggling or even felt stuck. Giving tailored advice to parents about the timing of disclosure (i.e. when to tell children), could be a particular challenge because of the variability in children's maturity and coping styles. Professionals were confident in their disclosure advice when they drew upon a discourse of early and open disclosure, which was viewed as more beneficial to children than concealment or delayed disclosure. However, some participants were more discerning in their approach, preferring to assess the individual, familial, social and disease context, and tailor their approach accordingly. The ability to accept uncertainty and trust one's clinical judgement was an important aspect of greater professional confidence and self-assurance. Nevertheless, this remains a challenging and sensitive area in which genetic health professionals express a need for more resources and the clinical time to undertake this work. Given the importance of this issue to patients, future research is needed to develop and evaluate interventions which assist parent/child communication about serious inherited conditions, and help develop professionals' confidence and skills in this area.

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Compliance with Ethical Standards

Conflict of Interest Karen Forrest Keenan, Lorna McKee and Zosia Miedzybrodzka declare that they have no conflict of interest.

Human Subjects and Informed Consent All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

Animal Studies No animal studies were carried out by the authors for this article.

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Table 1. Main themes and sub-themes

Offer professional involvement	Professional help and advice with family communication; Offer to help tell children; Chip away; Use best route
Encourage early disclosure	Advocate early disclosure to children; Incremental approach; Alert but don't alarm
Limited role	Difficult to give advice to parents; Parental responsibility to tell; Be guided by parents
Challenges	When is right time to tell children?; Individual differences in children; Parents versus children's needs; Difficult areas