



NIH PUBLIC ACCESS

## Author Manuscript

*Intellect Dev Disabil.* Author manuscript; available in PMC 2011 July 5.

Published in final edited form as:

*Intellect Dev Disabil.* 2010 April ; 48(2): 99–111. doi:10.1352/1934-9556-48.2.99.

## Narrating Disability, Narrating Religious Practice: Reconciliation and Fragile X Syndrome

**Marsha Michie**[Research Assistant] and

Center for Genomics and Society, University of North Carolina-Chapel Hill, 27599-7240

**Debra Skinner, PhD**[Senior Investigator]

FPG Child Development Institute, University of North Carolina-Chapel Hill, 105 Smith Level Rd., Chapel Hill, NC 27599-8180

Marsha Michie: michie@unc.edu

### Abstract

This article examines the place of religion in the narratives of mothers of children with fragile X syndrome. In semistructured interviews, a majority of women combined narratives of religious practice with illness narratives, interpreting their children's disabilities within a religious framework. Informed by Arthur Frank's (1995) concept of "wounded storytellers," the authors articulate a *reconciliation narrative* that mothers commonly used to describe their transition from viewing disability as a burden or challenge to seeing it as a blessing, or as a part of God's purpose or plan for their lives. The authors discuss the significance of narrative for better understanding religious perspectives on disability and conclude with the implications of these findings for practitioners and future research.

---

It's so funny how the blessings come. Like now I feel like the luckiest person in the world to have been able to experience Danielle and how much joy she brings. But at the time that I'm sleep deprived and postpartum and breastfeeding and just, like, trying to get a shower in, the word "blessing" never at all came to mind. ... Yeah, I do feel like religion plays a big part in helping you handle it or understand it, but not initially. It comes later.

—Karen, mother of a 2-year-old girl with fragile X syndrome

Karen (all names in this article are pseudonyms), like most mothers, found a great deal of joy in her children. Deeply religious, she often referred to herself and to her family as "blessed." However, unlike most mothers, Karen knew that Danielle, her 2-year-old daughter, might never go to college, get a job, or get married and might require someone to care for her throughout her life. Danielle's developmental delays and challenging behaviors required continual attention. Nevertheless, Karen said she felt blessed. While talking with an interviewer, she wove religious understandings of Danielle's disability into her accounts. As such, her *disability narrative* became a narrative of religious practice as well, a story in and through which Karen made spiritual meaning out of raising a child with a disability. This article examines a body of such narratives, stories in which both religious and genetic understandings shape families' experiences of a genetic disorder and its place in their lives.

Medical anthropologists study narratives of illness or disabling conditions as a means of chronicling personal experiences and as a way that people create understandings and manage emotions around these experiences (Frank, 1995; Kleinman, 1988; Mattingly & Garro, 2000). Individuals use narratives to reframe their perspectives on disability and, in so doing, enhance their coping strategies, create a sense of well being, and generate an acceptance of disability as a part of life (Traustadottir, 1991; Turnbull et al., 1993). Having a

child with a disability may cause parents to reformulate notions of themselves as parents; to engender reflections about the relationship of self, not only to the child, but to larger social and religious worlds; and to reinterpret the past, reframe the present, and anticipate the future (Raspberry & Skinner, in press; Skinner, Bailey, Correa, & Rodriguez, 1999). Narratives are an important source of data for examining how parents construct complex and personal understandings of their child's disability and of themselves in relation to it and a primary key for viewing this meaning-making process (Landsman, 2000, 2005; Mattingly & Garro, 2000).

Similarly, studies of religious life increasingly rely on personal narratives as a way to access lived experience. Suggesting that "there is something fundamentally religious about narrative structure," Roof (1993, p. 298) noted that the very act of creating a story "forces questions of interpretations" (p. 298). Because narratives must place events in a meaningful sequence, they are particularly valuable for studying religious lives as culturally situated, ongoing constructions. The structure a narrator imposes draws on available and acceptable discourses in the narrator's local cultural context, which guide him or her in making those experiences meaningful (Wuthnow, 1997; Yamane, 2000). Narratives with religious dimensions have often been described among people facing chronic illness or prolonged suffering or caregivers to those who are (e.g., Bingley et al., 2006; Frank, 1995; Griffith, 1995). Geertz (1973) observed more than 3 decades ago that all religions must cope with challenges to our ability to interpret and comprehend life, particularly suffering and events we cannot explain analytically.

The role of religion in the lives of families of children with disabilities has been the focus of only a few studies, most of which use measures of religious affiliation and participation as measures of religiosity. These studies have found that religion plays a supportive role for some families, providing both practical and spiritual aid as well as religious education and rituals that are meaningful and comforting to the family (Fewell, 1986; Rogers-Dulan, 1998; Rutledge et al., 1995; Tarakeshwar & Pargament, 2001). In its more personalized form, as faith or spirituality, religion may give individuals strength, patience, and a sense of God as a supportive partner in daily life and stressful times (Fewell, 1986; Pargament et al., 1990).

For the most part, research on parents' responses to having a child with an intellectual disability has focused on possible negative outcomes and has found that this event can increase parents' stress, sense of burden, and depression (Baker, Blacher, Crnic, & Edelbrock, 2002; Baker et al., 2003; Blacher, Neece, & Paczkowski, 2005; Bode, Weidner, & Storck, 2000; Dumas, Wolf, Fisman, & Culligan, 1991; Olsson & Hwang, 2001). The methods used in these studies measured these outcomes quantitatively but were not designed to assess how parents constructed personal, social, and religious meanings around their child's disability—meanings that may have cast the ways disability has affected them and their family in a more positive light.

When parents have the opportunity to narrate their experiences of disability, they may talk about the everyday challenges of raising a child with a disability, but they do not always, or even primarily, focus on the deficits or pathologies of their experiences. Instead, they often describe their child in a more positive and meaningful way and the child's disability as an event that has taught them valuable lessons, made them more tolerant and less judgmental of others, and united the family (Affleck & Tennen, 1993; Patterson & Leonard, 1994; Poston & Turnbull, 2004). They sometimes speak of positive transformations in themselves and their relationships with others and in their perspectives on life because of the experience of parenting a child with a disability (Saetersdal, 1997; Scorgie & Sobsey, 2000; Scorgie, Wilgosh, & McDonald, 1996; Skinner, Bailey, Correa, & Rodriguez, 1999). Parents highlight the strengths of their child while downplaying characteristics that others might

perceive as limitations (Landsman, 2005; Rapp, 2000; Whitmarsh et al., 2007). Those few studies that have asked parents of children with disabilities to talk explicitly about the role of religion in their lives have found that, for many families, religion offers support (Poston & Turnbull, 2004) and an interpretive framework for positive reframing of the experience of disability and its potential purpose in one's life (Skinner, Bailey, Correa, & Rodriguez, 1999; Weisner, Beizer, & Stolze, 1991).

Particularly useful in examining the role that religious perspectives play in shaping narratives of caregiving and disability is the notion of the "wounded storyteller," a person who experiences illness and narrates this experience (Frank, 1995). Widely invoked in studies of illness narratives (e.g., Hinton & Levkoff, 1999; Petersen, 2006), the wounded storyteller gives voice to a body that has been subjected, not only to illness but often to invasive medical treatment. The act of storytelling also creates connections between the teller and the hearer, who, like every other human, is himself "wounded" at some point in his life. In addition, and most important, through this practice, the storyteller recovers/ discovers his or her own voice and story, within and against the official medical "story" of charts, test results, and diagnoses and, in so doing, speaks for others who have not found their voice (Frank, 1995).

Instead of measuring religion in terms of religious affiliation or participation, a "lived religion" perspective gives more importance to the everyday religious lives of individual believers over these religious classifications (McGuire, 2008; Orsi, 1997). From this perspective, religious practices and identities are dynamic, constantly evolving within the contingencies of everyday life, and the notion of "living religion" captures this sense of improvisation and variety (Tyson, Peacock, & Patterson, 1988). Practices may include stereotypically religious behaviors, such as church attendance, or they may be activities of meaning-making that are as simple as telling one's story or informally talking to God. A lived-religion approach attempts to look at people's daily lives the way they themselves do—"making do" in the thick of it, without the benefit of a stable *blueprint* (the way culture has sometimes been imagined). As such, lived religion offers a new perspective on the experience of caring for children with disabilities, a responsibility in which the women we interviewed found a complicated blend of fulfillment and frustration, meaning and disorder. In the analysis that follows, we examine how mothers' illness narratives that make sense of the child's disability also use religious themes and, thereby, become narratives of religious practice.

## Study and Method

This study examined the place of religion in the narratives of mothers of children with an inherited genetic disorder, fragile X syndrome (FXS). We conducted this study as part of a larger investigation of family adaptations to FXS that assessed mothers on a variety of measures related to maternal outcomes (stress, depressive symptoms, anger, anxiety, hope, optimism, quality of life) and responsivity (Bailey, Sideris, Roberts, & Hatton, 2008; Brady, Skinner, Roberts, & Hennon, 2006; Wheeler, Skinner, & Bailey, 2008). For the present study, we analyzed data from a 2004 semistructured interview conducted with a subset of 60 mothers, an interview designed to provide more in-depth information on their adaptations to or experiences of raising a child with FXS. Women were recruited from families in the United States who had at least one child under the age of 12 and diagnosed with full-mutation FXS, which meant that all women in the study were carriers of FX (children do not inherit the full mutation from the father). These women were recruited through existing studies at the University of North Carolina-Chapel Hill (UNC) and UNC's online fragile X participant research registry. We also posted notices on the FXS parent listserv and FXS family support groups. In addition, we distributed brochures to other investigators and

professionals in the field of FXS to pass to participants in their studies. In all of these approaches, the recruitment material was phrased to invite participation in a study that examined how families' lives are affected by having a child with fragile X to learn more about sources of support, perceptions, and resources that affect a family and their ability to best care for their children. Religion as a topic of interest in the study was not mentioned in the recruitment process. Families interested in participating in the study contacted the study coordinator via a toll-free telephone call, e-mail, or return of a prepaid response card. Mothers provided written informed consent for their own and their child's participation in the study.

The 60 mothers who participated in the in-depth interviews ranged in age from 22 to 49 years, with an average age of 36. Of these, 40 were non-Latina White, 19 were Black, and 1 was Latina. Thirty-eight were Protestant, 12 were Catholic, 3 were Jewish, 2 held some other religious affiliation, and 5 had no religious affiliation. Seventeen of the 60 households had an annual income below \$26,000, 23 households had an income between \$26,000 and \$65,000, and 20 had an annual income greater than \$65,000.

Only 2 mothers knew their carrier status before they began having children. (Female carriers have a 50–50 chance of transmitting the FX gene to their daughters and sons.) Their sons who had FXS exhibited moderate to severe intellectual impairment, a range of language disorders, and social and behavioral difficulties, including problems with attention, impulsivity, anxiety, and arousal (see Hagerman & Cronister, 2002). Some also met the diagnostic criteria for autism (see Bailey et al., 1998; Rogers, Hehner, & Hagerman, 2001). Their daughters with FXS were overall less severely affected, but some exhibited intellectual impairments and other characteristics of FXS.

The semistructured interview was designed to explore mothers' understandings of FXS, their perceptions of their own and their children's quality of life, child-rearing strategies, and sources of support. We included a specific set of questions designed to elicit information on religiosity. We asked, "Some people think about an illness or disability in religious terms. Do you think about it this way sometimes? In what way? Do others in your family think about [child's condition] in a religious way? What do they say?" Although references to religion occurred spontaneously throughout the interview, most religious narratives occurred in response to these questions. Interviews were approximately 90 minutes and were digitally recorded and transcribed verbatim. Transcriptions resulted in 1,640 single-spaced pages of interview data.

Mothers also completed a modified version of the Fewell Religion Scale (Fewell, 1986; Skinner, Correa, Skinner, & Bailey, 2001). This scale is organized into two empirically derived subscales: institutionalized religion as a form of social support and religion in its more personalized form as beliefs and faith as a support. We modified the wording of the questions to reflect current use and our focus on fragile X (e.g., "child with fragile X" instead of "handicapped child"). We also modified the scale by adding three items to assess self-reported religiosity, religious affiliation, and frequency of participation in church. These items were not part of the subscales and were analyzed separately. For all mothers, Cronbach's alpha coefficients on the subscales were .87 (Institutional Support) and .93 (Personal or Spiritual Beliefs), indicating that the two subscales of the adapted Fewell Religion Scale were internally consistent. This scale was administered approximately 6 months before the interview as part of a set of quantitative assessments to measure family adaptation to FXS. Although it is possible that the scale and other measures influenced mothers' responses in the interview, the length of time between administration of the measures and the different nature of the wording of the items and the interview questions decreased the likelihood that mothers' narratives were influenced by the religion scale.

Our examination of narratives in the semistructured interviews was informed by Frank's (1995) discussion of illness stories and his injunction to hear these wounded storytellers thinking "with" stories instead of "about" them (p. 23). We also used accepted narrative analysis methods of anthropologists and sociologists, focusing on the cultural and linguistic resources individuals drew on to formulate stories that made personal sense of the flow of events in their lives (Riessman, 1993; Skinner, Bailey, Correa, & Rodriguez, 1999; Skinner, Rodriguez, & Bailey, 1999). For this analysis, we collated all references to religion in the interview transcripts, and we examined how mothers incorporated religious beliefs or discourses into narratives of their everyday experiences and understandings of childhood disability. We also recorded elements or themes of each mother's narrative in data matrix displays (Miles & Huberman, 1994) to do a systematic content analysis and comparison of how many mothers incorporated specific elements, such as the child being a blessing or FXS being part of God's plan. Descriptive statistics and frequencies were calculated for responses to the Fewell Religion Scale.

## Results

Of the 60 mothers we interviewed for this study, 37 (62%) indicated in their narratives (through substantive references to God, faith, and/or religious practices such as prayer) that religion was a significant source of meaning, support, or encouragement to them in their daily lives. Nearly identical proportions of both White and Black mothers responded in this way. Mothers from lower income households were somewhat more likely to narrate religious understandings, but over half the mothers in both lower and upper income groups made such references. The sample included only 1 Latina mother, who did not give a religious narrative, although Skinner et al. (2001) have indicated that these kinds of narratives are prevalent among Latina mothers of children with disabilities. Of the 37 mothers who produced religious narratives, 8 were Catholic (67% of the 12 Catholics interviewed), 28 were Protestant (74% of 38 Protestants interviewed), and none were Jewish (of 3 Jewish mothers interviewed). One mother, who was Unitarian, made significant references to religion as a source of meaning (of the 2 mothers whose religious affiliation was "other"), and none of the 5 mothers who were religiously unaffiliated made such references.

The importance of religious faith for the majority of mothers was also confirmed by their responses to the Fewell Religion Scale (Fewell, 1986). Forty-one mothers (68%) responded that religious faith was "important" or "extremely important" to them and their families. Over half the mothers (52%) said that having FXS in their family had brought them "somewhat" or "much" closer to their faith; another 17 (28%) said they remained "equally" close to their faith. Thirty-three mothers (55%) said that their religious faith had helped them "quite a bit" or "a lot" in understanding fragile X in their family. Of the thirty-seven mothers whose illness narratives contained significant religious content, 30 indicated on the Fewell Scale that their religious faith was "extremely important" or "important," and 5 indicated religion was "somewhat important." It is interesting to note that 1 of the 2 women who did not stress the importance of religious faith was Wanda, whose lengthy religious narrative is given below. These 2 women were ambivalent in their interviews about whether they were "religious," but they still went on to narrate religious understandings of their lives. This seeming inconsistency may reflect the more general American ambivalence about the term *religion*, especially among Baby Boomers and later generations, which has been noted by social scientists (Bellah et al., 1985; Churchill, 2009; Hall, Koenig, & Meador, 2004; Roof, 2001). People may not think of themselves as religious because they do not go to church or strongly adhere to a particular established doctrine but may still use religion as a way of understanding events in their lives. The analysis that follows examines the narratives of those mothers who talked about disability within a religious framework—broadly

understood to include personal, organizational, and interpretive dimensions of religion—and the ways in which these narratives both reflected and helped create their experiences of living with a genetic disorder in their families.

### Religion and Wounded Storytellers

Writing about illness narratives, Arthur Frank (1995) quoted a fellow wounded storyteller, saying, “Serious illness is a loss of the ‘destination and map’ that had previously guided the ill person’s life: ill people have to learn ‘to think differently’” (p. 1). Although parents of children with disabilities may not themselves be ill in the conventional sense, they are often wounded. Learning the genetic diagnosis for their children often means that they, as mothers, lose their “destination and map,” giving up on dreams that parents of typically developing children enjoy and being forced “to think differently” about their own lives, careers, and families.

The majority of mothers used a religious framework as one way to make sense of why FXS happened to their children, what it meant for themselves and their lives, and its meaning in the larger world. This religious understanding did not supplant their understanding of FXS as a genetic condition, however. All mothers had at least a minimal understanding of the genetics of FXS. They had traveled an often long and rocky path searching for a diagnosis. Yet their understanding of FXS was not solely informed by biomedical genetic models of disease. They also brought other interpretive frameworks into play in constructing their experiences of FXS, their child, and themselves as mothers. For most of them, those frameworks included—indeed, were often built around—religious understandings of the world.

### Reconciliation Narratives

Frank (1995) identified three types of illness narratives that encompass the stories he most frequently encountered among wounded story-tellers, naming them “restitution,” “chaos,” and “quest” narratives. We propose a narrative genre that reflects the predominant story told by these mothers of a child with an intellectual disability: a *reconciliation narrative*. This narrative genre is distinct from the ones Frank described in that it does not focus on the theme of “getting well,” on a sense of feeling constantly overwhelmed, or on a heroic return from an illness experience. Rather, a reconciliation narrative describes a transition from viewing a disability as a burden or challenge initially to being more or less at peace with what is eventually perceived as a blessing, or as a part of God’s purpose or plan. It is important to note that the word *reconciliation* has a long association with religious contexts. Historically, the term has been used to refer to bringing a person back into harmony with God, especially readmitting a person to the church, or to atonement, whether through sacrifice or mercy. Our use of reconciliation also resonates with the term’s frequent use to mean bringing apparent discrepancies or disunion into agreement.

We first present the story that 1 mother, Wanda, produced in her interview, as a helpful lens through which to see the reconciliation narrative as a coherent whole and as a way to feature its major components. We then examine in more detail the structural parts of the reconciliation narrative through other women’s stories.

Wanda had two sons with FXS, and her 3-year-old, Derek, was severely affected. She needed her husband’s help to physically restrain Derek to cut his hair or brush his teeth, and she foresaw that she would probably have to care for Derek for the rest of her life. Wanda began her narrative by describing a period of discord, dominated by negative emotions like anger, guilt, and grief.

At first it was like, “Oh, my God. Why did you do this to me?” “What did I do to deserve this? I must have done something.” I thought it was a punishment, in a way. I thought, first of all, “Why would something be wrong with one of my kids? What did I do to deserve this?” and then, “Oh, my God. Why do two of them have it? Oh, my God. I don’t know any families with two disabled kids. What did I do to deserve this?” I thought about it really negative.

Continuing her account, Wanda narrated her journey toward a new understanding. For Wanda, as for many mothers, this turn was prompted by someone close to her, in this case a friend’s sister-in-law. This person offered a different perspective in the form of a poem, a perspective that was then bolstered by Wanda’s own experiences as a nurse.

And then, actually, what kind of made me change my thought about it was a friend’s sister-in-law gave me a poem called “Heaven’s Special Child.” And it was about—I’m going to cry. It’s so touching. I’ll have to show it to you before you go. It’s about how, when there is a special child, that God and the angels meet and pick a loving family to send them to because they need special care. So, in a way, I kind of think this wouldn’t have happened to my kids if I couldn’t deal with it. That God knows that I could deal with it, and that’s why it happened to me. Because a lot of families—I think sometimes especially young families wouldn’t deal with it. And, I’ve seen sometimes especially—I used to be in nursing and stuff before I decided to stay home with the kids. I see a lot of kids that have disabilities—even as mild as fragile X—that their families give them away because they can’t deal with it.

Wanda finished her narrative by describing her present reconciliation, the very different perspective she had developed that brought the challenges she and her children faced into harmony with a sense of broader purpose.

So I think this would not have happened to us if I couldn’t deal with it. So, in a way, I kind of think it’s a blessing that a child with special needs was given to a family that could deal with it, and would make it a good, loving environment. So, I think I kind of went from thinking, “Oh, this was given to me because I did something wrong”—like “Oh, where did I screw up” or that it was my fault, that it was something I did—to thinking of it as a blessing. So that’s probably the little bit of a religious way that I think about it: that both of my boys were a gift from God, for a reason—that it happened for a reason... People say—my brother says that and my mom—that they’re my angels. That they came to keep me on a good path, and to give me a loving family.... If I didn’t have kids, especially special needs kids, I probably wouldn’t have done that. I’d probably have been out partying.

The narrative Wanda offered was a religious one from beginning to end. She began by questioning God but with a conviction that what happened to her was more than the consequence of a random mutation. She looked for purpose and meaning in her child’s disability even if it meant that she was being punished for doing something wrong. Wanda recalled her initial anger and guilt but framed these negative emotions within a religious context. Operating within an essentially religious understanding of the world, she responded to the unexpected event of having a child with a genetic disorder with the religious tools already in her repertoire. She interpreted her questioning as a natural, even expected, part of her personal relationship with God. In her reconciliation narrative, Wanda came to terms with her son’s disability within a broader discourse of purpose and faith.

### **Disability, Diagnosis, and Discord**

Wanda’s initial “really negative” reaction to her sons’ FXS diagnoses is not an uncommon story. Even though most mothers spoke of their child in positive terms and many said that they believed their child was here for a special reason or purpose, they may not initially have

viewed the event of disability in their lives in this way. In telling her story, Karen recalled her initial period of discord:

When we had Danielle, the first thing I didn't think was "blessing." And so I had guilt because of that, because I am religious and I was like, "Gosh, I should feel blessed. I've got this beautiful little baby." But I'm thinking, "Mine's broken. This one's broken."

Karen recalled that her initial reactions were dominated by feelings of grief. She said, "It really made me feel good when somebody told me that hearing a diagnosis was like going through the death of a normal child, because that's what it felt like.... All of a sudden that slate's wiped clean. There may be no college, no marriage, no grand-children; we don't save for a wedding anymore."

Like Frank's (1995) wounded storyteller who had lost her "destination and map," Karen found herself in new territory, grieving the loss of her shattered dreams and plans for her child's future. Note, however, that Karen's comparison of her feelings with that of a parent experiencing "the death of a normal child" took place in retrospect and at least partially through the interpretive lens of what someone told her about what it was like to receive a genetic diagnosis. Her experiences were mediated through support groups, individuals who offered perspectives on the situation they faced, and discourses that circulate through the disability community.

Most mothers in our study initially felt responsible for their children's condition, even though only 2 of them knew they were carriers of FXS before having children (Raspberry & Skinner, in press). Rebecca, whose son had FXS, expressed this sense of responsibility: "That's difficult, when a mother looks at her child who's stumbling and can't walk. And, you're looking at him and going, 'This is not his fault. This is directly because of me.'" Rachel, a mother of twin boys with FXS, recalled that she blamed both herself and God after first learning that her sons had FXS.

I can remember going home and thinking—just having these panic attacks. And I knew in my heart what it was....I think in hindsight it was because at that point I was blaming myself. And seeing myself as being so selfish for putting them through this....And then I was very, very, very mad at God. And I never lost my faith. Because I knew they were going to be okay. They were going to be what He wants them to be. And that's the main thing. But I think anybody that says they've not been angry at God lies. Because I think He expects that.

Jennifer, a mother of two sons with FXS, said that she still occasionally questioned God as to why, when her chances should have been "fifty-fifty," both of her children turned out to have FXS. She said, "Probably it's only been two or three times I've done this...broken down and been angry and like, 'Why wasn't I given just one child?' He gave me two." Sharon recounted her conversations with God, dialogues that reflected an ongoing struggle to view her young son as a blessing: "Sometimes I'll be like, 'You're my little angel baby.' But...sometimes I'll sit there and, 'Why did You do this to me?' It's both ways."

### **Journey to Blessing**

Nearly all the women who talked about their initial state of discord, a time they felt angry, guilty, or full of self-pity, also moved quickly in their narratives to another stage, a journey that led them to a more positive view of themselves and the demands thrust on them as mothers of children with FXS. Rachel, who spoke above about being angry at God, recalled a turning point when she felt God let her know that she could cope, that she could look at her situation in a way that focused on the blessing rather than the "curse" of having a child with FXS. She said, "We lost our house. We had bankruptcy. I mean, we've lost almost



everything. And yet, I think He was reminding me too, ‘You haven’t lost your family. You’ve got that.’ And that’s more important than anything on this earth.” Carla, who had already given birth to two sons with FXS, felt as if Satan himself was trying to influence her to abort her third child, whispering to her, “You should get rid of this baby. Don’t take a chance on another fragile X child!” Yet, almost immediately, she recalled, “Faith really kicked in and said, ‘Too bad! I was not raised that way and I am not doing that! He wouldn’t give me something that I didn’t need.’”

Mothers often connected this turning point to support from others. They recalled advice that helped them reframe parenting a child with disabilities in a positive way, particularly in a way that attributed a higher purpose to having a child with a disability. For example, Amber recounted that her father-in-law, after learning her son’s diagnosis, wondered aloud, “What have you done to deserve all this?” She said, “He meant it in a loving way....And I guess I felt that way too. But [my husband’s] mom was like, ‘Well, this happened for a reason. And you’re just going to have to deal with it with all of our help.’”

Several mothers remembered others telling them that God gives special children to special parents. This message was not always well received. Amber recalled that when people would say this to her husband, “He’d just want to smack them because he was so angry. And I got kind of tired of hearing it, too.” Nevertheless, when Amber’s husband heard the same thing from a father of a young man with Down syndrome, he thought that “coming from him it sounded better than coming from a stranger or just somebody down the road.”

Stories that circulate throughout the disability community by word of mouth or the Internet also provide new perspectives. Rapp (2000) referenced a common example, one that is identified elsewhere as “Welcome to Holland.” The story, which uses an unplanned vacation detour as a metaphor for having a child with disabilities, reminds parents that even though they may have missed seeing red roses in Italy, they instead got “blue tulips” in Holland, “and that’s quite special, too” (Rapp, 2000, p. 198). Rapp observed that through the circulation of this “parable of acceptance,” parents came to refer to the “blue tulips rewards” as a shorthand phrase for their perspective on disability. Karen, quoted above, also talked about the “Welcome to Holland” story and marveled that “little things that are maybe cheesy for some people” helped her to rethink her situation:

You find strength in things that have happened negatively and you can turn them good, and I think that has helped me. And you always wonder—what makes you turn that over? Is it God? Is it that you’re lucky that you view things this way? I don’t know...You can either look at it negatively, like “boo hoo, poor me,” or you can look at Holland and all the beautiful things it has.

Indicative of the way that these discourses are shaped locally by the networks that circulate them, Karen’s reference to the story did not shorthand “blue tulips” or even mention them at all. Karen also thought of the story as speaking to a more general perspective on life, not solely to the experience of raising a child with disabilities. She said of the story, “I kept that from high school...and then to go back and read that later after I had a special child, you can apply that to any part of your life and how you want to view things.”

Some mothers, like Wanda above, referenced another text, a poem called *Heaven’s Special Child* (author unknown, n.d.). This poem is widely available on the Internet, but mothers who mentioned it had usually received it from people who knew of their child’s disabilities. In this poem, the angels meet in heaven to decide who will receive a special child: “Please, Lord find the parents who/Will do this special job for you/They will not realize right away/The leading role they’re asked to play/But with this child sent from above/Comes stronger faith and richer love.” Janet received this poem in an anonymous letter. She said, “Those

kinds of things are comforting, that God didn't pick you and say, 'Okay, this is your punishment.'" The poem's message, of the blessings that come from raising a child with a disability, not only gives comfort but also facilitates a reinterpretation of these mothers' situation: raising a child who, in the words of the poem, will "require much extra care / From all the folks she meets down there."

### Reframing and Reconciliation

Wanda had reframed her experiences parenting two boys with FXS within a religious perspective, confident that there was purpose behind every turn her life had taken. Her account touched on several themes that commonly appeared in other mothers' narratives: having her children saved her from taking a ruinous path, being especially prepared for the responsibility of parenting children with disabilities, and being the best choice for the challenging task she had been handed. Sandra, mother of both a son and daughter with FXS, told a similar story:

I, by the time I was in fifth grade, knew how to read and write Braille. So I would type up the worksheets for the kids [who were blind] that were in the class. And my mom, without sounding mean, said, "I don't know where you get that from. You don't get it from me." I think that I had been prepared my whole life for this. Of course, I don't know why; I have no idea why. I think probably I was a bit of a wild thing in college. I think I just needed to be grounded again. I don't know, I don't know why else. It's really odd. Why did I do all these things? It's not upsetting to me. I meet mothers every day—a woman called me this morning. They can't handle it. They can't handle it. And it's so normal to me....I just think he's with us for a reason, versus someone else.

In retrospect, Sandra felt that having her children diverted her from a potentially destructive way of life as a "wild thing." She saw her early desire and aptitude for working with children with special needs as a seemingly preordained preparation for parenting the children she was meant to have. This belief was important to Sandra's narrative in two ways: It strongly supported her conviction that she was the best choice for the job of parenting her children with special needs and it served as evidence that God had a purpose in giving her two children with FXS.

Several women expressed a similar sense that having a child with disabilities changed their lives for the better. Evelyn said she thanked God for her children because they "kept me going, kept me alive." Felicia noted that, because of her experiences with a son with FXS, she now goes to church more often. She reflected, "As you get older, you realize, 'Maybe this benefits me for a reason.' I used to go out to some clubs every weekend. That's the only thing that slowed me down from going down the road so much, from going out so much." And Beth, although "mad at God" some days for giving her and her child the fragile X gene, concluded, "I'm glad some days that He did because I think if I didn't have it, I would be such a different person—and, I think, a person that I would not like."

This sense of a higher purpose pervaded many of the mothers' narratives, and sometimes became the overarching theme of their entire narrative. Wanda summarized her story by concluding that "both of my boys were a gift from God, for a reason." Likewise, Alicia declared that God had a special purpose for giving her a daughter with FXS:

I feel that this is why God gave me Sara. I'm a stable person. I've always been a homebody. And, [God thought] "she'll be able to take care of a child with special needs." I think that's why He gave me her....I think there's always a reason behind everything. And I think it's all God. It's God's work.

For Alicia, as for other mothers who gave religious narratives, the belief that God has “a reason behind everything” helped her to see herself as a competent parent, perhaps even the best possible candidate for parenting a child like hers. Tonya, whose son had FXS, compared herself with her siblings and came to a similar conclusion that she was “the person that could handle it the best.” Evelyn, mother of two boys with FXS, also expressed a conviction that her children were “meant” for her: “I have asked God, ‘Well, what is my talent?’ And I’ve had one cousin say, ‘Well, your talent is caring and giving.’”

Mothers whose disability narratives carried this sense of a larger purpose often related that their beliefs helped them cope with their current challenges and eased concerns for the future. As Kelli expressed,

Knowing that obviously I can’t control whether my child has this or not, then I’m just going to trust God to show me how He’s planning on using this for our good. And that just takes away a lot of anxiety that I think you could be overwhelmed by if you’re thinking on all what you should do to solve this. And I can’t solve it, so I just—you do what you can do to educate and teach your kids, and leave the rest to God, and He’ll take care of it.

Framing the experience of raising a child with a disability in religious terms does not negate the challenges of that experience, as indicated by the other kinds of narratives these women told. Nor does every mother endorse religion as a means of support or way to understand her life. A few mothers even said that they were annoyed with hearing that they were “chosen.” Leslie, mother of a young son with FXS, said, “When somebody says, ‘Joey’s blessed to have you,’ I’m like... ‘So, what in my life have I done that I deserve this much work?’” Yet, even Leslie said that she had a sense of a larger cause for having FXS in her family, one that she attributed to “bad karma.” What Leslie articulated clearly in her narrative was the deep conflict that she felt between resenting the challenges placed on her and appreciating that her son “made me a better person.” Even for mothers who saw their challenges from a religious perspective, troubles and anxieties did not, of course, simply evaporate. Beth made that clear, saying that, in “real depressed times when I feel hurt I question God. I do ask Him, ‘Why did you do this to me?’” Yet, she concluded, “There are days that I thank Him. Because, I think, because of it, it makes me stronger.”

## Discussion

Women in this study experienced their religious lives from the unique perspective of being a caregiver to a child with disabilities and, in turn, experienced disability through a religious lens. For some, the very act of narrating their stories of living with disability became a religious practice, as they found meaning in their children’s disabilities and in their roles as caregivers. Those mothers who provided religious narratives made reference to notions of purpose or blessing even as they spoke of their challenges and disappointments. These seemingly conflicting narratives, of the struggles of caring for a child with disabilities and of purpose and positive blessings, never canceled one another out. Rather, they existed side by side: for some mothers, merging almost seamlessly, and for others, vying for the narrative foreground. This juxtaposition is the crux of the reconciliation narrative; it brings difficulties and a sense of purpose into focus together, within a larger scheme of meaning. If anything, the multiplicity of stories women told reminds us of the importance of narratives for articulating, reinforcing, and even building a sense of identity. Narratives of illness and disability are particularly important to their tellers because they speak from and about a position outside the mainstream, challenging both hearer and storyteller to understand an occurrence that may seem unfair or even inexplicable. In situations like the ones these caregivers face, constructing a religious perspective—piecing it together out of personal experience, institutional supports, and resources from friends and the larger culture—is an

everyday activity that infuses even mundane and painful tasks with a sense of meaning and purpose.

There are limitations to this study. Mothers' perspectives and experiences were the main focus of the study and we lacked data on fathers' perspectives. Although we hypothesize that some fathers would have narrated similar accounts as those analyzed here, we do not know how those accounts and the prevalence of accounts among fathers would vary. In addition, although our final sample included families from across the United States and from a range of incomes and education levels, we cannot claim our sample was representative of U.S. families who have an identified child with fragile X. Thus, we cannot generalize findings from this study to the larger population. Although we did recruit through family support networks, a majority of the families were recruited through previous FXS studies and professionals in the field. The majority of families in the sample were not active in FXS networks. It is unclear how this variation may have affected mothers' accounts.

Although it may seem surprising to some that a majority of the women, many of them White, middle class, and educated, would cite their religion or faith as a source of support, and even more surprising that these mothers would situate their understanding of their child's disability within a religious framework, when viewed in the larger U.S. context, this is not an unusual perspective. 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). Ninety percent of Americans believe in God or a higher power, 80% self-identify as Christian, and over half participate in some activity of a religious group at least once or twice a year (Davis & Smith, 2009).

Not all mothers in our study found their reconciliation through a religious lens, of course. There are many other perspectives for understanding disability, and, for this study, we did not systematically analyze nonreligious narratives of mothers' perspectives on their lives. Nevertheless, nearly all the women we interviewed saw their children in positive terms, even if, as for Leslie (quoted above), those terms were not particularly religious. This observation is consistent with other studies that have found that parents and caregivers of people with disabilities work to find positive conceptions of their lives and of those in their care (see, e.g., Bogdan & Taylor, 1989; Goetting & Goetting, 1993). In addition, although religious beliefs figure into illness narratives cross-culturally, the specific ways they blend are certainly culture specific. In narratives, we can see how individual bodily experiences shape, and are shaped by, cultural meanings (Garro & Mattingly, 2000). For the women we interviewed, all Americans, those cultural meanings are partly products of Christian notions of a personal God and individualistic piety, which are so prevalent in the United States. The reconciliation narrative identified here comes into being within that context, shaped in large part by local discourses that incorporate those aspects of American Christian thought. Through published stories, poems, and advice from family and friends, these women, like all storytellers, learned what kinds of stories made the most sense of their experiences within their cultural context. Hence, it is not surprising that the women who offered religious narratives in interviews were nearly all Protestant or Catholic. With only a small sample of mothers from Jewish or other religious traditions, we cannot offer any insight into whether religious narratives of disability might occur among these populations and what form these might take. These differences by religious affiliation invite additional study.

For practitioners working with families of children with disabilities, families who overtly express religious perspectives may cause discomfort or worry that they take a fatalistic view of their child's condition. Although some older research on religion and disability suggested this was the case, particularly for some minority populations, more recent studies (see Skinner, Correa, Skinner, & Bailey, 2001), including this one, have suggested the contrary.

The mothers in this study were powerful advocates for their children and often articulated a sophisticated comprehension of the genetics of FXS. Medical practitioners, educators, and parents who serve as advocates or counselors for other parents may encounter elements of this reconciliation narrative. It may be useful to recognize that, for parents who do have a religious perspective, constructing this kind of narrative can help them see their child and their family's situation in a positive light. Understanding that these caregivers are not substituting religious knowledge for medical knowledge may assist professionals in creating cooperative and beneficial relationships for the improved care of children and adults with disabilities.

## Acknowledgments

Preparation of this article was supported by the University of North Carolina (UNC) Fragile X Research Center (funded by the National Institute for Child Health and Human Development; Grant P30 HD003110-S1) and the UNC Center for Genomics and Society (funded by the Ethical, Legal, and Social Implications Research Program, National Human Genome Research Institute; Grant 5P50HG004488).

## References

- Affleck, G.; Tennen, H. Cognitive adaptation to adversity: Insights from parents of medically fragile infants. In: Dokecki, PR.; Saner, RM., editors. *Ethics of dealing with persons with severe handicaps: Toward a research agenda*. Baltimore: Brookes; 1993. p. 135-150.
- Bailey D, Mesibov G, Hatton D, Clark R, Roberts J, Mayhew L. Autistic behavior in young boys with fragile X syndrome. *Journal of Autism and Developmental Disorders*. 1998; 28:499–508. [PubMed: 9932236]
- Bailey D, Sideris J, Roberts J, Hatton D. Child and genetic variables associated with maternal adaptation to fragile X syndrome: A multidimensional analysis. *American Journal of Medical Genetics A*. 2008; 146a:720–729.
- Baker BL, Blacher J, Crnic K, Edelbrock C. Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *American Journal on Mental Retardation*. 2002; 107:433–444. [PubMed: 12323068]
- Baker BL, McIntyer LL, Blacher J, Crnic K, Edelbrock C, Low C. Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research*. 2003; 47:217–236. [PubMed: 12787154]
- Bellah, RN.; Madsen, R.; Sullivan, WM.; Swidler, A.; Tipton, SM. *Habits of the heart: Individualism and commitment in American life*. Berkeley: University of California Press; 1985.
- Bingley AF, McDermott E, Thomas C, Payne S, Seymour JE, Clark D. Making sense of dying: A review of narratives written since 1950 by people facing death from cancer and other diseases. *Palliative Medicine*. 2006; 20:183–195. [PubMed: 16764223]
- Blacher J, Neece CL, Paczkowski E. Families and intellectual disability. *Current Opinion in Psychiatry*. 2005; 18:507–513. [PubMed: 16639109]
- Bode H, Weidner K, Storck M. Quality of life in families of children with disabilities. *Developmental Medicine and Child Neurology*. 2000; 42:354. [PubMed: 10855659]
- Bogdan R, Taylor SJ. Relationships with severely disabled people: The social construction of humanness. *Social Problems*. 1989; 36:135–148.
- Brady N, Skinner D, Roberts J, Hennon E. Communication in young children with fragile X syndrome: Mothers' perspectives. *American Journal of Speech-Language Pathology*. 2006; 15:353–364. [PubMed: 17102146]
- Churchill LR. Religion, spirituality, and genetics: Mapping the terrain for research purposes. *American Journal of Medical Genetics Part C (Seminars in Medical Genetics)*. 2009; 151C(1):6–12.
- Davis, JA.; Smith, TW. *General social surveys, 1972–2008* [machine-readable data file]. The Roper Center for Public Opinion Research, University of Connecticut [Distributor]; Storrs, CT. Chicago: National Opinion Research Center [Producer]; 2009.

- Dumas JE, Wolf LC, Fisman SN, Culligan A. Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality*. 1991; 2:97–110.
- Fewell, RR. Supports from religious organization and personal beliefs. In: Fewell, RR.; Vadasy, PF., editors. *Families of handicapped children: Needs and supports across the life span*. Austin, TX: Pro-Ed; 1986. p. 297-316.
- Frank, AW. *The wounded storyteller: Body, illness, and ethics*. Chicago: University of Chicago Press; 1995.
- Garro, L.; Mattingly, C. Narrative as construct and construction. In: Mattingly, C.; Garro, L., editors. *Narrative and the cultural construction of illness and healing*. Berkeley: University of California Press; 2000. p. 1-49.
- Geertz, C. Religion as a cultural system. In: Geertz, C., editor. *The interpretation of cultures*. New York: Basic Books; 1973. p. 87-125.
- Goetting A, Goetting MG. Adoptive parents to children with severe developmental disabilities: A profile. *Children and Youth Services Review*. 1993; 15:489–506.
- Griffith ME. Stories of the South, stories of suffering, stories of God. *Family Systems Medicine*. 1995; 13(1):3–9.
- Hagerman, RJ.; Cronister, A., editors. *Fragile X syndrome: Diagnosis, treatment, and research*. 3rd ed. Baltimore: Johns Hopkins University Press; 2002.
- Hall DE, Koenig HG, Meador KG. Conceptualizing “religion”: How language shapes and constrains knowledge in the study of religion and health. *Perspectives in Biology and Medicine*. 2004; 47:386–401. [PubMed: 15247504]
- Heller T, Markwardt R, Rowitz L, Farber B. Adaptation of Hispanic families to a member with mental retardation. *American Journal on Mental Retardation*. 1994; 99:289–300. [PubMed: 7865204]
- Hinton WL, Levkoff S. Constructing Alzheimer’s: Narratives of lost identities, confusion and loneliness in old age. *Culture Medicine and Psychiatry*. 1999; 23:453–475.
- Kleinman, A. *The illness narratives: Suffering, healing, and the human condition*. New York: Basic Books; 1988.
- Landsman, GH. “Real motherhood,” class, and children with disabilities. In: Ragone, H.; Twine, FW., editors. *Ideologies and technologies of motherhood*. London: Routledge; 2000. p. 169-187.
- Landsman GH. Mothers and models of disability. *Journal of Medical Humanities*. 2005; 26:121–139. [PubMed: 15877195]
- Mattingly, C.; Garro, LC., editors. *Narrative and the cultural construction of illness and healing*. New York: Cambridge University Press; 2000.
- McGuire, MB. *Lived religion: Faith and practice in everyday life*. Oxford, England: Oxford University Press; 2008.
- Miles, MB.; Huberman, AM. *Qualitative data analysis: An expanded sourcebook*. 2nd ed. Thousand Oaks, CA: Sage; 1994.
- Olsson MB, Hwang CP. Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*. 2001; 45:535–543. [PubMed: 11737541]
- Orsi, R. Everyday miracles: The study of lived religion. In: Hall, DD., editor. *Lived religion in America: Toward a history of practice*. Princeton, NJ: Princeton University Press; 1997. p. 3-21.
- Pargament KI, Ensing DS, Falgout K, Olsen H, Reilly B, Vanhaisma K, Warren R. God help me: I. Religious coping efforts as predictors of the outcomes to significant negative life events. *American Journal of Community Psychology*. 1990; 18:793–824.
- Patterson, JM.; Leonard, BJ. Caregiving and children. In: Kahana, E.; Biegel, DE.; Wykle, ML., editors. *Family caregiving across the lifespan*. Thousand Oaks, CA: Sage; 1994.
- Petersen A. The best experts: The narratives of those who have a genetic condition. *Social Science & Medicine*. 2006; 63:32–42. [PubMed: 16431006]
- Pew Global Attitudes Project. Among wealthy nations...: U.S. stands alone in its embrace of religion. 2002. from <http://pewglobal.org/reports/pdf/167.pdf>
- Poston DJ, Turnbull AP. Role of spirituality and religion in family quality of life for families of children with disabilities. *Education and Training in Developmental Disabilities*. 2004; 39:95–108.

- Rapp, R. Extra chromosomes and blue tulips: Medico-familial conversations. In: Cambrosio, A.; Lock, M.; Young, A., editors. *Living and working with the new medical technologies*. Cambridge, England: Cambridge University Press; 2000. p. 184-208.
- Raspberry K, Skinner D. Negotiating desires and options: How mothers who are carriers of FXS experience reproductive decisions. *Sociology of Health and Illness*. (in press).
- Riessman, CK. *Narrative analysis*. Newbury Park, CA: Sage; 1993.
- Rogers S, Hehner E, Hagerman R. The behavioral phenotype in fragile X: Symptoms of autism in very young children with fragile X syndrome, idiopathic autism, and other developmental disorders. *Journal of Developmental and Behavioral Pediatrics*. 2001; 22:409-417. [PubMed: 11773805]
- Rogers-Dulan J. Religious connectedness among urban African American families who have a child with disabilities. *Mental Retardation*. 1998; 36:91-103. [PubMed: 9573719]
- Roof WC. Religion and narrative. *Review of Religious Research*. 1993; 34:297-310.
- Roof, WC. *Spiritual marketplace: Baby Boomers and the remaking of American religion*. Princeton, NJ: Princeton University Press; 2001.
- Rutledge CM, Levin JS, Larson DB, Lyons JS. The importance of religion for parents coping with a chronically ill child. *Journal of Psychology and Christianity*. 1995; 14:50-57.
- Saetersdal B. Forbidden suffering: The Pollyanna syndrome of the disabled and their families. *Family Processes*. 1997; 36:431-440.
- Scorgie K, Sobsey D. Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation*. 2000; 38:195-206. [PubMed: 10900927]
- Scorgie K, Wilgosh L, McDonald L. A qualitative study of managing life when a child has a disability. *Developmental Disabilities Bulletin*. 1996; 24:68-90.
- Skinner D, Bailey D, Correa V, Rodriguez P. Narrating self and disability: Latino mothers' construction of meanings vis-à-vis their child with special needs. *Exceptional Child*. 1999; 65:481-495.
- Skinner D, Correa V, Skinner M, Bailey D. The role of religion in the lives of Latino families of young children with developmental delays. *American Journal on Mental Retardation*. 2001; 106:297-313. [PubMed: 11414871]
- Skinner D, Rodriguez P, Bailey D. Qualitative analysis of Latino parents' religious interpretations of their child's disability. *Journal of Early Intervention*. 1999; 22:271-285.
- Tarakeshwar N, Pargament KI. Religious coping in families of children with autism. *Focus on Autism and Other Developmental Disabilities*. 2001; 16:247-260.
- Traustadottir R. Mothers who care: Gender, disability, and family life. *Journal of Family Issues*. 1991; 12:211-228.
- Trute B, Hiebert-Murphy D. Family adjustment to childhood developmental disability: A measure of parent appraisal of family impacts. *Journal of Pediatric Psychology*. 2002; 27:271-280. [PubMed: 11909934]
- Turnbull, AP.; Patterson, JM.; Behr, SK.; Murphy, DL.; Marquis, JG.; Blue-Banning, MJ., editors. *Cognitive coping, families, and disability*. Baltimore: Brookes; 1993.
- Turnbull, AP.; Turnbull, HR. Participatory research on cognitive coping: From concepts to research planning. In: Turnbull, AP.; Patterson, JM.; Behr, SK.; Murphy, DL.; Marquis, JG.; Blue-Banning, MJ., editors. *Cognitive coping, families, and disability*. Baltimore: Brookes; 1993. p. 1-14.
- Tyson, RW., Jr.; Peacock, JL.; Patterson, DW. *Diversities of gifts: Field studies in Southern religion*. Urbana: University of Illinois Press; 1988.
- Weisner TS, Beizer L, Stolze L. Religion and the families of developmentally delayed children. *American Journal on Mental Retardation*. 1991; 95:647-662. [PubMed: 2059415]
- Wheeler AC, Skinner D, Bailey DB. Perceived quality of life in mothers of children with fragile X syndrome. *American Journal on Mental Retardation*. 2008; 113:159-177. [PubMed: 18407719]
- Whitmarsh I, Davis A, Skinner D, Bailey DB. A place for genetic uncertainty: Parents' valuing an unknown in the meaning of disease. *Social Science and Medicine*. 2007; 65:1082-1093. [PubMed: 17561324]

- Wuthnow, R. The cultural turn: Stories, logic, and the quest for identity in American religion. In: Becker, P.; Eiseland, N., editors. Contemporary American religion: An ethnographic reader. Walnut Creek, CA: AltaMira Press; 1997. p. 245-265.
- Yamane D. Narrative and religious experience. *Sociology of Religion*. 2000; 61:171–189.