Perspective

Ensuring full participation of people with disabilities in an era of telehealth

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ABSTRACT

The widespread use of telehealth resulting from the COVID-19 pandemic has the potential to further exacerbate inequities faced by people with disabilities. Although, for some members of the disability community, the option to engage with telehealth may result in reduced barriers to care, for others, inadequate attention to the design, implementation, and policy dimensions may be detrimental. Addressing such considerations is imperative to mitigate health inequities faced by the disability community.

Key words: telemedicine and telehealth, disabled persons, accessible design and implementation, health policy, COVID-19

INTRODUCTION

The COVID-19 pandemic has ushered in a new era of telehealth. The use of telehealth prior to the COVID-19 pandemic was minimal, with less than 1% of Medicare primary care visits provided through telehealth.[1] In this paper we draw on the Office of the National Coordinator for Health IT's definition of telehealth to encompass the use of electronic information and telecommunications technology to deliver clinical health care and health-related education and conduct public health activities.[2] Policy changes during the pandemic reduced barriers to delivering telehealth,[3] resulting in almost half of Medicare primary care visits now being provided through this mode. As telehealth adoption becomes widespread, it is estimated that 20% of all office, outpatient, and home health care visits offered through Medicare, Medicaid, and commercial insurance could be shifted to virtual care.[4]

Though telehealth has expanded access to care,[5] there are concerns that its increased use, even after the pandemic has subsided, will exacerbate health inequities, primarily among populations affected by the digital divide.[6,7] Populations that are frequently cited as affected include those who live in rural areas, older adults, people of color, and those with low socioeconomic status (SES).[3,7,8] Although race itself has shown minimal independent association with the digital divide,[9] racial and ethnic minorities remain significantly more likely to experience its impacts because they are disproportionately represented within the low SES population.[10] Concerns are rarely expressed, however, about people with disabilities, a population often absent from frameworks focused on health equity and the digital divide.[6,11] Yet, mounting evidence demonstrates the ways in which individuals with disabilities experience both health care and health outcomes which are consistently worse than those of their able-bodied counterparts.[12,13] As such, there remains a pressing need to explicitly consider how changes in the prevalence and ubiquity of telehealth impact people with disabilities. Such a focus not only addresses the needs of people with disabilities but also, drawing

on a framework of intersectionality,[14] further addresses the needs of older adults, people of color, and people of low SES. On the whole, people identifying as members of these demographic categories are in aggregate overrepresented in the disability community,[15,16] though such disproportionality does not necessarily hold for all types of disabilities (eg, hearing loss[17]). Although the rise in telehealth may have benefits for some people with disabilities, without adequate attention to its design, implementation, and policy context, there is a significant risk that changes to the use of telehealth will exacerbate health inequities for people with disabilities.

POTENTIAL BENEFITS OF TELEHEALTH FOR PEOPLE WITH DISABILITIES

Given the heterogeneity of the disability community, the potential benefits and adverse consequences of the movement to telehealth will be differentially experienced. For some, access to widespread telehealth services may improve health care access and quality. In-person visits often require engagement in onerous patient preparation[18] prior to physically entering the clinical space. Activities, such as coordinating accessible transportation, scheduling caregiver assistance, and experiencing public spaces may be challenging for people living with a wide range of disabilities, including but not limited to those with mobility restrictions, neurological conditions, cognitive disabilities, and/or mental health conditions. Additionally, people with disabilities frequently encounter another layer of barriers upon entering the clinical space. Despite provisions within Title II and Title III of the Americans with Disabilities Act (ADA),[19] guaranteeing the accessibility of both public and private health care facilities, those attempting to engage in traditional clinical visits often encounter barriers such as inaccessible medical equipment, waiting rooms, and bathrooms as well as lack of appropriate accommodations,[20,21] including wheelchair assistance and sensory-friendly spaces. For some, telehealth may serve as a means of avoiding everything from minor inconveniences to significant harms. In other cases, people with disabilities can experience benefits arising from the use of telehealth instead of in-person visits, such as lower transportation costs and increased access to specialists.[22,23] Yet, if telehealth technologies are not designed, implemented, and contextualized within appropriate policies, these benefits cannot be realized and instead could worsen health inequities within this population.[24]

DESIGN CONSIDERATIONS

The design of multiple forms of telehealth technology is largely inaccessible. For example, video-based telehealth services remain inaccessible to many with communication-related disabilities (ie, individuals who are deaf, hard of hearing, deafblind, blind, low-vision, and speech disabled), as well as individuals who have intellectual disabilities.[25] Likewise, patient portals remain inaccessible to a wide-range of people including some of those mentioned above and those who rely on assistive technology to interact with technology-based systems. Consequently, it is essential that software developers redesign the range of telehealth technologies, both web-based and app-based, to guarantee that such technologies are accessible and are responsive to the unique ways in which people with disabilities might engage others in their health care. In other words, designers must account for unique needs related to both usability and usefulness. Based upon best practice for accessibility and preliminary findings from our Agency for Health Care Research and

Quality-funded study[26] on the needs of people with disabilities for health information technology, these design considerations should include:

- Compatibility with external assistive technology devices and with accessibility features native to all operating systems;
- Intuitive user interfaces that prioritize understandability of icons and text, as well as streamlined navigation;
- Multiple available modes of communication to allow patients to select the mode that is most accessible to them (eg, ability to send voice-based messages through patient portals and text-based messages during a telemedicine encounter);
- Compliance with WCAG AAA guidelines[27] not only for default settings but also settings allowing for personalization;
- Consistently implemented standards and plug-in solutions to enable sign language or the appropriate interpretation and closed captioning on the same screen as the services being provided even for unscheduled appointments;
- Best practices for user-centered design to reduce overall physical and cognitive burden;
- The ability to receive all communications in plain language;[28] and,
- Features facilitating multiple and differential users. This type of access includes enabling multiple users of the same account through proxy status as well as the ability for multiple individuals to join a telemedicine encounter if more than one type of assistance is required (eg, both a qualified sign language interpreter and a family member).

IMPLEMENTATION CONSIDERATIONS

Even with the accessible design of telehealth technologies, without adequate attention to their implementation, such technologies will further increase health inequities for people with disabilities. It is well documented that the disability community experiences disproportionately less access to broadband services and both ownership and use of hardware through which telehealth may be accessed.[29] Lack of access to adequate bandwidth and up-to-date hardware can result in canceled appointments, disconnection, and misinterpretation—all of which may cause lower quality of care.[30] For individuals living with communication-related or intellectual disabilities such implementation failures may be particularly harmful. Furthermore, limiting these negative consequences requires both expanded broadband access and capacity and internet standards for telehealth and necessitates that health systems provide the technology required by patients to meaningfully interact through telehealth platforms.[31]

At the level of the health system, additional considerations relate to training both for providers and patients in the use of telehealth technologies. In particular, patients may need assistance learning how to use new forms of technology, including the ways in which they can configure the technology to be accessible for them. Some individuals with disabilities may benefit from a "test run" to minimize stress associated with a new form of interaction.[32] Training and resources need to be developed and made available to providers who are less familiar with ensuring the highest degree of accessibility. Health care systems must make available necessary personnel (eg, qualified sign language interpreters, speech to speech translators, and readers) and help providers integrate these accommodations into standard clinical workflow. Closed-captioning, alt text, audio description, and large text options must also be provided. Attending to these implementation factors will further ensure that peo-

ple with disabilities are able to fully engage with a broad range of telehealth services.

POLICY CONSIDERATIONS

Another consideration that is essential to reducing unintended inequities resulting from telehealth is the policy context. As individuals with disabilities cannot be excluded, denied, or given differential care,[33] all covered entities (ie, health programs and activities that receive federal funding[34]) must ensure accessibility of all programs delivered through electronic and information technology under Section 1557 of the Affordable Care Act.[35] Additionally, under Titles II and III of the ADA, providers are required to communicate effectively with patients and their companions.[36] Although these policies exist, there is a high level of ignorance surrounding the enforcement of this legislation. Individuals with disabilities are only starting to advocate for their rights to telehealth services due its novel use, and many more education and collaborative efforts are needed.[37] While express regulations about the requirement to ensure accessible telehealth services do not exist, the US Department of Justice requires such telehealth providers to be subject to the same accessibility obligations.[38] Accessibility of telehealth would be accelerated by the development of clear, specific, and enforceable standards for digital web accessibility,[22] which would ensure accessibility be taken into account in design phases before telehealth technology is implemented in a health care setting. Without regulations defining the requirements for digital accessibility, there will be inconsistencies in providing care to the disability community.

Even for whom there may be perceived benefits, if telehealth is to be designed and implemented in fully accessible ways, it is imperative to note the potentially harmful unintended consequences for people with disabilities, which may arise through pervasive use of telehealth, even if all accessibility needs are met. In some ways, the current reality serves as a demonstration project for telehealth, providing insight not only into clinical effectiveness but also cost-effectiveness.[4,39–41] Evidence supporting telehealth as a measure of cost containment could result in rapid adoption without appropriate guardrails, preventing misuse by providers or the distancing of populations in need of regular, in-person medical services. Such outcomes would disproportionately affect members of the disability community, many of whom rely on regular access to in-person treatment and others of whom will continue to find in-person interaction more accessible than any telehealth alternative. As a result, it is imperative that a range of health and patient-centered outcomes are tracked by disability status as a means of monitoring and proactively addressing any unintended consequences. In addition, the Health Insurance Portability and Accountability Act (HIPPA) flexibilities for telehealth services poses particular threats to members of the disability community,[42] for whom breaches in cyber security may lead to particularly detrimental consequences, given the increased probability of potentially sensitive and stigmatizing health information in comparison to their able-bodied peers. There is therefore a pressing need to reinstate the regulations in ways that do not permit individual clinicians to make decisions about the level of cyber security provided by the platforms used.[42] Informatics professionals should endorse policies that both legislatively mandate and enforce accessibility and advocate for a thorough assessment of potential unintended consequences for people with disabilities resulting from extant policies. It is further essential that informatics professionals urge the widespread dissemination of existing policies that require patient engagement as a means of enforcement.

CONCLUSION

The pandemic has led to an unexpected and unplanned for proliferation of telehealth as a vehicle for health care delivery. Although people with disabilities are a health disparity population often overlooked in the assessment of differential impact of health information technology, consideration of and responsiveness to their unique constellation of needs is imperative in this new era of widespread telehealth. Failure to explicitly account for people with disabilities in the design, implementation, and policy dimensions of telehealth will lead to further marginalization and poor health outcomes for the more than the 61 million Americans with disabilities.[15]

AUTHOR CONTRIBUTIONS

RSV conceptualized the paper and led the drafting of the initial manuscript. CCR, HC, LT, OF, and CWS contributed to the initial drafting. RSV and PK led the funded studies from which lessons learned were incorporated and CWS and CCR supported the study from which the design considerations were drawn. All authors contributed to editing and revising the manuscript and approved the final version.

CONFLICT OF INTEREST STATEMENT

None declared.

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