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ORIGINAL RESEARCH

"They Just Want to Know" - Genetic Health Professionals' Beliefs About Why Parents Want to Know their Child's Carrier Status

Danya F. Vears[1,2,3] · **Clare Delany**[4,5] · **John Massie**[3,4,6,7] · **Lynn Gillam**[2,4]

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Abstract In the context of a child being diagnosed with a genetic condition, reports from both parents and health professionals suggest many genetic health professionals are reluctant to provide carrier testing for unaffected siblings, despite the lack of evidence of harm. We propose that genetic health professionals' understandings of why parents want to have their children tested may contribute to their reluctance to test. We draw on interviews with 17 genetic health professionals, reporting their beliefs about parents' motivations for testing and their intentions to communicate results to their children. Data were analyzed using inductive content analysis. Genetic health professionals reported attributions that contrasted with reasons parents actually report. These disparities fall into two categories: 1) attributing reasons that parents do not themselves report (i.e. for reassurance about their child's health), and 2) not recognizing the reasons that parents actually do report for wanting testing (i.e. to communicate the information to their child). By identifying that genetic health professionals may be misattributing reasons to parents for desiring their child"s carrier status, they may be missing an opportunity to assist parents to make decisions that are in line with their values and the best interests of the family.

Keywords Genetic testing · Carrier testing · Children, parenting · Gatekeeping · Genetic counseling · Communication · Disclosure

✉ Danya F. Vears
danya.vears@kuleuven.be

1 Center for Biomedical Ethics and Law, Department of Public Health and Primary Care, KU Leuven, Kapucijnenvoer 35, 3000 Leuven, Belgium

2 Centre for Health Equity, Melbourne School of Population and Global Health, University of Melbourne, Parkville, Australia

3 Murdoch Childrens Research Institute, Parkville, Australia

4 Children's Bioethics Centre, Royal Children's Hospital, Parkville, Australia

5 Department of Medical Education, Melbourne Medical School, University of Melbourne, Parkville, Australia

6 Department of Respiratory Medicine, Royal Children's Hospital, Parkville, Australia

7 Department of Paediatrics, University of Melbourne, Parkville, Australia

Introduction

When a child is diagnosed with a genetic condition, some parents want to know whether their other unaffected children are carriers of the condition (Balfour-Lynn et al. 1995; Barnes 1998; Brunger et al. 2000; Fanos and Mackintosh 1999; Vears et al. 2016a). However the decision about whether genetic carrier testing in children should be performed may be contested, with genetic health professionals and parents holding different views. The majority of international guidelines which address carrier testing in children recommend delaying testing until the child either reaches the age of majority or has the capacity to make an autonomous decision about testing (Borry et al. 2006; Botkin et al. 2015; Committee on Bioethics, Committee on Genetics, and American College of Medical Genetics and Genomics Social Ethical and Legal Issues Committee 2013; Human Genetic Society of Australasia 2008; Lucassen et al. 2010; Ross et al. 2013).

These recommendations are based on a range of concerns, primarily for the child, which correspond with a number of ethical principles. This often includes reference to the desire for beneficence where guidelines propose that as carrier testing provides no medical benefit in childhood, it should be

avoided. They also draw on aspects relating to non-maleficence, including concerns for psychological or social harm to the child, which may result from their parents obtaining this information about them, and misunderstanding or misusing it. And, perhaps most commonly, they make heavy reference to autonomy and paternalism, stating that providing carrier testing, and allowing parents to make this decision on their child's behalf, removes the child's right to decide whether they want testing performed when they are capable of doing so (American Medical Association 1995; American Society of Human Genetics Board of Directors and American College of Medical Genetics Board of Directors 1995; British Medical Association 1998; Clarke 1994; Committee for Public Relations and Ethical Issues of the German Society of Human Genetics 1995; Nelson et al. 2001; Ross et al. 2013; The Japan Society of Human Genetics, Council Committee of Ethics, et al. 2001).

However, these concerns are based on opinions or anecdotal experiences of health professionals, rather than evidence. Systematic review of the literature does not support the claim that there is harm from carrier testing in childhood (Vears and Metcalfe 2015; Wade et al. 2010). In addition, the risk of parental misunderstanding may be over-estimated. Carriers are now more commonly identified in childhood through newborn screening, and societal understandings of genetics are far better than in the past, particularly in children and young adults (British Medical Association Ethics Department 2012). For these reasons, The British Medical Association (BMA) revised their guidelines in 2012 to allow carrier testing for children if parents have had genetic counseling and there is no likelihood of harm (British Medical Association Ethics Department 2012).

Some parents already receive carrier results for their unaffected children in the context of another child being diagnosed with a genetic condition (Balfour-Lynn et al. 1995; Lavery 1998; McConkie-Rosell et al. 1999; Meldrum et al. 2007; Vears et al. 2016a), although reports from both parents and health professionals suggest that practices vary (Borry et al. 2007; Fryer 2000; Multhaupt-Buell et al. 2007; Noke et al. 2015; Vears and Metcalfe 2015). A study by Noke et al. 2015 in the UK showed that of the 25 health professionals interviewed, 16 (64%) recommended parents have carrier testing performed for the older siblings following the diagnosis of a child with sickle cell disease, with only 6 (24%) discouraging testing. This is in contrast to our previous report of the interviews we conducted with genetic counselors and clinical geneticists in Australia (Vears et al. 2015). In our study, while some of the Australian health professionals stated that they facilitate carrier testing in children if parents persist with their requests, all the participants indicated that they initially discourage carrier testing in children, with some pre-emptively recommending against it (Vears et al. 2015). This accords with other studies which have identified that although genetic health professionals are willing to facilitate carrier testing in children, this is by far the minority (Borry et al. 2007; Fryer 2000; Multhaupt-Buell et al. 2007).

Interestingly, studies suggest that genetic health professionals place little importance on the guidelines when making decisions about whether carrier testing should be performed during childhood (Noke et al. 2015; Vears et al. 2015). Yet they seem reluctant to perform carrier testing in children, despite the lack of evidence of harm. There is a small body of literature examining the interpretation and reasoning health professionals are using in these clinical situations. Studies from the UK and Australia, including our previous report, identified that genetic health professionals focus on preservation of the child's future autonomy, the potential reproductive and medical implications, and parental anxiety when making decisions about testing unaffected siblings (Noke et al. 2015; Vears et al. 2015).

In this paper, we take a somewhat different approach. We focus on another aspect which we believe may influence genetic health professionals' reluctance to perform carrier testing for children – their understanding of why parents want to have their children tested and what the parents intend to do with the information. This exploration is important given that genetic health professionals are effectively the gatekeepers to genetic testing for these parents and their interpretations and ethical analysis of risks and benefits are likely to shape their responses to parents' requests.

To explore this question, we draw on our interviews with genetic health professionals, reporting their beliefs about two matters: 1) why parents want to know their child's carrier status, and 2) parents' intentions to communicate carrier results to their children.

Methodology

Design and Participants

This study utilized a qualitative methodology drawing on two theoretical frameworks: social constructivist theory and critical theory (Saleeby 1997; Scott and Marshall 2009). Genetic health professionals were recruited as key informants with experience in pediatric genetic testing via genetic health services in each State of Australia. To identify key informants, the administrative offices of genetic health services were contacted by DV by telephone to get email addresses for the genetic health professionals within the service who worked in the pediatric genetic clinic. Following identification of one key informant at the service, snowball sampling

was employed. This sampling method was appropriate in order to purposefully recruit genetic health professionals who would have exposure to requests for carrier testing in children and therefore information pertinent to the research. Genetic health professionals with less than 3 years experience were excluded. Potential participants were invited to participate by DV via email.

Procedures and Instrumentation

Participants were interviewed in person or over the telephone by DV using a semi-structured interview guide (designed by DV, LG and CD). The interview guide was based on review of the existing literature and comprised 10 main questions designed to explore their practices and views relating to carrier testing for children. The interview guide was piloted on two genetic counselors who gave feedback on the experience to help refine the questions. Here we report on two aspects of these interviews 1) beliefs about parents' reasons for wanting to know their child's carrier status in the context of having another child diagnosed with a genetic condition (participants were asked "Why do you think parents want to know the carrier status of their children?"), and 2) opinions about parents' intentions to communicate information about their child's carrier risk or status to the child (participants were asked "Do you think parents intend to communicate carrier status information to their children?").

Interviews were audio-recorded, transcribed verbatim, and analyzed using inductive content analysis in which content categories are derived from the data, rather than predetermined (Downe-Wamboldt 1992; Graneheim and Lundman 2004; Schamber 2000). Each transcript was coded into broad content categories. Sections of the data within the broad categories were then compared and more specific subcategories were developed. All interviews were coded by DV; LG and CD coded a subset to confirm the coding scheme.

This study was approved by the Human Research Ethics Committee at The University of Melbourne, Victoria (ID 1137204).

Results

Participant Characteristics

Seventeen genetic health professionals participated in the study with at least one from each State and Territory in Australia. This comprised 10 genetic counselors and 7 clinical geneticists, 11 (65%) of whom were female. The health professionals had a mean of 14.4 years experience in their respective professions (range 8–25 years) and 13.2 years in the pediatric genetic setting (range 6–25 years).

Participants' Beliefs about Parents' Motivations for Testing in their Children

Genetic health professionals attributed a wide range of reasons to parents who wanted carrier testing performed for their other children in the context of a child being diagnosed with a genetic condition in the family. They reported a general sense that parents were anxious about the health of their children with some genetic health professionals discussing parents' desires for reassurance. Some believed parents want testing to confirm their other children are not affected with the genetic condition in the family, rather than to find out their carrier status per se.

> *Sometimes that's what they're worried about. They actually think the kid might have cystic fibrosis. They're not actually worried about carrier status. They're worried that they've got the disease.*
>
> *Interview 6, Genetic Counselor*

> *Probably not worrying about carrier status [for Fragile X syndrome], they want to know whether there's any risk, there's any possibility of future developmental implications because of their family history.*
>
> *Interview 13, Clinical Geneticist*

Others suggested that, rather than wanting to identify *whether* their child is a carrier, parents particularly want reassurance that their child is *not* a carrier of the condition. Two clinical geneticists discussed the concept of guilt in relation to parents" desires for reassurance that they had not passed on the mutation.

> *They want to sort of round things off…I think they want to have good news that they're not a carrier so that they can draw a line under it, that part of their life.*
>
> *Interview 7, Genetic Counselor*

> *Most of the time I guess it's for reassurance, isn't it? Like families would often want to know for reassurance so that they could know that they haven't got [the allele] and its not going to impact on them in the future.*
>
> *Interview 2, Genetic Counselor*

> *We often talk about guilt, and you know I do think that that's a factor for some parents, and particularly the*

ones who are really pushy who just desperately want to think that that they haven't passed it on to all their children and that they don't have to go through the same thing.

Interview 15, Clinical Geneticist

One clinical geneticist proposed that parents' desires for carrier information about their children might be based on a lack of understanding about what it means to be a carrier or the implications for the child's health and reproductive risks.

If someone is found to be a carrier of a rare disorder by chance or because they've got a sibling that's affected, all that means is that we now know the name of one of the many recessive disorders they're a carrier for… So when you view it in that context, it's almost irrelevant in terms of that person's health or identity or anything like that, but some parents struggle to grasp that.

Interview 11, Clinical Geneticist

Many genetic health professionals believed that parents "just want to know" this information about their children. They felt that this might be driven by curiosity, a need for control of the information, or the desire to know the genetic status of each of their children, particularly if they had learned the carrier status of another child through prenatal testing. They also thought parents might view early testing as convenient if it is performed at the same time as other tests.

Most parents they, when they say they just want to know and they want, I think they just want to have control of that knowledge, even though it doesn't have the, particularly with CF, not the health implications that you'd be concerned about. And I think it's a frustration for parents not to have that knowledge which they feel is easily obtained.

Interview 7, Genetic Counselor

I have those that are just really anxious and focused, that might have had prenatal testing on some pregnancies so they know the result on some of their children, and they don't know the result on all of their children.

Interview 12, Genetic Counselor

She was concerned about them being carriers, she knew that they had a high risk of being carriers and thought, while we're doing all this genetic testing, let's just get them done. So we, there wasn't any concern, worrying symptoms for those children. Just their parents wanted that information so they had it all done and didn't have to revisit the question about genetics and carrier testing again.

Interview 9, Genetic Counselor

Parents' need to know their child's carrier status was interpreted as a coping strategy by some genetic health professionals, who noted how the uncertainty of "not knowing" could be disruptive in parents' lives.

I think some parents in this setting, they just feel the need to have the information… Sometimes it might be framed in the context of affecting their future reproductive decisions or affecting the medical needs of their child, but I think often those are secondary. I think it's just that they feel they want the information. They're not comfortable not knowing once the issue has been raised.

Interview 11, Clinical geneticist

Although this participant stated they could appreciate parents' need for information seeking as a form of control, and their frustration at being told they cannot have testing, they attributed this to parents' inability to comprehend why postponing testing is necessary for the child.

Being a parent myself, I can understand why parents ask and want to have that information and want to have some control over something. They, obviously in some cases, they don't have much control over the actual disease…It must be a very frustrating place to be for some of these parents who can't get their head around why we think autonomous decision making is important.

Interview 7, Genetic Counselor

Three participants felt that parents might request carrier testing because they believe they are acting in their child's best interests or want to help their children. The same three participants mentioned parents' desires to communicate the information to their children.

Others I think do it so that they've got that knowledge to then help their child, you know, and then will disclose it to their children…whenever they feel it's the most appropriate time. So I think some parents do it more for themselves, and I think some people do it more sincerely for the children. But I think it varies.

Interview 14, Clinical Geneticist

Two participants mentioned parents might be concerned for the reproductive health of their children, with one referring to the idea that the parents are worried the child will be faced with the same challenges they experienced.

I have the situation where someone is identified in a family with Fragile X…and then the parents are really concerned about the other siblings, and even if they haven't got problems they still want to know, are they going to be carriers? Are they going to be facing those issues that the mum is now facing with prenatal options? That type of thing.

Interview 12, Genetic Counselor

Finally, one genetic health professional commented that they do not usually ask why parents want carrier testing done in their children, focusing more on helping parents understand when might be the right time.

I can't say I can think of when I've actually asked specifically why they want it done, although it's usually the way in which they ask is sort of, when can we do that? and…when is the right time to do that?' kind of thing and can they do it now?', not so much a why?.

Interview 16, Genetic Counselor

Despite a number of genetic health professionals feeling parents' reasons for requesting testing for their children are well intentioned, others implied that parents' reasons are not substantial enough to warrant testing. One commented that parents might not be able to make sound decisions about carrier testing for their children.

Look, I can certainly understand where they're coming from, and I think it's easy for us as professionals to be rational about it (chuckles), and I think it is harder for a parent to be rational about it.

Interview 5, Genetic Counselor

Another highlighted how parents can become combative in the face of being told they are not allowed to access testing. They described how the argument becomes about the parents' right to have information regarding their children rather than the actual carrier status. However, it was acknowledged that both parties engage in the battle and lose sight of the child.

I'm sure for some it starts as a request that they just assume won't be a problem, and then it gets into a fight and they become, each party becomes stubborn and wants to win the battle, and it doesn't become about the children anymore, it becomes about the battle and winning battles.

Interview 15, Clinical Geneticist

Participants' Beliefs about Parents' Intentions to Communicate Carrier Results

As part of discussions about communication of carrier results, participants were asked their views about whether parents intend to disclose information about their child's carrier risks or status to their children. In answering this, they drew on their experiences with parents disclosing carrier information to their children. In general, the genetic health professionals felt that parents intend to communicate carrier information to their children.

Mostly yes. We have a few cases where it's not, but in most cases, yes, they do and they try and work out when is the best time and ask for advice on how to do that.

Interview 12, Genetic Counselor

Families see it as important and I've had a couple of families say "we have to go home and put this in our will so that they know if something happens to us they need to know this".

Interview 10, Genetic Counselor

I'm less comfortable with testing small children and on the occasions where that has happened definitely I talk to the parents about have you thought about when you would tell them and the parents are very open to talking about that. 'Cos you I guess you could argue that if a parent is motivated to have the testing done they're doing that with the intention of having that for their child's information at a later stage.

Interview 1, Genetic Counsellor

However, some acknowledged that they had no way of knowing whether parents actually do communicate carrier status to their children because they do not have the opportunity to follow up with families. Yet, some felt that unless you have evidence that disclosure will not take place, you need to trust that parents will tell their children information about their carrier status.

I've never had anyone who's indicated they weren't going to let their children know. But of course the time lag between event and disclosure is so many years that I've

got no idea whether it happens or not.

Interview 15, Clinical Geneticist

Well, wouldn't it be nice if that were true [that parents disclose carrier information to their children] but of course that's not the reality of it. But I guess you, unless you've got evidence to the contrary, you do have to leave that responsibility with the parents. And it is probably fair to say unless you have some evidence to the contrary then you don't really have any legitimate basis to, you might say, try and intervene at that point.

Interview 17, Clinical Geneticist

In some interviews, the participants were concerned that parents may not know how to tell their children their carrier status. Others flagged that parents might forget to tell their children, the information might get lost, or that parents may decide not to disclose.

I know of at least one example where the information, in the setting of a chromosome translocation, the information's got lost somewhere along the way…There was a record that the parents were given the information about their child, but then the child grew up and became an adult and then had trouble with their own reproduction, and of course the condition was re-diagnosed in that person. So I can only speculate about what happened, whether the parents forgot, or whether they chose not to disclose the information.

Interview 11, Clinical Geneticist

There may be some parents who, for various reasons, shall we say, not necessarily healthy ones, seek information and choose not to disclose. And we've had one ugly experience with that, well I mean, not because we did it but it relates not to a gene test but it was a carrier test for a chromosome translocation.

Interview 3, Clinical Geneticist

A few participants recounted instances where disclosure had not taken place and the detrimental effects that had on the families.

One of the instances that I'm thinking about was the situation where a young woman was at risk of [being a carrier of] an X-linked disorder…the girl was about 8 or 9 at the time…and the family could never quite bring themselves to tell this girl, and she was furious when she finally found out when she was in her late teens, maybe early 20s, and it caused a huge destruction in the family. So I have seen it go wrong.

Interview 8, Clinical Geneticist

For some parents I think that having the information and then having to decide 'when am I going to have to tell people?', 'when am I going to tell my daughter?', can become a burden for parents and I have seen some really sad outcomes when parents have not actually been able to decide when is a good time and it's just been delayed and delayed and delayed.

Interview 4, Genetic Counselor

Discussion

This is the first paper to provide an in-depth exploration of the attributions genetic health professionals make about parents' reasons and motivations for wanting to know their unaffected children's carrier status in the context of having a child diagnosed with a genetic condition. Interestingly, very few of the genetic health professionals interviewed described parents' motivations for having carrier status information to be about benefitting the child. Instead, they suggested parents' reasons were based on how the information would primarily benefit the parents, such as reducing their anxiety or fulfilling their curiosity. These reported attributions contrasted with parents' actual reasons as reported from parental data from our study with Australian parents and also from other studies that have reported parents' reasons for wanting to know their child's carrier status, many of which have a more child-centered focus (Barnes 1998; Brunger et al. 2000; Dunn et al. 2008; Fanos and Mackintosh 1999; Jolly et al. 1998; McConkie-Rosell et al. 1997; McConkie-Rosell et al. 1999; Thomas et al. 2007; Vears et al. 2016b).

Studies have indicated that some parents want to know their child's carrier status out of interest, for the convenience of having testing performed earlier in childhood, or because they feel that the uncertainty of not knowing their child's carrier status may place additional strain on the family whereas a definitive answer would provide peace of mind (Chapple et al., 1998; Fanos and Mackintosh 1999; Jolly et al. 1998; Thomas et al. 2007; Vears et al. 2016b). Many parents are keen to communicate the information about their child's carrier status to their children in order to inform them about their reproductive options, and prevent them experiencing the shock of learning their carrier risks by having an affected child (Barnes 1998; Jolly et al. 1998; Thomas et al. 2007; Vears et al. 2016b). They want to be prepared to answer their children when they start asking questions (Jolly et al. 1998; Vears

et al. 2016b). Other studies have reported parents' concerns about teenage pregnancy and hope to prevent their children engaging in "risky" sexual activity (Barnes 1998; Fanos and Mackintosh 1999; McConkie-Rosell et al. 1999; Thomas et al. 2007). Finally, some parents want their children to grow up with the information about their carrier status so they can integrate it into their self-identity (McConkie-Rosell et al. 1999; Vears et al. 2016b).

A key finding of this study is that health professionals attribute reasons for wanting carrier status to parents which are contrary to those reasons presented by parents as reported in the literature. A second, and related, finding is that some health professionals seem to be unaware of the main reasons parents report for desiring carrier testing for their children.

First, if we compare the reasons presented by genetic health professionals with those reported by parents, we see that some genetic health professionals make assumptions about the reasons parents have for wanting carrier testing for their children. Genetic health professionals in our study assumed that parents want reassurance that their children are not carriers. This is in contrast to responses by the parents in our other Australian study who reported desiring the certainty of knowing their child's status as a motivation for testing, rather than wanting more general reassurance about the test result for themselves (Vears et al. 2016b). Genetic health professionals also seem to be making assumptions about parents' anxieties for the health of their children. The genetic health professionals expressed the view that parents might be anxious about the health implications of being a carrier and that their misunderstandings about this, as previously reported by Noke et al. (2015), may be driving their desire for testing. Along with their apprehension that parents' anxiety, should carrier testing take place, would result in changes in the parents' perceptions of their child, this suggests that genetic health professionals are assuming that parents will misunderstand the medical, social or reproductive implications of being a carrier. This belief is interesting, given these parents are also carriers of the condition, and have first-hand experience of the difference between being a carrier and having the condition. This attribution that genetic health professionals appeared to be making based on their interpretations and assumptions about parents' views contrasts with studies of parents' actual views. In our Australian study, very few parents of children with genetic conditions reported concerns for their child's health as a reason for wanting carrier testing, and those that did were parents of children with haemophilia, where carrier daughters are potentially at risk of excessive bleeding (Vears et al. 2016b).

Second, there was little acknowledgement of some of the reasons parents present, as reported in previous studies, particularly those that were more focused on benefits to the child or the family as a whole. Specifically, very few genetic health professionals mentioned that parents might want carrier testing performed in order to inform their children of their carrier status and subsequent reproductive risks. This is interesting given this was the main reason parents reported for wanting to know the carrier status of their children in our Australian study (Vears et al. 2016b).

It is possible that genetic health professionals may be uncertain whether parents will successfully follow through with their intention to communicate the information to their child. Although the genetic health professionals stated that they think parents have good intentions to disclose carrier status information to their child, a lack of follow up with these families means genetic health professionals do not have the opportunity to find out what happens to the genetic information after it has been conveyed to the parents, a gap which has been mentioned by others (Bache et al. 2007). They also expressed concerns about parents' abilities to communicate carrier status to their children. It is possible that genetic health professionals are more likely to encounter instances where communication has failed and individuals who were tested as children later had difficult reproductive experiences because they were not informed of their carrier status, (compared to those instances where communication goes well), thus potentially biasing their views about whether parents will effectively pass on the information. It seems that genetic health professionals' concerns that parents will be complacent about communicating carrier status to their children prompt them to withhold testing. In contrast, parents in our Australian study seemed confident they would not forget to disclose information about their child's carrier status and felt well equipped to do so (Vears et al. 2016b). This desire to communicate carrier status to their children was often the primary motivation for wanting their child tested, and many of these parents who had received carrier testing for at least one of their children had either communicated their status to them or indicated that they intended to do so (Vears et al. 2016b). This suggests that genetic health professionals' concerns about parents forgetting or failing to communicate carrier information to their children may not be well-founded.

The genetic health professionals did mention some reasons that aligned with those presented by the parents, including that parents might find it convenient to have carrier testing performed in their children when they are younger so neither the children, nor the parents, have to revisit the idea. However, these types of reasons were often framed by the genetic health professionals as superficial or trivial reasons for wanting testing, as exemplified by the genetic counselor who stated that parents just want to "round things off." Health professionals in the UK have also admitted to questioning parents' motives for requesting testing in their children, identifying "just needing to know" as a reason parents want carrier testing (Noke et al. 2015). This research suggests that while the genetic health professionals acknowledge that parents have reasons for wanting to know their child's carrier status that do not relate to medical benefit, they appear to make judgments about

whether these reasons are "good enough" to provide testing, often finding them lacking.

Practice Implications

Alongside the assumptions genetic health professionals make about the reasons parents want testing and their tendency to discount the primary motivations of parents for wanting carrier information, namely to benefit their children, this then leads us to question whether it is the proper role of the genetic heath professional to determine whether parents' reasons are "good enough" to warrant testing. Are genetic health professionals ethically justified in overriding parents' decisions regarding carrier testing in their children, on the basis of their assumptions about the parents' reasons for wanting testing?

In the medical setting, there are a number of ethical frameworks that have been proposed to make decisions about when parents' wishes regarding their child's medical care should be respected and when practitioners should intervene (McDougall and Notini 2014). The point at which it is acceptable to override parents' decisions is when that decision is likely to lead to serious harm for the child (Diekema 2004; Gillam 2016; Ross 1998). In our opinion, the evidence currently available does not indicate that there is *any* harm from performing carrier testing for children. This suggests that carrier testing in childhood should be a decision that falls within the scope of parental decision-making and that genetic health professionals are not ethically justified in refusing testing (Vears 2016). This is in line with the latest BMA recommendations which ultimately place the decision regarding whether carrier testing takes place in the hands of the parents (British Medical Association Ethics Department 2012).

Even if there is no harm in carrier testing, it could be suggested that when parents' motivations are problematic, this could itself be a strong reason not to agree to parents' requests. The importance of parents' motivations is specifically addressed by one of the above-mentioned frameworks, the Zone of Parental Discretion (ZPD). It proposes that parents' motivations underpinning their decisions should not *in themselves* influence whether decisions fall within the zone where parents' decisions should be respected (Gillam 2016). This is because the point at which intervention is appropriate is based purely on the impact the decision will have on the child, namely whether it will result in probable harm (Gillam 2016). This may seem counterintuitive to genetic health professionals who are influenced by parents' reasons for wanting to know their child's carrier status when deciding whether to facilitate testing (Vears et al. 2015), perhaps because they are sub-consciously linking what they believe to be parents' reasons with some sort of negative effect on the child. But the case for a negative impact would need to be made specifically on an individual basis, because there is no definitive link. Even if parents want carrier testing for their own reassurance, there is no reason why this parent-focused reason should result in harm to the child tested. On the contrary, it seems more likely that all the children in the family will be better off if their parents are coping more effectively.

This research affirms that it is still important that genetic health professionals openly explore with parents the reasons they want to know their child's carrier status. However, they need to refrain from making quick judgments that the parents' reasons are not "good enough," based on assumptions that flawed parental reasoning associated with requests for carrier testing will result in flawed future parenting or some other harm for the child. Exploring parents' reasons in a non-judgmental way will allow genetic health professionals to assist the parents to make a decision which best suits their family, and it also creates an opportunity for the genetic health professional to determine whether the parents have misunderstood the potential implications of their child being a carrier, to ask about their intentions to communicate the information, to give them strategies to do so, and to address any additional concerns.

Study Limitations and Research Recommendations

This study is limited in that the interviews are from genetic health professionals based in one country, and therefore the findings reflect the health care system and practice norms of that country. Moreover, qualitative data are not intended to be generalized to the population of interest. Further exploration of genetic health professionals' understandings of parents' motivations driving desires for carrier testing in their children in other contexts would enhance this discussion.

Conclusion

This study has provided valuable insights into how genetic health professionals' attributions of parents' motivations for wanting to know genetic information about their children might be driving their reluctance to provide testing. This is important since gaining an understanding of the potential drivers for these attitudes and practices provides a basis on which to build more ethically appropriate practice. We have highlighted that it is ethically appropriate for parents to obtain carrier status information about their child on the basis that there are more benefits than harms associated with having this information. This means parental reasoning may not be ethically important. However, we suggest that discussions with parents about their reasons can assist in clarifying concepts for parents and that genetic health professionals could shift their starting point to the belief that parents want to inform themselves, and eventually their children, with their child's best interests at heart. This then allows an open exploration of parents' understanding and an opportunity for genetic health professionals to assist parents to make decisions that

are in line with their values and the best interests of the family (McConkie-Rosell and Spiridigliozzi 2004).

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Compliance with Ethical Standards

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Conflict of Interest Danya Vears, Clare Delany, John Massie and Lynn Gillam declare that they have no conflict of interest.

Ethical Approval All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). This study was approved by the Human Research Ethics Committee at The University of Melbourne, Victoria, Australia (ID 1137204).

Informed Consent Informed consent was obtained from all participants for being included in the study.

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