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Influence of Community-Level Cultural Beliefs about Autism on Families' and Professionals' Care for Children

Christina D. Kang-Yi,

University of Pennsylvania

Roy Richard Grinker,

The George Washington University

Rinad Beidas,

University of Pennsylvania

Aneesa Agha,

University of Pennsylvania

Rachel Russell,

Action Wellness, Philadelphia

Sandeep B. Shah,

New Hampshire Department of Education Vocational Rehabilitation

Kathleen Shea,

Temple University

David S. Mandell

University of Pennsylvania

Abstract

This qualitative study aimed to understand how community-level cultural beliefs affect families' and professionals' care for children with autism and developmental delays in immigrant communities, as a first step towards promoting early identification and access to early intervention services. The study was part of the larger New York City (NYC) Korean Community Autism Project, which was designed to identify strategies to increase awareness of autism and reduce delays in treatment seeking within the NYC Korean-American community. Our study elicited early childcare workers' and church leaders' beliefs about autism and developmental disorders and, in particular, early intervention. We also elicited responses to newly developed outreach materials targeting this community. An inductive approach was used to identify concepts and categories associated with autism. Our study confirmed that discomfort, stigma and discrimination are the prevailing community attitudes toward autism and developmental disorders in the Korean-American community. Families' and professionals' understanding of autism and their care for children are affected by these community beliefs. Approaching immigrant communities with

Corresponding author: Christina D. Kang-Yi, Department of Psychiatry, Perelman School of Medicine, University of Pennsylvania, 3535 Market Street, 3rd Floor, Philadelphia, PA 19104., ckangyi@upenn.edu.

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general information about child development and education rather than directly talking about autism and developmental disorders is likely to engage more families and professionals in need for diagnostic evaluation and early intervention for autism.

Keywords

autism; community-level cultural beliefs; families' and professionals' beliefs; outreach strategies

Introduction

Cross-cultural studies of autism have shown that culture shapes the way families, professionals, and communities understand and treat developmental disorders (Daley, 2002; Ravindran & Myers, 2012; Raghavan, Weisner, & Patel, 1999). Of the developmental disorders, interpretations and treatments of autism are particularly susceptible to the influence of culture because there is no agreed-upon cause for the disorder; diagnosing autism relies heavily on behavioral criteria, and behavioral norms vary considerably across cultures (Deweerd, 2012; Ravindran & Myers, 2012). Additionally, the absence of any universally accepted, scientifically valid treatments, and the variety of treatments available, such as behavioral, cognitive, pharmaceutical, sensory, relational, vitamin, and diet therapies (Christon, Mackintosh, & Myers, 2010; Goin-Kochel, Mackintosh, & Myers, 2007), makes it more likely that treatment decisions will be based on local beliefs and values (Bernier, Mao, & Yen, 2010; Daley et al., 2011; Ravindran & Myers, 2012). The effect of broad social changes on autism prevalence has been demonstrated recently by the more than 300% increase in the rate of autism diagnoses in special education enrollment records during a period (2000–2010) when the proportion of children in special education remained constant and when other classifications, such as intellectual disability, declined (Polyak, Gubina, & Girirajan, 2015).

Although the volume of international research on how culture influences the understanding of autism is steadily increasing (e.g., Brezis et al., 2015; Cascio, 2015; Daley, Singhal, & Krishnamurthy, 2013; Daley, Weisner, & Singhal, 2014; Grinker, 2007), cultural beliefs about autism among those who live in multicultural environments, such as immigrant families living in the United States (US), are relatively unknown. The United Nations Population Funds reports that in 2013, 232 million people (3.2% of the world's population) lived outside of their country of origin and about one half of migrants are women, mostly of reproductive age. Considering the changing prevalence estimates of autism and the trend of global migration (Boyle et al., 2011; Kim et al., 2011; Elsabbagh et al., 2012), understanding immigrant families' knowledge and perceptions of autism and their decision for treatment is important to effectively collaborate with immigrant families to meet their needs.

The importance of understanding immigrant families' perception of autism is also evidenced by recent studies showing that immigrant families' perception of autism cannot be understood simply within the dimension of acculturation because immigrant families frequently stay connected with their native culture (whether or not they were born there) and social networks. On-going interactions between original and new cultures, social systems,

networks, and relationships affect strategies for coping with autism and help constitute hybridized perspectives on autism. For example, Wang and Casillas (2012) found that Mandarin-speaking Asian-American parents still maintain strong psychological ties to their original communities as a way of coping with relocation, and feel more comfortable with Mandarin language and culture regardless of length of residency in the US or degree of fluency in English. However, the authors also found that Asian-American parents of youth with an autism spectrum disorder stayed in the US for what they perceived to be the best outcomes for their children and were open to using both scientifically-based therapies and folk practices to treat their children. In a study of immigrant parents from the Arab world, Asia, Africa, Latin America, and Europe, Pondé and Rousseau (2013) found that parents' perceptions of autism in their children are influenced both by their cultural or geographic origin and the dominant biomedical and other health-related discourses in their new society, which was Montreal, Canada. While limited in quantity, these few studies have made important contributions to cross-cultural research by describing how immigrants navigate between cultures, and how, as a result of their experiences in different communities, they develop a hybridized perspective on autism and autism treatment (Bagnoli, 2007; Kirmayer, 2012; Pondé & Rousseau, 2013). These studies highlight the degree to which immigrant populations form social networks – defined by shared language and culture – within which they structure health care, education and social supports. These networks may also be transnational, personal (involving interaction with friends and relatives) and impersonal (involving the circulation of information through various media, such as radio, television and the Internet).

For the last twenty years, studies of Korean immigrants in the US have emphasized the limits of treating the Korean and the American in the hyphenated form Korean-American as mutually exclusive and even challenged the notion that the terms Korean and American are analytically separable (Kim & Hurh, 1993). Rather, immigrant populations constitute new transnational cultures of relocation or displacement, building new webs of cultural beliefs and practices. Moreover, the definition of an “immigrant population” as a distinct community should not mask its complexity and diversity across any number of factors such as class, geography, education, age, and religion. Child-rearing practices, for example, within any immigrant community will differ depending on location, time of immigration, socioeconomic status, education level, and age, among other factors. As has been well-documented, Korean-American parents who were born in the US often conflict with Korean-born grandparents who have different ideas about child development and child-rearing, and who may obtain their information from different sources. In addition, professional knowledge within a community may vary considerably based on training, age, location and time in the US. Because knowledge and the loci of knowledge vary across and within communities, any plan to increase awareness and use of services must identify means of dissemination that take these differences into account. Diversity within a community, however, does not equate to a lack of shared beliefs, attitudes, and forms of social organization, as studies of Korean culture and language have shown. On certain topics, such as the stigma related to psychiatric conditions, and the structure of childhood education, there is remarkable uniformity among Koreans in both Korea and in the US (Grinker, 2007; Grinker & Cho, 2013; Kang-Yi, Grinker, & Mandell, 2013).

The present qualitative study was part of the larger New York City (NYC) Korean Community Autism Project designed to identify effective strategies to increase awareness of autism within the NYC Korean-American community and help Korean families detect symptoms of autism, and developmental delays more generally. In developing an outreach plan to increase awareness of autism in the Korean community in the New York City area, we paid special attention to the role of churches in Korean-American life. Studies of autism among Asian-American families emphasize the role of religion and churches in shaping beliefs about the causes of autism as well as help-seeking strategies (Grinker, Kang-Yi, Ahmann, Beidas, Lagman, & Mandell, 2015; Twoy, Connolly, & Novak, 2007). Twoy et al. (2007) found that Asian-Americans who identify English as their second language are more likely to seek spiritual support as they cope with a child's diagnosis and care, and several Korean-American participants in Grinker et al.'s (2015) study on cultural adaptation and translation of autism outreach materials in Korean explained autism as God's will or punishment. This religious belief may be more salient in the Korean immigrant communities than it is in their country of origin as 71% of Korean-Americans are Christians (Pew Research Center, 2012), while only about a quarter of Koreans in South Korea identify as Christians (Korean Culture and Information Services, 2015; Min & Kim, 2005).

The goal of the specific investigation presented here was to understand Korean immigrant families' and professionals' beliefs and attitudes towards autism and other developmental disorders as the first step towards promoting early identification and access to early intervention services. We elicited shared beliefs about autism and other developmental disorders within the community that professionals identified as barriers to care and early intervention. This exploratory project used an inductive approach, consistent with grounded theory, to identify concepts and categories associated with autism (Schatzman & Strauss, 1973), and targeted two groups: early childcare workers and church leaders.

Methods

Context and Setting

As of 2010, there were 1.7 million Koreans living in the US, a 39.6% increase from 2000 (US Census, 2012). Koreans account for 9.9% of the total Asian population in the US; 9% of them reside in New York (Pew Research Center, 2013; US Census, 2012) and more than 70% of Koreans in New York live in New York City (Pew Research Center, 2013). Sixteen percent of Koreans living in New York City are children aged less than 18 and 50% of all Koreans in the city have limited English proficiency (Asian American Federation, 2013).

The Community Advisory Board created to partner with the study team in carrying out the project suggested focusing our outreach effort on Korean churches and early childcare centers because the majority of families are members of Korean churches and many families send their children to Korean early childcare centers in New York City. Korean-American church staff in New York City, including lay church leaders, serves a variety of functions in the Korean community, such as distribution of community news, occasional childcare and psychological counseling (Min, 1992). A census report from the Asian American Federation designed to advise census workers on how to gather census data among Koreans in the US noted "censuses should be solicited from preachers and priests in the community," in large

part because Korean clergy have so much influence over the members of their communities, and have extensive social networks (Kang, 2006, p. 145). The community advisory board members mentioned that many Korean parent caregivers who own or work in small businesses tend to work long hours and prefer sending their children to Korean early childcare centers because Korean early childcare centers tend to operate longer hours than the mainstream ones. Additionally, parent caregivers who mostly speak Korean feel more comfortable with early childcare workers who can speak Korean.

Participants

Early childcare workers and church leaders in the NYC Korean-American community were recruited through purposive and snowball sampling. Early childcare workers and church leaders (including pastors, lay church leaders, Sunday school teachers, and other church staff) were recruited through telephone outreach, dissemination of an information packet on child development developed by the Autism Speaks Foundation and the Centers for Disease Control and Prevention, and community meetings. Four early childcare workers and nine church leaders were recruited and participated in the study. Although our study recruited parent caregivers, we excluded parent caregiver interviews from the study as there were only two parent caregivers who participated in the study and this concerned the study team about the lack of representativeness.

Procedure

Open-ended semi-structured interviews that lasted 45–60 minutes were conducted via phone and were recorded for later transcription. The study protocol and details of informed consent were approved by the Institutional Review Board of the University of Pennsylvania. Interviewees were given study information during telephone recruitment and received detailed information about the study, an informed consent form, and the information sheets on child development via email or mail prior to the interviews. The information sheets included Developmental Milestones, Developmental Screening Fact Sheet, Warning Signs of Autism and M-CHAT Screening Tool (Robins, Fein, & Barton, 1999), and Tips for Talking with Parents. The interviewees were asked to provide feedback on the cultural appropriateness and usefulness of the outreach materials, in addition to sharing their experiences of autism and developmental delays, thoughts and opinions on facilitators and barriers to increasing awareness of autism and early intervention for children with autism, and perception of community-level response to autism and developmental delays. Consent was obtained verbally in the beginning of the phone interview and a \$25 gift card was provided to each interviewee as compensation.

Data were collected between September 2013 and August 2014. The first author (CK) conducted 13 interviews in Korean and one interview in English, and research staff at the University of Pennsylvania's Mixed Methods Research Lab (MMRL) conducted one interview in English. Language selection for the interview was based on interviewee preference. We developed a semi-structured interview guide to collect information about participants' knowledge of and experiences with autism and other developmental disorders with a focus on social and cognitive impairments, diagnosis and referral to early intervention services, and strategies to increase awareness of autism and information dissemination in the

NYC Korean community (See Appendix A). Interviews conducted in Korean were translated and transcribed in English by a professional translator.

Analysis

Transcripts were analyzed in an iterative process using NVivo 10 (QSR International, Australia) based upon a grounded theory approach (Charmaz, 2014) with the expectation of approximately 12–15 interviews to reach thematic saturation (Guest, Bunce, & Johnson, 2006). We completed thirteen interviews, at which point we had reached saturation – that is, additional interviews were no longer contributing any new information. Through a close reading of two transcripts, the investigators developed a set of codes that were applied to the data. Two investigators coded a subset of transcripts (20%) and inter-rater reliability was found to be strong ($\kappa=.86$) (Landis & Koch, 1977). Coding discrepancies were resolved through discussion and consensus. Broad codes were further divided into sub themes to identify key concepts.

Results

Table 1 presents the demographic characteristics of study participants. Nine church leaders and four early childcare workers were included in the study. Eight participants were male and five participants were female. Mean ages of early childcare workers and church leaders were 47 and 55 years, respectively. All church leaders and three early childcare workers preferred being interviewed in the Korean language. All participants had college degrees. All but one church leader had Master's or doctoral degree. Mean years of living in the US ranged from 21 years to 23 years. On average, early childcare workers had worked in the childcare field for 21 years and church leaders had worked in the field for 22 years. Regarding the representativeness of the study sample, although the nine church leaders represented only about 10% of the 107 Korean churches identified in the NYC Korean community, they mostly represented large-size churches that Koreans in the NYC area perceive to be the major churches of the Korean community. We identified 14 early childcare centers in the NYC Korean community during the recruitment period. Our early childcare worker group represented 35% of the early childcare centers.

We found little variability in theme, vocabulary, and opinions about barriers to care, knowledge of autism, attitudes towards developmental disabilities attributed to the Korean community, and communication between early childcare workers and church leaders. The most common and salient themes triangulated across the both groups were professionals' concern about parents' denial of the existence of a developmental problem, discomfort speaking about autism to others, lack of acceptance of a specific diagnosis, and fear of discrimination, and stigma. These themes appeared in the discourses of all participants. Because beliefs about autism were similar between early childcare workers and church leaders, we did not stratify responses by respondent type.

Community Attitudes toward Autism: The Many Meanings of “Discomfort”

All the participants – early childcare workers and church leaders – described the attitude toward autism within the Korean-American community as one of “discomfort,” with

discomfort defined in terms of “reluctance” (*kkuh-ryeo-ham*) and “pity” (*bul-ssang-ham*). By reluctance, early childcare workers and church leaders noted that they were hesitant to speak to a parent of a child with a disability for fear that whatever concern they expressed would be construed as pity, and pity construed as condescending. One response to this discomfort is reluctance and often the act of avoidance to interact with the child or family. Church leaders and early childcare workers commented that families with autistic children recognize that they are treated differently or avoided and are thus concerned about how they appear to others in public. Early childcare workers and church leaders were clear that the understanding of autism as something that demeans the value of one’s family results in a sense of shame, defined as being the object of others’ critical gaze, and a fear that either acceptance or disclosure of a diagnosis will negatively affect the child’s future.

Both participant groups consistently called for more openness and disclosure about autism in the community, implying that people try to hide their child’s disability. Examples of such discomfort included the belief that people stare at children with autism, view them as “bizarre,” (*isanghan*) and do not want their own children to interact with them. There is also a fear of both child and parents being socially marginalized, and this fear is prevalent among Koreans in Korea (Grinker & Cho, 2013, p. 67). Early childcare workers and church leaders described Korean parents feeling ashamed about their child’s autism or developmental disorder as evidenced by requests to keep their child’s condition confidential, and stated that one should not openly announce or discuss a diagnosis of autism with others and should use great care and caution when talking to parents about whether their undiagnosed child should be screened for autism. The causes for discomfort related to autism included not having enough knowledge about autism to speak about it intelligently; not knowing how to speak about a sensitive topic like a child’s disability, or even knowing whether it was socially appropriate to speak about it; and believing that by recognizing a disability they were revealing a family’s secret, or insulting or shaming the family of the child. Early childcare workers and church leaders reported that one of the major dilemmas was what to do when they identified a child who might have a developmental problem, but whose parents had yet to seek expert evaluation. One church leader noted:

It’s really hard to bring up any personal issues of people unless they come up to me first to ask for help. Asians feel ashamed of and sensitive to their family’s dishonoring issues. It’s not easy for them to talk about such issues.

Another church leader said:

Although the Korean public sentiment [towards autism] has changed nowadays, topics such as ‘autism’ or ‘developmental disorder’ are still very distant and special to most Korean parents. So, you should be cautious when reaching out to the public on topics such as these. People tend to show not much interest in these topics, because if you do, it will make people believe that you have significant someone who has such disorder. They tend to be still shameful about acknowledging [such fact]. So, the strategy in approaching the Korean parents has to start from education in general and then narrow it down to a specific disorder such as autism or developmental disorder. These specific topics work better on individual level or on small scale rather than on a large public.

Most early childcare workers and church leaders reported that parents might be insulted by the suggestion that their child should be screened for autism and might respond by resisting professional help. One participant said that the church would not want to make recommendations to parents or be proactive in seeking services, because it might damage the family's image. All early participants worried that the difficulty of initiating conversations might lead to delays in seeking treatment.

The concept of parental "denial" was also widely used by our interviewees, by which they meant a parent's insistence that clinical identification of a diagnosable developmental disorder in the child is untrue. Most church leaders and early childcare workers expressed reluctance to broach the topic of autism in their church and early childcare centers.

Church leader: If they accept the issue, nothing will be a problem. But if they don't realize it or deny it, then I will be very cautious, because if I say that the kid has a problem while the parents deny it, then I can't recommend the solution to them. It is very uncomfortable for them if they think their child doesn't have a problem but the pastor is saying that their kid has a problem.

Early childcare worker: Although the mother might want to deny it, but I think accepting the diagnosis the most important first step.

Some early childcare workers and church leaders nonetheless considered it important to discuss.

Church leader: I don't think it is comfortable. Not just for autism but if parents have a kid who has a similar problem, it would not be easy for them to talk about it with others. While it is not comfortable to talk about it, the issue should not be concealed at the same time. Rather than hiding about the issue, it would be better to be open about it so that people can look for solutions, treatment for the kid and ways that can better the situation. Especially in the church setting, it is better to be open about the issue so that normal kids can be more careful and so do other parents which will ultimately be more helpful for the kid [with autism]. People have been trying to be more active in seeking for the solution rather than hiding about [the issue regarding children with autism].

All participants described the Korean-American community as divided on both how to behave towards families of autistic children, and disclosure of the condition, with some people showing little reluctance and treating families with a child with autism "like they treat other families," openly discussing autism, and others being more inclined to hide it. Church leaders mentioned that the younger generation in the Korean community is more "open-minded" about autism and other types of disabilities while older generation tries to hide matters related to autism and developmental disorders. Although all of the participants considered autism incurable, they also believed that children with autism can improve if given appropriate interventions.

Some church leaders and early childcare workers expressed the view that Korean-Americans were simply not interested in the issue of autism because it did not affect them; they said,

only people who know an autistic child or parents of an autistic child would be concerned about autism as exemplified by the following statement:

Early childcare worker: I don't think they have any interest in general. Only parents who have a kid with autism have interest. Otherwise, they don't seem to have any idea on how to make it better for autistic people.

Some church leaders explicitly compared autism among Koreans in Korea, Koreans in the US, and non-Koreans in the US. They suggested that Koreans in Korea are the least aware of autism as a diagnosis, a spectrum, and a condition in which one can influence outcomes through interventions. One participant remarked that Koreans and Korean-Americans were both more uncomfortable with autism and judgmental of parents of children with autism than their non-Korean counterparts. The evidence they offered for this greater bias is the degree of denial and shame associated with having a child with a disability in Korean families. A few church leaders said that in Korea, people would typically try not to make a "big deal" about a child's developmental problem. To do so would draw attention to the child. A parent might try to ignore or deny any sort of problem and as a result, not seek any special services for the child. The church leader seemed to suggest that the parental response to potential stigma was silence, hiding, or inaction. Church leaders recognized that there were fewer organizations to support and inform people in Korea (though not one of our interviewees in the US cited any particular American advocacy or support group), and that Americans and Korean-Americans were more understanding and better able to utilize services because of the greater availability of services in the US. In other words, in a context in which there are few services for a condition, there are few incentives to diagnose that condition.

Most church leaders and early childcare workers stressed that there was increasing awareness and "tolerance" of autism, just as their community had become more tolerant about other types of disabilities. While disability rights advocates in the US would not likely to endorse the concept of "tolerance" in a disability rights movement, as it suggests enduring rather than appreciating difference, our participants recognized tolerance as clear evidence of progress in their community. Church leaders explained that this change was most apparent in younger generations of Korean-Americans, who were more open-minded than their elders, and more interested in finding solutions for dealing with autism.

Discrimination and Stigma

Despite the growing openness in the younger Korean generation, both groups reported that Korean parent caregivers are still unwilling to access available services. Early childcare workers and church leaders suggested that since parents might not admit that their child has autism, having conversations with parents about getting help for a child is difficult. Some church leaders said that Koreans have difficulty in revealing private family matters to pastors or other church people as they feel shame. There are some people who talk about their own individual problems, but not about their children's. Participants mentioned that since the Korean-American community is small, people tend to find out what parents say about their children. The early childcare workers and church leaders we interviewed felt that they should talk to the parents of a child who shows symptoms of autism to help connect them

with appropriate evaluation and support. However, they remained deeply concerned about the shame associated with a child's disorder, especially in what interviewees described as the Korean and Korean-American "competitive society (*kyong-jang-sa-hoe*)" and "inferiority complex (*yeol-deung-ui-sik*)" for one's child to reach the pinnacle of academic achievement (matriculation at prestigious universities), and for one's child's success to promote the family's prestige and social (if not economic) mobility (Seth, 2002). In our interviews, fear of stigma and discrimination faced by children with autism and their families regarding causes and features of autism was also pronounced due to theories of causation that included family's wrongdoings, a curse, mental illness, and genetic abnormalities in the parents' lineages. Church leaders stated that Koreans might even avoid marrying someone who has a close family member with disability.

Church leader: Autism in Korean society is seen as something terribly wrong, and in extreme cases, people gossip about curse or mental illness in the family when they see an autistic child.

Church leader: Koreans – even if they're living in the US – tend to think that a child's disorder is the result of someone wrongdoings, or something bad that runs in the family. As a matter of fact, until recently, and even now, many Koreans avoid marrying someone from a family with a disabled person.

Church leader: In the case of my daughter, she had a lot of mental pressure from her in-laws in the early days of marriage. So that played a part [in her giving birth to an autistic child].

One church leader recounted a story about a child being mocked and avoided in other churches because of his/her behavior.

The Role of the Church in the Community

As exemplified in the three quotes below, church leaders shared their ideas and strategies for how to diminish stigma and create a better world for families affected by autism. Many church leaders believed that church should be involved in the lives of children with autism and other disabilities, but primarily by offering what they described as a warm and embracing attitude. A few participants went further to suggest that church leaders should educate church congregation members and other children about autism and how to facilitate supportive social interactions with them. However, some participants said that their churches cannot offer any clinical intervention for children and families dealing with autism and developmental disorders as churches are not professional organizations with funding and experts to support the families. The churches did not provide clinical interventions and rarely provided referrals for clinical intervention.

Church leader: So my personal opinion is that each and every person gathered at church has their own weakness and shortcomings. Autism and developmental disorder are just a part of those. So the church should be a community where each other's weakness is accepted and embraced. The congregation should support each other and fulfill their shortcomings. So it is perfectly normal to see autistic children or children with developmental disorder, and their parents in a church.

Church leader: The Church congregation consists of various people who have different thoughts, attitudes, and who are at different stages of their religious lives. So even though most people in the church seem to be understanding and tolerant of such children and their families, they lose their tolerance once they witness these [autistic] children act weirdly. So, I feel that my role as a pastor and church leader is to make the congregation understand what [this disorder] really is.

Church leader: I don't think there's anything else church can do [for these children] other than giving them more love and also pray for the family. After all, a church is not an institution that offers treatments.

Church leaders discussed particular services that their churches or other churches provide for children with autism. Some churches bring in special teachers and hold support groups for autistic children and their families. One church held a seminar about autism to educate the community.

Church leader: So far, there are no families among my congregation who have autistic children. But back in Chicago [where I was before coming to NY] there were parent organizations and support groups for autistic children, and also a church – not a local one but a collaboration of many churches – that supported families with autistic children.

Church leader: Right.... In my church, we have a child with developmental delay, and we invite a special teacher to come every Sunday to take care of that child.

Discussion

The results of our study investigating Korean immigrant families' and professionals' beliefs and attitudes towards autism support previous research findings that communities create and negotiate their own cultural meanings of developmental disorders (Grinker et al., 2012). They also reveal that community beliefs about autism and developmental disorders influence families' reaction to their child's conditions and affect professional efforts to provide services.

Both church leaders and early childcare workers endorsed the view that members of the Korean-American community have attached feelings of discomfort and negativity about autism. As found in previous research (Grinker et al., 2015), shared beliefs about autism and developmental disorders in the Korean-American community include a family's wrongdoings, a curse, parental mental illness (especially in the mother), or an impaired genetic line.

This study result supports previous research finding (Grinker et al., 2015) on the belief about causality that included poor parenting, low parental intelligence, poor family environment during pregnancy, and "lack of love" (*aejŏng kyŏlpip*). In this view, parents fail to attach to their children and, as a result, children with autism in Korea are often diagnosed with Reactive Attachment Disorder (RAD), a diagnosis that presumes there has been some form of abusive caretaking. Shin et al. (1999) has argued that RAD is a condition that "mimics"

autism, and those mothers are the primary source of pathology in children with the apparent symptoms of autism.

The cultural beliefs about autism between the NYC Korean community and South Korea are consistent with reference to marginalization and stigma. We find that community members stigmatize people with autism and their families by avoiding them. As Grinker and Cho wrote about autism in urban South Korea: “Social acceptance, while seldom acknowledged as a primary goal, is as important as the more frequently stated academic goals because so much more is at stake than just the child. What happens to the child happens to the mother. If the child is exiled and stigmatized, so is the mother” (Grinker and Cho, 2013, p. 67). Grinker and Cho describe that parents in Korea show resistance to recognition of a developmental problem based on 1) a desire to define the child, and therefore the family in general, as “normal”; 2) a distinction between social and intellectual domains of child development, in which mothers localize the problems they will acknowledge as deficits in a discrete area of development rather than as a global or pervasive impairment; and 3) the rejection of a label as they fear that labeling will index a permanent condition. Similarly, in an earlier study conducted in New York with Korean-American families, Korean-Americans characterized parents of children quite judgmentally, with terms such as “irresponsible,” “cold,” and “unable to relate” (Grinker et al., 2015, p. 2334). The same study showed that parents of children with autism are in turn marginalized from their circle of potential social supports.

The participants in our study reported that families with a disability are at risk of being marginalized. The participants in this and in previous studies of children’s developmental disabilities among Koreans and Korean-Americans recognize that education, or what is often referred to in Korean and Korean-American communities as “education fever” (*gyoyungnyeol*) remains parents’ primary concern (Im, 2001; Park, 2007). What they want, and what they worry about the most, is success on a social battlefield comprised of highly motivated parents and children. Because of marginalization, a child with an identified disability is likely to have little chance at winning the competition described as “competitive society” (*kyong-jang-sa-hoe*.)” Much of early childcare workers’ and church leaders’ discomfort speaking with parents about autism stems from this understanding.

Despite the common concerns among our study subjects about how to feel, think, and speak about autism, this small number of interviewees possessed different levels of knowledge about autism and child development in general based on training, age, time in the US and their personal experience in Korea and the US. Additionally, despite the discomfort and stigma, the early childcare workers and church leaders stated that the Korean community in the New York City is changing and the younger Korean generation in the community is more open-minded toward autism and tends to welcome outreach efforts to increase early detection of autism in the community. The difference in the openness toward autism and other developmental disorders between the Korean community in the US and South Korea and the difference by generation within the Korean community in the US may indicate a hybridized perspective on autism and autism treatment that has been created through the particular ways in which Koreans in the US network and use information in the new immigrant society (Bagnoli, 2007; Kirmayer, 2012; Pondé & Rousseau, 2013). The study

participants shared that the younger generation tends to take information more from sources in English, while the older generation learns about new information through Korean newspapers, TV and Internet. Interactions of these generations within each family are likely to contribute to creating a hybridized perspective on autism in the Korean community in the US.

Both early childcare workers and church leaders called for more openness and disclosure. Our research suggests that a community-wide approach encouraging more accepting and embracing attitudes towards autism can serve as the first step towards ameliorating the stigmatizing environment. Culturally appropriate community-wide outreach programs can also help increase awareness of autism and developmental disorders and connect Korean families with early intervention resources. To minimize stigma and discomfort, these strategies should target all parents and caregivers with standardized information on child development, child education, and parenting. Some childcare workers and church leaders suggested that in order to initiate effective communication with families, they might invite parents of a developmentally delayed child to the classroom or playground where they could see how their own child's social skills differed from their peers. Our interviews point out the importance of offering early childcare workers and church leaders opportunities to learn how to address a child's behavioral symptoms, and minimize the bias and discomfort that stand in the way of early intervention. One strategy is to offer educational workshops, perhaps hosted at community churches, that provide continuing education credits for health professionals and teachers, and that might, as a result, facilitate conversations about autism in Korean-American church congregations and eventually minimize stigma, marginalization, denial, and discomfort in the community.

A series of parenting seminars that teach child developmental milestones at early childcare centers could also provide parents with a more comfortable environment to learn about child development and developmental screening. Early childcare workers mentioned that it is difficult for Korean parents to have a class visit as most Korean parents have full-time jobs working longer hours than a typical 9am – 5pm schedule. Thus, a series of brief mini-seminars are likely to be more effective. For the parents who cannot attend seminars, early childcare workers and church leaders suggested making information sheets available by placing them in the entrance area. Community-wide public health initiatives that promote widespread dissemination of general parenting skills with a minimal level of engagement, such as the Primary Care Stepping Stones Triple P (PCSSTP, Hodgetts, Savage, & McConnell, 2013; Tellegen & Sanders, 2012; Whittingham, Sofronoff, Sheffield, & Sanders, 2009), have proven to be an effective strategy for parenting for families with children with disabilities as well as autism, may also be an effective outreach strategy for Korean parents. This type of community-wide outreach focusing on general parenting is likely to increase Korean parents' comfort level of talking about autism. Experienced parent advocates who have a child with autism can play an important role in reaching out to other parents within the Korean community.

The role of churches in the Korean-American community in supporting families coping with autism and developmental disorders emerged as a critical part of Korean-American social experience. Korean-Americans tend to view Korean churches in the US as offering a warm

and embracing environment for children with autism, their families and church congregations. Korean church leaders believe that churches should be involved in the lives of children with autism. It was not surprising to us that church leaders believe they are an important element in guiding child-rearing since many Korean-Americans, especially the first generation, focus on the development of their social networks within Korean Christian churches (Farver & Lee-Shin, 2000; Hurh & Kim, 1988; Mangiafico, 1988).

As has been demonstrated in the literature on parents' adaptations to developmental delays in other contexts (see, for example, Raghavan et al., 1999), religion often plays a role in the lives of developmentally delayed children and their parents, not so much because religious beliefs and practices directly alleviate suffering, but because religion provides a structure for integrating children and their families into community life. Additionally, churches provide a mechanism for addressing public health issues, even if indirectly. Indeed, the health services literature shows that church-based health interventions have been previously used in studies to reduce HIV-related stigma (Berkley-Patton et al., 2010; Derose et al., 2014), promote cancer-screening behaviors among Latinas (Allen, Leyva, Torres, & Bartholomew, 2014), to promote lifestyle changes including physical activity, dietary habits and controlling blood pressure and blood glucose (Pengpid, Peltzer, & Skaal, 2014; Tussing-Humphreys, Thomson, Mayo, & Edmond, 2013; Wang et al., 2013; Wilcox et al., 2010), and to reduce cardiovascular disease in mid-life and older African Americans (Ralston et al., 2014). Church leaders who participated in our study distinguished their churches from service providers saying that churches are not service providers and cannot offer treatment for children with autism. Previous research (e.g., Harachi, Catalano, & Hawkins, 1997) also noted that recruiting for parenting programs among Hispanics and Pacific Islanders was most effectively done in churches, where community members believed they would encounter moral and ethical behavior, while African-Americans saw the involvement of clinical information and interaction with child specialists in a church to be a profane intrusion.

Considering these findings, church-based outreach designed to minimize stigma at individual, congregation and community levels might be effective in increasing awareness of autism for children with autism, as most Korean families are involved in church congregations and receive emotional support from the church. An outreach program that leverages church congregations' broad reach and ability to influence can be an effective tool for reducing disorder-related stigma (Derose et al., 2014). Yet, church leaders are often ambivalent about how to address autism. On the one hand, they know that for children to receive help, parents must seek an evaluation. On the other hand, they also know that developmental problems, if identified and then disclosed to the parents' community, could result in stigma and marginalization. Church outreach should focus on supporting church leaders by providing consultation on "how to talk to parents about a child with developmental issues" and "how to create a church congregation that welcomes families with a child with autism and other developmental disorders." Creative church-wide outreach such as using a pew card that includes information on autism may increase families' comfort level about autism.

Limitations

Our study sample was limited to 13 participants with only four early childcare workers. Thus, the insights into Korean-American families' cultural beliefs are mostly gained through the lens of church leaders and we cannot distinguish differences in perception by different demographic characteristics. However, we did reach thematic saturation that we did not identify further significant variation in themes by respondent status. We could not include the two parent caregiver interviews in the data analysis due to the lack of representativeness. Thus, our study findings on parent caregivers' perception of autism are limited to the data collected through early childcare workers and church leaders, and parent caregivers may have more varying degrees of themes than we identified in this study. Future research that provides a holistic and well-rounded portrait of parental caregivers including investigation of indigenous perspectives/phenomenology, potential assets, strengths, and the nature of their personal relationship with their child is important. Geographically, interviewees were mostly from one concentrated area (Queens) of the NYC Korean-American community. Although Queens has the highest population of Korean families living in New York City, perceptions may reflect unique geographical characters.

Conclusion

Our study illustrates the ways in which culture influences beliefs about autism and decisions about help-seeking. Professionals' understanding of autism and their care for children are affected by these community beliefs. The uniformity of themes around stigma, shame, denial, and discomfort reveal the importance of creating a community environment that prioritizes minimizing the stigma attached to autism. Although there is some openness toward autism and developmental disorders, approaching immigrant communities with general information on child development rather than directly talking about autism and developmental disorders is likely to engage more families and professionals in need of diagnostic evaluation and early intervention for autism. In-depth learning about immigrants' cultural beliefs and understanding their approach toward autism and developmental disorders as part of their world view is critical to effectively reach out to immigrant communities avoiding an invasive approach.

Our study was limited to identifying themes through professional interviews. Future study that identifies parent caregivers' perception of their comfort level of communicating about child's development with their church leaders and in the community is important. By emphasizing the church and church leaders in our study, we also hope to draw attention to the importance of context in outreach; that is, the importance of identifying the people and places through which information about sensitive topics can be most appropriately and effectively communicated. Few topics are more sensitive for parents than a childhood developmental condition. Further research on engaging church leaders to play an intermediary role in reaching out to families, providing information and connecting families with referral sources is likely to provide specific church-based outreach strategies.

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Appendix A. Interview Guide for Church Leaders

CHURCH LEADER INTERVIEW

Introduction:

Like we mentioned in the consent form, your participation in this interview is voluntary. You can skip questions if you feel uncomfortable.

Every child develops differently and at their own pace. In certain situations, however, one might be concerned if a child isn't meeting certain developmental milestones/seems to be falling behind. Delays can occur in different areas of development. We are interested in talking to you today about developmental delays, such as cognitive and/or social delays. By cognitive delay, I mean not using 2–4 word sentences ('I want water') by 2 years old. By social delay, I mean not being interested in interacting with other children by 2 years old.

We are interested in talking to you today about developmental delays and, more specifically, autism. We will be talking to a number of church leaders to get a sense of how autism is perceived and handled in the Korean-American community (or anyone of Korean descent). Hearing about your experiences is very important to us because of the central role of the church for Korean-American families. Please keep in mind the context of the church environment and your role as a leader of the church as you answer these questions.

Do you have any questions before we get started?

1. Do you know anyone with a developmental delay/autism? If so, can you tell me more about what happened? Do you know what kind of developmental delay it was?
2. How would you expect a child with a developmental delay to look or act?
3. In your opinion, what causes developmental delays?
4. If you suspected that a child had a developmental delay, what would you do about it?
 - a. What factors might influence how you handle the situation?
 - b. How would you talk to the family about it? What language would you use? (i.e. autism, developmental delay, etc.)
5. What information would be useful to have in this situation?
 - a. Where would you go for information? Who would you talk to?
6. Where might you send the family/child for help or additional support? (i.e. agencies, organizations)
 - a. What would prevent the family from using these services available through community agencies?

- b.** What could you expect the child and his/her family to gain from using these services available through community agencies?
- 7.** How capable and comfortable do you feel referring a child who might benefit from services?
 - a.** What things make it feel manageable? What things make it more difficult?
 - b.** What would make you feel more comfortable and capable?
- 8.** How do you see the church being involved in the life of children with autism?
Now I'd like to talk to you specifically about autism, a term used to describe a spectrum of behaviors related to some social and cognitive impairments.
- 9.** Can you tell me what you know about autism? How did you learn about that?
 - a.** (if not mentioned already) Have you heard of the agencies: Autism Speaks, Autism Match, or Early Intervention?
 - b.** What do you know about these agencies? Can you tell me about any experiences you have had with them?
- 10.** What is the general opinion of autism in the Korean-American community (or anyone of Korean descent)?
 - a.** How comfortable do you think Korean-Americans feel talking about autism?
 - b.** How comfortable do you personally feel talking about autism with patients?
 - c.** (If not specifically mentioned) Could you describe any stigma related to autism in your community?
- 11.** If a child is diagnosed with autism, how does that influence the child's experience in church?
 - a.** How would that diagnosis affect them as they grow older?
 - b.** Who is it important to share that diagnosis with? Why?
- 12.** Has anything happened in the past 2 months that has affected how you think about autism? (IF YES, GO ON TO PROMPTS, IF NO CONTINUE TO NEXT QUESTION.)
 - a.** Tell me more about that?
 - b.** Where did the information come from – news source (print or online), community event, individual, etc.?
 - c.** How do you feel your understanding of autism has changed?

Now, I'd like to talk to you specifically about some materials recently development and distributed in your community about developmental delays and autism.

13. Please take a moment to look at these. Have you seen these before?
14. What do you think is the overall message of these materials?
15. Where should these materials be distributed? Who would you show them to?
 - a. Newspapers, Korean TV channels, churches, schools, etc.?
 - b. What is the best way to share this information to the Korean-American community (or anyone of Korean descent)?
16. How would they be helpful? What are barriers that would get in the way of these materials being widely distributed?
17. Is there anything else you think is important to understand about Korean-Americans and how they think about autism or developmental delays in general?

Thank you so much for your time!

Biography

Christina D. Kang-Yi, PhD, is Research Assistant Professor of Psychiatry at the Perelman School of Medicine, University of Pennsylvania. Dr. Kang-Yi's research focuses on improving mental health policy and service delivery designed for youth and adults. She has published on disparities in service delivery and evaluation of behavioral health interventions and outcomes based on public-academic partnership.

Roy Richard Grinker, Ph.D. is Professor of Anthropology and the Director of the George Washington Institutes of African Studies and Ethnographic Research in Washington, D.C. His recent works focuses on cross-cultural analyses of treatment and awareness of autism in sub-Saharan Africa and South Korea.

Rinad Beidas, PhD, Assistant Professor at the Perelman School of Medicine, Department of Psychiatry, University of Pennsylvania, researches the dissemination and implementation of evidence-based practices (EBPs) for youth in community settings. In 2015, Dr. Beidas was honored as the recipient of the President's New Researcher Award from the Association for Behavioral and Cognitive Therapies for her work in understanding how to most effectively support therapists, organizations, and systems in the implementation of EBPs. Dr. Beidas earned her PhD in clinical psychology at Temple University.

Aneeza Agha, MA, is a Project Manager at the University of Pennsylvania. Ms. Agha is currently evaluating primary care clinical programs at VA Medical Centers nationally through the Center for the Evaluation of Patient Aligned Care Teams (CEPACT). She has mixed methods research experience in the areas of HIV/AIDS prevention and care, minority populations, vulnerable populations, and health disparities.

Rachel Russell, BA, currently works as a Medical Case Manager at Action Wellness, a social services agency serving individuals living with HIV and other chronic illnesses. Ms. Russell contributed to this research as a Research Coordinator at the Mixed Methods Research Lab at the University of Pennsylvania. Rachel has worked on qualitative and quantitative research related to mental health mindfulness interventions, HIV/AIDS stigma, and co-occurring mental illness and HIV/ AIDS diagnoses.

Sandeep Bikram Shah, MPH, MSW, is currently working as a Business Relations Consultant for New Hampshire Department of Education, Vocational Rehabilitation. Prior to this Mr. Shah worked at Mixed Method Research Lab at University of Pennsylvania as a research coordinator. He received his Master's in Social Work and Public Health from University of Pennsylvania and his BA in Social Welfare from University of California, Berkeley. Mr. Shah has extensive working experience at various non-profits including community foundations and also worked in a financial industry prior to joining Mixed Method Research Lab.

Kathleen Shea, MS, is a Senior Research Coordinator at the Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities. Ms. Shea has coordinated research projects examining the impact of state-level policies on the delivery of services to individuals with autism, and currently coordinates and provided support for policy projects for the Eastern Region of the Autism Services, Education, Resources, and Training Collaborative (ASERT) in Pennsylvania. Ms. Shea's research interests include the impact of health policies on access to community-based services for adults with psychiatric and developmental disabilities.

David S. Mandell, ScD, is a Professor of Psychiatry and the University of Pennsylvania's Perelman School of Medicine, where he directs the Center for Mental Health Policy and Services Research. His published research examines strategies to improve service delivery to people with psychiatric and developmental disabilities, especially individuals with autism.

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Table 1.

Demographic Characteristics of Study Participants.

	Early Childcare worker	Church Leader	Total
Total	4	9	13
Gender			0
<i>Female</i>	3	2	5
<i>Male</i>	1	7	8
Interview Language			0
<i>Korean</i>	3	9	12
<i>English</i>	1	0	1
Education Level			0
<i>High School</i>	0	0	0
<i>College Degree</i>	4	1	5
<i>Master's Degree</i>	0	5	5
<i>Doctoral Degree</i>	0	3	3
Mean Age	47	55	51
Mean Years working for the Organization	8	17 *	12.5
Mean Years working in the Field	21	22 *	21.5
Mean Years in the US	21 **	23	22

* Not reported by one participant in this category.

** Not reported by one participant in this category who was born in the US.