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Research Article

Confronting Barriers to Equitable Care: A Qualitative Analysis of Factors That Inform People with Mobility Disabilities' Decisions to Self-Advocate in the Context of Healthcare

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Background. One in 5 people in the United States live with disability; however, the public health needs of this community have been largely overlooked. Although U.S. law mandates the availability of accessible medical exam equipment, people with mobility disabilities (PWMD) frequently encounter barriers that require self-advocacy to receive basic primary care. *Objective.* The purpose of this study was to qualitatively explore the impact of healthcare access barriers—specifically, the experiences of the need to self-advocate and factors that inform decisions to make accommodation requests—for PWMD. *Methods.* Qualitative semistructured interviews were performed across two phases of data collection with each of the 6 participants. Interpretative phenomenological analysis was used to highlight the essence of participants' experiences in making decisions to request healthcare accommodation. *Results.* Participants included a purposive sample of self-advocates with physical disabilities (3 men and 3 women). While individual approaches to self-advocacy varied, participants identified a process of "recognizing the normalization of disability discrimination and disability stigma" which necessitates the development of "agency in self-advocacy." This process has a lasting impact on people that includes a shared embodied experience of disability, as well as a sense of empowerment based on their collective and individual identities. *Conclusions.* Findings have implications for supporting individual disability consumer advocacy efforts as well as the need to address the normalization of disability discrimination within healthcare systems levels.

1. Introduction

Despite the existence of civil rights legislation, people with mobility disabilities (PWMD) experience socially constructed barriers to participating in every aspect of community living, including accessing basic health services. Full participation in accessing healthcare often requires PWMD to self-advocate for disability-related accommodations, such as adjustable exam tables or accessible weight scales [1], to receive appropriate preventative, primary, and specialty healthcare services [2]. Despite a growing body of literature on identifying and describing the existence of barriers to care, the continued lack of disability-related accommodations, and research linking barriers to health disparities for PWMD, there is limited knowledge of how people make sense of these experiences and then use this

to inform their decisions of when and how to self-advocate within the healthcare system. Little to no research examines the factors that inform a person with mobility disabilities' decision to advocate or not. What is known is that a lack of disability-related accommodations in healthcare exists [3]; however, understanding what supports or thwarts individual efforts of self-advocacy to access necessary healthcare is underexplored. Therefore, this research study sought to understand the impact of healthcare access barriers—specifically, the experiences of the need to self-advocate and factors that inform decisions to make accommodation requests—for people with mobility disabilities.

1.1. Barriers to Healthcare Access. The United States Americans with Disabilities Act [4] has made entry into buildings and offices less of a challenge [5], reducing physical

access barriers for PWMD. Today, the most significant barriers preventing access to care include: accessing medical diagnostic equipment [6, 7], access to exam tables, rooms, and weight scales [8], access barriers due to provider attitude [9, 10], and access barriers from economic and systemic mechanisms [11–13].

While PWMD are at greater risk for some illnesses and chronic conditions due to their impairment [14], this fails to fully explain the inequities in chronic disease and mortality rates of PWMD compared to their nondisabled peers [15, 16]. Attitudinal barriers exist that PWMD may not need preventive and health promotion referrals [17]. Importantly, these attitudinal barriers may emanate from perceptions of quality of life of PWMD. A recent survey of practicing US physicians found a significant majority reporting PWD having worse quality of life than people without disability [18]. These inaccurate perceptions may influence clinical care decisions, including referrals by physicians when working with PWMD. Disparities in healthcare receipt and health outcomes for PWMD likely result from inequitable practices and programmatic policies that neglect, if not ignore, the need to implement and enforce the rights to healthcare access guaranteed by the ADA. This places the onus on the person to self-advocate for access to the basic healthcare services those without disabilities readily receive.

1.2. Self-Advocacy. The healthcare setting is one area of daily life, beyond the routine, where PWD have a greater need to advocate due to a lack of knowledge of providers on disability and healthcare needs [19], continued reports of inequitable provision of health services [1], and ableist perceptions of physicians [18]. How experiences of discrimination of PWMD within a healthcare environment impact the decision-making process to advocate—or not—for disability-related accommodations for equitable care is not known. Descriptions exist from consumers of frustrations and fears of providers withholding or refusing treatment if a request is made [20]. Dillaway and Lysack [21] found consumers elect not to pursue preventive care due to past negative experiences, and it requires "considerable agency in overcoming barriers" (p. 257). Yet, these researchers did not examine the many factors that supported that agency. Moreover, self-advocacy in a healthcare setting requires confronting long-standing dogmas dealing with health and disability [22–24] that may produce obscure but real contextual barriers to a person having the agency to self-advocate.

There does exist a limited body of literature, primarily on employment and education, exploring PWD's requests for accommodations and factors that influence a person to pursue these requests (see, for example, [25–27]. These studies describe how an individual's past experiences, perceptions of fairness, administrative or workplace cultural attitudes, and system-level factors influence a person's decision to advocate or not for accommodations more significantly than does knowledge on rights to disability-related accommodations. In addition, Kailes et al. [20] hypothesized that self-advocacy efforts are negatively impacted by the "four F" experiences—frustration, fatigue, fear, and failure

(p. 5)—that develop as the result of repeated discrimination, microstressors [28], and microaggressions [29]. These factors have been documented to contribute to poor health outcomes in other minority communities facing racial and ethnic forms of discrimination [30–32].

Understanding the experiences of PWMD when confronted with barriers and the need to repeatedly request disability-related accommodations may expose how these experiences impact not only immediate care needs but contribute directly or indirectly to secondary or chronic conditions as perceived by the person. Contextual factors of the environment that support or prohibit a person's choice to advocate for what they know they need in a healthcare setting can provide valuable information on how to reduce healthcare access disparities. Therefore, this study sought to understand the meanings PWMD give to healthcare access barriers, their understandings of why there continues to be a need to self-advocate for disability-related accommodations in healthcare, and the factors that influence their decisions to self-advocate or not. Specifically, this study examined three broad research questions: (1) how do people make sense of barriers to healthcare; (2) what factors influence decisions to advocate or not; and (3) what is the perceived impact of barriers to care.

2. Research Process

Interpretative phenomenological analysis (IPA) approaches were used for all data collection and data analysis in this research [33]. IPA is a qualitative methodology aimed at gaining an in-depth interpretation of individual experiences and is characterized by its emphasis on experience, ideography, and interpretation. It is therefore well suited to understanding how individual PWMD make sense of their healthcare and advocacy experiences while also recognizing these experiences are subjectively interpreted by both participants and researchers [34].

2.1. Recruitment. Participant recruitment began following approval by the Institutional Review Board (IRB). Recruitment occurred via an IRB flyer disseminated to disability advocacy organizations and through snowball sampling methods [35]. IPA research is committed to understanding how a particular phenomenon is experienced and interpreted from the perspective of a specific group of individuals that "represent a perspective, not a population" [33], p. 49). A purposeful selection of participants was used to ensure participants identified as having experienced healthcare access barriers necessitating self-advocacy. Due to the detailed case-by-case analysis of each participant interview, relatively small homogeneous samples are recommended in IPA research—between three and six participants [33].

2.2. Sampling. Based on critical reflection, existing literature [36], and input from disability community members, disability studies scholars, and researcher mentors, experiencing a lack of accessible medical diagnostic equipment and

appropriate disability-related accommodation was identified as particularly salient amongst people with physical disabilities who use wheelchairs for mobility, indiscriminate of SES or insurance coverage. Therefore, the discrimination experienced within the healthcare system and the need to self-advocate for disability-related accommodations were determined to be the critical factors that defined the homogeneity of the target population.

2.3. Inclusion/Exclusion Criteria. Three men and three women older than 18 years of age who self-identify as a person with a physical disability who uses a wheelchair as their primary mode of home and community mobility; identify as self-advocates in their healthcare experiences; are knowledgeable in rights to accommodations in healthcare; and who have had a minimum of one healthcare visit in the last 24 months that might necessitate a physical accommodation were purposively recruited for this study. In order to fully explore the factors that influence decisions to advocate or request accommodations, participants in this study required an understanding of their entitlement to make the request and their perceptions of being a self-advocate. Screening questions included asking participants about their experiences with disability advocacy efforts as well as their knowledge of disability-related civil rights. Individuals were excluded if they were unable to participate in an extended interview process of up to 2 hours based on their own subjective report of performance capabilities and an inability to provide informed consent, unable to communicate verbally in English, used to surrogate decision-makers on health-related issues, and self-identified as being a person with mental and/or intellectual developmental disabilities.

Participants represented a diverse demographic; however, to preserve anonymity, specific demographics are not reported. Participants were assigned pseudonyms for all reporting of the study findings. A short description of personal characteristics is provided in Table 1.

2.4. Data Collection. Data collection occurred in two phases and was carried out by the first author. Phase 1 involved audio-recorded semistructured individual interviews using the interview schedule (supplementary material (available here)) to address the key research questions. To ensure that the interview schedule reflected the perspectives and input from the disability community, a pilot interview was conducted with a leader in the disability community who identifies as a healthcare advocate and is knowledgeable in the legal rights to accommodations in healthcare. This individual met all of the study's inclusion/exclusion criteria, so that the individual experiences might easily translate to those of recruited participants. Phase 2 involved a second clarifying interview with the participant to check for emergent themes and to clarify the analysis done by the primary investigator of their individual interview. The clarifying interview goes beyond being a form of member checking; in IPA research, the clarifying interview is an approach used to clarify, with the participant, the interpretations made by the researcher during the first round of interviews [33]. The clarifying interview occurred after the analysis of individual cases had provided emergent themes and before initiating the analysis of themes across cases. These two phases occurred across a timeline of ten months. All interviews were performed in a location selected by the participant, most often at participants home and alone.

This two-phase interview approach was designed to ensure research participants were partners in identifying the meanings of the experiences reported and analyzed by the primary investigator. This process helped rebalance the power relationships between researcher, and participants and avoid replicating the power hierarchies that permeate mainstream disability research [37, 38].

2.5. Data Analysis. Interviews were transcribed verbatim and deidentified by the first author. Data were analyzed using multiple phases of iterative and inductive approaches. All phase 1 interviews were completed prior to initiating the analysis of individual cases. The phases of the analysis followed IPA recommendations [33] and included: initial prolonged engagement with a single transcript; coding each transcript descriptively, linguistically, and interpretively to develop code categories; analysis across transcripts to identify emerging themes from individual code categories; cross-checking emergent themes with a data analysis team; grouping emerging themes into corresponding interview questions to guide the second clarifying interview; a final comparison of themes from individual interviews with emergent master themes and subthemes from across cases; and, finally looking for patterns across cases to identify what are the most potent themes [33].

2.6. Techniques for Establishing Trustworthiness and Researcher Reflexivity. This study incorporated strategies to address concerns when reporting qualitative research (supplementary material) [39] that include: credibility (use of debriefing and member checking (clarifying interview)), transferability (use of dense descriptions), dependability (audit trail, researcher diary, and data analysis team), confirmability (use of a reflexive journal) [40], and attention to validity and rigor (attending to the seven-criterion checklist for quality IPA research [41], p. 24). Following the interviews, the main author recorded all recollections of participant reactions to questions including nonverbal communication and facial expression, as well as how the interviewer's own presentation may have been interpreted positively or negatively by the interviewees. This author continually considered their role in the construction of this research–attending to *"where I am coming from"* - "positionality" [42], p. 4) and outsider status as it influenced researcher interpretations and the interpretations made by participants of researcher questions during interviews. During the initial reading of the interview, transcripts, notes, and memos were included and cross-checked with notes from the author's reflection journal. These have been used to explore how the researcher's personal characteristics may have influenced the responses of an interviewee. All of these processes were used to "inform the analytic logic and interpretive authority of the final product" [43], p. 413).

TABLE 1: Participant demographic information.

Pseudonym	Age	Gender	Racial identify	Disability onset
Lynn	58	F	Caucasian	Birth
Marcus	34	M	African American	Birth
Eve	53	F	Puerto Rican	Acquired -spinal cord injury (SCI)
Thomas	56	M	Puerto Rican	Acquired -SCI
Lala	55	F	African American	Birth
Gary	31	M	Caucasian	Acquired -SCI

3. Findings

Eight themes emerged from across the analysis of the six participant interviews, two with strong subthemes. These themes are as follows: (1) normalization of disability discrimination (NODD), (2) knowing what you need, (3) understanding rights, (4) context informs self-advocacy, (5) advocacy fatigue, (6) self-perceived burden, (7) impact on health, and (8) empowerment through agency in self-advocacy. The interviews lasted between 1.5 and 2 hours, attending to participant's need for breaks or more time to discuss their experiences of concern. Participant demographics can be found in Table 1.

The first author's position as an experienced healthcare provider was acknowledged both for how experiences and personal knowledge informed beliefs about disability and also for how it might influence the participants. Personal experiences in self-advocacy shaped ideas about "what self-advocacy is" or what it means to decide to self-advocate—but from the author's own social, political, economic, cultural, and able-bodied world. By acknowledging and making explicit positionality, that includes identifying as a cisgender female and white among other privileged identities, this author/researcher purposefully integrated strategies to minimize potential biases at each stage of the research process including during theme development. See Table 2 for themes and subthemes.

3.1. Theme One: Normalization of Disability Discrimination. All participants in this study described experiences of everyday clinical policy or provider practices that exclude, marginalize, degrade, disrespect, and put them at risk for inadequate or incompetent care. Eve related her distress of being trapped in a healthcare setting without access to a bathroom:

> There were no bathrooms that were accessible. The whole hospital! . . . I was there for a fractured femur. I was a patient there for 6 days. They wanted me to use a bedpan! I'm like "I'm sorry, I can't use a bed pan I'm a quadriplegic that's just way too difficult for me and it's just not going to work'.

These everyday discriminatory practices are so normalized, the participants described providers who often do not even recognize them. Thomas' description of a barrier to entry into a medical office highlights how these practices are interpreted by PWD as exclusionary and dehumanizing.

> This never crosses their mind . . . who's going to be there to open the door to get into my doctor's office, because there's not an accessible entrance, or door. They have a little side window, so I tap on the side window, and if there is somebody in the waiting room they'll come but if not it takes a while, you know? You know, I have two dogs at home, and when they want in, they sit at a window and they stare. I think about my dogs every time I'm tapping on that side window trying to get somebody's attention, it's like, "damn, I know how my puppies feel" . . . I mean it shouldn't be that way. Doc, get a buzzer here, get a doorbell so I can ring it and have some dignity about it when I'm doing it!

Lynn coined the term "normalization of disability discrimination" (NODD) for this type of exclusionary practice which resulted from the failure to enforce access, equitable care, and equitable equipment design for PWD in healthcare environments. Participants also identified small gestures of discrimination and microaggressions connected to NODD, as explained in the following quotation from Gary:

> It's like making it more awkward just from like the subtle like. . .. "uuughhhh" (imitating a long sigh from provider). . ..like the little "huh" (with a rolling of eyes) or like this (facial expression of imposition) and so, and so . . .they pretty much [are] saying that "honestly, normally they don't deal with people in wheelchairs."

How participants interpreted and made sense of NODD appeared to impact behavioral and emotional responses and informed the participant's decisions to self-advocate for disability-related accommodations. Lynn provided insight into the significant role NODD plays in how providers approach and interact with PWD and how this is experienced by PWD.

> There are so many things going on in that process of normalizing – there's what's happening from the perspective of the discriminator there's all kinds of layers of what's going on with them. And then as the victim of, as the person being discriminated against – I think there's a lot of things behind that realization. Interviewer: And that decision you make when you decide not to request the accommodation when you believe you should request one for what-ever reason? Lynn: And that is actually the normal response. . .that "they" would expect.

TABLE 2: Themes and subthemes.

Themes	Subthemes
Normalization of disability discrimination (NODD)	Providers don't understand health and disability
Knowing what you need	
Understanding rights	
Context informs self-advocacy	Influences of significant others
Advocacy fatigue	
Selfperceived burden	
Impact on health	
Empowerment	

Lynn's assessment of NODD acknowledges how it shapes provider-patient relationships in healthcare. The "normalized" approaches in provider practices that discriminate contribute to "normalized" responses from the PWD. Recognizing discrimination is the first step in shifting PWDs perspective from accepting the status quo to the response, that is, a determined act of self-advocacy agency within the healthcare system.

3.1.1. Subtheme: Providers Do not Understand Health and Disability. The majority of participants perceived that providers are often ignorant of or have limited knowledge, understanding, or experience in working with PWMD; exposing this important subtheme of NODD. As a result, participants recognized they might have to self-advocate to circumvent providers' attitudes and clinical decisions to receive equitable care.

Participants reported stress, indignity, lack of respect, fear, and frustration in provider visits because providers did not understand how to care for PWMD. These participants echoed Gary's impression that: "*You have to advocate so doctors get it right...because most providers have no idea.*" Participants recognized a critical factor that drove their need for self-advocacy was when provider authority tried to overrule their own decisions in care. It made sense to participants that their need to self-advocate was in part based on resisting provider efforts to assert authority, independent of accommodation needs. They also interpret providers' practices to be informed by disability stigma and bias that do not allow for health and disability to coexist. The impact this has can be traumatic. Eve shared a powerful example about how degrading practices like public stripping [44] are institutionalized under the guise of medical education.

The PAs were starting to undress me and the doctor was in the room with a medical student. And I was like "hey, wait a minute what's going on here?" And they were like "you know, we need to take your clothes off because he's going to be doing some exams down there" or something like that. I was getting upset because they were just undressing me right in front of everybody and in front of him and in front of the students. Without asking me or nothing! Just undress me, they took my pants off my underwear, everything. I was like so humiliated.

Eve saw these practices as not only inexcusable and disrespectful but also discriminatory. She felt the providers devalued her as a person on the basis of her disability. This diminished status, sensed by many of the participants as second-class citizenship, stripped them of authority over their bodies' health.

Each of the participants described recognizing their own authority as a prerequisite to advocacy and vital to their ability to manage their health. Acknowledging the connection, Gary said, "*Ever since I've taken control of my body . . . I feel better.*" The participants found provider ignorance more tolerable and easier to address than arrogance and assumed authority. Lynn states it quite simply, "*If you just wait–you know, I can tell you exactly what to do.*"

3.2. Theme Two: Knowing What You Need. How each participant interprets what is important enough to self-advocate for varies considerably depending on multiple intersecting contextual and personal factors. Knowing what you need to maintain and manage your health is a life-long process. Participants learned through observation, through exposure to role models, and through trial and error. Even when participants knew what they needed, they reported challenges with convincing providers to listen. As described by Thomas: "*It took a significant amount of time for me to convince him to initiate an intervention immediately cuz* [because] *my blood pressure was shooting up and I knew what was taking place.*"

Paternalistic power structures within healthcare can be challenging to confront and make participants second-guess themselves. For example, Gary, relatively new to self-advocacy, described the impact provider authority had on diminishing his own emerging expertise: "*When they recommend something, and refuse or rebut you all it does is remove the progress you've made to be in control over your own body . . . making you second guess or be less confident.*" This statement underscores the importance of Gary's confidence in knowing what his body needs as a prerequisite to self-advocacy for those needs. Gary wavered between advocating for what he intrinsically understood he needed and listening to his provider's expertise. Other participants described how acute, in the moment needs pushed them to strongly advocate when providers failed to provide accessible care: Lynn: "*They start anticipating what I need... not even saying how about I go here? ...I have very poor upper body balance–so then I had to raise my voice and say "STOP–I'm going to fall!" (in loud voice).*"

Participants also described how their individual self-advocacy benefited the disability community as a whole. For example, Marcus described choosing self-advocacy to

educate providers not only on his specific care needs but on the existence of NODD and stressing the rights of PWD.

> Marcus: *I understand that for certain situations I need to ask for an accommodation and like I said, if you don't ask they don't know…they won't know what to do. You know? So, being able to talk to my doctor about what I need ….*
>
> Interviewer: *Yeah, you're not just your diagnosis?*
>
> Marcus: *Right, about what I need, so he understands what needs to be done and then he can take that experience and sort of, if he's got another patient with disability, it might be different but at least he has a better understanding of how to handle, how to handle himself in that situation. You know?*

Many of the participants described advocating for provider respect to counteract the discrimination they experience in healthcare. The participants learned that this was vital to their own health and wellness but also part of a broader resistance to inequitable healthcare provision.

3.3. *Theme Three: Understanding Rights to Care.* Understanding rights to care and how to incorporate this knowledge into advocacy efforts was another important factor for the majority of participants in making decisions to advocate. Physical access and access to medical services for PWD are legally required in the United States [45]. Thomas was convinced that: "*Somewhere within the administrative body they know what their legal requirements are under the ADA*' yet failed to implement this legal requirement. Many participants interpreted this failure to comply as indifference.

> Lala: *Instead of making accommodations they're like "well look, you have to try to get on here" and they don't make any type of accommodations and I felt embarrassed and then I became upset and I'm like "you need to make some type of accommodation" … they just don't want to help at all.*

According to Eve, the disability community has some responsibility to make providers and healthcare systems care:

> *You'd think that they would be thinking about the people that can't stand and think ahead like that but they're not.*
>
> Interviewer: *Why?*
>
> Eve: *Maybe because they just don't care? And maybe because we're not voicing our needs as much? Because we don't speak up and say anything when it is important. But there are very little of us that are experienced and we're not saying anything.*
>
> *So, they get away with it.*

Participants in this study had a firm grasp on their civil rights to access; however, they described using caution in how they used it. Lynn described how she uses the language of the ADA versus claims of legal rights to access, to help her work with providers without putting them on the defensive:

> *It seems to me, maybe it's different for others but the ADA, citing the ADA is not too effective. Now…I will use the language of the ADA, to sound intelligent, right. To be assertive, it helps me to be assertive to know the language of the ADA.*
>
> Cuz, [because] *that's what works for me right now. Like,"You do know that the law does require that we be provided equal service, I mean that's just fairly common knowledge."*

Many of the participants described educating providers on their failure to accommodate as the sole reason for making their request. They choose to advocate for accommodation to make a point of the injustices they endure because of provider failure to offer accessible medical equipment. Lynn: "*All I can think of is the need to be weighed. I request it, although I know I'm not going to get it, I just want it to be on the record. "Here's another request for an accessible weight scale" and I hope it adds up somewhere.*"

3.4. *Theme Four: Context Informs Self-Advocacy Strategies.* Participants described how contextual factors influence their self-advocacy and their approaches. Interpretations from past encounters taught them the importance of incorporating strategies to preempt negative disability stereotypes as part of their efforts to access care. Lynn used subtle ways, and Eve was more overt, to counteract disability stigmas and heighten collaboration and teamwork within the healthcare visit. For example, Lynn understood her demure personality might be mistaken for passivity and submissiveness in provider visits. She was conscious that these behaviors are linked to disability as well as to feminine stigma, and she sensed that provider authority might be reinforced if she "allows" her shyness to surface. Instead, she prepared for healthcare visits in order to project confidence and control, a role she resented having to play. Lynn: "*It's a survival tool… I cannot be passive or show that I'm uncertain, even if I am. It's a performance, is what it is. Even if you don't feel like performing it's a performance and I would not have learned that if I didn't have to learn that.*"

Eve was sensitive to other disability stigmas she interpreted providers may have for her and was careful to avoid any image that might link this stigma to her during provider visits:

> Interviewer: *Is there a higher standard for PWD to look, um, put together?*
>
> Eve: *Oh yeah, presentable. To look decent. Cuz,* [because] *if you don't they're going to think you are just some homeless guy downtown. Looking for a quick fix.*

Eve also avoided behaviors that could be interpreted as being belligerent or "angry cripple" or "angry feminist" and thereby dismissed:

Because anybody can be a loud mouth and walk around and yell out things with a stick but who's going to hear you? Is it going to accomplish anything? I think um, there's a way there's a way to um, there's a way to get things done...the right way, the appropriate way.

Eve approached her advocacy and complaints in a respectful yet forceful and productive manner that led to permanent changes in policy and accessibility. Eve: "*I felt proud of myself ... yeah, I felt powerful. Because I made changes, I know they made changes in that clinic.*"

3.4.1. Sub-Theme: Influence of Significant Others. Participants recognized how significant others can serve as allies and influence provider behavior to increase the chances of accessible and equitable care. However, at times they intentionally choose to exclude significant others in contexts of healthcare decision-making to ensure providers respect their authority in their care decisions. Thomas described the challenges he assumes by attending provider visits without his family but also his hopes of what it will accomplish:

I don't want to be dragging my family there simply to help me out ... it's not fair to them, it's not fair to me, and ultimately if all I do is, is lean on my family and others and don't have the doctors and the nursing staff do what they can do and should be doing then it's going to make it more difficult for me the next time -- and --- it's going to make it difficult for someone that comes behind me that doesn't have the voice or the strength to speak for themselves. So, it's hard and it's a challenge.

Thomas understood provider visits will be completely different with his family present. While things may be easier in the moment, Thomas risked his authority in that encounter and future visits. Lala describes her perception that providers are more attentive when others are present, although she questioned the sincerity of their attentions: "*I see a big difference when I have someone with me. You know that amount of respect that they think that they will give me. Cuz,* [because] *they're going to give me my respect but they try to give me [shows a tiny sign with fingers and thumb].*"

While participants valued the support, they were cautious that it did not distract from their own authority. Lala: "*Like I said when my brother was there and my friend...they [providers] actually try to over talk me to them. And my brother is like "look, she's right here".*" These participants understood the positive as well as the negative effects a significant other can have on self-advocacy.

3.5. Theme Five: Advocacy Fatigue. Basas [26] calls the need to continually request accommodations *advocacy fatigue* and suggests that this state "diminishes emotional and physical health" due to "ongoing exposure to stress and discrimination" (p. 1). Although only three of the participants described this state as directly impacting their decision not to self-advocate for accommodations, these decisions extend to understanding self-advocacy decisions. Interestingly, the three participants who described experiences aligned with advocacy fatigue had the longest history of disability activism and a long history of work within the disability community on issues of healthcare access. Thomas acknowledged the irony he and other participants see in the need for advocacy in healthcare settings:

When I first got injured and got out of the (hospital) and then went to different doctor's offices and clinics, eye care clinics, and dental clinics, I thought I'd be at home, that I'd be welcome and that you know, that - this is one segment of the population that would get [emphasis] me! And that is certainly far from the truth.

Lynn was a matter of fact about her decision not to advocate: "*I'm not going to keep asking the same clinic for an accessible exam table when I know they don't have it. So, then I just don't ask, I don't. One example is I did not, I have not had a gyny* (gynecology) *exam for probably 15 years. Because, just the issue of the exam table.*" Lynn's fatigue came from repeatedly confronting inaccessible healthcare settings and unaccommodating providers. However, the overarching cause of advocacy fatigue was the never-ending demand of advocating across clinical experiences: "*It's frustrating because I've had that experience too many times so that there is an additional level of discouragement, like "here we go...this again!*"

These participants made judgements based on an assessment of their health concerns, the probability of receiving disability-related accommodation, and their own emotional and physical capacity to confront discrimination in the moment.

3.6. Theme Six: Self-Perceived Burden. Five participants described how when accessible equipment or accommodations are not readily available, it creates extra effort and work for themselves and for the staff. They recognized that if providers lack understanding, training, or resources to implement the accommodations, the demand on both parties multiply. They expressed concerns about being a burden to healthcare providers including technicians, nurses, and office staff. These participants described feelings of guilt, responsibility, and concern for repercussions in care when "asking too much" of providers. Some participants perceived their own inability to adapt to their provider's way of approaching them as a cause for not advocating: Gary: "*I feel like again, it's hard for me because I don't want to be a problem, I don't want to be an issue in any situation, and I know that I would just be asking for a simple thing but you're really inconveniencing them, which is how I look at it.*"

Participants describe how these perceptions stem from systematic and normalized processes that mark their differences [46]. The failure to have readily available accessible equipment also creates scenarios where safety risks for staff were considered, but the result was their concerns as a patient were neglected: Eve: "*I have felt like a burden like ok like I'm a challenge, "How are we going to get her on the table, how*

are we?" . . . which you know it's, I guess a legitimate thing for them to be concerned." Lynn empathized with the providers as she analyzed the context and what a request would mean, convincing herself not to advocate for her own interests:

> These are nurses, their bodies are being put under strain period . . . I can feel from them not knowing what to do and being afraid for their own safety. You know, I feel that and that helps me, in somehow and way, not just the exam table but – I know they say they could get me on it but – ohh. . .(shrugs) there's that too.

Self-perceived burden to providers directly influenced participant decisions not to advocate for disability-related accommodations. At times, the participants forego their own health needs to avoid this sense of burden. Decisions that may have a lasting impact on their own health and well-being.

3.7. Theme Seven: Impact on Health. Advocacy fatigue was associated with a sense of emotional drain experienced when visiting providers. This and other negative experiences of failure to be accommodated were perceived to directly impact participants health. Lynn explained that with every provider visit, the memories from past negative encounters invoked anticipatory anxiety and fear: "*So, there's kind of a dread that I carry with me when I go to the doctor, um, about just attitudes.*" Lynn also described how the discrimination she experienced negatively impacts her self-image: "*It's a reminder that I'm abnormal and that the accommodation is seen as something special. Not as a right.*" Gary echoed Lynn's reflection on how healthcare experiences stay with a person long after the actual visit:

> Interviewer: *So emotionally it affects your emotional health?*
>
> Gary: *Ya, it definitely does. And I've been like, you know, like it's, where it's like, embarrassing and then you go home and it ruins your day. You know what I mean? It's like "That Sucked!" And then that feeling transitions to the people around you, sadly you know?*

The impact of experiences of discrimination created a build-up of stressors and microaggressions [47] that negatively impact participants' emotional health. Discrimination was both subtle and overt and had strong, lasting impacts on emotional and mental health. The lasting impact of fear, anxiety, embarrassment, and humiliation added stress to these participants' lives. It also made sense to participants for reasons to choose not to self-advocate. How this stress impacted their overall health is difficult to quantify; however, Lynn provides a possible scenario:

> So, let's take the physical: I'm going to postpone and I have postponed-my treatments have been delayed at times, because I have postponed the visit. Because I know it's not accessible – so in my own mind I down play the symptoms I'm having. So physically when you delay the diagnoses you

delay the treatment. . .sometimes it's more complicated than it would have been so I think that's all physically related.

Lynn's experiences are consistent with the literature demonstrating that both experienced and anticipated stigmas decrease health seeking behaviors as well as quality of life [30, 48].

3.8. Theme Eight: Empowerment through Agency in Self-Advocacy. The participants reflected on how normalized processes and inept practices maintain provider authority over the health and healthcare of PWMD. Although participants identified different paths, they all came to a point when they recognized knowing what they needed, their right to request, and strategies for requesting as steps toward being more empowered: Lynn: "*You know, the language of accommodations–reasonable accommodations just seems to, it makes me feel more empowered because it is reminding me that I have a right - so using the language of the ADA or any terminology is helpful to me.*"

Having knowledge and believing in their own capacity as self-advocates was a vital factor participants identified as changing the tenor of a healthcare visit. Participants described using their knowledge to support their authority, as well as making decisions to self-advocate, positively impacting the quality of their care and provider behavior. Thomas credited educating providers on his right to accommodation to improve healthcare experiences:

> I've had a number of good experiences with my doctor's but only after I've educated them, on what the legal requirements are and who I am and um, and that, to listen to me. You know after we've been able to communicate that then I, you know, then doctor's offices they welcome me with open arms and I don't feel um, I don't feel rushed, I am listened to, and I'm given prompt care and . . .it's worked out.

The participants' understanding of the social construction of their exclusion from primary and preventative healthcare is what provides them with the agency to make a fully informed decision to self-advocate. For the participants, successful advocacy experiences in confronting NODD created a lasting sense of empowerment for future agency in decisions to request accommodation.

4. Discussion

This study explored the meaning that barriers to healthcare have for PWMD as well as the personal and contextual factors that influence decisions to self-advocate for accommodations. Analysis across cases identified eight common themes. These themes fall into three broad conceptual categories that align with the research questions: (1) how do people make sense of barriers to healthcare; (2) what factors influence decisions to advocate or not; and (3) what is the perceived impact of barriers to care, while individual

approaches to self-advocacy varied, participants all made sense of barriers to healthcare because they recognized a normalization of disability discrimination and disability stigma, which in turn influenced provider understanding of disability, necessitating the need to develop agency in self-advocacy. Decisions to self-advocate were complex, and participants described weighing a variety of contextual and personal factors when deciding to advocate or not. This process has a lasting impact on people's emotional and mental health as well as a sense of empowerment based on their collective and individual identities as PWD. The findings from these themes are considered with a critical reflection of how they are informed by past research on healthcare access barriers for PWD and the use of critical theories and the social model of disability to analyze and highlight the essence of participants' experiences.

4.1. Making Sense of Barriers to Care. Routine experiences of one-on-one discrimination dominated participant descriptions of experiences in healthcare encounters. Despite the United States Americans with Disabilities Act (42 U.S.C. § § 12101–12213) and Section 504 of the [49] (29 U.S.C. § 792 *et seq.*) that legally require services to all healthcare be accessible, people with mobility disabilities continue to experience barriers to primary and preventive healthcare [50, 51]. These barriers exist despite the presence of easily implemented alternatives [7]. Many of the experiences described by participants are supported by research on lack of access to preventive care [52, 53], provider offices [54], and equipment [20]. Providers' lack of knowledge, ignorance, and/or stigmas about disability described by participants is also supported by literature exploring the attitudinal impact on access for PWD [18, 55, 56]. The participants' reflections on the causal factors of these barriers shed light on the meanings they give to the experiences. The majority of participants made sense that barriers to healthcare stem from a normalization of disability discrimination in healthcare as well as a lack of provider knowledge about how to provide care for PWD.

Participants describe the normalization of disability discrimination (NODD)—perceptions of discrimination experienced as the status quo—that go virtually unnoticed in the day-to-day practices of healthcare organizations by administrators and providers. Although individual providers at times were overtly discriminatory, participants believed that societal and administrative influences support perpetuating microinequities that are the scaffolding for a culture of prejudicial behavior against PWD, reproducing access barriers and provider knowledge across contexts of care. Dillaway and Lysack [9, 21] have extensive research on women with disabilities' healthcare access barriers and report across all of their studies that "the primary social barrier women discuss is providers' lack of education and training" (2015, n.p.). Similarly, participants in this study shared sophisticated insights that inadequate provider knowledge and unconscious bias limited their capacity to offer appropriate care.

While providers' limited knowledge was a key determinant for all participants in recognizing access required self-advocacy, most participants also perceived broader societal or administrative level causes to understand why this type of barrier exists. Other research on providers and healthcare administrators' lack of knowledge on appropriate accommodations and care [3, 36] supports the claims of participants that systemic discrimination perpetuates the lack of accommodation and training on disability as well as biased behaviors of providers.

Participants described recognizing subtle as well as overt acts of discrimination as part of routine healthcare practices. In fact, the majority of participants described their recognition of disability discrimination as a fundamental a priori step to becoming aware of the necessity for self-advocacy. For example, Gary described reflecting on how bodily difference, rather than health and well-being, became the focal point for healthcare encounters as raising his awareness of the need to self-advocate. He described how many individual provider experiences left him feeling bad physically and emotionally. Overtime, he recognized a consistent pattern of discrimination and that the problem was not with him or his body but with issues of access and attitudes within the healthcare system. While providers may not perceive it, participants recognized NODD and how it led to their marginalized status within healthcare environments. Understanding and recognizing NODD made sense to participants as the reason behind the need to self-advocate. The findings suggest negative provider behaviors and disparate practice patterns, a lack of provider knowledge of disability and negative disability stereotypes, and the perpetuation of inaccessible diagnostic medical equipment may be seen as external representations of a pervasive process of normalized disability discrimination in healthcare.

4.2. Factors That Influence Decisions to Self-Advocate. Three themes arose from interpretations of experiences when participants elected to advocate: "knowing what you need," "understanding rights to care," and "context informs self-advocacy strategies." Each of these themes describe a process of learning. The iterative processes participants describe of developing agency in self-advocacy are supported in the literature of social learning theory [57]. Agency is the capacity to exert control, but Berger [58] expanded this definition to include "the possibility of transforming the social relations of personal experience" (p. 311). Through self-advocacy, participants sought to redistribute power imbalances among privileged providers. Self-advocacy was not limited to access to services but also as a means of ensuring their dignity was respected. Unfortunately, participants' stories provide many examples of degradation and humiliation.

The most seasoned healthcare advocates among the participants saw advocacy as a way to get appropriate care but also as an opportunity to promote healthcare equity for the broader disability community. Indeed, while advocacy was typically motivated by individual health needs, all participants, even those not confident in their advocacy ability, recognized the need to advocate in healthcare encounters to expose larger social injustices. These participants felt an obligation to others in the disability community who did not have the ability to self-advocate.

Participants acknowledged that rights-based knowledge provided "*the language*" for advocacy and acts of provider education. Participants described preferences for using the ADA to frame advocacy requests but Lynn epitomizes participants' reluctance to use phrases such as "*the ADA says*" preferring to state "*an accessible table would be one that lowers down*" as approaches they interpret as more acceptable to providers. Fear of retaliation or alienating providers prompted a more restrained use of the law versus formal enforcement. These concerns are supported in the literature [59]. Participants similarly interpret that brandishing the ADA upfront in accessing care is ineffective, potentially risking backlash (Thomas, Eve) or rejection (Lynn, Gary) from providers. Despite the reluctance to cite, the ADA participants appreciated that it establishes their right to accommodation and described incorporating it as part of their varied strategic approaches in self-advocating.

Advocacy fatigue and self-perceived burden to providers were identified as two main reasons that caused participants to choose not to self-advocate. In particular, feelings of fatigue or emotional exhaustion were described by four participants in making "in the moment decisions not to advocate for accommodation. Participants described that NODD was so pervasive "battling" the system became an essential but often dreaded part of seeking healthcare. Participants Lynn, Eve, Thomas, and Lala, who describe self-advocacy in healthcare as a "fight" for access and equity experienced the phenomenon of advocacy fatigue. These four participants described advocacy's emotional toll as "*frustrating*", "*stressful*", "*draining*" and believed that these experiences negatively impact their physical as well as emotional health.

Basas [26] theorizes that experiences of compassion fatigue, burnout, and stress recognized in rights-based advocacy efforts are also experienced by the recipients of social services. She identified the lasting impact caused by individual advocacy efforts when coupled with a corresponding commitment to collective community activism as advocacy fatigue. There is little literature describing the phenomenon of advocacy fatigue among the disability community when confronting healthcare access barriers. Advocacy fatigue likely contributes to what Gill [60] described as "disability burn-out" disabled people experience with "years of exposure to disability prejudice and devaluation" (p. 180).

The decisions to not self-advocate were also influenced by perceived self-burden to providers. Five of the six participants interpreted being a burden to providers as a reason not to self-advocate. Lala was unique in her defiance to this label and asserted that she never felt she was a burden. Indeed, she interpreted providers' attempts to make her feel guilty as a way of manipulating her into compliance. "*They try to make me feel like I am bothering them*". Self-perceived burden research almost exclusively investigates the perceived burden to caregivers of individuals with long-term progressive chronic conditions or persons in palliative care or at the end of life [61]. Future research should examine how perceptions of being a burden to a provider influence healthcare encounters and outcomes.

4.3. The Perceived Impact of Barriers. Findings from the reports of all participants correspond to other literature describing how experiences of stigma and discrimination reduce their likelihood of seeking out or delaying visits to necessary care [48, 62]. However, the impact of perceived discrimination and stigmatization was interpreted by participants to have a much broader effect on their health, as participants reported physical and emotional stress and a loss of feelings of dignity and respect as a direct result of encounters with providers. The negative impact of discrimination is consistent with research with other stigmatized groups [63, 64].

Participants' accounts of the impact of negative experiences in accommodation requests can be understood by examining literature on the impact of microaggressions or from literature exploring the physical/biological impact of discrimination [65, 66]. This literature supports claims that health is negatively impacted by perceptions of discrimination. Other research describes how contextual factors, similar to those perceived by study participants, such as a lack of control over their care, feelings of rejection, and perceived prejudice, can contribute to stress and poorer health [30, 67, 68]. Gary offered a glimpse into the health effects of provider discrimination. Gary's pride in his decision to self-advocate for his needs was evident in his claim that, "*Ever since I've taken control of my body . . . I feel better*". He recognized that as he gained control or authority over his body, he experienced a greater sense of well-being.

Experiences of medicalization by providers were understood by participants as the cause of self-advocacy and a critical step in the process of developing their own strategies of self-advocacy as strategies of resistance in health and healthcare promotion. As participants took authority over their bodies, they increased their agency in self-advocacy by integrating their understanding of the laws that support their right to accommodations, empowering them as a disabled individual, and recognizing the membership of a collective disability community of . Research aligning identity with group membership supports individual self-esteem and self-efficacy in resisting the negative consequences of discrimination [63, 69]. However, literature does exist critiquing or warning of supporting efforts to embrace and herald individualized self-advocacy as a tool or necessary skill set for a person with disability and that true disability advocacy crosses to the entirety of the disability collective [70, 71]. The meanings of participants' experiences in successful advocacy are all related to aligning their identity with being part of the minority disability community on the basis of demanding just and equitable care delivery. This advocacy aligns with critiques and supports the understanding that disability self-advocacy may be a process that extends to and includes the collective community—including those that may participate "only by their presence" [72], p. 135).

This study's findings align with Engel and Munger's [25] that the relationship between disability rights and disability identity holds the key to understanding how specific provisions of the law "become active in the lives of their intended

beneficiaries" (p. 142). They conclude that if rights holders cannot recognize unjust and disparate treatment "they may come to accept as natural and appropriate what might otherwise be considered exclusion or discrimination" (p. 144). Participants not only recognized discrimination embedded in healthcare, but they also had the power supported by legal rights and embodied authority to get their needs met. With learned approaches and increased knowledge, participants' rejection of medicalization and social construction of barriers to healthcare empowered their disability identity development and promoted agency to self-advocate.

4.4. Study Limitations. There are several limitations of this study that include the use of a single researcher during data analysis. Steps taken to reduce this limitation included returning to the participants for the clarifying interview, using the data analysis team, and discussing emergent themes with a qualitative research mentor (second author). Another limitation was the decision to lessen the homogeneity of the participants by including both males and females and PWMD who identify as self-advocates. The sample size does limit the findings to the participants in this group, who are informed only by self-advocates and PWMD, and therefore they are not generalizable to the larger population of PWD. However, the differences within the group that include gender, race, age, and physical disability offer some evidence that these shared experiences may be similarly reported by others with physical disability.

4.5. Implications. Identifying and acknowledging that a normalization of disability discrimination exists in healthcare is critical to reducing its impact. The implications of these findings can be used to: (1) inform and support community advocacy efforts in accessing care; (2) offer greater insight into needed changes within healthcare systems to make them more inclusive of PWD; and (3) provide further evidence of the need for stronger enforcement of the ADA across all of healthcare.

5. Conclusion

The normalization of disability discrimination (NODD) and the exclusion of PWD from healthcare are a matter of fact, and the practical solutions are twofold: PWD and their Allies must expose discrimination for what it is, and healthcare organizations must take responsibility for failing to support accessible environments perpetuates microinequities in care delivery and prejudicial behaviors and attitudes of providers.

Each participant interpreted the meaning of their healthcare experience from the embodied position of disability. How they make sense of barriers to care as discrimination as well as its normalization is a first step to an empowered agency in healthcare. Recognizing the oppressive processes that continue to view the disabled body as the property of the provider is critical to understanding that these same processes will not view that same body as healthy.

Data Availability

This manuscript is the synthesis of the doctoral dissertation of the corresponding and first author and can be found at the University of Illinois, Chicago's research repository.

Ethical Approval

Our study was approved by The University of Illinois at Chicago Office for the Protection of Research Subjects Institutional Review Board(approval no. 2016-0891). All patients provided written informed consent prior to enrollment in the study.

Conflicts of Interest

The authors declare that there are no conflicts of interest regarding the publication of this article.

Acknowledgments

Supplementary Materials

(i) Interview question schedule. (ii) Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist [39]. (*Supplementary Materials*)

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