BEST PRACTICE PATIENT TEACHING STRATEGIES TO PROMOTE HEALTH LITERACY WHEN WORKING WITH INDIVIDUALS WITH DEAFNESS

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Abstract

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The Deaf culture encompasses a large group of deaf or hard of hearing individuals who distinguish themselves with the use of American Sign Language. This population is at risk for health complications due to issues related to health literacy. Limited existing literature, lack of successful teaching strategies, and minimal recommendations for improving healthcare education for this population poses a significant health disparity. Improving patient education using a variety of teaching methods such as the teach-back method, alternative visual formats, and appropriate use of interpreters may improve education and health literacy for this population. The effectiveness of any method must be assessed with each individual to fully address the needs of this at risk population.

This paper reviews the current recommended guidelines for providing patient teaching to individuals with deafness. Adapting effective teaching strategies to the Deaf culture are presented to improve patients’ health literacy.

Key words: Deaf, Hearing Impaired, Patient Teaching, Health Literacy, Decreasing Health Care Costs, Teach-Back Method, Interpreter Use
# TABLE OF CONTENTS

ABSTRACT ........................................................................................................... iii

INTRODUCTION ................................................................................................. 1

BACKGROUND ................................................................................................. 2

LITERATURE REVIEW ....................................................................................... 3

  UNDERSERVED DISADVANTAGED MINORITY ................................................... 4

  RISK FOR MISSED PREVENTION ................................................................. 5

  PATIENT TEACHING ADAPTATIONS ............................................................ 7

GAPS IN THE LITERATURE ............................................................................... 8

RECOMMENDATIONS FOR FUTURE PRACTICE .......................................... 9

  TEACH-BACK METHOD .............................................................................. 9

  DVD EDUCATION FORMAT .................................................................. 10

  INTERPRETER USE ..................................................................................... 11

LIMITATIONS .................................................................................................... 12

CONCLUSION .................................................................................................... 12

REFERENCES ..................................................................................................... 14
Introduction

The prevalence of hearing loss in the United States (U.S.) has increased, the current estimation of individuals residing in the U.S. with hearing loss in one or both ears is about 48 million (Lin, Niparko, & Ferrucci, 2011). “While ‘deaf’ is a medical diagnosis, ‘Deaf’ is a cultural identity with its own unique language” (Farber, Nakaji, & Sadler, 2004, p. 1208). The approximate number of individuals with deafness that identify with the Deaf culture is difficult to measure. The Deaf culture consists of individuals with deafness that distinguish themselves by the use of American Sign Language (ASL) as their primary language. Census data focus only on spoken languages and individuals with deafness may not choose to associate with a signing community (Mitchell, Young, Bachleda, & Karchmer, 2006). As a result there is no known population estimation for Deaf ASL users but the estimated use of any signed language at home is 100,000-15,000,000 in the U.S. (Mitchell, et al. 2006).

American Sign Language involves communications with hand signs, facial gestures, and body movements. Although it may appear to be pantomiming, it contains its own unique sentence structure and conjugations that make it unlike any spoken language (Lane, Hoffmeister, & Bahan, 1996). American Sign Language is not a manual form of English making written communication difficult for some ASL users to understand (Barnett, 2002a; Lieu, Sadler, Fullerton, & Stohlmann, 2007; Schwartz, 2008). Not all individuals with deafness are proficient in lip reading because only 30-45% of the English language is visible on the lips (Barnett, 2002a; Schwartz, 2008). Sign language interpreters have varying levels of skill in specific settings and have to overcome a variety of ASL dialects (Barnett, 2002a; Lieu, Sadler, Fullerton, & Stohlmann, 2007; Schwartz, 2008).
Often, assumptions are made by hearing individuals that written communication and education materials are an effective means of informing individuals with deafness about health care issues and appropriate treatment options. The varying degree of medical terminology comprehension in the Deaf population depends on the degree of hearing loss, age of hearing loss, education, personal experience, and non-deaf relationships (Lieu et al., 2007; McMillan, Bunning, & Pring, 2000; Meador & Zazove, 2005). These factors may make it difficult for health care providers to identify effective communication methods with individuals with deafness potentially resulting in poor patient education and future health barriers within Deaf culture (Schwartz, 2008).

This paper examines research literature focused on individuals with deafness that use American Sign Language and associate themselves with the Deaf culture. Teaching strategies and best practices methods recommended for educating this population will be explored. The implemented teaching strategies will be compared for effectiveness as well as suggestions for future research and practice. The aim of this paper is to describe effective teaching strategies that could be implemented when working with individuals with deafness to improve the effectiveness of patient education.

**Background**

Historical oppression, lack of common knowledge, limited targeted health campaigns, and poor use of auxiliary aids have increased the Deaf culture’s risk for preventable health complications (Lane, Hoffmeister, & Bahan, 1996; Meador & Zazove, 2005; Barnett, 2002b; Schwartz, 2008). Often, healthcare professionals are unaware of the health literacy needs related to the Deaf population or lack competency in
communicating with Deaf patients (Barnett, 2002a; Barnett, 2002b; Meador & Zazove, 2005; Schwartz, 2008).

Health literacy is the ability of an individual to understand basic health information and make appropriate health decisions (Agency for Healthcare Research and Quality [AHRQ], 2011). Lower health literacy levels are linked to an increase in the use of emergency care, increased hospitalizations, inappropriate self management of chronic diseases, limited preventative care, and high mortality rates (AHRQ, 2011). A national action plan has been created with seven goals targeting the issue of health literacy, which is considered a national concern as well as a community issue (U.S. Department of Health and Human Services, 2010). These goals include making information accurate and accessible, promote informed decision making through improved communication methods, use developmentally appropriate terminology, support local efforts to increase the health literacy of the local population, build partnerships to develop guidelines, increase research efforts, and promote awareness in addition to suggestions for practice improvement (AHRQ, 2011). Some of this work includes an increase in federal policies to increase patient centered care and improve health literacy which will be tied to reimbursement rates for Medicare patients (Kohl et al., 2012). Meeting health outcomes and reducing the cost associated with chronic health conditions will be evaluated through patient surveys and decreased hospital readmission rates (Kohl et al.). Thus health literacy is becoming an important issue that must be addressed in a variety of ways, including the Deaf population.

**Literature Review**
An electronic database literature review was performed using the search terms: patient teaching AND deaf for CINHAL and PubMed for 2008-2013. Inclusion criteria included English manuscripts, humans, and adults. CINHAL returned five results and PubMed returned 20 unduplicated results. A total of 20 articles were excluded. Exclusions were made if the population did not focus on people with deafness or only focused on correcting deafness with hearing aids, cochlear implants or teaching the deaf person to adapt to verbal communication. One article was excluded because it focused on the health defects associated with deafness and provided no patient teaching. Two additional articles were excluded because they focused on screening methods for identifying deafness early in children. A total of five articles were identified for inclusion in this literature review. These articles focused on identifying the Deaf population as an underserved minority, the risks associated with this population not receiving preventative health care, and the adaptation of current teaching methods.

**Underserved Disadvantaged Minority**

One study identified a nationwide shortage of mental health professionals and that the Deaf population is an underserved group in critical need of mental health services (Wilson & Wells, 2009). The application of telehealth where the provider uses telecommunication and information technology to provide assessment, diagnosis, intervention, consultation, supervision, education, and information across distance has been effective for rural populations. Other populations have had found this alternative delivery of services to meet their satisfaction and be cost effective. A comparison study using fifty-five deaf and hard of hearing participants that communicate in ASL were provided a lecture on depression with one using telehealth and the other a printed format.
Interpreters were provided to both groups to clarify words only if requested by the participants. No significant difference was found between the groups pre and post test to determine gained knowledge. Satisfaction results were also the same between the two groups. Cost analysis was assessed hypothetically by questioning the savings for individuals to receive this information in their home rather than a community center or office and the mental health practitioner providing the information from their home or office instead of traveling. The savings of such services offered via telehealth would outweigh the cost of purchasing telehealth equipment and upgrading it at least every three years (Wilson & Wells, 2009).

Deaf ASL users are a linguistic minority with barriers to health education programs and mass media health care messages resulting in health disparities due to disease misconceptions (McKee et al., 2011). In another study, 22 Deaf ASL users from Rochester New York were placed in facilitated focus groups to discuss knowledge, understanding, and identify barriers associated with cardiovascular disease. Through videotaped sessions and coding of interviews the research team identified that all the participants used ASL, were college educated, and had an average age of 55 years. The knowledge of cardiovascular health varied widely within the participant sample. Many participants lacked family history knowledge about cardiovascular risk factors but had a basic understanding about the risks of smoking and the benefits of exercise. In addition, the participants had confusion regarding medications. Some thought Tylenol and Aspirin were the same and that blood draws for anticoagulant monitoring was an infusion of the anticoagulant. Participants in this study had access to ASL fluent medical providers as well as medical websites specifically targeting Deaf ASL users. They gained knowledge
about cardiovascular disease through celebrity examples yet found closed captions
difficult to understand at times when medical terminology was used. Much of the
knowledge gained by this population was through personal experiences potentially
limiting the accuracy and chance of exposure to correct information. Barriers identified
included avoidance of health care due to poor communication. Deaf individuals that lose
their hearing before acquiring a spoken language seek medical services less often than
individuals that lose hearing later in life. Recommendations include taking time to assess
the current knowledge of the deaf individual during the medical visit and when providing
education, utilize Deaf health educators when available and appropriate, and increase the
access to ASL web-based health education (McKee et al., 2011).

**Risk for Missed Prevention**

Deaf ASL users are at risk for significant health disparities related to preventative
health issues not being identified (McKee, Barnett et al., 2011). A study with 89 deaf
participants were surveyed using a touch screen computer, permitting the individual deaf
person to select between ASL, Signed English, and written English. Data collected about
preventative services offered included influenza vaccination, colonoscopy and cholesterol
screening. All the information was self reported on the part of the patient. No health
records were reviewed to verify the participants’ answers. The survey identified that if
the provider communicated with the patient in ASL the patient was more likely to receive
the influenza vaccine than patients whose providers attempted to communicate without
using ASL. There was no significant difference between ASL and non-ASL using
providers when assessing colonoscopies and cholesterol screenings (McKee, Barnett et
al., 2011).
Patient Teaching Adaptations

Two of the studies found focused on the Deaf population and patient teaching using culturally appropriate methods to adapt standard teaching topics. According to Fung, Faratro, D’Gama, & Wong (2007), deafness increases the difficulty of educating patients about challenging topics such as home hemodialysis and presented a case study of their interaction with one deaf patient. Standard teaching methods were altered to use an interpreter proficient in ASL, pictures, videos, and diagrams. Lip-reading and note writing were also used as additional methods of communication. The dialysis machine was manipulated to vibrate when alarming so the patient was able to assess for problems as needed. Additional follow up questions and documentation was completed via email and relay text telephone (Fung et al., 2007). Effectiveness of this patient teaching experience was not measured or evaluated for patient understanding.

Using previous studies from 1999-2006 that identified Deaf and Hard of Hearing individuals as lacking awareness regarding cancer prevention a pre and post survey was performed of 197 deaf and Deaf persons (Zazove, Meador, Reed, Sen, & Gorenflo, 2012). A successful cancer prevention education video using spoken English was adapted for ASL users. An ASL interpreter window was added to the video along with captions using a literacy level of 6th grade or lower. This video was reviewed, critiqued, and edited for understanding and ASL accuracy based on a Deaf focus group feedback. All the participants were divided into two groups. A control group viewed the video in spoken English and the experimental group viewed the ASL adapted video. Both groups took a computerized pre-test and post tests but displayed no significant difference in gained knowledge after viewing the video. The sample population used in this study originated
from the same community background and the participants only viewed the video once. All participants completed a demographic survey that included the reason they lost their hearing, if they were a member of the Deaf community, if they used a computer, if they were married, and if their spouse had a deaf or hearing diagnosis. Participants with hearing spouses had higher test scores on both pre and post test regardless of which video they viewed. Computer use was lower for participants that lost their hearing from meningitis compared to those that lost their hearing from rubella, birth complications, hereditary or other reasons. This study suggested improving the effect of this intervention by allowing the participants to view the video multiple times to increase the overall retention of knowledge. The computerized evaluations may have been a barrier due to lack of computer use so screening participants prior to the intervention or having an alternative assessment format prepared may improve future results. The video itself was not created for individuals with deafness but rather an adapted hearing version. Creating a video that is culturally appropriate for the Deaf population may be more effective than an English version (Zazove et al., 2012).

Gaps in the Literature

This literature review did not provide data, identify or evaluate an effective education method that applies to the Deaf population. Many of the studies reviewed were conducted in densely populated Deaf ASL communities with universities and medical facilities that can meet the needs of the Deaf culture. Rural areas or communities that have a minority population of Deaf ASL users may not have the supportive resources available to make these suggested interventions. Some recommendations of the teaching methods identified within the literature found that information needs to be clearer,
targeted to the proficiency of the individual, and perhaps repeated multiple times. No current literature was found implementing these methods. The lack of literature focused on this population leaves significant gaps in useful teaching methods and prevents moving culturally appropriate interventions forward. The Deaf culture has been identified as a population at risk for poor prevention, limited health literacy, and increased health care costs but requires more focused interventions to make a significant impact into changing this risk.

**Recommendations for Future Practice**

The Deaf culture needs to be acknowledged by all health care providers as an at risk population. Barriers to health literacy and adequate patient teaching require specific assessments on an individual basis. Miscommunication can lead to perceived non-compliance or discrimination and further damage the relationship between the individual with deafness and health care team. To improve the experience and the interaction between the health care provider and the Deaf patient some assessment tools and teaching methods may need to be considered. Three methods show promise in meeting the Deaf patient’s educational needs, the teach-back method, teaching tools using culturally appropriate information, and the proper use of interpreters can effectively increase the health outcomes of this population.

**Teach-Back Method**

Identifying the specific needs of the individual with deafness is important to ensure that education is appropriate. The effectiveness of the teaching method depends on the individual’s proficiency with the learning format. Education that is outside the individual’s knowledge base and presented in a format that is unfamiliar to them will not
be effective. Integrating a teach-back method will give the educator guidance about the patients understanding of the knowledge being taught as well as the effectiveness of the teaching method (Bradke & Brinker, 2011). This method requires the learner to be involved by teaching the educator what they learned. The educator is then able to assess the knowledge passed on to the learner and make corrections as needed (Bradke & Brinker). This method can be implemented with all patients thus supplying the health care provider with a universal tool that can be adapted to meet the needs of the individual patient.

**Digital Versatile Disc (DVD) Education Format**

Methods of instruction that are easily accessed and cost effective are ideal within the medical setting. Using a DVD format to create education materials containing captioning, subtitles, and sign language interpreters may increase the accessibility of appropriate information and provide an alternative to written materials. According to Fleming, Reynolds, & Wallace (2009), this method of instruction can be tailored to a specific audience, easily produced, and is cost effective. Allowing communities with a smaller population of ASL users to create education materials that contain appropriate terminology for the specific Deaf population they serve, will promote better understanding of health care issues. Improving access to care through improved education materials might make up for the lack of supportive services that Deaf ASL users can obtain in larger communities. Fleming et al. (2009), recommends keeping information concise and divided into segments no longer than ten minutes allowing the learner to process the information provided. Interaction capability within a DVD format allows individual flexibility and the opportunity to review information as needed.
time to assess the patient’s communication needs, setting up the room effectively, and adjusting the speed of the conversation will improve the outcome of using an ASL interpreter.

**Limitations**

The literature review was not conclusive and lacked information about improving patient education for individuals with deafness. Education strategies focused on small sample sizes or populations of Deaf in densely populated areas that did not show significant improvements to the overall knowledge and cannot be applied to larger groups. Further interventions need to be studied and evaluated for effectiveness but limited suggestions are derived from the current literature.

**Conclusion**

The Deaf culture was defined and the literature was reviewed for current patient education techniques specific to this population. Effective patient education depends on the individuals’ current level of knowledge, their understanding of the terminology, method of instruction, and the provider’s knowledge of assessing for learning effectiveness. Implementing an assessment tool to identify the learning needs of the individual person can allow the health care provider to adapt as needed. The creation of alternative education materials such as DVDs to target individual Deaf culture groups will increase the accuracy of knowledge and promote health literacy. Improving health literacy has shown a decline in hospital admissions in other low literacy populations but no current literature has made the connection to the Deaf population. Finally, by using interpreters effectively to promote the best communication possible and educating the
specific individual, health care providers can increase personal health management outcomes and improve navigation of the complex health care system.
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