Deaf Access to Health Care

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Abstract

Modern medical professionals strive to provide culturally competent care; however,

Deaf[1] culture remains overlooked. Common language and experience draw deaf

individuals together as a cultural group. Ignorance about Deaf culture perpetuates

barriers to holistic care in the medical setting. Deaf patients receive misdiagnoses,

delayed treatment, and privacy breaches. Deaf culture understandably avoids healthcare

and is characterized by numerous health disparities as a result. Obstacles hindering Deaf

access to healthcare are directly opposed to the intended therapeutic relationship and

holistic care. Increased awareness of Deaf culture is required to improve the Deaf's

access to healthcare.

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[1] The word *deaf* should be capitalized when referring to the people group or culture and lowercase when referring to the medical condition (Velonaki et al., 2015).

Deaf Access to Healthcare

A Deaf individual enters the emergency department doubled over from intense abdominal pain. The receptionist does not know sign language and just hands the patient some paperwork and points to the chairs after realizing yelling and over-pronunciation is not working. The process of filling out the paperwork is extremely difficult due to both the presence of the pain and the fact that English is a second language for this patient. Upon being called back, a written note is given to the patient stating that an interpreter cannot be immediately obtained. The healthcare professionals begin physical assessments and insert an IV without attempting any further communication. After eventually relieving the patient's pain with medication, no further intervention occurs until an interpreter arrives hours later. There is no accurate history or informed consent obtained nor therapeutic relationship formed in this scenario; there is only confusion, mistrust, and delayed care.

This is not an extreme or rare situation; similar miscommunications with Deaf patients occur repeatedly in healthcare facilities despite preventative regulations. Numerous negative past experiences have fostered poor relationships between medical professionals and the Deaf and have discouraged the Deaf from seeking future medical aid. This avoidance of healthcare promotes severe health disparities among members of Deaf culture. Therefore, it is urgent to establish the necessity of cultural competence; analyze characteristics of Deaf culture; examine current health disparities among the Deaf; explore the legal qualification for and availability of interpreters; and consider the vitality of communication and holistic care to the medical profession in order to make recommendations for improving Deaf access to healthcare.

Cultural Competence

Cultural competence includes the mindset, actions, and standards necessary to provide medical care to patients from a different culture. People are constantly migrating across geographic boarders, and America itself is commonly known as a melting pot of cultures. Every culture possesses their own unique outlook, priorities, and needs. A medical professional must first understand a patient's cultural background in order to provide quality care (Elsevier, 2015).

Vulnerable populations are those considered to be at risk for disadvantages, health disparities, and poor medical outcomes. Cultural competence may help to offset social, economic, political, and environmental obstacles. In fact, cultural competence is the primary measure employed to eliminate health disparities and improve access to healthcare. Cultural competent healthcare is essential to the quality of life of cross-cultural patients. The necessity of promoting cultural competence in the actual practice of healthcare professionals today cannot be overemphasized (Elsevier, 2015).

To address this urgency, ten guidelines for implementing culturally competent nursing care were developed through the joint efforts of the Expert Panel on Global Nursing and Health, the American Academy of Nursing, and the Transcultural Nursing Society. All of the contributors had nursing experience in foreign cultures all over the world (Elsevier, 2015). The guidelines were based on the principles of social justice confirming that each person should receive fair and equal access to healthcare and on the fundamentals of basic human rights (Douglas et al., 2014). Seventy-eight nurses from sixteen different countries reviewed the first draft of guidelines and provided suggestions for revision. The final draft published in 2012 contained the following ten guidelines:

knowledge of cultures, education and training in culturally competent care, critical

reflection, cross cultural communication, culturally competent practice, cultural

competence in healthcare organizations and systems, patient advocacy and

empowerment, multicultural workforce, cross cultural leadership, and evidence-based

practice and research. The guidelines were deemed universally applicable and were

endorsed by the International Council of Nurses (Elsevier, 2015).

　　　　The document included an explanation of each guideline. The first guideline sets

the foundation for the others by stating that nurses and other healthcare professionals

must first gain knowledge about the patient's culture. Pertinent aspects such as values,

beliefs, behaviors, worldview, family, communication, history, and traditions should be

considered along with many others. A nurse with a vast understanding of a patient's

culture will be able to show respect, ask the proper questions, and provide any necessary

accommodations. However, it is nearly impossible for all nurses and other healthcare

workers to be experts in all the specifics of every one of the world's cultures. Thus, it is

necessary to employ an assessment framework to build upon when approaching an

unknown culture (Douglas et al., 2014). All individuals must first evaluate their own

views or biases in order to develop respect while avoiding prejudice and stereotyping

(Douglas et al., 2014; Eckert & Rowley, 2013).

Deaf Culture

　　　　Culturally competent practice is rapidly increasing in prevalence today, yet one

culture in particular is largely being ignored–that of the Deaf (Eckert & Rowley, 2013;

Velonaki et al., 2015). A framework is necessary in order to address the first of the

cultural competency guidelines and explore the complex cultural aspects that contribute

to a Deaf patient's perception of health and access to healthcare. The following examination of Deaf culture will, therefore, be guided by the twelve domains of the Purnell Model for Cultural Competence. The individual categories require varying levels of discussion depending on their relevance to the culture; thus, the two domains of *death rituals* and of *spirituality* are considered in the same section (Purnell, 2013).

Overview and Heritage

Deaf culture is vastly different from other people groups. The unique heritage is usually adopted by the choice of the deaf individual instead of the traditions being handed down through a generational lineage (Richardson, 2014). Thus, it is a horizontal cultural transmission rather than a vertical one (McKee, Schlehofer, & Thew, 2013). This peculiarity is due to the majority of deaf children being born to hearing parents who possess no knowledge of Deaf culture. All deaf individuals may choose to become involved in the hearing culture or the Deaf culture regardless of their cultural upbringing. Those joining the Deaf community are enculturated by exposure to shared values, sign language, and traditions during fellowship with other members (Richardson, 2014).

Deaf individuals possess various levels of hearing and often identify themselves somewhere along the spectrum of hard of hearing to profoundly deaf (Richardson, 2014). A distinction is made between *Deaf* culture and *deaf* as a medical condition through capitalization (Velonaki et al., 2015). It is important to note that the terms *hearing impaired* and *disabled* are considered extremely derogatory in Deaf culture due to their focus on inability instead of cultural empowerment (Barclay, Rider, & Dombo, 2012). With varying levels of acceptance, Deaf culture may also include certain hearing people such as sign language interpreters and hearing family members into the Deaf community.

Joining the Deaf community depends on interest, acceptance by preexisting members, and sign language fluency (Richardson, 2014). The relationships may be expressed in a circle diagram which looks like a target. The inner circle consists of those who are Deaf. The next outer circle contains children of Deaf adults (CODA). Then, the next ring represents sign language interpreters and others who are fluent in sign language and involved in Deaf culture. The next circle is students and others who are in the process of learning to sign. The outermost circle represents those who do not know sign language or are unfamiliar with Deaf culture. The closer to the inner circle, the greater the potential for a closer, stronger relationship with the Deaf community (Thorn, 2014).

There are Deaf people scattered throughout every country, yet due to its unique formation, Deaf culture is mostly similar around the globe. Statistics are also often hard to obtain due to specifying what defines being *deaf*. In America, 2 or 3 out of every 1,000 babies are born with detectable hearing loss in one or both ears. About 2% of 45-54 year olds, 8.5% of 55-64 year olds, 25% of 65-74 year olds, and 50% of those 75 and older have significant hearing loss (National Institute on Deafness, 2016). A federal survey asking about deafness has not been conducted since 1930, but the United States Census Bureau estimates the American deaf population to be over 10 million, and the survey by Income and Program Participation estimates 1 in 20 Americans are deaf or hard of hearing. There are no statistics on how many deaf people are engaged in Deaf culture, however (Richardson, 2014). Further discussion will focus on members of Deaf culture unless otherwise indicated.

The major concerns for modern education center on the method of language acquisition among the Deaf. Ninety percent of deaf children are born to hearing parents.

Those with hearing parents tend to be taught English and have delayed language acquisition while those with Deaf parents learn to communicate in sign language much earlier (Hoffmeister & Caldwell-Harris, 2014; Richardson, 2014). Studies show that the critical period for development of language skills spans the early months to the first few years of a child's life (National Institute on Deafness, 2017). The results of delayed language acquisition–supported by intellectual functioning tests and social adjustment scores–are significantly lower functional literacy, intellect, social skills, and communication abilities in those with hearing parents and significantly higher intellect, social skills, independence, responsibility, and maturity levels in those with Deaf parents (Richardson, 2014). It is estimated that 44% of Deaf adults never graduated from high school with only 5% obtaining a college degree (Mathews, Parkhill, Schlehofer, Starr, & Barnett, 2011).

Deaf education has a lengthy history which serves to explain several aspects of modern Deaf culture. In 1815, Thomas Hopkins Gallaudet traveled from America to Europe in order to learn how to teach the Deaf. During this time, he met Frenchman Laurent Clerc who had lost his hearing at one year of age in a fire and who then taught at the Royal Institution for the Deaf. Gallaudet had been planning to learn sign language and then return to America alone, but he asked Clerc to accompany him (Smith, n.d.). Thus in 1816, they traveled from France to Hartford, Connecticut, in order to found the American School for the Deaf. Education was solely conducted by the manual method meaning through the use of sign language. However, there were many considerations which threatened Deaf culture. Some educators thought sign language should follow the grammar and sentence structure of English and some supported Deaf education with

oralism. Oralism is strict use of spoken language and lip-reading which is now known as speech-reading (Trent, 2014). Much debate occurred about oral versus manual methods of education, but at first, oralism was clearly favored much to the despair of the Deaf (Gallaudet University, 2005). Sign language was seen as hampering the process of learning spoken language (Moores, 2010).

The first International Congress on the Education of the Deaf occurred in Paris, France, in 1878. It convened to determine a method to standardize the oral method of Deaf education. In 1880, the second congress in Milan, Italy, made a monumental declaration: to officially recognize the oral method as the acknowledged medium of Deaf education (Gallaudet University, 2005). However, despite the fact that this decision was about Deaf education and would greatly affect Deaf culture, absolutely no Deaf individuals were allowed to be involved in the congress or in the making of its resolutions. The decision instigated a worldwide ban on sign language. Teachers lost their jobs, Deaf children were forbidden to sign, Deaf individuals were prevented from holding influential leadership positions, and every attempt was made to eliminate Deaf culture (Moores, 2010).

In 1990, a method combining lip-reading and sign language became acceptable. This allowed the manual method to experience growth, but the oral method remained predominant until around 1963. The manual method became increasing more widespread with great effort over time (Gallaudet University, 2005). In 2010, the twenty-first International Congress on the Education of the Deaf met in Vancouver, British Columbia. With Deaf involvement, it recalled the 1880 resolutions and denounced them in favor of sign language use and the encouragement of Deaf contribution to society (Moores, 2010).

Denying access to sign language is a violation of human rights (Eckert & Rowley, 2013).

The Deaf have a right to be acknowledged as a culture with their own language. Deaf

history has had lasting effects upon Deaf culture (Moores, 2010). It was this history of

oppression that caused the formation of animosity towards those outside of the Deaf

community (Barclay et al., 2012).

Audism is a term which expresses the discrimination equivalency of racism or

sexism aimed at Deaf culture. Tom Humphries coined the word in 1977 in order to

describe the injustices, oppression, and loss of autonomy caused by the perceived

supremacy of the hearing population. Audism carried out overtly, covertly, and

aversively has had a tremendous impact upon Deaf culture throughout history. Overt

audism is equivalent to the major policies and restrictions upon the Deaf which occurred

during the nineteenth and twentieth century. Covert audism is more disguised

discrimination such as unequal job opportunities. Aversive audism is the declaration of

equality while practicing inequality through displaying anxiety around or simply avoiding

the Deaf. Audism in general is widely understood and experienced by the Deaf on a

daily basis. It includes the medical view that deafness is a disability or a condition to be

treated and leads to a denial of the Deaf as a culture and identity. Audism stands in direct

contrast to a Deaf-centric view which encompasses the pride and commonality expressed

in Deaf culture (Eckert & Rowley, 2013).

Communication

Deaf individuals may employ many different methods of communication

including written language, spoken language, lip-reading, cued speech, and sign

language. Sign language in America may take the form of American Sign Language

(ASL), Signed Exact English (SEE), or Pidgin Sign English (PSE) which is now known

as contact language (Engelman et al., 2013; Mathews et al., 2011). Contact language is

the use of ASL vocabulary in an English word order but without the addition of

noncritical words such as articles or of specific signs for English word endings and

inflections (Pidgin Sign English, n.d.). SEE is a precise signed representation of English

with additional signs for word endings and inflections (Signed Exact English, n.d.). The

drawback to contact language and SEE is that movement is only ¼ as fast as a spoken

word which makes the act of paring each spoken word with a movement into a long

sequence of signs which surpasses the processing and short-term memory capabilities of

human beings. The benefit of ASL is that each sign is defined by its hand shape,

orientation, location in space, movement, and facial expressions known as non-manual

markers. These parameters communicate a great deal of simultaneous information

beyond the capabilities of a simple English word (Hoffmeister & Caldwell-Harris, 2014).

Learning written or spoken English is often expected by hearing parents and is

often necessary in order to communicate with non-signers (Richardson, 2014). English is

based on sounds not heard by people who are deaf whereas ASL depends on visual

communication (National Institute on Deafness, 2017). The two languages have vastly

different sentence structure, grammar rules, and dialects. The particular challenge for the

Deaf is learning English through solely a written medium in a classroom-type setting

instead of having the social and contextual clues which are present when hearing children

learn English (Hoffmeister & Caldwell-Harris, 2014). For most Deaf individuals,

English is their second language (Mathews et al., 2011). English is a difficult language to

master as one's second language due to the presence of anomalies such as rule exceptions

and figurative language (Hoffmeister & Caldwell-Harris, 2014). A small minority of

Deaf children read at their age level; the average literacy of the Deaf is often around a

second to a fifth grade reading level (Mathews et al., 2011; National Institute on

Deafness, 2017). However, Deaf children raised using ASL achieve an eighth to a ninth

grade English reading level. This allows the individual to relate new English words and

concepts back to their own language of ASL in order to achieve greater understanding,

memory, and mastery of English. Those lacking an initial foundation in ASL, experience

much greater difficulty throughout the process (Hoffmeister & Caldwell-Harris, 2014).

Literacy level depends on the individual and their particular situation. Low literacy leads

to potential misunderstandings. Further, handwritten messages are time-consuming and

potentially illegible (Mathews et al., 2011).

It is frequently assumed that all Deaf people lip-read; however, each individual

has varying skills in this area due to personal language preference. Even the most skilled

lip-reader in optimal conditions can only understand 30-40% of the words due to many

sounds looking the same on the lips. Conditions are rarely optimal due to poor lighting,

facial hair, and an indirect line of sight causing crucial information to be frequently

missed. These factors also make it difficult to copy the lip formation of spoken English

when learning to speak (Richardson, 2014). The presence of audism, unfortunately,

places pressure upon the Deaf to prove their capabilities to the hearing culture. For this

reason, Deaf people–afraid of looking stupid if they ask for clarification–often nod and

pretend to understand even if they did not (Luckstein, 2012; Richardson, 2014).

It is a misconception that there is one universal sign language when, in fact, there

are hundreds of different sign languages in existence today. American Sign Language

(ASL) is a combination of American Indian and French signs and is arguably the third or

fifth most common non-English language in America (Harrington, 2016; Richardson,

2014). In addition to using signs and fingerspelling, ASL conveys meaning through

context, specific body language, and facial expressions. It is far from being simply

gestures. ASL is a completely distinct language from English, has no written form, and

has its own grammar rules and syntax (McKee et al., 2013; Occupational Outlook

Handbook, 2015; Richardson, 2014). The fact that ASL has no written form makes the

signing Deaf unique from other minority populations (McKee et al., 2013). Touch such

as hugging when greeting one other is encouraged in Deaf culture (Richardson, 2014).

An estimated 500,000 deaf Americans use ASL (McKee et al., 2013).

Communication in sign language may occur through means such as technology,

family and friends, or professional interpreters. In general, Deaf culture favors direct

communication, but technological advances have been beneficial in many ways. Video

relay service (VRS) employs a sign language interpreter to facilitate a telephone

conversation between a signing and a non-signing person who are in separate locations.

The interpreter is responsible for relaying information between the two people having the

phone conversation. Thus, the interpreter communicates with the Deaf person in sign

language via a video connection and with the hearing person by spoken language via a

regular phone. VRS is funded by the Federal Communications Commission and is free

for callers. Video remote interpreting (VRI) is another available technology. It allows

rapid access to a real-time interpreter on screen for a signing and non-signing person in

the same location when an interpreter cannot be physically present with them. VRI has

widespread use and is often available in hospital emergency rooms to allow for quality

communication among Deaf patients and non-signing healthcare professionals. Unlike

VRS, there is a fee for using VRI (Minnesota Department of Human Services, 2016).

The disadvantage of technology use is lack of personal interaction and loss of subtle body

language and facial expressions. Technology also enables videos to be recorded in sign

language for teaching purposes, but this method does not allow the individual to ask

questions for clarification (Richardson, 2014).

Frequently, signing family and friends are asked to interpret. However, their

signing skills will vary and their vocabulary may not be adequate for the topic of

discussion. Should the topic be private, confidentiality becomes an issue. The situation

represents a conflict of interest due to the existing relationship. Family and friends may

not convey the complete meaning or will try to be helpful by speaking for the Deaf

person (Richardson, 2014).

Professional sign language interpreters are supposed to be qualified but are not

required to be certified. "A qualified interpreter is one who can, both receptively and

expressively, interpret accurately, effectively, and impartially, using any necessary

specialized vocabulary" (National Association of the Deaf, 2017c, para. 4). It is

necessary that they be familiar with the terminology required of the situation. Medical

interpreters must know medical terminology and its meaning so that they can accurately

convey the concepts of discussion (Aharonson-Daniela, Tannenbaum-Baruchia, & Feder-

Bubis, 2012; Occupational Outlook Handbook, 2015). Confidentiality remains an issue

especially since the interpreters are typically already involved in the Deaf community and

might know the individual personally already (Richardson, 2014). Interpreters must be

sensitive to ethics, privacy, and the patient's situation (Occupational Outlook Handbook,

2015). Qualified interpreters may be scarce and difficult to obtain especially on short

notice (Aharonson-Daniela et al., 2012). This difficulty stems from inadequate

knowledge of the method for requesting an interpreter and the limited supply of qualified

interpreters who are both located in the area and available at the moment when they are

needed. Qualified interpreters tend to be more abundant in population-dense urban areas

than in rural regions (Cawthon & Leppo, 2013).

Family Roles and Organization

Communication has massive implications for socialization and family

organization. Most hearing parents expect their deaf child to assimilate to the hearing

world and thus never learn sign language to communicate with them. Deaf individuals

are therefore isolated even when physically surrounded by their own family members.

The language barrier also hinders the formation of peer friendships. It is largely shared

experience and audism oppression from a predominantly hearing world which draws deaf

people together into the Deaf culture. Deaf individuals instantly connect with each other

over their commonality and thrive in Deaf social environments. Deaf culture actually

becomes the *family* for those who are isolated from theirs. Thus, the traditional family

and home may not be where Deaf children learn about life. Identity and self-worth are

developed during Deaf fellowship rather than in the home. Social gatherings among the

Deaf are frequent and long lasting in order to increase the time spent with others who

have common experiences and understand the same language. Events will likely not

begin or end on time. This is what characterizes Deaf culture as a *being* culture rather

than a *time-conscious* one (Richardson, 2014).

Workforce Issues

The primary workforce issues relate back to audism as well. The view that

deafness is disabling has caused the hearing community to view the Deaf as incompetent.

As a result, fewer opportunities are available to the Deaf in the hearing society. Despite

modern declarations of equal opportunity employment, capable Deaf individuals continue

to face discrimination in the workplace (Sirch, Salvador, & Palese, 2016). Studies have

shown that Deaf individuals tend to hold low-status jobs and have higher unemployment

rates (Richardson, 2014). The Deaf population does share several socioeconomic

characteristics with other groups not having English as their primary language (Mathews

et al., 2011). This discrimination has a significant impact upon Deaf culture (Sirch et al.,

2016). Deaf individuals are valuable contributors to societies which embrace diversity

(Moores, 2010).

Biocultural Ecology

Biocultural ecology cannot be precisely defined due to the extensive span of Deaf

culture around the world. Yet a commonality is that deafness may obscure signs and

symptoms of genetic problems or another illness. Healthcare providers may focus on the

deafness instead of exploring comorbidities or may not perform a thorough assessment

due to the communication barrier (Richardson, 2014). Deafness may also distract from

analyzing the patient's condition as cultural or communication differences are mistaken

for medical conditions (National Association of the Deaf, 2017b). Further, the frequency

of mental health issues in the Deaf population is 40% while it is 25% in the hearing

population (Richardson, 2014). Depression and anxiety are particularly prevalent due to

barriers to mental health services. Diagnosis and treatment of psychological disorders

especially depend on deep, meaningful, confidential communication between the patient

and provider (The health of deaf people, 2012). Factors which contribute to the higher

incidence of depression in the Deaf population stem from communication barriers and

include longer time before diagnosis, misdiagnosis, miscommunication of symptoms, and

reluctance to ask questions or seek help due to stigma. Screening methods are often

inadequate for the Deaf population, and medical professionals are not aware of this

cultural need (Richardson, 2014). This lack of research and awareness is alarming and a

part of audism which should be addressed (Sirch et al., 2016). Medical professionals

must understand Deaf culture in order to understand the individual's experience,

perceptions, and emotional condition (The health of deaf people, 2012).

High-risk Behaviors

High-risk behaviors stem from audism. The hearing culture does not recognize

the Deaf as a culture and ignores its unique needs (Sirch et al., 2016). There is a severe

lack of research into the health of Deaf people which puts them at great risk (McKee et

al., 2013). Simply obtaining a doctor's appointment is more difficult for Deaf patients

than for hearing (Aharonson-Daniela et al., 2012). Health promotion education is

severely lacking among the Deaf. This places them at unnecessary high risk for frequent

development of preventable chronic diseases. Further, regular physicals and screenings

are not performed due to healthcare avoidance (Richardson, 2014). In the presence of

these conditions, there is also limited education available about necessary lifestyle

modifications, medications, or additional treatments to manage their disease. The limited

research that has been performed found an increase in hypertension, hyperlipidemia,

diabetes, and cardiovascular disease among the Deaf (Emond et al., 2015). The Deaf are also at a high risk for depression and obesity (Engelman et al., 2013).

The Deaf population do not receive adequate education about topics such as safety, mental health, alcohol, drugs, and sex (Heiman, Haynes, & McKee, 2015; Richardson, 2014; Smith, Massey-Stokes, & Lieberth, 2012). A study among 57 well-educated Deaf adults resulted in one third scoring below the ninth-grade level in defining health-related vocabulary. The evidence indicates fund-of-information deficits, which means that the Deaf population has significant limitations in factual knowledge as compared to the general population without considering IQ and education. This disparity is due to multiple factors including erroneous information from peers, inadequate signed instruction in the school setting, and limited available sources on Deaf-specific needs. Parents of Deaf adolescents often have limited ASL abilities or are unable to communicate with their children at all making the abstract conversation on the topics involved in health education especially difficult. Therefore, Deaf adolescents turn to fellow Deaf peers, the internet, and the media for their information. Written sources are frequently written at a high literacy level. Adolescents in general do not distinguish between credible and non-credible sources and develop a distorted perspective on these topics (Smith et al., 2012). There is a high incidence of alcohol use, substance abuse, multiple sexual partners, sexually transmitted infections (STIs), child sexual abuse, intimate partner violence, prostitution, rape, molestation, infidelity, and divorce in the Deaf community. The Deaf community also has a high incidence of gay, lesbian, bisexual, and transgender people. The prevalence of these behaviors may make them

seem normal to the adolescents raised in the Deaf community, thereby perpetuating their

practice (Heiman et al., 2015).

Due to cultural incompetence, state emergency management agencies are

unprepared to support the Deaf population in emergency situations such as natural

disasters, terrorist attacks, and nuclear-chemical disasters. Training programs focusing

on aiding the Deaf during emergency situations only began after 911. There are currently

only 15 of these programs in existence in American, and no evaluations have been

published on their effectiveness. The Deaf are not equipped to prepare for, respond to, or

recover from disasters (Engelman et al., 2013). Deaf people may not be made aware of

the danger in adequate time due to alarms systems based solely on sound. Therefore,

they are at higher risk for injury from fire, tornadoes, flooding, and other natural and

man-made disasters. In mass-casualty situations, emergency service resources are

already overwhelmed and unable to accommodate the extra need for interpreting services

by the Deaf population (Aharonson-Daniela et al., 2012). There are also numerous

examples of Deaf individuals being killed by the police during lawful interactions (Eckert

& Rowley, 2013).

Nutrition

Nutrition among the Deaf is too broad to precisely define. Specific food choices

depend on personal preference and the influence of the country of residence. Education

about balanced meals and nutritional treatment of health issues is again hampered by

communication barriers. Food, in general, often plays an important role at their social

gatherings (Richardson, 2014).

Included in the deficient health promotion education available to the Deaf is education on proper nutrition and exercise. The prevalence of diabetes and obesity among the Deaf can be linked to this. Erroneous knowledge on subjects such as nutrition and high-risk behaviors is propagated among the Deaf without access to the factual sources to disprove these myths rooted deeply in Deaf culture (Smith et al., 2012).

Pregnancy and Childbearing Practices

There are not very many pregnancy rituals specific to the Deaf culture, but there are major considerations for patients in this area. Included in the deficient health promotion education available to the Deaf is education on women's health, safe sexual practices, and healthy progression of the pregnancy process. Deaf patients must be carefully screened for sexual abuse and STIs due to their prevalence in the Deaf community. There is currently a significantly lower incidence of HIV testing performed in Deaf females (Heiman et al., 2015).

Expecting parents who are Deaf need the same access to care and support as hearing parents. Deaf parents tend to hope that their children will be born deaf but will still accept a hearing child. This view stands in stark opposition to the hearing culture's views on deafness as generally undesirable. Children, spouses, relatives, and friends who are deaf are readily welcomed into Deaf culture due to their commonalities (Richardson, 2014).

Death Rituals and Spirituality

Deaf culture also does not define any specific death rituals. Views about the afterlife depend upon each person's religion and spirituality. Spirituality is affected by the discrimination which the Deaf experience. Due to communication barriers, their

access to diverse religious organizations is limited. Barriers that previously hindered the

Deaf culture's acceptance of Christianity are being broken down by churches

understanding Deaf culture and encouraging members to play an active role in the

church. With English as a second language, reading religious texts such as the Bible had

been difficult, but recent sign language translations of the Bible are improving

accessibility. Some hearing churches provide a sign language interpreter. These

churches interpret the sermon but are still unable to remedy the social isolation of its

Deaf members from the rest of the congregation. Potentially unqualified interpreters and

social isolation result in a poor church experience and will often keep Deaf individuals

from spiritual growth or from regular church attendance. However, a Deaf church is one

that consists of Deaf church leaders and members. Deaf churches are better equipped to

meet the cultural, social, and spiritual needs of its members (Barclay et al., 2012).

Deaf people may seek spiritual understanding of their deafness and view God in a

positive or negative light accordingly. For example, deafness could be viewed as a test, a

punishment, or a gift from God. This affects self-image. The majority of Deaf culture

views their deafness in a positive light (Barclay et al., 2012).

Healthcare Practices

The healthcare practices of Deaf culture deviate from western medicine in its very

definition of deafness. As explained in depth, the Deaf are proud of their culture and

perceive deafness as a common trait which draws them together. However, the very

model of western medicine is to treat that which deviates from the norm. Deafness is

defined as not being able to hear and is considered an abnormal medical condition

requiring a cure. The medical model therefore, perpetuates a sense of disability and

inferiority. This audism perspective results in numerous beliefs which directly oppose

Deaf culture. Using sign language and socializing with other Deaf people are

discouraged while invasive procedures are encouraged. The focus is often wrongly

placed on the deafness rather than on the reason the patient is seeking care (Eckert &

Rowley, 2013; McKee et al.; Richardson, 2014; Trent, 2014).

According to western medicine, cochlear implantation is the treatment of choice

and should be done in every case in order to cure deafness (Richardson, 2014; Trent,

2014). Since December 2012, there have been approximately 324,200 cochlear implants

worldwide with about 58,000 of those in American adults and 38,000 in American

children (National Institute on Deafness, 2016). Cochlear implants do not completely

restore normal hearing (Richardson 2014). Deaf culture in general does not approve of

cochlear implants and views their use as a method of eugenics to eradicate deafness

(Trent, 2014). Those who have this surgery might even be shunned by the Deaf

community. Thus, those with cochlear implants may be caught in the middle without

solace in either the hearing or Deaf cultures. Children who receive cochlear implants do

not learn sign language, have delayed language acquisition, and report a lower quality of

life. Those in the Deaf culture do not believe that hearing parents are given enough

information about cochlear implants, are made aware of alternatives to surgery, and

consider their deaf child's wishes. It would be preferable for hearing parents to become

active in the Deaf community in order to understand the culture and their child's wishes

before taking such drastic action (Richardson, 2014).

Healthcare Practitioners

Vastly differing perspectives and communication barriers serve to foster distrust

between the members of Deaf culture and healthcare professionals. The communication

barrier leaves Deaf patients intimidated to ask questions or explain symptoms and the

medical professional unable to discuss informed consent and treatment options (McKee

et al., 2013; Richardson, 2014). The Deaf perceive medical professionals to have bad

intentions and an unwillingness to understand their needs (Richardson, 2014). Healthcare

practitioners who do not sign and are unfamiliar with Deaf culture fall into the outermost

circle of the circle diagram of Deaf relationship discussed earlier. Therefore, the

implication is a very low potential for the formation of a strong therapeutic relationship

necessary for holistic care (Thorn, 2014). After repeated bad experiences, members of

the Deaf culture conclude that healthcare will only result in delayed, incorrect treatment.

Thus, members of the Deaf culture tend not to seek care until they are very sick. Deaf

patients will also choose a less effective treatment if they cannot understand the new one

(Richardson, 2014). Leaving appointments with doubts about the care they received,

Deaf patients tend to visit multiple providers searching for one who is able to

communicate with them on some level (National Association of the Deaf, 2017d;

Richardson, 2014).

In addition to mistrust for healthcare professionals, the Deaf population possesses

a mistrust for medical researchers. Very little research is available on the Deaf. This is

due to a lack of awareness by the researchers of the need for further studies as well as the

hesitation of the Deaf to participate in the studies. Researchers tend to be ignorant about

Deaf culture and push the Deaf away by exhibiting a culturally incompetent manner

similar to that already discussed. Researchers build on the medical model of deafness

and focus on cures. For example, much attention is given to genetic testing and

engineering in order to eradicate the condition of deafness. The Deaf is the only minority

population to have genetics threaten a valued trait. Communication needs required for

informed consent are left unmet such as inadequate literacy level and lack of

opportunities for questions to be answered. The Deaf are also not given opportunities to

provide input into the studies. As a result, ethics are violated, and the health disparities

of the Deaf are perpetuated (McKee et al., 2013).

Current Practice and Health Disparities

The majority of healthcare professionals are unable to communicate effectively

with their Deaf patients. Problems stemming from these tense encounters with healthcare

professionals are far from simply being inconvenient. Interpreters are not obtained. The

right questions are not asked or answered (Richardson, 2014). A trusting relationship is

not formed. An accurate history and detailed report of symptoms cannot be obtained. A

thorough assessment cannot be performed (Atkinsona & Wolla, 2012). Frustrations arise

towards the ineffective communication. Diagnoses are delayed or incorrect leading to

increased hospital stay, expense, and health risks. Privacy is breached. Many procedures

are performed without the patients' true informed consent. Patient outcomes are

extremely poor. Printed patient education materials only provide limited information in a

hard-to-understand format (National Association of the Deaf, 2017d; Richardson, 2014).

Informed consent forms contain complicated information and are generally written at a

high school level or higher making an opportunity for explanation essential for all

patients. A study showed that 40-80% of hearing, English-speaking patients did not

understand the content of the forms without assistance. Deaf patients must have access to

an explanation and chance to ask questions (McKee et al., 2013).

Medical professionals often are culturally incompetent and stereotype Deaf

patients. A study of hospitalized male Deaf patients in a European country investigated

their perspectives of the experience. The results showed vulnerability, being outside their

comfort zone, a disconnect between care and needs, and disempowerment (Sirch et al.,

2016). Deaf patients, understandably, avoid the healthcare system. An entire culture is

severely lacking the absolutely essential health promotion education, screening, and

appropriate treatment. The current culturally incompetent healthcare practices and

practitioners are continually propagating health disparities in the Deaf culture

(Richardson, 2014). Several of these health disparities have already been discussed. The

Deaf have a high incidence of preventable chronic diseases due to a lack of education on

lifestyle modification and adherence to treatment (Emond et al., 2015). The Deaf are at

increased risk for obesity, depression, and interpersonal violence (Engelman et al., 2013).

There is also prevalent hypertension, diabetes, hyperlipidemia, and cardiovascular

disease. The full extent of the health disparities of the Deaf is unknown due to lack of

research (Emond et al., 2015).

Legal Aspects and Ethics

The Americans with Disabilities Act (ADA) of 1990 mandates that interpreting

services be made available if needed. It requires the procurement of qualified interpreters

or another provision for communication (Richardson, 2014). Title II of the ADA

mandates access to public healthcare while Title III addresses private healthcare access.

Title VI of the Civil Rights Act of 1964 requires language access in healthcare settings

for those with limited proficiency in English (National Association of the Deaf, 2017d).

The National Association of the Deaf (NAD) Law and Advocacy Center serves to

advocate for equal Deaf access to healthcare and mental health services. It also guides

VRI use in hospitals (National Association of the Deaf, 2017b).

         The Joint Commission and Office of Minority Health national standards mandate

culturally appropriate services for vulnerable populations and minorities. While the

specific groups are left unspecified, these policies are applicable to the Deaf population.

The ADA indicates the cost for linguistic services should come out of the organization's

overhead expenses. Thus, the hospital is to be responsible for paying for reasonable

accommodations such as interpreters and closed captioning. There is an allowance for

not requiring the organization to pay if it is an undue burden. Unfortunately, some

organizations use this clause to refuse to pay for interpreters and may still expect family

members to interpret (National Association of the Deaf, 2017a; Richardson, 2014). The

Declaration of Rights of Persons Belonging to National or Ethnic Religious and

Linguistic Minorities was developed by the United Nations in 2003. The document

supports cultural competency by equating the diminishing a minority culture with a crime

against humanity (Richardson, 2014). If these policies were consistently followed,

communication barriers for the Deaf in the healthcare setting would be greatly lessened

(National Association of the Deaf, 2017d).

         There is a high demand for qualified and certified sign language interpreters

(National Association of the Deaf, 2017c). Registry of Interpreters for the Deaf (RID)

sets high certification standards for interpreters. Those seeking national certification

must have a bachelor's degree and pass the following three-part evaluation: a knowledge

examination, a performance examination, and an interview (Registry of Interpreters for the Deaf, 2015). The median pay for the interpreter occupation in general in 2015 was $44,190 per year and $21.24 per hour. This role is expected to increase by 29% from 2014 to 2024 at faster rate than the average growth rate for all occupations (Occupational Outlook Handbook, 2015).

American Nurses Association (ANA) has established a code of ethics for nurses. The code consists of nine provisions of nonnegotiable standards of practice and the obligations of nurses when providing care to their patients. The first three present necessary values and commitments, the next three describe duty and loyalty, and the final three address expanded duties beyond the walls of the hospital. Each of these provisions is broken down further into subcategories. Among numerous other things, the code promotes the following: respect for human dignity, commitment, health promotion, advocacy, privacy, research contributions, safety, integrity, nursing judgement, holistic care, and social justice. The code holds that health is a universal right and that all patients should be treated according to its standards. The code of ethics also establishes a goal of eliminating health disparities (American Nurses Association, 2015). The Deaf patient population should not be an exception to these standards of nursing care.

Communication and Holistic Care

Holistic care and therapeutic communication are foundational principles in nursing. The focus of holistic care is to meet patients' physical, spiritual, mental, and emotional needs. The medium for providing such inclusive care is therapeutic communication in a trusting relationship. Therapeutic communication includes appropriate nonverbal expressions, maintains privacy and integrity, and occurs at the

speed dictated by the patient. It occurs in two directions and entails an open environment

for expressing compassion, listening to concerns, providing education, and answering

questions. Therapeutic communication is necessary for informed consent in which the

patient fully understands a procedure or the consequences of refused treatment, feels free

to state any concerns or ask any questions, and expresses understanding and agreement to

undergo the proposed therapy. Multiple significant consequences arise when

communication falters due to a language barrier. The patient's quality of care is

significantly reduced and becomes focused solely on life-sustaining physical needs while

ignoring the equally important spiritual, mental, and emotional aspects of the patient.

Unfortunately, this severely handicaps the level of care a nurse is able to provide for the

patient. Further, without communication, obtaining legal consent becomes impossible.

Therefore, it is vital to address all obstacles to communication before initiating care of

any patient in the healthcare setting (Kourkouta & Papathanasiou, 2014).

     Therapeutic communication suffers in the absence of a qualified medical

interpreter. Any patient in the unfamiliar setting of a hospital needs support and

guidance. Deaf patients have increased concerns such as recognizing when their name is

called in the waiting room. Diseases, procedures, and medication instructions are crucial

to present in a manner that the patient understands and feels free to have any questions

answered. This is completely impossible through the medium of lip-reading guesswork

or by a low-literacy patient reading pages of complex documents. It is also unacceptable

for the appointment to occur without adequate information passed between healthcare

professionals and the patient. There is only confusion, frustration, and safety risks

(Mathews et al., 2011).

Recommendations

The health disparities of the Deaf are truly appalling, and currently, there is almost no awareness in the medical profession about the unique needs of the Deaf population. However, Deaf access to healthcare can improve through modifying the knowledge, attitudes, and behaviors of healthcare professionals (Velonaki et al., 2015). Having already addressed the first of the ten cultural competency guidelines with an in-depth examination of Deaf culture, the other nine guidelines become a resource for further recommendations for appropriate care of Deaf patients (Douglas et al., 2014). Legal interpreter requirements and the ANA Code of Ethics also dictate proper interactions with patients. There is truly no shortage of recommendations on promotion of awareness, therapeutic relationships, communication, advocacy, and research but these must be put into widespread practice in order to begin improving Deaf access to healthcare (American Nurses Association, 2015; National Association of the Deaf, 2017a).

One of the first interventions should be raising awareness of and providing education on cultural competency as it relates to Deaf culture. Medical professions should receive education and clinical training on cultural competence. Receiving basic instruction on what to do in a cross-cultural situation beforehand will definitely relieve the discomfort when engaged in an actual patient encounter (Douglas et al., 2014; Emond et al., 2015; Luckstein, 2012). It is vital to also expand public awareness of Deaf culture and the social ills of all forms of audism (Eckert & Rowley, 2013). Once awareness of the need for cultural competency is raised and a universal framework is learned for approaching a cultural assessment, successful practical application may be readily

accomplished in numerous cross-cultural situations. The Joint Commission is

increasingly requiring continuing education in cultural competence for accreditation. A

healthcare professional with this training will know how to be culturally sensitive and ask

appropriate questions of the patient and family in order to meet special needs and provide

optimal care (Douglas et al., 2014).

The cultural competency deficits in the emergency management system must also

be addressed. The Federal Emergency Management Agency's (FEMA) Office of

Disability Integration and Coordination mandates program modifications in order to

provide effective communication and equal access. Emergency preparedness training

focused on aiding the Deaf population should be conducted for state, local, and

community agencies and responders as well as among members of the Deaf population.

These should provide education on alert systems, packing an emergency kit,

communication, evacuation, and safety. These trainings must be evaluated for

effectiveness and nationally standardized (Engelman et al., 2013). Interventions should

be employed such as installing flashing alarm systems as dictated by Title III of the ADA

(National Association of the Deaf, 2017a).

One specifically interesting method to help healthcare professionals improve their

Deaf cultural competency is to conduct a Deaf Strong Hospital (DSH). This exercise

which began at University of Rochester School of Medicine and Dentistry role-plays

scenarios in which the healthcare professional become the patient in a sign language-only

environment in order to experience what it is like to not understand or be able to

communicate in a healthcare setting. Students experiencing these simulations expressed

personal frustration and gained awareness of the need for improved Deaf access to

healthcare (Mathews et al., 2011).

Development of specialty services specifically for Deaf patients would be an ideal

situation where the sign language-speaking staff fully understood their patients and

communication barriers were broken down. There are examples of these such as a

monthly Cognitive Disorder Clinic just for Deaf patients held at the United Kingdom's

National Hospital for Neurology and Neurosurgery. It is doubtful that specialized clinics

for the Deaf population will suddenly become widespread, but there is hope for such

progress in the future through spreading awareness of the need (Atkinsona & Wolla,

2012). Even in non-Deaf hospitals, interventions could be employed to make it more

Deaf-friendly. Online scheduling of appointments, documentation in the medical record

of the Deaf patient's preferred method of communication, and visual alerts in the waiting

rooms could make the hospital experience much less threatening (Emond et al., 2015).

Healthcare professionals must reach out to the Deaf population in order to restore

trust and a therapeutic relationship. While it is not expected that all healthcare

professionals learn to sign, knowing some basic conversation skills in sign language

communicates a caring attitude and makes the Deaf patient more comfortable (National

Association of the Deaf, 2017d). This is because when a healthcare professional learns

about Deaf culture and takes steps towards learning sign language, the relationship

potential is increased as represented by moving into a more central circle on the circle

diagram of Deaf relationships (Thorn, 2014). A certified interpreter should still be

brought in to accurately convey critical information. To aid communication, any

available visual diagrams should be used during explanations, and medical jargon should

be avoided (National Association of the Deaf, 2017d).

Communication needs must be met in every circumstance for appropriate access

to healthcare. Family members should not be used as interpreters as there will be a

conflict of interest. They may have inadequate signing skills and vocabulary for the

situation and may intentionally or unintentionally relay false information (Richardson,

2014). Every attempt should be made to secure a qualified interpreter as quickly as

possible. If possible, the interpreters should be unfamiliar with the patient on a personal

level, but still be given a few minutes with the patient before interpreting in order to

introduce themselves and assess the patient's language skills and preference of ASL,

SEE, or contact language. Interpreters must have a full understanding of privacy

standards and not be permitted to share patient information. Throughout this process,

medical professionals are responsible for ensuring privacy is not breached (Douglas et al.,

2014).

When using interpreters, the healthcare professional should look and talk directly

to the patient and not the interpreter (Luckstein, 2012). The medical professionals should

observe and adapt to appropriate cultural behaviors such as physical touch, body

language, eye contact, time consciousness, and spatial distance after noting the defining

characteristics of interaction among the patient, family, friends, or interpreter (Douglas et

al., 2014; Luckstein, 2012)

Healthcare professionals should still behave in a culturally competent manner and

attempt communication in the absence of an interpreter even if the process requires extra

time or effort. If the Deaf patient prefers to read lips, communication should occur in an

area with good lighting and minimal visual or auditory distractions. It is especially

important to ensure one has the patient's attention before beginning to speak. While

facing the patient, speak clearly at a regular rate while avoiding over-pronunciation.

Ensure understanding by asking open-ended feedback questions. Literacy level should be

assessed before communicating through written notes or distributing crucial information

in written form (Luckstein, 2012; Sirch et al., 2016).

In the medical realm, nurses specifically hold the distinction of being patient

advocates. Nurses should always uphold the standards expressed in the ANA Code of

Ethics (American Nurses Association, 2015). It is especially important for nurses to

exercise their voice and advocate for those of a different culture who feel even more lost

in an unfamiliar medical environment. Nurses are in the position to discover specific

cultural needs and to take steps towards meeting them (Douglas et al., 2014). This is

especially important when encouraging Deaf patients to take an active role in their health

and to ask questions when something is not understood (Luckstein, 2012). However, the

Deaf culture's view on advocacy must be taken into consideration. The Deaf view the

term *advocate* as one who takes control and is in charge of the details of the change. The

term *ally* is defined as one who empowers and supports the Deaf in taking decision-

making roles and leading their own process of change for the better (Baker-Shenk, n.d.).

The patient will receive optimal care when cultural considerations are met and holistic

care is provided. Nurses should, therefore, use their role as patient advocate to empower

their Deaf patients and promote autonomy through their involvement in their own care

and in the improvement of their culture's access to healthcare (Douglas et al., 2014).

Advocacy can also be employed on a larger scale in the community. Identified needs should be evaluated for ways to prevent reoccurrence. Nurses should be knowledgeable about relevant community resources in order to connect patients with them. It is necessary to employ leadership in order to raise awareness of a cultural need and to take steps towards reversing health disparities. The nursing process must begin with an assessment of the Deaf population and their unique health disparities (Douglas et al., 2014). In order to conduct research, the researchers must first regain the trust of the Deaf population due to the negative past history discussed previously. This requires time spent in the community interacting with the Deaf and learning their values. If researchers studied Deaf culture, refocused their research, and ensured informed consent, much could be done to improve the health of Deaf people. Even sensitive areas of research which were previously viewed negatively could be redirected. For example, genetic research discussed earlier could be refocused on conditions to which the Deaf population is particularly susceptible in order to improve screening and health promotion. This method would improve health without attacking the identity of their culture. Deaf individuals should certainly also be encouraged to participate on the research committees in order to promote empowerment and autonomy for guiding research topics (McKee et al., 2013). After the planning process, evidence-based interventions implemented into practice must be evaluated for effectiveness (Douglas et al., 2014).

For example, a recommendation for implementation of Deaf-appropriate health promotion education is to present the material in their first language of ASL. In an ASL video format, captioning could also be utilized (Smith et al., 2012). Having the instruction delivered in person allows for questions and feedback (Richardson, 2014).

Education materials must take literacy level into account. Since the Deaf currently

exhibit serious health promotion deficits, education is needed on numerous topics. After

the education session, follow-up in essential to test the efficacy of the intervention. A

study showed increased results following repeated exposure to the education content

(Smith et al., 2012).

Conclusion

The Deaf are a unique culture which is often overlooked. This results in cultural

incompetence and health disparities. The only way to end the vicious cycle of distrust

and poor patient outcomes is to take action to promote cultural competency. Awareness

must be spread especially among healthcare professionals about the details of Deaf

culture in order to stop audism and promote improved, research-based care.

Communication could be improved by using the recommendations which have been

discussed. Medical professionals must understand their culture in order to establish

therapeutic relationships with Deaf patients; and the Deaf must know that healthcare

professionals are accepting and have their best interest in mind. Uninhibited access to

culturally competent healthcare will vastly improve the health outcomes of the Deaf

population by providing health promotion education, encouraging trusting relationships

with healthcare professionals, and ensuring timely and appropriate treatments.

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