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Perspectives of Interactions with Healthcare Providers Among Patients Who Are Blind

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Abstract

Healthcare providers' (HCPs) stereotypes about the incompetence of blind and low-vision patients may lead them to patronize blind patients, over-focus on impairments, and neglect the presenting problem. The content of perceived HCP stereotypes about blind patients in the clinical setting was examined from the patient perspective with seven focus groups, including a total of 42 individual participants. Most participants reported an interaction when their HCPs treated them as if they were incompetent, and discussed how perceived evaluations of their warmth and competence impacted whether their HCPs trusted and respected them. Participants also discussed their evaluations of their HCPs' warmth and competence, and how these evaluations impacted their trust and respect for the HCP. These results provide insight into blind patients' experiences interacting with their HCPs and can inform interventions to 1) help HCPs avoid stereotypic attitudes and 2) improve HCPs' comfort and abilities when working with patient with disabilities.

Keywords

Blindness; health personnel; focus groups; judgment and decision making; stereotypes

Introduction

The National Council on Disability urged researchers and healthcare providers (HCPs) to eliminate health disparities faced by people with disabilities by examining how stereotypes about disability affect the quality of healthcare provided to persons who are blind and have

Informed Consent and Confidentiality

I confirm all personal identifiers have been removed or disguised so the persons described are not identifiable and cannot be identified through the details of the story.

low vision (National Council on Disability, 2015). There are more than 7.5 million blind people in the United States. (Erickson et al., 2017). This proportion is projected to increase with aging in the population (Varma et al., 2016). In the United States, the classification for blindness includes distance visual acuity of 20/200 with optimal correction in the eye that can see the furthest, or having a visual field equal to or less than 20 degrees (Vashist et al., 2017), including individuals with varying degrees of usable vision ranging from these cutoffs to no light perception whatsoever. Despite established links of stereotypes to health disparities, blind persons' experiences of stereotypes and prejudice in the healthcare setting are understudied (National Council on Disability, 2015).

Stereotypes of Warmth and Competence

Little is known about the content of stereotypes and how they result in prejudicial treatment of people with disabilities in the healthcare setting (Dovidio & Fiske, 2012; Frederick, 2015). The Stereotype Content Model is a framework for examining perceptions about blind persons' warmth and competence. Thus, this model was used to understand blind persons' perceptions of how they are evaluated by their HCPs and the healthcare implications of these evaluations. According to the Stereotype Content Model (Fiske et al., 2007; Ho, 2011), a perceiver's stereotypes and prejudice consist of their perceptions of a target's concern for the well-being of others (warmth) and capacity to attain positions of status (competence). Blind persons are presumed to have good intentions (high warmth), but limited in ability to achieve status (low competence) (Fiske et al., 2007; Fraser et al., 2016). Thus, blind people are often approached with pity (Fiske et al., 2002; Fiske et al., 2007).

As a result of HCP perceptions of blind patients' warmth and competence, blind patients may not be directly spoken to by their HCPs (Fraser et al., 2019), and their health concerns may be over-pathologized and treated more intensively (e.g., by unnecessary institutionalization) (Dovidio & Fiske, 2012; McColl et al., 2008). People with disabilities are often aware of disability-related stigma and stereotypes that can discourage them from seeking healthcare (Fraser et al., 2016). It is crucial to examine patients' perceptions of engaging with HCPs to identify barriers to healthcare that contribute to health disparities for blind people.

Respect and Trust

Trust in healthcare providers is associated with better patient health outcomes, engagement in the treatment plan, and patient satisfaction with the HCP (Williams & Bigman, 2018). Perceived discrimination stemming from a lack of perceived respect (e.g., perceptions of being treated as low in competence) leads to mistrust of medical authorities and medical information (Cuevas et al., 2016; Plaza, 2014) and may lead to patient disengagement in medical treatment (Williamson & Bigman, 2018). Blind patients become mistrustful towards HCPs as a result of negative interactions (Frederick, 2015; Ho, 2011) and may attribute their negative experiences to perceived discrimination leading to dissatisfaction and disengagement in healthcare. Patients' perceptions that their HCPs do not view them as competent may undermine the trust that is fundamental to encouraging health-promoting behaviors (Dovidio & Fiske, 2012; Ho, 2011).

In this study, qualitative data was collected regarding blind persons' perspectives on how their HCPs evaluate their warmth and competence, and on the level of respect with which they were treated by HCPs. The following three research questions were used to guide the proposed inquiry:

1. What are blind patients' perceptions of how their HCPs perceive them and their competence?
2. What are blind patients' experiences interacting with their HCPs when making a treatment decision?
3. How do these interactions affect blind persons' overall functioning and health?

Method

Focus groups were conducted to corroborate themes related to the Stereotype Content Model and to identify additional themes characterizing nuances of the patient experience. Focus groups are effective at inducing discussion from participants with marginalized identities who may be more forthcoming about experience and perspectives in the company of peers (Krueger & Casey, 2002; Robinson, 1999). Ninety percent of themes can be discovered in three to six focus groups (Guest et al., 2017), and having five to seven participants per focus group promotes participant engagement in discussions and is a manageable size for the moderator to facilitate (Krueger & Casey, 2002). The focus groups in this study followed these guidelines.

Participants

The Institutional Review Board of a university in the southwestern United States approved this study (study number 1076587-1). A recruitment email was distributed to national and state organizations of the blind listservs. Inclusion criteria were blindness, age of 18 years or older, English literacy, and phone proficiency. Forty-eight blind people from across the United States were invited to participate in this study and 42 participants completed the full study. Participants were mostly female (90.48%) and White (92.86%). The average age was 53.31 years ($SD = 13.67$) and participants reported, on average, 16.94 years of education ($SD = 2.60$), equivalent to a bachelor's degree and an additional year of graduate studies.

Procedure

Seven focus groups, each consisting of four to eight participants, were conducted during the end of June and beginning of July 2017. The researchers sent prospective participants the informed consent document and a Qualtrics survey, including a measure of demographics. After completing these documents, participants were contacted by email and/or phone to be scheduled for a focus group session.

Focus groups were conducted using the conference call platform [freeconferencecalls.com](https://www.freeconferencecalls.com). This auditory platform was selected over a traditional in-person approach to focus group interviewing because it reduced potential interviewer bias due to varying degrees of usable vision and physical presentation (Heydarian et al., in review). It also removed the barrier of transportation to and from an interview site; transportation is a barrier

that disproportionately affects people with disabilities (Iezzoni et al., 2006). Focus group sessions were two hours long. The first author moderated all focus groups, following a semi-structured interview guide.

The moderator opened the focus group discussion by introducing herself, then informed participants of the purpose of the research and their rights as participants. In order to preserve confidentiality, participants agreed to keep responses of other participants confidential and used pseudonyms when contributing to the discussion. The moderator outlined rules of engagement and then facilitated discussion. Rules of engagement included stating pseudonym before making contributions to the discussion, and using respectful language when bringing up a point or challenging another participant's point of view. Participants were assured that there were no right or wrong answers and that it is okay to agree or disagree with other participants. The interviewer facilitated the discussion by posing a question from the interview guide, gave each participant a chance to be the first to answer a question if they chose, and called on less-forthcoming participants to ask if they wanted to add to the discussion. Finally, participants were thanked for their participation and dismissed.

Data Analyses

The research team transcribed all focus group recordings and conducted thematic analysis on the transcriptions (Braun & Clarke, 2006). Data preparation and analysis was conducted across two phases. Phase 1 included the research team transcribing all focus group data and triple-checking transcriptions to ensure accuracy. Next, the first author developed the codebook of inductively derived themes and two independent coders used this codebook to complete the first round of inductive coding. The first author and two independent coders, then, defined inductive themes and the independent coders completed the inductive coding. In the second phase, unresolved quotes were reexamined by independent coders. Then, the first author and coders met and defined deductive themes to add to codebook. Finally, the independent coders completed deductive coding, the first author checked all codes within the context of their transcriptions to ensure their accuracy, and coded meaningful passages left out by coders.

Results

The domains of competence, warmth, respect, and trust emerged in discussions of how HCPs perceived blind patients. See Tables 1 – 3 for a summary of themes that emerged in response to each of the three research questions along with sample quotes and participant characteristics. Each participant's age, gender, and focus group are reported for contextualization. The remaining demographic characteristics are reported in aggregate in the Participants section of this manuscript to preserve participant anonymity.

Q1: What Are Blind Patients' Perceptions of How Their HCPs Perceive Them and Perceive Their Competence?

Competence and Impression Management—Ten participants across five focus groups expressed that they had positive experiences with their HCPs because they were

treated as competent (e.g., “[HCPs] don’t assume that I don’t know what I’m talking about.” Female, age 64). However, 30 participants across all focus groups reported instances where they felt their HCPs believed them to be incompetent. They described incidents where HCPs expressed surprise about the patient’s ability to recognize sensations in their own bodies (e.g., “They feel like because you’re blind, you can’t do anything! Like, you are totally incapable and not ...the fact...that you know what you need. ‘Oh, how can you know that you have a headache? You’re blind.’” Female, age 40). Twenty-four participants across all focus groups noted pressure to appear competent or warm. One such participant discussed the excessive burden this pressure places on the patient:

If you ... walk tall with your big stick, people are a little bit more open toward you. If you look confident, look like you know where you’re going, they seem to be a bit more open. But, that’s still...unfair ‘cause if you’re... sick and you’re going to the hospital or you’re going to see your doctor and you feel under the weather, it’s not fair of them to judge you because you’re not looking confident. (Transgender, age 35)

Despite efforts to appear competent, 11 participants across all focus groups reported being unsuccessful at convincing the HCP of their competence (e.g., “they [HCPs] take it [assertiveness from patient] more as almost an affront.” Female, age 56). Seventeen participants across all focus groups reported cases where assumptions of their incompetence seemed to cause an HCP to refuse treatment (e.g., “He [the doctor] had almost gotten another friend of mine who is blind killed because she was diabetic and he refused to forward the insulin [prescription] to her hospital stay just because he thought she was being crazy, which she absolutely was not.” Transgender, age 35).

Addressing the Blind Patient—Twenty-three participants from all focus groups reported that, instead of addressing the patient directly, some HCPs addressed the nearest sighted person (e.g., “I’ve had healthcare providers in particular ask the person who is just randomly standing next to me, and asking as if they were my companion. ‘Can you fill out the paperwork for him?’” Male, age 53). Furthermore, three participants in three focus groups reported that HCPs directed questions about their healthcare to their children (e.g., “I remember one time I went in [to the doctor]...and I had my daughter with me, who was eight or nine at the time, and they were going to ask [her] the questions.” Male, age 57). When seven participants across five focus groups discussed their experiences as caregivers, they reported HCPs interfering with their caregiver role:

Even if you can get people to deal with you directly, it’s really hard to take the next step and have them deal with you when you’re the caregiver. My husband has routine colonoscopies that you always have to bring somebody with you. Sometimes they’ve been fine with my being blind and sometimes they freak out because they’re like, “How are you going to get him home?” And I’m like, “Well, if I drove ... he would still walk and get in the car. I’m going to call a cab or Uber and go home with him.” (Female, age 54)

Trust and Respect—Participants discussed how HCPs, to varying degrees, seemed to trust the medical information provided by blind patients. Five participants from three focus

groups believed that their HCPs trusted them (e.g., “I feel like the doctor...takes the time to get to know me, that there’s more trust.” Female, age 32). HCPs who were described as being respectful and not assuming low competence were also reported to give more consideration to the patient’s perspective and the medical information that the patient shared with them (reported by 31 participants across all focus groups; e.g., “All my positive experiences are with doctors who seem to respect that a) I have some...medical background and b) that I know my body very well.” Female, age 54). Conversely, 12 participants from all focus groups reported thinking that their HCPs did not trust them and did not listen to the information they provided (e.g., “When I say something, it’s like, ‘Well, what does she know? She’s only a blind person, right?’” Female, age 58).

Furthermore, 27 participants across all focus groups expressed lack of respect from their HCPs (e.g., “It makes you think that you’re more of an object for someone’s entertainment instead of an actual human being.” Male, age 28). Fourteen participants from six focus groups reported feeling as if their HCP perceived them as an inconvenience (e.g., “I couldn’t do it [fill out intake forms]. The nurses wouldn’t do it, so they called up somebody from the staff and she didn’t want to do it ‘cause she wanted to go home early.” Male, age 72).

Thirteen participants across all focus groups reported that they were treated with pity by their HCPs (e.g., “There’s the pity and the [attitude of] ‘Oh, we feel so sorry for you and we can’t fix you.’” Female, age 56). Five participants across four focus groups reported that their HCPs adopted a patronizing tone of voice when talking with them (e.g., “They think you’re blind and so they have to speak really loudly to you. Or they speak really slowly and over-enunciate.” Female, age 62). Two participants in separate focus groups reported that HCPs provided unsolicited help with simple tasks (e.g., “The nurse takes you back and you’re doing the pee-in-the-cup thing. So, she starts to take the cover off [of the cup] and I said ‘...I got myself here, I think I can [get the cover off the cap].’” Female, age 54).

Q2: What Are Blind Patients’ Experiences Interacting with Their HCPs When Making a Treatment Decision?

Shared Decision-Making—Twelve participants across six focus groups reported that HCPs shared clinical decisions with them, informed their patients about treatment options, and considered their preferences:

Usually, they’ll...tell me why they’re doing things. If they give a valid reason, I’m willing to go along with it, but we’ve worked out different...courses of care...you want me to give myself a shot?...How about something else? Especially because they’ve got lotions and stuff that will absorb through the skin and will have the same [effect]. (Male, age 53)

Alternatively, according to six participants across four focus groups, due to competence assumptions some HCPs did not share enough information with their patients to allow them to participate in medical decision-making. Also, five participants across three focus groups reported that HCPs failed to review medical conditions and treatment options with blind patients, did not review side effects of treatments with patients, and did not allow patients to authorize decisions about themselves:

I was having some problems and I went to see an OB-GYN...he evaded my questions...I said, "What should we discuss?...Do I need a definitive surgery?"...He's like, "I wouldn't worry about it. It's just a minor problem." Well, it turned out to be a very major problem [requiring a hysterectomy]...He did not address...my concerns. The fact that this man spoke louder, he thought that because I couldn't see,...I didn't understand questions or answers...and he [would] rather talk to my mom than me.(Female, age 39)

Mistrust—Patients' impressions that their HCPs perceived them as incompetent led to patient mistrust regarding the HCPs' diagnostic and treatment decisions. Fifteen participants across six focus groups perceived and disagreed with HCPs' judgment of their incompetence. They reported that this led them to question other judgments made by their HCPs such as clinical judgment:

Because she made such a big deal about blindness that when blindness really had nothing to do with it. But she wasn't really taking me seriously. So I guess I have less confidence that she'd actually be able to figure out what was going on. (Female, age 32)

Q3: How Do These Interactions Affect Blind Patients' Overall Functioning and Health?

Refusal of Service—Seven participants across four focus groups discussed how their HCPs refused them services due to assumptions of incompetence or discomfort about working with blind patients (e.g., "They almost wouldn't let me do it [get hormone replacement therapy] because of the injections thing. And ... I was like, 'Yeah, I know I can stab myself in the leg with the needle.'" Transgender, age 35).

Respect—Most (31) participants across all focus groups reported an instance of feeling respected by some of their HCPs, noting that in these interactions they felt treated like whole and valued people:

Whenever she [HCP] has a question about blindness it's something like, "what is the best way to do this for you?" And then whatever I tell her is the best way to do it for me, she does it after that. (Female, age 37)

One participant inferred that her HCP perceived her as competent because the HCP addressed family planning with her:

The medical resident conducting the exam said, "...We know that you're not planning on getting pregnant right now, but if you decide...that you want to start a family, we have a really good prenatal clinic here and we can put you on multivitamins ... We can hook you up with an OBGYN."... Even though I wasn't planning on getting pregnant, I thought it was really cool that she didn't assume that because I was blind that I couldn't be a parent. And she just, like, probably said the same thing to me that she says to other 30-year-old female patients who come in. And I just thought that was cool. (Female, age 32)

However, 23 participants across all focus groups expressed that some of their HCPs did not consider their concerns and that this discouraged some participants from seeking future

healthcare (e.g., “I’ve been through four primary cares because they don’t care. They don’t want to hear you, they don’t listen. They just yell at you for your numbers that might be too high or too low.” Female, age 67).

Discussion

This study characterized some of blind persons’ clinical interactions with HCPs, particularly how respect and trust relate to HCPs’ views of blind persons’ warmth and competence (as reported from patient perspective). Given the strong relationship between trust in the HCP and healthcare outcomes for people with disabilities, these data provide an important perspective on how HCPs can provide appropriate care for blind patients.

For those participants who reported positive experiences interacting with their HCPs, they tended to feel respected. These findings connected the Stereotype Content Model (Fiske et al., 2007) with findings of Cuevas and colleagues (Cuevas et al., 2016), demonstrating that patients’ perceptions of HCPs’ evaluations of their warmth and competence affect the extent to which patients feel respected and trusted. The findings in the current study also clarify the distinction between trust and warmth. In previous literature, trust was described as interchangeable with warmth (Fiske et al., 2007; Ho, 2011). However, results from the current study demonstrate that trust may depend on an evaluation of warmth and competence. Specifically, in examples from the present data, participants reported that their HCPs seemed to evaluate their warmth and competence in order to decide whether to trust the health information they shared.

We found that HCPs’ engagement of their patients in decision-making is shaped by the HCP’s assumptions of the patient’s warmth and competence. This resulted in the patient mistrusting the decisions and recommendations of the HCP. Conversely, some participants reported feeling respected and trusted by their HCPs. In many of these cases, participants reported feeling more involved in the decision-making process, and more trusting of the decisions and information provided by the HCP. It is possible that HCPs make assessments of patient competence and then decide how much of the patient’s input to elicit and consider.

In this study, we found consequences of deviance from expectations of incompetence. Some participants reported facing opposition from HCPs when acting as caregivers for others. In previous literature, those initially perceived with pity forfeit the perceiver’s pity if they deviate from their respective stereotypical prescriptions (Frederick, 2015). Future studies may examine potential causes for the shift from being pitied to being perceived as deviant.

In this study, participants reported being refused service because of their disability and essentially forced to disengage in their healthcare, replicating previous literature (Harrington et al., 2009). Also, in this study, participants reported greater satisfaction with the results of their healthcare when HCPs treated them with respect. These findings replicate and extend previous research conducted with ethnic minority patients (Cuevas et al., 2016; Major et al., 2013). Future research may examine the effects of patient experiences on their responsiveness to treatment.

When participants discussed positive experiences, they noted that their HCPs reviewed information about basic health behaviors when applicable, such as discussing planning for parenthood. The fact that this was a noteworthy characteristic of a positive experience suggests that HCPs often fail to share information about basic health prevention behaviors and to engage participants in a discussion about lifestyle and health promotion (Drum et al., 2005).

Limitations and Future Directions

Although this study yielded a unique and rich qualitative dataset, there are a few limitations to note. Most participants in this study were female, White, over 50 years old, and highly educated. It may be the case that blind patients' experiences vary across different sexes, races/ethnicities, and ages. HCPs' stereotypic perceptions of blindness may be compounded with other stereotypic perceptions related to sex, race/ethnicity, and age, affecting the way HCPs interact with different blind patients. Future research will examine the differences between experiences of blind people with intersecting marginalized identities. Furthermore, it is possible that other participants agreed or disagreed with the themes, but failed to express this. Lastly, recall bias is a limitation of focus group research. To address this, future research can replicate the results from this study by using methods where data is collected independently.

Conclusion

These data characterized the experiences of blind people interacting with their HCPs. A striking number of this sample reported being treated as incompetent and cold by some of their HCPs. In many cases, this treatment compromised patient independence and autonomy in managing their own healthcare. Findings from this study characterized perceived stereotype content from the perspectives of the target of these stereotypes—blind people. Furthermore, this study linked the Stereotype Content Model with perceiver's trust and respect. Finally, these findings indicate that HCPs should confront stereotypic assumptions about blindness in order to promote patient autonomy and engagement.

Implications for Practitioners and Families

Results from this study can inform best practices regarding the way that HCPs interact with blind patients in order to improve patients' clinical experiences and increase their engagement in making decisions about their own health. Specifically, HCPs should address adult patients directly, regardless of a perceived disability, rather than addressing the nearest person who is presumably a non-disabled caregiver.

HCPs should avoid spending too much time in the appointment discussing the patient's disability if this is not the reason for the patient's appointment. It is, however, important to consider accommodations and ensure that information is being conveyed in a manner that is accessible to patients. HCPs should allow the patient to decide when to bring up their disability, if at all.

Finally, HCPs should cover standard health information with all patients, regardless of disability, or lack thereof, in clinical visits. All information on such topics as reproductive

health should be covered with blind patients. Failure to address basic health prevention behaviors may be due to assumptions of patient incompetence. The content of assumptions should be further examined, and training programs should be developed to help HCPs recognize and override these assumptions.

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Table 1

Results Q1: What are blind patients' perceptions of how their HCPs perceive them and perceive their competence?

Theme	n	FG	Quote
Competence and Incompetence			
Competence	10	5	"They don't assume that I don't know what I'm talking about or anything." - Sarah, FG 2
Incompetence	30	7	"They feel like because you're blind, you can't do anything! Like, you are totally incapable and not ...the fact...that you know what you need. 'Oh, how can you know that you have a headache? You're blind.'" - June, FG 2
HCP response to patient competence	17	7	"He [doctor] had almost gotten another friend of mine who is blind killed because she was diabetic and he refused to forward the insulin into her hospital stay just because he thought she was being 'crazy,' which she absolutely was not." - Mel, FG 5
Addressing the Blind Patient			
Does not address patient	23	7	"I've had, like, healthcare providers in particular ask the person who is, like, just randomly standing next to me, and asking, like, as if they were my companion. 'Can you fill out the paperwork for him?' And they'll just say, 'I'm just standing here.'" - Moe, FG 5
Addresses child	3	3	"I remember one time I went in...and I had my daughter with me, who was like eight or nine at the time, and they were gonna ask [her] the questions." - Carl, FG 2
Addresses patient	5	4	"He always spoke to me. He didn't, like, refer to the other person as if maybe I couldn't understand what he was talking about. It was just a straight conversation." - Nancy, FG 1
Interference with caregiver role	7	5	"Even if you can get people to deal with you directly, it's really hard to take the next step and have them deal with you when you're the caregiver. My husband has routine colonoscopies that you always have to bring somebody with you. Sometimes they've been fine with my being blind and sometimes they freak out because they're like, 'How are you gonna get him home?' And I'm like, 'Well, if I drove ... he would still walk and get in the car. I'm gonna call a cab or Uber and go home with him.'" - Sue, FG 6
Warmth [and Impression Management]			
Makes effort to appear warm	6	4	"I just try to be a...pleasant patient, try to be fun, to begin with. I know it's not a fun thing to be, you know. I try to joke around with them. so...I'm guessing that's maybe part of why most of my experiences with healthcare people have been really good." - Sarah, FG 2
Burden to appear warm/competent	24	7	"If you ... walk tall with your big stick, people are a little bit more open toward you. If you look confident, look like you know where you're going, they seem to be a bit more open. But that's still again, I see that as kind of unfair cause if you're sick and you're going to the hospital or you're going to see your doctor and you feel under the weather, it's not fair of them to judge you because you're not looking confident." -Mel, FG 5
Cold	11	7	"They [HCPs] take it [assertiveness from patient] more as almost an affront." - Sophie, FG 5
Trust			
HCP does not trust patient	12	7	"When I say something it's like, 'Well, what does she know? She's only a blind person, right?'" - Lucy, FG 6
HCP trusts patient	5	3	"I feel like the doctor...takes the time to get to know me, that there's like more trust." - Annie, FG 3
HCP respect and trust [Interrelation of trust and respect]	31	7	"All my positive experiences are with doctors who seem to respect that a) I have some... medical background and b) that I know my body very well." - Tali, FG 3
Respect			
HCP does not respect patient	27	7	"It kinda makes you think that you're more of an object for someone's entertainment instead of an actual human being." - Kevin, FG 1
HCP views patient as inconvenience	14	6	"They wanted you to fill out all these forms and I couldn't do it. The nurses wouldn't do it, so they called up somebody from the staff and she didn't want to do it 'cause she wanted to go home early." - Bob, FG 3
Pity			
Pity	13	7	"There's the pity and the 'Oh, we feel so sorry for you and we can't fix you.'" - Sophie, FG 5

Theme	n	FG	Quote
Patronizing tone	5	4	"They think you're blind and so they have to speak really loudly to you. Or they speak really slowly and over-enunciate." - Helena, FG 4
Unsolicited help	2	2	"The nurse takes you back and you're doing the pee-in-the-cup thing. So she starts to take the cover off [of the cup] and I said, "...I got myself here, I think I can [get the cover off the cap]."
HCP patronizing belief	1	1	"He was telling me how he'll come take a tour when his kid is on school vacation ...he likes to take his son with him to different places where he works, and he said the blind rehab place would be a good place to take him cause he likes to ...show his son how the unfortunate live." - Beatrice, FG 6

Note. n = number of participants who made at least one response in accordance with a given theme. FG = the number of focus groups where the given theme was mentioned at least once.

Table 2

Results Q2: What are blind patients’ experiences interacting with their HCPs when making a treatment decision?

Theme	n	FG	Quote
Patient Involvement in Shared Decision-Making			
HCP does not engage patient	6	4	“I was having some problems and I went to see an, an OB-GYN... he evaded my questions... I said, ‘Well, what kind of treatment? What should we discuss? We need to discuss treatment options, you know. Do I need a definitive surgery? Or what?’ He’s like, ‘Oh well, you know, I wouldn’t worry about it. It’s just a minor problem.’ Well, it turned out to be a very major problem [requiring a hysterectomy] in the end... After that, I never saw a male GYN ever again because it just traumatized me that bad... it was a shame because he did not address any type of my concerns. The fact that this man spoke louder, he thought that ‘cause I couldn’t see, I must not been able to hear or I didn’t understand questions or answers or nothing and he want to rather talk to my mom than me. And he didn’t like the fact that I had to be a little bit assertive and say, ‘Look,’ you know, ‘I’m the patient here, what’s going on?’ And he says, ‘Well you have some problems.’ ‘Okay, what kind of problems? You need to tell me what problems I have’....well, it turned out to be major in the end.” - Georgina, FG 1
Patient not fully informed	5	3	“We don’t always know exactly what we’re signing because people don’t read it to us. And they say, ‘Oh it’s not really, it’s nothing to worry about. You just have to sign here.’” - Cheryl, FG 1
HCP engages patient	12	6	“Usually they’ll go ahead and tell me why they’re doing things if they give a valid reason you know I’m willing to go along with it but you know we’ve worked out different ...courses of care ...well you want me to give myself a shot? It’s like, well how about something else? You know, especially because, you know, they’ve got like lotions and stuff that will absorb through the skin and will have the same delivery process.” - Moe, FG 5
Participant mistrust in HCP diagnosis/ treatment prescription	15	6	“Because she made such a big deal about blindness that when blindness really had nothing to do with it. But she wasn’t really taking me seriously. So I guess I have less confidence that, like, she’d actually be able to figure out what was going on.” - Annie, FG 3

Notes. n = number of participants who made at least one response in accordance with a given theme. FG = the number of focus groups where the given theme was mentioned at least once.

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Table 3

Results Q3: How do these interactions impact blind patients' overall functioning and health?

Theme	n	FG	Quote
Other			
Refusal of services	7	4	"We actually had a really big issue about that and they almost wouldn't let me do it [get hormone replacement therapy] because of the injections thing. And ... I was like, 'Yeah, I know I can stab myself in the leg with the needle.'" - Mel, FG 5
Respect			
Consequences of feeling disrespected	23	7	"I've been through four primary cares because they don't care. They don't want to hear you, they don't listen. They just yell at you for your numbers that might be too higher or too lower or whatever." - Barbra, FG 4
Requesting independence/ respectful treatment	2	2	"People wanna be independent." - Kevin, FG 1
HCP respects patient	31	7	"Whenever she [HCP] has a question about blindness it's something like, 'What is the best way to do this for you?' And then, whatever I tell her is the best way to do it for me, she does it after that. So she's always been really amazing and I can tell that she's pushing her staff who interact with me to respond similarly because since I've started seeing her instead of seeing the guy who does my procedures, the staff's care has improved as well." - Jessica, FG 3
Regarding family planning	1	1	"[The medical resident conducting the exam] said, '...We know that you're not planning on getting pregnant right now, but if you decide...that you want to start a family, we have a really good prenatal clinic here and we can put you on multi-vitamins ... we can hook you up with an OBGYN.' ... Even though I wasn't planning on getting pregnant, I thought it was really cool that she didn't assume that because I was blind that I couldn't be a parent. And she just, like, probably said the same thing to me that she says to other 30-year-old female patients who come in. And I just thought that was cool." - Annie, FG 3

Notes. n = number of participants who made at least one response in accordance with a given theme. FG = the number of focus groups where the given theme was mentioned at least once.

1. An additional noteworthy point is that the sample size of the study reported in this manuscript alone is larger than any other sample size of a qualitative study conducted with blind people.