

Perspectives of Patients with Diverse Disabilities Regarding Healthcare Accommodations to Promote Healthcare Equity: a Qualitative Study



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BACKGROUND: Patients with disabilities often require healthcare accommodations in order to access high-quality, equitable healthcare services. While attention has been paid to accommodation needs in specific disability populations, limited research to date has explored healthcare accommodations that cross-cut diverse disability populations.

OBJECTIVE: To identify a deeper understanding regarding accommodations in healthcare settings that could apply across disability populations and promote equitable healthcare.

DESIGN: We conducted qualitative focus groups with patients with disabilities and caregivers to understand their experiences and preferences for healthcare accommodations.

PARTICIPANTS: We recruited patients and caregivers across all major disability categories to participate in focus groups. Participants were recruited through advocacy organizations and healthcare settings in Southeastern Minnesota.

APPROACH: A total of eight focus groups were conducted with 56 participants. Participants described their healthcare experiences and desires for healthcare accommodations. The multidisciplinary research team recorded, transcribed verbatim, and coded all focus groups. The team thematically coded transcripts using content analysis within and across focus groups to identify major themes.

KEY RESULTS: Patients identified four challenges and corresponding steps healthcare team could take to promote equitable care: (1) consistent documentation of disabilities and needed accommodations in the medical record; (2) allowance for accommodations to the environment, including adapting physical space, physical structures, and scheduling and rooming processes; (3) provide accommodations for administrative tasks, such as completing paper or electronic forms; and (4) adapt communication during interactions, such as speaking slower or using terms that patients can easily understand.

CONCLUSION: These identified themes represent specific opportunities for healthcare teams to effectively provide accessible care to patients with disabilities. Many of the

accommodations require minimal financial investment, but did require behavioral changes by the healthcare team to ensure equitable healthcare.

KEY WORDS: disability; equity; healthcare services

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INTRODUCTION

Maintaining optimal health is key to a person's ability to function and thrive in society; this is especially true for people with disabilities. Disability, which is defined by the Americans with Disability Act as having or being regarded as having a limitation in a major life activity, is a part of the human condition, and will continue to be a part of most people's lives as they experience health changes in themselves or in their families.¹ Approximately one out of every five people in the USA currently lives with a disability,² with that number rising as baby boomers enter older age and medical interventions increase survival rates of traumatic injuries, childhood syndromes, and degenerative diseases.¹ Efforts to address healthcare disparities for marginalized and vulnerable populations have grown in the last 30 years, but very little of that work focused on addressing the needs of the disability population and significant inequities.^{3,4} Such inequitable access to timely, appropriate healthcare is driven by factors such as difficulty finding a provider who is able and willing to see people with disabilities,^{5,6} negative attitudes and assumptions on the part of the healthcare team,^{7,8} medical environments that are not designed or built to accommodate patients with disabilities,^{9–11} diagnostic equipment that does not accommodate for people with mobility disabilities,^{9,10,12,13} and lack of training for healthcare professionals on how to care for patients with disabilities. Healthy People 2020 reported that 47.2% of adults with disabilities reported barriers to care that led to delays in receiving appropriate primary and preventive care.¹⁴ The experiences of patients with disabilities reflect the persistent barriers they face when receiving medical care.¹⁵ A survey of wheelchair users, for example, showed that 76.1% of them were examined in their wheelchair,

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69.7% were seated during their physical exams, and 54.1% felt that their care was inadequate.¹⁶ The consequences of inadequate access include higher morbidity of preventable diseases such as obesity and diabetes^{4,17}; higher rates of smoking^{18–20}; and lower rates of cervical and breast cancer screening^{21–24} among patients with disabilities.

The ADA requires that healthcare organizations provide equitable access to healthcare services and facilities.²⁵ The Patient Protection and Affordable Care Act's (ACA) Section 1557 further strengthens the ADA's mandate by prohibiting discrimination and requiring equity in the healthcare setting.^{26,27} Despite these policies, little evidence exists to inform the delivery of equitable healthcare for people with disabilities. Existing literature often focuses on single disability categories such as physically accessible medical equipment for people with mobility disabilities. For example, multiple studies have found that primary care practices rarely have equipment such as height-adjustable examination tables,^{9,28,29} and practice administrators and physicians have low knowledge on what accommodations are required.^{7,12} The ACA devoted Section 4203 to accessible medical equipment as a means to address this gap in equity²⁶ and some hospitals, clinics, and even insurance providers have begun to provide physically accessible equipment for patients.^{30–33} While these efforts are essential, they target only a limited segment of the disability population, potentially creating equity gaps across different disability categories. A comprehensive view must be taken to understand the range of accommodations that are needed to be inclusive and generalizable to all types of disabilities.

To address this gap, we conducted a qualitative study with patients and family caregivers across major disability categories with the goal of identifying a deeper understanding of accommodations in healthcare settings, with the objective of identifying actionable steps to advance healthcare equity for patients with disabilities.

METHODS

We conducted focus groups with English-speaking patients with diverse disabilities and caregivers. The original objective of the focus groups was to understand the participants' perspectives of disclosing a disability to the healthcare team, findings which are published in a previous paper.³⁴ In their narratives, the participants additionally described their experiences interacting with their healthcare team. The research team conducted a secondary analysis of the data with the emergent research question of understanding the experiences and preferences of accessible healthcare across participants with diverse disabilities. The research team approached the data with a content analysis qualitative methodology and determined that with the secondary analysis, we reached saturation of themes. We report the results from analyses in this paper. The Mayo Clinic Institutional Review Board approved all study procedures.

Participants

We recruited participants from patient support groups (e.g., Parkinson's Disease Support Group), the Center for Independent Living, disability patient advocacy organizations, state rehabilitation service offices, Senior Centers, and rehabilitation clinics in southeast Minnesota. We intentionally recruited participants who represented a range of types of disabilities, including hearing, visual, cognitive, communication, mental, physical, acquired, and developmental disabilities. We additionally recruited individuals who were caregivers to ensure that persons with disabilities who were unable to consent to participation in the study due to cognitive disabilities were represented. The research team screened potential participants to determine eligibility, namely self-identifying as having a disability or the caregiver of someone with a disability, and able to provide consent. When we recruited approximately 8–10 individuals available to participate at the same time, the research team then scheduled a focus group. The research team attempted to loosely organize the focus groups around participants with similar disability types, although several groups had a wide range of disabilities represented. During the screening process, we found that persons who reported a mental health disability appreciated smaller groups, and so we allowed for fewer people to participate in those focus groups. We continued recruitment until preliminary analyses indicated thematic saturation, and participants who represented all of the targeted disability groups were represented.

Data Collection

The 90-min focus groups occurred either at Mayo Clinic or at a community advocacy organization. The research team consented all participants in a private location immediately prior to the beginning of the focus group. All focus groups were led by a PhD-level trained qualitative researcher (MAM) with experience conducting research with patients with disabilities. Additionally, she is a licensed speech-language pathologist with experience providing supportive communication for individuals with speech, language, and other communication disabilities in group settings. An additional research team member was always present to assist with note taking. To facilitate participation, a Communication Access Realtime Translator (CART) was present for all focus groups. A CART professional, like a court reporter, transcribed the discussion in real time, which was then projected onto a screen in the room. This facilitated the participation of persons with hearing or cognitive disabilities. Additionally, the research team provided large-print written materials for participants with visual disabilities. The research team used the same focus group guide with all groups. The guide included open-ended questions that asked participants about their perspectives about (1) what they would want their healthcare team to know about regarding their disability, (2) their comfort with disclosing information about their disability, and (3) what disability questions healthcare systems and clinics should be asking. The guide was created by the research team, who ensured that the guide included plain language and was below a 6th grade reading level.

Analysis

The research team (MAM, JL, and JG) conducted a conventional qualitative content analysis of the focus group transcripts.³⁵ Aligned with conventional content analysis, the research team embarked on an inductive process in which the codes were derived from the text. This process began with two members of the research team (MAM and JL) reviewing all transcripts, and then independently developing and applying a codebook to an initial set of transcripts. These team members then met with JG to reconcile the coded transcripts and codebook in order to develop a consolidated codebook. This process continued until they decided upon a final codebook, which they then applied to the remainder of the transcripts. The team reconciled all discrepancies through consensus. The team entered the coded data into NVivo (version 9.0) for data management and then analyzed the data within and across focus groups to develop major themes that represented the participants' reported experiences.

To ensure rigor in the methods, the research team employed multiple quality methods. First, the research team included diverse perspectives, including persons with disabilities, caregivers of those with disabilities, and experts in disability equity. The team had a flattened power hierarchy in which all team members had equal power in decisions about the methods and results. The team regularly practiced reflexivity, naming biases and discussing each persons' role and effects in the research process. The team kept an audit trail of all decisions throughout the study.

RESULTS

We conducted eight focus groups with 56 participants (see Table 1). As intended, participants had a wide range of types of disabilities. Two focus groups consisted mainly of caregivers, although some caregivers also reported having a disability and described their own experiences. The groups ranged in size from 2 to 10, with an average of 7 participants. Participants ranged in age from 18 to 85, and 15 (27%) were male.

We identified four challenges and corresponding steps toward equity that healthcare teams could implement to provide accessible, patient-centered healthcare to patients with disabilities (see Table 2): identifying disability and accommodations, accommodations in the environment, accommodations for administrative tasks, and accommodations for communication. Although patients with different disabilities reported needs based on their particular disability, the themes were similar across disability types. Therefore, we will discuss the common themes and steps toward equity across participants.

Identifying Disability and Accommodations

Participants reported that teams need to be aware of their disabilities in order to provide healthcare accommodations. Caregivers of adults with developmental disabilities, for example, reported that providers were often unable to appropriately engage with patients to obtain a medical history because they were

Table 1 Description of Participants

Focus group	Number of participants	Types of disabilities or diagnoses represented
1	10	Parents of children with developmental disabilities
2	8	Adults with degenerative disabilities (e.g., Parkinson's disease) and hearing disabilities, and their spouses/partners
3	8	Parents of adults with developmental disabilities
4	10	Multiple disabilities including learning, mental health, mobility, and cognitive disabilities
5	7	Acquired and degenerative disabilities (e.g., multiple sclerosis, stroke, spinal cord injury)
6	3	Mental health disabilities
7	2	Mental health disabilities
8	8	Visual disabilities and developmental disabilities (e.g., cerebral palsy, spina bifida, and muscular dystrophy)

unaware of the presence of a disability. Other caregivers reported instances in which healthcare team members were taken aback when they realized their patient had a cognitive disability and was not participating as they initially expected the patient would.

My son looks pretty typical, and a lot of adults just by walking by him or taking a blood draw think he's typical. But how he as a nine-year-old reacts to having blood drawn or blood pressure taken – and a lot of times they say 'oh, I'm sorry, I didn't know he had a disability.'

Many wished that information about their disability was included in their medical record and that the information was available to all healthcare team members for both inpatient and outpatient settings. One participant suggested having wrist bands in the inpatient setting to serve as a disability alert.

And I went in the hospital, and when I was doing the whole intake part of it, I did mention that, like, I have a vision impairment, I'm not able to see that, can you show me where to sign. So then the person asked me if it was okay to put that on my wristband. Great, I don't have a problem with that, put it on my wristband. So even on the little chart across the wall where they leave you little messages and stuff. And they wrote on there that I was legally blind. Apparently, I didn't see it. The next day I was being told – well, when could I have started moving around. 'Well, I guess you probably didn't see that we wrote that on the chart.' And I was like, 'no.'

Despite almost all participants preferring documentation of disability status in the medical record, some expressed concerns about disability stigma by their healthcare teams.

Table 2 Themes and Actionable Changes

Theme	Description	Actionable changes		
		Processes and procedures	Materials and physical and virtual spaces	Staff and providers
Identifying disability and accommodations	Identify disability in the medical record and in person	<ul style="list-style-type: none"> • Ability for patient to self-identify as having a disability during registration • Ability to explain accommodations needed during patient registration or appointment scheduling • Option for the patient to either room early or wait in a private space 	<ul style="list-style-type: none"> • Obvious identifier within the medical record for patients' disability and accommodations needed for care • Inpatient identifiers (i.e., hospital bracelet, sign on door/above bed in room, in chart) 	<ul style="list-style-type: none"> • Avoid making assumptions based on recorded disability
Accommodations in the environment: physical space, physical structures, scheduling and rooming patients	Physical environment, medical equipment, and policies and procedures must be capable of adjusting to patient needs		<ul style="list-style-type: none"> • Wheelchair scale available • Hoyer lift (assistive equipment to lift the patient onto a table) or adjustable examination tables available • Ramps, door buttons • Accessible diagnostic equipment (i.e., mammography) • Wide doorways and wheelchair-accessible examination rooms • Forms available prior to appointment via mail or patient portal 	<ul style="list-style-type: none"> • Ask patient about preferences of waiting in examination room alone
Accommodations for administrative tasks	Administrative forms and pre-visit forms should be offered in multiple formats, different modalities, and administered at different times in the healthcare encounter	<ul style="list-style-type: none"> • If needed, provide in-person assistance with completing forms in private area • Ensure adequate time in between multiple visits within same healthcare system 		
Accommodations for communication during interactions	Interact with patients appropriately and ensure that your communication style and modality is patient-centered			<ul style="list-style-type: none"> • Utilize different modalities for patient information (i.e., videos, written instructions, diagrams, and audio) • Presume competence by addressing patient primarily • Pause and ensure patient understanding of plan after each major discussion point • Decrease medical jargon • Encourage post-visit follow up questions or more frequent appointment

They come with some preconceived ideas of what this person is or should be or what – because of the – they just don't know, and so [patients] are treated differently before they get into the room.

Other participants noted that providers unaccustomed to caring for patients with disabilities tended to anchor their line of questions on disability instead of the issue for which the patient was seeking care. For example, a patient reported coming in with a sprained ankle, and felt the healthcare team assumed the injury was related to his mental health disability. Another participant wished that providers would acknowledge her disability and then “let it gently shade your vision, but not color it.”

Accommodations to the Environment: Physical Space, Physical Structures, Scheduling and Rooming Patients

Participants described multiple ways the healthcare environment could be adapted to allow them to effectively move around and interact with their healthcare team. Lighting, location of furniture, and accessibility of medical equipment were all mentioned in the focus groups as important. For example, one participant with a visual disability and light sensitivity described needing overhead lights in examination rooms to be dim, and noted that providers often “throw the lights on” immediately when entering a room, rather than asking the patient about her light needs and preferences. The participant

emphasized that turning the lights on “blinds” her, which is a poor beginning to the clinical encounter.

Participants with physical disabilities, particularly those who used wheelchairs, reported that hallways, bathrooms, examination tables, and examination rooms were often too small or lacked accessible options. When asked what healthcare teams should ask regarding a patient’s accommodations when scheduling appointments, one participant with a physical disability stated: “I would probably want them to say: ‘Yes, of course, we have wide aisles and no stairs. Is there anything else that would be a physical limitation that would require assistance?’”

Many participants reported that since travel can be longer when arriving to a hospital or clinic and within facilities, they appreciated when their appointments were scheduled with adequate timing in between or when appointments were grouped by location. When scheduling accommodations did not occur, participants reported feeling stressed and rushed. Similarly, participants reported difficulty walking with their healthcare team members from the waiting room.

I’ve noticed lately is the speed at which people walk [...]. They go the speed of light. [...] you’re way up there and I’m way behind you. I know it’s a busy day and people are going back and forth, but you know, you want to be able to stick with them and get in the right place

Among participants with mental health or cognitive disabilities, many participants stated that healthcare environments can be stressful. Waiting rooms, for example, can be overstimulating for people with disabilities such as autism and Down’s syndrome. Emergency departments are also difficult settings as they can be anxiety provoking due to the uncertainty of wait times. Both caregiver and patient participants wished that, in these circumstances, they could be roomed early or wait in a quiet space until they could be seen. One parent of an adult with autism reported:

The waiting in the emergency room is very difficult with a child with autism and communication problems. So being able, like you’d said, to get in more quickly would certainly help the child and family members.

Another participant with a mental health disability reported increased anxiety when left alone in the examination room. She felt “deserted” and uncomfortable because she never knew when someone would be coming back. Instead, she preferred that a healthcare team member would stay with her in the examination room until her physician arrived.

Accommodation for Administrative Tasks

Caregivers and participants across multiple types of disabilities described significant challenges with administrative tasks

such as completing pre-visit forms and written screening instruments.

I think one of the biggest problems I’ve run into is that people don’t know what my diagnosis means. So when I say I have a tremor in my hand, they hand me a pen and a clipboard and I can’t move. I’m stuck in one spot saying, ‘Can you help me?’ And that’s more frustrating to me, I think. And then I have to answer the same question when I go to the next appointment.

Patients desired privacy and expressed discomfort with receiving assistance from a front desk staff member in an open waiting room. One participant reported feeling as though there was not a “safe place to ask somebody to read the form.” Another participant stated:

I don’t want to ask the lady at the front desk to read me what she just handed me. But they won’t let me see the doctor or nurse in a private setting where I could ask for them to read it to me until after I fill out the form.

One parent described difficulty trying to manage her adult child with autism in the waiting room, while also attempting to fill out paperwork for an appointment. The child was very anxious and required her to manage his behaviors.

I’ve been at the front desk and there’s been paperwork to fill out. ‘Well, you need to fill out this paperwork.’ And I can’t fill out the paperwork. This is – I’m not exaggerating – and she said, ‘Well, you won’t be able to have an appointment then.’ And I tried to clarify my situation, ‘I won’t be able to fill out this paperwork.’ And ‘Well you’ll – you can’t have the appointment without the paperwork.’

Accommodations for Communication During Interactions

Participants, regardless of disability type, reported that healthcare teams often spoke too quickly or used terms that patients had difficulty understanding. This was more pronounced when patients had communication, hearing, or cognitive disabilities.

Sometimes you have to think about the terminology you’re using. Some newer medical students or newer residents may like to use big words [...], it’s helpful for them to downgrade the language just a little bit and talk more – I don’t want to say down level, because you don’t have to talk down to them [...] Just adjust your terminology a little bit.

Participants stated that healthcare teams rarely used multiple modalities when communicating with them. Diverse

learning strategies such as writing down information were cited by participants as particularly important to their healthcare. A participant with a cognitive disability as a result of traumatic brain injury reported:

You may have explained things to me really well in the office and I may have really understood, but when I get to my car, it may be gone. [...] So having something in my hand, I've really appreciated the doctors who have written something down.

Many participants reported that when someone accompanied them to medical appointments, the healthcare team would often address that individual first, rather than the patient. This was frustrating for participants as they felt ignored or not included in their healthcare conversations.

And it's like, you know, please direct the questions or the comments or the care plan to me. I just have this person here to help me understand what you're saying, because sometimes they use big words or things that you don't really understand.

Participants recommended that healthcare teams address the patient first, ask who is accompanying them, and then inquire how the patient would like to integrate that person into the clinical encounter. Parents of adult children with developmental disabilities echoed this recommendation.

And then if the child says, 'Oh, I feel fine', then the doctor can say, 'Boy, I'm really glad of that, maybe I'll ask mom and dad too.' [...] And then you get the respect – you know, you're instilling mutual respect with the patient while also respecting their fears.

Participants proposed the patient portal as one solution to communication challenges because it allows for virtual communication after the visit. For example, participants suggested the ability to use the patient portal to ask follow-up questions, check in with the healthcare team outside of the office, and clarify treatment plans. The option to continue communicating with a provider virtually relieved the pressure on patients to remember everything said during the clinical encounter.

DISCUSSION

Our study engaged people with a wide range of disabilities to identify accommodations necessary for equitable healthcare. Identified accommodations fell into three categories: accommodations in the environment, for administrative tasks, and in communication during interactions. Participants requested that their disability and accommodation needs be recorded in their medical record.

The themes and accommodations we identified are similar to and complement patient requested accommodations in published studies. For example, studies with persons with mobility disabilities report that participants believe physically inaccessible medical environments, including inaccessible weight scales and examination tables, negatively affect the quality of care they receive.^{11,36–38} In studies with persons with autism, deafness, and other types of communication disabilities, participants describe preferences for how their healthcare teams communicate with them.^{39–43} Consistently, patients want to be treated with respect and request that the healthcare team be flexible with the modalities they use to communicate. To date, these studies have focused on one or two types of disabilities. Therefore, the unique contribution of this study is the engagement of patients with a wide range of disabilities to identify accommodations that cross-cut disability categories.

In the following study, participants requested similar accommodations across disability types, even if the reason for the accommodation was different. For example, participants with fine motor, visual, learning, and cognitive disabilities all reported needing staff assistance with completing paperwork when in the office. Narrowly considering one accommodation with a specific disability type can be limiting. For example, staff could erroneously assume only patients with mobility disabilities benefit from height-adjustable examination tables. Consequently, patients with visual disabilities who would benefit from a height-adjustable table might not be scheduled in a room with a clinic's accessible table.

Almost one-third of persons with disabilities in the USA have more than one type of disability.⁴⁴ Providing accommodations for only one disability might inadequately support a patient's overall quality of care, as well as limit the effectiveness of implemented accommodations. For example, one of our study participants was blind and had a hearing disability. He required staff to read him medical forms to him in a quiet room so that he can hear what is being said. Without addressing both his visual and hearing needs, the accommodation for his visual disability is ineffective. Recognizing that accommodations can be applied broadly, healthcare organizations and teams can focus on implementing a core set of accommodations that are provided to all patients with disabilities, rather than having separate lists of accommodations for each type of disability.

Historically, accommodations have focused on the built environment, which has perpetuated the idea that accommodations are costly and burdensome.⁴⁵ While the physical environment is essential for accessibility, many of the concerns raised by our participants focus on adjustment to healthcare teams' attitudes and communication styles. Healthcare facilities, even those with limited financial resources can immediately take steps to improve the culture of disability among their providers and staff, and adjust their visit workflows to better accommodate patients with disabilities.

The first step healthcare facilities and teams need to take toward equitable care is to consistently document patients'

disability status in the medical record.⁴⁶ With this in place, teams can begin to identify gaps in the quality of care as related to disability. Once identified, healthcare teams can ask patients how to best provide care for their needs. Many of the accommodations cited by participants require the team to adjust how they interact with the patient. Examples include writing detailed and concrete plans out, simplifying medical jargon, and allowing patients to room early, none of which requires significant financial commitment. With these recommendations, healthcare organizations can begin to make concrete steps in advancing equitable healthcare for patients with disabilities.

There are several limitations of this study. First, the study was only conducted in southeastern Minnesota. The experiences and recommendations from the participants might not be generalizable outside of this geographic region. We did not collect information on participants' race and ethnicity as the geographic region is primarily White, non-Hispanic. Providing race and ethnicity data on the participants could be identifiable. While we sought to capture the full scope of the disability healthcare experience, it is possible that some disabilities were missed and therefore we did not reach saturation of themes. The focus of the study was originally on adult care, so we did not fully explore the experiences of minors with disabilities. The limitations of our study, however, should not negate the significance of the themes that emerged. Given the alignment of our themes with the principles of patient-centered care, our study findings are likely relevant across disabilities and generalizable to other geographic regions.

CONCLUSION

Access to high-quality healthcare that facilitates optimal health can be complicated for people with disabilities. Developing a greater understanding of healthcare experiences across all disability types will be necessary to identify interventions to improve healthcare equity for this population. Creating solutions that consider the diverse needs of the disability population is critical to ensuring equity in healthcare delivered to all patients with disabilities.

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Declarations:

Conflict of Interest: The authors declare that they do not have a conflict of interest.

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