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Negotiating Desires and Options: How Mothers Who Carry the Fragile X Gene Experience Reproductive Decisions

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Abstract

This paper contributes an empirically-based analysis of how women negotiate reproductive desires and constructions of risk in light of genetic information for a single gene disorder with known inheritance patterns. Fragile X syndrome (FXS) is the most common cause of inherited intellectual disability and female carriers have a 50% probability with each pregnancy of transmitting the FX gene. We present data from interviews conducted with 108 mothers across the U.S. who participated in a longitudinal, mixed methods study on family adaptations to FXS and who have at least one child with FXS. Women's accounts of their reproductive desires, actions, and reasoning indicate that the known 50% risk of transmitting the FX gene was a powerful deterrent to attempting to have more children through unmediated pregnancy. The majority (77%) decided not to have any more biological children after carrier diagnosis. This decision often required revising previous plans for how many children they would have, how and when they would have them, and what kind of mothers they would be. However, genetic risk was not a primary consideration in the reproductive calculations of 22 women who chose to continue planned and unplanned unmediated pregnancies. Though women's reproductive negotiations are constrained by medical discourse and practices, they are also unpredictable and emerge out of lived experiences and sometimes ambivalent ways of reckoning. While increased availability and accuracy of genetic information and testing contribute to certain forms of family planning that prioritize genetic risk management, we also find that some families call upon alternative understandings and desires for making a family to articulate genetic risk and negotiate their reproductive futures.

Keywords

USA; reproductive decisions; fragile X syndrome; genetic risk; mothers; women

Introduction

A variety of personal experiences, familial demands, and cultural forces shape reproductive desires, defined by Belanger (2006) as a vision of the ideal number and gender of children to bear, hopes and aspirations for one's reproductive life, and satisfaction with or regrets for past choices or outcomes. Pressures to reproduce (or not) in certain prescribed ways may be

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powerful; but the ways in which women actively negotiate their reproductive desires and options and co-produce or contest these larger societal forces and discourses are equally compelling (Browner, 2001; Ginsburg and Rapp, 1991, 1995; Lock & Kaufert 1998).

One powerful field within and against which women negotiate reproductive options is medical genetics. The discourse of medical genetics, which includes its language, practice, and materiality (Foucault, 1994) as well as the potential of medical genetics for treatment, cure and disease prediction, has lived consequences as it circulates throughout the research lab, clinic, public sphere, and into the private realm where reproductive paths are forged (Latimer et al., 2006; Lock & Farquhar 2007; Wilce 2009). Rapidly increasing discoveries of genetic causes of disease amplify notions of reproductive risk and individual responsibility for managing that risk (Hallowell, 1999a; Heyman et al., 2006; Kerr & Cunningham-Burley, 2000; Lemke, 2002). When one is diagnosed as a carrier of a disease with significant physical or cognitive implications, predominant socio-medical narratives frame one's reproductive decisions in terms of genetic risk and responsibility (Novas & Rose, 2000; Rose, 2001), holding individuals accountable for evaluating their genetic risk information and acting accordingly (Browner et al., 2003; Kerr, 2003; Polzer, Mercer & Goel, 2002; Raspberry & Skinner, 2007; Robertson, 2000). Depending on the disorder and the degree of risk, "acting accordingly" is most often interpreted as not taking the chance of transmitting defective genetic material and reproducing a child who could be affected.

Genetic risk, however, is inherently uncertain as both reproductive risks and potential health outcomes are given in probabilities that leave room for multiple interpretations and social constructions of risk, and in turn, other forms of reproductive decisions that can be counted as responsible (Raspberry & Skinner, 2011). Even for single-gene disorders like Huntington's disease (HD) or fragile X syndrome (FXS the most common cause of inherited intellectual disability) for which penetrance and prognosis are well-known, individual or familial constructions of reproductive risk may not coincide with the statistical probabilities given by medical genetics. Some of this divergence likely results from different understandings of probabilities communicated by genetic professionals (Hunt, Castañeda & Voogd, 2006; Michie, Lester, Pinto, & Marteau, 2005), and constructions of "the odds" within lived experiences of risk and uncertainty. As Cox and McKellin (1999) found for families at risk for HD, the construction of hereditary risk and its relevance were shaped by complex social, biographical, and temporal factors that went beyond a Mendelian calculus.

Parents who have already had one child with a genetic condition are a valuable group in which to examine reproductive decisions, as their constructions of reproductive risk are made in the context of the experience of raising an affected child (Kelly, 2009). Here we continue this line of inquiry through a study of 108 families of children with FXS. FXS is a single gene disorder caused by mutation of the FMR1 gene on the X chromosome. Although variability exists, males with FXS usually exhibit moderate to severe intellectual impairment and a range of language, social, and behavioral difficulties (Hagerman & Cronister, 2002).Females may exhibit no symptoms but often display mild to moderate cognitive delays and problems with attention (Bailey et al., 2008; Loesch, Huggins, & Hagerman, 2004). Amidst this variability in prognosis, is the certainty that children of a female carrier have a 50% chance of having the syndrome or being a carrier. (A man has a 50% chance of passing the FX gene to his daughters, but only in its carrier state.) This pattern of inheritance and the potential severity of FXS make reproductive decisions highly salient for carriers and their families.

Our focus in this study is how women who have the fragile X gene and their partners make sense of scientific odds and reconcile their perceptions of reproductive risk with their desires to make a family. In this analysis, we do not regard reproductive decisions as rational

calculations, nor as unconstrained "choice." As Reuter (2007, p. 238) contends, in the context of today's geneticization, a "new biopolitics of risk" constrains choice and agency regarding how one uses genetic information. We approach these decisions, and these mothers' narrations of their decisions, as complex and situational negotiations that vary over time and circumstances (Cox, 2003; Downing, 2005).

The Study

For this analysis, we examine data from interviews conducted with 108 families across the United States who participated in a longitudinal, mixed methods study on family adaptations to FXS (see Bailey, Sideris, Roberts, & Hatton, 2008; Wheeler, Skinner, & Bailey, 2008). Fifty-six percent of the families were recruited through existing studies at the University of North Carolina at Chapel Hill and the university's online FXS participant research registry; 16% were recruited from a FXS parent listserv and family support groups; and 28% were recruited through other investigators in the field of FXS who gave our recruitment materials to participants in their studies. Recruitment material invited participation in a study examining how families' lives are affected by having a child with FXS. This recruitment strategy resulted in families from 29 states in the final sample. All regions of the U.S. were represented. The study was approved by the University of North Carolina Sociobehavioral IRB.

Mothers were the primary respondents. They ranged in age from 20 to 49at the initial interview with most being of reproductive age when their children were diagnosed with FXS. Of the 108 women, only 21 had made an explicit choice not to have another child before finding out their carrier diagnosis. All but four women had one child with FXS before learning they were carriers. Two-thirds (66%) had one child with the full mutation FXS, 29% had two children with FXS, and 6% had three children with FXS. Of the 108 children who were the focus of the assessments, 91 (84%) were male. Approximately one-third (32%) of the families were low-income (defined as below 200% of poverty guidelines). Eighty-four (77%) mothers were white, 21 (19%) African American, 2 (2%) Hispanic), and 1 (1%) was of Middle Eastern descent.

Methods and Analysis

Research assistants conducted three semi-structured interviews with each mother from 2003 to 2007. Women were interviewed when they joined the study, and 18 and 36 months later on a range of topics of interest to the larger project, including their understandings of FXS, perceptions of their quality of life, child-rearing strategies, sources of support, and how FXS had affected different aspects of their lives. We asked explicit questions about their past reproductive choices and future reproductive plans. These interviews were conducted in the family's home and lasted about 90 minutes. They were digitally recorded and transcribed verbatim.

To analyze how these women experienced reproductive choices as carriers of FXS, both authors read each semi -structured interview to gain a holistic sense of how they described their reproductive experiences, negotiations, and desires. The first author then systematically collated and recorded in data display matrices (Miles & Huberman, 1994) women's responses regarding how their reproductive decisions were influenced (or not) initially when learning they were carriers; their understanding of reproductive risk; and their accounts of the experiences and meanings that accompanied their choices, including their sense of ambivalence about knowing and choosing. Their responses were mapped across the three interviews for each family. Using the constant comparative method (Strauss & Corbin, 1990), we then extracted reproductive themes within each mother's account, compared these

across mothers, and modified our interpretations of how these mothers talked about and enacted their reproductive desires, options, and decisions.

Understanding Odds and Reproductive Risks

When a woman is diagnosed as a carrier of the FX gene, decisions about her own and her family's reproductive future often move from the realm of private desires to a more public discourse of risk, responsibility, and fate. Female carriers have a 50% probability with each pregnancy of transmitting the FX gene. In this section, we examine how women understand and negotiate these "odds" in light of their desires to make a family.

Overall, women's understandings of their risks for having another child with FXS reflected biomedical knowledge of the genetics of fragile X, in conjunction with metaphors of chance and religious beliefs about God's purpose. Most referred to the 50% probability as a risk to be managed and controlled, primarily by not reproducing. Rachel, mother of a three-year-old son with FXS, explained that since she did not want to have another affected child, she was unwilling to risk this happening:

> I wish it were something where you could just have more kids and you'd know they'd be okay. Or you wouldn't have to have that fifty-fifty chance of they could have it, they may not have it. Because as much as I love [my son] and love having him in my life, I can't say that I'd want another kid with fragile X.

Notably, 62 of the 108 families decided not to have more biological children after learning their risk of passing the FX gene (another 21 families reported they had made this decision before the diagnosis). For more than half of the families then, knowing their risk was a deterrent to an unmediated (i.e., not technologically assisted) pregnancy.

Along with references to their fifty-fifty odds, mothers also talked about reproductive risk in terms of gambling metaphors, luck, and chance. These expressions may derive in part from biomedical and genetic counseling explanations of reproductive risk, but they also are common ways of understanding life risks in general. For example, Michelle described her use of preimplantation genetic diagnosis to conceive three children as an attempt to avoid "the gamble" of transmitting the gene: "Well we knew before we got married, and we just figured we would not be having any of our own kids because I was not willing to take the gamble." Kim, who continued an unplanned pregnancy and now has two daughters with FXS, described her unwillingness to "deal the cards" again. The majority of mothers employed gambling metaphors to describe a heightened awareness of reproductive risk, one to be avoided by preventing future pregnancies. Some mothers, however, knew the odds but were willing to take a chance. Karen used the same gambling metaphors but with a different outcome. She explained her decision to have more children: "It was like, 'I can handle this. Let's just roll the dice again and let's see what we get.'"

The 50% probability of transmitting the FX gene is a predictable one from a medical genetics perspective. However, whether it will be transmitted on any particular "roll of the dice" is an unknowable and chance occurrence. For example, Patricia, who knew she was a carrier before having two children, explained her reproductive risk as both known *and* subject to chance: "We worked with a genetic counselor. Pretty much drew a simple grid—boys and girls—and the statistics on having them. Kind of a roll of the dice." The genetic counselor's grid allowed Patricia to "know" her risk of having a child with FXS, yet when her daughter inherited the gene but her son did not, Patricia invoked chance: "I mean it's just genetic. It's not something I brought on myself. It's just the way the cards are dealt." Despite understanding the statistics of risk, Patricia characterized her children's genetic inheritance as the deal of a "genetic hand," a matter of unpredictable chance.

Chance may be out of one's own control, but subject to a higher power. Religious metaphors were frequent in talk about reproductive risk. Notably, women did not make religious references exclusively, but in combination with talk of statistical odds. Thirty-one women contextualized these odds within God's design or plan. Martha, who knew she was a carrier before having children, spoke of her confidence in God's plan as a basis for why she twice decided to become pregnant: "When we were deciding whether or not to have kids after I got my diagnosis, we did turn to religion a lot, and we looked at scriptures like, 'We'll never get more than we can handle.' 'That things are for a purpose.'" Attributing gene transmission to a divine purpose can lessen the unpredictability of "chance", provide a rationale for taking that chance, and introduce a sense of control over the situation, though the control is given up to God. At the same time the outcome is unpredictable since one does not know what God's hand will deal. Lynn, who purposefully had a child after her first was diagnosed and now has two boys with FXS, explained that though she and her husband were not planning another pregnancy, they would accept another child as part of God's plan: "So if the Lord somehow intervened and I did get pregnant, we would just know that that's His plan, and we'd deal with that and pray that He gave us a child we needed."

Unlike the notion of "rolling the dice" and seeing what might happen, perceptions of FXS as part of "God's plan" can thus confer the quality of a predetermined genetic fate or destiny. Reproductive risk is still unpredictable in the sense that one does not know God's will or one's genetic fate until it happens, but the responsibility for the outcome is in God's hands. The decision is already made. Those who hold this belief, however, do not always see God's will as particularly fair or reasonable. Mary, who had two sons with FXS, voiced her frustration with what she viewed as God skewing the odds:

> When I am having a hard time, I'll be like, I'll ask God: "Why did you give me two children." I mean that it's unfair. It's not like I have one child. It's like, "You have given me this thing that's 50/50 and I've had two miscarriages…and then two children affected with this" …so it's like, my gosh, even though it's 50/50, it doesn't seem like it.

In these instances, reference to "God's will" helps to explain the genetic outcome. On the other hand, the majority of women who talked about God's plan in terms of the child already born also decided not to have more children, suggesting through their actions that there were limits to allowing God to intervene and decide their genetic legacies.

Mothers' perceptions of risk changed over time in relation to their reproductive experiences. Some constructed their future reproductive risk as elevated if they had already given birth to two or more children with FXS. Daria explained that since she already had two children with FXS, she saw her chance of having a third child with the syndrome as greater than 50%: "I've only wanted two all my life if I was to ever have kids. But now that they've both got it, I've got even more chances for another kid to come out even worse, and I don't want that to happen." For Daria, this notion of elevated risk also included elevated severity—a third child could be more severely affected than her first two. It is worth noting that although the transmission of the FX gene from a carrier mother can result in either carrier *or* full mutation status, and that a girl with FXS would likely be less affected, mothers did not take gender or mutation status into account; they talked almost exclusively in terms of their risk of having an affected child.

In summary, we found that these women's accounts of their reproductive risk included statistical ratios of "a fifty-fifty chance," gambling metaphors such as "roll the dice" and "deal the cards," and for some, religious-based explanations such as "part of God's plan." These different illustrations of risk, while not mutually exclusive, invoke particular notions of individual responsibility, control, and genetic fate or chance. In the following sections we

explore these notions further through women's evaluations of their reproductive options and their reasons for taking the action they did.

Forging and Following Reproductive Paths

The ways in which women viewed their reproductive options were inseparably linked to their interpretations of risk and chance. Yet the narrow scope of feasible options calls into question how much "choice" they actually had. Although not everyone was aware of all possible options, reproductive "choices" included unmediated pregnancy, assisted reproductive technologies such as in-vitro fertilization (IVF) with preimplantation genetic diagnosis (PGD), prenatal testing, adoption, and not having children. As we discuss below, mothers' deliberations indicate that in practice the evaluation of these options as personally viable often depended on religious values and other moralities; past experiences; financial and emotional resources; values of family; and understandings of reproductive risk. An acceptable option for one woman not to have children at all–may be unimaginable to another.

For two-thirds (73), being diagnosed as a FX carrier played a principal role in how they constructed their subsequent reproductive choices, with most deciding that the risk of passing on the FX gene was one they did not want to take. In contrast the other 35 women said that the diagnosis did *not* influence their reproductive decisions in any way, although 21 clarified that they had decided not to have more children before they found out their carrier status.

For most women, the diagnosis destabilized their ideal of how many children they would have, how and when they would have them, and what kind of mothers they would be. Not only did they revise their images of family, but they also changed their ways of family-making. Their reproductive calculations took into account a combination that included reproductive risk; emotional and financial impact of another child with FXS, including their ability to handle their existing child's future needs; and the likely social judgments they would incur if they knowingly took a risk and conceived a child with FXS. Under the weight of these concerns, the majority of families (77%) did not try to have any more biological children though for most, this decision was neither easy nor straightforward.

Negotiating Reproductive Desires and Acts

The complexity of negotiating reproduction as a carrier of an X-linked disorder was reflected in women's accounts of their desires and experiences through time. Elizabeth, mother of a three-year-old boy with FXS, likened the disappointment of learning her carrier status to that of having infertility: "It's kind of in a way finding out that you have infertility …which unless you're willing to roll the dice, you're not going to conceive a child the way you thought you were going to, the way you always dreamed of it." Reluctant to take the risk but wanting a second child, Elizabeth and her husband pursued different options and eventually adopted a girl from China (after a failed attempt at IVF with PGD). Like those who experience infertility, women often found themselves considering, and trying, ways to have a child other than through an unmediated pregnancy, alternatives that had not figured into their previous plans for making a family. For others, an unintended pregnancy resulted in rethinking their already revised reproductive futures. Joanne recalled that after finding out her son had FXS, she decided against having a second child, but that her plans changed again when she became pregnant despite using birth control:

> The knowledge that I was a carrier very distinctly is the reason why [my husband] and I made the decision not to have more children…I was on birth control and we were not going to have any more children and that 0.1 percent chance happened,

> and Amy was conceived despite my being on birth control. And I'd say that's where religion comes in and feeling like everything happens for a reason and that there must have been a very significant reason that she's joining us.

Joanne reasoned that a divine purpose guided the pregnancy and birth of her daughter (who has FXS), one that superseded her contraceptive intentions. Other women continued unplanned pregnancies after prenatal testing gave negative results (6) or provided the information that they would have another child with FXS (6). As indicated by these mothers' experiences, a diagnosis transformed a familiar reproductive terrain into an unknown geography, one that required them either to explore reproductive paths that diverged from former expectations, or not to travel those paths at all.

Stacy's account of her own and her sisters' experiences further exemplifies the complexity of navigating reproductive options and desires, and highlights the conflicting motivations that enter into determinations about whether and how to have children. Stacey recalled that she was pregnant when her 15–month-old son was diagnosed with FXS. She informed her four sisters that they could be carriers, and advised them to be tested. After receiving a positive amniocentesis for FXS, Stacey terminated that pregnancy. She reflected that raising two babies with FXS was more than she and her husband felt they could manage at that time. However, Stacey also emphasized that they definitely wanted to give their son an unaffected sibling either using IVF with PGD, or prenatal testing and pregnancy termination. Being a carrier did not thwart her desire for another child, but motivated her to explore ways of doing so without passing on the FX gene.

Three of Stacey's sisters also tested positive as carriers, while the fourth, because she planned never to have children, decided to forgo testing. Of the two sisters who found out their carrier status before having children, one chose to utilize IVF—first with PGD and her own eggs, then through IVF with egg donation—and became pregnant on the second attempt. The other sister also wanted children, but for her, reproductive and genetic technology options were not feasible because of their high costs. She did not consider taking a chance as an alternative, and expressed uncertainty about having children at all. A third sister who already had two unaffected boys when she learned her carrier status decided not to have any more children. Notably, although Stacey and her four sisters each took different approaches in the ways they used genetic information, they all agreed that they did not want to transmit the FX gene. Stacey explained: "You could stop it from generation to generation. Like my family – that's one thing we did say, no one will carry – you know, we do want to stop it with our generation." This pledge is indicative of how the authority of genetic information reverberates on individual as well as familial levels. All five sisters decided to act in a way that interpreted risk unequivocally to mean not chancing reproduction.

This decision not to reproduce was enacted by 62 women who wanted more children. Some took measures to ensure they would not unintentionally become pregnant, like tubal ligation and vasectomy. Daniela, mother of a seven-year-old son, explained that the diagnosis pushed her husband to have a vasectomy even though they had previously envisioned having four children:

> We had always talked about having four kids. Thinking about having four Marks running around is like "Oh, yeah. Right." And that changed drastically when we found out about Mark. In my mind, there was no question that we were not going to have any more kids biologically. It took [my husband] a little longer to come to that conclusion.

For families who had left open the possibility of having another child, the diagnosis provided a decisive reason to close that door. Sarah, who has two children with FXS, explained the impact of her youngest son's recent diagnosis: "We've made the decision not

to have any more children because of the fragile X being in our family. Not that – I don't know that we would have had any more children, but we were debating. But I don't think we will because of that now." Sarah's comment not only points to the deterrent effect that a diagnosis can have, but also emphasizes the construction of fragile X as "*being in our family.*" The heritability of FXS had a profound effect on the "choices" women viewed as open to them. For many, finding out carrier status propelled them prematurely towards a definite decision not to have more biological children, a formerly undesirable option.

Alternatively, some women were open to having another child: there were mothers like Stacey who were evaluating different options for having a *biological* child, others who were more ambivalent about their plans, and a small number (10) who purposefully chose to initiate an unmediated pregnancy. For those who remained undecided, the diagnosis changed their outlook on having children, but had not led to a definite resolution. Barbara, a mother of three boys (the two youngest have FXS), was considering PGD as an option:

> I would desperately love to have another typical child. I'm not willing to take the risk of having another fragile X child. We've talked about the pre-implantation genetic diagnosis. [My husband] is not sure that he thinks that it's normally appropriate. I said, "God messed with us so we can mess back!" is my comment. You know, my reasons for having kids are totally different now. I want a typical sibling for Andy [unaffected oldest son], and I want someone to help Andy… I'm not sure those are appropriate reasons to have another one.

Barbara's comments reveal the multifaceted motivations and rationales that often pulled these mothers in different directions. While unequivocal about not taking a risk on an unmediated pregnancy, Barbara also expressed her profound desire to have another typical child, but reflected on whether her reasons for expanding the family were justified. She was unwilling to place her reproductive future in God's hands, though her husband had reservations about using reproductive technology. In the face of these conflicting desires and self-reflection, some mothers chose not to choose until time resolved the issue for them.

There was a small group of women who were neither ambivalent about, nor steadfastly opposed to, having more children. Ten women purposefully planned to get pregnant, regardless of the risk. They gave various reasons for this decision, including the hope that they would be lucky, their faith in God's plan, and their acceptance of all children, disabled or not. These women talked about wanting to have a "typical child" or a larger family or giving their current child a sibling. They accepted the possibility of having another child with FXS, as well as emphasizing the 50 percent chance that they would *not* pass on the gene. In contrast to those who ruled out an unmediated pregnancy, these "risk-taking" women focused more on their desires and the positive reasons to have another child, rather than on fears of transmitting the FX gene. When Evelyn made the decision to get pregnant, she already had a son with FXS and a daughter who is a carrier. Evelyn was against pregnancy termination and refused prenatal testing, preferring to accept "what God gave us": twins, a boy and a girl who both have FXS. Evelyn explained that at the time of her decision, her "ticking biological clock" and longing for a large family were stronger motivations than any worries about risk. Though Evelyn continued to place high value on a large family, she acknowledged feeling the weight of carrying the FX gene more heavily after learning her twins' diagnosis and that all four of her children had inherited the FX gene.

For Catherine, taking a risk on an unmediated pregnancy was not her first choice, but over time it represented the most direct way to give her son the sibling she wanted him to have:

> We decided to have another child—went through the whole PGD process. That didn't work so we just decided that it was important for Ben to have a sibling

> regardless. And if we had two kids with fragile X, then at least they would have each other. That's kind of how we looked at it so we decided to do that and he does not have fragile X.

Catherine emphasized that although her second son did not inherit the FX gene, she and her husband had been open to that possibility and would have been happy "either way."

Some mothers talked about their decisions to have more children, regardless of the outcome, within a context of valuing all life no matter how different it might be. Even after her son and daughter were diagnosed with FXS, Beverly initiated an unmediated pregnancy because of her concern that to pre-select an unaffected pregnancy would indicate a negative valuation of her children:

> And we're pro-life and if we didn't have more, that would be saying Robert [oldest boy] and Jessica [oldest girl] weren't worth it. Or if we tried to do something different, it would be saying "They're not good enough for me. They're not good enough for us."

Beverly's deeply held values of family and all forms of life led her to become pregnant three times after learning she was a carrier. She gave birth to two more boys (one with the full mutation and one who is a carrier) and a daughter (who did not inherit the FX gene). Although exceptional, Beverly's choice reflects the diversity of positions, values, and experiences that women engage with in making reproductive decisions (see also Raspberry & Skinner, 2011).

In negotiating their reproductive futures, families balanced different, and sometimes conflicting, circumstances, values, and outcomes. Alongside visions of a large family, they weighed their fears of having a severely affected child, willingness to use prenatal screening, calculations of the odds, and faith in God's plan. Such calculations were not easy and straightforward. Reproductive paths were necessarily forged in the midst of various circumstances, one twist among many in the flow of life. Even women who had made a firm decision sometimes expressed ambivalence about their choices. This sense of ambivalence was even more pronounced in women's musings about what they would have done if they had known they were carriers before having any children.

Ambivalence and Genetic Knowledge

Women's musings on hypothetical reproductive scenarios prominently underscore their feelings of ambivalence when trying to reconcile reproductive choices with desires for larger families. While most avowed that a person has a "right to know" her carrier status, they were more uncertain regarding the best time for learning this information, particularly as it pertained to themselves and how this information might have impacted their reproductive decisions. Valerie, who has three sons (one has FXS, one is a carrier), expressed the inherent difficulty in determining the ideal timing:

> I mean a part of me says yes, I would have wanted to know. But then the other part of me is glad that I didn't because I might not have had any children or the children that I have, and I wouldn't trade one of them for anything, not even Josh [who has FXS]. So I love them just as much. But personally I feel like people have a right to know as soon as that information is out there.

Like Valerie, most women in part wished they had known they carried the FX gene before having children, but also were concerned about how that information would have reconfigured their families. They affirmed that finding out carrier status before having children would have been preferable, yet simultaneously were thankful that they did *not* know beforehand. Almost all said that they might not have had the children they love today

if they had known earlier that they were carriers. Carrie, a mother of two sons with FXS, expressed her "mixed feelings :

> Well me personally, I'm not sure that I would have wanted to know just because I don't know if I would have ever had the children...But at the same time, I think it would have been nice to have been given that option, you know, to decide. But it's kind of a mixed feeling about the whole thing. I don't know because you can say, "I would have liked to have known before I had them," but at the same time I probably wouldn't have had them.

Overall, most women asserted that knowing they carried the FX gene before having had children would have made an irrevocable difference in their lives, a difference that many found challenging to contemplate. We suggest that this "hard hypothetical" derives in part from the tension between a sense of responsibility of not wanting to risk transmitting the FX gene to one's progeny and deep-seated values and dreams of having children and a family—a tension that is perhaps without resolution. It is difficult to imagine a decision that would lead to a life in which one's children did not exist.

Conclusion

This paper contributes a nuanced analysis of a range of reproductive choices over time in families who have a child with an inherited disorder. We found that women's reproductive negotiations, as others have shown for prenatal testing (Markens, Browner & Preloran, 2010; Markens, Browner & Press, 1999; Reid et al., 2009; Rapp, 1999), are constrained by medical discourse and practices, but are not always predictable as they also emerge from lived experiences and sometimes ambivalent ways of reckoning. Women's accounts of their reproductive desires, actions, and reasoning in light of knowing they are carriers of FXS indicate the range of factors that contribute to understandings of reproductive options and futures, and the diversity of how genetic information may be taken up and used. The ability to care for another child with FXS; emotional and financial impact on the family; elevated senses of risk; willingness to use prenatal screening or other technologies to eliminate the risk; leaving the choice up to God or fate; desires for a typical child who could aid the affected child; valuing diversity and not devaluing disability—these were primary considerations that families did not simply enter into an equation, but weighed and felt daily through lived experiences of parenting a child with a disability. Their accounts also make clear the conflicts that arise from putting genetic knowledge into practice, and the complexities of reconciling desire and risk.

It is not surprising that the majority of women viewed the 50 percent risk of transmitting the FX gene as a powerful deterrent to having more children. Choosing not to reproduce, or to reproduce only with the assistance of technologies that eliminate the known genetic risk, indicates these women were acting in ways that some have described as characteristic of the genetically responsible citizen, one who is unlikely to reproduce if at risk for a serious genetic condition (Kerr and Cunningham-Burley 2000; Lemke, 2004). In the present study, genetic information has affected the kinds of families reproduced, shaping the genetic bodies of one's own and possibly one's relatives' progeny. There productive actions of the majority of families support the position numerous social theorists and bioethicists have predicted (Alper et al., 2002; Andrews, 2001; Duster,2003): that as genetic testing increases prenatally and for carrier status, more families will make choices not to risk reproducing known genetic markers of disease and disability.

Yet the reproductive actions of a substantial minority offer an interesting counterpoint to this argument. The accounts of women who initiated or continued unmediated pregnancies indicate that religious beliefs intertwined with the roles of risk, gambling, and chance

informed their choices and moral reckoning for their actions. While all women portrayed themselves as being responsible mothers, making "appropriate" choices, and "doing the right thing" (Hallowell, 1999b), they also characterized their decisions as individual ones not to be imposed on others. The "risk-takers," though, countered censure of their choices with explicit valorization of their roles as mothers who loved and appreciated all their children, a rejection of value distinctions between those with disabilities and those without, a sense of increased empowerment and life purpose, a heightened awareness of their own parenting strengths and limits, and for some, a willingness to accept God's will (see Raspberry & Skinner, 2011). Whether the reproductive actions of this risk-taking group of women qualifies as resistance to a genetic moral order, and their accounts read as an authoring of "alternate stories about risk, morality, and choice" (Leontini, 2010, p. 16) is open for debate, but they do reveal the complexity and heterogeneous ways that genetic information may be given meaning literally to conceive the desired family.

Studies of families of children with disabilities show how parents construct a variety of beliefs that help them make sense of disability and confer value on their child and their lives (Kelly, 2005; Landsman, 2003, 2005). In this study, all but four women learned they were carriers after having a child affected by FXS, and therefore confronted their reproductive futures having gone through this process. The personal experience gained from parenting a child with FXS may have provided more clarity to a decision either not to have, or to feel capable of raising another child with FXS. These experiences also may have made some mothers disinclined to rely on prenatal testing for selective purposes. Carriers who do not already have a child with FXS may have more uncertainty about the stakes of passing on the syndrome (see Kay & Kingston, 2002). Yet ambivalence was not absent from women's accounts, being particularly reflected in how they responded to the "hard hypothetical," expressing some desire to know their genetic status before having children, but recognizing the unimaginable outcome that this may have kept them from having the children they now love. It is also important to note that some of the mothers found out their carrier status many years prior to our first interview with them. Whether the *retrospective* telling of reproductive decisions make such negotiations seem more certain or uncertain than they were originally is something we cannot answer.

Also notable were how religious beliefs were narrated along with notions of probability and "the odds", and how reproductive outcomes were a matter of faith for many families. Although we interviewed families across the U.S. and from a range of income and education levels, we do not know if they are representative of those who have an identified child with FXS or children with other inheritable genetic disorders; and we do not know if a true representative sample would view disability within a religious worldview to the degree we found. Our sample was predominantly Christian (25% Catholic and 61% Protestant), but only slightly more so than the U.S. population as a whole. Religion is a pervasive and enduring feature of American life, and Americans are by far the most religious of all the highly industrialized nations (Pew Global Attitudes Project, 2002), so it should not be surprising that nearly one-third of the women framed their reproductive outcomes in terms of "God's plan," transferring responsibility to God for their past and potential children's genetic status. The notion that "things happen for a reason," including whether a child will be born with FXS, can serve not only to relieve one of personal responsibility for reproductive outcomes but also provide a sense of security and control in an otherwise uncertain situation of chance events (see also Michie & Skinner, 2010). Given the small number of families from non-Christian traditions, we do not know how other religious beliefs may intersect with reproductive decision-making. Neither can we say how our findings compare with studies on populations outside of the U.S., where religion may play a lesser or greater role in family planning. This research is yet to be done.

These families are homogeneous by genetic condition. The specifics of the condition—its severity, penetrance, age of onset—all have implications for reproductive decisions. Being a carrier of Tay-Sachs disease, an inherited neurological disorder that results in early death entails different reproductive negotiations and considerations than for example being a carrier of hereditary deafness. The conclusions drawn here are based on specifics of FXS, but also speak to broader questions of the uses of genetic information to inform the kinds of families being produced, and the ways families negotiate these reproductive "choices" in light of known genetic risk.

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