**Research Article**

**Communication Accessibility: Barriers to Patient Portal Adoption for Deaf and Hard of Hearing Populations**

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**How to cite this article**: Vander Ploeg T, et al. (2022) Communication Accessibility: Barriers to Patient Portal Adoption for Deaf and Hard of Hearing Populations. Int J Nurs & Healt Car Scie 02(11): 2022-158.

**Submission Date:** 10 October, 2022; **Accepted Date:** 27 October, 2022; **Published Online:** 31 October, 2022

**Abstract**

Deaf and hard of hearing populations have negative experiences with the healthcare system from infancy on to adulthood. They experience ineffective health communication that leads to lack of autonomy. Ineffective health communication makes the healthcare system inaccessible leading to poor health outcomes. The purpose of this paper is to explore the barriers to patient portal services among deaf and hard of hearing populations and to discuss ways to improve the utilization of patient portals to promote accessibility in the healthcare system. Three main barriers were found: lack of medical staff trained to work with deaf and hard of hearing patients, inadequate interpreting services, and communications written at a high grade level that is difficult to understand. Healthcare systems need to address these barriers and make patient portals more accessible by collaborating with deaf and hard of hearing patients to improve health information communication and accessibility.

**Keywords:** Deaf and hard of hearing; Health communication; Patient portal

**Introduction**

Deaf and hard of hearing is a phrase that can be used to describe people that have had hearing loss before or after verbal language development and who may or may not identify as deaf or hard of hearing [1]. Some reports (i.e., the National Deaf Center) use the word deaf to include all groups with hearing loss to recognize their shared experiences in life [2]. This paper uses deaf and hard of hearing and people with hearing loss to describe a heterogeneous population recognizing both the differences from person to person and the experiences shared by many people with hearing loss in healthcare systems.

Deaf and hard of hearing people often face barriers that involve communication and discrimination beginning from infancy [3,4]. Most deaf children are born to hearing parents [5]. Hearing parents may not be aware of what a deaf child needs to be able to communicate and thrive. Low expectations for communication are reinforced in the deaf person’s life as parents often do not learn sign language, which excludes the child from conversations concerning important family medical history [6]. At the same time, healthcare systems often fail to encourage parents to get interpreters for the child’s doctor appointments [7]. When this happens, the child learns that other people will take care of their health issues instead of learning to advocate for themselves.

Hearing loss can affect how both the healthcare provider and patient communicate with each other. Lack of clear communication results in misunderstandings, thus causing issues with the diagnosis and accuracy of the treatment plan [8]. noted that, in the absence of effective communication, most deaf patients did not understand their diagnosis or the treatment guidelines. Many of the patients (61%) said their healthcare provider did not understand them unless they had the help of an interpreter. Misunderstandings can be caused by healthcare providers being impatient with deaf and hard of hearing people, missing the opportunity to inform their patient about healthcare services or medical procedures which leads to insecurity and fear during an appointment [8]. Such experiences may lead the patient to believe the healthcare provider assumes that deaf people have an inherent health deficit that affects how their healthcare provider will treat them [9]. If these experiences and behaviors continue to be reinforced, the consequences could be profound and result in misunderstandings leading to improper treatment, medical non-compliance, or avoidance of the healthcare system [1,10].

According to the Society for Health Communication [11], health communication, a multidisciplinary field, is both an art and science that engages best practices in communication to further the health and well-being of individuals and populations. The American Public Health Association has recognized health communication as an integral field within public health education and promotion [11,12], a leader in promoting health communication research, identified five domains for organizing health communication: communication in the delivery of care, communication and health promotion, health risk communication, E-health communication, and communication in managing health care systems. Ruben [13] advocates for effective communication processes to foster accurate patient reporting and disclosure, engagement in decision-making, effective use of health care options, and improved patient outcomes. Effective and efficient communication processes may also positively impact health care provider-patient interactions and trust. This paper captures barriers to health care information and communication for deaf and hard of hearing individuals that intersect with all five health communication domains but more explicitly within the delivery of care and e-health communication domains.

Patient portal services, an example of communication in the delivery of care and an E-health communication tool, may be the gateway for individuals with hearing loss to experience clear communication with the healthcare system. Patient portals allow secure online access to a patient’s electronic medical record and enable electronic communication with healthcare providers. Patient portals are essential communication tools for the delivery of patient-centered care. They give patients more control over their healthcare and promote patient-centered engagement leading to improved health communication. Patient‐centered communication have significant implications on individuals as well as their families [14]. Currently, however, deaf, and hard of hearing patients are less likely to use patient portals than hearing patients [15]. Therefore, the introduction of patient portals and ongoing support can help to fill the gap in clear health communication between the healthcare system and their deaf and hard of hearing patients. The most benefit may be produced when patient portals are introduced at an early age because regular exposure could normalize the use of patient portals to access the healthcare system.

Encouraging and supporting patient portal use for deaf and hard of hearing people can provide much needed accessibility into the healthcare system. Once deaf and hard of hearing people can access the healthcare system through patient portals, other areas of the healthcare system will be easier to navigate to create positive and more medically productive experiences. However, limited knowledge exists on the deaf and hard hearing populations’ utilization of portal services.

**Purpose Statement**

This paper explores barriers to utilizing patient portal services as an equity issue of access to health care information among deaf and hard of hearing populations to improve the utilization of patient portals to promote healthcare system accessibility.

**Theoretical Framework**

The Levesque’s conceptual framework addresses the complex and dynamic nature of healthcare system access [16]. Access to healthcare is more complicated than just measuring the availability of services. It is essential to consider the multilevel issues and interplay from both the healthcare system and prospective patients’ perspective [16]. Levesque’s framework recognizes the complex dynamics between services offered by organizations and the patient’s ability to find and use these services through the lens of a conceptualized framework. This framework helps to ensure that the diverse issues associated with accessing the healthcare system are examined to assess barriers and interactions between the healthcare systems and the people they serve.

In addition, Levesque’s conceptual framework delineates the areas of accessibility into six concepts: identifying healthcare needs; perceiving these needs and the desire for healthcare; seeking healthcare services; reaching out for healthcare; obtaining healthcare services; and satisfying healthcare needs [16]. These concepts of accessibility to the healthcare system have corresponding dimensions for both the healthcare system and people needing health care. Many of these dimensions are interrelated, which makes this framework a fluid and dynamic system [17]. This framework is also supported by the health communication domains or benchmarks noted by Kreps [12].

This paper addresses the first three access areas which include identifying healthcare needs, perceiving these needs and the desire for healthcare, and seeking healthcare services. Exploring the deaf and hard of hearing populations’ process along with the healthcare system’s process offers insight into current communication experiences and expectations of accessibility, as well as equity of health care access.

**Search Strategies**

The literature searches were completed using PubMed, CINAHL, and Project MUSE databases. Project MUSE is a database promotes and disseminates peer-reviewed humanities and social science academic content [18]. This database includes the American Annals of the Deaf journal and other material from Gallaudet University Press, which is produced by a deaf university. The chosen phrases and keywords were Patient Portal use in the healthcare system, deaf, patient portals, electronic services, healthcare, and medicine. A Boolean search was conducted in CINAHL using deaf or hard of hearing or hearing impaired or d/hh, patient portals or MyChart® or electronic health services or web portals [19]. These results were limited to being published in the English language and peer reviewed. The initial searches yielded 62 articles which resulted in 12 articles after a review for relevancy.

Further articles were found using snowball retrieval using the reference lists of articles. Other articles focusing on how deaf patients experience healthcare were retrieved using Google scholar. Articles were screened and chosen to compliment and add insight to the deaf experience and barriers involved in the healthcare system.

**Literature Review**

**Health Disparities among the Deaf and Hard of Hearing Populations**

Approximately 38.2 million Americans aged 12 and older have hearing loss in both ears while 60.7 million have hearing loss in at least one ear [20]. This number does not include the two to three out of every 1,000 infants who are born with detectable hearing loss in one or both ears [5].

The first deaf person many hearing people meet is their child. More than nine out of every 10 clinically deaf children are born to hearing parents [5]. Hearing parents are generally unaware of the communication needs of a child with hearing loss. This can lead to “Dinner table syndrome,” which is when children with hearing loss miss incidental learning about their family's health history and how to use the healthcare system because they are not included in family conversations [6]. Missing this information can result in unfamiliarity with basic first aid, ignorance of inherited health concerns, inability to report familial health history due to unawareness, and lack of skill in properly utilizing the healthcare system. These inequities, created by a lack of incidental learning, are directly connected to how people with hearing loss are treated in a hearing world. When the hearing culture is the main source for incidental learning about personal and family health history, the deaf and hard of hearing populations are often excluded from this important information.

Deaf and hard of hearing people are recognized as a disabled group by the Americans with Disabilities Act [21]. As a disabled group, they often experience audism, which is a type of discrimination based on the ability to hear that devalues people with hearing loss [22]. Discrimination throughout their lives contributes to attaining low education and potentially resulting in higher unemployment rates compared to people without disabilities [22]. In the U.S., only 53% of people with hearing loss were employed compared to 75.8% of hearing people [2]. High unemployment rates due to low education among the deaf and hard of hearing populations make public insurance their main source of health coverage [6]. Therefore, addressing employment rates starts with addressing education level attainment [2].

In the U.S., only 18.8% of deaf adults have college degree compared to 34% of hearing adults [2]. Deaf and hard of hearing people tend to fall behind in education due to learning reading and writing skills in English with English as their second language. Alexander [23], states that deafness presents significant educational difficulties for children in acquiring English language skills. Booth [24], explains that this difficulty is unique because the deaf learner is not able to hear how English words are pronounced. As a result of this learning challenge, deaf students tend to graduate from secondary school with 4-7 grade reading levels [9]. Because lower reading levels decrease the availability of health information, people with hearing loss have reported poor health knowledge [6]. Lack of health knowledge can increase misunderstandings related to health issues, result in unintentional noncompliance with health activities and treatments, and lead to poor health outcomes.

Deaf or hard of hearing adults living in a hearing world often have negative experiences during everyday interactions with hearing-abled people. When people with hearing loss are left out of social situations, not included in family conversations, or caused to feel unsafe because of communication issues, it can result in an increase of negative health effects. Children are particularly at higher risk to early adverse social experiences [25]. These negative social experiences and socially induced stresses can increase the risk of chronic illnesses and have negative effects on neurodevelopment and the immune system later in life [25]. When communication is compromised from an early age, social, educational and employment disparities are created. These disparities are all directly related to health disparities and inequities because they have negative effects on developmental health, health knowledge, and access to healthcare, which has an overall negative impact on health.

**Communication Methods Used by the Deaf and Hard of Hearing Populations**

People with hearing loss face health disparities due to lack of effective communication. Thus, it is important for the healthcare system to train their healthcare providers to consider communication methods people with hearing loss use. Trained healthcare providers understand and are understood by their patients when they use proper communication tools. These communication tools are American Sign Language (ASL), lip reading, and written communication.

**American Sign Language**

Berman et al. [26] estimated that about one million people with hearing loss use ASL as their primary method of communication. Contrary to the popular misperceptions, ASL is not the English language in visual form. ASL is an independent language that has no written form, but it has its own grammar and lexicon that is vastly different from the English language [6,26]. ASL also includes facial expression (e.g., to distinguish statements from questions) and body shifts to designate a change in character roles while telling a story [6]. When a deaf person learns the English language, they are indeed learning a distinctly separate second language. Proficiency in ASL varies from person to person and this should be taken into consideration when using an ASL interpreter [26]. When an ASL interpreter is requested by the patient, healthcare systems are required to provide this service as mandated by the Americans with Disabilities Act [27]. In most cases, having an ASL interpreter may be the only way to ensure symptoms, diagnosis and treatment plans are communicated clearly.

**Lip Reading**

Deaf and hard of hearing patients are regularly expected to be able to read lips for communication. Lip-reading can be effective for some deaf people depending on the residual hearing and skill of the patient. However, it is a misconception among the public that all deaf people can read lips and understand a full conversation. Instead, deaf people usually understand less than 30% of the spoken conversation through lip-reading [6]. Deaf people rely on context and other clues to fill in the gaps to understand what is being verbally communicated. This requires a realistic expectation of deaf people’s ability to read lips, which is especially significant in the healthcare setting. If lip-reading is being used, both the healthcare provider and patient should assess how the conversation is understood and make clarifications to ensure the patient and healthcare provider have been communicating clearly.

**Written Communication**

Hearing people in the U.S. tend to assume that the English language is the deaf and hard of hearing person’s primary language and that they are proficient in written English [6]. Instead, English is a second language deaf people learn through instruction. Using written English as a second language creates a disparity between deaf and non-deaf learners in terms of levels of proficiency. McKee et al. [6], found that the mean reading level for deaf adults was lower (around 6th grade) compared to hearing adults (around 10th grade). Graduating with lower reading levels is a result of educational disadvantage [9]. This creates challenges when the healthcare system’s expectations of written English proficiency are too high and can result in poor communication with patients with hearing loss.

ASL is often the preferred and clearest form of communication by the deaf and hard of hearing populations. However, there are many instances where an interpreter would be appropriate, but is not provided [26]. Techniques, like lip-reading and writing, are limited in their ability to communicate accurately and effectively and should not always be relied upon [6]. Additionally, when in-print and online health information is written at or above the 12th grade reading level, it is not effective for many patients with hearing loss [26,28]. Ineffective communication leaves significant gaps in the healthcare experience where questions are not answered and diagnosis and treatment plans are not understood [26]. Without the healthcare system providing effective communication, it is very difficult for patients with hearing loss to navigate this system and meet their healthcare needs.

**Barriers to Accessing the Healthcare System**

Healthcare systems do not always consider the wide variation in level of hearing loss, English usage, education background and communication preferences for their patients with hearing loss, which can create barriers for these patients. These barriers include improperly trained healthcare providers and staff, limited use of interpreting services, and the reading level and format of written health information for patients [9].

**Training Healthcare Providers and Medical Staff**

At a medical appointment, hearing loss can affect how both the healthcare provider and patient understand each other. If there is not a proper mutual understanding through clear communications, the diagnosis and treatment plan can be inaccurate and unsuccessful [8].

Even though clear communication is important for safe medical care, few staff are trained to communicate with deaf and hard of hearing patients [3,29] note that most healthcare staff have little experience with sign language users. This inexperience and unfamiliarity with deaf people’s communication needs often lead to negative attitudes toward patients with hearing loss resulting in perceived or real discrimination [3]. One example of this is that there are medical records noting that a full patient history was not taken with the documented reason being that the patient was deaf [3]. If healthcare providers and staff are not trained to work with the needs of patients with hearing loss, they may fail to communicate effectively and thus fail to provide appropriate care. When healthcare providers and staff fail to give proper care, patients experience negative feelings, like fear, insecurity, and impatience, which creates an emotional distance between them and the healthcare system [8].

**Limited Use of Interpretating Services for the Deaf and Hard of Hearing**

Those with hearing loss face additional barriers involving failure to use interpreting services when it is needed. Healthcare providers are expected to provide an ASL interpreter and to schedule them in a timely manner [21]. However, even though healthcare providers are responsible for scheduling an interpreter, they may not be proficient with the scheduling process [9]. If an interpreter is not scheduled, the deaf and hard of hearing patient is left without an interpreter or they are given the burden of self-advocacy to make sure an interpreter is successfully scheduled [9]. Without an interpreter, patients with hearing loss are at risk of misunderstandings and receiving the wrong information required to manage their health properly [9,26] explain that inadequate communication, because of the lack of an interpreter, raises concerns of treatment accuracy, negative patient outcomes, and decreased patient satisfaction.

Failure of the healthcare system to provide an ASL interpreter can happen for several other reasons. While in-person interpreters are preferred by many deaf and hard of hearing people, hospitals tend to only offer Video Remote Interpreters (VRI) as an alternative to the in-person option [1]. Even worse, some healthcare providers do not believe they need to provide an interpreter at all and try to write back and forth or have family interpret instead [1]. Other healthcare providers report that interpreters are too expensive and consider interpreting services as unnecessary [30]. Despite these misconceptions, an in-person ASL interpreter is the best way to ensure clear communication between deaf patients and their healthcare providers.

**Portal Services**

When thinking about all the challenges and barriers the disenfranchised deaf population experiences, one can imagine how motivated a deaf person needs to be to productively engage with the healthcare system. This shows that there are many areas the healthcare system needs to improve so deaf patients can access health information and have autonomy over their own health decisions. It is fortunate that there is a system already in place that could be used to lower barriers, provide effective communication, and improve accessibility. This system is patient portals, like MyChart® [19].

Patient portals patients to access, download, and transmit their medical records. Patient portal availability is driven by consumers’ desires for medical transparency and a perceived positive impact on health outcomes [31]. Financial incentives and penalties have encouraged adoption by healthcare organizations, which has resulted in the implementation of patient portals in about 86% of healthcare practices [15]. The Affordable Care Act has also increased healthcare organizations’ adoption of patient portals by supporting the efficient delivery of healthcare [32].

Unfortunately, even though patient portals could be used to make healthcare services more accessible and equitable, there are still barriers for the deaf and hard of hearing populations. Carini et al. [33] reports that even though patient portals are not a new technology, they are not implemented well [28]. recognize that healthcare staff are not trained to give their deaf and hard of hearing patients the significant guidance they need in how to use patient portals. This could lead to confusion and stress because the information is not communicated in a way that facilitates understanding [28]. Staff can fail to schedule an ASL interpreter for an appointment created online because they lack the skills and training [9]. Patients can also find that the information provided in the patient portal is not written at a reading level that promotes understanding and usability [33]. These barriers result in deaf and hard of hearing people using patient portals less often [31,34]. Grossman, et al. [31] call this intervention-generated inequity because while a health intervention like patient portals should provide health equity, it is instead unusable by underserved patients because barriers to utilization are not addressed.

**Patient Portal Accessibility**

Healthcare systems need to be culturally competent to confidently work with deaf and hard of hearing patients through the patient portal. When patients have issues that need to be addressed, hospital personnel need to have the training to be able to provide effective assistance [28]. Patient portal content creators can make videos in ASL for clear communication and, if more information is needed, supply links to explanatory information [28]. Deaf and hard of hearing populations also need to be invited to give feedback on accessibility to improve patient portals [28]. In doing this, healthcare systems can create best practices to promote accessibility for all levels of health literacy with the goal of improving communication and participation [28]. When healthcare systems provide content that communicates clearly, they become more accessible. Health outcomes may improve as it enables both the deaf and hard of hearing patients and the healthcare providers to have clear communication and avoid misunderstandings.

**Discussion**

The review of the literature revealed several barriers affecting the deaf and hard of hearing populations’ utilization of healthcare services. Levesque’s theoretical framework recognizes that both the healthcare system and the deaf and hard of hearing populations have their roles in improving accessibility to the healthcare system. To improve the deaf and hard of hearing populations’ access to the healthcare system, patient portals should be improved with the purpose of removing barriers and creating accessibility.

To achieve this purpose, healthcare systems need to implement a process that: trains their healthcare providers and staff to be aware of the need for clear communication when corresponding with and talking to patients with hearing loss; provides a streamlined procedure to schedule an ASL interpreter for appointments; and offer written communications at an appropriate reading level or replaced with videos in ASL. Healthcare systems should prioritize their deaf and hard of hearing patient’s communication needs and ensure healthcare providers and staff are equipped to provide clear communication.

Training healthcare providers for cultural competency contributes to improved skills in working with deaf and hard of hearing patients, which improves accessibility and reduces healthcare disparities [35]. When healthcare providers learn about deaf and hard of hearing people, they can use that information to ensure clear communication in the future. Kuenburg et al. [35] found that when first year pharmacy students performed healthcare tasks in the role of a patient using another language, there were significantly improvements in attitudes towards their non-English-speaking patients. Thew et al. [36] report that these experiences have both short-term and long-term benefits for healthcare providers. As healthcare providers and staff gain experience working with patients with hearing loss, they gain new skills and confidence to improve how they work with these patients in the future.

Patient portals, by design, need to be improved. They need to include a way to schedule an ASL interpreter when patients schedule their appointment. This will make sure scheduling an interpreter is not overlooked and can ensure a qualified interpreter who is also the appropriate gender identification needed to ensure the patient is comfortable and feels safe. Patient portals also need to use an appropriate English proficiency level, or have videos produced in ASL, to ensure patients receive clear information and instructions. ASL videos can be created to provide training, which will give clear instructions for portal utilization and clear information, so the portals can be used confidently and appropriately.

**Ongoing In-Person Support**

Patients with hearing loss need assistance with learning how to use patient portals [28]. This is even more important for minorities who utilize portal services at lowest rates compared to the overall deaf and hard of hearing general population [15]. Ensuring patients know how to use these portals can be a stronger driving force in their adoption and utilization.

Research shows that ongoing patient portal assistance is important for vulnerable populations like deaf and hard of hearing populations. The use of proxies along with active promotion of and training in patient portal use facilitated utilization and resulted in patient satisfaction [33]. In addition, training and assistance programs for vulnerable populations have the best evidence for improving portal use [31]. When minority patients overcome barriers and activate their patient portal accounts, they use their account functions similarly to high-activation groups [15]. This research shows that with in-person training and support, healthcare systems can play a significant role in improving portal use for their deaf and hard of hearing patients.

**Improving Patient Portal Utilization**

Hospital policies supporting accessibility and use of patient portals for deaf and hard of hearing people is one recommendation for health organizations to focus. Patient portals provide an opportunity to improve healthcare access and equity when implemented with vulnerable populations in mind [31]. warns that if healthcare systems do not intentionally develop, implement, and evaluate strategies to reduce disparities, health inequities can become worse with the introduction of patient portals. Carini et al. [33] suggest that patient portals need to address cultural and literary barriers to make healthcare systems equitable, effective, and safe. Hospital policies should intentionally include and prioritize utilization goals for deaf and hard of hearing populations to ensure patient portals focus on removing barriers to accessibility. Then, to ensure that patient portals are adaptable and continue to be accessible for deaf and hard of hearing people, healthcare systems also need to create policies to address patient portal accessibility on an ongoing basis.

**Limitations**

A foundational limitation is the difficulty in finding a consistent definition of, and statistics specifically identifying, the deaf and hard of hearing populations that use ASL. This lack of evidence is partially because the deaf and hard of hearing populations are heterogeneous, including varying degrees of hearing loss, age of hearing loss onset, preferred language, and cultural affiliation [27].

There is also limited research on the deaf and hard of hearing populations’ use of patient portals partly due to the exclusion of the deaf and hard of hearing [37,38]. Most research focuses on the use of qualified interpreters. While this is valuable information, more research on accessibility drivers, like patient portals is needed for developing strategies for effective health communication.

**Conclusion**

Deaf and hard of hearing people face barriers to accessing healthcare services when the healthcare system fails to accommodate their health communication needs. Patient portals present an opportunity to remove those barriers and improve health communication and equity. Healthcare systems need to work with deaf and hard of hearing patients to improve utilization of patient portal services. When healthcare systems and patients work together, they can create accessible, equitable, and productive patient portal experiences. Positive experiences supporting accessibility and clear communication will also improve the patient/healthcare provider communication. When equitable accessibility and clear communication are achieved, patient portals will be an effective tool for deaf and hard of hearing people to improve health communications with healthcare providers.

**Disclosure Statement**

No potential conflict of interest has been reported.

**Funding**

No funding has been received for this paper.

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