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“Communities” in Community Engagement: Lessons Learned from Autism Research in South Africa and South Korea

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Scientific Abstract

Little research has been conducted on behavioral characteristics of children with ASD from diverse cultures within the US or from countries outside of the US or Europe, with little reliable information yet reported from developing countries. We describe the process used to engage diverse communities in ASD research in two community-based research projects—an epidemiological investigation of 7–12 year olds in South Korea and the Early Autism Project, an ASD detection program for 18–36 month old Zulu-speaking children in South Africa. Despite the differences in wealth between these communities, ASD is under-diagnosed in both settings, generally not reported in clinical or educational records. Moreover, in both countries there is low availability of services. In both cases, local knowledge helped researchers to address both ethnographic as well as practical problems. Researchers identified the ways in which these communities generate and negotiate the cultural meanings of developmental disorders. Researchers incorporated that knowledge as they engaged communities in a research protocol, adapted and translated screening and diagnostic tools, and developed methods for screening, evaluating, and diagnosing children with ASD.

Introduction

To date, little research has been conducted on behavioral characteristics of children with ASD from diverse cultures within the US or from countries outside of the US or Europe, with little reliable information reported from developing countries. Researchers do not yet know if the onset and symptoms of ASD are consistent across cultures, or how cultural differences interact to influence the type and range of impairments that are essential to or associated with ASD, its prevalence, or acceptability and effectiveness of treatment. Robust studies of cross-cultural differences in ASD are needed for improving early detection, generating more accurate estimates of prevalence, and delivering services in culturally diverse communities. For example, deficits in eye gaze are intertwined with many core features of ASD but little research is available on how cultural differences in the use of eye gaze during interaction may affect early diagnostic features. There are also significant cultural differences in childhood experience and expectations for individuation and development of competency—for example, the value of talk by young children, expectations for children to initiate communication, and responsiveness of adults to children’s speech, all of which can influence the detection and parental reporting of symptoms of ASD (Grinker et

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al., 2011). This article argues that culturally specific understandings of illness, disease, and developmental disorders call for different approaches to engaging communities. We describe a range of ethnographically informed strategies for recruitment and stakeholder participation, including—but not limited to—primary research participants in two studies involving the detection of ASD in children (in South Korea and South Africa). The first study involved community engagement in relation to a total population epidemiological study of ASD; the second involved community engagement to develop innovative ways to reach low resource and underserved populations and to develop and test a community-based autism detection program. In both cases, local knowledge helped researchers to address both ethnographic as well as practical problems. Researchers first identified the ways in which these communities generate and negotiate the cultural meanings of developmental disorders. Researchers incorporated that knowledge as they engaged communities in a research protocol, adapted and translated screening and diagnostic tools, and developed methods for screening, evaluating, and diagnosing children with ASD.

The Concept of “Community”

Definitions of “community engagement” and related concepts such as “community-driven model,” the Participant, Organization, Protocol and Community Involvement (POPCI) model, and “communitarian research” (Fuqua et al., 2005; Wyatt et al., 2003) generally refer to the process by which researchers enlist the cooperation and collaboration of those they wish to study. A commonly used approach to build community engagement is community-based participatory research (CBPR). CBPR is a commonly used collaborative approach to the research process that addresses a need identified as important to the community and, through a partnership, formulates the methods for implementing the research. It has been employed in a wide range of research concerning social policy (Minkler & Wallerstein, 2003), guidelines of “best practices” (Frankish et al., 1997), the development of communication skills to reduce health disparities (Horowitz et al., 2004), and the dialogic development of the research questions themselves (Mosavel et al., 2005). Here, dialogic development refers to the way in which communities participate with researchers in the selection of research topics and design.

Each of these approaches relies on a concept of “community” that is commonly ill-defined. Indeed, the term is often used to refer to any population of research participants regardless of context. We follow MacQueen and colleagues’ (2001) general definition of community as “a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings” (2001: 1930); however, we emphasize that a definition of any specific community must be defined locally. What constitutes a “group,” a set of “social ties,” “perspectives,” and sense of place varies according to cultural context. For example, in the South Korean study discussed below, stakeholders objected to the definition of their community initially held by the researchers since it included both the poor and wealthy, uneducated and educated, as members of the same research participant group. As another example, research in progress among second- and third-generation immigrant mothers in the US from Mexico, by several authors of this paper, has had to take into account the relationship between acculturation and the influence of social ties. As has been well documented (Eisenhower & Blacher, 2006), among second and third generation Latino families in the U.S., extended family members play an important role in determining health-seeking behaviors for children, yet among many first-generation immigrant migrant-workers, mothers are often the sole decision makers. Even within what appears to be a single, homogeneous community, such as migrants working on tomato farms in a southwestern Florida town, as observed by several of the authors, there is considerable variability. Looking in on this community from the outside, many researchers and health-care providers are unaware that the workers may not share the same perspectives or belief systems. Workers migrated from a range of different countries and there are frequently significant language variances even among migrants from the same country. Ambiguities of community identification can affect the comparability of research studies because, as Dyches and colleagues (2004) note, studies frequently confuse racial and immigration status, or ethnicity and parental place of birth.

Definitions of community are therefore exercises in cultural translation, as researchers seek to communicate with and understand their potential research subjects in local terms as much as possible. Indeed, procuring valid data may hinge on researchers' development of culturally-sensitive recruitment methods, culturally-specific ethical considerations, local interpretations of the researchers' motives, and a working knowledge of the power relations within a community. As our examples below demonstrate, community-based research facilitates the crucial recruitment phase as well as participant retention by limiting or managing negative views or misunderstandings of the researchers, procedures or goals of the study, though the process may be slow and proceed piecemeal. For example, because a single research document, such as an informed consent form or an information sheet, may unintentionally be culturally biased (Marshall, 2007), most studies would benefit from assistance of community members in writing and editing the document. A consent form may assume a level of education, familiarity with the language used by the researchers, or literacy that research participants do not possess, or include a concept that researchers take to be universal, such as "confidentiality," but which may be foreign to communities embedded in different webs of power relations. Participants who have experienced an extended history of authoritarianism, or may be part of small-scale, tightly knit communities where even initial contact with researchers may constitute a breach of the "Western" sense of privacy, or live in a community in which medical researchers have previously violated the trust of research participants have specific concerns that must be explicitly addressed (Burhansstipanov et al., 2005; Escobedo et al., 2007; Kaufert & Kaufert, 1998; Marshall, 2007).

The researcher is thus inevitably a cultural broker, involved in a dynamic relationship between the study aims and various communities' expectations. The concept of CBPR provides a useful framework for building these relationships. It acknowledges that there are distinct interests among the various stakeholders involved—whether they be the researchers, funders, or communities—and that there must be dialogue every step of the way (from defining research goals and collecting data, to data handling and intervention design) in order to carry out ethical and meaningful research. For example, the goal of one study might be to describe, rather than treat, a specific behavior, yet parents of the participants may expect the child to improve–no matter how clearly the researcher believes the informed consent form states that the study may yield no immediate benefit. Indeed, while researchers may be convinced of the logic and worth of their goals, such as diagnosing autism among young children, researchers may encounter a pre-existing historically specific pattern of expectation. In communities throughout the world with an extensive history of contact with nongovernmental organizations (NGOs) involved in economic development and social welfare projects (Ferguson, 1990), or that have been subject to the whims of transitory outsiders with seemingly unlimited wealth, researchers may be treated with deference, but also with suspicion. Therefore, as health researchers broaden their data collection to underserved regions of the world, there is potential for unforeseen breaches in what communities consider the ethical conduct of research, or at least the appearance of inequalities in power (Marshall, 2007).

Although numerous studies show that community involvement improves research outcomes (Clark et al., 2010; Horowitz et al., 2009; Hurst & Nader, 2006; Israel et al., 2005; Jarmon, 2011; Leung et al., 2003; Perry, 2011; Pinto et al., 2008), there is no one-size-fits-all protocol for engagement. Language and cultural differences, family and community gatekeepers, and mistrust about exploitation and ethnic stereotyping are among the common barriers for researchers (Aroian et al., 2006; Ejiogu et al., 2011). Mistrust is more salient among ethnic minorities and other communities marginalized from care, and programs to strengthen family involvement in care have been disproportionately targeted towards Caucasian populations (Myers et al., 1990). Indeed, although there is a tendency among researchers to idealize community partnerships as seamless, egalitarian, and empowering (Israel et al., 1994), power relations are an inevitable part of any form of research, especially in post-colonial settings or where there are disparities between researcher and researched in terms of wealth and access to symbolic capital—such as Internet, travel, language, and other markers of status and prestige (Marshall, 2007). Because the reasons for mistrust vary, so do the efforts to address them. In a study of parenting programs, for example, Harachi et al. (1997) note that building trust and achieving successful recruitment among Hispanics and Pacific Islanders is most effectively carried out in churches, where there is an expectation of ethical behavior, insulated from the outside, profane world. In contrast, successful recruitment of African-Americans or American Indians occurs in schools and community centers, but not in churches where research activities are considered a profane intrusion. Recruitment of American Indians requires contacts with an elder or other tribal leader while recruitment among Hispanic groups requires contact between the study participant and someone previously known to him or her. To cite another example, a study of stressors in Arab Muslim mother-child relationships in the US by Aroian and colleagues (2006) highlights the necessity of understanding cultural norms prior to beginning research. Many of their traditional recruitment efforts such as flyers in local mosques and letters of support from imams failed to attract participants because women were hesitant to speak with someone they did not already know. The authors admit that without their panel of cultural experts they would not have known how to establish the personal and culturally appropriate relationships that allowed them to not only recruit but also retain participants for the five year study period (see also Marshall, 2007).

In some cases, as the role of stigma in the South Korean example discussed below highlights, there are challenges in recruitment even when the study population appears easily accessible and identifiable. In others, such as the South African case presented here, the problem lies in identifying any children, whether families are willing to participate or not. Within the U.S., some groups, such as Latinos who have children with ASD, are more difficult to reach because they are more likely to use “nontraditional” treatments than the general population (Levy & Hyman, 2005), and thus may be invisible to researchers relying on clinic populations. Skinner and colleagues (1999a; 1999b), for example, report that 55% of their sample of Latino parents of children with development delays (n=250) view ASD as a sign from God and a challenge to their ability to parent; an ideology of *marianismo* (an idealization of the feminine) encourages self-sacrifice, charity, and a view that mothers should not depend on others for the care of their children (Blacher & McIntyre, 2006; Njoku et al., 2005).

In order to improve detection of ASD and access to services, ethnographically informed community engagement is vital to understanding when and by whom symptoms of ASD are recognized, the range and priority of different treatment systems in societies with plural medical systems (e.g., folk medical beliefs, bio-medical care, educational, and social work), and how family members interpret the symptoms of ASD through the lenses of these systems. Successful community-based research on ASD requires knowledge about how the burden of care is distributed amongst family members, what families know or understand about services, and how they conceptualize advocacy and treatment.

Epidemiological Lessons from Community Engagement Experiences in South Korea

The next section of this paper describes the process of ethnographically informed community engagement in relation to a total population epidemiological study of ASD in South Korea. This site was selected for several reasons. First, no epidemiological study of autism had ever been conducted in South Korea. Second, the research was initiated because anthropological research (Grinker, 2007) showed that parents of children with ASD, pediatricians and other experts, felt powerless to increase autism awareness in the country, and especially the concept of an autism spectrum. In comparison to North American and European countries, ASD and other developmental disorders are seldom diagnosed in South Korea, in large part because the disorders are so highly stigmatized and are conceptualized as severe rather than moderate impairments. Community stakeholders, such as a special educators, psychologists, and parents of children with developmental disabilities, thought that prevalence data could provide the ammunition to expand local definitions of autism, decrease stigma, and push for increased special education services.

Methods

The majority of prevalence studies of ASD, such as those conducted by the U.S. Centers for Disease Control and Prevention (2009), which has generated a prevalence estimate of approximately 1% for the US, are based on a method that employs careful review of records, but does not involve direct testing or observation of children in their homes or in clinical or institutional settings. A recent study in Koyang City, South Korea that employed a population-based direct screening, observation, and diagnostic confirmation and required extensive community engagement, has yielded far higher prevalence estimates (Kim et al., 2011).

The South Korean study was based on the hypotheses that 1) there are children with ASD in every country that do not appear in records, because for culturally specific reasons they are not receiving special education services, and that 2) record reviews will therefore lead to underestimates of prevalence. Researchers screened for ASD among 36,886 children ages 7–12 year olds (36,592 in regular schools, and 294 in special education schools), and conducted comprehensive assessments and diagnostic evaluations for screen positive children whose parents agreed to participate in the study. In order to minimize the possibility for cultural bias, the researchers translated, back translated, and validated the ASSQ, ADI-R, and ADOS for Korean children, and then employed a team of American and Korean diagnosticians to validate all final clinical diagnoses. The hypotheses were confirmed for this setting as the research yielded a prevalence estimate of 2.64% (Kim et al., 2011), higher than ever reported in all previous studies. Two-thirds of the children diagnosed with an ASD in the context of the project had been unrecognized and untreated even though their range of functional impairments were identified clearly in screening instruments, and their case status was confirmed through multiple diagnostic stages. These stages included the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2002), Autism Diagnostic Interview – Revised (ADI-R; Lord et al., 1994), and clinical assessment by a multi-national team of child psychiatrists. Additional details on the methods of the epidemiological study, including community engagement, are included in the published findings and supplemental materials (Kim et al., 2011). This research was reviewed and approved by the human subjects institutional review board at George Washington University and Yale University.

Community engagement and direct screening and observation go hand in hand. In South Korea, between 2005 and 2009, Grinker conducted three focus group meetings with parents of children with ASD (n=16), and four focus groups with teachers from regular and special education schools (*n*=31), in addition to numerous individual and group interviews throughout the South Korea. The goal of these groups was to assess potential concerns or misunderstandings about the study, risks and benefits to the participants, and the specific instruments to be used. To maximize participation in the epidemiological study, feedback from the focus groups was used to guide and revise the study procedures, including the language used in informational sessions and consent forms. Based on the focus groups, which indicated that parents and teachers would be unlikely to participate if the researchers employed clinical language, the researchers replaced scientific terminology in consent forms and informational materials with colloquial language and described the symptoms of ASD without employing the term itself as parents reported during the focus groups that they did not want to think about their children in clinical terms.

Given the stigma associated with ASD in South Korea and the fear that a diagnostic label of ASD would negatively affect a child's life, career, and marriage prospects, both parent and teacher focus groups also indicated the need to go beyond typical Institutional Review Board (IRB) and international standards to ensure confidentiality. The researchers and focus group participants then worked together to craft both the confidentiality procedures and the descriptions of those procedures in the information sheets, which researchers then distributed at local schools. As the study progressed, parents told the team anthropologist that they were more likely to participate in the research because they believed their child's test results would be more confidential than if they sought diagnostic evaluations through the Korean national health care system, which they believed would maintain identifiable records in perpetuity. They indicated that following diagnosis they would be more likely to seek services without insurance coverage, as they would continue to be concerned about confidentiality.

Local Korean researchers associated with the epidemiological study also worked with the Board of Education of Koyang City to establish what is now a long-lasting partnership for research on developmental delays in the city's elementary school children. Throughout the study, the investigators maintained regular contact with the Board to discuss and resolve any complaints from the teachers or parents at participating schools, to report on the survey progress and preliminary findings, and to provide educational sessions for the staff. As evidence of stakeholder "buy in," the Board subsequently committed funds to screen all first graders for developmental disabilities, and worked with the researchers to build the methodology (Kim et al., 2011).

Results

One of the benefits of the epidemiological study was the screening and diagnosis of higher-functioning children with ASD, a group of children who are less likely to receive a diagnosis than more affected children, and may therefore not receive special education or other services, such as speech or occupational therapy, in school. In the Ilsan district of Goyang City, where the study discussed below was conducted, only 0.8% of students attend special education schools or classes, a rate comparable to special education enrollment nationally (0.75%) in South Korea (Korean Ministry of Education, 2010), but far below special education enrollments in western Europe and North America. The epidemiological study thus unmasked cases of ASD that would have been invisible to epidemiologists relying solely on a records-based approach. These cases were masked in large part because ASD is highly stigmatized in South Korean culture and therefore not commonly diagnosed. Focus groups and other interviewees emphasized that ASD is stigmatizing because, in the participants' view, it is a hereditary disorder that impugns the genealogy and complicates marriage opportunities for extended family members. Interviewees did not distinguish between heredity and the more general concept of genetics, which is comprised in part by de novo mutations, or genetic but non-inherited cases. Parents with and without a child with

ASD believed that parents of children with ASD are denied raises and promotions at work and are marginalized from desirable social networks. They asserted that, hypothetically, parents who wish to sell an apartment in which their child with ASD lived would receive less money than a comparable apartment whose owners showed no evidence of childhood illness (Grinker, 2007).

Mistrust of the medical community was also revealed in the rejection of the diagnosis itself, an act in which parents reject expertise in favor of their own views. Transcripts of interviews show that members of the community whose children with ASD were able to function at or near grade level at school were aware of the concept of ASD, but rejected the diagnosis in favor of an alternative, commutable category of “border children” (*gyôngye-sôn*). Parents stated that their children have a social rather than an intellectual delay while “normal” children have either no delay or have a delay in the intellectual domain only. For parents, the concept of the border thus serves several functions. It helps them to mediate (or resist) an opposition between fixed and mutable labels, and to distinguish between social and intellectual aptitude. The latter distinction offers a way for parents in particular to localize their children’s problems as deficits in a discrete area of development rather than as a global or pervasive impairment. Downplaying the pervasiveness of ASD as a group of social and communication deficits, allows the parent to imagine a child moving back to “normal.” Furthermore, the symptoms associated with ASD were not seen as problematic unless those symptoms negatively affected the child’s or the child’s classmate’s academic achievement. Even when a teacher or school administrator reported a behavioral problem to a parent, the parent viewed disruptive behaviors as a failure of socialization and therefore a problem for parents—not teachers or doctors—to ameliorate. As the primary caregivers, mothers bear the weight of their child’s stigma as everything from the mother’s prenatal mood to post-natal diet is viewed as a potential cause of ASD. Given these attitudes, it is not surprising that parents asked the anthropologist: “Why, unless there was complete confidentiality, would any parent tell the truth about her child?”

The Early Autism Project in South Africa

The second section of this paper describes community engagement to develop innovative ways to reach low resource and underserved populations and to develop and test a community-based ASD detection program. The need for this study originated when the provincial government of KwaZulu-Natal (KZN) recognized that children in the province with ASD and other developmental disabilities were underserved, and that those children who did receive services should have received them at an earlier age. As is true in many low and middle-income countries, practical medical concerns are a barrier to care for ASD since early diagnosis coincides with a period in children’s lives when issues determining short-term survival compete with developmental disabilities for prioritization by service providers, local officials, and parents (Durkin, 2002). In response to these needs, Chambers, a South African speech-language pathologist, who had obtained her Ph.D. in communication science and disorders at Florida State University with a specialization in autism, returned to South Africa and met with key stakeholders in community health in KZN (Kauchali, Killian, & Chhagan). Together they formed a team of researchers to improve early detection of autism, and established the Early Autism Project, a community-based early detection program for children with ASD.

Methods

In contrast to South Korea, where researchers sought assistance from the community to screen and diagnose 7–12 year olds, where school is mandatory for the studied age group, and children were therefore easy to locate, the South Africa research study – the Early Autism Project – has focused on identifying children with ASD aged 18–36 months. The study, directed by Chambers and Kauchali, is based in KZN. This research was prospectively reviewed and approved by the IRB at Florida State University and George Washington University, the ethics review committee at the University of KwaZulu-Natal, and the KZN provincial Department of Health.

The on-going study recruits Zulu children using an adaptation of the multi-stage screening and evaluation process of the FIRST WORDS® Project. For this study, researchers employ an ASD-specific screening interview adapted from the Early Screening for Autism and Communication Disorders (ESAC; Wetherby et al., 2007) for low-resource settings, and examine early behavioral markers of ASD using two different video recorded observation methods—the structured observation of the Communication and Symbolic Behavior Scales (CSBS; Wetherby & Prizant, 2002) and a naturalistic observation of everyday activities—to compare children from South Africa and the US. Clinical diagnoses of ASD are based on proposed criteria of the 5th edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; American Psychiatric Association, 2011) and are confirmed or ruled out by trained clinicians using the ADOS (Lord et al., 2002) and a series of reliability checks.

The first step in community engagement was to identify stakeholders and arrange ethnographic interviews. These included parents, teachers, health care professionals, traditional healers, and clergy. Chambers and Grinker conducted a series of focus groups with parents, early childhood educators, nurses, and other stakeholders, and group interviews with these stakeholders to elicit explanatory models of ASD held by interviewees, ascertain the range of health care settings and services for children with developmental disorders, and begin the adaptation and translation of screening and diagnostic tools into Zulu. Focus groups were group discussions of specific components of the research (for example, consent forms, administration of surveys, and locations for research); group interviews were open-ended discussions of participants' general experiences raising young children and the kinds of research they felt were most relevant to their daily lives.

In the second step, researchers recruited bilingual Zulu/English-speaking parents to participate in a series of cognitive interviews in order to evaluate and offer suggestions for revising 193 statements and questions from the original English standardized evaluation instruments, all of which were developed in the US. Approximately 36% of the 193 questions and statements were revised as a result of this process; 45% of the revisions involved simplifying the English wording for greater clarity, 28% involved replacing English idiomatic expressions, 15% involved replacing ambiguous English words with more specific ones, and 12% involved eliminating or replacing content that was not culturally relevant. Overall, this technique proved to be an effective tool for assessing the clarity and cultural relevance of these instruments prior to translation. After the cognitive interviewing, a professional translator completed a forward translation, followed by a back translation, and then problematic words or phrases were identified and addressed to create a final translated version of each tool, as recommended by the World Health Organization (2006).

Results

During the focus groups, the researchers identified several categories of stakeholders: clinicians (including nurses), traditional healers, parents, day care center directors/ employees and managers of children's homes. Clinicians at community health centers and anti-retroviral distribution centers reported that they frequently see children whom they suspect have developmental delays, but have identified them only because the children accompany their parents to the clinics. Traditional healers such as the *izangoma* (diviners) and *izinyanga* (healers) were reluctant to speak with researchers, possibly because they feel like they are in competition with the mainstream medical establishment. Both parents and clinicians laughed when asked whether parents consult the healers when they have a child with the symptoms of ASD. The discomfort was in large part due to embarrassment about the persistence of traditional beliefs in a modern context, and parents admitted only after considerable prodding that they did seek the assistance of traditional healers, if only because their parents and grandparents insisted on it. In more remote areas, where there may not even be a medical clinic, an interviewee stated, “there are people known to the community who have healing powers particularly for challenges that children face.” Parents, the most obviously interested members of the community, responded positively to the research goals during focus groups, but were not keen on helping to edit information sheets or shape the language of the study. Many agreed to allow researchers into their homes to interview children in their everyday setting if the appropriate procedure was observed: meeting the father and other family members prior to the videotaping so that when the researcher arrived the next day he or she would not be considered a stranger. The anthropologist also initiated a role-play in which one parent, acting as the researcher, approached another parent to recruit the child into the study. Observations of these exchanges served the researchers well, as community members modeled the conversation, and the researchers were subsequently welcomed into several homes with few concerns raised about the purposes or confidentiality of the study.

Interviews and focus groups identified few barriers in terms of recruitment and potential community participation, other than the significant institutional challenges of locating toddlers at risk for ASD. Two important factors were identified by interviewees were poverty and the AIDS epidemic. Poverty diminished the possibility that parents would seek medical care or specialized educational services, such as nursery schools, for children who were not seriously impaired. Therefore, young children were being cared for either in their homes or in day care facilities (widely called *crèches*). The vast majority of *crèches* are home-based and informal, at a cost of as little as 100 Rand (approximately $12 US) per month. The study anthropologist traveled to rural and peri-urban areas, asking passersby for the location of *crèches*, and then meeting with their directors. He found that even centers based in small homes cared for as many as 50 infants and toddlers, with only a few staff. They acknowledged that given the high numbers of children, identifying mild symptoms of autism was difficult if not impossible. The HIV/AIDS epidemic also poses a challenge. Since many hundreds of thousands in KZN are orphans with have multiple caretakers (and residences) during a single year, any particular teacher or provider may have had few opportunities to observe a child’s development over time. Numerous interviewees recommended that we find young children at risk of developmental delay at the antiretroviral distribution centers. However, HIV/AIDS in children could potentially confound screening and diagnosis – since one manifestation of HIV/AIDS in children is developmental delay (Chung & Grinker, 1992).

During group interviews, various stakeholders described normative behaviors for toddlers. However, unlike South Korea, where community members performed their own expertise with regard to 7–12 year olds, Zulu speakers asserted little knowledge about meaningful differences in development between children from birth to three, and had few expectations about social and intellectual milestones. “Before the age of 2,” one interviewee noted, “it’s all ‘bah, gah,’ so you can’t tell many differences.” Yet the same interviewee, who cares for 65 children, some as young as 3 months, had known children who were eventually enrolled in special education schools. Regarding eye gaze, *crèche* staff expected two year olds to look towards them or at their faces when communicating, but not to make direct eye-to-eye contact. In fact, they noted, as a child gets older, direct eye contact with a peer or elder is generally discouraged and seen as disrespectful. .

One of the consequences of the focus groups and group interviews was that parents and other stakeholders, including providers, freely discussed topics that they had never before discussed openly. These included the range of medical pluralism in South Africa, the constraints on identifying children with developmental challenges, and the importance of pre-existing social ties to the delivery of care. Many interviewees, even those with children with ASD, knew little about the condition. The participants noted repeatedly that these discussions inspired them to engage in future discussions with other parents and providers on the question of how to provide appropriate care to children with developmental disorders. Yet they were conflicted about the utility of early detection and diagnosis given the lack of resources and services and raised the ethical question, relevant to research on ASD throughout the world, of the value of a diagnosis in a society that has yet to embrace it and has few services designed for that specific diagnosis. They were also conflicted about the benefits of a “western” versus a “traditional” diagnosis. Parents interviewed during the study noted that the “western” diagnosis of ASD alleviated their anxieties about spiritual causation and provided a useful framework for them to understand their children’s condition. However, in doing so, the diagnosis also affirms that it is the child, and not the child’s social network, that is sick. In contrast, a parent who consults a traditional healer typically learns that it is the society, not the child, that is afflicted. The ancestral spirits were displeased with some event or failure to follow custom, and expressed their displeasure through the child. Appeasement and cleansing rituals are often used to placate the ancestors and reaffirm the belief that an illness emanates not from the body of the innocent child but from society.

Discussion

Studies of ASD in South Korea and South Africa illustrate the value of culturally informed approaches to community engagement, both as a method to understand how cultural differences influence identification and management of ASD, and as a pragmatic strategy to implement research protocols. Both projects illustrate that the shared ideas and practices that comprise culture fundamentally influence the meanings that people impart to illnesses and shapes the experience of illness, whether and what kind of help is sought, what type of support is available, and how much stigma individuals and communities associate with the illness (Kleinman, Eisenberg, & Good, 1978).

A critical first stage of both studies was the process of community engagement, which paved the way for the identification of recruitment sources, cultural adaptation of methods, and successful implementation of community-based research in settings with low availability of clinical and educational resources for children with ASD. In South Korea, a total population study required extensive dialogue between researchers and the community. The study yielded a prevalence rate significantly higher than previous estimates in other countries in large part because of extensive community participation. In South Africa, the effort to identify behavioral markers that distinguish young children with ASD from those with typical development depends on extensive outreach to recognize barriers to identification and care. In addition to promoting mutual benefit for researchers and communities, cross-cultural community-based research studies, or studies of sub-cultures in a single community, can advance knowledge of the interactions among genetic, environmental, and cultural factors on the expression of ASD. Cultural differences may be evident in the behavioral phenotype of ASD, recognition and interpretation of symptoms by caregivers, the decisions parents make regarding screening, evaluation and treatment, and interactions between families and the healthcare system. The results of such research should lead to culturally sensitive screening and evaluation methods that may decrease the age at which children with ASD are diagnosed and, in turn, advance global ASD research.

Culturally-informed research may also yield more robust and valid data on developmental disorders more generally. Indeed, the burden of developmental disorders across the globe has not been fully appreciated, partly as a result of a dearth of sound epidemiologic and clinical research from lower and middle-income countries (Maulik & Darmstadt, 2007), and poorly adapted measurement instruments that are often culturally inappropriate for low resource settings. A significant factor hindering research on developmental disorders is age of onset, which has several consequences for parents' motivation and ability to seek diagnosis and intervention. First, in many countries facing high child mortality rates, parents, clinicians, and researchers are understandably less concerned with early diagnosis of ASD and services for children with developmental disabilities than with short-term survival (Durkin, 2002). Second, stigma and fear may be great enough to discourage any form of disclosure of a child's special needs. Third, given the absence of research on developmental disorders, established and documented norms of child development are not available in most populations, yet it is by now a truism that what counts as normal or abnormal development will vary from culture to culture. Thus, when even the most well-validated instruments are used in novel cultural settings, the validity of results from developmental testing may be limited. Extensive qualitative interviewing and ongoing dialogue with members of the community are required to understand how they conceive, identify, manage, and talk about the various symptoms of developmental disorders such as ASD.

Conclusion

When taken together, the two projects described here suggest that culture is not a variable to be controlled for or overcome; rather it is integral to the way in which a condition is experienced, defined and managed. Unfortunately, medical research has conventionally treated culture as an impediment to the implementation of research or clinical protocols. The research reported here highlights the vital role that local knowledge plays in helping to analyze the relationship between ASD and culture, shape research projects, and facilitate community engagement.

Despite our focus on communities in South Korea and South Africa, however, international studies such as these, aimed at improving detection in culturally different contexts, are also relevant to research and clinical care among diverse groups in North America and Western Europe. In the U.S., for example, research on ASD has shown clearly that health disparities exist and cultural variation may be one contributing factor. Children of lower income, minority, and rural families in the U.S. may receive a diagnosis up to a year and a half later than their wealthier, white, urban counterparts (Mandell et al., 2002; Mandell et al., 2005; Mandell et al., 2009). Moreover, minorities in the U.S. underutilize available health care services, especially child health and mental health services (Alegría et al., 2008; Gonzalez et al., 2010). Unfortunately, the emerging literature reveals that even when controlling for structural factors such as poverty, insurance, and access to services, which often confound the search for socio-cultural barriers (e.g., culture, language, patient-provider relationship), ethnic minorities underutilize available health care services, especially child health and mental health services (Alegría et al., 2008; Gonzalez et al., 2010). As important as it is to understand culture abroad, ASD researchers must also understand the significance of culture in their own backyard. As the Surgeon General's 2001 report aptly stated, the delivery of appropriate and effective mental health services requires an appreciation of the culture of both patient and provider: "Culture is a concept not limited to patients...clinicians and service systems, naturally immersed in their own cultures, have been ill-equipped to meet the needs of patients from different backgrounds." The promise of community engagement is dialogue and self-reflection. If researchers and the stakeholders in the communities in which they work understand and influence each other, they have the potential to accelerate the translation of science, improve community health service, and reduce health disparities.

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