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Original Research

Attitudes Toward Fragile X Mutation Carrier Testing from Women Identified in a General Population Survey

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Fragile X syndrome is primarily due to a CGG repeat expansion found in the FMR1 X-linked gene. In a previous study, we conducted focus groups with women to assess their attitudes towards fragile X carrier screening. In this follow-up study, we conducted in-depth interviews of general population reproductive-age women who were identified as carriers. We explored their attitudes toward testing for carrier status of the fragile X mutation. These women underwent screening primarily to participate in a research project rather than in search of a diagnosis for specific symptoms. As such, these women were wholly unprepared for positive carrier results. Their responses about their results and carrier screening, in many cases, were being worked out over the course of the interview itself. The most salient finding of this work is the apparent lack of relevance of carrier status to these women. Many expressed that although the information could be relevant in the future, it is not relevant at this stage of their lives in terms of family planning (either with respect to having unaffected offspring or to premature ovarian failure) and personal relationships. Although issues of abortion seemed prominent in the focus groups, we found that carrier status did not have an apparent effect on women's attitudes about termination. We hypothesize this may be related to the fact that women had not processed their new carrier status and had not related it to previously-formed personal opinions. The findings of this work have significant implications for genetic counseling and population screening. Genetic counselors should be mindful that general population women may not recognize the immediate importance of their carrier status even when literature is provided and discussed prior to providing a sample. As part of comprehensive genetic counseling, counselors should identify the reproductive life stage of the woman receiving the new information and help her identify when this information would be more meaningful in her life. Counselors can assist in setting up a personalized road map with specific types of services that will be more applicable to the woman as her carrier status becomes more relevant.

KEY WORDS: population screening; fragile X syndrome; carrier testing; *FMR1*.

INTRODUCTION

In over 95% of individuals with fragile X syndrome a type of inherited X-linked mental retardation, fragile X syndrome is caused by a CGG hyperexpansion in the FMR1 gene. Since the discovery of the FMR1 gene and an accurate DNA test widely available, population screening for fragile X syndrome has been a topic of consideration.

Currently, fragile X screening is offered prenatally/preconceptually to individuals with a family history of fragile X syndrome or mental retardation. The feasibility of newborn screening is being considered; however, there are many roadblocks that need to be addressed prior to its initiation. Proponents

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argue that early diagnosis is beneficial in itself, in that it provides important information for family planning and allows initiation of potential interventions (Bailey, 2004). However, the lack of a proven intervention to ameliorate symptoms at this time leads others to argue that newborn screening is premature. Other possible target populations for screening include, but are not limited to, infants with developmental delay and women of reproductive age. With the established premutation-associated phenotypes of premature ovarian failure (POF) and fragile X tremor ataxia syndrome (FXTAS), screening issues need to be re-considered.

In this report, we will consider an important target population for population screening that has been discussed minimally in the literature, namely, women of reproductive age. There are many issues that need to be considered prior to instituting a population-based screening program, including the significance of the condition, the clinical and analytical validity of screening tests, feasibility of implementing the screening program, and access to results and resources needed to implement the program. Population screening for other genetic disorders such as cystic fibrosis is now widely available. Prior to population screening implementation, studies and surveys of the general population and the population at increased risk were conducted with several focusing on the emotional response to genetic testing (Mennie *et al.*, 1993; Clayton *et al.*, 1996; Henneman *et al.*, 2001). As part of the investigation of the feasibility of implementing a screening program, we have initiated studies to understand the attitudes of women with respect to carrier testing for the fragile X mutation and the effects of obtaining this genetic information.

Understanding the attitudes related to clinical and population testing has been restricted to individuals who are in families with fragile X syndrome. Previous studies to identify attitudes on carrier testing for fragile X syndrome have been based on women at risk for carrying the fragile X mutation identified from families with fragile X syndrome. Information was obtained using questionnaires and follow-up interviews (e.g., McConkie-Rosell *et al.*, 1997; McConkie-Rosell *et al.*, 1999; McConkie-Rosell *et al.*, 2000). Other studies on attitude and uptake of carrier screening that include the general population have been limited to women in prenatal settings (Cronister *et al.*, 2005; Fanos *et al.*, 2006). There has been no assessment of attitudes of the general population in a preconceptual setting. Furthermore, no studies have been conducted concerning the effect of learning ambiguous results related to risk of having affected offspring (i.e., women who carry alleles with 50–60 repeats).

Our previous study confirmed many of the findings of McConkie-Rosell and her colleagues on attitudes toward carrier testing identified among women from fragile X syndrome families (McConkie-Rosell *et al.*, 1999; Anido *et al.*, 2005). Our most important finding was that attitudes of women in families with fragile X syndrome toward screening and use of the information cannot be easily transferred to the general population. Women whose carrier status was identified secondarily to their child's or family member's diagnosis of fragile X syndrome had a difficult time formulating their own opinions and feelings about carrier testing. Their relationship and experience with their child with fragile X syndrome led to the inability to abstract their attitudes. They expressed a different level of importance or consequence of carrier testing for them compared with that for their daughters.

In this follow up report, we have conducted in-depth interviews with women from the general population who were identified as premutation carriers. In these studies, we hoped to gain insight into each woman's motivation, understanding, and attitude toward their knowledge of their carrier status and to achieve an understanding of what information is needed to prepare those in the general population who elect carrier screening.

Based on our previous findings, we considered that Adult Learning Theory may provide a framework for our current analyses. Adult Learning Theory, or andragogy, contends that "adults are highly pragmatic learners" (Wlodkowski, 1999). That is, in part, adults are motivated to learn things that they need to know or things that help them cope effectively with their own real-life situations (Knowles, 1999). Our hypothesis, borne out in this work, is that women who are diagnosed through population screening and have no experience with fragile X syndrome may be wholly unprepared and need significantly more information, although their current stage of life may have a significant impact on their perception of the relevancy of that information. Clearly, education programs outlining the implications of carrier testing for fragile X syndrome or any genetic disorder are necessary before population screening programs should be initiated.

STUDY POPULATION AND METHOD

Study Population

Interviews were conducted between 2002–2004. Women participating in the interviews were drawn from the Emory Study of Adult Learning (ESAL). The goals of ESAL were to (1) characterize the neuropsychological and reproductive profile of individuals who carried high repeat alleles, a research question, and (2) offer carrier screening for fragile X syndrome, a community service. A brief description of fragile X syndrome and the inheritance was described in the materials provided to each participant. Risks associated with identifying carrier status were outlined in both the brochure and the consent form including emotional risks associated with the potential of having a child or grandchild with fragile X syndrome, the risk of premature ovarian failure (POF) and the potential of insurance discrimination. At the initiation of these studies, POF was the only phenotype that was well-established among premutation carriers. The tremor/ataxia syndrome (FXTAS) had not been identified. Thus, in recruitment/study materials, only the risks for reproductive failure were described. Human subjects and ethical issues for these studies were reviewed by the Internal Review Board (IRB) at Emory University School of Medicine and approved.

Source Sample

All participants in ESAL were between the ages of 18–50 years, lived in the metropolitan Atlanta area and had English as their primary language (requirement for neuropsychological testing). For ESAL, the study team was on site to describe the goals of the study, answer questions initiated by the potential participant, and provide a study brochure. When possible, a video created for the study by the team was shown. Potential participants had the option of recontacting the study team for further clarification of the study. All individuals provided a buccal sample for CGG repeat analysis once a consent form was discussed and signed. If a participant for ESAL had more than 40 repeats, they were invited to participate in a follow-up study that included psychometric testing and administration of a reproductive, medical history and demographic questionnaire. For every participant enrolled in ESAL, an individual was recruited who had fewer than 41 repeats and matched by gender, age, ascertainment site and ethnic/racial group for the same follow-up protocol. A genetic counselor disclosed DNA result information to participants who requested them. During results disclosure by phone, focused genetic counseling was provided. The call ranged from 30–60 min and covered fragile X syndrome characteristics, carrier characteristics (specifically risk for POF and risk for subsequent generations for fragile X syndrome), fragile X syndrome inheritance, known risk of CGG expansion in fragile X syndrome families, unknown risk for expansion in the general population, and carrier risks for siblings. Local genetic counseling/testing contact information was provided. Additional information on fragile X syndrome and prenatal testing was mailed to the participant with their result letter. Comprehensive genetic counseling was made available by phone and/or in-person. Comprehensive genetic counseling would include reviewing the risks, benefits, and limitations of fragile X syndrome carrier testing. Prenatal testing and artificial reproductive technologies would be explained in detail. Psychosocial issues would be address and cover topics such as how to share carrier status information with other family members. Also, a complete pedigree would be constructed, evaluated for other potential genetic disorders, and referrals made based on the pedigree.

Interview Sample

For this study, we focused on women age 18–45 who were premutation carriers (50–199 CGG repeats) with no known family member with fragile X syndrome. All women enrolled in ESAL meeting these criteria were approached to participate in the interviews. In 2002, of 12 who were eligible through the ESAL protocol, 8 participated, 1 refused, and 3 were lost to follow-up, resulting in a response rate of 66.67%. Interview participants ranged in age from 21 to 44. The women's premutation CGG allele sizes ranged from 55 to 63. The average time a woman knew her carrier status was 17 months (2–36 months). All were Caucasian; half were married. Two had children and five were actively thinking about having children. All had some college education. Three of the eight women had additional contact with the genetic counselor to receive comprehensive genetic counseling prior to the interview. All asked brief questions after the interview to review their carrier status information. One

woman requested comprehensive genetic counseling after the interview.

Procedures

This study was conducted using eight semi-structured qualitative in-depth interviews. All interviews were conducted by one interviewer (A.A.) and each lasted approximately one hour. Seven interviews were conducted in person. Due to scheduling, one interviewee was unable to complete the interview in person. The study team members conducted a pilot study of three interviews using in-person and phone methods and determined that they were unable to differentiate between interview methods, so the eighth interview was completed by phone.

The interviewer followed the same guide for all participants. The interview guide was developed by the study team based on data gathered in a prior focus group study using similar wording obtained from the focus group participants (Anido *et al.*, 2005). Following a pilot of two interviews (not included in analysis), minimal revisions were made. The final guide consisted of 28 questions covering topics including testing experience, POF, affect of information on relationships, and family planning. All participants were audio recorded with consent. Tapes were transcribed and the participants' grammar was not corrected in order to preserve the flavor of the sessions.

The analysis team consisted of a Master's trained public health professional with experience in qualitative research, a Ph.D. medical geneticist and a pediatric genetic counselor. Data were analyzed independently by each of the study team members using an approach similar to interpretative phenomenological analysis (Chapman and Smith, 2002). Consistent with content analysis (Patton, 2002), each member of the study team repeatedly reviewed the transcripts for recurring primary patterns. Salient words, phrases, and passages were highlighted and labeled with a representative word or phrase, which became the structure of the themes which emerged from the data. After completing independent analysis of a transcript, team members then compared their assessments to discuss classification and development of themes. Study team members worked for consensus on each theme and, as such, did not calculate inter-rater reliability. Discrepancies were discussed until agreement was reached. Salient supporting passages were identified and checked against original recordings for accuracy as needed. Themes were then compared to existing literature to determine consistency or novel findings. Throughout the Results section, we include supporting passages from the interviews. The code after each quote designates the different participants.

RESULTS

As mentioned in the Introduction, we used Adult Learning Theory as a framework for considering the various themes that came forward in the interviews. We categorized the identified themes into the following broad categories: (1) the processing of test results; (2) the motivation for carrier testing; (3) the initial reaction to test results; and (4) the interpretation and use of the test information.

Processing the Test Results

The interviewer for this study was the genetic counselor that all of the women had spoken with in a previous setting as she provided their results. This occurred between 2–36 months prior to the in-depth interview. During the interviews for this study, however, it was evident that most of the women had not fully processed the information during this time and were, in fact, processing the information during the course of the interview, as evident by comments such as the following:

> In terms, oh, oh, I hadn't thought about it until just right now (laugh) (P1)

> But I have a stack of information and I'm definitely going to go look it over again 'cause now you know doing this interview brought this back to mind a lot more. (P2)

In many of the quotes below, the act of processing is notable. In addition, many times the woman was unable to articulate her ideas, presumably because she had not considered the issue before the interview. This is evident throughout the theme passages that follow.

Motivation for Carrier Testing

One important finding that may influence the context of the women's reaction to results is based on the motivation to participate in this study. For most, the motivation to participate was to enhance research, not to actively seek carrier testing. Although

the recruiting material highlighted that participation would involve genetic testing for fragile X syndrome and that fragile X syndrome was an inherited mental retardation disorder, most did not digest this information. Importantly, the women were not actively seeking carrier testing. Some of the statements below indicate that the participants did not understand the type of information that a screening test would provide and, thus, their motivation and initial reaction was shaped accordingly.

> I like being part of research studies so I mean I didn't even think that I was a carrier, I had no idea, I didn't even know what Fragile X was but I like learning new things and I like being part of studies so I just did the test. (P3)

> Being a psychology major, I know how annoying it is to try to get participants . . . I didn't think it would shed a light on anything for me personally and that didn't factor into my decision to be tested. (P1)

Initial Reaction to Test Results

The initial reaction varied considerably from *intrigued* to *shocked*. When first receiving their results, women responded with statements such as the following:

> I wasn't angry at all, I was like ok and I knew a little bit about, about fragile X at that point and being a carrier and I was like oh, it's not that big of a deal I guess right now so. (P4)

> I was just kind of interested and intrigued to see what that means. I mean pretty much knew that it wasn't going to mean that I couldn't have children but it just meant I had to keep my ears open and ask more questions . . . I didn't feel upset or angry or anything, just kind of, I mean, I, you just have to take what you're given and work with it so I wasn't upset (P3)

> I was kind of thrown back and I was kind of like I guess angry to some extent because like who are these people doing the test, telling me my children are going to have fragile X. And it's and then you start to realized while they're not telling me that, they're telling me there's a chance but then who are they to scare me like that. So you do get angry because I don't want to be told that and then you're like ok whatever. (P5)

As discussed below, this initial reaction appeared to be related to the stage of life of each woman.

Interpretation and Use of Test Results

Our most salient finding was that a woman's stage of life appeared to define the interpretation of the carrier status information and the subsequent use of that information in life planning. This was evident for several significant issues that surround genetic information including finding relevance of the genetic information, passing the information to other family members and partners and applying the information to family planning. For some women, the information had little relevance, apparently due to the lack of the application of that information at that current time.

> At least at this point, at this point in my life it's not something that I, that I think about daily. So I mean it's, it's not something that's hard for me to deal with yet. I'm sure later on when I have to like, make, make choices, make choices like that then, then it will be more difficult and it will play a larger role in my life but right now I'm really, really glad that I know but there's still like a certain ambivalence in terms of like it's not effecting me right now type thing. (P1)

> I'm already 44 so (laugh) . . . I don't, I didn't think anything of it really. (P6)

> . . . like I said, it's just one of those things you just have to remember when it's time for me to have kids or whatever so (P4)

For other women at a different stage of their life, the information had more relevance. They took action and actively processed the information.

> I think I freaked out a little bit . . . it's kind of shocking because it's something that you can't change and something you didn't know before now. You can't change the fact that you know it and you know obviously could affect your behavior. (P2)

> It means that I need to be careful before I get pregnant. To me it all relates to pregnancy, it doesn't really affect the rest of my life. So the definition to me is just to be cautious, to be, to be aware. (P5)

For the majority of women, providing their information about carrier status to their family was not problematic. However, providing the information to their partners primarily depended on the seriousness of their current relationship. This again reflects the stage of their life.

> Well, I'm not, I'm not, I don't have a boyfriend so it hasn't affected that . . . (P1)

> Also I think when I found out I wasn't seeing anybody so it was sort of like it was a very future thing, very far away. You know it affected only me for the moment but now you know that I have, I'm in

> a serious relationship, it affects more than one person and has more relevance probably. (P2)

As seen below, it was apparent that the majority of these women were speculating and for the first time forming their opinions at the time of the interview. This was seen regardless of the stage of life they were in.

> Well I think you; you get to this state where you obviously have something more to think about in the future. You know the choice of whether or not to tell the person you're seeing like if it's going to be, if you're, end up, gonna end up being with the person and having children then do you want to tell them just before kids and then all of a sudden their like 'why didn't you tell me this before this, this is important.' Or, or you know you tell them before and they get a little weirded out by it. It's important to, to know I think because then you can, you have time to decide whether you want to you know tell the person after you get married, before you get married. I think it's important to tell them before. In any case you shouldn't hide something like that but yeah I just, what was the question again? (laugh) (P2)

Interestingly, the young women were forming and voicing their specific opinions (at the time of the interview) about the issue of prenatal diagnosis and the option of terminating a conceptus with fragile X syndrome. Some had difficulty extending their opinion to themselves.

> I don't actually know what it's going to belike when I'm pregnant because I've never been pregnant and I don't actually know what it's going to be like if I ever get a positive. My baby has Fragile X, I don't really know what it's going to feel like and I can't ever know that till it happens and right now I say that I would abort that baby and I don't know if that would change when I'm pregnant. (P3)

> . . . it was like I'm, in general I'm pro choice but I, I wonder, I don't know it's, it's hard to say like I hadn't, I hadn't thought about, I guess I hadn't thought about abortion. I guess, I guess it would be . . . I would be really, I think I, I think what I would do . . . I think I'd probably be like spend time with children with Fragile X because it's not, I don't think it's fair to if the child is going to just, the child is going to suffer then I, like that's not fair. But on the other hand if it's just my wanting to not deal with it then that's not fair, that's not fair either. So I think I would, I think I would talk to mothers of children you had it, watch their interactions. It would be, I'm sure it would be a very very stressful pregnancy but I, I don't, I don't know. I think it would be very situational. It would also depend on like where I am in my life and but I hadn't thought about abortion after finding results of prenatal testing.(P1)

> I think a lot of things have affected my feelings on termination . . . . I'm obviously pro-choice. I would never say to someone else that they couldn't make that choice but for myself, I've definitely started thinking whether I would do it or not . . . . I mean two years ago if you had said "you know you're pregnant and what are you going to do?" . . . . I would probably have said "I'd have an abortion" but now I, I'm a little iffy on that. I don't, don't think that I would necessarily answer so quickly. (P2)

Others had definite opinions on whether termination was an option. Regardless of the opinion, it did not change in light of knowing their carrier status.

> I mean it's just I've had the same feeling about abortion even before that, I just look at it as a child. (P7)

> I've always been pro-choice so it's not an issue to me. In my situation it would be my choice. Regardless of the reasoning someone has to abort a child, it's their choice. It didn't change my mind because to me you don't know if someone else is a carrier and they choose it abort, it's their choice. (P5)

For some women, the risk for having no children due to POF outweighed the risk for having children with fragile X syndrome. This risk for POF was more concrete than the potential risk for having a child with fragile X syndrome since POF has a direct effect on their personal reproductive health. This concern may also be influenced by their immediate stage of life.

> Yeah, if it prevents me from getting pregnant then yes it does bother me a lot. If it's not, it's just a couple of years earlier than the norm; I don't have, I don't care. (P5)

> I worry. I mean I'm really worried about the pre-menopause—losing the opportunity to have children. That's, that's the biggest thing with me and this whole thing is children just because I'm at that age and part of you goes 'do I wish I didn't even know?'. (P8)

> I, I mean, because the actual being the carrier doesn't affect me because obviously I can't feel the difference in my, in my genes so it's more, it's more, it's more about like the, I think like, I guess well, I guess my biggest fear might be like with the pre-menopause might be getting it so early that I can't have children. (P1)

> Then the other issue is the early menopause and that scared me more than the other because it would just, I'm going to put off having kids as long as I can and if that, if the case were that I would expect to have menopause earlier then I would kind of have to rearrange my schedule. (P3)

DISCUSSION AND IMPLICATIONS

In our initial study, we conducted focus groups with reproductive age women to determine their attitudes toward carrier testing for fragile X syndrome. As a result of that work (Anido *et al.*, 2005), we hypothesized that women who do not have experience with fragile X syndrome and are diagnosed through population screening may be wholly unprepared and need significantly more information. For women with a family history of fragile X syndrome, the revelation of their carrier status often came as a result of seeking a diagnosis for their child, thereby beginning the inexorable link between their experiences and those of their child. For the general population women, however, the revelation of carrier status did not come as a result of seeking a diagnosis. In fact, for most if not all of these women, it did not even come as a result of seeking genetic information. The resulting information came as a surprise, but for most women, was put quickly out of mind. They noted the significance of their carrier status, but due to different factors, did not find it relevant to their current situations or life stage.

For women with a family experience of fragile X syndrome, it was difficult if not impossible for these women to separate their own experiences from those of their children (Anido *et al.*, 2005). In contrast, the women of the general population were notably less articulate about their experiences of their carrier status. For most, they appeared to be processing the subject over the course of the interview. In fact, many specifically said that they do not generally give the subject much thought or that they were responding from more of an off-the-cuff stance than a well thought out perspective.

The most prominent finding in these interviews is a lack of relevance of carrier status to the women interviewed, which is consistent with "just-in-time" learning as described in Adult Learning Theory (Wlodkowski, 1999). Adult Learning Theory posits that adults have an orientation towards relevancy—there must be a reason to learn something. This results in what is referred to as "just-in-time" learning, wherein the adult learner processes that information which is relevant and applicable to them at the time they need it. This missing relevance of the women's carrier status is apparent relative to their current stage of life, either in terms of family planning or relationship status. If a woman was not currently in the process of planning her family or was not in serious relationships, her carrier status did not have significant relevancy for her. In this regard, test results obtained through prenatal carrier screening are clearly relevant to a woman for her current pregnancy. In one study, women found fragile X prenatal screening a favorable experience (Fanos *et al.*, 2006); however, fewer options are available for a woman with a positive prenatal test result compared to one who had preconceptional carrier screening.

In our prior study, we uncovered salient feelings on the issue of abortion and as such, in these interviews included questions related to termination. In this study, however, women reported no change in their feelings on abortion as a result of their carrier status. The women moved from the subject quickly and no themes were apparent. The change in feelings we expected to see, based on the previous work, were not borne out in this study. We suggest that this may be due to the fact that the women have not processed the information and that currently it is not relevant enough to change their view on more important and personal subjects such as abortion.

Similarly, the subject of POF was only relevant in our findings inasmuch as it was relevant to the women at that particular time. Questions specific to POF were included in the in-depth interviews based on findings from our previous focus groups. As each woman was processing the questions during the interview, the idea of their own reproductive fitness was a specific tangible idea and a topic of strong concern. However, the idea of POF was not such a strong concern that it was the reason why they sought out testing (or would seek out carrier testing).

Study Limitations

There are two primary study limitations. First, the women who were interviewed are not necessarily representative of the general population. They had to consent to participate in a research protocol that was not population-based and for which there was no method to identify the reason that women did not participate in the survey. Second, these women were recruited and tested as part of a research study. We recruited them—they did not come to us seeking genetic testing. Thus, the setting was different from what would occur for a population screening protocol in a medical setting. Nevertheless, the intention of this and any qualitative study is to provide data for insight and direction based on the perceptions and opinions of these women. Although we recognize that the results cannot be generalized to

the population, we made every effort to represent the widest range of opinions possible. This report is meant to summarize the major patterns and themes in the data.

CONCLUSIONS

When disclosing carrier results to women in the general population, genetic counselors should be mindful that women may not recognize the immediate importance of this information, even when literature is provided and discussed prior to obtaining a sample. As part of comprehensive genetic counseling, counselors should identify the reproductive life stage of the woman receiving the new information and help her identify when this information would be useful. Counselors can assist in setting up a personalized road map with specific types of services that will be more applicable to the woman as her carrier status becomes more relevant.

If population genetic screening of reproductive age women is offered, women may view knowing their risk for POF as a tangible benefit from the test. Finally, the atmosphere in which carrier screening is offered will affect the relevance of this information. If offered in a medical setting rather than through research, the reactions and processing of the results could be different than what we found in our study.

Future studies should re-evaluate attitudes for population carrier testing with the added information on the risk of the premutation associated, late-onset tremor/ataxia syndrome (FXTAS). Some may consider that such studies should be done once more information is obtained on FXTAS with respect to the natural history among men and women and associated risk factors. However, the potential for population screening is being evaluated now. Thus, studies should move forward quickly. Lastly, additional studies need to be conducted among other cultural/ethnic groups that make up a large proportion of the United States population. Attitudes may differ significantly and will point to different education needs.

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