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Health Literacy and the Disenfranchised: The Importance of Collaboration Between Limited English Proficiency and Health Literacy Researchers

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Abstract

Inadequate health literacy and limited English proficiency are associated with poor health care access and outcomes. Despite what appears to be an interaction phenomenon—whereby the rate of inadequate health literacy is particularly high among limited English proficiency populations—researchers in health literacy and limited English proficiency rarely collaborate. As a result, few health literacy instruments and interventions have been developed or validated for smaller linguistic populations. Interventions to improve health outcomes for people with low health literacy and limited English proficiency show great potential to alleviate many of the health disparities currently experienced by some of the most disenfranchised individuals in our health care system, those from smaller linguistic minority groups, including Deaf American Sign Language users. It is critical for health literacy and limited English proficiency researchers to work together to understand how culture, language, literacy, education, and disabilities influence health disparities and health outcomes. It is important to ensure that research is collaborative and inclusive in order to broaden the reach of future interventions to smaller linguistic minority populations.

The health care system is struggling to care for an increasingly diverse patient population (National Center for Education Statistics, 2001; Smedley, Stith, & Nelson, 2003; U.S. Census Bureau, 2011). It is unfortunate that the details of this diversity, including language preference, literacy, and culture, have in general been examined independently. Few studies have concurrently explored health literacy and limited English proficiency (LEP). A recent PubMed search by the coauthors using the health literacy and LEP as MeSH keywords generated 5,158 health literacy references and 595 LEP references, but only 36 overlapping references. The paucity of publications on this topic underscores the need for better collaboration between these fields.

More than 90 million Americans have inadequate health literacy (Nielsen-Bohlman, Panzer, & Kindig, 2004) and more than 24.5 million Americans experience LEP (U.S. Census Bureau, 2010), not accounting for people with LEP among the population of unauthorized or undocumented immigrants in the United States (Passel & Cohn, 2011). In addition, this estimate does not include approximately 500,000 Deaf American Sign Language (ASL) users (Harrington, 2004; Schick, 1988).

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It is not well established what proportion of LEP individuals have inadequate health literacy, but overall it is thought to be higher than that of fluent English speakers (Berkman et al., 2004; Nielsen-Bohlman et al., 2004). Several populations at risk for LEP (no English spoken before starting school, Hispanic adults, and those with disabilities) are overrepresented among those with below basic prose literacy on the National Assessment of Adult Literacy (Baldi, 2009). However, more important than establishing a precise prevalence estimate of inadequate health literacy and LEP is to understand their health consequences. In isolation, both pose significant barriers to health care communication (Baker, Parker, Williams, & Clark, 1998; Fernandez et al., 2004; Graham, Jacobs, Kwan-Gett, & Cover, 2008; Paasche-Orlow & Wolf, 2007; Schillinger et al., 2003; Wilson et al., 2005). Together, the damaging effects of inadequate health literacy and LEP on health communication and outcomes are likely magnified (Sudore et al., 2009). This may be due to synergistic negative effects in phenomena such as socioeconomic position, access to care, access to information, as well as perceived and experienced discrimination (Egede, 2006).

Quality measures mandated by the Centers for Medicare and Medicaid Services heavily rely on improved patient communication and outcomes (Centers for Medicare & Medicaid Services, 2012). There is great interest among hospitals, managed care, and outpatient health centers to develop effective communication strategies to deal with diverse patient populations. Many of these approaches will require interventions to deal with the complexities of handling patient populations who experience LEP and inadequate health literacy. Unfortunately, the current research environment is poorly equipped to provide innovative approaches and interventions to increase the ability of a health consumer with LEP and inadequate health literacy to make appropriate health care decisions. Researchers must work together to understand how culture, language, literacy, education, and disabilities all play elemental roles in promulgating health disparities and health outcomes.

Benefits of Collaborative Research

Despite an increasing number of interventions designed to improve health knowledge, and disease management, few studies evaluate whether these interventions are reproducible in smaller language minority populations and among individuals with a range of health literacy (Sarkar et al., 2008; Schillinger et al., 2008). Many interventions intended to address LEP may also be appropriate for those with low health literacy as well as the converse. The hybridization of LEP and health literacy research would further enhance the ability to develop novel approaches and interventions that can potentially be interchangeable for diverse communication needs. Furthermore, health literacy research could greatly benefit from the infusion of transdisciplinary approaches provided in the fields of linguistics and cognitive science. LEP research could gain from standardized measures and instruments available and emerging in health literacy research.

LEP research has demonstrated the benefits of language concordance and the use of interpreters including higher rates of appropriate health care visits, improved treatment adherence, and improved satisfaction (Graham et al., 2008; MacKinney, Walters, Bird, & Nattinger, 1995; McKee, Barnett, Block, & Pearson, 2011; Regenstein et al., 2008; Timmins, 2002). Interventions involving the use of community health workers, health coaches, language interpreters, and language-concordant providers are common approaches for LEP populations. However, it is unclear whether these interventions can improve health literacy among these populations. In addition, novel approaches for inadequate health literacy through the use of technology (e.g., virtual health coaches) have not yet been adequately examined in LEP populations. Health information technologies have promising potential to tailor health information to language and cultural needs and help people access to health materials in a variety of modalities when and where they may be needed (Munoz et al., 2009). Further research is needed to determine how this can be applied effectively for people with LEP and inadequate health literacy.

Populations Who May Benefit From Collaborative Research

Spanish-speaking populations, by virtue of their size, have garnered the majority of LEP and non–English health literacy research funding in the United States. Despite the fact that more than 376 languages are used in the United States, a review of the literature reveals very few of these studies extend beyond English and Spanish. Schillinger, Bindman, Wang, Stewart, and Piet (2004) demonstrated that even when accounting for language barriers, inadequate reading and health literacy were highly prevalent in one Latino population sample; only 55% of Hispanics have a high school diploma, and only 10% have a bachelor's degree (Schillinger et al., 2004). Inadequate health literacy may be even higher for smaller linguistic minority groups as a result of a paucity of accessible media and patient education.

Certain immigrant populations and Deaf ASL users live in relative isolation. These populations provide unique research challenges and opportunities because of reduced social interactions with the media and limited contact with allopathic norms, public health and prevention messaging, and health education. These groups experience poor patient–provider communication and frequently rely on inaccurate and inconsistent information from their social networks and the Internet (McKee et al., 2011; Valentine & Skelton, 2009; Vernon & Lynch, 2003).

Deaf ASL users, in particular, present a unique study population because they struggle with poor communication (i.e., due to hearing loss), language discordance, and possibly inadequate health literacy partly because of decreased opportunities to correct misinformation, and limited health surveillance (McKee et al., 2012). Deaf ASL users are considered an LEP population by the U.S. Department of Health and Human Services (U.S. Department of Health and Human Services, 2001); yet, they are rarely included in health literacy and LEP research studies. This is likely due to limited health and demographic information about Deaf ASL users, scarcity of adapted and validated research surveys and instruments in ASL, difficulty recruiting and accessing this population for research, inadequate supply of Deaf ASL proficient investigators, and concern about handling potential cognitive issues when present.

The exclusion of linguistic minorities is ultimately due to the fact that they are minorities. The research funding and the workforce are limited. Investigators want to have the largest possible impact and have research products that reach a critical mass. Although smaller language populations may be challenging to recruit and study, they are often most in need; work with such populations underscores a striking absence of health information accessible in languages beyond English and Spanish. Rudd and Anderson (2006) argued that existing health literacy interventions can be modified to apply to at-risk individuals and that environmental evaluations of health care systems to reduce literacy and language barriers could benefit a broad array of patients. The same approach to currently existing health literacy and LEP research tools and interventions can help identify critical steps needed to create greater inclusivity in research.

Future Implications

LEP and health literacy researchers should design research that advances knowledge regarding the intersection between these fields of inquiry. Approaches likely to promote this agenda include the following:

- Funding agencies should encourage collaboration between researchers through targeted requests for applications for research that incorporates both fields.
- Researchers should place special emphasis in developing tools and disseminating interventions that can be readily adapted and translated into languages for validation and use in other populations.
- Institutional review boards should give special consideration to smaller linguistic minority populations, including Deaf ASL users, to ensure that research is inclusive whenever possible.
- LEP and health literacy investigators should design research that implements novel strategies using information technology and other methods to lower communication barriers and bridge health care gaps more effectively and efficiently.
- Opportunities for collaboration and dissemination of innovative cross-disciplinary approaches, such as symposia and conferences with a special emphasis on bringing health literacy and LEP investigators together should be advanced.
- Academic institutions and research facilities should increase the number of researchers and staff from diverse backgrounds to improve recruitment of challenging-to-reach populations and provide greater social and cultural awareness necessary to establish rapport with targeted populations.

Conclusion

The fields of LEP and health literacy have largely functioned as separate silos of research, failing to address the needs of these unique and underserved populations in the U.S. health care system. It is clear that collaboration is needed between experts in these fields to help develop a variety of interventions and tools to assure the most vulnerable patients are not left behind. Without attention to the interaction between health literacy and LEP populations are at great risk for experiencing increasing health disparities.

Given that language and health literacy are integral to patients' ability to comprehend and act upon health recommendations, it is crucial to find ways to understand the joint effects of these phenomena. Researchers should view health literacy through multicultural and multilingual lenses to help develop novel communication strategies and technologies that can be implemented in the increasing number of linguistic minority and LEP populations, including Deaf ASL users in the United States.

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