Perceived Disability-Based Discrimination in Health Care for Children With Medical Complexity

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abstract

BACKGROUND AND OBJECTIVES: Disability-based discrimination in health care can lead to low quality of care, limited access to care, and negative health consequences. Yet, little is known regarding the experiences of disability-based discrimination in health care for children with medical complexity and disability. An understanding of disability-based discrimination in pediatrics is needed to drive change and improve care.

METHODS: We conducted in-depth, semistructured interviews with caregivers of children with medical complexity and disability. Participants were purposefully recruited through national advocacy and research networks. Interviews were conducted via video conferencing, recorded, and transcribed. Data collection and analysis occurred iteratively. An inductive thematic analysis approach with constant comparison methods was used to identify themes that form a conceptual framework of disability-based discrimination in health care.

RESULTS: Thirty participants from diverse backgrounds were interviewed. Six themes emerged, forming a conceptual framework of disability-based discrimination in health care. Three themes described drivers of discrimination: lack of clinician knowledge, clinician apathy, and clinician assumptions. Three themes described manifestations of discrimination: limited accessibility to care, substandard care, and dehumanization.

CONCLUSIONS: Children with medical complexity may face disability-based discrimination in health care. Themes describing the drivers and manifestations of discrimination offer a conceptual framework of disability-based discrimination. Understanding the drivers and acknowledging perceived manifestations can provide insight into improving patient care for children with disabilities.

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WHAT'S KNOWN ON THE SUBJECT: Disability-based discrimination in health care can lead to gaps in care and poor health outcomes for patients with disabilities. Evaluation of physicians has demonstrated a lack of confidence and skill in caring for patients with disabilities which may perpetuate disparities.

WHAT THIS STUDY ADDS: Caregivers of children with medical complexity report experiences of disability-based discrimination in the healthcare of their child. These experiences are driven by clinician knowledge, apathy, and assumptions, and manifest as lack of access to care, substandard care, and dehumanization.

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Discrimination in health care occurs in 1 out of every 5 patients.[1] Although racial and gender discrimination in health care are important topics of active research, disability-based discrimination in health care is largely overlooked, particularly in children with disability.[2] Disability-based discrimination in health care is complex and may reflect physician lack of confidence and skill in caring for patients with disabilities, lack of available time or resources for complex care, or explicit and implicit biases including inferences regarding quality of life and worthiness.[3–5] Regardless of root causes, disability-based discrimination in health care can impact patient health and well-being, leading to poor outcomes with severe consequences.[6] Adults who have experienced disability discrimination report significantly higher rates of depression, poor mental functioning, and overall worse health and quality of life than those who have not.[7,8] Disability discrimination can also harm patient clinical outcomes by potentiating gaps in health care access and avoidance of necessary care for vulnerable patients, further exacerbating inequities.[9–12]

Children with medical complexity represent a subset of children with disability who have substantial health needs and disability leading to frequent interactions with the health care system.[13] The experiences of these children in the health care systems are unique, and their perspectives of disability-based discrimination in health care are poorly understood. A deeper understanding of perceived experiences of discrimination through caregiver perspectives is needed to inform education and interventions to improve care for children with medical complexity. Therefore, the primary objective of this study was to qualitatively describe the perspectives and experiences of family caregivers of children with medical complexity regarding disability-based discrimination in health care.

METHODS

Design

This is a qualitative study using semistructured individual interviews and a thematic analysis approach to inductively identify themes related to disability-based discrimination from the perspective of caregivers of children with medical complexity.[14] The research team for this study consisted of a pediatric critical care physician, a general pediatrician, 2 physical medicine and rehabilitation and disability physicians, a pediatric palliative care physician, and 2 qualitative research experts. The consolidated criteria for reporting qualitative research checklist was used during study design, analysis, and reporting.[15]

Eligible participants were parents/caregivers of a child with medical complexities who were aged ≥1 year and reported a disability related to physical, cognitive, communication, and/or social functioning. Medical complexities were defined as having ≥2 organ systems affected and either technology dependencies, functional impairments, or high health care resource utilization. In addition, the caregiver must have perceived that their child experienced discrimination in a health care setting because of disability, which was assessed during a screening questionnaire before enrollment (Supplemental Information).

Parents/caregivers of children with medical complexity were recruited and selected by purposive sample techniques to participate in an interview to explore experiences of discrimination in health care. Participants were recruited through a variety of methods to ensure a diverse and geographically broad sample with experiences in different health care settings in the United States. First, participants were recruited through flyer advertisements distributed by Family Voices, Inc, a national family advocacy group working to support families of children with special health care needs. Additional participants were directly recruited through medical clinics focused on care of children with medical complexity through the Children and Youth with Special Healthcare Needs National Research Network, a research network of major pediatric hospitals in the United States. Sampling was continued until thematic saturation occurred.

Participants received a gift card after their participation to compensate for their time and expertise. This study was approved by the institutional review board, and informed consent was reviewed before participation in the study.

Data Collection and Processing

Individual in-depth interviews of 30 participants were conducted between November 2021 and August 2022. An interview guide was developed in conjunction with parent partners recruited through a local parent advisory council. The guide was organized around a stigma framework and included open-ended questions and probes related to experiences of discrimination, impacts on the child, and impacts on caregivers (Supplemental Information). Ć[16] Interview questions were piloted with a parent of a child with disability and refined for phrasing and content on the basis of feedback.

Interviews were conducted in English (by S.G.A.) or Spanish (by C.D.) on the basis of participant preference. All interviews were conducted via video conferencing because of geographic distribution of participants, with only the participant and the interviewer present. Interviews lasted between 30 and 90 minutes, and were audio-recorded and transcribed verbatim by a third-party transcription service.

Participants completed a demographic survey for the purpose of describing the sample and ensuring recruitment of a racially, socioeconomically, and geographically diverse population. The survey included questions related to age, sex, race and socioeconomic status, and information regarding their child including age and number of health care visits annually.

Data Analysis

Data analysis and data collection occurred iteratively, to revise the interview guide and develop a more nuanced understanding of disability-based discrimination in health care. We applied grounded theory principles to build our conceptual model on the basis of the experiences of participants. Grounded theory is defined by systematic collection and concurrent analysis of qualitative data to allow themes and theories to emerge from the data themselves rather than building from a priori hypotheses.[14]

Data management and analysis were conducted using Dedoose software (Version 9.0.54, Los Angeles, CA: SocioCultural Research Consultants, LLC). Coding began with a line-by-line evaluation of the first 5 transcripts by 2 analysts (S.G.A. and R.K.D.). The analysts met to review codes and reach consensus on an initial codebook that captured emerging themes related to disability-based discrimination in health care. The codebook was refined as researchers revised and expanded codes with subsequent analysis. All transcripts were dually coded (S.G.A. and R.K.D.) to ensure trustworthiness. Any coding discrepancies were discussed and resolved through consensus.

After coding, the analysts ran code reports and wrote analytic memos in which codes and text were evaluated for concepts and categories of data and comparison among participants. The research team discussed codes and memos to group concepts and evaluate for emergent themes using axial coding. Data collection and analysis were complete when thematic saturation had occurred, which was determined when no new themes or information emerged and themes were felt to adequately determine a conceptual framework.[17]

RESULTS

Participants

Overall, 30 participants were recruited from 15 states (Fig 1). The majority of caregiver participants were female (25 of 30), ranging from ages 26 to 55 years old, and married (20 of 30). Their children with medical complexity ranged from age 18 months to 18 years. Most caregivers reported that their children had >20 health care encounters annually and were insured through Medicaid. Child and participant characteristics are shown in Table 1.

Six themes emerged surrounding perceived disability-based discrimination in a health care setting. Three themes were categorized as perceived drivers of discrimination (clinician lack of knowledge, clinician apathy, and clinician assumptions) and 3 themes were categorized as manifestations of discrimination (limited accessibility to care, substandard patient care, and dehumanization). These themes generate a framework of experiences of interpersonal discrimination in a health care setting for children with medical complexities and their families (Fig 2).

FIGURE 1
Geographic representation of participant location by state.

Drivers of Perceived Disability-Based Discrimination

Table 2 summarizes the themes regarding perceived drivers of disability discrimination. Participants discussed clinician knowledge of disability and medical complexity as a key driver of discriminatory treatment. Clinician knowledge gaps were perceived to impact treatment decisions, interactions with the child, and communication to the caregivers. One mother described seeking health care for her child with a genetic condition associated with disability and complex medical needs:

> "*What I've often found is, we got a lot of blanket statements about the nonviability of this diagnosis or just … what am I trying to say? Just the hopelessness around the diagnosis. But not many providers actually knowing what to do to treat, right?*"

Participants also felt that clinicians lacked interest in their children, or were reluctant to care for children with disabilities. To many participants, lack of interest or apathy was described as clinicians perceiving that their child may not be worthy of care. One mother described her perception that physicians would rather not care for children with medical complexity:

> "*My perception is that [clinicians] wanted to take care of the patient that didn't have a severe, special need. I don't know. They just didn't seem like they cared to even treat [my daughter].*"

Finally, participants discussed clinicians' personal assumptions that drove discrimination. Subthemes included negative assumptions about patients based on disability, and explicit and implicit bias regarding quality of life because of disability. One mother described physicians

TABLE 1 Child and Caregiver Participant Demographic Information

	N = 30
Child characteristic	
Child's age in y, median (IQR)	9 (4.5–13)
Child's sex, *n* (%)	
Female	12 (40)
Male	18 (60)
Race, *n* (%)	
White	21 (70)
Black	8 (27)
Asian American	1 (3)
Ethnicity, *n* (%)	
Hispanic	4 (13)
Non-Hispanic	26 (87)
Child's primary insurance coverage, *n* (%)	
Insurance purchased through provider	11 (37)
Medicaid/public insurance	16 (53)
Military insurance/Tricare	3 (10)
Average annual health care encounters,[a] *n* (%)	
0–10 encounters	7 (23)
11–20 encounters	7 (23)
>20 encounters	16 (53)
Participant characteristic	
Age in y, median (IQR)	40 (35–42)
Female, *n* (%)	25 (83)
Race, *n* (%)	
White	22 (73)
Black	7 (23)
Asian American	1 (3)
Ethnicity, *n* (%)	
Hispanic	4 (13)
Non-Hispanic	26 (87)
Marital status, *n* (%)	
Married	21 (70)
Divorced	4 (13)
Single	5 (17)
Highest education level achieved, *n* (%)	
High school	6 (20)
Bachelor's degree	12 (40)
Masters' degree	9 (30)
Doctorate degree	2 (7)
Not reported	1 (3)
Employment status, *n* (%)	
Full-time employment	15 (50)
Part-time or contract work	7 (23)
Unemployed	6 (20)
Retired or not reported	2 (7)
Average estimated annual household income, $, *n* (%)	
<50 000	7 (23)
50 000–99 000	12 (40)
100 000–150 000	5 (17)
>150 000	5 (17)
Not reported	1 (3)

[a] Estimated annual average number of health care encounters, including emergency department, urgent care, inpatient, outpatient, and subspeciality care.
IQR, interquartile range.

limiting treatment options on the basis of assumptions of child's disability:

> *"They are acting as you're a waste of resources or you are not worth whatever, and they're gate keeping … They're being influenced by their perception of disability or kids with this diagnosis or whatever it is. They act as gatekeeper and you are trying to do everything you can to knock that gate down."*

Another mother described challenges with clinicians' quality-of-life assumptions because of disability influencing medical decisions:

> *"A lot of times, these [clinicians] that are counseling you on these (medical) decisions, they see such a small piece of that person's life. They either only see them when they're in the hospital and they're at their sickest, or they only see them when they come in for an appointment, so they see them for 30 minutes every 3 or 6 months or something like that. So, I don't think it's not necessarily with bad intent, but they don't have a positive impression of disabilities or medical needs and things like that."*

Manifestations of Perceived Disability-Based Discrimination

Table 3 summarizes the themes regarding perceived manifestations of disability-based discrimination in health care. First, experiences of clinician unwillingness to welcome or provide care for disabled children in their practice limited options for care. One participant described her experience with finding a primary care physician:

> *"[My child] has specialists. I need [the pediatrician] for the simple, basic pediatric stuff. Like write the referrals, take her weight, do her annual checkup. [The pediatrician] said 'I really don't think that I can serve you.' And I say, 'Can you just be honest with me? What is it?' She goes, 'I'm just not comfortable. I'm not comfortable caring for your daughter.'"*

Additionally, lack of appropriate accommodations inhibited care for some families. Examples of missing appropriate accommodations included lack of wheelchair scales, accessible doors, wheelchair ramps, and parking for larger vehicles. The experiences of feeling unwelcome at a medical practice and being provided reasonable accommodations were further challenged by cultural, racial, and language barriers that were perceived to further decrease willingness to care for a child with disability. For example, participants from minoritized groups described interactions in the health care system where treatment of pain was inappropriate because of assumptions of race, language services were not offered so care was not adequate, and interactions with clinicians were strained because of racial and ethnic differences.

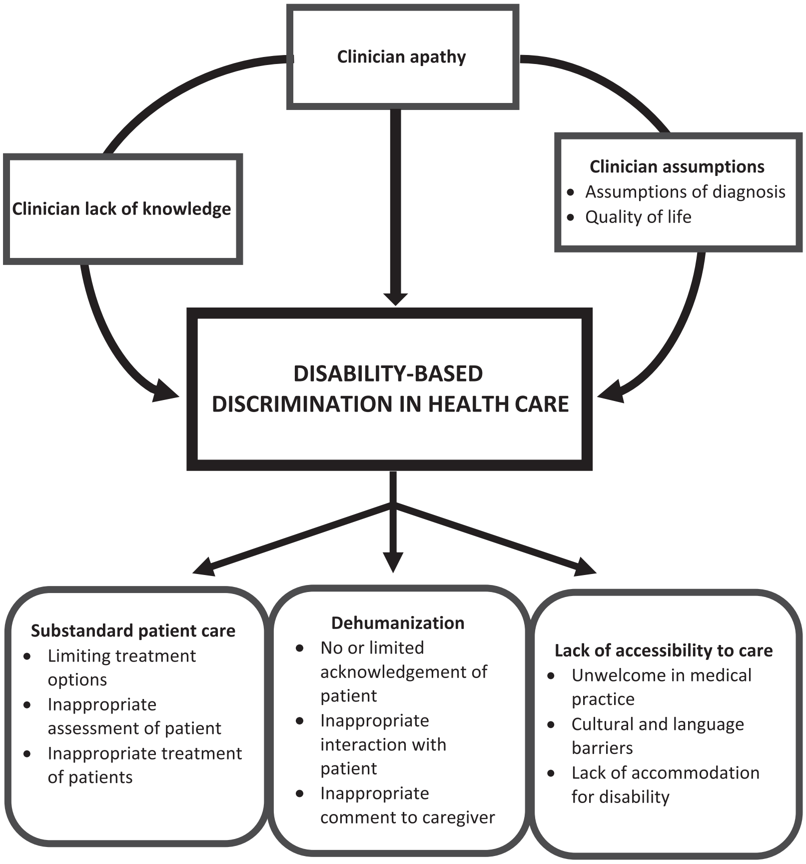

FIGURE 2
Conceptual framework of interpersonal disability-based discrimination in health care.

Participants also described substandard health care experiences where they perceived clinicians' medical decisions as being influenced negatively by the child's disability. This often presented as clinicians not offering all available treatments or attempting to influence participants' decisions on the basis of the child's disability. One participant described the experience of her daughter with disability and a new cancer diagnosis with high remission rates:

> "*[Doctors told me], 'She's been through so much. And do you really want to put her through more?' All these things and I'm thinking, if this were a typical child, would you be telling this parent, 'Don't treat this cancer?' Or would you be saying, 'Here's the number to St. Jude's?'*"

Substandard treatment also manifested in management of pain, because caregivers often perceived discrimination because of disability in clinician lack of acknowledgment of pain or lack of appropriate treatment of pain in children with disabilities. One mother described an experience where her child did not receive adequate pain medication for a painful procedure because the child lacked linguistic communication:

> *"I think the assumption is pain looks like they'll pull away, pain looks like they'll cry, pain looks like that. She doesn't respond to pain that way, but it is still painful to her. It's still aversive."*

Another theme encompassing disability discrimination emerged as dehumanization of children with disability. Dehumanizing events emerged as lack of acknowledgment or communication with the patient, inappropriate interactions with the patient, or inappropriate comments to the caregiver. This mother described the dehumanizing treatment:

> *"They mistreated her, and treated her like a robot. Every single time a nurse walked in the room, they treated her like she was not even there."*

Another participant referred to a conversation with her physician regarding how the parent reads books to her daughter:

> *"[The doctor said], 'Well, you can [read] if it makes you feel better, but she's not really learning, and she's not really responding like other kids. She responds like a dog.'*

TABLE 2 Illustrative Quotes for Themes Describing Drivers of Perceived Disability-Based Discrimination in Health Care for Children With Disability

Drivers	Exemplar Quote
Clinician knowledge	[The provider] didn't have that knowledge. And nor did anybody teach her to listen, listen to a parent. It only takes about a minute to realize if a parent knows what they're talking about when they're talking about their kid's medication and medical issues and things up under that medical umbrella.
Clinician apathy for patients with disability	When we had to leave that appointment and he had to know that the doctor didn't think it was important to help him. It was shattering … He pieces it together, that there are things that [the doctor] won't take seriously because he's in a wheelchair.
Clinician assumptions	
Assumptions about patient based on diagnosis or disability rather than individualized care	And because he doesn't make eye contact, part of the things that come along with having his syndrome. He just isn't your typical child that's going to look at you in the eyes when you're talking to him. And so, they just assume that, because he's nonverbal and he's not making eye contact, that he just doesn't understand what's going on or doesn't understand what they're saying, when that's really not the case. He's a very intellectual child.
Assumptions regarding quality of	I had a few remarks made by my doctor, as well, kind of in a similar vein of basically that it was inhumane basically for somebody to be disabled and for you to support their life knowing that they're going to be disabled. Which I can tell you right now, yes, she is disabled, and she's literally the happiest 1-year-old I've ever met in my life. She smiles and plays and interacts more than any 1-year-old I've ever met.

> *That's literally what he said. Those were his words, and you think this is the clinic for people with special health care needs."*

DISCUSSION

In this study, caregivers of children with medical complexity describe discrimination against their children in the health care setting. This data informed a conceptual framework of interpersonal disability-based discrimination in pediatric health care (Fig 2), which includes drivers and manifestations. This framework validates caregiver experiences and can help clinicians to recognize and address microaggressions and explicit discrimination in health care encounters, and also identifies specific targets for better preparing the health care workforce to render quality care to pediatric patients with disability.

Clinicians' lack of knowledge regarding disability was perceived to be a key driver of discrimination. Although this driver emerged from caregiver perceptions in our study, previous research aligns with this assessment, because clinicians commonly report significant gaps in knowledge and skills, as well as a general lack of comfort in caring for patients with disability.[18] Unfortunately, lack of knowledge likely contributes to attenuated and substandard care for children with disability. In a survey, physicians reported a lack confidence in providing quality of care for adult patients with disability, with only 56% strongly agreeing that they welcomed patients with a disability into their practice.[5] Accessibility to quality care for patients with disability is further inhibited by lack of appropriate accommodation, as was found in our study. Previous research has noted that physicians lack knowledge about reasonable accommodations for disabilities, and do not feel obligations to provide accommodations.[18,19] Although not yet studied well in pediatric health care, clinicians' limited self-efficacy in caring for patients with disability may perpetuate disparities in health care accessibility and contribute to poor health outcomes.[20–22]

Across the interviews, clinicians' implicit bias toward individuals with disabilities emerged as a key driver of discrimination. Caregivers shared examples of clinicians assuming children with disabilities have a negative quality of life or are less worthy of care, leading to biased medical decision-making, dehumanizing encounters, and substandard care with suboptimal outcomes. When quality of life assumptions are conflated with futility, resource rationing and fatal medical decisions can result.[6,23,24] Importantly, previous research has shown clinician assumptions of quality of life in both adults and children with disability are often grossly incorrect.[5,25] Clinicians often predict quality of life to be poor for patients with disability as compared with patient- or parent-reported quality of life, which is often reported to be good to excellent.[25] This concept is known as the disability paradox and represents a significant implicit bias against disability because of mispredictions of quality of life by health care professionals.[26]

Finally, clinician apathy emerged as a driver of disability-based discrimination in health care. For many caregivers, this driver often led to encounters in which clinicians were perceived to dehumanize children with medical complexity or have a negative attitude regarding disability. This lack of interest may stem from clinician inexperience, feelings of burden because of structural barriers, or implicit bias.[18] Caregivers reported strategies to mitigate dehumanization of their child, including sharing stories of their child and posting pictures in their hospital room to demonstrate their life outside of the hospital.

The emergence of lack of knowledge, bias, and apathy as key drivers of disability-based discrimination in health care

TABLE 3 Themes, Subthemes and Exemplar Quote for Manifestations of Perceived Interpersonal Disability-Based Discrimination in Health Care for Children With Disability

Theme	Subtheme	Exemplar Quote
Limited access to care	Unwelcome in medical practice	And then she said, “But here’s the thing.” She’s like, “Honestly, we don’t want to work with autistic children.” And she said, “They’re just really hard.” And she said, “So, you know, we just are really hopeful that someone in the community will want to work with him, but we’re not it. We are going to focus on working with children who are not autistic.”
	Cultural and language barriers	I mean, they don’t look for an alternative, they don’t make any effort to say, “Okay, wait a moment, let me see if I can find you any person who speaks the language; let me see if I can find you a translator, even if it is by telephone; let me see how I can help you, even in writing; write me in Google Translate, whatever you want to tell me,” that is, no, that is, it is a thing like, “I do not want you.”
	Lack of accommodation for disability	I would say hospitals don’t seem to take into account disabilities architecturally, like automatic doors are not always a thing. And I think that, when there’s, even equipment is not always appropriate, like most clinics won’t have a wheelchair scale. So, I think that their at least mobility or special needs that require adaptations are not always given a lot of thought. I think sometimes the doctor, when they have these complex kids, feel overwhelmed and almost like, “It’s an unfixable situation. So, let’s not offer the same things.”
Substandard care	Limiting care	He is less intrinsically motivated to work on OT stuff and it’s also just harder for him. It’s challenging stuff. And I think they’re using that as an excuse to say like, “Oh, he is not going to make progress. So, why bother investing resources in him?”
	Inappropriate treatment of pain	So, the most common thing that we face is the disbelief of medical professionals about his pain … there is a stigma that comes from way, way back that Black people can endure more pain than other ethnicities, which is absolutely a myth.
Dehumanization	Not acknowledging patient during care	And she kind of called the doctors out and said, “You guys treat her like she’s a vegetable or that she’s invisible. You completely look past her, instead of looking at her.” They didn’t treat her like she was really alive. They absolutely looked at her as if she was a vegetable and completely nonresponsive, which is not the case.
	Inappropriate interaction with patient	Some will ignore her until it’s time for the exam. That’s really irritating because we’re not there for me. If we’re there for me, fine. But if we’re there for her, she is your patient, not me. Some won’t even address her. They walk in and address me and ignore her. She may not talk a lot, but her ears are just fine. And that’s the other thing, they talk about them like they’re not there.
	Inappropriate comments to caregiver	And a nurse was like, “What is wrong with him? Why does he act like this?” And I was like, we were, first of all, in a children’s hospital. You would think he would understand kids with disabilities. It was so disrespectful. I thought, there’s nothing wrong with him. He’s 2. He’s very delayed developmentally. He is confused. He has extreme anxiety.

OT, occupational therapy.

identifies an urgent need for further education and disability training in clinicians. As the number of children with medical complexity increases, it is imperative that postgraduate medical education curricula address these knowledge gaps. Unfortunately, current training in disability is felt to be inadequate in medical and nursing education, leading to gaps in knowledge and negative attitudes of health professionals toward persons with disability.[27–31] Pediatric clinicians would benefit from increased education with curriculum focused on patients with medical complexity and disability.[32] One potential intervention is the incorporation of established core competencies for health care professionals into accreditation and licensure standards.[33] Other potential education-focused interventions for improving knowledge and regarding disability and medical complexity and reducing bias in pediatric trainees may include contact-based approaches or immersive curriculum.[34–37]

There were limitations to this study. First, because participants were recruited from clinics or advocacy organizations that serve families with children with complex medical needs, the sample may be biased to exclude patients who do not have access to comprehensive care or are not part of a disability-focused community. The recruitment of these samples was purposeful for qualitative research, but may not reflect the experience of other caregivers of children with disability. In addition, the experience of interpersonal discrimination represents an interaction between at least 2 people. In this study, only caregivers of children with disability were participants and therefore this conceptual model lacks the perceptions of clinicians in caring for children with disability. Given the focus of perceptions of discrimination, the caregiver experience develops an important model, and future work should focus on improved understanding of clinician perceptions and experiences in pediatric health care.

CONCLUSIONS

Children with medical complexity are dependent on the health care system to meet their health needs. Unfortunately, their experiences in health care are threatened by discrimination because of their disability. The results of our qualitative study provide a conceptual framework of disability-based discrimination in health care for children with themes emerging encompassing both the drivers and manifestations of discrimination between clinicians and their pediatric patients. Addressing the drivers and acknowledging perceived manifestations can provide insight into improving patient care for children with medical complexity and all children with disability.

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