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RESEARCH ARTICLE

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DEAF PATIENTS HAVING DIFFICULT ACCESSING HEALTH CARE DUE TO COMMUNICATION ISSUES

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ABSTRACT

Deaf/deaf populations who are primarily American Sign Language (ASL) users have difficulty accessing health care due to communication barriers related to poor sign language resource utilization by health care workers and providers. A lack of communication between deaf patients and health care providers leads to mis-communication, misunderstanding, misdiagnoses, and poor outcomes. Clinical questions for this project are: How can improved communication in health care for the deaf patient improve access, understanding, and outcomes, as compared to poor or inappropriate communication? How can routes of communication be improved for the deaf patient in accessing health care? The purpose of this mixed methodology project is to determine how this population feels about the health care they receive, and if improving modes of communication would significantly improve their health care experiences, understanding, and overall outcomes. Theoretical frameworks utilized are Betty Neuman's Systems Model, Joyce Travelbee's Human-to-Human Relationship Model, and the Behavior Change Cognitive Theory. Investigation for this project was conducted in Tucson, Arizona, involving the Deaf/deaf population within local and surrounding communities, some who are patients of local medical practices, some friends and family members who are also Deaf/deaf, and others who are students of a local Deaf/deaf school. Qualitative questions were used to gather data, which were scored by a Likert scale and analyzed in a quantitative manner using charts. Results indicate moderate dissatisfaction with communication processes, poor understanding of directions given, and decreased over-all health outcomes based on current practices.

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INTRODUCTION

Definition of Terms includes: deaf - the word deaf with a lower case d means unable to hear (ASL University, 2015). Deaf - the word deaf with an upper case d refers to the Deaf community and its related beliefs and values. It is used when referring to a member of the community or the community as a whole (ASL University, 2015). ADA - Americans with Disabilities Act is legislation that was passed in 1990 to protect people with disabilities from discrimination in employment, transportation, public accommodations, and communication and government activities (USDL, 2015). AHFP - Abundant Health Family Practice, which is a private family practice in Tucson, AZ. (AHFP, 2015). ASDB - Arizona School for the Deaf and Blind, which is a boarding

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school for the deaf/Deaf and blind in Tucson, AZ. (ASDB, 2015). ASL - American Sign Language, which is the primary language used by the Deaf community and many deaf or hard of hearing people in the United States. It is a visually perceived gesturing- based language using the hands, body, and facial expressions (ASL University, 2015). HOH (hoh) - Hard of hearing (ASL University, 2015). A significant percentage of deaf and hard of hearing patients who live in the United States of America require health care (NIDCD, 2014), (Elliott, 2015). The main issues facing deaf individuals in accessing health care services appear to be a lack of deaf awareness, patient difficulty in booking appointments via telephone, and communicating with health professionals, (Wilson, J. A., & Wells, M. G., 2009), (Elliott, 2015). It is not uncommon for deaf and hoh individuals to receive poor, improper, and even unethical health care, secondary to complicated social and cultural factors (Barnett *et al.*, 2011), (Elliott, 2015). Health care professional's perceptions of deaf/Deaf population, and interpretation interactions, can

significantly impact the care a deaf/Deaf patient receives (Schofield & Mapson, 2014). The deaf/Deaf population also suffers more than double with mental health problems due to isolation, secondary to deficits in communication (Levine, 2014), (Elliott, 2015). According to the National Institute on Deafness and Other Communication Disorders, statistics reveal that about two to three out of every thousand children in the United States are born with some significant level of hearing loss unilateral or bilateral (NIDCD, 2014), (Elliott, 2015). More than 90 percent of deaf children are born to hearing parents, many of whom do not learn to sign (NIDCD, 2014), (Elliott, 2015). Standard school hearing tests in the United States indicate that one in eight children, twelve years old and older, have hearing loss unilaterally or bilaterally; approximately thirty million (NIDCD, 2014), (Elliott, 2015). Men are more likely than women to report having hearing loss with aging. Approximately 2% of adults aged 45 to 54 have hearing loss that is significantly disabling. The rate increases to 8.5 % for adults aged 55 to 64. Nearly one quarter of those aged 65 to 74 and half of those over 75 have profound hearing loss (NIDCD, 2014), (Elliott, 2015). Twenty eight million Americans are deaf or hard of hearing (Chong-hee, 2011).

Lack of communication between a deaf patient and a health care provider leads to mis-communication, misunderstanding, misdiagnoses, and poor outcomes (US Department of Justice, 2010), (Elliott, 2015). According to the ADA guidelines (ADA, 2012), (Elliott, 2015), medical providers are required to establish effective communication with patients through reasonable accommodations (ADA National Network, 2012), (Elliott, 2015). The ADA is a federal law, enforced by the Department of Justice, prohibiting discrimination on the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation, and telecommunications (US Department of Justice, 2010), (Elliott, 2015). The ADA offers specific guidelines related to health care access and communication issues for deaf patients and necessary accommodations. The definition of accommodations includes resources in medical provider's offices or any health care facility (ADA National Network, 2012), (Elliott, 2015). Guidelines specific to this law require medical providers to ensure deaf or hoh patients are provided with communication that is efficacious to their care and wellbeing (ADA National Network, 2012), (Elliott, 2015). Guidelines also state that if necessary, medical practitioners must provide out of their financial budgets sign language interpreters, unless the provider is able to establish significant difficulty or financial hardship to their practice (ADA National Network, 2012), (Elliott, 2015). The purpose of this mixed method project was to determine if improving modes of communication and incorporation of sign language and videophone services among health workers could optimize health care access for deaf/Deaf patients who use sign language. The purpose is also to determine if better, more appropriate communication improves dissemination of information and positive medical outcomes, and how those routes of communication could be improved.

MATERIALS AND METHODS

Theoretical foundations or methodology of this project is based on The Betty Neuman Health Care Systems Model which uses both qualitative and quantitative data that is reliable (Alligood, 2014). The model evaluates various qualitative elements by means of Wholistic approach to the patient care,

including physiologic (quantitative), psychological (qualitative), spiritual (qualitative), sociocultural (both qualitative and quantitative), and developmental (both qualitative and quantitative) aspects of human beings (Alligood, 2014). This project design also uses the Human-to Human Relationship Model by Joyce Travelbee and the Behavior Change Cognitive Theory. Methodology used was both qualitative and quantitative, primarily utilizing qualitative research for collecting data in order to determine how Deaf/deaf people feel about communication difficulties in trying to access health care. Quantitative research was also used in order to analyze that data. The design utilized multiple case studies, questionnaires, and interviews of Deaf/deaf patients within a single family practice. The sample population was chosen from AHFP, a private nurse practitioner owned and run family practice, and the ASDB, both located in Tucson, AZ. The practice owner and project facilitator is fluent in American Sign Language and is a primary care provider caring for a growing number of deaf/Deaf patients.

Information was collected from the noted population using a mixed methodology, in order to answer two clinical research questions: 1) How can improved communication in health care for the deaf patient improve access, understanding, and outcomes, over a three to twelve month time frame as compared to poor or inappropriate communication? 2) How can routes of communication be improved for the deaf patient in accessing health care?

The first phase utilized interviews and qualitative questionnaires with Likert scale scoring. The questions were designed to explore deaf patients' difficulty, or ease, in accessing health care based on communication barriers. The second phase utilized a quantitative method, which evaluated several developed themes from the qualitative data. The data was evaluated utilizing quantitative methods of scoring and analyzed with descriptive statistics via the SPSS data system in order to summarize the findings.

RESULTS

In collecting and analyzing the data from 35 questionnaires, the researcher has been able to answer the research questions but in doing so, has identified several questions that could easily be used for further research. The data was analyzed in a non-evaluative, unbiased, organized manner that relates to the clinical question(s). Analysis of 14 survey questions answered by 35 participants in a patient survey was completed. The first research question was answered as follows: survey questions one, three, nine, ten, and fourteen indicate that there is significant difficulty in accessing proper healthcare. There is difficulty with communication and understanding, which creates potential inability to make safe health decisions, and there is dissatisfaction with current health care among the deaf/Deaf, and deaf/mute population. This breakdown in communication results in poor understanding of how to take medications and other information to make safe health decisions, breeding dissatisfaction with current health care received and poor health outcomes. Improving all of these areas would significantly improve access, understanding, and health care outcomes in this population. Similarities were found in those patients using oral speech communication along with ASL and those using ASL without oral/speech. According to the data, those experiencing breakdowns in communication were actually less in the non-oral group (those

using ASL only), but only slightly. This aspect of communication (ASL with oral or ASL alone) is being considered for further research. The second research question was answered by data collected from survey question 13, with 27 of the 35 participants feeling that video interpretation would be a helpful tool during health care visits. There were several additional comments on the collected surveys indicating that having an ASL interpreter or a provider who signs would be a preference. In the event an interpreter or signing provider was not available, video interpretation would be appreciated. There were also a few other comments indicating that providers and medical staff should be trained further in understanding deaf/Deaf culture and using proper communication.

Completed data analysis for this project indicates there is a statistically significant gap in health care related to the deaf/Deaf population and communication barriers. Data confirmed that more than half of the participants surveyed experience misunderstanding, miscommunications, and difficulty making safe health decisions which in many cases led to poor outcomes. Working to correct these communication barriers could have a significant impact on decreasing misunderstandings and miscommunications, increasing the ability to make safe health decisions, and improving overall outcomes. Deafness, or profound loss of hearing, continues to pose a complex problem when it comes to communication, both for the patient and for the provider. Various alternative modes of communication must be used in order to properly meet both parties' needs. Effective communication is vital for the development of healthy and functional relationships. In order for the patient and provider to have a healthy relationship and work together towards the improvement and maintenance of that person's health, there must be good communication. Appropriate communication promotes proper understanding, self-awareness, and the ability to improve and maintain health (Elliott, 2014-15). Many deaf/Deaf patients have had a history of being rebuffed and belittled; some have learned to depend on others to mediate between them and health care providers in order to access services, including health services. There continues to be a need for a process of engagement with deaf users of services in assisting them to expect more in accessing health care. Processes include the need for interpreters, video services, and text abilities for evaluating participatory interventions to assist deaf users of services. Without these services, deaf/Deaf patients are not comfortable enough to engage assertively with the health system (Kritzinger, Schneider, Swartz, & Braathen, 2014), (Elliott, 2014 – 2015). Patient communication is an important aspect in medical care and management of any patient, including those who are deaf.

DISCUSSION

This projects qualitative study framework utilizing the Systems Model by Betty Neuman, the Human-to Human Relationship Model by Joyce Travelbee, and the Behavior Change Cognitive Theory looks at the sample deaf/Deaf population in a holistic manner and allows the researcher to gather qualitative data based on experiences with health care communication. It also evaluates potential behavioral changes within the medical community in order to improve communication processes. Support related to proper communication for deaf/Deaf children, deaf/Deaf adults, and their families are pervasive and wide reaching (Poon, 2013).

This mixed methodology project could advance scientific knowledge and deaf/Deaf population health outcomes by addressing how utilizing better modes of communication will significantly improve access to health care, patient understanding, and medical health outcomes. One mode of communication that will improve access for this population is video interpretation services. This service allows for a means of communication for a signing patient when there is not an available in person interpreter or a signing provider. This resource would significantly improve patient understanding of provider recommendations, decrease miscommunications and misunderstandings, and improve overall health outcomes by allowing patients to make well informed safe health decisions. It would also significantly improve satisfaction with health care, improve deaf/Deaf patients' experiences, increase understanding, and improve over-all outcomes. This resource is accessible for a nominal fee and can be set up in any clinic situation. Data analysis revealed several additional questions that could be used for future research. One of the primary questions for future research relates to deaf/Deaf literacy (ability to read and write) in conjunction with difficulty in health care communication. Is there a correlation or equivalency between the hearing and deaf/Deaf population related to illiteracy and health care communication? Is there a difference between deaf patients (those who have hearing loss) and Deaf patients (those are deaf and have grown up among all deaf people using sign as their primary communication) regarding prejudices about health care in general? Do these two populations have different feelings about what is an acceptable mode of communication?

Making an effort to learn about various disabilities and common needs related to the deaf/Deaf populations allows for a change in thinking, and potentially, the willingness to meet those accommodations. Searching out available resources and funding options will help to build a program that is able to accommodate those with disabilities. Resources such as video telecommunication can be utilized in medical offices free of charge through various video phone companies. Smart phones can also be used for texting with deaf patients to remind them of appointments and so on. Learning sign language is an option for improving communication with deaf patients, improving their understanding of personal healthcare matters, and improving over-all outcomes (Elliott, 2015). Even if the best possible interpreting services were to be available in health services, deaf/Deaf people who have grown up in exclusionary and discriminatory contexts (in all probability, most deaf/Deaf people in the world) have additional barriers to navigate. Many will have a history of being rebuffed and belittled; some will have learned to depend on others to mediate between themselves and services, including health services. There is no question that in low and middle income contexts in particular, there is an urgent need for provision of interpreting services (Young & Hunt, 2011). A more subtle and complex challenge is a process of engagement with deaf/Deaf users of services to assist them to expect more, not to silence themselves in these contexts, and to expect and demand the same access to health care that others enjoy (Cripps & Cooper, 2012). As urgent as the need for interpreters is, there is an equivalent need for evaluated participatory interventions to assist deaf users of services to feel comfortable enough to engage assertively with the health system (Kritzinger, Schneider, Swartz, & Braathen, 2014), (Elliott, 2015).

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