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Strategies for Disseminating Information on Biomedical Research on Autism to Hispanic Parents

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Abstract

Low income Hispanic families experience multiple barriers to accessing evidence-based information on Autism Spectrum Disorders (ASD). This study utilized a mixed-strategy intervention to create access to information in published bio-medical research articles on ASD by distilling the content into parent-friendly English- and Spanish-language ASD Science Briefs and presenting them to participants using two socially-oriented dissemination methods. There was a main effect for short-term knowledge gains associated with the Science Briefs but no effect for the dissemination method. After 5 months, participants reported utilizing the information learned and 90% wanted to read more Science Briefs. These preliminary findings highlight the potential benefits of distilling biomedical research articles on ASD into parent-friendly educational products for currently underserved Hispanic parents.

Keywords

Biomedical Research on Autism; Hispanic/Latino; Health Literacy; Racial Disparities

Autism Spectrum Disorders (ASD) represents a group of neurodevelopmental disorders that cause significant impairments in language, learning, thinking and social communication. There is growing evidence that the prevalence of ASD is continuing to rise, from 1 in 110 (1%) in 2006 (Centers for Disease Control, 2009) to 1 in 68 (1.5%) in 2014 (Centers for Disease Control, 2014). The clinical, policy and economic implications of these trends are far-reaching as ASD affects families across the world, independent of race or socioeconomic status (Shin Kim et al., 2011). The increased prevalence and public awareness of ASD has also created a surge of published research studies on the multiple causes of and emerging treatments for ASD. While the findings of these studies have tremendous relevance for parents attempting to make decisions about seeking an ASD diagnosis for their child and/or appropriate interventions, most lay parents have limited or no access to published research articles. Even if these articles were easily available to the lay public, the frequent use of specialized vocabulary, complex scientific and mathematical content, and discussion of similar or conflicting results among studies could leave most parents struggling to understand which scientific discoveries have relevance for their child.

Health Literacy and Racial Disparities

Research has shown that limited health literacy is associated with negative health outcomes for chronically underserved racial and ethnic groups (Agency for Healthcare Research and Quality, 2004; Andrulis & Brach, 2007; Flores, Milagros, Olivar, & Kastner, 1998; Kripilani et al., 2006). Health literacy is the degree to which individuals are able to obtain, process, and understand basic information to make appropriate health decisions and effectively navigate the healthcare environment (Institute of Medicine, 2004; Sheridan et al., 2011; U.S. Department of Health and Human Services, 2000). More than 90 million Americans have inadequate health literacy (Institute of Medicine, 2004). Andrulis & Brach (2007) contend that health literacy is a minority health issue, citing that 40% of American adults have limited health literacy and of these, over half are nonwhite and/or Hispanic. Analysis of the 2003 National Assessment of Adult Literacy (NAAL) for the U.S. Department of Education

revealed stark racial and ethnic differences (Kutner, Greenberg, Jin, & Paulsen, 2006). Specifically, while a quarter of non-Hispanic white adults scored in the basic or below-basic levels of literacy, almost half of Alaskan Native/Native Americans, well over half of black Americans, and two-thirds of Hispanic Americans scored at this level. Promising research suggests that effective strategies to increase health literacy can mediate the well-established negative effects of race and ethnicity, low education, immigration status, and low income for marginalized populations (Flores et al., 1998; Cooper, Hill, & Powe, 2002; Von Wagner, Steptoe, Wolf, & Wardle, 2008; Portes, 1998).

Limited English Proficiency

While data are still emerging, theorists and researchers suggest the damaging effects of limited health literacy are magnified when an individual also has limited English proficiency (LEP) (McKee and Paasche-Orlow, 2012; Sudore et al., 2009). Reports of individuals with both of these characteristics include an increased likelihood of experiencing confusion and difficulty making sense of relevant health information with respect to keeping healthy, disease prevention practices, early detection of diseases and treatment, and correct use of prescription drugs (Fernandez et al., 2004; Graham, Jacobs, Kwan-Gett, & Cover, 2008; Kreps & Sparks, 2008; Ronsaville & Hakim, 2000; Wilson, Chen, Grumbach, Wang, & Fernandez, 2005). They also lack information to make health, mental health, and childcare decisions, have poor patient/provider communication and rely frequently on informal social networks and the Internet for information which may be inaccurate and inconsistent. More than 24.5 million Americans report having LEP (U.S. Census Bureau, 2010), excluding immigrants in the U.S. who are undocumented (Passel & Cohn, 2011). Although the field lacks precise data on the proportion of individuals with LEP who also have basic or below basic health literacy, it is thought to be higher than that of fluent English speakers (Agency for Healthcare Research and Quality, 2004; Institute of Medicine, 2004). Baldi's Technical Report (as cited in McKee & Paasche-Orlow, 2012) provides preliminary evidence of the interaction of these two variables in reporting that populations overrepresented among those with below basic prose literacy on the NAAL included groups at risk for LEP, i.e., no English-spoken before starting school and Hispanic adults.

Reducing the Demands of Health Information Products and Communications placed on Vulnerable Populations

Andrulis and Brach (2007) contend that culturally diverse individuals with limited literacy and LEP are among the most vulnerable patients in the nation. Challenging the construct that health literacy is solely a characteristic of the individual, i.e., the individual's capacity to read, understand, process and act on health information, these authors instead argue that health literacy is the result of a match between the individual's skills and competencies *and* the demands the health information product places on the consumer to decode, interpret, and assimilate health messages. When targeting culturally and linguistically diverse communities, health communications researchers advocate for educational products and delivery methods that go beyond language translation (Gannotti, Kaplan, Handwerker, & Groce, 2004) and assimilate the unique values and world views about disease, illness,

development, disability, prevention, and health promotion of their audience. The way the message is packaged (i.e., how much, who delivers it, and how it is delivered) is as important as the content of the message (Huhman et al, 2008). With respect to the Hispanic population, a number of researchers have also described the importance of considering the “relationship-focused” (Raval, Subramanian, & Raval, 2007) orientation of the Hispanic culture when designing interventions, i.e., valuing interpersonal networking and relationships based on personal knowledge, trust, warmth, and caring—frequently called “high context” cultures (Blacher & Widaman, 2004).

Health Literacy and Culturally and Linguistically Diverse Parents of Children with ASD

Within the disability field, similar findings have been documented for culturally and linguistically diverse parents of children with ASD, including enhanced risk for poor healthcare decision-making, significantly later diagnosis of ASD, greater difficulty accessing and utilizing ASD and related services, receipt of a different mix of services than their mainstream counterparts, and perceptions of lower quality in the healthcare received (CDC, 2014; Magaña, Lopez, Aguinaga, & Morton, 2013; Mandell et al, 2009; Parish, Magaña, Rose, Timberlake, & Swaine, 2012; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007; Zuckerman et al., 2014). It is notable that identification rates of Hispanic children with ASD not only lags behind non-Hispanic white families but all minority groups, warranting special attention to this population (Travers, Krezmien, Mulahey, & Tincani, 2014). Consistent with McKee and Paasche-Orlow’s (2012) findings, parents of individuals with DD from all ethnic groups have reported they lack information to make good decisions and the few studies on sources of information used by these groups identified family and friends as their primary source of healthcare information (Blacher & Widaman, 2004; Mandell et al, 2009; Portes, 1998; Thomas et al., 2007). The DD field lacks systematic research on effective strategies to address the health literacy needs of chronically underserved racial and ethnic groups accessing services.

The goal of this study was to develop and field-test an educational product called “Science Briefs” that was designed to improve parental access to information in published biomedical research on ASD in an effort to enhance their understanding of evidence-based causes and emerging treatments for ASD. The intervention was geared towards the Hispanic population because they experience barriers to accessing healthcare information due to limited English proficiency, living in linguistically isolated households (Umpierre et al., 2014), and having a significantly increased likelihood of having basic and below basic levels of literacy (Yin et al., 2009; Kutner, Greenberg, Jin, & Paulsen, 2006; McKee and Paasche-Orlow, 2012; Sudore et al., 2009). In addition to being among the fastest growing ethnic groups in the nation, a disproportionately high number of Hispanic families live below the poverty level (26%), are less likely to have insurance and are more likely to be unemployed than other ethnic or racial groups (Yin et al, 2009).

This study used a non-randomized mixed-strategy intervention that had two components: (1) the development and evaluation of a culturally responsive parent-friendly educational

product called “Science Briefs” which are distillations of published biomedical research articles on ASD and (2) the delivery of the Science Briefs to parents using two relationship-oriented dissemination methods. Three hypotheses were proposed. (1) Exposure to the study’s Science Briefs would lead to significant short-term increases in participant knowledge of the scientific content of each Science Brief; (2) Utilizing a socially-oriented dissemination method for the Science Briefs would enhance short-term knowledge gains; and (3) Five months post-intervention, study participants would report they utilized the information learned and a desire to read more Science Briefs.

Methods

Research Design

A 2×3 design was utilized--2 levels of language (English and Spanish) and 3 types of dissemination methods (Science Educators, Peer Support and Science Brief only-no human facilitation). Ninety participants were initially targeted for recruitment, randomly distributed across each of six levels of the 2×3 research design. As compensation for their time, all participants were given a \$40 Target gift card at completion of the intervention.

Sample and Sampling Procedures

The study team sub-contracted with a long-standing community based organization (CBO) that provides education, support, and advocacy services to Hispanic families with children with DD, to recruit participants for this study and provide culturally sensitive supports to sustain their participation. Recruitment and support activities were provided by part-time bilingual/bicultural Hispanic parents of children with ASD employed by the CBO and trained by project staff to recruit and support participants using the IRB-approved protocol, which waived informed consent. Participants were identified through the CBO’s database of over 2000 Hispanic families that had used their services. This singular source for participants facilitated recruitment because of the trust the participants had in the CBO, but also introduced a potential sampling bias. However, the demographics of the sample show participants had the characteristics we were targeting. See Participant Characteristics.

Our original research design planned equal numbers of English- and Spanish-speaking participants across the three dissemination conditions, with 15 participants per cell for a total of 90 participants. However, three modifications to our original design were made at the request of our community partner. First, we enrolled twice as many monolingual Spanish-speaking participants than those in the English-speaking group because our community partner argued that this sub-group had a greater need for the study’s intervention because they experienced greater barriers to accessing information on ASD than their English-speaking peers. Second, no formal testing of the English proficiency of participants was conducted to assign participants to language groups, as the team’s community partner felt this type of testing would discourage participants new to research from volunteering. Finally, assignment to one of the three “dissemination” groups was not random; participants were permitted to pick the group to which they were assigned to allow participants new to research to carpool with participants they knew.

Participant characteristics—Criteria for inclusion in the study included being of Hispanic descent or the spouse/partner of a Hispanic parent, and having at least one child with ASD. Only one parent/caregiver per household was allowed to participate. Both English-speaking and Spanish-speaking participants were recruited for participation. Eighty-three (83) participants were enrolled in the study using the modified research design. As can be seen in Table 1, approximately two-thirds of participants self-identified for the Spanish-speaking group and one-third self-identified for the English-speaking group. Ninety-two percent (92%) of participants returned to participate in the face-to-face administration of the demographic survey after the intervention was completed. Table 2 contains demographics of the sample. All participants were female, except one; the mean age of participants was 41 years, ranging from 25–59 years; 22% were born in the US and of those born elsewhere, 67% were born in Mexico. Eighty-two percent (82%) of participants had one child with ASD, the remaining 18% had two or more children with ASD. Mean years of education completed was 11.5 (ranging from 2–18 years) and participant self-reports of their English language proficiency (i.e., how well they spoke, understood and read English) on a scale of 1 (not at all) to 4 (pretty well), averaged “3” (pretty well). Over 77% were married or living with a partner; 36% reported working outside of the home; the mean household income was ~ \$30,000 and 41% of participants reported owning their own home. Overall, participants had less than a high school education, participant reports of English language proficiency suggested the majority felt they spoke English pretty well, and the mean household income was slightly above the federal poverty level (U.S. DHHS, 2013) for a family of four during the time of this study.

The Intervention

Product development—Two social marketing focus groups consisting of 10 bilingual (English/Spanish) and 10 monolingual Spanish-speaking parents of children with ASD were convened and facilitated in English and Spanish respectively, to inform the structure and format of the Science Brief and research topics of interest.

Structure and format of the Science Brief: Each group (English- and Spanish-language) attended two separate sessions held one week apart. During the first session, participants were given paper samples of the following components of the science briefs and asked to mark things they liked and didn't like independently: (1) 4 sample science briefs varied in style (newspaper article, fact sheets, etc.), section headings, length, and organization; (2) samples of photographs, fonts, and graphs/charts. At the end of the session, focus group facilitators solicited individual preferences and their reasons followed by a group discussion to clarify the group's recommendations for the layout and content of the Science Brief.

During the interval before the second session, the product development team compiled the list of Focus Group recommendations and used these to create 3 versions of a Science Brief to be reviewed during Session 2. As with the first session, the participants were asked to review each Science Brief prototype, circling things they liked, crossing out things they didn't like, followed by a facilitated consensus-building group discussion of what should guide the structure, format, and content of the study's Science Briefs. Results of this last session are summarized in Table 3. The final prototype for the Science Briefs contained

three sections reflecting standard research sub-headings followed by plain language descriptions, (1) Study Purpose (What questions are the researchers trying to answer?), (2) Research Design (What did the researchers do?), (3) Results (What did the researchers find?) and two user-centered sections, (4) What does this mean for my child? and (5) a Glossary of medical/scientific terms.

Research topics of interest: During the second day of the focus groups, participants were asked what type of research they were interested in learning about. While the response to this open-ended question varied, broad areas of inquiry identified by participants included: Is there a cure for Autism? Did I cause my child's Autism? I have more than one child with Autism but they are so different; how can that be? My child was normal until s/he got his/her MMR immunization. Why doesn't my child with ASD learn like my other children? My child doesn't seem to notice us, he's in his own world. Some children with ASD can talk but mine doesn't—why not? My friend is using a special diet to “cure” their child's ASD—should I use that too? For the purposes of this study, we selected bio-medical research articles that fell into the following three broad categories (which are consonant with research studies of the Autism Intervention Research Network—Physical Health (2015) over the past several years): (1) multi-factorial causes of ASD, (2) “cures” and treatments for ASD, and (3) genotypic and phenotypic expressions of ASD. We attempted to select articles that would provide a foundation for understanding ASD within these three areas and we specifically avoided reviews of the literature because of the innately complex nature of this type of publication. See Table 4 for the titles of the eight articles selected for distillation.

Distillation process: According to the Institute of Medicine (2004), health literacy requires three elemental skills—the ability to interpret *written* documents, i.e., *text or prose*; understanding and using *quantitative* information (quantities, numbers and computations embedded in text or tables) (Kutner et al., 2006); and understanding and communicating *spoken* information. While not specifically noted by the Institute of Medicine, *science* literacy, which refers to the individual's capacity to use scientific knowledge to draw evidence-based conclusions about specific phenomena (Holbrook & Rannikmae, 2009), can be considered a fourth essential skill in understanding biomedical research on ASD. To address both the health and science literacy needs of a basic/below basic literacy audience, we utilized the following strategies in the product development process. First, the guidelines recommended in the Center for Health Studies (CHS) Readability Toolkit (Raval, Subramanian, & Raval, 2007) were used in part for the core distillation process—see Table 5. Second, when possible, we converted prose and quantitative findings in the text of the article into pictorial and/or visual images, i.e., tables, graphs, figures, and scales (Tait, Voepel-Lewis, Zikmund-Fisher, & Fagerlin, 2010). These were especially useful when comparisons were being reported (males v. females, controls vs. experimental, or changes over time, etc.). Third, to maximize learning of new terminology, research/medical terms were followed by a simple definition in parentheses in the narrative, and repeated again in the Glossary at the end of the Science Brief. Fourth, following the “less is more” principle for low-literacy consumers (Peters, Dieckmann, Dixon, Hibbard, & Mertz, 2007), the design team limited the amount of content distilled from the original research article to no more than six cogent learning units. While each Science Brief provided distilled content from the source article

for each of the five sections of the Science Brief, the topics for the six learning units in the body of the brief, were selected for deeper discussion and elaboration of content which either represented major discoveries of the article, methodology common to large bodies of research, and/or what was basic foundational science knowledge on which the reader could build over time. Sixth, because scientific publications are written for a highly trained academic audience with pre-existing background information on the topic of the publication, foundational information not in the source document was added to Science Briefs to prepare the lay reader for the scientific content of the article. For example, a Science Brief on genetic causes of ASD might include an introductory review of genetics, or why twin studies are used in genetics research. Finally, we personalized the research to parents of children with ASD, by adding a section entitled "What does this mean for my child?"

Articles were "distilled" by graduate students enrolled in a non-profit science education program associated with the home university of the students. Project staff trained students in the distillation process and all briefs were reviewed and edited by the product design team throughout the development process. All Science Briefs were translated into Spanish using certified translators, which were then reviewed by the team's community partner to identify any cultural or language nuances (Andrulis & Brach, 2007) related to ASD and disability that might not be understood by the reader (Kreps & Sparks, 2008). Both English and Spanish versions were used for the field-testing of the eight Science Briefs.

Dissemination methods—In Condition 1, discussion of the Science Briefs was facilitated by graduate students in biomedical engineering, occupational therapy, and psychology who assisted the project in developing the Science Briefs. Because of their academic training, these facilitators (Science Educators) were permitted to discuss the scientific content of the briefs, although were not allowed to introduce any new information not in the Science Brief. Discussion of the Science Briefs in Condition 2 (Peer Support) was facilitated by parent staff of the community partner staff who were parents of children with ASD and had training and technical expertise in peer support. Peer Support staff were encouraged to engage participants in a discussion of Section 4 of the Science Briefs, "What does this mean for my child?" but responses to questions about the content of the Science Brief were not permitted. Questions raised by participants were added to a list of questions that were given to project staff to answer, which were sent to all members of the group by the CRAs at a later time. In Condition 3 (Science Briefly only-No Facilitation), participants read the science briefs individually while listening to the audio recordings with no interaction with others.

Uniform process for each condition: All participants read all eight Science Briefs. To control for variability in the reading ability of participants (which was not formally assessed), printed copies of the Science Brief were "read" while listening to an audio recording of the science brief in the language of the group, regardless of group assignment. Participants in the two "facilitated discussion" conditions (Science Educator and Peer Support) attended four (4) 90-minute sessions across four consecutive weeks; two science briefs were read and discussed at each session. To reinforce learning, facilitators stopped at the end of each of the four major sections of the Science Brief and engaged participants in a

discussion of what was just read/heard. In Condition 3 (Science Briefly only-No Facilitation), participants met two times for two hours, “read” and listened to recordings of four science briefs each session.

Measures and Procedures

Demographics of participants—A 17-item demographic survey was completed in the language of the participant’s assigned group to elicit information on each participant’s (and their spouse/partner’s) gender, age, place of birth, years of education, employment and marital status; family income and home ownership, and ages and number of children with ASD. In addition, participants were asked to self-report their level of English reading, comprehension and speaking ability on a 4-point Likert scale, with 1=not well to 4=very well. At the recommendation of our community partner, the survey was administered in person to minimize the effects of the unknown literacy level of participants and after participants had completed the intervention to provide time for participants to build trust with the research team and minimize suspicion around providing sensitive personal information to the study team (e.g., birthplace, employment status, household income; any identifying information about their children).

Readability levels of the Science Briefs—The readability level of each Science Brief was assessed using multiple modalities consistent with best practices (Ridpath, 2006), including the Fry Readability Scale (Fry) (Fry, 1977), Flesch-Kincaid Grade Level (Flesch-Kincaid) (Flesch, 1949), PMOSE/IKIRSCH (Mosenthal & Kirsch, 1998), and Simple Measures of Gobbledygook (SMOG) (McLaughlin, 1969; McLaughlin, 2008). Inter-correlation of data from all four measures was computed prior to estimating the mean readability level of each Science Brief.

Short-term knowledge change—Subject knowledge of the content of the briefs was measured through pre-post testing using a written test of 5–6 key concepts in the Science Brief prior to “reading” the brief and immediately after the brief had been read, heard, and discussed. Tests were delivered in the language of the group to which participants were assigned. Test items on the post-test were identical to the pre-test but re-ordered using a table of random numbers. Data were collected during each session by members of the evaluation team. To control for the unknown variability in the reading ability of participants and their familiarity with testing procedures, all test items were read out loud in the target language of the assigned group.

Participant self-reports of impacts 5 months post-Intervention—Long-term effects of the intervention were measured through an automated cell phone survey delivered 5 months after participants completed the intervention. The survey consisted of four questions: (1) Please tell us something you learned or remember from the science briefs that you didn’t know before, (2) Did you talk to anyone about what you learned? [If yes], can you tell us whom you talked to and what happened? (3) How do you feel now when you think about biomedical ASD research? (4) Would you like to read more science briefs about ASD? Why? To assure a delivery system that would maximize the response of participants who varied in educational level and familiarity with research activities, collaboration

between the engineering team and our community partner was encouraged which led to the following. First, the community partner assured the engineering team that most of their families had cell phones. Second, the following modifications to the system design for the automated phone survey were recommended: use of a recognizable local area code instead of the area code which came with the software, an introduction and voice prompts recorded by the familiar voice of the CBO's parent recruiter as opposed to using speech synthesis, minimal use of button presses, a dialog structure based on a linear sequence of the four open-ended questions, and a memory storage capacity large enough to record any length of response, so that the respondent is not cut-off when they are speaking.

Results

Readability Levels of the Science Briefs

As can be seen in Table 6, the Fry Readability, Flesch-Kincaid, and PMOSE/IKIRSCH were highly inter-correlated (.61–.72), but the SMOG was not (–.06–.34); hence, SMOG scores were eliminated from the final estimates of the mean readability score of each Science Brief. Table 7 displays the readability scores of the eight Science Briefs across the three remaining measures of readability. As can be seen, the mean readability score for the Science Briefs was at the 9th grade reading level, with a range between the 7th and 12th grade. This is higher than the 6th grade reading level recommended for a lay readership (McLaughlin, 1969), but within the range recommended by our focus group (9th–10th grade). It is possible that the inclusion of scientific terminology in the Science Briefs as recommended by focus group participants, and explanations of scientific phenomena contributed to this higher reading level.

Outcomes of the Intervention

Short-term knowledge change—The results of paired t-tests of changes in test/re-test knowledge test scores for each science brief are displayed in Table 8. It is notable that despite the higher readability level of the Science Briefs than originally planned, there was a consistent increase in knowledge after reading the Science Briefs ranging from a low 6% increase for the Science Brief on Ultrasound & ASD to a high of a 21.1% increase for the Science Brief on Risk Factors & ASD, using the participant as her own control. These increases were statistically significant for all of the Science Briefs ($p < .001$ level, with the exception of the one on “Ultrasound and ASD” which was significant at the $p < .05$ level). It appears that exposure to the Science Briefs was effective in increasing short-term participant comprehension of key biomedical and research concepts in the educational product.

Self-report of Participant Impact 5 months Post-Intervention—Of the 83 participants that completed the study, 40 (48%) responded to the automated follow-up survey. While this may appear to be a low response rate, in a meta-study of opinion poll response rates, Holbrook, Krosnick, and Pfent (2008) reported the mean response rate was 30% \pm 13% s.d., suggesting this result is reasonable if not good for an automated system. The accommodations made to the design of the system may be responsible for this response rate.

Transcriptions of responses to the four open-ended questions were subjected to qualitative analyses which identified themes related to what participants remembered about the Science Briefs, whether they utilized the information 5 months after the intervention, and if so, in what way. Four broad themes emerged. First, participants remembered the Science Briefs and generally they indicated that what they learned was meaningful. They reported learning about specific causes of ASD (e.g., genetic factors, environmental factors, gene/environment interaction), scientific evidence about treatments they did not know before (e.g., gastrointestinal issues and evidence-based dietary treatments), and they learned there was insufficient evidence behind some of the treatments they were using for their children (e.g., special diets). Some participants were relieved to learn that their child's autism was "not their fault." A fair number of parents found it validating that they actually know a lot about ASD, e.g., "I shared the information I learned with other parents with kids with autism.. it's amazing how much we [parents] know about autism...[even though] we don't know [all] the scientific terms or any of that."

Second, participants expressed a variety of feelings and emotions about autism research, both global and specific. Many described their gratitude that so many researchers are studying ASD, e.g., "[it] makes me very happy to know they are not giving up and that one day there can be an answer." At the same time, there were feelings of being overwhelmed by the amount of information they didn't know, "they mentioned ultrasounds, the shots, the blood type the mother and father have..it's just so many [variables] and a bit too much for me to ... understand." There were also expressions of frustration around how much is still unknown about autism, "I don't feel any different because they haven't found anything definite yet." Finally, parents want a cure, "every parent, including me, would like to know how we can take this [autism] away from our children."

Third, 83% of participants stated they spoke to others about the knowledge they gained. Of these, the majority stated they spoke to other parents raising children with autism, a third reported talking to family members, and 17% talked to friends. Only two (5%) stated they spoke to no one and seven (12%) did not respond to the question.

Finally, when asked if they were interested in reading more Science Briefs, over 90% responded affirmatively and 9% did not respond. No negative responses were given. The three most common reasons given for wanting to read more Science Briefs were (1) to gain more knowledge (64%), (2) to help their child (29%), and (3) to share knowledge with others (17%).

Effects of facilitated delivery of Science Briefs—We hypothesized that the transmission of information contained in the Science Briefs to the targeted population would be further enhanced using relationship-oriented facilitated discussions of the Science Briefs. Mean knowledge gains were greatest for participants in the Science Educator condition (21.1 %); followed by the "Science Brief only" group (19 %), with the smallest gain for participants in the Peer Support group (14.2 %). The pre-post knowledge increase within each condition was statistically significant; however, analysis of variance (ANOVA) revealed no significant differences in the magnitude of knowledge change among the three conditions ($F(2,70)=2.31, p=0.11$).

ANOVA showed significant differences in the duration of responses across the three conditions ($p < 0.01$). A t-test of the differences in mean duration of response between participants in the Science Educator and the Peer Support groups was highly significant ($p < 0.001$); whereas the difference in the mean duration of responses between participants in the Science Educator and the Science Brief Only Group and between the Peer Support and the Science Brief Only group was marginally significant ($p < 0.07$). These results suggest that participants seemed to have more to say about what they learned and how they used the information when the science briefs were discussed by someone who seemed to be an expert on the scientific content of the briefs, i.e., Science Educators.

Conclusions and Discussion

McKee & Paasche-Orlow (2012) argue that the field still lacks information on the salient attributes of “diverse” populations beyond their race and ethnicity, which can inform evidence-based interventions to address chronic disparities in access to healthcare and healthcare outcomes for vulnerable and disenfranchised populations. They and others specifically note that interventions designed around literacy level, limited English proficiency, and culture as appropriate for sub-groups can mitigate the longstanding impact of poverty, race and ethnicity (Andrulis & Brach, 2007; Kreps & Sparks, 2008). This study addressed these three variables in designing an educational product in English and Spanish that provided Hispanic parents of children with ASD with access to the content of published biomedical research on ASD. Our Science Brief was uniformly effective in short-term knowledge gains (test/re-test) across the eight Science Briefs developed for this study using the participant as her own control. Participant self-reports at 5 months post-intervention revealed that participants remembered the content of specific science briefs and the majority of participants reported that they spoke to friends, family, and others about what they learned. Qualitative analysis of responses to the open-ended questions included an explicit desire on the part of participants to learn as much as they could so they could help their children with ASD, that participants learned things they did not know before and felt a deep appreciation that so many researchers were studying ASD “so that one day there can be an answer.” While the successful transmission of information from research studies led to participant reports of positive benefits, this intervention also opened the door to fears and worry regarding new information (e.g., environmental toxins), and expressions of frustration that answers to questions about the causes of and treatments for ASD remain elusive. Yet, 90% of participants reported they wanted to read more science briefs.

The absence of significant effects associated with the facilitated discussions of the Science Briefs (Science Educator and Peer Support) was unexpected given the research on Hispanic preference for socially-oriented dissemination methods. Several explanations are possible. First, it is possible that the design of the Science Briefs may have been powerful enough to outperform any enhanced discussion. Second, the pairing of “reading” the Science Briefs with the audio-recording of the Science Brief may have minimized one of the benefits a facilitated discussion has for participants who otherwise might have had difficulty reading the Science Briefs. Third, the use of multiple graduate students teaching in the Science Educator condition without controlling for their teaching effectiveness may have flattened

the magnitude of effect for this condition. Finally, the study may have been underpowered to detect moderate sized differences in dissemination method.

Limitations of the Study

Because this study was designed to leverage an earlier effort to increase the participation of Hispanic parents of children with ASD in biomedical research on ASD many of the participants recruited were new to research. Consequently, at the request of our community partner, compromises were made to our study design to create a supportive environment for these new research participants, including a lack of random assignment to the dissemination conditions to allow participants to attend research activities with friends and or acquaintances, no testing of literacy level, and allowing participants to self-select the language of the group to which they were assigned. We also did not have a control group of non-Hispanic white participants to further elucidate the role of ethnicity and language to the short- and long-term outcomes of our intervention. While the magnitude of effects associated with all eight Science Briefs were consistent, the preliminary nature of our findings cannot be generalized. We cannot disentangle the contribution of language, ethnicity, and socio-economic status from our findings.

Future Directions

Due to the limitations of this study, a key need for future research is to replicate this study using a randomized controlled trial in order to maximize the generalizability of our findings. Moreover, rigorous studies to validate the discrete design features of the Science Briefs that appear to be causally related to participant outcomes will provide the field with guidelines to replicate product features for other topics of interest and customized to the needs of other underserved populations. Well-designed studies of the independent and interactive effects of participant literacy level, LEP, and culture on the design of Science Briefs will provide the field with information on how to customize educational products for diverse populations with one or more of these barriers to accessing information. Similarly, separate studies of the effects of diverse methods to disseminate the Science Briefs that are sufficiently powered will provide the field with information on layered interventions (product and dissemination method) for groups that have significant health and science literacy needs. Finally, replicating this research with other underserved groups that differ by race, culture, language, and disability, will provide the field with a broad foundation of evidence that will have the power to systematically reduce chronic inequities for underserved groups that can be scaled up for maximum impact.

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Table 1
Final Sample by Language of the Intervention and Type of Dissemination Method

Preferred Language	Type of Dissemination Method			Total
	Science Educator	Peer Support	Science Brief only	
English	10	8	8	26
Spanish	16	20	21	57
Total	26	28	29	83

Table 2

Demographic Characteristics of the Sample

Variable	Mean or %	S.D.	Min.	Max.
Age (years)	40.7	7.15	25	59
% Born in US	21.8%	41.55	0	100
% Born in Mexico	66.7%	47.45	0	100
% with 1 child with ASD	82.1%	38.62	0	100
Years of school	11.5	3.65	2	18
Speaks English* (1–4)	3.00	1.46	1	4
Understands English* (1–4)	3.15	1.47	1	4
Reads English* (1–4)	3.15	1.44	1	4
% Married/Live w/partner	76.9%	42.41	0	100
% Works outside of home	36.1%	48.37	0	100
Income (1=\$15K, 5=\$60K)	2.57	1.26	1	4
% Owns their home	40.5%	49.43	0	100

* 1 = not well, 4 = very well

Table 3

Focus Group Results-- Content and Layout of the Science Brief

1. Content
1a. General Comments/Recommendations
Anything in Spanish is extremely helpful. Will read anything that says Autism.
Parents are looking for answers that give them hope--should be serious but uplifting.
Every child is different, so information needs to be broad. Not everything will be of interest to all families.
Parents want a summary of all research article sections, background, methods, results, conclusions, what this means to me and my child.
Most would scan the contents and look at the conclusions/recommendations.
Parents wanted to know who conducted the study and where it was conducted
Each brief should aim for 9 th -10 th grade reading level.
1b. What does this mean for my child/family?
The most important section is "what this means for their child and their autism."
Parents want this section to tell them what the article found. E.g. no link to autism and vaccine in this study, further studies needed.
But, they want information so they can make their own decision.
1c. Charts and Graphs
Liked the charts and graphs but want the information in them explained in simple terms. They did not like complex graphs/data--bad memories of science and math classes in school (K-12).
Liked the bar chart the best. Easy to understand.
Spanish language group did not understand line graphs and what "flat" and "steep" meant.
1d. Glossary
Glossary is very useful.
2. Layout/Design
2a. General Comments/Recommendations
Two-page brief is too short; four-page is better. Parents won't read it if it is too long.
Liked distinct sections and section headers to easily navigate the pages.
A photo on the first page will draw the parent to pick up the brief.
Keep the title bar at the top of the page with larger font.
2b. Photos and Images
Very strong feelings that the people in photos look Hispanic.
Photos and images should help readers to understand the content.

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Photo of brain is OK but want to see brain of child with autism next to it—want to know how the child with autism is different.
Did not like cartoon-type graphics of people; OK when talking about the synapse and neuron.
2c. Use of Color
Like color coding for sections of the Science Brief.
Liked highlight of words that can be found in the glossary.
Be careful using colors – make sure it prints well in black and white.

Table 4

Final Article Titles--Science Briefs

1	<i>Time Trends in Autism and MMR Immunization Coverage</i>
2	<i>Antenatal Ultrasound and Risk of ASD</i>
3/4	<i>Evaluation, Diagnosis, and Treatment of Gastrointestinal Disorders in Individuals with ASDs: A Consensus Report (converted into two parts--Part 1 and Part 2)</i>
5	<i>The Neurobiological Context of Autism</i>
6	<i>Cerebellum, Language, and Cognition in Autism and Specific Language Impairment</i>
7	<i>Heritable and Nonheritable Risk Factors for Autism Spectrum Disorders</i>
8	<i>Identifying Environmental Contributions to Autism: Provocative Clues and False Leads</i>

Table 5
 Modified Guidelines from the Center for Health Studies Readability Toolkit (Ridpath, 2006)

<ul style="list-style-type: none"> <input checked="" type="checkbox"/> <i>Use plain language</i> <input checked="" type="checkbox"/> <i>Use the active voice</i> <input checked="" type="checkbox"/> <i>Use headings that are clear and descriptive</i> <input checked="" type="checkbox"/> <i>Use short sentences and paragraphs</i> <input checked="" type="checkbox"/> <i>Use figures and pictures to clarify written concepts</i> <input checked="" type="checkbox"/> <i>Emphasize desired behaviors rather than medical facts and motivate consumers to take action</i> <input checked="" type="checkbox"/> <i>Allow adequate white space and margins</i> <input checked="" type="checkbox"/> <i>Test written information for the appropriate reading level and complexity of the content</i> <input checked="" type="checkbox"/> <i>Less is more—no more than 6 cogent learning lessons^a</i> <input checked="" type="checkbox"/> <i>Include research/medical terminology but follow with a simple definition in parenthesis, and repeated again in glossary at end of the Science Brief^b</i> <input checked="" type="checkbox"/> <i>Substitute pictorial information for prose and convert quantitative and numeracy concepts into visual images, such as tables, graphs, figures, and scales^c</i> <input checked="" type="checkbox"/> <i>Add foundational information not in the article to prepare the lay reader for the content of the article^b</i> <input checked="" type="checkbox"/> <i>Personalize the research to the reader^b</i>

^a Peters, Dieckmann, Dixon, Hibbard, & Mertz, 2007

^b Authors

^c Tait, Voepel-Lewis, Zikmund-Fisher, & Fagerlin, 2010, as cited in Sheridan et al., 2011.

Table 6

Pearson Inter-Correlations of Readability Measures

	Fry Readability	Flesch-Kincaid	PMOSE/IKIRSCH	SMOG
Fry Readability	1.00	0.72	0.61	-0.056
Flesch-Kincaid	0.72	1.00	0.64	-0.07
PMOSE/IKIRSCH	0.61	0.64	1.00	0.34
SMOG	-0.06	-0.07	0.34	1.00

Table 7

Readability Levels of 8 Science Briefs

	Fry Readability Scale	Flesch-Kincaid Grade Level	PMOSE/IKIRSCH
Minimum	7	8.9	8
Maximum	11	11	12
Range	4	2.1	4
Mean	9.13	9.83	8.50
S.D.	1.25	.74	1.41

Table 8
Paired t-tests of Changes in Knowledge Scores Before and After the Intervention (n=83)

Science Brief Title	Pre (Prop. correct) (S.D.)	Post (Prop. correct) (S.D.)	Difference Pre-Post (Prop. correct)	t-value	p-value
1. Vaccines and ASD	0.44 (0.22)	0.57 (0.28)	0.13	4.75	<.001
2. Ultrasounds and ASD	0.62 (0.29)	0.68 (0.29)	0.06	1.82	<.05
3. GI, part 1	0.40 (0.23)	0.59 (0.29)	0.19	6.68	<.001
4. GI, part 2	0.43 (0.24)	0.61 (0.26)	0.18	6.58	<.001
5. Genetics	0.43 (0.26)	0.68 (0.31)	0.25	8.35	<.001
6. Comm. and the Brain	0.44 (0.25)	0.62 (0.27)	0.18	6.54	<.001
7. Risk factors	0.37 (0.26)	0.58 (0.28)	0.20	6.99	<.001
8. Environment	0.37 (0.26)	0.56 (0.32)	0.19	6.76	<.001
Total	0.46 (0.15)	0.65 (0.16)	0.18	13.1	<.001