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Teaming Together to Care for Our Deaf Patients: Insights from the Deaf Health Clinic

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Abstract

Deaf patients often struggle with accessing culturally competent care. Poor communication and inaccessible health information negatively impact Deaf individuals, resulting in poorer health outcomes and inappropriate health care use. To address this problem, the Family Medicine Department established the Deaf Health Clinic in 2015 through the efforts of healthcare providers fluent in American Sign Language. After that, the clinic faced several management issues, and implemented strategies to address them. The paper discusses lessons learned and suggests potential and tested solutions to reduce gaps in health care for Deaf individuals.

Introduction

Ensuring quality healthcare access for social minorities is a public health priority as part of the goal of promoting good health for all (U.S. Department of Health and Human Services, 2010). Through communication, language, and cultural barriers, the Deaf population often struggles with significant social exclusion and healthcare marginalization (Barnett et al., 2011; McKee et al., 2015; McKee, Moreland, Atcherson, & Zazove, 2015; Steinberg, Barnett, Meador, Wiggins, & Zazove, 2006). While approximately 15% of the U.S. population experiences a hearing loss, it is less clear how many of these individuals primarily communicate in American Sign Language (ASL) (Agrawal, Platz, & Niparko, 2008; Blackwell, Lucas, & Clarke, 2014; Zazove, Atcherson, Moreland, & McKee, 2015). Population estimates for Deaf signers in the United States range from 250,000 to 1 million, yet few healthcare efforts target this population (Mitchell, Young, Bachelda, & Karchmer, 2006).

Several studies indicate that Deaf individuals are more likely to experience lower socioeconomic status, poorer health knowledge, inappropriate health care utilization, and adverse healthcare outcomes compared to their hearing counterparts (Heiman, Haynes, & McKee, 2015; Kuenburg, Fellingner, & Fellingner, 2016; McKee, McKee, Winters, Sutter, & Pearson, 2014; McKee et al., 2015; McKee, Winters, & Fiscella, 2012; McKee, Winters, Sen, Zazove, Fiscella, 2015). Deaf individuals often encounter both social and informational marginalization and are at high risk for inadequate health literacy and knowledge (Heuttel, & Rothstein, 2001; Margellos-Anast, Estarziau, & Kaufman, 2006; McKee, Barnett, Block, & Pearson, 2011; Peinkofer, 1994; Tamaskar et al., 2000;

Wollin, & Elder, 2003; Woodroffe, Gorenflo, Meador, & Zazove, 1998; Zazove, Meador, Reed, Sen, & Gorenflo, 2009). Previous studies investigated how Deaf people were more likely to show a poor subjective health status (Zazove et al., 1993), and a heightened level of cardiovascular risk, food insecurity, intimate partner violence, and adverse childhood events (Barnett et al., 2011; Kushalnagar, Moreland, Simons, & Holcomb, 2018; McKee et al., 2014). Poor mental health, including depression, anxiety, social isolation, suicidal ideation, substance abuse, and post-traumatic stress disorders are commonly reported among this population (Barnett et al., 2011; Fellingner, Holzinger, & Pollard, 2012; Kushalnagar, Bruce, Sutton, & Leigh, 2017; Pertz, Plegue, Diehl, Zazove, & McKee, 2018).

From a socioecological perspective, health disparities among Deaf people are largely determined by the complex interplay between individual, interpersonal, communal, and social barriers (Smith & Chin, 2012). Considerable attention has been given to identifying the disparities faced by the Deaf population, including their healthcare barriers (Emond et al, 2015; Kuenburg et al., 2016). The limited availability of public health information and educational resources in ASL leads to serious knowledge gaps related to healthcare, well-being, and general health education among Deaf individuals (Kushalnagar et al., 2015; Pollard, Dean, O'Hearn, & Haynes, 2009). Barriers to accessing both physical and psychological health services for Deaf patients contribute to Deaf people's marginalization in healthcare (Pertz et al., 2018). Furthermore, healthcare providers rarely receive training on how to effectively communicate with and care for Deaf individuals, which can contribute to low provider-patient satisfaction and treatment adherence (Scheier, 2009; Steinberg et al., 2006).

In response to the Deaf healthcare gaps, the Department of Family Medicine at the University of Michigan Medical School established an integrated primary care clinic, The Deaf Health Clinic (DHC), tailored specifically to Deaf patients. This discussion lists both strategies and lessons learned from the DHC's efforts to address existing gaps in healthcare for Deaf people.

Background on the Deaf Health Clinic

The DHC was established in March 2016 within the Dexter Health Center, one of six health centers run by the University of Michigan's Department of Family Medicine in the Ann Arbor region. The general patient population, along with Deaf patients, are cared for by front-desk staff members, nurses, medical assistants, physicians, and social workers at the Dexter Health Center. The DHC, led by two Deaf, ASL-fluent physicians and one hearing, ASL-fluent social

worker, focuses on physical and mental health needs through in-person appointments, telemedicine, and telemental health (Pertz et al., 2018).

The DHC, initially a pilot project, received funding in October 2015 from the State of Michigan Medicaid Match Grant offered by the Michigan Department of Health and Human Services. In response to the National Association of Social Workers—Michigan Chapter’s white paper highlighting Deaf mental health disparities in the state of Michigan (National Association of Social Workers, 2014), the DHC’s objective was to provide an accessible, integrated mental health program for Deaf individuals in Michigan, scalable for other integrated health centers. A secondary purpose was the use of telemental health services to test its feasibility of mitigating mental health care gaps among Deaf patients. Given the pilot’s success (Pertz et al., 2018), the DHC was expanded to include all Deaf patients, regardless of history of behavioral or mental health issues. The DHC now cares for approximately 150 Deaf patients.

Management Issues and Suggested Approaches

Deaf patients often have complex health needs requiring both medical and social services, necessitating an integrated healthcare model within the DHC’s patient-centered medical home. Six care challenges are presented in this discussion along with management strategies implemented at DHC.

1. Medical Mistrust and Stigmatization

Deaf individuals experience stigmatization from both society and healthcare providers, affecting their general trust in healthcare (Atcherson, 2002; David & Werner, 2016; NASEM, 2016). Healthcare providers often view hearing loss (or deafness) as a deficit to remedy, which frequently conflicts with Deaf patients’ stance that their hearing loss is a cultural identity, not a disability (McKee, Schlehofer, & Thew, 2013). Furthermore, some healthcare providers assume that Deaf patients are ignorant and incapable of making health-related decisions, and regard sign language as gestural language (Iezzoni, O’Day, Killeen, & Harker, 2004; Lesch et al., 2019). There is also a lack of curriculum content regarding the sociocultural perspective of Deaf people and how to work with Deaf patients, which may contribute to negative experiences for both Deaf patients and their healthcare teams, resulting in medical mistrust (Iezzoni et al., 2004; Lesch et al., 2019; Steinberg et al., 2006).

The negative experiences that many Deaf patients reported experiencing prior to the DHC left them distressed, frustrated, and disempowered (Pertz et al., 2018).

Previous inadequate care, improper medications, and misunderstandings resulted in significant care gaps that often necessitated multiple “catch up” visits. Initial consultations also required a portion of follow-up appointments to be reserved for educating patients about how to make informed healthcare decisions and discussing their personal goals and needs. These additional steps were taken to rebuild trust and improve patients’ self-management abilities. The primary healthcare focus at the DHC is accessible, high-quality care that is holistic and culturally competent, rather than perpetuating a disease-centered model of care. This approach by our providers and staff has helped many Deaf patients to feel confident, often resulting in more honest and open discussions about their physical and mental health issues.

Few medical schools provide training on how to effectively communicate and care for the Deaf population. One such example is the “Deaf Strong Hospital” role-playing exercise given to first-year medical students at the University of Rochester's School of Medicine & Dentistry (Thew, Smith, Chang, & Starr, 2012). These students become "patients" who seek medical attention from "doctors" who are members of the local Deaf community. The experience of overcoming and understanding communication challenges and learning cultural competency are the main objectives of this exercise. Such health professional training programs are needed to reduce the negative social stigma that Deaf people often experience in healthcare (Thew et al., 2012). To address an ongoing gap in clinical immersion programs involving Deaf patients, the DHC provides clerkships for medical and social work students, which helps to train the next generation of healthcare providers to better understand how to communicate and care for the Deaf population.

2. Information Marginalization and Inadequate Health Literacy

Limited access to the auditory and language environment can constitute a major impediment to the development of Deaf people’s lifelong health literacy and outcomes (Hall, Smith, Sutter, DeWindt, & Dye, 2018). Since ASL is a visual–spatial language with a unique grammar and syntax unlike these of English, it cannot be directly translated into a written format (Holcomb, 2013); therefore, it comes as no surprise that Deaf sign language users often demonstrate lower levels of reading and writing proficiency compared to their hearing counterparts (Traxler, 2000). The “dinner table syndrome” (the common situation where Deaf people, despite their physical presence during family dinner conversations, are unable to understand what their family members are talking about) offers an example of the multifactorial pathways of concern regarding how poor family communication affects Deaf people’s health (Hall et al., 2018; Hauser, O’Hearn,

McKee, Steider, & Thew, 2010; McKee et al., 2015). Similar barriers to incidental and direct learning opportunities also occur in other settings, especially in healthcare settings for Deaf individuals, further impacting their health literacy and health knowledge (McKee et al., 2015).

Direct communication with ASL fluent providers at the DHC can give Deaf patients a sense of a breakthrough. However, addressing lifelong health knowledge gaps requires intensive education, additional time and team-based care (e.g. use of a nutritionist). Improvement with patients' health outcomes is usually gradual instead of quick. For example, some diabetic Deaf patients' conditions are so poorly controlled or even undiagnosed, often due to improper diet (e.g. heavy soda consumption) or lack of adherence to medications. Learning how to manage a complex disease requires extensive education, often in conjunction with a diabetic educator or a nutritionist over the course of multiple office visits. No one healthcare provider can do it all. Deaf patients still need to be able to digest the health information even deemed accessible. Realistic goals should be set between patient and provider at the end of each appointment. For example, a Deaf patient with poorly controlled diabetes should be counseled that this will likely require time, multiple visits and gradual titration of medications. To ensure patient comprehension, summarizing each step and teach-back is often used. Teach-back is an approach used by healthcare providers to confirm whether patients understand what is being explained to them. This requires patients (if they understand) to explain the information accurately back to the provider (Agency for Healthcare Research and Quality, 2015; Hommes, Borash, Hartwig, & DeGracia, 2018). Each patient is also provided an after-visit summary that provides a simple list of what is needed (e.g. upcoming tests or treatments).

At DHC, further issues often arose when patients struggled with reading medicine bottle information (e.g. directions and availability of refills), leading to medication misuse or lack of adherence. For example, some individuals are unfamiliar with certain medication names such as Lipitor or Zoloft, or misusing acetaminophen for cardiovascular protection instead of aspirin. As a result, extensive medication education is frequently done at DHC, which ensures that patients understand why they need a medication and what the medication does. This technique is also helpful to identify potential side effects or inappropriate medications. To address these concerns, Deaf patients are encouraged to bring all of their medications, including over-the-counter medications, for periodic reviews and to reduce potential polypharmacy.

DHC prioritizes efforts to teach Deaf patients not only how to best navigate and advocate for their healthcare but also to identify appropriate circumstances to seek

emergency services. The DHC physicians work closely with the social worker to help coordinate care between other clinics and providers. Additionally, the social worker reviews with the patient on how to access insurance, follow up on referral appointments, and identify accessible services in the community. Furthermore, the social worker closely assesses social determinants of health in Deaf patients due to their magnified risk for poor outcomes, including food insecurity, housing issues, personal safety and interpersonal violence, which are factors that can result in higher emergency department use.

DHC recognizes the importance of community-based education and the use of resources outside of the clinic to improve the health knowledge level of our Deaf patients. These educational resources include ASL accessible web-content (e.g., Deafhealth.org), video blogs from providers, and community health events in ASL (e.g. the Deaf Health Fair, quarterly Deaf Health Talks).

3. Healthcare Communication Challenges

The healthcare communication barrier is the number one complaint among Deaf patients and often is a reason for their transfer to DHC. Unfortunately, even with the passage of the Americans with Disabilities Act nearly 30 years ago, mandating that healthcare providers ensure effective communication for Deaf people, health care providers and systems frequently fail to provide appropriate accommodations, including sign language interpreters (Kuenburg et al., 2016; Lesch et al., 2019; Pendergrass, Nemeth, Newman, Jenkins, & Jones, 2017). Poor and inaccessible communication styles negatively affect the patient history, resulting in misdiagnosis and mistreatment and further eroding the Deaf community's trust and confidence in the current healthcare system (McKee et al., 2015; Mick, Foley, & Lin, 2014).

While the DHC has always had ASL-fluent health care providers, the clinic wanted to ensure effective communication from check-in to check-out. Various members of the health care staff, including a medical assistant and multiple front-desk staff members, undergo ASL training at designated lunch times. This helps with basic communication, but more importantly, makes the clinic more welcoming to the Deaf patient. The medical staff also employ sign language interpreters at the patient's first appointment (and if needed, subsequent appointments) to facilitate paperwork and demographic and background information entry. Limited use of two-way typing or printed and laminated instructions may also be used at times for scheduling appointments or referral services. The DHC uses hearing loss icon stickers on patient rooming folders in addition to flagging patients' electronic medical records to prompt staff to

approach the patient in the waiting room (versus calling out their names) when ready to be roomed.

Additionally, when Deaf patients are not able to see one of the three ASL health providers due to scheduling conflicts, the DHC arranges for a sign language interpreter through the Michigan Medicine Interpreter Services (2015) when working with a non-ASL fluent provider.

The DHC team is ASL-fluent, but it is important to recognize that Deaf patients often vary in their communication preferences and backgrounds. There is no one size-fits-all approach. For example, some Deaf individuals were not raised culturally Deaf and do not use ASL fluently, while other Deaf individuals prefer simultaneous communication. This diversity of backgrounds, language and communication preferences requires the DHC to identify the patient's communication and language preference early on in the process. This occurs at multiple points. First, when patients call to become DHC patients, the front staff identifies the patient's language preferences in the electronic health record system (i.e. MiChart). In addition to the language preference, there is a section to inform providers about the patient's special needs (such as a larger room for wheelchair maneuverability).

Another strategy that has helped improve communication between the provider and the patient is the use of a scribe. Scribes are used by both DHC physicians to take notes directly into the patients' chart. This frees up the physicians to not only sign with their hands, but also to focus primarily on the patient. The removal of a computer between a patient and a provider can help improve patients' satisfaction and communication while allowing for greater eye contact.

An equally important point is that healthcare communication extends to any telephone, videophone or portal-based communication (Kuenburg et al., 2016). While popular for some Deaf patients, both text and email communication are not yet permitted at Michigan Medicine due to patient confidentiality and security concerns. The healthcare providers have videophones available to both receive and call Deaf patients. However, a particular challenge is making sure that Deaf patients are aware that any urgent calls or requests should be made to our center call line rather than to specific videophones that may not be always manned by ASL-fluent providers. To avoid any misunderstandings, staff who handle the center's calls received training on how to appropriately work with a video relay service operator. The DHC also encourages Deaf patients to sign up for the HIPAA-compliant patient portal, a secure way to manage their health online and related health needs (e.g. requesting medication refills). However, for some Deaf

patients, these portal messages are used to initiate or schedule a videophone call with one of the providers. Patient portals are generally more effective with higher educated Deaf patients, but for those with lower literacy, training on appropriate patient portal use is essential.

4. Complex Patient-Provider Relationships

Deaf communities are relatively small and close-knit. Many ASL-fluent providers come from the same communities as many of their Deaf patients. Additionally, DHC's social worker serves as one of the ASL/English interpreters within Michigan Medicine, but not at Dexter Health Center. This overlap of interactions in personal and professional settings, a "dual relationship," presents unique challenges in establishing clear patient-provider boundaries. Due to the close community ties, and mixed professional roles, dual relationships are sometimes unavoidable (Gutman, 2005). The priority is always providing the best of patient care and to do no harm. Ethical codes help reduce potential conflicts or perceived conflicts, and always protect patients (see code of ethics from the following groups: National Association of Social Workers, National Council on Interpreting in Health Care, Registry of Interpreters for the Deaf). If a personal conflict arose, patients were referred out to other competent professionals. For most, the nature of the dual role was openly discussed with the patient(s) and the providers to mutually agree upon a suitable plan for ongoing treatment. In the situations where a dual role was found to be successfully managed, it was important to check with the patient often to ensure ongoing safety to the patient; it was paramount for the social worker to engage in high quality, frequent supervision in both professions, acknowledging ongoing risk, to ensure reduction of conflict dynamics.

Medical providers in rural communities inevitably experience similar challenges with dual relationships (Baca, 2011; Brooks, Eley, Pratt, & Zink, 2012; Davis & Roberts, 2009). In these cases, small patient populations may fear losing their provider and are therefore at risk of overlooking poor quality of care (Brooks et al., 2012; Davis & Roberts, 2009). Furthermore, potentially uncomfortable encounters with patients in public may limit providers' friendships and social outings, leading to social isolation (Brooks et al., 2012).

However, there are advantages to dual relationships. Clinical practice in close-knit communities provides greater context for patients' overall health and allows providers to deliver more efficient care (Brooks et al., 2012). This is no different when a Deaf healthcare provider cares for Deaf patients and understands the social and community context that the patient comes from. By emphasizing confidentiality, setting clear boundaries, defining roles, limiting self-disclosure,

and referring when necessary, medical providers can seek to balance dual relationships and patient safety (Baca, 2011; Davis & Roberts, 2009).

5. Gaps in Health Care

Hearing loss has been found to be strongly associated with substance use disorders, especially prescription opioid use disorders among those under 50 (McKee et al., 2019). In a review of DHC's Deaf patients' medical charts, nearly half of the patients had chronic pain issues (e.g., fibromyalgia, arthritis, repetitive use injury) (Pertz et al., 2018). Unfortunately, some patients arrived at the DHC with lengthy histories of controlled substances, sometimes even with minimal involvement with other interventions such as physical therapy or non-controlled substances. Despite inappropriate use of prescription opioids in multiple DHC patients, access to an accessible substance abuse treatment program remains unavailable in Michigan. Due to reimbursement and carve-out restrictions of Medicaid, many Deaf individuals are restricted to very few programs across the state. Unfortunately, such programs have traditionally not provided ASL interpreters, greatly impeding the ability for the Deaf patients to receive quality care elsewhere. Deaf individuals need substance abuse programs that are not only accessible, but also aware of key social and cultural factors (Kushalnagar, Hoglind, Simons, & Guthmann, 2019). The Minnesota Chemical Dependency program is one such program, yet Medicaid plans additionally exclude reimbursement to receive care across state lines. Making matters worse, the Michigan area lacks Medicaid providers who use ASL and treat addiction. Similar to mental health counselors, there is a need for addiction counselors and providers who can fluently sign. This gap has created challenges at the DHC in managing these patients effectively without the resources of a substance abuse program.

Additional challenges arise from a gap in linguistically and culturally appropriate psychiatric care for the Deaf population (Barnett et al., 2011; Fellingner et al., 2012; Williams & Abeles, 2004). Many psychiatrists lack formal training or experience working with Deaf patients, leading to consequences such as misdiagnosis, patient exclusion during the consultation, and longer hospital stays (Landsberger & Diaz, 2010; Landsberger, Sajid, Schmelkin, Diaz, & Weiler, 2013). Although there are some psychiatric programs for Deaf individuals outside of Michigan, Medicaid mandates Michiganders to receive care within Michigan, ultimately blocking any service, including available telemedicine services from providers outside of Michigan.

Many Deaf patients prioritize direct service from ASL-fluent providers over specialists. This can pose additional challenges especially when they present with

normally specialty-based management issues (e.g. psychosis which typically warrants an urgent referral to see psychiatry). Without adequate comprehensive behavioral health and psychiatric referral services, DHC's providers and staff at times must manage patients' psychiatric needs despite lacking primary expertise in these specialties. Developing a pipeline for Deaf health professional students can help to fill additional specialties such as psychiatry (McKee, Smith, Barnett, & Pearson, 2013; McKee et al., 2016). Furthermore, there needs to be greater effort to inform insurers about the importance of accessible care, wherever that may be located.

6. Sustainability of Clinical Operations

Deaf patients may require longer appointments to address multiple health concerns and to fill knowledge gaps (Kritzinger, Schneider, Swartz, & Braathen, 2014). This allocation of time can put a strain on the clinic's budget and resources. For example, established Deaf patients at the DHC were typically defaulted to a 30-minute appointment length. This differed from how the Dexter Health Center manages the general patient population. These non-Deaf patients largely follow a more traditional 15-minute appointment length, unless the patients have specific health conditions or comorbidities that require a longer visit length. To ensure that clinic operations remain sustainable, clear billing and coding options must be considered. For example, time-based codes should be used for any longer visits when applicable. Additionally, more complex care management codes should be considered, such as transitional care codes, when care coordination efforts occurred. Staff members should be appropriately reimbursed for any efforts provided during the appointment, including telemedicine.

Telemedicine is attractive to many of DHC's patients since many live over an hour away. Coverage for these services also vary among insurance plans. Unfortunately, many insurance companies which lack telemedicine reimbursement policies require prior approval (not always successful) before telemedicine services are paid. Yet, telemedicine does offer great promise to provide language matching between provider and patients regardless of their location (Crowe, 2017).

To assist in the sustainability of the DHC, services remain versatile by caring for Deaf as well as hearing patients. Few locations around the country have the volume of Deaf patients to provide health care solely to this population. However, by incorporating the DHC into a pre-existing outpatient family medicine facility, operations are more easily sustained. Furthermore, at a prior clinic, one of the

physicians had experience working with an ASL interpreter to serve multiple roles, including rooming assistance, paperwork, check in and out, and handling phone calls. This strategy may be useful for health centers with a larger volume of Deaf patients, especially where access to an interpreter department is lacking.

Conclusion

This discussion of successes and challenges at the DHC demonstrates the ongoing challenges to ensuring Deaf patients have equitable care. It also does offer a platform to expand accessibility of health services. Despite the many benefits of communication and culturally competent care that are associated with DHC, this integrated model should only serve as one element in a much broader scope of services for the Deaf population across the country. The next step toward systematic improvement of healthcare quality for Deaf patients includes the establishment of regional centers which specialize in medical care for this population, development of pipeline programs to increase the number of Deaf health care providers, and inclusion of Deaf health in health care curriculum. By learning from the challenges and successes outlined in the above paper, it is hopeful that future Deaf health centers can not only expand the opportunity to provide care for Deaf patients but also to be sustainable. Lastly, an increase in Deaf health professionals is needed to staff these future centers. These providers can directly improve the quality of communication and care for Deaf patients (McKee et al., 2013; McKee et al., 2016) and also provide opportunities for other health professionals to learn how to care and manage Deaf patients effectively.

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