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Cultural Adaptation and Translation of Outreach Materials on Autism Spectrum Disorder

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Abstract

In order to connect with families and influence treatment trajectories, outreach materials should address cultural perceptions of the condition, its causes, and post-diagnostic care. This paper describes the cultural adaptation and translation of the Autism Speaks First 100 Days Kit into Korean for the purpose of improving autism spectrum disorder (ASD) diagnosis, assessment, and interventions. The goal of this study is to describe a methodology for future cross-cultural adaptations and translations of outreach materials on ASD, using the Autism Speaks First 100 Days Kit as an exemplar. The research involved two stages of qualitative interviews: unstructured individual and group interviews with 19 Korean child health and education professionals in Queens, NY, followed by structured cultural consensus modeling interviews with 23 Korean mothers, with and without children with ASD, in Queens, NY and the greater Washington, DC area. We conclude that a systematic approach to cultural translation of outreach materials is feasible. Cultural consensus modeling yielded information about numerous barriers to care, had a demonstrable effect on the translation of the kit, and was efficient when employed with coherent segments of a relatively homogeneous population and focused on a single condition.

Introduction

Culturally sensitive outreach materials can reduce health-care disparities by providing culturally appropriate informational support to ethnic minority families (US DHHS 2001). In order to reach families and influence their treatment trajectories, outreach materials need to address cultural perceptions of the condition, its causes, and post-diagnostic care. The cultural adaptation described here is founded on the notion that cultural beliefs and discourse about a condition shape the way people identify and manage perceived abnormalities in a child's development. Biomedical approaches to disabilities and disorders often assume that disease constructs, such as autism or attention deficit disorder, are stable, uniform, or grounded in nature rather than culturally and historically contingent (Hahn and Kleniman 1983; Wilce 2009;). However, the presumption of an empirical pathology can mask the fact

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that disorders are also social and linguistic products (Danforth and Navarro 2001: 167; Grinker, Yeargin-Allsopp and Boyle 2011; Grinker et al. 2012;). We thus focus on *cultural adaptation*, the process of framing larger structures of meaning (concepts, ideas, problems) to fit the explanatory models of a distinct population (Kleinman, 1981).

While there have been attempts to translate autism-related screening and diagnostic materials into different languages, and while it is widely recognized that cultural beliefs about diagnosis, treatment and causes influence family decision making about healthcare, and ASD specifically (Spicer 2010; Stahmer et al 2011; Ravindran and Myers 2012; Guinchat et al 2012; Freeth et al. 2013) few researchers describe the processes of cultural adaptation or employ ethnographic methods. Guo et al. (2011: 715), for example, report on the clinical results of a translation and validation of the Autism Spectrum Screening Questionnaire (ASSQ) into Mandarin but do not report on the process beyond noting that the tool was translated by native-speaking experts who made "minor changes" to ensure the translation was "more culturally appropriate." Similarly, Canal-Bedia et al. (2010), in a study of the Modified Checklist for Autism in Toddlers (M-CHAT) in Spain, write that "some modifications were made to items 3, 5, and 23, after the short pilot study and prior to the validity study, in order to overcome cultural differences linked to the use of different toys in Spain (including new examples, and Spanish colloquialisms), but do not describe how those decisions were made, or how differences in types of toys between Spain and the U.S. constitute "cultural" difference.

Compared with the number of autism screening and diagnostic instruments for professionals that have been translated and validated in different languages (for example, Krug et al., 1980; Schopler et al., 1988; Lord et al., 1994; Ehlers et al., 1999; Rutter et al., 2003), there are few examples of translated outreach materials on autism for parents and families. Outreach materials are written documents available in print or online that are developed to reach and educate families who would otherwise not have access to this information. Since the purpose of outreach materials is to reduce disparities in early detection, diagnosis and treatment across ethnic groups, they should be both *linguistically competent* (in which organizations or individuals are able to communicate effectively with people who have different native languages) and *culturally appropriate* (in which information is shaped and presented for a specific audience whose linguistic and social contexts, and systems of belief, may differ significantly from those of the authors). In this paper, the term "translate" denotes both linguistic and cultural adaptation.

The goal of this paper is to describe a methodology for translating outreach materials for ASD, using the Autism Speaks First 100 Days Kit as an exemplar. The kit is a text designed for families and providers to assist them during the first three months following a diagnosis of autism. It provides an overview of ASD diagnosis, assessments, and interventions, and presents parent perspectives on the challenges of raising a child with ASD. The document was developed in 2008 by the Autism Speaks Family Services Unit, and is distributed free of charge throughout the U.S. Prior to our study, the document had been translated only into Spanish. With increases in both autism awareness and diagnoses across diverse populations, translating this guide represents a step toward supporting families for whom few resources are available. We present the methods used to translate the material into Korean and describe

how those methods facilitated the preparation of a culturally informed document for parents with varying levels of knowledge about autism. Because our intention is to provide a framework for future translations of outreach materials, we focus more on our general strategy than on the specifics of either Korean culture or this particular Korean language document.

The translation process described in this manuscript is part of a larger study to increase the early identification and treatment engagement of Korean children with suspected autism in the New York City area. Work on the Korean version of the First 100 Days Kit was guided by the recognition that the goal of translation is not term equivalence but rather the effective communication of a set of ideas that speak to a system of beliefs. Indeed, a cultural translation may be a better and more effective document than the original, especially if it is targeted towards a particular community, the members of which view the document as written by and for them (Maier 1995: 21).

We chose to translate the guide for the Korean population in the U.S. for several reasons. First, a recent population-based study of autism prevalence in South Korea reported that nearly two-thirds of children ages 7–12 with ASD in an urban location of South Korea were undiagnosed and had not received any special education or psychological treatment (Kim et al, 2011). Second, the Korean population in the U.S. has increased 33% since 2000 and of the 1.46 million Koreans living in the U.S., 70% are Korean-born and speak Korean at home (U.S. Census 2010). Third, since ethnic minorities in the US with mental disorders tend to be under-diagnosed and undertreated compared to white populations (Smedley, Stith, and Nelson, 2002; Kass et al, 1999; Wells et al, 2001, IOM, 2002), including autism (Mandell et al. 2002), it is likely that Koreans in the U.S. experience disparities in care attributable not only to socioeconomic factors (IOM 2002; US DHHS 2001; Sussman et al. 1987).

Methods

First Stage

Research was carried out in the United States, the intended location for deployment of the outreach materials. As is customary in first stage ethnographic inquiries, the first author conducted unstructured individual and group interviews. The goal of these interviews was to identify barriers to diagnosis and care, generate broad ideas about the range of cultural notions about developmental disorders in general (such as attitudes towards diagnosis or disclosure of a diagnosis), and elicit opinion about the needs of Korean clients with developmental disorders (e.g., lack of Korean-language services) First stage subjects were 19 Korean child health and education professionals (psychologists, pediatricians, teachers and social workers) who worked in Queens, NY and had experience working with the Korean population. These interviews were conducted in English.

Second Stage

The goal of the second stage was to determine how to communicate about ASD in the Korean language. This stage employed a version of "cultural modeling" or "culture as consensus" methods, which assess the degree to which individuals in a group share a set of

beliefs (Weller, 2007). This method, most well-known within the field of medical anthropology (see, for example, Dressler and Bindon, 2008; Garro, 2008; Dressler, McBalieiro and Dos Santos, 1997; Chavez et al., 1995), is predicated on the idea that informant consensus identifies and describes a cultural domain, defined as a set of items such as words or behaviors that are linked by semantic relations or families of meaning.

Cultural domains can be constructed through systematic inquiry using procedures such as free-listing, ranking, and pilesorts. Free-listing involves eliciting a complete set of terms after an informant is given a prompt (Borgatti, 1996). Participants are not expected to agree that every elicited term exists within a cultural domain. Ranking, which is carried out after the participant has finished generating his or her own terms, is the process by which informants sort through a set of terms to a particular prompt and rank them in terms of their importance – for example, ranking the top five causes of autism, or the top five terms that describe autism. Based on the relative rank of an item, saliency scores can be calculated using group data. A higher saliency score indicates more consensus across participants within the cultural domain. In pilesorts, participants group freelist items under single categories. In this project, pilesorts helped researchers to determine if two or more concepts were synonymous, similar, or distinct.

Korean mothers with little experience with autism as well as Korean mothers of children with ASD were recruited using a snowball method following a series of email and telephone requests at Korean community centers and churches for interviewees with Korean mothers. (Demographic information is listed in the online appendix). The first author interviewed 23 Korean mothers living in the greater New York City (n=13; Queens, Manhattan, and Fort Lee, NJ) and Washington, DC. (n=10, DC and Centreville, VA.) areas, with and without children with autism. Participants were given a choice as to the language used during the interview since they differed in terms of their levels of acculturation and language preference. Four interviews were conducted largely in English at the participant's request; 19 interviews were conducted in Korean. Of the interviews done in Korean, all were conducted by the first author with the support of a native Korean-speaking research assistant.

While the target population for the translation was mothers of newly diagnosed children, several Korean mothers whose children had been diagnosed some years earlier (n=5; ages 3–14) volunteered to be interviewed; we did not preferentially seek them out. None of the mothers were professionals in a health-related field, or identified as experts on autism. Mothers of children with autism indicated that they had gained extensive knowledge about autism through the media, with their primary source of information websites in South Korea. The mothers of children without autism identified the general Korean language media as their occasional source of information of ASD, had not consulted autism-specific internet sites, and had little knowledge about debates or controversies related to ASD published only in English.

Interviews were conducted in churches, community and day-care centers and lasted between 30 minutes and 2 hours. Ten of the 18 participants without children with autism (nine mothers born and raised in Korea, and one American-born Korean-American) said that they had never met an individual with autism.

Consistent with cultural consensus methods, the ultimate sample size was determined by when saturation was observed. Saturation in our study was defined as the point at which participants did not generate any new items during freelist exercises. Saturation of categories was achieved after 20 interviews but to ensure this finding, an additional 3 interviews were conducted. The total of 23 interviews is consistent with published consensus-modeling studies that suggest that saturation generally occurs between 20 and 40 participants (Borgatti 1999),

Free-listing, Ranking and Pilesorting—For free-listing, informants were asked to write as many words as they could think of on individual 3 by 5 inch note cards in response to three questions. Questions 1 and 2 were selected as open-ended unstructured questions to elicit as broad responses as possible and explore how research subjects who might know little or nothing about ASD distinguished between ASD and developmental impairments in general. Question 3 was selected because, as demonstrated in the literature, notions of causality have a direct impact on help-seeking.

1. Please tell me what words or phrases you think of when you think about children with developmental problems?

어떤 아이에게 발달 장애가 있다고 하면, 무슨 생각이 떠오러요?

2. Please tell me what words or phrases you think of when you think about autism?

자폐증이라고 하면, 무슨 생각이 떠오러요?

3. What causes autism?

자폐증의 원인이 무엇입니까?

After this step, informants reviewed the sets of cards containing responses to these questions provided by previous participants in addition to their own response cards. Using all the cards within each question domain, informants were asked to select the responses that best answered the question. Next, participants were asked to choose the top five responses and then told to rank them in order of importance. Lastly, participants were asked to group together items that were similar to each other (pilesort). During each step of the cultural modeling procedures, participants were asked to explain why they chose, ranked, or grouped particular items. The interviews were audiotaped and later transcribed for the analysis.

Results

First Stage Interviews: Helpseeking and Barriers

The interviews with Korean providers helped highlight patterns in helpseeking behavior and barriers to care among Koreans in their community, which coalesced around three themes: medications, availability of services, and diagnosis.

Medications—Providers unanimously indicated a fear of medications as the most salient barrier to care. They noted that unless they had no other options, parents of children with developmental disorders would likely use "traditional" remedies, such as herbal medicine

for restlessness or inattention, because they view them as less risky than allopathic medications. In this view, treatment should consist of behavioral modification, education, discipline, maturation, and divine intervention. A strongly negative view of psychotropic medications, they noted, was based on the beliefs that once a child begins a medication, he or she will be required to stay on the medication indefinitely, that medications mask symptoms, thus making intervention ineffective, that medication hides what one provider called the "underlying weakness of the mind that is the true cause of the disorder," and that medications decrease intelligence.

Availability of Services—The Child Center of New York in Flushing reported approximately 1,700 applications of services from Korean parents in 2012, an eight-fold increase over a 9 year period. There were approximately 250 Korean applicants for child clinical care in 1993, the year the Center opened. In 2012, they received approximately 1,700 applications. Schools typically instigate the visit to the clinic, as the parents are frightened, have little experience advocating for themselves in government settings, including public schools, and as a result can take a somewhat passive role and delay seeking services for as long as possible. A physician at the center described Korean families as having "a high tolerance for inappropriate behavior," as long as the individual is hidden from public view. Families dealing with a serious mental illness therefore tend to be socially isolated. A social worker and a physician with the Korean Behavioral Health Association described several autistic adults with significant functional impairments who received no ASD diagnosis until they had aged out of high school.

Identification and Diagnosis—Although Koreans in Queens appear to share an interest in promoting autism awareness, parents of a child with ASD are hesitant to disclose their own child's diagnosis to friends and relatives. One mother we interviewed, who has a son with autism, has been delaying a visit for years to South Korea because she is ashamed and has yet to figure out how to describe her child in terms that do not stigmatize her or her child. In the interviews, teachers reported an inability to organize parents into advocacy or support groups, in person or on the Internet. One teacher attempted to develop a blog and a listserv to provide information and news for parents of children with autism. She noted that many parents attended a workshop on ASD conducted by the Korean Teacher's Association in Queens, but that she was unable to convince any of the mothers to provide their email addresses. During a meeting our research team held with parents at a church, a woman who had attended her son's annual Individualized Education Plan (I.E.P.) meetings for 4 years claimed not to have any idea what his diagnosis or special education classification might be.

Second Stage Interviews: Salience and Semantic Domains

The researchers compiled the free-lists and determined the total number of distinct responses for each of the three questions. There were 38 for developmental problems, 80 for autism and 48 for causes. Saliency scores for ranked items were calculated by first assigning scores of 5, 4, 3, 2, and 1, in reverse order of an item's rank. Next an average score was determined for each item among those included in top five rankings. The higher average indicates higher salience. The results of freelists and salience scores are provided in the on line appendix).

When tabulating the freelist items, most terms and phrases were kept distinct rather than grouped into single constructs unless participants clearly identified the terms as interchangeable or highly similar during pilesort procedures. For example, participants repeatedly grouped together the phrases "in own world" (자기반의세상) and "isolation" (교립) in both domains of developmental problems and autism and so we treat them as a unitary concept. However, "out of touch" (무게님) remained distinct. In Korean, the term "isolated" (교립된) and "in own world" (자기반의세상) indexes a child who may be emotionally and socially remote, while participants regard "out of touch" (*mugaenyŏm*) as pejorative. Mugaenyŏm, for example, can be used to describe the actions of someone that does comprehend social context, or does not adhere to social norms, such as a youth who is disrespectful to his elders, or a person who wears clothes that are inappropriate for a particular occasion.

In the domain of causes of autism we combined two phrases under the single concept of emotional block/shock (마음의 문을 닫다, emotional block; and 정신적인 충격, emotional shock) since emotional block is construed as the result of shock, as in one mother's statement, "maybe the child had something traumatic, like his parents fighting when he was a baby or in the womb, and he protected himself by putting up a block." The idea of a block occurred repeatedly. One of the younger interviewees described her friend's child with autism by referring to both closure of the mind, and the broad spectrum of ASD. "For some people, it is like the door closed on his mind. So the person can make himself stop developing. His mind is closed. Then there are types, like my friend's son, who goes to high school and is able to stay home alone. In his case, it seems curable, but I don't know. And there are some children that we can't even touch, totally incurable, totally finished." We found no reason to distinguish these two terms for block since participants consistently sorted them together and because, in terms of meaning, each implied the other. Similarly, "bad parenting" was equated with "lack of love" by interviewees. Although "emotional block" might also appear to resemble other terms connoting detachment, such as "in own world" or "isolation," we treated the concept as distinct from the theme of detachment because of its close relationship to interviewees' theory of the etiology of autism and because none of the participants sorted them together as similar items.

Generally, younger mothers were more likely to mention biological and environmental causes, such as toxins, while older mothers emphasized social environmental causes, such as poor parenting or conflict within a marriage. Although none of the mothers interviewed for this study argued strongly that vaccines were related to autism, all Korean-American mothers mentioned the topic in interviews, and two listed (but ranked last) vaccines as one of the possible causes of autism. In comparing responses from Korean mothers in the greater New York and Washington, DC areas, we did not observe any notable differences in the data generated during cultural consensus interviews.

The prompt "developmental problems" elicited fewer than half the responses (38) as the word "autism," possibly because, as some respondents remarked, the term lacks specificity and might refer to motor skills. In contrast, the prompt of "autism" yielded 80 distinct responses, and nearly all terms in the developmental problems list reappeared on the list of responses for autism. The only terms unique to the prompt for developmental problems were "poor home education and childrearing," "genius," "unfriendly," "God," and "child's

education." However, these terms resembled others included under the category of autism, such as "God's punishment," "God's will," "poor parenting," "home environment," "hidden strengths," and "selfish."

The five most salient terms in the category of developmental problems were "isolation/in own world," "emotional block/shock," "difficulty communicating or relating to others," "conduct problems," and "repetitive behaviors." Most salient in the category of autism were "difficulty communicating or relating to others," "isolation/in own world," "mental retardation," "emotional block/shock," and "bad home environment" respectively.

English) had a significantly higher saliency in the category of autism than in the category of developmental problems. This reflected interviewees' belief that children with autism are more significantly impaired with intellectual and behavioral issues than someone who is developmentally impaired or delayed. The terms used under the autism category are also strikingly pejorative and were made more salient overall by their inclusion as top order items by women with an age above the mean in our sample. One mother, aged 62, listed in the order from most to least important with the following associations to the concept of autism: "spoiled," "tendency to break rules," "undisciplined," "cares only about himself," and "distracted." Overall, the highest saliency terms suggest a degree of damage having been to the child. Two older interviewees selected as a freelist item, but did not include as a priority term, *michyŏda* (의 왕), often translated as "crazy" but which has a stronger and more negative meaning than the English word, more in line with the English "insane" or "deranged."

An additional idea that influenced interviewee selection and characterization of terms was religion. Numerous interviewees selected God as a free-list item, and included God in their characterization of ASD and causes of ASD, and in reference to the topic of barriers to care. As one mother noted, "Why should I disrupt God's will?"

Discussion

In this paper, we argued that the translation of materials about ASD into foreign languages requires adaptation of those materials to address the beliefs and attitudes of particular populations, and that those beliefs and attitudes about ASD can be ascertained systematically. Our method had a demonstrable effect on the translation of the First 100 Days Kit. Moreover, our results suggest that the method can be highly efficient if employed with coherent segments of a relatively homogeneous target population and focused on a single condition such as ASD. Anthropologists have described such foci as "coherent subsystems of knowledge that tend to cohere and persist as a unit limited to primarily one aspect of culture" (Romney, Weller, and Batchelder 1986: 314–15). The method facilitates translation because it elicits, through interviews, the subsystem's semantic domain. We found that the dominant discourses in parent interviews revolved around three themes: isolation, causality, and stigma.

Isolation—Named symptoms of ASD include isolation (an inability to communicate with others, poor eye contact, and emotional block) and emotional damage (e.g., shock, lack of love). Isolation and damage were consistently linked to other negative valuations such as blockage and stigma. The idea of closure or blockage was an especially important theme for characterizing developmental problems and ASD, manifested in numerous phrases such as "difficulty relating to others" and "fighting against themselves."

Causality—Many of the high saliency items under the category of autism that express a negative view of autism also imply a particular theory of causality. Under causes, the highest saliency terms, in order of salience, were "unknown," "genetics," "brain damage," "environmental pollution," "poor prenatal environment," "emotional shock," "God's will," and "bad parenting/bad home environment." Subjects also clearly equated genetics with heredity rather than de novo mutations, so that autism, in their view, was more likely to occur in families with a problematic genetic history, low intelligence, or behavioral characteristics passed on to children. Poor parenting included the concept of "lack of love," an everyday and pejorative term that refers loosely to the diagnosis of reactive attachment disorder (RAD) and parallels the old American concept of the "refrigerator mother" (Shin et al.1999). Koreans frequently attribute children's disabilities to their parents, either through genes, poor tae kyo (prenatal practices), that might negatively affect the health and intelligence of babies, or mistakes in early parenting (Cho, Singer, & Brenner, 2000). Interviewees characterized parents of children with autism using adjectives such as "cold," "greedy," "unable to relate," and "irresponsible about medications." It is thus not surprising that interviewees also noted that parents of children with autism experience stigma, as they may be seen as inadequate parents and then marginalized from social networks.

Stigma—Stigma – a negative evaluation of the child – was a sub-text throughout the research, because interviewees stigmatized people with ASD, or the parents of someone with ASD. One woman, when asked to provide a list of words or ideas that came to mind when she thought about children with developmental problems, said, "I feel sad because there is no bond between the child and the mother and father." In addition to "lack of a bond between parents and child" (coded here under the category of poor childrearing), the additional terms she included in her cards were "stubborn," "egotistical," "disobedient," and "unstable." Stigma was also related to the whether a developmental problem or functional impairment is medical or non-medical problem, with the latter being more highly stigmatized. Deafness, for example might cause only mild shame, while autism would suggest that, in the words of one mother, " "the child's needs are not being fulfilled."

Given these findings, the translation of the First 100 Days Kit addressed ASD within this semantic domain. For example, interviews on causality elicited the concept of "lack of love." In response, we adapted the guide by writing sections on parent blame and attachment, and including explicit statements such as "In the past, some doctors in the US wrongly believed that the mothers of autistic children were emotionally cold and did not love their children." Other beliefs that emerged within the interviews and to which we responded included: the idea that children cannot be diagnosed with a developmental disorder prior to the age of three; the order of disclosure to relatives, friends, teachers, etc. after a diagnosis; *tae kyo* (the

totality of prenatal practices and experiences), a concept that has no equivalent term in English; and use of the Korean language among Koreans with ASD. In the translation process special emphasis was also placed on clarifying agency, since the Korean language is frequently written in passive voice, without a clear subject. In addition, the emotional tone and content of the English language version was inappropriate for Korean audiences. Because the mothers of autistic children noted discomfort with words and phrases that index strong emotion suggest that the author can define the reader's emotions, we revised numerous passages. "You may feel completely overwhelmed," was translated as "Many families are confused." We removed analogies to medical disorders and treatments (such as cancer and chemotherapy), replaced concepts like "intervention" with the Korean word for "treatment," and changed "outrage" to a Korean word for "upset."

Sustained effort was given to clarify the difference between heredity and genetics since much of the stigma associated with ASD stems from a belief that autism is genetic, with genetics defined as hereditary. Genetic disorders impugn the family line and threaten the marriage prospects of an autistic person's siblings. Because the interviews suggested that families might not wish to disclose their child's diagnosis to grandparents, who play a powerful role in family systems, and that parents are inclined to marginalize unsympathetic family members, doctors, and teachers, we revised the English language section on anger to include information about the importance of building social supports.

It is possible that another research team might elicit different semantic domains and salient concepts. There are, to our knowledge, however, no other published data on conceptions of ASD among Korean-Americans. Nonetheless, the findings in this study are consistent with those in previous publications on beliefs about ASD in South Korea (Kang-yi, Grinker, and Mandell 2012) and this concordance is not surprising given that Korean parents of autistic children in New York and Washington, DC cited South Korean websites as their primary sources of information on ASD.

Additional research is necessary to address the larger question of how culture influences the treatment, management, and course of autism over the lifespan in Korean-speaking populations. Such research may also inform the way families subvert either global or local clinical discourses on ASD – for example, by constructing indigenous diagnoses (Grinker and Cho 2013) – and use language to re-conceptualize ASD in moral and social, rather than medical, terms. Future research might also focus on the consequences of an autism diagnosis for Korean families, in particular, how parental belief systems influence educational strategies, social organization, and social and economic mobility.

Limitations of this paper include the small sample size and the snowball method of locating participants, both of which could have exaggerated the internal consistency in the data collected. However, the high degree of consensus at only 23 participants of different ages, education levels, and parenting experience, suggests that there is no reason to question unsystematic recruitment in this specific study. Additional limitations include the fact that we did not test for validity or reliability of the method, and did not attempt to compare our measures of consensus with other cultural consensus studies. Yet, the purpose of this particular study was less to define a distinct cultural pattern as valid for all intents and

purposes than to elicit the ideas, vocabulary, and meanings to be addressed for a specific translation project, and to describe this method for use in the translation and adaptation of other texts in other languages and locations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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