An Ethnographic Study on Religion, Spirituality, and Maternal Influence on Sibling Relationships in a Muslim Family with a Child with Autism

Brinda Jegatheesan, PhD

University of Washington &

Klaus Witz, PhD

University of Illinois at Urbana-Champaign

**Abstract:** This ethnographic study examined maternal influence on sibling relationships when one child has autism. The mother’s and typically developing son’s understanding of having a family member with autism was shaped by and imbued in their religion. The family’s religion and daily practices helped support the child with autism.

**Key Words:** Autism, Sibling Relationships, Religion Beliefs and Practice

Religious and spiritual meanings have been given to disability in many world cultures. Such meanings inform families’ understanding of children, parenting, and the nature of relationships between members of the family and the child with a disability. This study aimed to examine the nature of the maternal influence on sibling relationships when one child has autism and how the family made sense of their child’s disability. The study used an ethnographic approach. Results showed that the family’s Islamic faith was the primary framework through which they understood the meaning of having a child with autism and how to provide support.

Muslim immigrants in the U.S are often viewed as a single ethnic group (Mastrilli & Sardo-Brown, 2002) and their religion as monolithic (Joshi, 2006). However, the Muslim community in the U.S is enormously diverse, consisting of people from different historical, political, cultural, linguistic, and theological backgrounds (Reinhart, 2003).

The ultimate revelation of Allah (God in Arabic) to Muhammad, his prophet, is said to be in the *Qur’an*, the holy book. The Muslim people consider the *Qur’an* a book to guide them on how to live their lives intellectually and spiritually. While the *Qur’an* is considered to be divine, its interpretation is based on the human understanding of its words. The *Qur’an* exists in its original form and language, Arabic. The numerous interpretations are said to be the interpreters’ understanding of the holy text and therefore are not considered to be the text itself or a translation of it (Bazna & Hatab, 2005). In Islam, for specific sects of people were teachings on how to live right in one’s life.

Child Rearing Goals

The concept of *Fitrah***,** or the belief that children are born inherently good, greatly influences child rearing (Beshir & Beshir, 2004). Mothers are expected to teach their children how to pray, a socialization process perceived as integral towards becoming a good Muslim (Jegatheesan, 2005; Jegatheesan, 2009; Jegatheesan, Miller, & Fowler, 2010). The benefits of teaching children to pray were documented in a study done by Moore (2004). In Moore’s study, young Muslim children begin to learn to recite the *Qur’an* from the age of six or seven, an age group considered to have a “virgin memory” (p. 318) and not yet distracted by the opposite sex. Parents allow their children to observe prayers as early as three years old, helping the children to gradually acquire the skills they need to begin reciting their prayers independently by age seven. Scholars of other Islamic studies have documented similar age expectations for the acquisition of independent praying skill (Miles, 1996; Moore, 2004; Sarwar, 2000).

Disability in the Qur’an

Islamic scholars who have searched the *Qur’an* for mentions of disabilities have found reference to individuals with physical and intellectual disabilities, mostly in the metaphorical sense (Bazna & Hatab, 2005; Benzahra, 2002).Benzahra (2002), in her interpretation of the *Qur’an*, states that God calls on Muslims to take special care of individuals with disabilities, and that Muslims should not label them by their disabilities. The verses in the holy text emphasize that God made all men equal and that He measures an individual’s worth on spiritual and ethical development and not on physical attributes and material achievement (Bazna & Hatab, 2005; Benzahra, 2002). Bazna and Hatab (2005) also found that the *Qur’an* was “consistent with the view that every person is potentially perfect so long as they work on developing their innate and individual qualities to the limit of their individual differentiation” (p. 25).

The *Qur’an* also urges its community members to consider it a duty of every Muslim to provide care, respect, and support for individuals with disabilities (Benzahra, 2002; Gaad, 2001; Morad, Nasri, & Merrick, 2001), and stresses their full inclusion into society (Bazna & Hatab, 2005). According to Bazna and Hatab (2005), the essence of its interpretation on people with disabilities “concentrates on the notion of disadvantage that is created by society and imposed on those individuals who might not possess the social, economic, or physical attributes that people happen to value at a certain time and place” (p. 30). Furthermore, since this “disadvantage” is perceived as “created by society,” the authors state that it comes as no surprise that the holy text “places the responsibility of rectifying this inequity on the shoulder of society by its constant exhortation to Muslims to recognize the plight of the disadvantaged and to improve their condition and status” (p. 30).

To our knowledge, there have been no studies on Muslim families who have children with disabilities. Muslim families in the United States are one of the most seriously neglected groups in disability issues research: not much is known about how their family members come to understand disability and how these beliefs inform parents on parenting and socialization practices (Jegatheesan et al., 2010). The lack of research has been attributed as partly contributing to this knowledge gap (Ali, Fazil, Bywaters, Wallace, & Singh, 2001). Cultural and religious beliefs inform parents about how to raise and socialize their child (Jegatheesan et al., 2010; Shaked, 2005) and parents’ expectations of close family members such as siblings (Sage & Jegatheesan, 2010b).

This paper presents an ethnographic study of how Muslim parents begin to construct meaning around disability and how they interpret their child with a disability as a “blessing and a sign from God.” The study also illustrates the realities of the deeper experiences in the lives of the people concerned and in the development of the main protagonists over several years. The authors focus exclusively on the maternal influence on sibling relationships and especially the relationship between the mother and her developing son as they seek to understand their spiritual experience of having a son and brother with a severe disability in the family. This paper briefly addresses the father-child couple because there was minimal data on paternal influence on the relationship between the siblings.

Method

This ethnographic study aimed to examine the maternal influence on sibling relationships when one child had autism and how the family made sense of their child’s disability. The study was part of a larger ethnographic study that examined how children with autism in three multilingual South Asian Muslimimmigrant families were socialized into their society through their cultural and religious norms and values (Jegatheesan, 2005). The first author (ethnographer) conducted 17 months of fieldwork in the home and community environments of the families. More than 700 hours of observation yielded a large and rich data set. This study reports on the Khan family, the only family in the larger study with two children.

Participants included Ayoob and Fatima Khan, their six-year-old son with autism named Jalil and eleven-year-old son named Samir.Parents were in the age range of 30-40 years old and had lived in the United States for approximately 13 years.

Interviews and Observations

In-depth interviews were conducted with Fatima and Samir. Observations included interactions and communication between the couple (Fatima and Samir) and the triad (Fatima, Samir, and Jalil). Ayoob was also observed when he interacted with both of his sons. Although Ayoob was involved in his son’s lives, Fatima played an instrumental role in the socialization of the siblings’ relationship. Therefore, the authors focused primarily on the data collection with the mother and her two sons.

The interviews were more like informal conversations using open-ended questions, so the conversations could flow naturally. The first author observed the family and the parents’ and son’s comments about having a family member with a disability and shaped the interviews accordingly. During the observations, the first author began to notice that religious beliefs shaped the family’s understandings of having and supporting a child with a disability as well as the extent of maternal influence on sibling relationships.Interview topics included beliefs about having a family member with autism and sibling relationships, and the socialization of sibling relationships, and reactions and feelings about specific situations that were noted during observations (e.g., How Samir felt when Jalil indulged in autism-related behavior such as lining up objects, preference for sameness, and tantrums).

Observations of the interactions between the siblings and between the mother and her children were conducted at home. The goal of the observations was to document the interactions between mother and children in their daily life and the strategies used to socialize the child with autism and sibling relationship. Keeping this in mind, the first author observed interactions over different days of the week and at different times at home and in the community. Observations were video-recorded with permission of the parents.

Analysis

The analysis process involved grounded-theory analysis of the entire data corpus of narrative episodes, dialogues, and conversations (Charmaz, 2002; Glaser & Strauss, 1967). Since data analysis was inductive, codes were not established prior to the interviews and observations but instead generated from the data. Transcripts were reviewed repeatedly and systematically by the authors who coded for initial themes and developed a working definition for each code. These were iteratively evaluated against the data and against the two authors to ensure rigor in interpretation. Using the constant comparison method (Strauss & Corbin, 1990), codes were organized into categories. Themes emerged as the authors engaged in repeated discussions and reflections of the categories. The themes were continually cross-referenced with the narratives to ensure that the themes were consistent and grounded with the data.

The results of the study are presented in the form of an ethnographic case study in eight sections. The organization of the sections is explained at the end of section 1.

Findings

1. Background - the Khan Family

The Khan parents are multilingual immigrants from South Asia. Ayoob was the sole breadwinner of the family, and Fatima was the main homemaker in the house. The family prayed five times a day at home and in the mosque, fasted during Ramadan (the Holy month), and sent their children to Qura’nic schools. Elders in the family often prepared to take the journey to Mecca. Fatima frequently read to her sons from children’s Islamic books on how to live right.

Samir, the family’s other son, was an 11-year-old boy who liked to play sports and computer games. He was born in the United States. As the oldest son in a Muslim family Samir was expected to be understanding and accommodative of his brother’s needs. Samir attended a neighborhood public school and during weekends attended a Qura’nic school. His younger brother Jalil was 6 years old. Around the age of 29 months, Jalil began to show characteristics of autism such as sudden loss of language, and preference for being alone. Final diagnosis was made at age three after consultations with pediatricians and psychiatrists. At the onset of the study, Jalil was non-verbal and used gestures to communicate. He attended self-contained classes for children with autism in a public school and received sporadic therapy services.

The following ethnographic study first sketches the evolution of Fatima’s (the mother’s) subjective response to Jalil’s autism (section 2). Fatima went through some of the typical upheavals before diagnosis and when diagnosis became certain. In time, she formed an understanding that Jalil was a special child sent to her and her family by Allah. From that point on, she started sharing her new understanding with Samir. Much of the study becomes a story of their constant interaction and eventual team effort in dealing with the numerous situations caused by Jalil’s condition. The remaining sections (sections 3-8) focus on Samir, but always keeping in view his interactions and relationship with his mother and his brother with autism.

2. Fatima’s Initial Reactions to Jalil’s Diagnosis of Autism

Fatima went through some of the typical reactions of parents who realize their child has a significant disability (Goin-Kochel & Myers, 2005; Hutton & Caron, 2005). Soon after diagnosis, many relatives often expressed superstitious beliefs that they believed harmed the development of Jalil’s brain. These superstitious beliefs concerned maternal behavior during pregnancy such as stepping out during the eclipse, attending large and noisy community gatherings, and maternal diet. Stepping out during the eclipse was perceived by orthodox elders as a bad omen that affects the fetus, causing illness and/or disabilities. Similarly, would-be mothers attending crowded and noisy events were considered to be harming the child because exposure to such environments “disturb, alarm or shock the fetus,” leading to braindamage. Lastly, in terms of maternal diet, Fatima reported that she craved for and ate a lot of goat’s brain during her pregnancy, despite being advised against it. The brain of the goat has numerous intertwined nerves and as a result of Fatima’s consumption of this prohibited food, Jalil was believed to have developed similar brain patterns leading to malfunction of his brain. These beliefs were openly discussed at family gatherings. Fatima said that she felt guilty and sad when she heard these explanations. She found herself wondering if she had not righteously conducted her life. Fatima went through a period of intense questioning about her own life and actions. She said, “I asked Allah, ‘Why we get him like this? Why we deserve this,’ or I used to ask my husband, ‘What did we do wrong to have our son become like this?” Ayoob discounted the superstitious beliefs and said there must be a deeper explanation. Fatima’s mother-in-law thought that Jalil was *phir baba* “holy boy” and told Fatima that perhaps Allah has a plan for her, and that she should ask for an understanding of her son’s condition in her daily prayers. In time, Fatima came to accept that she had not committed any sin. She quietly “accepted my son as a gift…” sent to her “directly from God.” She called it fate and said, “I was okay because God gave us like that. He has a plan and I don’t know what it is. He will make him okay or not, that is whatever God wants. It’s not up to us.” Fatima explained further:

[1] Fatima: Now I have His special child, I need to know how to do everything for him. And so I prayed for God…I pray everyday and ask *Allah* to be with me and help me be a good mother to Jalil. God was listening because I feel better and have new energy and courage to try new things. I was not afraid. So that’s why I am like this now. My husband says I am changed.

Ethnographer: Changed?

Fatima: Yes! He says I have become strong...I am not like, before, when I would say, “Ah, okay, let it be or what can we do? Now I am like, “No Jalil can! And he will if we believe in him. Anything Samir can do, Jalil can do it also!” So, for example, last year [2003], the public library had a children’s Summer Reader’s Award. Children had to read 25 books and retell the story to the librarian in the library. Samir got the award. I am seeing how Jalil is looking at his brother’s award. And I feel sad. That evening, I said to my family, Jalil can get the award too! Everyone at home thought I had gone crazy. Next day, I went to the librarian and said, “My younger son has autism and he wants to try for the award. He can read but he cannot retell the story on his own. But he can retell the story through ‘questions and answers.’ So, if you ask him questions about the book, he will answer those questions. That way he will retell the entire story. And Jalil did it. He read 25 books in summer time and got his award. And the whole family was so happy…I don’t accept that my son cannot do something. I believe in my son and I know that *Allah* will be with him and he will be okay. I must give him the same opportunity as his brother. I am seeing how Jalil is happy with his reading award.

Fatima felt that her prayers continued to be answered. Her husband commented often that she became very forward in advocating for Jalil and had become very confident. She added that prayers were her greatest source of comfort and help. She said, “In my prayers I asked for God’s guidance. I asked, “How I can do things for my son, now he has this disability, still what more I can do for him? I want to try everything, I will keep trying everything.”

“Trying everything” for Fatima included learning about how to parent her son with autism through reading books and websites on autism and getting a diploma in child development, being actively involved in her son’s schooling and therapies, and ensuring that Samir was learning how to support his brother. Fatima involved and engaged Samir in helping Jalil overcome behavioral challenges, learn his school work, become competent in his communication, and teach him prayers. In this manner she pursued her feelings that she had religious duty to effect improvement or even a cure as the response to this God’s given challenge.

While people at the mosque and the Qura’nic school did not have knowledge of autism and how to support a parent with a child with autism, they were, however, supportive of Fatima’s desire to make sure that her son learned his religious duties. Fatima explained that although Jalil was the first child with autism in the Qura’nic school, the staff and teachers were accepting and supportive. She said:

“The principal of the *Qur’anic* school accepted Jalil even though autism was new to him. He had not seen a child with autism. Nobody had a child with autism in the class. And Jalil showed all the symptoms of autism like hand flapping, saying some garbled sentences over and over again. But they understood how important it was for me to help my son learn his prayers, learn Arabic and be in this school. They were supportive of my wish to sit with him in his class all the time to help him learn and help in the classroom if he does something that the teacher does not understand.”

Informal conversations between the author and the Qura’nic school teachers revealed that Jalil was viewed and treated just as any other child. Teachers admired and respected Fatima’s aspiration and perseverance to teach her son his religious ways. Jalil was frequently observed to be stubborn and indulging in repetitive behavior during recitation lessons. But teachers continued to be patient with him. Inaaya, Jalil’s Arabic teacher, explained her views on supporting Jalil to learn his prayers even though he had problem behavior:

“He is special but he is also *Allah*’s child like all others are. And his mother brings him to learn to pray even though he has a disability, and I think that she is amazing to do this. It is my duty to teach him however much he can learn. *Allah* knows the child’s heart is pure.”

3. Mother’s Teachings and Samir’s Early Responses to his Brother having Autism

Fatima shared her thoughts with Samir that Jalil was a special child of *Allah* whom *Allah* had made that way and that their family was the special family that *Allah* had chosen for Jalil. The Khan parents felt that if a child like Jalil were to end up in the wrong family he might suffer.

[2] Ethnographer: When he asked at that young age about why God sent Jalil to this family, what did you tell him?

Fatima: I tell Samir that *Allah* gave him to us because He knows that we will take care of him, teach him and not get angry and mad. I tell Samir not to compare his brother to him and his cousins. I tell him there maybe some things that his brother might do one day that he himself maybe cannot. We must believe in Jalil, believe in *Allah*. Samir is a good child. He understands.

For the Khans, being the special family involved both loving Jalil and taking care of his needs, teaching him, and practicing high standards of self-discipline and behavior for *Allah*’s sake. Family conversations about Jalil were of the following nature, “[*Allah*] knows that we will take care of him,” and “*Allah* wants to see that family members and Samir do not get angry and mad.” Fatima herself developed an awareness of Jalil as a special person in his own right rather than just a person with a disability. She said she believes that “there may be some things that Jalil might do one day that Samir maybe cannot.”

Fatima described Samir as a good child who listened to her and was empathetic of his brother’s disability. The following account of an observation illustrates how Samir helped Jalil in a mature manner, sacrificing his opportunity to play with his cousins:

[3] Six children were playing in the computer room. They were trying to encourage Jalil to be part of their game. Jalil became fussy, and whiny and did not want to play with them. …. When his cousins called out to him to come and play with them, he whined louder, and became visibly upset. His cousins turned to their own play and Jalil withdrew into a corner of the room, self-stemming himself. Samir kept glancing towards Jalil and then got up and went across to him. He sat by his side and put his arm around him. He asked him if he wanted to come and join him. When Jalil shook his head in negation, Samir asked him if he wanted to play something else. Jalil sniffed, wiped his nose with the back of this hand, kept fidgeting with his toy car and pointed to the computer. Samir took his brother’s hand, led him to the computer and set the computer game for him. He stood for a while by his brother’s side and watched him play frequently glancing towards his cousins playing, since he too wanted to play with them.

When the ethnographer a little later asked what Samir felt about his brother and what he felt about his brother’s disability, he said:

[4] He is still a human being. He is different but we are all different. He is different because *Allah* made him that way. Maybe we all have to learn from him something that we cannot learn without him. He has a lot of changing in his behavior to do. But even though he is so bad like screaming for the computer, he is not a terrorist. He does not hurt anybody or make anyone cry.

When asked about how he first reacted when he learned that his brother had autism Samir reported that he had wondered about the changes in his brother prior to his diagnosis. He said that he noticed that his brother “acted weird” and “screamed sometimes like he was mad about something” and he was increasingly “getting upset.”

[5] Samir: He was not the same suddenly.

Ethnographer: Not the same?

Samir: Yeah. Like he would shout and not tell us why he was angry. Or only open his mouth, make a face like sad face and not talk.

Ethnographer: So you were surprised.

Samir: Not! It was happening a lot. I asked him to say why he was mad at me and he would get more mad. He was not saying anything.

Ethnographer: What did you think?

Samir: Nothing. I got mad also.

Samir stated that when he first heard the word ‘autism’ during a family conversation, he did not think much about it and soon forgot. But Jalil’s language regression made his mother worry a lot. For the first six months, Fatima was the only one in the family who was convinced that something was wrong with Jalil. Her husband and his family told her not to worry, explaining that “boys speak late.” Samir witnessed his mother’s increased anxiety and in time he observed how once his mother convinced his father and grandparents, she scrambled to get an accuratediagnosis and make sense of their son’s condition. Samir shared a turning point experience:

[6] I became mad one time. It was my turn on the computer and Jalil kept pulling my hand and pointing for him to sit. I refused and he got mad. Then he ran down to my mother and began to cry. My mother came upstairs and told me to give him the computer. I was mad and told her he had finished his turn and now its mine. She asked me to get up and give the chair to him. I was mad at my mother and my brother.

Ethnographer: …. Did your mom say you were a good brother?

Samir: She talked with me and told me that Jalil is like that because of autism. It does some things to him. She told me that we should understand the autism and what it does. We must help him and not get mad at him.

Ethnographer: So your mom told you everything?

Samir: She told me that we must find out more and that I can help her to understand autism more. She said then if we understand autism we can help my grandmother, aunt and uncle understand it too. My mom said if we are helping Jalil, then others will see that and do the same. If we are mad, then they will be mad.

Ethnographer: Oh. Like be a good example.

Samir: Yes. So I found out more from the internet and my mom got some books.

Fatima had enlisted Samir as her and his dad’s ally in trying to help Jalil, and by getting more information and a more detailed understanding of autism they could possibly help the other family members.

4. The Family Learns Together About Autism

Fatima told the ethnographer that once Samir began to understand autism (as described in [6]), each day brought new insights to the two of them. Mother and son often talked about each other’s new insights about autism over an activity such as doing a puzzle or drawing with Jalil.As parents, whenever Fatima and her husband found out more about autism, they would talk to Samir, so that he would understand why his brother was changing. “Samir and Jalil are playing together and Samir must understand why sometimes his brother is difficult,” she said. Fatima reminded Samir that Jalil was sent by *Allah* because their family would take care of him and not be unkind to him. She told him, “He chose you to be his brother…In all the world, He made you and him brothers. So you have been chosen by *Allah* too.”

Fatima reported that Samir on his own started reading and learning about autism and ways to help his brother, but she was not aware of the deep effects the new orientation had on him until about half a year later when she talked to his teacher. The teacher showed her a copy of the New Year’s resolution [7] Samir had written in creative writing class at the beginning of the semester. This was a few months after diagnosis, when Samir was about 9 years-old.

[7] Creative Writing. January 11, 2001

In the year 2002, my New Year’s resolution will be helping my little brother speak since he doesn’t know how to speak. He is a kid who is autistic. “Autistic” means can’t speak. I’m going to try to make my brother speak.

Fatima had brought a photocopy of the writing to share with the ethnographer.

[8] He is a good child. I sometimes get upset thinking he is not patient enough with Jalil…He is thinking a lot about his brother and autism. I can see that in this writing…In his own way he is learning about his brother and how to help him…I was so proud. When I asked him about the New Year’s resolution, he said that he is going to try very hard to help his brother because he now understands a lot about it.

The creative writing example shows that Samir was independent in taking charge of his portion of the task in helping his brother. When the ethnographer showed him the copy and asked him why he wanted to help his brother to “speak,” he replied:

[9] If he can speak, he can tell me what he wants and I can help him. If he is afraid he can tell me, if he sad or mad he can tell me.

Ethnographer: And that’s important, Samir?

Samir: (nods in affirmation).

Through Samir’s conversations with his mother, the ethnographer learned that the learning process of autism was a shared family endeavor. Part of the endeavor involved telling Samir to “help,” “be patient,” and “not complain” about his brother. Fatima told Samir that “complaining will not change Jalil.” She also pointed out that “Jalil was unable to complain about his needs that were not met and his frustrations.” She told Samir, “We then must put him first by understanding him and being there for him. Not give in all the time, but be patient and help him.” The ethnographer asked Samir how he felt about this.

[10]Samir: I don’t know. I think about the autism and why Jalil had to get this. My mother said that my brother was not different because of autism but some people think it is like that. So we must learn more to understand Jalil. That’s what I am doing.

Ethnographer: Such as…

Samir: Like I look in the Internet. I read about it. I look at my brother and see how he is different. So it’s not difficult. He cannot speak now. But he can still communicate with his hands like this (gestures). So I must try to understand some new things to help him.

Ethnographer: What new things? Do you do some new things?

Samir: In my prayers I now ask *Allah* to help him be a good boy. Its new thing when I pray. My mother said we should all pray and he will be better in the future.

5. Deeper Communication

Samir was observed to be deeply empathetic regarding Jalil’s needs. The ethnographer often recorded that Samir went the extra mile to accommodate his brother. There were the occasional disputes, mainly over the use of the computer games. Samir was found to be tuning into his brother a lot and would often inform the ethnographer of particular things about Jalil. For example, he would tell her without her asking, “He likes to watch himself in the mirror and this time is best to talk with him because he responds,” or “It’s 30 minutes now and his computer time is up. Now he will call so sweetly, (in a sing-songy voice) ‘Samir, oh Samir. Come Samir, oh Samir.’”

[11] Ethnographer: Why does he say so many times like that?

Samir: Because he is smart. He knows that I will say, okay another 10 minutes because you called me so nicely. He is not stupid. He is smart. I watched him and he knows he can get what he wants from me if he is nice.

Ethnographer: So you know.

Samir: Yes, I watched him and also told my mom about this.

Ethnographer: Isn’t that real smart of Jalil? Wow.

Samir: He is more smarter. I am now seeing this more each day. I am watching him carefully.

Excerpt [11] shows that Samir’s whole understanding of Jalil has changed. At first (2-3 years ago), when Jalil cried, Samir did not know whether he really was crying or whether he was faking, but by the time of the conversation [11] he was very much in tune with him. He knew that his brother was faking, and Samir talked about this with humor. A few months later, the ethnographer recorded the following observation fieldnotes.

[12A] The two brothers were playing and then the car wheel broke. Samir spent 30 minutes trying to fix it for Jalil, who was teary about the broken car. During this time, I saw no verbal communication between the brothers. Samir would tap Jalil to reassure him, nod, and give him glances.

Afterwards the ethnographer asked Samir about this silent interaction.

[12B] Ethnographer: How did you know what your brother felt because you guys said nothing.

Samir: I usually know. I listen to him, actually, I look at him and then I know from his face what he feels. It is pretty easy.

Ethnographer: And you did not want to say anything to him?

Samir: No, it will make him more upset. And I don’t want him to cry. Then my mother will get mad at me because she thinks that I made him cry.

Ethnographer: Oh.

Samir: But also my mother said to me that if I listen carefully I can understand what my brother is feeling.

Ethnographer: Listen to what?

Samir: To him. Like he is sitting and I listen to him quietly. He can tell me with his feelings.

6. Feeling Others’ Needs

Often Samir was requested by his father to do simple tasks for his brother (e.g., tie his shoelaces, bring his coat, peel a banana). His father bestowed a lot of affection (hugs and kisses) on Jalil. Relatives at home also showered Jalil with tremendous amount of affection, and Samir was observed to quietly watch the love that surrounded his brother. Fatima was observed to be the only person who paid equal attention to both her sons.

When the ethnographer asked Samir what he felt about “so much of attention on your brother, everybody wants to hug and kiss him,” Samir responded in a mature way that he knew Jalil gets a lot more attention and that he understands and feels it is important to let Jalil know that “everyone at home loves him.”

7. Communicating with God through Prayers

The family put much emphasis on both children participating in the daily prayers. But the ethnographer saw Samir talking about *Allah* as playing a big role in Jalil’s behavior. This behavior is illustrated by the following observation in Samir’s bedroom as he taught his brother *Du’as* (short prayers). Samir was encouraged by his parents to teach his brother Du’as and *Surahs* (verses from the *Qur’an*). Samir took this responsibility very seriously:

[14] Samir: time to say your prayers Jalil.

Jalil: [No response.]

Samir: (taps on his arm) Time to say *Surah Fatiha*. Come on, its time

Jalil: (hits his hand off his [own] arm and screams a little).

Samir: Okay, I am going to say it and you listen. Okay Jalil. Its good for you to at least listen. You don’t have to say it. [Begins prayer:] *Bismillahir Rahmanir Rahim Alhamdu Lillahi Rabbil ‘alamin.*

Say Jalil, it’s good for you. You can say it softly okay.

Samir: *Bismillahir*

Jalil: *Bismillah*

Samir: *Rahmanir Rahim*

Jalil: *Rahman*…blender, it’s a blender. I got a blender [starts to go off into autistic-like echo]

Samir: *Rahmanir Rahim*, say like this. *Rahmanir Rahim.*

Jalil: Whoosh, blender. I like the blender. Whoosh, whoosh.

Samir: Okay say it in English. *Allah* please forgive me

Jalil: *Allah* please forgive me and make me a goooooood boy.

Samir: Very good. *Allah* will make you better.

There are several noticeable elements about the above exchange. Whenever Jalil did not respond appropriately, Samir was unruffled and patiently adjusted his efforts a little, demonstrating care and intimacy with brother (taps him on the arm, “Okay, I am going to say it and you listen …. You don’t have to say it” “You can say it softly okay”). At the end, when Jalil said one line spontaneously expressing his own feeling, Samir was completely satisfied: “Very good. *Allah* will make you better.”

Over a period of time the ethnographer watched similar interactions of Samir’s showing tremendous patience in teaching the *Surahs*. During this time Jalil would romp around and jump on the bed, or hop over the bed from side to side and making faces in the mirror. Samir, in the same tone, with the same gentle persistence would try to get his brother to repeat the *Surahs* after him. He would follow him around the room as he coaxed him. One day, his mother walked in and caught Jalil jumping. She wrapped her arms around Jalil and said, “Listen to your brother! Now say what Samir is saying or NO going to see Rudy (neighbor's dog that Jalil loved).” After the second such observation. the ethnographer talked to Samir about his patience and tolerance.

[15] Ethnographer: What about when you teach him his prayers. You have a lot of patience, Samir. Sometimes, I noticed that Jalil is very playful and he will not do it.

Samir: That’s okay. *Allah* understands because he is special. I must try and not give up.

Ethnographer: Not give up. Who told you that?

Samir: My mother. She said that I must try hard to teach him to pray. I tell my brother what to pray.

Ethnographer: Like what?

Samir: Pray for cure. For forgiveness.

Ethnographer: Forgiveness for what?

Samir: I don’t know. Maybe he did something and he must now ask for forgiveness and then he will become okay. He must ask *Allah* to forgive him.

Ethnographer: Is that WHY you want HIM to learn to talk?

Samir: One reason. I have many.

Ethnographer: Can you tell me?

Samir: Like I want him to play with me and not scream loudly if he wants something. Sometimes, I pray to *Allah* for making him alright because he gets mad and screams. But there are other things also. Like I want him to tell me if he had a sad day. Then I can help him. I can understand him better when he cries. Now, I don’t know if he is crying for fun or he is serious. Sometimes he plays a joke on everyone by faking it.

Samir then explained why it was important for Jalil to pray.

[16] Samir: We are praying everyday to *Allah* and I think *Allah* is listening to us. He is making him smarter and He is showing us in this way. I tell Jalil to pray and he is doing that now.

Ethnographer: So you think that Jalil is getting smart because you are praying for help.

Samir: Yes, but he must try too. It is good for him. He must ask. It can be a whisper but he must say his *Du’as* too. *Allah* will listen to him.

Ethnographer: You are sure?

Samir: Yes. He is better than last year. So it means he is getting better.

Discussion

Superstitious and Religious Beliefs and Biomedical Explanations on Disability

The Khan parents endured substantial stress and anxiety in understanding the cause of their child’s disability after a period of typical development. Medical and allied health professionals were frequently reported as being unsure about the cause of autism and frequently dismissed parent’s persistence in receiving an accurate explanation of the etiology of autism. Professionals were also reported as using extensive amount of medical jargon in their conversations, complicating the Khan parents’ ability to think clearly and fully comprehend their child’s condition. Ayoob and Fatima described this period as long, traumatic, and confusing and soon began to search for an understanding of their child’s disability on their own.

According to Fatima, superstitious beliefs that circulated in the family circle contributed to her having “bad feelings and reservations” about having a child with a disability. The prevalence of superstitious beliefs has been documented among individuals across cultures (Lamorey, 2002). However, Fatima, after having risen above superstitions beliefs, developed a spiritual understanding of why she had a child with autism.. She attributed her new understanding to her husband and her mother-in-law who believed in a religious explanation. She added that she also went through a period of questioning her life and thought about her actions and habits and came to an understanding that she had not committed any wrongful deeds that could have harmed her son. She then accepted her son as a blessing and from then on developed a deeper and fuller spiritual understanding of having a child with a disability. In a study of parents’ lay conceptions of autism (Gray, 1995), parents went through similar experiences, where the absence of explanations for the cause of autism led to them developing their own understanding of the disability, and in doing so achieved partial emotional closure. For the Khan family, although they were exposed to some medical explanations, the spiritual and religious explanations dominated their conceptions of having a child with autism.

Fatima had a theological belief that God had a plan for her and sent her a son with special needs. She reported that “acceptance” of *Allah*’s wishes were foremost and sought strength and guidance through prayers. Through continuous worship, she worked on building a bond with God to guide her in parenting her special child. Fatima’s fatalistic belief that “God will make him okay or not, that is whatever God wants,” was also viewed as being hopeful for a cure if God wishes. Fatima believed that her responsibility was to be a good parent and being a good parent included “trying everything” for her son and fulfilling her religious duties. In prayers, she asked for the presence of *Allah* in her life, for guidance on being a “good mother,” and to give her “new energy and courage.” She saw praying for a cure as part of continued effort of “trying everything.” Similar fatalist beliefs and the importance of striving for the better have been expressed by Islamic general practitioners in Yamey and Greenwood (2004). The authors report beliefs of Prophet Mohammed, who was to have said that ‘for every illness, there is a cure, except one, and that’s old age’ (pp. 457). Participants in their study believed that seeking medical help for recovery was part of their striving to do things for the better. Fatima was relentless in her effort to “try everything,” including asking for a cure in her prayers to *Allah* and then leaving it all in God’s hands (“God will make him okay or not is in his hands”).

Relationship Between Fatima and Samir – Helping to Understand a Brother with Autism

Fatima supported her typically developing son in understanding his brother with autism. She provided him with whatever information she had about autism, urged him to have a caring and compassion attitude through the teachings of Islam, and placed him in a teacher’s role, such as teaching his brother prayers. She also used conflicts between the brothers as teaching opportunities to provide Samir with guidance and feedback about desired and undesired behavior. Samir, in time, began to make connections with his brother, on each occasion, after much introspection, making changes in his interaction style. With an increase in the understanding of autism, conflicts between the brothers decreased substantially.

Fatima and Samir had very open communication about autism, its challenges and uniqueness. Increasing an understanding of autism was a shared endeavor with this dyad. On a deeper level, Fatima was the guiding light for Samir and began to inspire Samir on the spiritual realities of having a brother with autism. She frequently conveyed to him the richness of human experience and encouraged him to take a spiritual journey of discovering the essence of his brother. Soon he began to uncover, in bits and pieces, what it means to have autism, looking at it from the perspective of the one with the disability.

Unity and Team Spirit between Fatima and Samir – Reaching Out to Jalil

Fatima and Samir were a vitalizing force on one another, resulting in an evolving relationship. Sometimes Fatima was the one who knew a lot; at other times she would search on the Internet for information about autism, as did Samir, thus making them equal partners. Together, they sought to improve themselves constantly, to find new and innovative ways to reach out to Jalil, sharing experiences and strategies that were effective as well as their hopes, anxiety, and admiration for even Jalil’s smallest achievement. Fatima worked hard to educate her typically developing son and strived to fill Jalil’s environment with love, compassion, and encouragement. She made sure that Jalil had the same opportunities (e.g., reading competition) as his brother, ensuring that Jalil could manage even the toughest of tasks (e.g., getting the Summer Reader’s Award, participating in a *Qur’an* recitation competition) as long as he had appropriate support. Fatima’s religion urged her to keep an upbeat spirit and do all that she could to help her son with autism.

Recommendations

Fatima would have found beneficial being connected with other South Asian parents of similar cultural and religious backgrounds who have children with disabilities. She would have been able to share her everyday experiences of raising her sons and at the same time hear the stories of other parents in her circle of support. Particularly, at the time when Fatima was experiencing guilt and sadness because family members attributed her behavior during pregnancy as having caused her son’s disability, connections with other parents could have been an important source for emotional nurturance and comfort.

Similarly, Samir could have benefited from being connected with other children who have siblings with autism, especially when he was trying to understand his brother’s symptoms. Siblings of children with autism often assume the role of mentors and provide help on an ongoing basis (Benderix & Sivberg, 2007; Cuskelly & Gunn, 1993; Stoneman, 2005) and have been found to silently endure feelings of uncertainty and worry (Sage & Jegatheesan, 2010a). Particularly in Asian families, older children are often expected to demonstrate altruism in sibling relationships (Braun, 2008; Sage & Jegatheesan, 2010b). Samir would have found sibling support groups as a place to share his concern and emotions with peers who are in a similar situation. Being a part of a sibling group during these difficult times would have been greatly beneficial to him.

Finally, this study shows that the mother’s faith played an important role in her understanding of why she has a child with autism. The mother’s faith informed her child rearing beliefs and practices, and duties towards the child. The mother’s Islamic faith also helped to buffer her anxieties during difficult times. A deeper understanding of the impact of religion on a family’s comprehension of disability and their relationship with the child with a disability should be known to all professionals who work with culturally diverse families and their children with special needs.

**Brinda Jegatheesan, PhD**, University of Washington, researches the role of religion, culture and language in the development of children with disabilities and their learning across various home and community settings. Questions regarding this study should be sent to Professor Brinda Jegatheesan, Department of Educational Psychology, College of Education, Box 353600, University of Washington, Seattle, WA 98195. Email: [brinda@uw.edu](mailto:brinda@uw.edu).

**Klaus Witz, PhD,** has interests and publications in the areas of cognition, philosophy of science and education, religion, spirituality and the self. He is the author of, *The Supreme Wisdom of the Upanishads: An Introduction* (1998).

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