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# Development And Validation Of A Measure Assessing Blind Patients' Perceptions Of Their Healthcare Providers' Stereotype Content

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DEVELOPMENT AND VALIDATION OF A MEASURE ASSESSING BLIND PATIENTS'  
PERCEPTIONS OF THEIR HEALTHCARE PROVIDERS' STEREOTYPE CONTENT

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PERCEPTIONS OF THEIR HEALTHCARE PROVIDERS' STEREOTYPE CONTENT

by

NAZANIN MINA HEYDARIAN, MA

DISSERTATION

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## **Abstract**

People with disabilities (PWDs) constitute about 15-20% of the total population. Health disparities among PWD's are due, in part, to stereotypes about PWDs as incompetent. These stereotypes may lead some healthcare providers (HCP) to patronize PWDs, over-focus on the PWDs' impairments and potentially neglect their presenting problem. Moreover, if the PWD violates stereotypical assumptions, the HCP may actively interfere with the PWD's goals. This dissertation focused on the blind population because this is a large, stigmatized and understudied subpopulation of PWDs. In Study 1, the content of stereotypes about blind patients in the clinical setting were examined from the patient perspective by use of focus group interviews. The development of a measure assessing the perceived content of stereotypes faced by blind patients from their HCPs was motivated by the Stereotype Content Model (Fiske, Cuddy, Glick, & Xu, 2002) and prior literature reporting on the experiences of minority patients interacting with their HCPs, and written based on the experiences of blind patients. The latent factor structure was explored in Study 2 and validated in Study 3. The factor structure consisted of a two-factor model: the first factor assessed General discrimination by HCPs and the second factor assessed Stereotype Content Model-related aspects of interacting with HCPs. Future research should include testing the external validity of this scale with other sub-populations of PWDs. Furthermore, this measure may be used to evaluate training of HCPs to improve their service toward PWDs.

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## **Chapter 1: Introduction**

In the past two decades, researchers and public health officials alike have placed increasing emphasis on the importance of health disparities faced by people with disabilities (PWDs). Specifically, the Surgeon General highlighted health disparities faced by PWDs and urged researchers and healthcare providers (HCPs) to work toward eliminating these disparities. In order to reduce health disparities for PWDs, the 2005 Surgeon General Call to Action prioritized the increase of health and well-being for PWDs, and the examination and elimination of detrimental stereotypes about PWDs on the healthcare treatment of PWDs (Healthy People, 2010; USDHHS, 2002, 2005). Disabilities, and particularly sensory-related disabilities (e.g., blindness, deafness), are highly prevalent in the U.S. In 2010, one-in-five U.S. citizens reported having a disability (Brault, 2012; Center for Disease Control and Prevention, CDC, 2010). Disabilities affect people of all ages. Approximately 15% of adults under the age of 65 report having a disability (Drum, Kran, Culley, & Hammond, 2005). Approximately 1/3 of those reporting disabilities are between the ages of 25-61 years (Anand & Ben-Shalom, 2014). People with sensory impairments constitute 11% of the total disabled population, which is one of the largest subpopulations of the disabled population (Brault, 2012; Rosa et al., 2016). There are over 7.35 million blind people in the U.S. (2.3% of the total population). In the U.S., an estimated 1.9% of those between the ages of 16-64 years and 6.7% of those of age 65 years or older report having a significant visual impairment (Erickson, Lee, & von Schrader, 2016). The proposed set of studies were conducted with blind adults specifically. The criteria for defining legal blindness includes having a visual acuity of 20/200 with best correction in the best eye or having a visual field equal to or less than 20 degrees (Vashist, Senjam, Gupta, & Kumar, 2017).

A number of crucial demographic differences between PWDs and people without disabilities (PW/oDs) such as employment and income are associated with health outcomes and may be driving health disparities affecting the disabled population. PWDs spend about 2-3 fewer hours per week working paid positions compared with PW/oDs (Anand & Ben-Shalom, 2014). In a study conducted by Brault in 2010, it was estimated that 20% of PWDs were employed (37.7% of unemployed PWDs are those with visual impairments, Brault, 2010) versus 70% of PW/oDs, and 31% of PWDs lived in poverty versus 12% of PW/oDs (Brucker & Rollins, 2016). It is important to highlight employment here because it is linked with income, and income has been found to predict health outcomes (Brucker & Rollins, 2016; Iezzoni, Killeen, & O'Day, 2006, Jones & Tamari, 1997). The strikingly low employment rate and low average income of blind adults may limit access to quality healthcare with HCPs who may have better training in sensitivity to diversity. It also may impact the way that HCPs perceive and subsequently treat them.

The fewer hours that PWDs spend working, on average, sometimes goes towards the pursuit of health promoting activities. PWDs spend more time engaging in some health promoting activities related to rest and relaxation than PW/oDs. On average, PWDs spent about 1 more hour sleeping per night and 2-3 more hours pursuing leisure activities, such as socializing, relaxing, and attending recreational activities (e.g., sporting events). On average, PWDs spend 21-35 more minutes per day engaging in health-related activities such as taking medication and visiting doctors (Anand & Ben-Shalom, 2014). Analyses conducted on a national Canadian database revealed that PWDs were more likely to visit a general practitioner, specialist, hospital, and seek home care compared with PW/oDs (McColl, Shortt, Gignack, & Lam, 2011). This increased contact that PWDs have, on average, with HCPs may increase the impact

opportunities for HCP attitudes to impact PWD health. However, PWDs (Havercamp et al., 2004) and blind people (Crews & Campbell, 2004) spend less time than PW/oDs engaging in such health promoting behaviors as exercise.

Given the health behaviors profile of PWDs, they face significant health disparities. In addition to having poorer health than PW/oDs (Crews & Campbell, 2004; Havercamp et al., 2004), PWDs (Havercamp et al., 2004) and blind people (Crews & Campbell, 2004) are also more likely to report fair-to-poor health (Havercamp et al., 2004) than PW/oDs who tend to report better health. PWDs (McColl, Jarzynowska, & Shortt, 2010) and blind people (Crews & Campbell, 2004) report a higher rate of unmet mental and emotional health needs compared to PW/oDs.

## **1.1 SECONDARY HEALTH CONDITIONS**

In addition to disparities in reports of general health status, PWDs report health conditions secondary to their disability (e.g., chronic diseases) at a higher rate than PW/oDs. Some researchers suggest that secondary conditions develop in this population due to a lack of timely access to quality healthcare, which may exacerbate small health problems (Hwang et al., 2009; Krahn, Walker & Correa-De-Araujo, 2015). However given finding that PWDs spend more time seeking healthcare from HCPs (McColl et al., 2011) and engaging in treatment adherence (Anand & Ben-Shalom, 2014), it may be the case that there is a lapse in the clinical judgement and decision-making for their PWD patients which lead health concerns to become exacerbated into secondary health conditions.

Secondary health conditions are quite prevalent among PWDs. Eighty-seven percent of respondents with a disability reported a secondary condition (Kinne, Patrick, & Doyle, 2004). PWDs were found to be more likely to have a chronic disease (e.g., diabetes, cardiovascular

disease) than PW/oDs (Havercamp, Scandlin, & Roth, 2004). Crews and Campbell (2004) also found that there were higher rates of heart disease and hypertension among blind older adults.

## **1.2 BARRIERS AND RECOMMENDED SOLUTIONS**

Health disparities faced by PWDs may be upheld by barriers to healthcare (Crews & Campbell, 2004; Hwang, Johnston, Tulskey, Wood, Dyson-Hudson, & Komaroff, 2009). Hwang and colleagues (2009) identify two types of barriers: Process-related barriers and structural-environmental barriers.

Process-related barriers affect the secondary processes related to accessing healthcare. Process-related barriers include high cost of healthcare services (Iezzoni et al., 2006, Jones & Tamari, 1997; McColl et al., 2010), lack of health insurance and dependence on Medicaid (Iezzoni et al., 2006, Jones & Tamari, 1997), and lengthier transportation for PWDs to travel to medical appointments (Brucker & Rollins, 2016; Iezzoni, Killeen, & O'Day, 2006, Jones & Tamari, 1997). Some of these process-related barriers are reported by many different populations besides PWDs. Other process-related barriers such as high cost and complicated transportation may affect PWDs at a disproportionately high level due to the fact that PWDs, and blind people in particular, tend to have lower incomes and limited access to transportation compared to PW/oDs (Brucker & Rollins, 2016; Iezzoni, Killeen, & O'Day, 2006, Jones & Tamari, 1997).

Structural-environmental barriers affect access to the content of medical information due to system/structural/environmental obstruction. Structural-environmental barriers include lack of access to materials or screening equipment and inadequate communication (e.g., lack of non-visual methods of privately conveying personal and health information; Brucker & Rollins, 2016; Drum et al., 2005; Stein, Stein, Weiss, & Lang, 2009). PWDs have reported trouble finding caring and competent HCPs with specialized expertise accommodating what would be



process-related barriers (Iezzoni et al., 2006; Stein et al., 2009). PWDs also report needing to educate their HCPs about their disability, which takes time out of their appointment and reduces access to care (Jones & Tamari, 1997). An additional structural-environmental barrier that PWDs face when seeking healthcare is that HCPs often fail to share information about basic health prevention behaviors and fail to engage PWDs in a discussion about lifestyle and health promotion (Drum et al., 2005).

Solutions to process-related and structural-environmental barriers may help reduce barriers to healthcare for PWDs (Drum et al., 2005; Jones & Tamari, 1997; Stein et al., 2009). Process-related solutions include the following: Health centers facilitating transportation to and from facilities (Jones & Tamari, 1997), healthcare programs being prepared to universally serve PWDs as well as PW/oDs, and health care plans addressing all specialized health needs of PWDs (Stein et al., 2009).

Furthermore, structural-environmental related solutions include the following: Adjusting physical features of the facility such as entrance location and furniture placement in order to make the facility more accessible for PWDs (Jones & Tamari, 1997), enforcing compliance with ADA, providing accessible communication so that there are available personnel trained in translation and documents that are provided in accessible formats (Drum et al., 2005), and setting tax incentives for clinics to purchase accessible equipment, (Stein et al., 2009). PWDs, HCPs, government entities, and other stakeholders value the idea of universally accessible healthcare facilities and agree that changes should be made to increase accessibility of healthcare facilities (Jones & Tamari, 1997).

Despite its prevalence, blindness is among the most stigmatized of disabilities. Stigmatization is often driven by fear, and, indeed, blindness is the fourth most feared condition

after HIV/AIDs, cancer, and Alzheimer's disease (Zhang et al., 2015). There is a thorough history of the public's perception of blindness. Wagner-Lampl & Oliver (1994) and Mahoney (2014) discuss the historical notion of "better dead than blind" and that it persists in modern society.

This fear of blindness also exists in HCP trainees. Owwoeye, Ologe, and Akande (2009) surveyed medical students in their final year, after completing an ophthalmology or otorhinolaryngology rotation, about attitudes regarding disability. Most students regarded blindness as the worst disability to have and perceived that blindness negatively affects performance in academics, social, and family activities more than other disability.

### **1.3 SOCIAL AND MEDICAL MODELS OF DISABILITY**

Several theoretical models are used to view disability. Specifically, in discussions of disabilities, the literature often refers to the medical model and the social model (Olkin, 2022). Often, HCPs are trained to identify a medical ailment, deficiency, or otherwise abnormality in the body that impacts a patient's health and/or functioning, choose the best suited treatment, and implement that treatment to correct the abnormality. This approach of identifying an abnormality in need of correction is referred to as the medical model (Artman & Daniels, 2010; Olkin, 2002). This model is useful in addressing medical concerns with defined courses of treatment and serves in the continued development of medical technology which improves longevity and quality of life in general (Olkin, 2002). When considering more permanent forms of disability (e.g., blindness), however, , the medical model often falls short in guiding the response of HCPs as they may wish to cure something that has no cure or clear course of treatment (e.g., preserving or improving sight in someone who has little to no sight). With a medical model approach to disability, one can understand why HCP trainees reported fear of disability (Owwoeye et al., 2009).

Through the lens of the medical model, PWDs are considered to be incapable and less worthy of status, and, consequently, are often met with low expectations and pity (Olkin, 2002). Pity is paternalistic sympathy for those perceived to have good intentions, but lack status or competence (Dovidio & Fiske, 2012; Fiske, 2013; Fiske, Cuddy, Glick, & Xu, 2002). Beliefs that PWDs are unfortunate victims of impairment are considered disempowering and consequently more "disabling" than actual impairments (Blockberger, Armstrong, O'Connor, Freeman, 1993 as cited by MacMillan, Tarrant, Abraham, & Morris, 2014; Khadka, Ryan, Margrain, & Woodhouse, 2012; Smith, Geruschat & Huebner, 2004; Rosa et al., 2016). These beliefs are often, though not always, internalized by PWDs. Internalizing these beliefs may lead to behaviors or choices that have the unfortunate consequence of reinforcing these low expectations for PWDs (Watson & Larson, 2006). Thus, PWDs may not be given (or fail to take full advantage of) opportunities to practice and develop many skills necessary for successful daily functioning according to society's standards.

The social model explains disability as a product of an environment that does not accommodate certain physical difference. Along these lines, disability would otherwise be a less distressing and potentially reduced to a minor inconvenience and even a dimension of diversity if the environment was accommodating toward impairments. The shortcomings of policy implications of this model have been discussed (Shakespeare & Watson, 2010; Owens 2014). However the social model is a useful model to adopt on the individual level (Olkin, 2002): for example when a HCP interacts with a blind patient. Adopting this model with individual patients would allow HCP more creative freedom to identify what functional and health outcomes should be addressed with the patient and work to develop a plan most appropriate and feasible for the patient to improve functioning and health outcomes.

Often, in empirical research, disability is not examined as a social construct and physical and sensory disabilities are overlooked in diversity research (Rosa et al., 2016; Olkin, 2002). Given the fact that people with disabilities comprise one of the single largest minority groups in the U.S. (Olkin, 2002), the nature and impact of stereotypes about PWDs is relatively understudied (Rosa et al., 2016). This is particularly true for PWDs with sensory impairments (Brault, 2012). This dissertation aimed to examine the nature and impact of stereotypes about PWDs by examining the views of PWDs using a social psychological theory as a framework, thus, filling a critical knowledge gap. The next section will discuss a popular model of social stereotypes, which will be the basis of the proposed dissertation project.

#### **1.4 THE STEREOTYPE CONTENT MODEL AND BEHAVIOR FROM INTERGROUP AFFECT AND STEREOTYPES MAP**

Fiske and colleagues (2002) propose the Stereotype Content Model to explain the content of stereotypes, attitudes, and behaviors towards social groups. The Stereotype Content Model states that stereotypic perceptions and prejudice consist of two dimensions: Warmth and competence. The stereotype dimensions develop from social structures, warmth from cooperation/competition and competence from high/low status (Fiske, 2013; Fiske, 2015). Perceivers evaluate social groups along these two dimensions, have affective responses to the social groups, and may behave in either active or passive facilitation or interference behaviors toward the social groups (Cuddy, Fiske, & Glick, 2008; Fiske, Cuddy, & Glick, 2007). This model can help researchers understand the content of stereotypes about PWDs held by HCPs that may lead to affective and behavioral responses that contribute to health disparities for PWDs.

*Warmth*

Warmth is described as the intent to not harm and to be concerned with the well-being of others. Those viewed as warm are viewed as being trustworthy. Sometimes the terms “warm” and “trustworthy” are used interchangeably (Fiske et al., 2002; Ho, 2011). Someone perceived as being low in warmth would presumably disregard the well-being of others and would be disliked. Someone perceived as being high in warmth would presumably consider the well-being of others and would be liked (Fiske et al., 2002). Warmth leads the perceiver to associate the target outgroup with the following traits: Friendliness, helpfulness, sincerity, trustworthiness, and/or morality (Fiske et al., 2007).

### *Competence*

Competence is described as the capacity to achieve goals related to attaining position or status. Someone perceived as being low in competence would presumably lack the skills and abilities deemed necessary to attain status or be successful in a role of importance. Thus, a person perceived to be low in competence would be disrespected. Someone perceived to be of high competence would presumably possess skills to attain status and success in roles of value in a given society, and thus be respected (Fiske et al, 2002; Ho, 2011). Competence leads the perceiver to associate the target outgroup with traits such as the following: Personal ability, intelligence, creativity, skill, and/or efficacy (Fiske et al., 2007).

### *Combinations of the two dimensions—warmth and competence*

Stereotypical perceptions consist of a combination of the perception of a social group’s or individual’s warmth and competence (Cuddy et al., 2008; Fiske, Cuddy, & Glick, 2007; Fiske et al., 2002). Some univalent social groups are described in terms of high warmth-high competence. These social groups are considered to be successful and presumed to have the best interest of the perceiver in mind. Thus, perceivers react with respect and pride toward these target groups and

members of these groups. Other univalent social groups are described in terms of low warmth-low competence. These groups are presumed to be inconsiderate of the needs of the perceiver and incapable to secure status for themselves. Thus, perceivers react with contempt towards these target groups or individuals from these groups.

Most stereotypes of outgroups are ambivalent and can be described in terms of low warmth-high competence and high warmth-low competence. When outgroups are perceived to be low in warmth and high in competence, they are presumed to be inconsiderate of the well-being of the perceiver and untrustworthy, yet successful. Perceivers react with envy toward these targets. When targets are perceived to be high in warmth and low in competence, they are presumed to have good intentions but are incapable of attaining status. Thus, perceivers display the emotional reaction of paternalistic pity towards these targets (Cuddy et al., 2008; Fiske et al., 2007; Fiske et al., 2002).

Much of the literature suggests that PWDs (Cuddy et al., 2008) and blind people (Fiske et al., 2002) are perceived with pity. However, some recent research found that low warmth traits (e.g., bad, selfish, hypocritical, liar) were more readily associated with PWDs than with PW/oDs (Rohmer & Louvet, 2016). This may be explained by the perceivers changing their perceptions based on further information gathered about the target or the target's actions. For example, perceivers may change their perceptions of PWDs as high in warmth and deserving of pity to low in warmth and undeserving of pity.

### *BIAS Map*

Perceivers may have emotional responses (e.g., pitied, envied, contemptuous) and then behavioral responses to outgroups according to the perceived target's Stereotype Content Model profile. Behavioral responses include passive harm, active harm, passive support/facilitation, and

active support/facilitation. Active behaviors include those where the perceiver is directly intervening in order to support (help) or oppose (harm) what they perceive to be the target's goals (Fiske et al., 2007; Fiske, 2013). Passive behaviors include those where the perceiver indirectly intervenes to either support or oppose the perceived goals of the target.

Perceptions of low competence lead to passive harm and neglect of the group (e.g., refusing to help a patient complete intake forms), while perceptions of high competence lead to passive facilitation and association with the group (e.g., engaging a patient in a decision about their health). Perceptions of low warmth lead to active harm (e.g., withholding vital medical treatment), and perceptions of high warmth lead to active facilitation (e.g., helping a patient to find an exam room; Fiske et al., 2007; Fiske, 2013).

Passive harm refers to an inactive role of non-support where a perceiver would be indirectly involved in the opposition of a perceived goal of the target (Fiske et al., 2002). Passive harm may take the form of social isolation or neglect directed toward contentious and pitied targets. For example, perceivers may behave in an ostensibly polite way towards PWDs yet may not take the time to develop meaningful relationships with PWDs. In the medical setting, neglect/social isolation may manifest as less time spent conducting meaningful examinations with patients (Dovidio & Fiske, 2012; Jones & Tamari, 1997), omitting preventative health information (e.g., about nutrition, exercise, and sexual health information), conducting less thorough or completely foregoing certain examinations (Drum et al., 2005; McColl et al., 2008), and failing to engage the patient in the clinical visit (Cuevas, O' Brien, & Saha, 2016).

Active harm refers to the perceiver attempting to interfere with the achievement of the perceived goal of the outgroup member (Fiske et al., 2002). Active harm is typically directed toward outgroups that are perceived to be low in both warmth and competence such as

immigrants and homeless people (Fiske et al., 2002). As long as pitied outgroup members remain in their prescribed social status of limited power and influence, they will be treated with pity. However, if they deviate from their roles, they may forfeit pity and, instead, be treated with active efforts to suppress them (Fiske, 2013). For example, blind people may generally be pitied, but if they seek to do something stereotypically reserved for those considered to be of higher status (e.g., PW/oDs) such as having and raising children, they may be faced with overt opposition from authorities such as HCPs (Frederick, 2015).

Like passive and active harm behaviors, passive and active facilitation behaviors may be disadvantageous for the target. Passive facilitation refers to the perceiver acting in a supportive manner where they are indirectly involved in supporting the perceived goal of the target (Fiske et al., 2002). Passive facilitation is typically directed toward pitied outgroups. For example, perceivers may contribute financial or other resources to charities that serve PWDs. In the healthcare setting, HCPs may spend more time with their patients with disabilities (Drum et al., 2005; McColl et al., 2008). It should be noted that this finding is not at odds with findings showing that doctors spend less time covering critical preventative information in clinical visits with PWDs (Dovidio & Fiske, 2012; Jones & Tamari, 1997). Much of the extra time is often spent over-focusing on patients' disabilities and foregoing discussion of critical preventative information. This passive facilitation may sound good-natured, however, it may be done in a way that undermines the PWD's autonomy, is demeaning to the PWD, and/or fails to perceive and consequently serve the actual needs of the PWD.

A recent example of short-sighted passive facilitation is the Foundation Fighting Blindness #HowEyeSeeIt fundraiser campaign (<https://www.howeyeseeit.org/>; Foundation Fighting Blindness, 2016). This campaign aimed to raise funds for research in treatments



designed to prevent and cure blindness, however it perpetuated harmful stereotypes of incompetence as well as fear and stigma of blindness by using an incomplete and demeaning blindness simulation to raise awareness. As part of the campaign, non-blind people wore blindfolds to simulate blindness and attempted to carry out everyday activities (e.g., cooking, laundry, taking care of children) without any prior training in non-visual skills. Many of those who participated in the campaign were unsuccessful at the activities they attempted and were left with the impression that what they experienced was similar to blindness and, thus, that blind people are incapable of carrying out everyday tasks. The blind community expressed these concerns about the potentially harmful message delivered through the #HowEyeSeeIt campaign (National Federation of the Blind, 2016), but the campaign continued, regardless.

Uninformed facilitation behaviors such as the #HowEyeSeeIt campaign where the perceiver is acting based on only their perceptions of the target's needs and not the target's actual needs may undermine the target's autonomy. Facilitation may also be actively implemented. Active facilitation refers to the perceiver taking action in order to allow for the achievement of the perceived goal of the target (Fiske et al., 2002). For example, the perceiver may see a person with a white cane (a mobility tool and symbol of blindness) at a crosswalk. The perceiver may assume that the goal of this person at the crosswalk is to cross the street and assume that the person lacks the competence to achieve this goal and needs assistance. The perceiver may then take hold of the person's arm and attempt to guide the person across the street. This action may undermine the autonomy of the person who may have not consented to the ostensibly helpful behavior.

Pitied outgroup members may receive active facilitation that is actually harmful either because it violates autonomy, is disempowering, or is misinformed and causes more trouble for

the recipient of the supposed help. Fiske (2012a) supports that “over-helping” pitied people when they may not want or need the help can be harmful by affecting the pitied person’s self-efficacy to complete a task without the unnecessary help. A perceiver may not know that the help is unnecessary and view it to be a caring, nurturing gesture. Thus, if the person being over-helped rejects the excessive help, they may be perceived as ungrateful and deviant (low in both warmth- and competence-related characteristics; Fiske, 2012a; Gilbert & Silvera, 1996). The consequences of rejecting unsolicited help will be discussed further below.

Several examples of over-helping exist in the healthcare setting. The presenting health concerns of pitied targets may be over-pathologized and treated more intensively (e.g., by institutionalization, overmedication) compared to similar presenting health concerns by PW/oDs (Dovidio & Fisk, 2012; McColl et al., 2008). The intensive treatment may be inappropriate for the patient (Dovidio & Fisk, 2012). Due to assumptions of low competence, physicians may believe that “qualified” others (e.g., non-disabled friends or family members) should assist with PWDs’ self-care and to facilitate doctor visits. Some physicians reported requiring their patients with disabilities to bring an attendant with them to facilitate the doctor visit (McColl et al., 2008). The presence of an attendant may be unnecessary, and compromise autonomy and confidentiality of medical information. Thus, behaviors intended to be helpful may actually be harmful. There is qualitative evidence of HCPs over-helping PWDs (McColl et al., 2008), yet further research using other methodologies and including the perspectives of the PWDs is needed to determine the actual helpfulness or harmfulness of the facilitation behaviors.

#### *Moving from pitied to contemptuous*

Those perceived with pity forfeit the perceiver’s pity if they deviate from their respective stereotypical prescriptions. For example, a PWD may be perceived as moderately-to-highly

competent, but no longer warm. This PWD may also be faced with active or explicit opposition (Fiske, 2013; Frederick, 2015). This switch in emotional response to an outgroup may be due to the perceiver considering the deviance from a stereotypical role as a failure to consider the comfort or safety of the perceiver or of others. Blind people are viewed as deviant when they reject or otherwise do not fit societal prescriptions for roles of blind people (Frederick, 2015).

As an effort to restrain agentic expressions of pitied outgroups, HCPs may provide unsolicited and inappropriate intervention to PWDs (Frederik, 2015). Frederick (2015) conducted a qualitative study involving 26 blind, first-time mothers who described their experiences with postnatal care after giving birth to their first child. All participants had an activist orientation about their identities as blind people, were involved in blind parent support groups, and had sought out parenting preparatory materials prior to the birth of their first child. Furthermore, most participants had at least a post-secondary degree.

Despite their preparedness for motherhood, Frederick (2015) found that 54% of participants were visited by social workers after they gave birth. Many of these experiences with social workers and other HCPs were intrusive and inappropriately timed. One mother recounts that she awakened after giving birth, surrounded by the doctor and team of medical professionals who immediately began asking the mother about how she was going to take care of her child. In a more severe case, the newborn baby was put into foster care and the parents had to use legal and advocacy means to regain custody of their newborn child. The pretext of these actions is consideration for the newborn child's well-being. However, the pretext is shaped by presumptions of incompetence and discards evidence of competence, thus resulting in actions that only serve to distress the already well-prepared mothers.

PWDs become wary and mistrustful towards HCPs from negative experiences of interacting with HCPs (Frederick, 2015; Ho, 2011). Negative experiences of interacting with HCPs may lead to dissatisfaction with healthcare (Cuevas et al., 2016). It is important to understand stereotypes to increase health-promoting factors (e.g., patient engagement in treatment) and to enhance communication between HCPs and PWDs. Stereotypic attitudes held by HCPs may lead to patient dissatisfaction and contribute to health disparities.

Forming stereotypic attitudes and the expressions of stereotypes in actions are automatic processes (Dovidio & Fiske, 2012). Dovidio and Fiske (2012) argue that HCPs are just as prone to such biases despite the emphasis in the medical field on objectivity in evaluation of and providing prescription for patients. HCPs face demanding and cognitively taxing work, leaving them prone to making decisions about sharing important health-promoting information, making treatment decisions, and engaging the patient in promoting their own health on harmful stereotypes. HCPs are often given very little time to meet with each patient (Dovidio & Fiske, 2012). There has been some research on HCPs' attitudes toward PWDs, but more extensive research has been conducted on HCP attitudes toward other minority patients besides PWDs. The following portion of the review will draw from this knowledge base about other minorities when there is limited literature regarding PWDs.

HCPs make implicit and explicit stereotypic assumptions about patients with disabilities. Implicit stereotypical attitudes have been found in a range of professional HCPs and HCP trainees, including medical students (Bean, Stone, Moskowitz, Badger, & Focella, 2013; Hollingshead, 2016; Owioye, Ologe, & Akande, 2009), nursing students (Bean et al., 2013), physicians (Lepiece, Reynaert, van Meerbeeck, & Lorant, 2014), and emergency room HCPs (Puumala et al., 2016). Some HCPs have explicitly stated that they believe minority patients are

incompetent (Bean et al., 2013; Puumala et al., 2016) and that they feel uncomfortable working with minority patients (Amosun, Kambalame, Maart, & Ferguson 2013).

Explicit and implicit stereotypes displayed by HCPs both directly and indirectly affect the health of minorities (Major, Mendes, & Dovidio, 2013). Thus, HCPs are partially responsible for health disparities due to the assumptions they make about patients with disabilities (DHHS, 2005). Lawthers, Pransky, Peterson, and Himmelstein (2003) identified the need for some HCPs to change their attitudes about PWDs in order to enhance the care provided to disabled patients.

HCPs' stereotypic attitudes may directly impact their patients when HCPs rely on stereotypes to make incorrect diagnoses (Major et al., 2013). HCPs, particularly those who displayed higher implicit prejudice, prescribed opioids more readily for ethnic minority patients compared to non-minority patients (Burgess et al., 2008; Hollingshead, 2016; Moskowitz, Thom, Guzman, Penko, Mioskowski, & Kushel, 2001; Paradies, Truong, & Priest, 2013). The studies that reported ethnic demographic data for HCPs showed that the HCPs were mostly non-minority White (Hollingshead, 2016; Lepiece et al., 2014; Moskowitz et al., 2001), where their proportions of HCP ethnicity was reported as 40.2% by Hollingshead (2016), but as 95.9% by Lepiece and colleagues (2014). Doctors prescribed more drugs and spent less time examining Moroccan minority patients' medical histories compared to Belgian non-minority counterparts (Lepiece et al., 2014). These findings are consistent with findings of HCPs spending less quality time with PWDs (Dovidio & Fiske, 2012; Jones & Tamari, 1997).

HCPs' stereotypic attitudes may also indirectly impact the patient when the patient interprets HCPs' behaviors as motivated by stereotypes and prejudice (Major et al., 2013). Perceived prejudice leads to diminished satisfaction with care that leads the patient to distrust the

HCP and disengage in the promotion of their own health (Cuevas et al., 2016; Major et al., 2013).

## **1.5 PERCEIVED DISCRIMINATION AND TRUST**

Trust is the willingness to share something valuable (e.g., sensitive information) with another party, founded in a confidence that the party will guard the best interests of the person placing trust. Trust leads to engaging with a trusted party such as an HCP (Chen & Boothroid, 2005; Hall, Dugan, Zheng, & Mishra, 2001). Perceived discrimination stemming from a lack of perceived respect leads to mistrust of medical authorities and medical information (Cuevas et al., 2016; Plaza, 2014).

Trust in physicians leads to better health outcomes, greater engagement of the patient in the treatment plan, and increased satisfaction with the HCP for patients with disabilities (Chen & Boothroid, 2005; Hall et al., 2001). Ideally, patients trust that their HCPs are unbiased in their attitudes and have the patient's best interests in mind. PWDs may question HCPs having unbiased attitudes (Ho, 2011). Patients' perceptions of their HCPs as not viewing them as competent patients may undermine the trust that is fundamental to encouraging health promoting behaviors (Dovidio & Fiske, 2012; Ho, 2011).

Mistrust in HCPs is associated with dismissal of medical information and decline in seeking healthcare before problems exacerbate (Plaza, 2014). A qualitative study conducted with African American lesbian and bisexual women found that, because of the experience of perceived discrimination, over 1/3 of participants reported feeling discriminated against by their HCPs and reluctant to return to a HCP when necessary (Li, Matthews, Aranda, Patel, & Patel, 2015). A review of literature links African American patients' perceptions of discrimination with mistrust of both formal and informal sources of medical information (Plaza, 2014).

Perceived discrimination and perceived disrespect may also lead to mistrust in medical care and medical information. Cuevas and colleagues (2016) found that African Americans reported perceived discrimination by HCPs and clinic staff, and reported feeling disrespected by HCPs. Perceived disrespect (i.e., feeling unrightfully treated as incompetent) was attributed to limited engagement of participants in the dialogue with HCPs (Cuevas et al., 2016). There is evidence that suggests that African American patients and disabled patients are perceived similarly by HCPs in terms of the Stereotype Content Model: as generally low in competence and moderate (at best) in warmth (Fiske, et al., 2002). Thus, it is expected that PWDs will report perceived discrimination, feeling disrespected, and disengaging from dialogue in the healthcare setting.

## **1.6 SATISFACTION WITH HEALTHCARE**

Perceived discrimination may also lead to dissatisfaction in healthcare. Satisfaction with healthcare is a major indicator of patient health. Patient healthcare satisfaction is increasingly being used as an index of HCP performance and quality of care (Huang, Lai, Tsai, Hu, & Yang, 2004; Xesting & Vozkis, 2016). Patient satisfaction with healthcare predicts actual patient adherence to healthcare recommendations (Al-Refaie, 2011 as cited by Xesting & Vozkis, 2016). There are mixed findings related to satisfaction with healthcare among PWDs. The Surgeon General's report states that ¼ of PWDs under the age of 65 report difficulty in finding an HCP that they are satisfied with (USDHHS, 2005). Harrington, Hirsch, Hammond, Norton, and Bockenek (2009) found that 36.4% of PWDs reported educating their HCPs about their disability (suggesting a lack of training on the HCP's part), 24.4% reported leaving their appointment with the feeling that not all of their needs were met, and 2.1% report being refused service because of their disability. Most participants reported being very satisfied and somewhat satisfied with the

care they received from their HCP. On the other hand, Jha, Patrick, MacLehose, Doctor, and Chan (2002) conducted a cross-sectional study comparing Medicare beneficiaries with and without disabilities. PWDs reported being more dissatisfied with care than their PW/oD counterparts. The researchers concluded that enhancing PWDs' satisfaction may be accomplished by addressing transportation needs and ensuring that access to specialized care was provided (Jha et al., 2002).

Research examining patient satisfaction among blind people also yields mixed findings. Iezzoni and colleagues (2002) examined satisfaction with healthcare among blind and low vision Medicare beneficiaries (it is unclear how distinctions were made between blind and low vision in this study). Younger blind people tended to report the least dissatisfaction, even less than PW/oDs. Older blind people reported slightly more dissatisfaction with healthcare than PW/oDs. Low vision people reported the highest levels of dissatisfaction with healthcare. Blind and low vision patients reported greater dissatisfaction with availability of services, ease of access, and costs compared to non-disabled patients (Iezzoni et al., 2002). Low vision beneficiaries reported the most dissatisfaction with certain aspects of healthcare, even when compared to blind beneficiaries. For other aspects of healthcare, blind and low vision beneficiaries reported similar levels of dissatisfaction.

Examining the satisfaction of patients with disabilities about their healthcare is imperative for understanding and reducing health disparities, yet PWDs' perspectives are seldom examined (Hwang et al., 2009; Leplege et al., 2006). The Stereotype Content Model is a promising framework for conceptually organizing PWDs' perspectives of being discriminated against by HCPs. There is a need for further examination of the Stereotype Content Model-related perceptions of PWDs in their interactions with HCPs.



Examining patients' perceptions of engaging with HCPs allows researchers to identify the variables (such as unique barriers to healthcare) that contribute to health disparities for PWDs. de Vries McClintock (2016) and Durand, Steil, Boivin, and Elwyn (2008) conducted traditional in-person focus groups and virtual focus groups with a sample of 19 PWDs and PW/oDs. They found that PWDs reported more instances of feeling as if their HCP viewed them as incompetent (de Vries McClintock, 2016; Durand et al., 2008). This finding is promising in linking the Stereotype Content Model with PWDs' experiences of interacting with HCPs. However there remains a need to further examine PWDs' perceptions of how their HCPs treat them. Psychometrically validated scales are often used to measure subjective experience for research and health practice purposes. Thus, a rigorously designed, theoretically based psychometric tool would be instrumental in systematically assessing the perceptions of PWDs about their treatment by HCPs.

## **1.7 THE NEED TO DEVELOP A SCALE TO ASSESS PWDS' BELIEFS ABOUT THEIR HEALTHCARE**

A psychometric tool designed to measure the perceptions by PWDs of how they think their HCPs perceive them would greatly contribute to improving the quality of care for PWDs as well as allow researchers to examine research questions regarding the subjective experience of healthcare in the blind population. The Stereotype Content Model can serve as a theoretical basis for such a scale. Additionally, such a scale would need to be founded in the perspectives of PWDs themselves in order to be a valid measure of PWDs' perspectives.

Existing scales measure patients' trust in physicians and their satisfaction with care. It is important to assess the patient's perspective in order to determine how well they are receiving treatment from an HCP. Anderson and Dedrick (1990) developed the 11-item Trust in Physicians

Scale. Items were created using the perspectives of both patients and physicians. This measure demonstrated good reliability ( $\alpha \geq .85$ ). However, participants were middle-to-older-aged men with diabetes. Therefore, the experiences of these patients may not generalize to other populations. Hall and colleagues (2002) created the Wake Forest Trust in Physician Scale to measure trust in physicians. This 26-item scale had good psychometric properties ( $\alpha \geq .92$ , test-retest  $r = .75$ ) and was correlated with satisfaction with care ( $r$ s ranging from .75 to .09, all  $ps \leq .0001$ ). Though these scales were validated with minority participants, neither of these scales was developed from the perspectives of minority patients and lacked a clear theoretical framework. Using a theoretical framework would lend power to the scale developed and further contribute to an existing knowledge base.

On the other hand, the Scale of Anti-Asian Americans Stereotypes (Lin, Kwan, Chung, & Fiske, 2005) has a clear theoretical framework; it is based on the Stereotype Content Model. The scale measures stereotypes related to competence and warmth for Asian Americans. This scale further helps researchers understand stereotypes, prejudice, and discrimination toward Asian Americans. However, only 27 out of 296 participants in the study that led to item development identified as Asian. The scale was not validated by an examination of the perspectives of the target minority group (Lin et al., 2005).

A scale designed to measure PWDs' perceptions of stereotypes about them may be beneficial because it could lend further validity to the Stereotype Content Model as well as extend the theory with previously unexamined perspectives. It would be a contribution to the literature to generate items based on the affected minorities' perspectives of the stereotypes directed at them. This dissertation developed and validated a scale based in perspectives of blind adults and the theoretical framework of the Stereotype Content Model. Previously developed

scales are set up so that the perspective of the perceiver is that of a majority social group making evaluations about the target minority social group or individual, whereas the scale developed in this dissertation treats the minority group, blind patients, as the perceiver rather than the target to be evaluated by others.

## **1.8 AIMS AND HYPOTHESES**

For this dissertation, qualitative data on the perspectives of blind patients about their interactions with healthcare providers (HCPs) was collected and a measure was developed to assess these interactions. This study contributes to the knowledge base to enhance the healthcare of blind patients. It was expected that themes regarding HCPs' appraisals of participants' competence would emerge in qualitative data analysis. Findings from this first qualitative study would then inform the writing of a quantitative measure which would be developed and validated over the course of two subsequent studies. Scale items were written based on prevalent themes from the focus group. The measure was then refined and validated to create a measure of PWDs' perspectives of how their HCPs perceive them.

*Aim 1. Identify common themes from reports of PWDs' experiences interacting with their healthcare providers*

A qualitative, focus group interview study (Study 1) addressed Aim 1. Four research questions were posed: *Q1*: What are blind patients' perceptions of how their HCPs perceive them and their competence? *Q2*: What are blind patients' experiences interacting with their HCPs when making a treatment decision? *Q3*: How do blind patients evaluate these interactions with HCPs? *Q4*: How do these interactions impact blind patients' overall functioning and health? It was expected that PWDs would report that their HCPs underestimate their competence and, consequently, prescribe inappropriate, unfeasible, and potentially harmful treatments.

*Aim 2. Create a validated and reliable measure to assess how PWDs perceive that they are viewed and treated by their HCPs*

To address this aim, two studies were conducted to develop a scale based on the qualitative data from Study 1. A preliminary set of items was developed based on the themes from Study 1 that was tested in Study 2. This set of items was presented to participants and participants were instructed to rate the items to reflect how much the item described their experiences. Participants were also instructed to describe any related construct that was not addressed by existing items. In Study 3, the results and feedback were used to modify the scale. The modified scale was administered to a sample of blind adults with experience interacting with HCPs in order to establish reliability and validity.

## **Chapter 2: Study 1 Methods**

The 10-phase mixed-methods instrument development and construct validation (IDCV) process for scale development and validation was followed as a guideline in this study. The IDCV process uses qualitative, quantitative, and cross over qualitative-to-quantitative data (explained in the following paragraph), and thematic analysis, factor analysis, and correlations (Onwuegbuzie, Bustamante, & Nelson, 2010). This process builds on Campbell and Fiske's (1959) multitrait-multimethod matrix framework. Campbell and Fiske (1959) assumed that quantitative data is sufficient for developing quantitative scales (as cited in Onwuegbuzie et al., 2010). Onwuegbuzie and colleagues (2010) highlight the important role qualitative data and qualitative methodology can play in quantitative scale development.

A description of the 10 phases is presented in Appendix A. Phase 1—where constructs are defined and a strong theoretical framework is set in place by an in-depth, multidisciplinary review of literature—is satisfied by the review of literature summarized in the Introduction of this dissertation. The review of literature borrows from psychology, sociology, and rehabilitation counseling literature.

In study 1, data were collected across seven focus groups to identify nuances of themes from the Stereotype Content Model and identify other themes related to blind patients' perspectives of how their HCPs perceive them, their experiences interacting with their HCPs and making decisions, and how these interactions impact their health and functioning. Study 1 fulfilled Phase 2 of Onwuegbuzie and colleagues' (2010) IDCV process by building on the Stereotype Content Model themes with the perspectives and experiences of blind people themselves.

## 2.1 DESIGN

A focus group study was conducted (Krueger, 2002; Robinson, 1999) to deductively corroborate themes related to the Stereotype Content Model and to inductively identify themes that captured nuances related to the Stereotype Content Model as well as noteworthy themes unrelated to the Model. To ensure trustworthiness in the data collection and organization stages of the study, literature about conducting focus group interviews, interviewing techniques (e.g., Cuevas et al., 2016; Elo et al., 2014; Krueger, 2012), and cultural competence when working with blind research participants were studied (American Evaluation Association, 2011; Olkin, 2002; Samuels & Ryan, 2011). One practice interview was conducted with three blind volunteers to rehearse interviewing techniques and check the cultural competence of the interview questions prior to collecting data.

As the moderator, I used a semi-structured interview protocol when guiding a focus group discussion (see Appendix C and Appendix D for welcome script and prompts, respectively), used meaningful pauses to allow participants to collect and share their thoughts, and used probing questions such as “Would you explain further?” and “Would you give an example?” to gain a clear impression of the participants’ intended answers. During the interview, I, as the moderator, took notes on the themes brought up in the focus group interviews to keep in mind for thematic analysis.

I facilitated each focus group, operated recording equipment, and took notes on the session while facilitating the focus group interview. I also used a check list to ensure that she completed everything to prepare for the focus group including checking recording equipment, obtaining informed consent and confidentiality pledge, pressing the appropriate record button on the recorder at the beginning of the interview, recording the start time on the checklist, pressing

the end record button on the tape recorder at the end of the interview, and record the end time on the checklist sheet (see Appendix E for checklist).

## **2.2 PARTICIPANTS**

A key informant sampling procedure was used to identify participants able to provide the best responses to address the goals of the study (Gilchrist & Williams, 1991)—blind adults. An email was distributed to the National Federation of the Blind and American Counsel of the Blind listservs with information about the study, and interested participants were instructed to contact me and my team of research assistants (See Appendix B for recruitment statement). A sample of blind adults were invited to participate in this study. Participants were mostly female ( $n = 38$ ) and White ( $n = 39$ ). The average age was 53.31 years ( $SD = 13.67$ ) and participants reported, on average, 16.94 years of education ( $SD = 2.60$ ). Data on all study materials were collected online and/or over the phone according to participants' expressed preferences in order to ensure accessibility. The research team regularly asked participants about their needs and preferences for comfortable access of all study materials. Focus group proceedings were completely auditory and conducted with cultural sensitivity (American Evaluation Association, 2011; Olkin, 2002; Samuels & Ryan, 2011).

These blind adults were asked to nominate other potential participants. Seven focus groups consisting of 4-8 participants each were conducted (for 42 individual participants total). The number 4-6 participants per session is recommended by Krueger (2002) as an ideal number for the encouragement of participants to engage in the discussion. The number of participants in each focus group was close to this range. There were a few cases where participants needed to be scheduled into a "full" focus group of six people due to scheduling limitations. Only one focus group (Focus Group 1) reached eight participants. This was because one participant called in a

day earlier than when they were scheduled. Since participants were members of a special population, discussing a specific shared experience (e.g., interacting with healthcare providers in the clinical setting), data are likely to be trustworthy (Elo et al, 2014).

### **2.3 MEASURE AND PREPARED QUESTIONS**

Participants completed an accessible informed consent document or gave verbal consent as described in further detail in the Procedure section below. Participants completed a demographics questionnaire. Participants were also asked about their overall mental and physical health, blindness, and other physical and sensory disabilities (See Appendix F for screening form and Appendix G for questionnaire). All questionnaires were administered in an accessible format.

Focus groups were recorded using a Sony media make believe digital recorder™, iPhone voice memo, the recorder that was part of the freeconference.com calls platform, Audacity and M-Audio Producer USB microphone™. Interviews were conducted via conference calls, using the platform, freeconferencecalls.com. Interviews were each 2 hours long. The interviews followed a semi-structured format (see Appendix D for interview questions). However, as the moderator, I took the liberty to probe for more information or clarification at any time during the interview. The semi-structured format also granted participants some freedom to direct the focus group discussion.

### **2.4 PROCEDURE**

The Institutional Review Board of the University of Texas at El Paso approved this study. Participants were recruited from the University of Texas at El Paso Campus Accommodations and Student Services program, National Federation of the Blind, and American Council of the Blind email lists. Interested participants contacted the research team. Then research assistants



and I sent the prospective participants the informed consent form, demographics questionnaire, a health and activities questionnaire, and the stereotype content questionnaire (Fiske et al., 2002) as electronic documents that may be enlarged, accessed with a screen reader, and/or read into a braille display. Participants also had the option to call the lab phone and complete these forms and surveys over the phone with a member of the research team. After completing the informed consent and demographics form, participants were contacted by email and/or phone (according to each participant's preferred mode of contact) to schedule an interview time.

Focus group interviews took place on conference calls. This purely auditory interview platform was meant to eliminate any bias that varying usable vision among participants may have introduced in an in-person focus group interview setting. This platform also removed the barrier of transportation, making it easier for interested and qualified people to participate. Prior to interviews, participants were encouraged to identify a quiet and comfortable place where they may participate in the conference call with no interruptions. I fulfilled the role of moderator and, thus, opened the focus group discussion by introducing myself, then informed participants of the purpose of the research and their rights as participants. I then began to facilitate the focus group through discussion of the semi-structured interview protocol (See Appendix C for Welcome Script). I, as the moderator, explained that the data collected from the focus group would be confidential and that subject numbers and pseudonyms would be associated with responses instead of participants' actual names. Participants agree to preserve the confidentiality of the responses contributed by their fellow focus group participants. As the moderator, I encouraged participants to share their experiences, thoughts, and feelings related to the topics addressed by the predetermined questions and welcomed other comments that fit within the scope of the interview.

The moderator used interviewing techniques including summarizing participants' statements, and asked questions to gain further insight on the content and structure of participants' thoughts. I also moved the discussion forward and kept the discussion within the scope of the interview. When all participants finished discussing their answers to a given question from the semi-structured protocol, I summarized the participants' responses, asked if the summary was accurate, and asked if participants had anything to add to the summary. Participants were encouraged to correct or add to the summary I provided. Then I posed the next question. This procedure was repeated for each question. After all questions were discussed, I asked if participants wished to bring anything else to the attention of the group related to the topic of the interview, and concluded the interview. Finally, participants were thanked for their participation and dismissed from the study.

## **2.5 THEMATIC ANALYSES**

Data provided by key informants were collected during focus group interviews, transcribed, and analyzed. The entire research team, consisting of four research assistants and I, served as transcribers and conducted transcriptions. The transcribers were instructed to type everything that the participants and moderator said, verbatim. To do this, they were instructed to stop the audio file when they needed time to type what they heard. The transcribers listened to the interviews several times while reading along in the transcription in order to ensure accuracy. Instructions for transcribing included the following: If participants quote others when telling a story, the transcribers were instructed to use apostrophes ('). In order to convey the full content of transcription, the transcribers included filler sounds such as "um" and "uh" in the transcriptions as well as the speech of the moderator on the audio recording.

Transcribers were each assigned one to two focus group recordings at a time to transcribe. After the first drafts of transcriptions were completed, these transcriptions were reassigned to a different transcriber for an additional review. For this additional review, transcribers listened to the given focus group recording while reading the respective first draft transcription. They corrected errors in the first draft. I conducted a final review of all transcriptions by listening to each of the focus group recordings while reading their respective transcriptions, and correcting errors in the transcriptions. See Appendix H for a schedule of transcription assignments including which transcriber was assigned to which stage of transcription.

Coding was conducted after transcriptions were complete. Two of the four research assistants served as coders and were trained to code the focus group transcriptions. Their training and instructions included this Thematic Analyses section, guidelines established by Braun and Clarke (2006), and an instructional meeting conducted by me prior to coding. This instructional meeting included a review of thematic analysis and a demonstration of using NVivo 11 (QSR International, n.d.). NVivo is a database management tool used to code and organize various forms of data including multiple text files. Throughout the coding process, the coders were encouraged to refer to the audio recording several times and consulted each other for interpretations of sections of transcriptions. This process maximized the trustworthiness of results by ensuring accuracy of representing the intended meaning of participants (Elo et al., 2014).

A codebook was used to organize the data (DeCuir-Gunby, Marshall, & McCulloch, 2011; Miller & Crabtree, 1999). A thematic analysis (Braun & Clarke, 2006; Krueger, 2012; Pope & Mayes, 1995) was conducted on the transcriptions of the focus group interviews. The

process of thematic analysis entails reading through the transcriptions of the focus group interviews and recording common patterns of responses or “themes.” The codebook including theoretically derived themes was written by me. This codebook consists of a set of predicted themes and their associated definitions. The codebook provided a standard guideline by which quotes from participants were sorted into themes. The codebook was written after several readings of Dovidio and Fiske (2012) and Cuevas and colleagues (2016), the key articles that outline the theoretical framework for this dissertation. This codebook developed for this project went through revisions and additions as inductively derived themes were identified during focus group interviews and data analysis.

There were two stages of coding: In the first stage, coders identified meaningful sections of passages within the scope of research questions and conducted the initial sorting of passages into predetermined themes, using the codebook. In the second stage

, I read all of the sections of passages sorted into all of the themes and reviewed the fit of sections of passage within the themes assigned by coders. I also read all transcriptions in their entirety to include passages in the analysis that may have been overlooked before.

The two coders analyzed the focus group interviews under my supervision. Interviews were coded using NVivo 11 software (QSR International, n.d.). This software was used by coders to analyze the transcriptions by selecting sections of passage illustrative of a single given theme. Quotes were tagged with the participant’s nickname and coded with the name of the theme that they most closely aligned with conceptually. Both theory-driven (deductive) and data-driven (inductive) stages of analysis were used to sort quotes into themes. The coders examined the transcribed quotes for theory-driven themes according to the codebook. The codebook includes an “other” theme that consists of quotes that were not initially placed in a theme. Coders

examined the quotes within the “other” theme and reconsidered whether these quotes fit within any existing theme, belonged in a separate new theme, or remained in the “other” theme.

The first stage of coding was carried out independently. Following the independent coding phase, coders held meetings to resolve coding discrepancies. During these meetings, all coders were encouraged to share their perspectives about the placement of a quote openly and freely (DeCuir-Gunby et al., 2011). During these meetings, coders resolved most coding discrepancies through discussion and subsequent placement of initially discrepant quotes within an existing theme. The placement of some quotes remained unresolved after this first coder meeting. Coders then independently reexamined the discrepant quotes and reconvened to discuss the categorization of these quotes. Coders decided that some quotes did not fit within any deductive theme. Coders also independently and collectively determined new themes within which these quotes belong. The coders inductively identified themes that were mentioned in focus groups and add them into the codebook (Charmaz, 1990; Heydarian, 2016). Since coders selected the sections to code while independently coding, there was variability in the words included in the selected passages by each of the coders. For instance, considering a passage of transcription where a participant might have spoken four sentences about a given noteworthy experience, Coder 1 may have tagged the entire second sentence and half of the third sentence while Coder 2 may have tagged the entire third and fourth sentence. Although these two sections of passage were part of the same story and perhaps same theme discussed by the same participant, there was mismatch between the two sections of passage tagged by each of the two coders. Because of this mismatch, it was not possible to calculate valid Cohen’s kappa coefficients to determine the interrater reliability of the themes.

## **Chapter 3: Study 1 Results**

Themes were extracted from the thematic analysis of focus group interviews. Themes that were conceptually similar with one another were organized into categories. These themes and categories are discussed below, according to the research question that they answered. Exemplary quotes from focus group participants are presented to illustrate the theme's content. Pseudonyms that participants selected appear next to quotes of their transcribed speech. For each theme, the number of focus groups that the themes appeared in and the number of total participants across all focus groups who mentioned the theme are reported in order to show the prevalence of the topics conveyed by the themes. This reporting is meant as an approximation of participant agreement. It is possible that other participants agreed or disagreed with ideas expressed by other participants, but did not express their agreement or disagreement.

### **3.1 RESEARCH QUESTION 1: WHAT ARE BLIND PATIENTS' PERCEPTIONS OF HOW THEIR HCPS PERCEIVE THEM AND PERCEIVE THEIR COMPETENCE?**

Participants made comments regarding how they thought their HCPs evaluated their competence, how HCPs responded as a result of their competence evaluations, and the degree to which HCPs seemed to respect participants and trust the information provided by them. Participants also discussed how they thought their HCPs evaluated their warmth. Participants attributed these evaluations of competence and warmth to the HCP's presumed degree of comfort or discomfort with blindness.

#### **3.1.1 Competence**

Three themes from the category competence answered the research question asking about how participants thought they were viewed by HCPs. These themes included. Competence Assumption High, Competence Assumption Low, and Patient Burden to Appear Competent.

### *Competence assumption high*

Ten participants across five focus groups expressed that they felt they had positive experiences with their HCPs because they were being treated as if they had a high level of competence. Sarah from Focus Group 2 described her experience with her HCPs: “they don’t assume that I don’t know what I’m talking about or anything.”

### *Competence assumption low*

Thirty participants across all seven focus groups noted instances where they felt as if their HCPs believed them to be low in competence. Participants noted instances when HCPs expressed surprise in the patient’s competence to complete everyday self-care activities such as getting dressed independently. June from Focus Group 2 said

They feel like because “you’re blind, you can’t do anything!” like, you are totally incapable. And not ...the fact that you have feelings, that you know what you need, that ‘Oh, how can you know that you have a headache? You’re blind.”

### *Patient burden to appear warm/competent*

There were 24 participants from all seven focus groups who commented on the feeling of needing to appear warm or competent in front of HCPs. Some participants reported that it was their duty to educate HCPs about how competent blind people actually can be and to teach them that stereotypes about low competence are not necessarily true. It implies that patients, as part of educating, must appear warm and competent. Participants in Focus Group 4 reported feeling the need to appear competent as blind patients in order to be treated with respect from healthcare providers. Participants in Focus Group 5 acknowledge the pressure to appear competent constantly, however they pointed out how this expectation may be placing a burden on the blind

patient who is, more than likely, coming to an HCP with some discomfort and not feeling well.

Mel's response (Focus Group 5) characterizes this idea:

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 and stuff cause I don't think anybody does that to people who aren't sighted or who are sighted...I don't want to imply that you have to look confident or anything I actually think that's kind of unfair and frustrating that you get more help if you look more confident cause I don't think that's true in the sighted world so it's sort of frustrating that when you have a disability and you need help you have to look a certain way in order to get the help you need I do think that's really unfair and unfortunate.

Katie from Focus Group 7 told a story about her blind friend who had to advocate for himself and convince the HCP of his competence in order to preserve his independence. He was in his forties and lived alone and independently in his own apartment when he started to have problems with his kidneys and had to start dialysis:

At one point, he called me and he was just in tears ... I said, "what happened? Was it painful?" ... He said no, the doctor came up and said "well I understand ... you're blind as well and I'm really having a hard time sending you home from this appointment." That was to do with his kidneys. And he said, "because I'm told your, you have nobody at home. There's nobody- you'll be sending" and so she just kept going, pounding that in.



You can't possibly be single and alone and be blind. "I'm really thinking about sending you to a rehabilitation center..."

### **3.1.2 HCP response to patient competence**

HCPs may also be responding with treatment decisions and the level at which they engage their patients in the appointment based on their impressions of patient competence. At times, the patient is not successful at convincing the HCP of their competence. There were 17 participants across all seven focus groups reporting such instances. In one case, an HCP withheld vital treatment because of assumptions of patient incompetence. In some cases, the HCP refused medical services to the participant upon discover of the participant's blindness. This may be attributed to the HCP's stereotypes about the competence of blind people and lack of knowledge about how to accommodate such patients.

Some participants described instances when they were refused medical service by HCPs. This refusal of service ranged in seriousness from an inconvenience for example, in Moonbeam's case where the HCP called her house to cancel her appointment when she was already on route with her paratransit to the appointment, to a potentially harmful situation such as in the case of Mel's friend who needed her diabetes medication forwarded to the hospital where she was being treated, and the doctor would not do it. "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 uh just because he thought she was being crazy quote unquote which she absolutely was not."

Also of note, there was evidence that HCPs may be over-pathologizing the health concerns of blind patients and consequently administering inappropriate treatments such as unnecessary institutionalization due to assumptions of patient incompetence. Katie described the

experience of one of her blind friends interacting with a healthcare provider who learned of his blindness and based on that, was considering sending him to an assisted living institution.

The doctor came up and said “well I understand...you’re blind as well [as having to conduct dialysis] and I’m really having a hard time sending you home from this appointment...because...I’m told you have nobody at home. There’s nobody...” and so she just kept pounding that in. ...you can’t possibly be single and alone and...be blind. And I mean it was the blindness that freaked them out and...she goes “I’m really thinking about sending you to a rehabilitation center...”

#### *Addressing the blind patient*

Competence assumptions made by HCPs about blind patients may be inferred by whether or not they directly addressed questions about the adult patient’s health to the patient themselves. Twenty-three participants across all seven focus groups made remarks about HCPs addressing the nearest sighted person who was often virtually a stranger to the patient instead of addressing the patient themselves. Moe from Focus Group 5 described his experience:

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.”

Often, participants reported “speaking up” and reminding the HCP that they could be addressed directly. In other cases, the sighted person directed the HCP to address the patient directly. In some instances, participants noted that the HCP directly addressed them. The fact that being addressed directly is a noteworthy experience speaks to how often HCPs do not directly address the patient. This tendency to address the person that the HCP assumes is the caretaker of the

patient implies that the HCP is making assumptions about the patient's ability to independently answer questions about their own health.

#### *Interference with patient independence*

Participants discussed their experiences as care takers interacting with HCPs. These participants reported concerns about their HCPs interfering with their role as care takers. Paula from Focus Group 5 and Sue from Focus Group 6 discussed opposition faced by blind caretakers of people in need of care. Sue discussed how the hospital where her husband received surgery resisted when Sue wanted to take her husband home from the hospital:

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 care giver. 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 I would, he would still walk and get in the car I'm gonna call a cab or Uber and go home with him'

Other participants reported that they felt their HCPs perceived them to be low in competence because they perceived their HCPs to express assumptions that they had a sighted caretaker. Some participants noted that they were treated as if they also had other disabilities such as psychological disabilities.

### **3.1.3 Trust**

In the literature, trust is used interchangeably with warmth (Fiske et al., 2002; Ho, 2011). However in this study, the theme of trust seems to be more closely related to evaluations of competence that would lead an HCP to either trust or mistrust health information provided by a blind patient.

### *HCP mis-/trust in patient's information.*

Participants discussed how different HCPs seemed to trust the medical information that they shared to varying degrees. HCPs who were described as being more 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 in the course of treatment, often times considering the accessibility of the treatment plan for the patient. Tali from Focus Group 3 described how she felt that her HCPs trusted the information she gives them about her health: "all my positive experiences are with doctors who seem to respect that a) that I have some health you know medical background and b) that I know my body very well."

#### **3.1.4 Respect**

In response to this first research question regarding participants' perceptions of how their HCPs evaluated their competence, themes related to respect, the belief that one is being treated as warm and competent, were extracted from the focus group interview content.

### *HCP does not respect patient*

Twenty-seven participants from all seven focus groups expressed that they did not feel as if they were being treated with respect by their HCPs. Participants reported feeling treated as less than human. Kevin from Focus Group 1 said "It kinda makes you think that you're more of an object for someone's entertainment instead of an actual human being." Participants reported feeling as if their HCP perceived them as an inconvenience. Bob from Focus Group 3 described such an experience:

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.

### **3.1.5 Warmth**

Although the aim of this first research question was to examine how participants thought they were viewed by their HCPs in terms of competence (one dimension of the Stereotype Content Model), participants also discussed how they thought their HCPs viewed them in terms of warmth (the second dimension of the Stereotype Content Model).

#### *Warmth assumptions (high and low) about patient*

Some participants reported that they might have come off as cold to the HCP. Sophie from Focus Group 5 said that “they [HCPs] take it [assertiveness from patient] more as almost an affront.” Other participants reported that they felt as if their HCPs regarded them as warm. Sarah from Focus Group 2 explained how she tries to be warm:

I just, try to be a good patient, 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, that’s I guess why, well I don’t know if that’s why, but I’m guessing that’s maybe part of why most of my experiences with healthcare people have been really good.

### **3.1.6 Attributions**

In response to the first research question, participant made attributions about patient and HCP characteristics that may lead to a positive or negative interaction with an HCP. In particular, the theme Comfort/discomfort with blindness was an attribution that patients made related to how they thought their HCPs perceived them and their competence.

#### *Comfort/discomfort with blindness*

Participants described getting the impression that HCPs were afraid of blindness, particularly avoidant or fearful around the patient, appeared uncomfortable around a blind patient

who appeared competent, and seemed to panic once they learned that the patient was blind. Mel from Focus Group 5 described this perceived discomfort:

Sighted people seem to be really scared of blindness just as a concept period and to encounter it like you know they don't wanna admit that you're blind and they get upset that you're blind and you know and in the meantime you're just like 'hi it's not bothering me that much but your behavior is.'

In participants' positive experiences, HCPs were reported to appear comfortable with blindness. Daphne from Focus Group 3 described her HCP as someone who was comfortable around her as a blind patient. She said "he just didn't bat an eye, my blindness didn't bother him."

### **3.2 RESEARCH QUESTION 2: WHAT ARE BLIND PATIENTS' EXPERIENCES INTERACTING WITH THEIR HCPS WHEN MAKING A TREATMENT DECISION?**

Participants discussed their involvement in shared decision-making, their trust in the medical decisions made by their HCPs, the effective and ineffective methods that HCPs used to communicate with them, and the pity that they perceived their HCPs to approach them with.

#### **3.2.1 Patient involvement in shared decision-making**

Some HCPs did not share enough information with their patients to allow them to participate in medical decision-making. Some HCPs reportedly did not share enough information about medical conditions and treatment options with their blind patients, did not review side effects of treatments with patients, and did not allow patients to authorize decisions about themselves. Cheryl from Focus Group 1 described an experience of not being fully informed about documents needing signatures: "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'"

Some HCPs did share clinical decisions with their blind patients. These HCPs reportedly informed their patients about treatment options and considered their preferences. For example, Moe described his experience:

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 you know courses of care depending on in...it's...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 or anything like that

### **3.2.2 Trust**

#### *Participant mis-trust in HCP diagnosis/prescribed course of treatment*

Patients' perceptions of HCPs perceiving the patients as incompetent led to the patient mistrusting the HCPs' diagnostic and treatment decisions. Mel and Annie reported feeling mistrustful about their doctor's advice because they perceived their doctors as seeing them as incompetent. Such patients might lose trust in their HCPs because they perceive the judgment of low competence as incorrect which may call into question the correctness of the HCP's other perspectives such as their clinical judgment.

Bob did not trust his doctor's diagnosis because the doctor was impersonal. The HCP may be perceiving the patient as incompetent and then treating the patient with coldness. When the patient detects unfavorable judgments of their competence and that, as a result, the HCP is treating them with less warmth, this may lead the patient to mistrust the diagnosis and treatment of the doctor regardless whether this diagnosis or treatment is truly correct or incorrect.

### 3.2.3 Communication

Participants also discussed effective and ineffective communication strategies that their HCPs tried with them. These communication strategies were sometimes used when conveying information critical to decision-making.

#### *Effective*

Thirteen participants across six focus groups described instances where HCPs communicated effectively with them by doing such things as not asking “weird questions” (as described by Jessica from Focus Group 3) about blindness and communicate effectively with their patients about the medical concerns at hand and openly acknowledging their knowledge gaps about blindness and accommodations. Jessica described her interactions with her HCP: “she [HCP] talks to me like she would talk to anybody else. Blindness has never been a thing and whenever she has questions about it they aren’t the nosy sort of questions.”

#### *Ineffective*

Patients described the ease of communication with their HCPs. Nineteen participants across all seven focus groups noted that HCPs have trouble listening to and communicating with blind patients. Georgina in Focus Group 1 described her experience with an HCP who had trouble listening to her: “she [HCP] just was not receptive and it had to take me telling her 5 or 6 times that I can sign my own name. I can make decisions for myself.” HCPs were reported to ask inappropriate and, often, irrelevant questions about blindness when the patient came to the HCP with an unrelated presenting concern. Hannah from Focus Group 2 retold her experience with one doctor “one of my doctors said ‘well, you’re blind, how do you eat?’ It’s, like, what does that have to do with anything?”



### 3.2.4 Pity

There were 13 participants across all seven focus groups who reported that they were treated with pity by their HCPs. Participants reported being treated with pity when their HCPs adopted a patronizing tone of voice when talking with them and providing unsolicited help to the participant with simple task such as opening doors. Beatrice from Focus Group 6 described an experience where her internist expressed a patronizing belief:

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, 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.

## 3.3 RESEARCH QUESTION 3: HOW DO BLIND PATIENTS EVALUATE THESE INTERACTIONS WITH HCPS?

Participants evaluated their interactions with HCPs in terms of HCP warmth and of the patient-HCP relationship, and attributed their interactions to HCPs' degree of understanding of blindness, HCP characteristics, and patient characteristics.

### 3.3.1 Warmth

Participants described some of their interactions in terms of warmth. Some participants described their HCPs as warm and that they had a warm relationship with their HCPs.

#### *Warmth of HCP*

Participants described the warmth of their HCPs. Many HCPs were described as warm and using humor to warm the atmosphere of the clinical visit. Skye described warm HCPs in the following terms: "you'll have a doctor who's interested in whatever your hobbies could be and how they can help you." Other HCPs were described as being cold. For example, Bob from

Focus Group 3 said “They [doctors whom he had negative experiences with] didn’t want to sit there and listen to ya.”

#### *Warm relationship*

Twelve participants reported having a friendly relationships with their HCPs whom they also regarded to be competent HCPs. Participants described their relationships as warm, friendly, and described their HCPs as being “like family.” Paris from Focus Group 6 said “I have wonderful relationships with my physicians.”

### **3.3.2 Attributions**

Participants also attributed the quality of their interactions with HCPs to the degree of the HCP’s understanding of blindness, HCP characteristics, and patient characteristics.

#### *Degree of understanding about blindness*

HCPs may base the way they interact with blind patients on their own understanding of blindness. This understanding may vary in accuracy and depth. Eleven participants across five focus groups reported that their HCP’s understanding of blindness was also a contributing factor to the quality of healthcare that they received. Some participants speculated that their HCPs must have limited-to-no prior exposure interacting with blind people and, as a result, may be more prone to letting stereotypes guide the way they view and interact with blind people. Paula in Focus Group 5 described a phenomenon she experienced as a blind clinician. Paula described her working situation where as a therapist in a clinical setting alongside other HCPs. As soon as the clinic hired someone who embodied incompetence stereotypes, then Paula’s colleagues started to treat her differently and to talk about blindness differently. When Paula tried to use herself as an example to disprove the stereotype, her colleagues would qualify her as the exception to the stereotype. Paula said

The stereotype was so ingrained that even having had extensive experience with a competent blind person as soon as they saw somebody who wasn't, their ability to perceive blindness as something other than a major obstacle and a serious impediment and annoyance disappeared and that was just so sad to me.

#### *HCP characteristics*

Twenty-one participants across all seven focus groups also attributed the interactions they had with HCPs to individual difference of the HCPs such as gender or personality of the HCPs. Hannah from Focus Group 2 said "it's a personality thing, I think, sometimes with doctors." Opinions on gender differences were mixed. Some participants reported preferring male HCPs where as others had an aversion to male HCPs. Georgina from Focus Group 1 was one such person. She said "after that I never saw a male GYN ever again."

#### *Patient characteristics*

Eleven participants across six focus groups discussed patient characteristics besides blindness, which may be driving the nature of the interactions with HCPs. Some participants attributed their negative interactions with HCPs to the patient's personality, lack of eye contact with the HCP, and gender differences where female blind patients experienced the most patronizing behaviors where they were "talked down to" more than male blind patients and treated less like autonomous adults. Mel and Lazlo from Focus Group 5 also mentioned that they thought that ethnicity contributed to the experience where blind adults of minority ethnicity such as Latino/as and African Americans had more negative experience with their HCPs. Mel said

A lot of my friends they are black or Hispanic and they're also blind and they get treated very differently and I think I hear a lot more negative stories from them than I do from

myself which is bad because I have a lot of negative stories as it is but that they've got it worse even.

### **3.4 RESEARCH QUESTION 4: HOW DO THESE INTERACTIONS IMPACT BLIND PATIENTS' OVERALL FUNCTIONING AND HEALTH?**

Participants described their responses to both positive and negative interactions with HCPs. Participants also described accommodations that were present or absent which impacted their overall functioning in the healthcare setting. Finally, participants described their responses to receiving or not receiving the respect of their HCPs.

#### **3.4.1 Participant response after negative/positive experience**

Six participants across four focus groups discussed their responses to interactions with HCPs. When participants reported having a negative interaction with their HCP, they also reported experiencing a loss of independence and feeling powerless, not following HCP recommended course of treatment, not returning to that HCP, and avoiding the doctor altogether. Barbra from Focus Group 4 explained this: "I never went back to him because I didn't want to start anything and I didn't like him. That's usually what I do: I don't go back if I didn't like them." When participants reported having a positive experience interacting with their HCPs, they reported returning to that HCP.

#### **3.4.2 Accommodations**

In response to the fourth research question, participants discussed how their HCPs were accommodating or were not accommodating. Participants also described structural barriers and facilitators, and efforts they initiated to prepare for their healthcare appointments. These different elements of accommodations impact blind patients' overall functioning in the healthcare setting.

*HCP don'ts*

Thirty seven participants across all seven focus groups reported that some healthcare providers violate confidentiality without the consent of the patient by reading aloud sensitive medical questions in front of other patients or sharing sensitive medical documents with others presumed to be the patient's care taker or the patient's children without the patient's consent. June described the potential risks involved with such violation of confidentiality:

We had this on the news here in [City]. There was a person that was, in this case, deaf, and the person broke, it somebody broke into their home and because they thought 'oh gee, they're handicapped, they're gonna have pain medication.' So you've gotta be careful what is shared out and when and to whom.

Participants also reported some HCPs refusing or interfering with accommodations that participants provide for themselves. For example, some participants reported that their HCPs made their guide dogs wait in the waiting area. Beatrice in Focus Group 6 described how HCPs took away her white cane. Participants described how inadequate or even inappropriate accommodations were presented to the patient. Bob from Focus Group 3 described how HCPs did not use proper sighted guide techniques when attempting to lead him into an exam room. He reported that HCPs would push him from behind and as someone who's balance is "not great" as he described it, he would be at increased risk of falling.

#### *HCP dos*

At times, HCPs do take measure to provide appropriate accommodations in line with patient needs and preferences. These HCPs reportedly asked patients what accommodations were needed and listened to patient's answers, making an effort to secure accommodations and offer help when the patient requested help. These HCPs were also reported to advocate for patients to ensure that patients got appropriate accommodations and did not get inappropriate,

disempowering treatment such as having staff members opening doors for them as Sue from Focus Group 6 described. Sue said “the only thing that I would say is you need to make sure you ask people what they need or want.” As a result of the latter efforts of HCPs, patients benefit from the resources provided to them that allow them to manage their own health. June from Focus Group 2 said:

Being diabetic... Yes, we have audible meters, but lining a blood droplet up especially since it's so tiny, and that little thing on the meter, is not as easy as people think it is.

And, so she sat there with me with my glucometer trying to figure out “hey, you know, let's try this, let's try that”

*Touch.* Participants noted instances where their HCP touched them and it was either a negative experience or a positive experience. In situations where the HCP does not warn the patient about when and how the patient will be touched, patients report feeling startled and distressed as a result. Participants described how, in positive interactions, the HCP explained exactly what was going to happen and why especially when they would touch the participant. Cheryl described how her gynecologist used this approach to preparing her for a cervical exam, by letting Cheryl feel the speculum so that she would be informed about what the apparatus was like to prepare her for a pap smear.

### *Preparation*

Forty-one participants across all seven focus groups discussed how they prepare for their healthcare visits. Participants reported arranging for accommodations ahead of time to be able to access documents such as appointment scheduling on online portals, intake forms, and post-visit surveys. Eleven participants reported mentally preparing for healthcare visits and that many of

these preparative measures were anxiety-provoking. Petra described her experience preparing for HCP visits in Focus Group 7:

I am in [City, State] it's a fairly sizable town. So I do have to get transportation. And ...I do try to come up with questions. Sometimes I do have to use my husband or another reader to read things like medicine bottles to get that list together. Now that we have the health app on the iPhone, it's a little easier to just maintain it there and then when they wanna know, here, have this. I'm also diabetic, so, I log my blood sugars regularly and have, since I've been diabetic, I've had to find a way to print them out for a doctor to read. Thank goodness there's good apps for that. Well at least there so that you can throw it in Excel, copy it to Word and print it out, but some things are more of a hassle than others. I need to give them print, I know that, so I just try to do it.

#### *Structural barriers and facilitators*

Structural barriers present in the healthcare system were discussed by 19 participants across all seven focus groups and included information materials such as educational pamphlets and prescription/referral forms offered in print only, inaccessible vital medical equipment such as insulin pumps and PIC lines cleaning techniques. Participants talked about their experiences with getting instructional information in an inaccessible print format. This theme overlapped with the theme, Preparation, as six participants mentioned that they took steps to access the information on the initially inaccessible document by using technology or human resources available to them, or by requesting that the HCP make accommodations such as explaining the information on the document. Katie described her experience, receiving important information about her newly diagnosed diabetes in an inaccessible format:

One of the worst experiences I had when I was newly diagnosed diabetic and I went into the doctor's office and the first thing that happens, the nurse hands me this like half inch-thick booklet of print. When I was already, you know, I was already so overwhelmed by [the diagnosis], couldn't even think straight. And I just cried. It's so unnecessary because all she would've had to do was ask, "how can I help you? Can I send you some websites?..." you know? Rather than just throwing me a bunch of stuff that she already knew I wasn't gonna be able (Lucy: use it) to use.

On the other hand, comments were made about accommodations present and accessible equipment in the healthcare setting. Bert, in Focus Group 6, described technology that helps blind people access information on their medicine bottles: "[ScripTalk] it's a machine where you put the pill bottle on it and it will tell you."

### **3.4.3 Respect**

Participants described how feeling respect or disrespect from their HCPs impacted their satisfaction with their healthcare and their likelihood to seek future healthcare.

#### *HCP does not respect patient*

Participants (N = 23) also expressed feeling that their HCPs do not consider their concerns and that this discouraged them from seeking future healthcare. For example, Barbra from Focus Group 4 said "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."

#### *Patient seeks respect/HCP respect patient*

Some interactions with HCPs may lead to patients feeling respected or disrespected. This may impact their future likelihood to see an HCP about a health concern. Two participants



reported wanting independence and seeking the respect of their HCP by requesting respectful treatment from their HCP. Kevin from Focus Group 1 said “People wanna be independent.” Thirty-one participants across all seven focus groups reported feeling respected by their HCPs, noting that they felt as if they were treated like whole and valued people and that their HCPs seemed to be comfortable with people with disabilities in roles of influence. For example, Jessica from Focus Group 3 described her experience;

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.

## **Chapter 4: Study 1 Discussion**

At the onset of this study, it was expected that PWDs would report perceived discrimination, feeling disrespected, and disengaging from dialogue in the healthcare setting. The results of this study supported these predictions. Results from Study 1 answered the four research questions posed: *Q1*: What are blind patients' perceptions of how their HCPs perceive them and their competence? *Q2*: What are blind patients' experiences interacting with their HCPs when making a treatment decision? *Q3*: How do blind patients evaluate these interactions with HCPs? *Q4*: How do these interactions impact blind patients' overall functioning and health?

### **4.1 RESEARCH QUESTION 1: WHAT ARE BLIND PATIENTS' PERCEPTIONS OF HOW THEIR HCPs PERCEIVE THEM AND THEIR COMPETENCE?**

In general, participants who reported negative experiences reported that their HCPs did not perceive them to be competent, as thirty participants reported not feeling viewed as competent by their HCP, while only ten participants reported feeling viewed as competent. This was manifested in many ways such as HCPs indirectly addressing the participant and, instead, addressing their caretaker. This phenomenon was called non-person treatment and found with people who use wheelchairs (Cahill & Egglestin, 1994). Cahill and Egglestin (1994) stated that PWDs, like children, are treated as "open persons" dependent and powerless. Thus people who interact with them address their companions as if they are their caretakers with questions pertaining to the PWD. In the present study, HCPs may have assumed that the participants were incapable to answer for themselves and assumed that the closest sighted person to them was their caretaker. In some cases as in Lucy's, Carl's, and Bob's, HCPs addressed others present such as children accompanying the participants about the participants' medical information. This may suggest that HCPs regard PWDs as even less independent than children.

For those participants who reported positive experiences interacting with their HCPs, they tended to report feeling respected by their healthcare provider and addressed on a “higher” more “intellectual” level. These findings connected the Stereotype Content Model (Fiske et al., 2002) with findings of Cuevas and Colleagues (2016), demonstrating that perceptions of HCPs’ evaluations of patient’s warmth and competence affect to what extent patients feel respected by their HCPs and think that they can trust their HCPs.

#### **4.2 RESEARCH QUESTION 2: WHAT ARE BLIND PATIENTS’ EXPERIENCES INTERACTING WITH THEIR HCPS WHEN MAKING A TREATMENT DECISION?**

In positive experiences, participants reported feeling more involved in the decision-making process, and more trusting of the decisions and information provided by the HCP. In these cases, participants felt better informed and more like their preferences were considered when treatment courses were planned.

The positive or negative experience may be due to the HCPs’ underlying assumptions of competence. Fourty participants reported negative interactions where their HCP did not treat them with competence, resulting in the patient mistrusting the decisions and recommendations of the HCP. It is possible that HCPs make assessments of patient competence and then make a decision about how much of the patient’s input to elicit and consider.

#### **4.3 RESEARCH QUESTION 3: HOW DO BLIND PATIENTS EVALUATE THESE INTERACTIONS WITH HCPS?**

Evidence from this study indicated that, generally, blind patients evaluate their interactions with HCPs in many ways. Some of these ways included having in-/effective communication with HCPs and receiving or not receiving in-/effective accommodations. Participants also discussed their perceptions of how their HCPs evaluate their warmth and

competence. Most felt that they were presumed to be incompetent by their HCP. Participants varied in their degree of trust in HCP's clinical skill and decision-making. Some participants attributed the quality of their interactions with their HCPs to individual differences such as in gender or race of the participant or of the HCP, and personality of the participant or of the HCP.

#### **4.4 RESEARCH QUESTION 4: HOW DO THESE INTERACTIONS IMPACT BLIND PATIENTS' OVERALL FUNCTIONING AND HEALTH?**

Participants reported greater satisfaction with the results of their healthcare when HCPs treated them with more respect and as competent and warm adults. Future research may further examine the effects of patient experiences on specific health outcomes such as responsiveness to treatment.

In previous literature, trust was described as interchangeable with warmth (Fiske et al., 2002; Ho, 2011). In this dataset, participants discuss trust as an outcome of the HCP being competent and warm such that HCP may win the trust of their patients by demonstrating their competence as HCP and embodying characteristics of warmth (e.g., friendliness, approachability). Participants evaluate their HCP's competence and decide to deposit trust or not in that HCP.

#### **4.5 IDENTIFYING AND ADDRESSING PROCESS-RELATED AND STRUCTURAL-ENVIRONMENTAL BARRIERS**

Evidence from this study supports findings reported in the literature about barriers including process-related barriers and structural barriers. Participants reported such process-related barriers, including high cost of healthcare services (e.g., Kathy discussing the high cost of the quieter MRI; Iezzoni et al., 2006, Jones & Tamari, 1997; McColl et al., 2010), limitations of care due to health insurance (Iezzoni et al., 2006, Jones & Tamari, 1997), and lengthier

transportation for travel to medical appointments (Brucker & Rollins, 2016; Iezzoni et al., 2006, Jones & Tamari, 1997).

There was also much evidence for the existence of structural-environmental barriers that affect access to the content of medical information due to system/structural/environmental obstruction. Some structural-environmental barriers mentioned by participants in this study included lack of access to materials or equipment and inadequate communication (e.g., lack of non-visual methods of privately conveying personal and health information; Brucker & Rollins, 2016; Drum et al., 2005; Stein, Stein, Weiss, & Lang, 2009). On the other hand, in positive relationships with HCPs, participants reported these barriers less frequently. In some cases, such as Cheryl's, they noted that their HCPs were effective at reducing or removing these barriers by using effective non-visual means to communicate health-related information. Barriers that affect blind patients' access to important elements of healthcare were identified and expanded upon in this study.

This study also replicated and expanded on previous findings of PWDs reporting trouble finding caring and competent HCPs with specialized expertise working with PWDs (Iezzoni et al., 2006; Stein et al., 2009). Participants in this study also report feeling the need to educate their HCPs about their disability. Some participants noted that this was "unfair" because it took extra energy from the participant and takes time out of their appointment, reducing access to care (Jones & Tamari, 1997). An additional structural-environmental barrier that was found in this study was that HCPs often failed to share information about basic health prevention behaviors and fail to engage PWDs in a discussion about lifestyle and health promotion (Drum et al., 2005). When participants discussed positive experiences with their HCP, they noted that their HCPs reviewed information about basic health behaviors when applicable such as discussing

planning for parenthood with female participants in their 20s-30s, This too was tied to assumptions of competence.

Participants also discussed solutions to process-related and structural-environmental barriers that have also been recommended in the literature (Drum et al., 2005; Jones & Tamari, 1997; Stein et al., 2009). One process-related solution proposed by Jones and Tamari (1997) that participants expressed using and appreciating was services provided by community organizations such as churches to transport PWDs and older adults to and from facilities. This confirms the ecological validity of this proposed solution since the population being served confirms the usefulness of the solution. Participants also discussed structural-environmental related solutions including training staff or other personnel to providing accessible communication such as medical documents in formats accessible to the patients. Similar suggestions were documented by Drum and colleagues (2005),

## **4.6 COMPETENCE**

### **4.6.1 Perceived stigma about blindness**

Participants perceived the stigma towards blindness reported in the literature (Zhang et al., 2015). Some participants noted that their HCPs seemed uncomfortable or uneasy around them. Fear of blindness has been reported by HCP trainees (Owoeye et al., 2009). This study demonstrates that patients that are the object of stigma perceive their HCPs' uneasiness.

### **4.6.2 Over-pathologizing**

Indication of HCPs' assumptions of the incompetence of blind patients was observed in this study. Dovidio and Fiske (2012) and McColl and colleagues (2008) theorized that presenting health concerns of pitied targets would, in some cases, be over-pathologized and treated more intensively than necessary by such means as unnecessary institutionalization and

overmedication. Some participants in this study reported that either they or their blind friends had experienced an HCP attempting to send them to a nursing home or inpatient services when it was not necessary.

#### **4.6.3 HCP perceptions that participant had a caretaker**

Participants reported many instances where the PWD expected there to be a “qualified” other such as a sighted friend or family member accompanying the participant to the appointment to help with forms, and often the HCP would directly address these others who were perceived to be the participant’s care taker about the participant’s medical information. In a few cases, some HCPs refused to see the participant because they were not accompanied by someone else. This finding replicates results reported by McColl and colleagues, 2008.

In Study 1, it was reported that some doctors would not give enough guidance about treatment courses due to assumptions that the patient had a caretaker who could assist them. Other HCPs withheld prescription altogether because of assumptions of incompetence. These findings extend the findings of previous research to the blind population (Burgess et al., 2008; Hollingshead, 2016; Moskowitz, Thom, Guzman, Penko, Mioskowski, & Kushel, 2001; Paradies, Truong, & Priest, 2013).

It was expected that blind adults would report that their HCPs underestimate their competence and, consequently, prescribe inappropriate, unfeasible, and potentially harmful treatments. We found support for this. In addition, participants also reported positive experiences with HCPs where participants felt that HCPs treated them as if they were competent and prescribed or administered appropriate and effective treatment.

#### **4.6.4 Deviance from pitied role**

Findings from this study also supported the phenomenon of deviance from low competence expectations of blind people and, as a result, how HCPs reacted. In previous literature, those perceived with pity forfeit the perceiver's pity if they deviate from their respective stereotypical prescriptions. It was expected that blind participants who expressed such deviance from assumptions of incompetence by doing such things as taking on caretaker roles or appearing assertive with HCPs would be perceived as moderately-to-highly competent at best, but no longer warm by the HCP, and faced with active or explicit opposition (Fiske, 2013; Frederick, 2015). There was some evidence of this reaction to deviance in Study 1. Some participants reported their experiences as caretakers and facing opposition from HCPs because of their caretaker role. Future studies may seek to focus on this topic to examine the temporal precedence of the movement from being perceived with pity to being perceived as deviant to establish the causal relationship.

Bean and colleagues (2013) and Puumala (2016) found that some HCPs explicitly stated their beliefs of the incompetence of minority patients. Furthermore, Amosun and colleagues (2013) reported that HCPs reported feeling discomfort about working with minority patients. Some participants in this study reported that their HCPs explicitly questioned their competence. This supports existing literature and adds to external validity by extending these findings to blind patients.

In previous literature, it was reported that, as a result of their feelings of discomfort, some HCPs spend less quality time with PWDs (Dovidio & Fiske, 2012; Jones & Tamari, 1997). Participants in this study commented on their feelings of how their HCPs spent the clinical time with them. Some participants reported that their HCPs spent too much time explaining



unnecessary information and not enough time covering important information. Some participants reported feeling more satisfied with their experiences interacting with HCPs when the HCP spent more time with them. Other participants reported feeling satisfied when HCPs spent less time with them, yet covered what was necessary. This study demonstrates the nuances of the use of time and extends the findings of Dovidio and Fiske (2012) and Jones and Tamari (1997) to blind adult patients.

In previous research with ethnic minority patients, perceptions of prejudice led patients to have diminished satisfaction with care, to distrust the HCP, and to disengage from their own healthcare (Cuevas et al., 2016; Major et al., 2013). This finding was supported in the present study, and thus extended to the population of blind adult patients. Also, as reported in previous literature (Harrington et al., 2009), two participants in this study reported being refused service because of their disability and essentially forced to disengage in their healthcare.

#### **4.7 TRAINING**

Some participants from this study commented on whether or not they think HCPs can and should be trained in cultural competence, and made suggestions for training content. Lawthers et al., 2003, In addition to this, some researchers have identified the need for some HCP to undergo training to change their attitudes about PWDs in order to enhance the healthcare provided to this population (Pransky et al., 2003). The findings from this study can inform the design of interventions tailored towards enhancing healthcare for blind patients based on specific suggestions made by blind patients.

#### **4.8 STRENGTH OF USING FOCUS GROUPS FOR THIS STUDY**

The focus group is ideal for the purposes of Study 1 because of the discussion dynamics. For example, if one participant brings up an idea, other participants can also interact with that

idea and express their agreement or disagreement with the idea. This dynamic gives the focus group an advantage over individual interviews where some of these ideas may not have been introduced and agreement or disagreement with them would not have been addressed.

Furthermore, net time is saved with agreement in focus groups. If a topic with high consensus is being discussed, one participant may explain the idea in adequate terms that also capture the way other participants think and feel about the given topic. In this case, the first participant may take some time to explain the idea and its details and then other participants would simply indicate that they agree with the way the idea was explained and maybe even add to the explanation of the idea. This would save the time spent exploring the idea because it would not be repeated in detail several times.

Another benefit of the interaction intrinsic to focus groups is that participants may learn new information. Also, some participants may have felt that focus groups provided a cathartic opportunity for them to discussing issues that they typically did not have the opportunity to discuss with others who would had similar experience. For example, Kathy's anxiety about getting an MRI seemed to reduce throughout the discussion. Alternative ideas were presented to her and the experiences of other blind people who had previously had MRIs were shared. The focus group discussion also helped Jasmine learn about accessible medical labeling options.

If future studies seek to replicate this methodology, it is recommended that one person first identifies all possible code-able responses and then two independent raters code the themes. This would make it possible to calculate interrater reliability. This procedure was adopted in Study 2.

In Study 1, each of the two raters selected the passages to be coded from the transcriptions of all focus group interviews. This method left room for much variability in what

were considered as codeable responses and it was not possible to calculate valid interrater reliability of the themes. Thus for the analysis of qualitative data in Study 2, the research team designated one person to first identify all possible code-able responses and then two independent raters rated these cod-able responses.

## **Chapter 5: Study 2 Methods**

A pool of 37 items was developed based on themes from Study 1, approved by the dissertation committee, and administered to participants in this study (See Appendix G). The purpose of this study was to use participant feedback, item frequencies, and exploratory factor analysis to reduce the list of items and to determine the factor structure of the resulting scale.

Qualitative data were also collected. Study 2 fulfilled Phases 3 and 4 of Onwuegbuzie and colleagues' (2010) IDCV process where the initial scale was developed and field tested, and phases 4, 6, and 7 where quantitative and qualitative analyses were conducted (see Appendix A for IDCV process). The online scale was tested and revised to ensure accessibility with screen reader software for Mac (VoiceOver) and Android phones (Voice Assistant), and JAWS for Windows. Sixteen individuals who had participated in Study 1 volunteered to provide feedback on the accessibility of the Qualtrics survey. These volunteers provided feedback that the research assistant followed in order to produce a survey that was accessible for most users.

### **5.1 PARTICIPANTS**

Participants were recruited at an information table set up in the exhibit hall at the National and Texas State National Federation for the Blind Conferences, by word of mouth from Study 1 participants and those who were earlier participants of Study 2, and on social media. Of the 144 blind adults who participated in this study 98 identified as female and 103 identified as non-Hispanic White. The average education in years was 17.45 (SD = 13.99) years, consistent with obtaining a bachelor's degree with some additional years of study. Participants were entered into a raffle for a chance to win a \$100 gift card.

## **5.2 MEASURE**

A pool of 37 items was written based on Stereotype Content Model-related themes that emerged from Study 1 focus groups (see APPENDIX I). The items were written with the intention to have good face validity. Items were rated on a seven-point Likert-type scale, ranging from “1 - strongly disagree” to “7 - strongly agree”, and “4 - neither agree nor disagree” as the mid-point.

## **5.3 PROCEDURE**

Participants received an email with information about the purpose of the study and a link that they could follow to the survey on the Qualtrics platform. Participants read an informed consent document. Those who wish to continue participating electronically signed the consent document and provide basic demographic information. Participants completed the scale by responding to each item. Items were presented in randomized order and the following attention check was interleaved within the scale items: “Please leave this question blank, it is to screen out random responders” (Frankowski et al., 2016). Participants were encouraged to complete the entire survey, but they were free to leave items blank if they chose to do so.

### *Qualitative measures*

Along with completing the scale itself, participants were asked to assess the scale for “clarity, aesthetics, relevancy, tone,” time taken to answer the item, and “cultural competence” (Onwuegbuzie et al., 2010; see Appendix G for qualitative prompts that accompanied the measure in Study 2). To this end, eight qualitative prompts were provided to guide participants' feedback about the scale. After completing the scale, participants were thanked for their participation and given a space where could enter their email address for a chance to win a drawing for a \$100 gift card. The gift card drawing was conducted after all of Study 2 data were collected and the gift card was awarded to the raffle winner.

## Chapter 6: Study 2 Results

### 6.1 QUANTITATIVE RESULTS

Overall, 37 items were written based on qualitative results. First these items were examined for floor and ceiling effects. Those items that had less than 10.9% of total respondents responding on either side of the midpoint scale option were eliminated (Frankowski et al., 2016; See Table 1), which led to the deletion of 13 items. These items were removed because there was very little variability in how participants responded to them.

**Table 1.** *Items that were eliminated in Study 2 and justification*

<b>Item</b>	<b>Reason for eliminating item</b>
1. Healthcare providers write my prescriptions in a format that is accessible to me	<i>Loadings &lt; .32</i>
7. Healthcare providers treat me the way that they do because of my gender/sex more than based on my blindness/visual impairment	<i>Loadings &lt; .32</i>
10. <i>RC</i> Sometimes, I may come off as cold to the healthcare provider	<i>Left out of Study 3</i>
<i>RC</i> Healthcare providers are usually unaware of accommodations for blind people	<i>Floor/ceiling</i>
Healthcare providers listen to what I say about my health	<i>Floor/ceiling</i>
With proper training, healthcare providers can learn how to better interact with blind patients	<i>Floor/ceiling</i>
Most healthcare providers treat me with kindness	<i>Floor/ceiling</i>
I think the key to a positive experience with a healthcare provider is clearly stating my needs	<i>Floor/ceiling</i>
I consider it my responsibility to educate healthcare providers about blindness	<i>Floor/ceiling</i>
I must appear confident in front of healthcare providers	<i>Floor/ceiling</i>
<i>RC</i> Sometimes, I need to prove to healthcare providers that I am capable	<i>Floor/ceiling</i>
Healthcare providers explain what they will do before they do it	<i>Floor/ceiling</i>
I usually enjoy when healthcare providers use humor	<i>Floor/ceiling</i>
My healthcare provider listens carefully to my concerns	<i>Floor/ceiling</i>
Healthcare providers are accepting of my guide dog	<i>Floor/ceiling</i>
I have friends/family who assist with healthcare visits	<i>Floor/ceiling</i>
21. <i>RC</i> My limited/lack of eye contact makes some healthcare providers uncomfortable	<i>Irrelevant content</i>

A power analysis sample size estimate was calculated for the remaining 24 items. For a model with 251 degrees of freedom,  $\alpha = .01$ , power = .95 for a test of close fit where the RMSEA statistic equaled .05 and .08 under the null and alternative hypotheses respectively, an estimated sample size of  $N^* = 134$  was needed to test this model (quantpsy.org online utility for power analyses and sample size determinants; Preacher & Coffman, 2006).

Using *Mplus* (Muthén & Muthén, 1998-2018), an exploratory factor analysis was conducted with the remaining 24 items in order to identify the latent underlying factors within the measure (Fabrigar, Wegener, MacCallum, & Strahan, 1999). The exploratory factor analysis used the MLR estimator which accounts for missing and non-normal data, and factor loadings were rotated using Geomin rotation—a form of oblique rotation. Although the dimensions of the stereotype content model are orthogonal, an oblique rotation was used because oblique rotations do not necessarily restrict the factors to being correlated. Thus in this study, an oblique rotation will allow for the examination of the nature of how factors in this scale relate with one another (Costello & Osborne, 2005). The goodness-of-fit test was significant, indicating that a significant amount of covariance was unaccounted for by this model;  $\chi^2(229) = 360.53, p < .001$ . Fit indices were acceptable according to Hu & Bentler (1999); RMSEA = .063 (should be  $< .06$ ), 90% CI: 0.050, 0.075; CFI .862 (should be  $> .90$ ), SRMR = .058 (should be  $< .09$ ), AIC = 12435.912. RMSEA is a noncentrality-based index. This index is based on the noncentrality parameter (as opposed to a central parameter) because, in this case, the aim of the test is to reject the alternative hypothesis stating that there is a significant difference between the model and the data. RMSEA is also a measure of model parsimony, as the fit index gets worse as additional nontrivial parameters are added to the model. SRMR is used because it is an absolute index (does not use an alternative hypothesis testing approach) that is less affected by factors such as large

sample size, model size, or the distribution of variables. AIC is also an absolute index that is used when comparing across models. CFI is a normed relative (or comparative) fit index. This is a relative fit index because it is testing the model against the null model (a model with no latent factors) that has been normalized so values are between 0 and 1. These fit indices are used together to optimize the chances of identifying a model that is actually true in the population and rejecting a model that is actually not true in the population. (Hu & Bentler, 1999). A parallel analysis of eigenvalues was conducted and the analyses suggested that two factors were extracted. The two factors were not significantly correlated;  $r = .154, p > .05$ . The items associated with Factor 1 seemed to measure General Quality of Healthcare (Eigenvalue = 7.327) and items associated with Factor 2 seemed to measure Stereotype Content Model-related Concepts (Eigenvalue = 2.257). Factor 1 accounted for 30.53% of the variance and Factor 2 accounted for 9.40% of the variance.

Factor loadings were examined and those items with factor loadings  $< .32$  were suppressed (Tabachnick & Fidell, 2001 as cited by Costello & Osborne, 2005). This process also eliminated two items (See Table 1). Furthermore, there were five items that loaded onto both factors with loadings close to or greater than  $.32$  (See Table 2). According to Costello and Osborne (2005), if there are a sufficient number of items that load on to one or the other factor with loadings greater than or equal to  $.5$ , then the items that load onto both factors may be removed from the scale. However, if this guideline was followed, this would lead to a measure with 16 items on Factor 1 and two items on Factor 2. Most of the five cross loading items conceptually fit with Factor 2 – Stereotype Content Model-related Items. Thus, the decision was made to retain these four items and test them in the subsequent confirmatory study. See Table 2 for factor loadings of items that were retained in this study.



**Table 2.** *Items that remained after floor and ceiling effect checks and exploratory factor analysis*

#	Item	Factor 1	Factor 2
2	Healthcare providers ask how I prefer to be accommodated	0.53	
3	Healthcare providers provide reasonable accommodations	0.63	
4	RC I feel healthcare providers are often in a rush to finish with my appointment	0.36	
5	RC Healthcare providers touch me without a warning	0.41	
6	RC Compared to other patients, I am more likely to be treated unfairly in the healthcare setting	0.61	
8	My personality influences how healthcare providers treat me more than my blindness does	0.54	
9	Healthcare providers treat me the same as other patients	0.70	
11	RC At times, I may come off as aggressive to the healthcare provider		0.65
12	RC At times, healthcare providers may think that I am intimidating		0.53
13	Healthcare providers treat me like a whole person	0.73	
14	RC When I come to an appointment with a sighted person, healthcare providers address them instead of me	0.57	
15	RC Healthcare providers often ask me irrelevant questions about my blindness	0.53	
16	RC My privacy is not respected when I get help with filling out forms	0.44*	0.30
17	RC Healthcare providers are often uncomfortable when I am around	0.51	0.32*
18	RC I often think that healthcare providers feel sorry for me	0.43	0.32*
19	Healthcare providers support me in pursuing activities I enjoy	0.50*	-0.36
20	Healthcare providers take time to know me	0.66	
22	RC I often need to demonstrate my intelligence for healthcare providers	0.42	0.30*
23	Overall, my interactions with healthcare providers have been positive	0.74	
24	Healthcare providers recognize that I can take care of myself	0.80	

Note. # = the item number. The same item numbers from the initial list of 37 items that were generated from Study 1, RC indicates the items that were reverse coded for analysis and scoring purposes. Factor 1 – General Quality of Healthcare, Factor 2 –Stereotype Content Model-related Items. \* indicates the factor that crossloading items align with this factor conceptually.

### **6.1.1 Participant ratings of measure**

Participants rated the measure as a whole on language clarity, how natural the measure sounded, the relevance of the issues addressed in the survey, and how much time they thought it took them to complete the survey. They made responses on a six-point, forced choice scale ranging from 1 – very unclear/unnatural/irrelevant to 6 – very clear/natural/relevant. On average, participants rated the measure high in clarity ( $M = 5.39$ ,  $SD = .71$ ), natural tone ( $M = 5.10$ ,  $SD = .78$ ), and relevance ( $M = 5.13$ ,  $SD = .96$ ). Participants reported that the survey took them a little less 30 minutes, on average, to complete ( $M = 28.89$ ,  $SD = 13.46$ ).

## **6.2 QUALITATIVE RESULTS**

Initially, functioning as first rater, I wrote one codebook for the coding of each of the eight open-ended questions that participants responded to (for a total of eight codebooks). One research assistant served as second rater who then viewed the codebooks and made edits. I reviewed and approved these edits. The second rater and I then used the codebooks to independently code all of participants' responses to each of the eight open-ended questions. After the independent coding, I compared the codes I created with those of the second rater using an Excel match formula. Percent of match at the raw (more stringent) and lenient levels was calculated to assess interrater reliability between the two coders. This was conducted instead of calculation of Kappa coefficients because of their ease of interpretability. Also, the second rater and I were trained in conducting thematic analysis and familiar with the codebook, and there was no concern that we were guessing which themes to assign codes (McHugh, 2012). I felt confident that there was minimal guessing, if at all, because I supervised the process. Also there were more than two theme options for coding, thus guessing, if at all present, would be less likely to artificially inflate or suppress percentage agreement. Upon review of the coding, even in

cases where there was disagreement on the coding of responses, the rationale was clear for why the second rater and I would code a response the way that they did.

The number of matching responses was divided by the total number of coded responses to calculate the raw agreement percent. As the first rater, I conducted a lenient coding where there was disagreement among my and the second rater's coding. For this lenient coding, disagreements where the themes were conceptually similar were coded as agreements. For example, if I, as the first rater, rated a response as "Example 9" and the second rater rated the same response as "Relates to Example 9," this was coded as agreement for the lenient coding. The calculation of the lenient percent agreement was similar to the calculation of the raw percent agreement where the total number of instances of agreement between the two raters for the lenient agreement was divided by the total number of coded responses. See Table 3 for total number of coded responses per prompt, raw interrater agreement, and lenient interrater agreement.

In order to determine the final assignments of the codes that were disagreed upon—those responses that were assigned to one theme by the first rater and another theme by the second rater, I served as the "tie breaker" and decided which theme assigned by either of the two raters, me or the second rater, was retained as the final theme for a response to be coded in. The counts in Table 3 represent the final theme assignments of each coded response.

**Table 3.** *Raw and Lenient Percentages of Agreement Between Raters*

Q#	Question	N	Raw %	Len %
Q1	How clear was the language of the items in the measure that you just completed?	175	68.00	73.71
Q2	Please give specific examples of questions that sounded natural or unnatural.	122	63.03	79.51
Q3	Please give specific examples of relevant or irrelevant questions. Elaborate	166	62.87	76.05
Q4	How would you describe the tone of the survey?	176	83.05	84.75

Q5	Please give specific examples of items where the tone of the question stood out to you.	92	70.97	78.50
Q6	Do you get the feeling that the people who wrote these questions have an accurate idea of the experience of blind and low vision patients? Please explain why or why not.	205	65.70	79.71
Q7	Please share your thoughts about the survey that you just completed.	164	70.91	72.12
Q8	Are there any topics that you think should be mentioned that were not mentioned in the survey? Please specify in the space provided.	132	73.68	74.44

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Note. Q# refers to the number of the prompt. This number corresponds with the order in which the prompt was presented. N, in this case, refers to the total number of coded responses to the respective question. Raw % refers to the percentage of agreement when taking a more stringent approach and comparing exact coding. Len % refers to the percentage of agreement when taking a lenient approach and comparing similar coding

After this thematic analysis of responses the themes were organized into categories by me, the first rater. The percent of responses within each category was calculated by summing coded responses within the respective category divided by the total number of responses. This percent is reported in Appendix J.

Qualitative results reflected that most participants viewed the measure as clearly and naturally worded, addressing topics relevant to the blind community, in a respectful and sensitive tone, and written in a way that gave them the sense that the author of the items was in touch with the blind community. Additionally, participants reported that the measure was comprehensive, concise, and thought-provoking. Participants also expressed their own experience interacting with HCPs and made recommendations addressed to HCPs about how to improve treatment for blind patients. Participants requested more items on accessibility topics and mentioned that future directions should include items for different HCPs (e.g., doctors of different disciplines, therapists, receptionists) and should also assess the experiences of blind patients with intersecting identities that may impact their experience interacting with HCPs (e.g., women, members of the LGBTQ community). Some participants gave feedback about the survey's accessibility and requested clarification on instructions. These recommendations were considered

when designing the survey for Study 3. See Appendix J for a full summary of qualitative results with example quotes.

One item was excluded due to irrelevant content. The item “My limited/lack of eye contact makes some healthcare providers uncomfortable” was eliminated because many participants reported being able to establish eye contact despite blindness. Some participants reported having enough usable vision to establish eye contact within a certain amount of distance. Other participants reported that they are able to go through the motions of establishing eye contact even if they do not have enough usable vision to see the other person’s eyes.

## **Chapter 7 Study 2 Discussion**

In this study, a pool of 37 items was tested and reduced to a two-factor measure of 20 items. This study served the purpose of identifying the factor structure to be confirmed in Study 3. Some questions remained about the best possible placement for four of the 20 items, so these were included in Study 3 for further examination.

Qualitative data was also produced and analyzed. Participants gave feedback for redesigning the measure and the scale options. Some of this feedback such as confusion about the attention check item was applied to change the materials for Study 3. Other recommendations such as that about the wording of items, scale response options, and suggestions for additional items to include were not implemented in the measure tested in Study 3. Specific items were tested in Study 2 and a factor structure was extracted based on those items. The purpose of Study 3 was to confirm that factor structure, but if items were changed after Study 2, than Study 3 would no longer be confirming the same items and underlying factor structure from Study 2. Thus, it was not possible to change the item wording between Study 2 and Study 3. However, future studies can build from the validated scale, implement more participant feedback, and re-test the factor structure and validity in order to strengthen the measure.

In this study, participants mentioned themes that had also emerged in Study 1. These themes included privacy concerns, unexpected touch, and condescending tone related to interactions with HCPs. This further validates these constructs. Participants in this study also made suggestions for improving healthcare. In future studies, such suggestions can be examined more closely and applied in interventions with HCPs.

## 7.1 FUTURE DIRECTIONS

One future direction would be to design a culturally competent attention check. The attention check used in this study was “Please leave this question blank, it is to screen out random responders” (Frankowski et al., 2016). Some participants reported confusion over this item because when a screen reader is reading the survey, this attention check might sound like a response option. Since there was confusion about the attention check, qualitative responses were examined for participants who failed the attention check and if participants appeared to be making an effort to answer qualitative questions despite a failed attention check, their data were retained. Common knowledge-type questions may still confuse some participants as it might sound like there was a random pop up that was not part of the survey. One benefit of a mixed methods design is that a researcher may approximately determine the degree of effort a participant exerted for the study. One lesson learned about this study is that, despite making text in the survey accessible to screen readers, there may still be some aspects of the design that are inaccessible.

Initially, this study was going to include a set of qualitative questions accompanying each of the 37 items, this would have resulted in 259 questions which would have fatigued participants, especially since most of those questions would have been open-ended. This item-level qualitative data would have allowed for the quantizing and factor analysis of quantized data. However, since this fine grained level of qualitative data was not possible, it was not possible to conduct the crossover analyses. The practice of crossover analysis may be more feasible for a shorter measure where the collection of finer-grained qualitative feedback would be less cumbersome on participants such as future iterations of this scale that are shorter in length. For shorter scales, researchers may also choose fewer than seven qualitative questions to

accompany each item to further lighten the participant burden. Additionally, since most of the qualitative responses were feedback about the scale, it did not make sense, conceptually, to factor analyze the qualitative responses and compare them with the factor scores of the measure about experiences interacting with HCPs. Also, those researchers who may wish to conduct crossover analyses may wish to have an independent coder who is unaware of the predictions and theoretical framework of the study to conduct the coding of responses to avoid the possibility of hypotheses shaping the coding.

One content point that emerged from this and the previous study was the experiences of blind people managing their diabetes. As a result, a follow up study is being conducted to focus on examining the barriers that blind adults with diabetes face as they manage their chronic disease. Additionally, future studies may examine the experiences of blind adults with intersecting minority identities more closely.



## Chapter 8: Study 3 Methods

The goal of Study 3 was to confirm the factor structure of the measure identified in Study 2. In addition, this study sought to assess the convergent and discriminant validity of the revised measure.

This study addressed phases 5 and 6 of Onwuegbuzie and colleagues' (2010) IDCV process as the scale was revised based on results from Study 2 and administered to a new sample, and the resulting data were quantitatively analyzed. This study also addressed phase 10 of Onwuegbuzie and colleagues' (2010) IDCV process through the overall evaluation of the final scale and conclusions drawn. See Appendix A for the 10 phases of Onwuegbuzie and colleagues' (2010) IDCV process.

### 8.1 PARTICIPANTS

A sample size testing for close fit for 21 items, two factors, 188 degrees of freedom, desired power of .95,  $\alpha = .01$ , RMSEA null = .05, and RMSEA alternative hypothesis = .08 determined that a sample size of 163 participants was needed. Participants were 214 blind adults recruited from National Federation of the Blind and American Council of the Blind listerves, social media pages, and word of mouth. The majority of participants were female ( $n = 141$ ) and non-Hispanic White ( $n = 144$ ). On average, participants were 48.63 years old ( $SD = 15.79$ ) and most reported their highest degree of education as a bachelor's degree. Only participants who did not participate in Studies 1 and 2 were eligible to participate in Study 3. Participants were given the opportunity to enter a drawing to win a \$100 gift card.

### 8.2 MEASURES

The following measures were used to determine construct validity.

*Patient Satisfaction Questionnaire*

The Short Form Patient Satisfaction Questionnaire (PSQ-18) is a 18-item questionnaire that measures overall patient satisfaction with healthcare (without reference to any particular event) by examining the following six subscales (Cronbach  $\alpha$ s and p = item numbers for the respective subscale are presented in parentheses): General satisfaction ( $\alpha = .75$ , p = 2), technical quality ( $\alpha = .74$ , p = 2), interpersonal manner ( $\alpha = .66$ , p = 2), communication ( $\alpha = .64$ , p = 2), financial aspects ( $\alpha = .73$ , p = 2), time spent with doctor ( $\alpha = .77$ , p = 2), and accessibility and convenience ( $\alpha = .75$ , p = 4; Marshall & Hays, 1994). The items were rated on a 5-point Likert-type scale. Responses ranged from “1 – Strongly Agree” to “5 – Strongly Disagree”, with “3 – Uncertain” as the midpoint. This scale demonstrates good convergent validity, as it correlated well with a 6-item measure of general patient satisfaction ( $r = .93$ ,  $p < .001$ ) and with a 1-item measure of visit-specific satisfaction ( $r = .35$ ,  $p < .001$ ; Marshall & Hays, 1994; Marshall et al., 1993). See Appendix K for the scale. Higher scores indicated greater levels of agreement. This scale was used to assess convergent validity with the scale being developed in this dissertation.

#### *Wake Forest Trust in Physician Scale*

As discussed above, the Wake Forest Trust in Physician Scale was used to measure trust in physicians (Hall et al., 2002). The 26 items were rated on a Likert-type scale. Response options ranged from “S – Strongly Agree” to “SDA – Strongly disagree”, with “N – Neutral” as the midpoint. This scale had good reliability (Cronbach  $\alpha \geq .92$ , test-retest  $r = .75$ ) and was correlated with satisfaction with care ( $rs \leq .09$ ,  $ps \leq .0001$ ). For this study, disagreement was coded on the lower end of a five-point scale and agreement was coded on the higher end. Thus the higher the score, the more trust participants reported in their HCPs. See Appendix I for full scale. This scale was used to assess convergent validity with the scale being developed in this dissertation (see Appendix L).

### *Discrimination in Medical Settings Scale*

This is a 7-item scale that measures instances where participants indicate feeling treated differently in a disadvantageous way in the healthcare setting. A sample item is the following: “A doctor or nurse acts as if he or she is better than you.” Items will be rated on a 5-point Likert-type scale. Responses may range from “1 – never” to “5 – always”, with “3 – sometimes” as the midpoint (Peek, Nunez-Smith, Drum, & Lewis, 2011). Higher scores indicate more perceived discrimination. The Cronbach  $\alpha$  was = .89, test-retest reliability was = .58 ( $p < .0001$ ). This scale demonstrated convergent validity. This scale correlated significantly with societal discrimination and the African American Trust in Healthcare Scale ( $ps \leq .02$ ). See Appendix M for full scale. This scale was used to assess convergent validity with the measure being developed in this dissertation.

### *Marlowe-Crowne Social Desirability Scale*

The short form of the Marlowe-Crowne Social Desirability Scale (Reynolds, 1982) was used to determine discriminant validity. Social desirability is the extent to which participants respond in a way that gains the approval of others within a given culture (Crowne & Marlowe, 1960; Peek et al., 2011; Reynolds, 1982). Social desirability is a non-pathological characteristic assessed in research about attitudes (Peek et al., 2011), and in personality and clinical research (Reynolds, 1982). The short form Marlowe-Crowne Social Desirability Scale is a subset of 13 items from the 33-item standard scale. The 13-item short form designed by Reynolds (1982) demonstrates good reliability (Kuder-Richardson 20 = .76; Reynolds, 1982; Cronbach  $\alpha$  = .89, test-retest reliability = .58; Peek et al., 2011) and validity as evidenced by high product-moment correlations with longer forms of the Marlowe-Crowne Social Desirability Scale and other social desirability scales ( $r = .93$  with Marlowe-Crowne Standard,  $r = .41$  with Edwards SDS). This

social desirability scale has been used to establish discriminant validity of the Discrimination in Medical Settings Scale, a scale that measures similar constructs that the present measure assesses (Peek et al., 2011). See Appendix N for the short form.

### **8.3 PROCEDURE**

Participants followed the same procedure as in Study 2 with the exception of responding to qualitative prompts. The order of measures and items was randomized to eliminate the possibility of order effects. In the presentation of items to participants, items from different scales were interleaved with one another. Upon completion of this study, participants were given the option to enter into a raffle for a chance to win a \$100 gift card.

## Chapter 9: Study 3 Results

The goal of Study 3 was to confirm the factor structure of the measure that emerged from the exploratory factor analysis in Study 2 (see Table 2 for items). This was a 20-item, two-factor model. The first factor consisted of items measuring the General Healthcare Experience of blind patients, and the second factor consisted of items measuring the dimensions of the Stereotype Content Model and the BIAS map. Four of the 20 items retained from study 2 (17, 18, 19, and 22) crossloaded with both factors. These four items were retained in Study 3 for further examination because they conceptually aligned with the two factors.

Confirmatory factor analyses were conducted in *Mplus* (Muthén & Muthén, 1998-2018) to confirm the factor structure of the model identified in Study 2 and to compare that model with other potentially better fitting models. Reliability was calculated for the final model as well as for the other scales in the survey. Next, construct validity was assessed, and composite scores for the two factors were created and correlated with the Patient Satisfaction Questionnaire, Wake Forest Trust in Physicians Scale, Discrimination in Medical Settings Scale, and the Marlowe-Crowne Social Desirability Scale.

Three models were tested and compared: A two-factor model, a bi-factor model, and a single-factor model. Local fit information including modification indices and standardized residuals were examined to determine how well the model explains the covariances between items. The wording of items was also examined along with this local fit information to determine which items' residuals should be correlated in the model, should model fit need to be improved. Items 2 (Healthcare providers ask how I prefer to be accommodated) with 3 (Healthcare providers provide reasonable accommodations), 20 (Healthcare providers take time to know me) with 23 (Overall, my interactions with healthcare providers have been positive), 13 (Healthcare

providers treat me like a whole person) with 18 (*RC* I often think that healthcare providers feel sorry for me), and 11 (*RC* At times, I may come off as aggressive to the healthcare provider) with 12 (*RC* At times, healthcare providers may think that I am intimidating) were highly correlated. For the two-factor model from Study 2, the crossloading items were assigned to either of the factors. Item 19 was assigned to Factor 1 while items 17, 18, and 22 were assigned to Factor 2. The two factors were set to correlate. According to model fit criteria (Hu and Bentler, 1999; RMSEA < .06, CFI > .95, and SRMR < .09), this model demonstrated fair fit; RMSEA = .065, 90% CI = .053, .076; CFI = .896, SRMR = .065; AIC = 11509.558. Next, a single-factor model was tested. This model had poorer fit compared to the two-factor model; RMSEA = .068, 90% CI = .057, .079, CFI = .884, SRMR = .067, AIC = 11527.347. Finally, a bi-factor model was tested. For this model, all items loaded on a general factor, but the items about the General Healthcare Experience also loaded onto an independent grouping factor and the items that measured dimensions of the Stereotype Content Model also loaded on an independent grouping factor. While this model demonstrated the best fit of the three models, the solution was uninterpretable; RMSEA = .053, 90% CI = .040, .066, CFI = .937, SRMR = .047, AIC = 11441.819. Specifically, the bi-factor model resulted in negative factor loadings and non-statistical factor loadings on the grouping factors. So, the two factor model was the model used to compute scale scores and correlate with other measures to determine construct validity. The first factor represents the quality of the interaction with the HCP in general while the second factor represents items that make up the stereotype content model. The two factors were very strongly correlated ( $r = .869, p < .001$ ).

Next, the reliability coefficients were computed and examined for the full scale, for factor one, and for factor two. Reliability was good for the full scale ( $\alpha = .922$ ) and for factor one ( $\alpha =$

.912), and fair for factor two ( $\alpha = .776$ ). Estimates of test score reliability were also calculated for the Patient Satisfaction Questionnaire, the Discrimination in Medical Settings Scale, and the Wake Forest Trust in Physicians Scale. The Patient Satisfaction Questionnaire consisted of six subscales that were each comprised of two or three items. Although the original publication reported Cronbach's  $\alpha$  for subscales of the Patient Satisfaction Questionnaire, each comprised of as few as two items (Marshall & Hays, 1994), Spearman-Brown coefficients are reported for this study because they are a more appropriate estimate of reliability for scales consisting of two items (Eisinga, Grotenhuis, & Pelzer, 2013). The following reliability estimates were observed for the respective subscales: General Satisfaction  $r_s = .796$ , Technical Quality  $r_s = .760$ , Interpersonal Manner  $r_s = .674$ , Financial Aspects  $r_s = .827$ , Accessibility and Convenience  $r_s = .725$ , Time Spent with Doctor  $r_s = .776$ . These reliability coefficients were comparable with those found by Marshall and Hays (1994). The Discrimination in Medical Settings Scale ( $\alpha = .901$ ) and the Wake Forest Trust Scale ( $\alpha = .963$ ) both demonstrated good reliability in this sample, equivalent to reliability reported by Peek and colleagues (2011), and Hall and colleagues (2002) respectively.

After reliability coefficients were calculated, scale scores were computed for all scales and subscales including for both factors of the scale developed in this study. The scale scores of the scale being developed in this study were correlated with the test scores of the Patient Satisfaction Questionnaire, the Discrimination in the Medical Setting Scale, the Wake Forest Trust in Physicians Scale, and the Marlowe-Crowne Social Desirability Scale to assess construct validity. It was hypothesized that the observed scores from the items representing general satisfaction with health care would correlate positively with Patient Satisfaction Questionnaire subscales and with the Wake Forest Trust Scale, negatively correlate with the Discrimination in

the Medical Setting Scale, and be uncorrelated with the Social Desirability Scale. Similarly, it was hypothesized that the scores from the factor that represents the stereotype content model would positively correlate with the Patient Satisfaction Scale subscales and Wake Forest Trust Scale, negatively with the Discrimination in Medical Settings Scale, and uncorrelated with the Social Desirability Scale.

Hypotheses were mostly supported (see Table 4 for correlations). As predicted, scores representing general satisfaction correlated positively with all Patient Satisfaction Scale subscales and with the Wake Forest Trust Scale. Also, general satisfaction correlated negatively with Discrimination in the Medical Setting such that higher scores in general satisfaction were associated with discrimination. Contrary to hypotheses however, scores representing general satisfaction significantly correlated with the Social Desirability Scale.

As predicted, the scores representing the stereotype content model were significantly correlated with four of the six Patient Satisfaction Scale subscales, with the Discrimination in Medical settings Scale, and the Wake Forest Trust Scale. In addition, scores on this scale correlated negatively with Discrimination in the Medical Setting such that the higher participants scored on the stereotype content model factor, the less discrimination in the medical setting they reported. Unexpectedly, this subscale also significantly correlated with the Marlow-Crowne Social Desirability Scale.

**Table 4.** *Study 3 Correlations between factors of the measure developed in this dissertation and measures meant to assess construct validity.*

Measures	Factor 1 General Healthcare	Factor 2 SCM- related
PSQ General Satisfaction	.681** H	.397** H
PSQ Technical Quality	.590** H	.333** H
PSQ Interpersonal Manner	.595** H	.378** H
PSQ Communication	.669** H	.412** H
PSQ Financial Aspects	.372** H	.238**



PSQ Accessibility and Convenience	.528** H	.292**
WF Trust	.650** H	.382** H
DMS Mean	-.747** H	-.605** H
MC SDS	.150*	.289**

Note. SCM – Stereotype content model, \* - significant at a < .05, \*\* - significant at a < .001, H – correlations in direction and strength consistent with predictions.

## **Chapter 10: Study 3 Discussion**

This study confirmed the two-factor structure of the measure. The General Healthcare factor (first factor) included items measuring how accommodating HCPs were, things that HCPs did that made participants uncomfortable, and perceived discrimination. The Stereotype Content factor (second factor) included items about giving the impression of social coldness to the HCP, making the HCP uncomfortable, HCP's perceptions of the patient's warmth and competence—items which related to the stereotype content model. In general, the measure developed in this study showed good reliability. Reliability coefficients for the other measures were equivalent to previously published results.

Correlations among scale scores to assess construct validity mostly supported hypotheses. Both General Experience and Stereotype Content aligned with hypotheses. Scale scores were positively correlated with patient satisfaction in general, satisfaction with the technical quality of the service provided by HCPs, satisfaction with the interpersonal manner of HCPs, satisfaction with communication with HCPs, and satisfaction with the convenience of getting medical care, and trust in physicians. Furthermore, scale scores were negatively correlated with perceived discrimination in the medical setting.

However, contrary to hypotheses, the scale scores were correlated with the scores from the social desirability scale, suggesting, at first glance, that participants may be reporting their experiences with HCPs and experiences with stereotypes and discrimination more positively because of social desirability. This finding was inconsistent with tests of discriminant validity of the Discrimination in Medical Settings scale (Peek et al., 2011). Upon further examination of the literature, a clarification on the definition of social desirability was adopted: One that considers social desirability both an item characteristic and an individual trait (McCrae & Costa, 1983).

When considering social desirability as a potential item characteristics, items can be written in such a way that lead participants to respond in a manner that presents them in a positive light. Accordingly, social desirability embedded in items would affect participants' scores across the sample. This is difficult to assess for (McCrae & Costa, 1983). However, following McDonald's (1999) guidelines for writing concise items in language that does not lead participants to respond in one direction or another may reduce the possibility of participants responding in a more positive manner as a result of how items are worded. Additionally, reading participants' qualitative feedback from participants to gain insight on how they interpreted and reacted to items from the scale can help in identifying items that lead participants to respond in a socially desirable manner. Thus social desirability as a result of item characteristics was not a concern in this dissertation.

Social desirability may also be conceptualized as an individual trait. Through McCrae and Costa's (1983) review of the literature and their own empirical research, they found that social desirability as an individual characteristic actually measures "need for approval, social naiveté, and social adjustment" and was associated with personality dimensions where higher reports of participants' neuroticism were associated with the endorsement of common yet undesirable thoughts and behaviors (as measured by the Marlowe-Crowne social desirability scale). Additionally participants rated as higher in extraversion and openness endorsed fewer socially undesirable thoughts, feelings, and actions. Thus the correlation of social desirability with the two factors of the scale developed in this dissertation may actually be assessing the correlation of personality traits such as neuroticism, extroversion, and openness with Stereotype Content and General Healthcare. Future research may include a measure of personality factors in the assessment of the discriminant validity of the scale developed in this dissertation.

Taken together, the scale developed in this dissertation may have little-to-no social desirability is a characteristic of item wording. If the Marlowe-Crowne Social Desirability Scale is analogous with personality (with higher scores on the Social Desirability Scale mapping on to openness and extraversion and lower scores mapping on to neuroticism), the findings of small-to-moderate positive correlations between Marlowe-Crowne Social Desirability with general healthcare and stereotype content in this study are consistent with the findings of McCrae and Costa (1983): Participants who are more agreeable and extraverted may be those with higher scores on the Social Desirability Scale and may be more inclined to report slightly more positive experiences with healthcare providers and slightly fewer concerns of Stereotype Content. The smallness of these correlations as well as qualitative feedback obtained in the previous study indicate that participants, regardless of personality, are indeed perceiving that they are viewed as less competent and experience barriers related to their blindness in their interactions with healthcare providers.

Along these lines, it is important to consider that the items of the Discrimination in the Medical Setting Scale are worded in a univalent manner, asking about experiences participants had facing discrimination and not asking about the absence of discrimination (Peek et al., 2011; see Appendix M). This may allow for the entanglement of item-level social desirability with experience of discrimination. It is possible that the wording of the Discrimination in the Medical Settings Scale is embedded with item level social desirability and, thus, is predisposed it to be uncorrelated with the Marlowe-Crowne Social Desirability Scale—a measure of individual-level social desirability.

Many participants across the three studies mentioned that opportunities to discuss such discrimination were rare. This finding lends further validation to the qualitative design choice of

focus groups in which participants were made comfortable to discuss these experiences without worry of being judged or misunderstood. Future research may focus on demonstrating the discriminant validity of the scale developed in this dissertation with other variables besides social desirability such as personality.

Although it was not expected, we also found that participants who reported feeling treated as more warm and competent reported fewer financial concerns about their healthcare and were more satisfied with the availability and convenience of their healthcare. It is possible that socioeconomic status moderated the effect of blind identity on feeling treated with warmth and competence. Previous literature shows that socioeconomic status is associated with perceptions of warmth and competence (Fiske et al., 2002). Future studies should control for the potential effects of socioeconomic status in the study of another social identity and perceptions of being treated as warm and competent. Lee and Fiske (2006) examined content of stereotypes regarding different immigrant groups that vary in nationality and socioeconomic status on average. They found that immigrant groups were associated with ambivalent stereotypes that were different depending on the group—some groups were viewed as high in warmth and low in competence while others were viewed as low in warmth and high in competence. Variability regarding stereotype content for a dimension of minority status (e.g., disability) may depend on socioeconomic status as well.

## **Chapter 11: General Discussion**

This study examined some passive and active harming and helping behaviors demonstrated by HCPs towards blind patients (Fiske et al., 2007; Fiske, 2013). Some participants in Study 1 described that passive and active helping behaviors could be short-sighted and unhelpful in reality. For instance, when an HCP is using a slower or high pitch voice, they may believe that they are helping the participant to better understand them when in reality they are being perceived as condescending. Participants recommended that the best way to figure out which accommodations are appropriate would be to ask the patients themselves. Future studies could further examine how patients are engaged by the HCP and what methods are most effective.

There is qualitative evidence of HCPs over-helping PWDs—providing what they think is helpful when it is actually unnecessary (McColl et al., 2008). This study further contributes to the evidence of overhelp that PWDs are often faced with. The scale is possibly the first quantitative effort to assess this in the blind population. Future iterations of the scale will continue to refine associated questions and factor structure.

In the present set of studies, many participants qualitatively and quantitatively reported feeling viewed as incompetent. This finding replicates previous results with the broader population of PWDs (de Vries McClintock, 2016; Durand et al., 2008). The fact that this finding was replicated with blind adults may mean that the measure produced in this dissertation can generalize to the wider population of PWDs. This will be subject matter for future studies.

### **11.1 FUTURE DIRECTIONS**

Future research may replicate the validity of this scale and test its external validity with different groups of PWDs (e.g., deaf adults, people with mobility impairments). The scale may

then be used as an outcome variable when examining the effectiveness of interventions to enhance clinical interactions between PWDs and HCPs.

In this study, model fit indices, reliability for each factor, correlations between factors, and correlations of factors with other scales to replicate convergent and discriminative validity were conducted. An additional study with a new sample may be conducted to replicate the factor structure and convergent. Future research may further assess discriminative validity using scales measuring constructs personality dimensions.

Valeras (2010) conducted interviews with six adults with chronic physical impairments that are not automatically apparent to a casual observer. Participants had impairments since at least age 13 years. Valeras (2010) found that people with invisible impairments are conscious of the stigmatized status of PWDs, and consider when they will disclose their impairment and adopt the label of “disabled” and when they will choose to not disclose and pass as a PW/oD. One future direction of this research would be to examine how PWDs with varying levels of visibility of disability perceive the perceptions of their HCPs about them.

Human characteristics such as agency and warmth are ascribed to those perceived as complex agentic individuals (Fiske, 2013). When perceivers view a target as agentic, they recognize that the target has individual agency, thoughts, motivations, and is interesting to get to know about. The interpersonal Orientation Scale measures how people are inclined to perceive others—as agentic individuals or as more simplistic stereotypical members of an outgroup. Future research may examine the interpersonal orientation of HCPs with PWDs and examine how their patients perceive their interactions with these HCPs. Furthermore, future studies may seek to understand under which circumstances PWDs may be perceived as being complex, agentic, warm individuals. This may be examined from the HCP’s perspective evaluating the

PWD, but it may also be examined from the PWD's perspective regarding how they perceive the HCP to perceive them. In this case, such a future study may use the scale developed in this dissertation.

### *Interventions*

One promising avenue of training HCPs to manage their prejudices about disability might be adapted mindfulness training. Mindfulness helps to manage cognitive load which has been linked with biased treatment of minority patients (Dovidio & Fiske, 2012). Kruglanski and Freund (1982) found that participants make stereotypic judgments when they are under time pressure (conditions under which HCPs often operate) and decreases when they fear that their decision will be judged. Burgess and colleagues (2016) found that mindfulness training for HCPs helped them challenge their biases against patients of minority ethnicities. Future studies may test mindfulness-based interventions on HCP and examine the resulting perspective of the PWDs being served by using the measure developed in this dissertation as a dependent variable and determine the effectiveness of the intervention in improving the way that HCPs interact with PWDs.

Additionally, HCPs may benefit from learning to conduct a task analysis or deconstructing tasks into specific steps and use more detailed descriptions and accessible techniques to convey health information, treatment steps, or treatment options to blind patients. Columna et al. (2016) found that after learning to describe tasks in greater detail improved parents' ability to teach their blind children basic physical activity tasks (e.g., running, throwing). It is important to underscore that the dynamic of an adult-to-adult relationship such as the HCP-patient relationship differ from those of a parent interacting with their child. This considered, training HCPs to identify modifications and to engage in detailed task analysis may



increase their confidence and creativity to best serve their patients with disabilities when communicating health information and courses of treatment.

## **11.2 CONCLUSION**

In conclusion, the first *objective* of this dissertation to examine the perceptions of PWDs about their experiences interacting with HCPs and PWDs' perceptions of how HCPs view them was met. This dissertation contributes to the literature on the perspectives of blind patients about how they are treated by HCPs, their relationships with their HCPs, and their satisfaction with their healthcare. The second objective to develop a standardized and validated measure to assess the quality of these experiences and perceived stereotype content was partially met. The measure developed in this dissertation can be studied in future efforts to further establish its validity. In future research, this measure can be used to examine the quality of interactions of PWDs with HCPs and lead to the improvement of the quality and effectiveness of these interactions as experienced by PWDs.

The perspectives of blind participants highlights which stereotypes affect them most as well as how these stereotypes affect them, elaborating on how blind people fit within the Stereotype Content Model. This research also illuminating parts of the Stereotype Content Model and BIAS map that need clarification. Specifically, helping and harming behaviors are more accurately described as facilitation and interference because the target acting on perceptions of competence and warmth, and emotions of pity/envy/contempt/admiration often does not have an accurate idea of what would be a truly helpful or harmful gesture. This knowledge will guide future research and development of materials to help HCPs more effectively interact with blind patients.

In the *long-term* the measure created in this dissertation is the only rigorously developed measure of its kind and, as such, provides future researchers with a tool to develop an in-depth understanding of blind people's and PWDs' perspectives of clinical interaction and the healthcare they receive, and improve the quality of healthcare delivered to members of these populations. This research may contribute to increasing the capacity of HCPs to suppress stereotypes about PWDs as incompetent and work with PWDs as individuals with unique strengths and challenges.

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## Appendix A

### Onwuegbuzie et al. (2010) instrument development and construct validation framework for scale development using mixed methodology

Phase	Description	Study	Details
1	A review of literature to establish theoretical framework and define constructs	Introduction	Borrows from psychology, sociology, and rehabilitation counseling literature.
2	Phase 2 consists of grouping information, open coding, and constructing themes from Phase 1 and conversations with informants.	Study 1	Builds on the Stereotype Content Model literature
3	The scale is written based on Phases 1 and 2. The scale is administered to participants along with open-ended questions prompting feedback regarding face validity and interpretation accompanying each scale item. These open-ended questions associated with each quantitative item will allow for the generation of quantizable qualitative data that can be used in crossover analyses.	Not conducted	Eight open-ended questions written to elicit feedback from participants about the measure were presented at the end of the measure. Item-level feedback was not obtained to avoid participant burden. Crossover analyses were deemed unnecessary and therefore were not conducted.
4	Each item is assessed for “clarity, esthetics, relevancy, tone,” time taken to answer the item, and “cultural competence” of the item (i.e., is it phrased in a way that is considerate of the culture of the participants)	Study 2	The measure as a whole was quantitatively assessed on the six criteria.
5	Data are collected for an EFA. Participants are instructed to rate to what degree they think that the item belongs in a scale measuring the construct of interest, and to summarize the item in their own words.	Not conducted	A power analysis determined the sample size necessary for an EFA. Participants did not give item level feedback, but instead gave measure level feedback in order to reduce participant burden.
6	The EFA is conducted on the data collected in Phase 5.	Study 2	A sufficiently powered EFA was conducted on data collected in Study 2.
7	The qualitative data collected along with the quantitative scale from Phase 5 is analyzed.	Study 2	The qualitative data collected in Study 2 was analyzed using thematic analysis.
8	The qualitative data from Phase 5 is quantized and a factor analysis is conducted with these quantized data	Not conducted	This phase was not conducted.



	to examine underlying factor structures		
9	The factors generated from the EFA calculated with the quantized qualitative themes will be correlated with factors generated from the EFA calculated with the revised quantitative scale itself.	Not conducted	This phase was not conducted because qualitative feedback was not quantized.
10	Phase 10 includes synthesizing the results and discussing their meaning and implications.	Discussion	Results from Studies 1,2 and 3 were compared and their implications were discussed.

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*Note.* Diss Part is the part in the present dissertation in which the respective phase was incorporated. EFA – exploratory factor analysis.

## **Appendix B**

### **Statement for Recruitment**

I am interested in hearing about your experiences interacting with healthcare providers such as doctors, nurses, therapists, and others. I am a National Federation of the Blind National and Texas State scholarship winner. I am conducting my dissertation research, assessing the experiences of blind patients interacting with their healthcare providers. I am conducting focus group interviews with blind adults with any experience interacting with a healthcare provider or healthcare staff. I am inviting you to share your experiences. If you are interested in sharing your experiences, please contact me via phone at (915) 747-8659 or via email at [nmheydarian@miners.utep.edu](mailto:nmheydarian@miners.utep.edu).

## Appendix C

### Script: Introduction

Welcome and Thanks for taking the time to join us to talk about your experiences with healthcare providers and how you think healthcare providers could improve the way they communicate with patients. My name is Nazanin Heydarian and my role is to guide the discussion. I am a blind Health Psychology doctoral student from the University of Texas at El Paso. I am having discussions like this with several groups. You were invited because you have experience interacting with healthcare providers as a blind person.

I'm going to be using a set of standard questions that was approved by my dissertation committee to guide our discussion. I will switch between going in order of the roster and allowing anyone to chime in in no particular order. Please state your name before you make a comment so that everyone knows who is speaking.

There are no wrong answers. Rather there are differing points of view. Please feel free to share your point of view even if it differs from what others have said. You must listen respectfully as others share their views. Both negative and positive comments are helpful. If you need to step away from the call, please put your phone on mute by pressing \*6 and rejoin us as quickly as you can and unmute by pressing \*6 again.

If you get echoing problems, there are a few things that you can try. First, mute and unmute your phone using the phone features (e.g., iPhone itself has a mute microphone switch). Second, use \*6 to mute yourself on the conference call platform. Third, quickly leave the call by hanging up the phone and rejoin it by calling back in.

If I get kicked off the internet

Remember not to breath directly into the receiver of the phone or the microphone if you are calling on the computer.

I'm tape recording the session because I don't want to miss any of your comments. I ask that only one person speaks at a time so that I can fully hear what you have to say. You will be using nicknames that you made up. Before you make a comment, please announce your nickname so that we may follow along with who is speaking. You may be assured of complete confidentiality. The recording will go back to my trained research team to help us develop a scale to help healthcare providers improve their interactions with their blind patients.

Let's begin by learning more about each other. When I read your nickname, take about 30 seconds to tell us about yourself

Opening question...

Note. This script is adapted from the script provided by Krueger (2002).

## Appendix D

### Focus Group Prompts

Let's talk about your experiences interacting with healthcare providers in different circumstances. A few examples of healthcare providers might be eye doctors, general practice doctors, nurses, therapists, or receptionists. A few different circumstances might include your experiences having children, your experiences in emergency care or other experiences with healthcare providers

Think of the effort that goes into preparing for a visit with a healthcare provider. How do you prepare yourself? What arrangements did you have to go through, behind-the-scenes, to get ready for and arrange your visit with this HCP?

How do you think this compares with the efforts that others put in? Do you make an effort in the meeting with the healthcare provider to share information or to keep the healthcare provider engaged? Please explain further.

How do you think that your blind friends are treated by healthcare providers? Have your friends who are blind shared stories about their interactions with healthcare provider? Is this something that you think about before a visit with a healthcare provider? During a visit with a healthcare provider?

Do healthcare providers learn how to treat you the way you want to be treated over the course of a single meeting? After several meetings? Do they stop doing the things that you don't like within a single meeting? After several meetings?

Think about a time when you had a **good/positive experience** with a healthcare provider.

- **What was it like?** [if not specified] Could you tell me what kind of care provider this was? How many times/long had you been seeing this care provider?
- **How did you respond to this experience in the moment?** How did it make you feel? Did you do or say anything in response to this experience?
- **What do you think the healthcare provider thought of you as a person? How could you tell?**
- Did the care provider address you in a way that suggested they think that you're smart? Able to take care of your own health? Able to carry on every-day tasks?
- Did the care provider seem to like you? Did they seem comfortable talking to you? Did they seem comfortable working with you as a patient? Why do you think this?
- Did they seem to believe/trust the information you gave?
- In this positive situation, what kind of language did the [healthcare provider] use to communicate with you about your health concern(s)? Did they use other ways of communication (like a figure, table, or model)? Did they seem to consider what you had to say? Did the HCP seem to respect you? How could you tell?
- Did the healthcare provider seem to care about you as a patient? How could you tell?
- **How did you feel about the outcome of the visit?**
- Did you feel comfortable **raising all of your health concerns** with this [healthcare provider]? Why or why not?

- Do you think that the [healthcare provider] **made a good decision**? Why?
- Do you think that the [healthcare provider] **made a bad decision**? Why?
- Were you satisfied with how much information the [healthcare provider] shared with you? Why or why not?
- Did you feel uncomfortable raising all of your health concerns with this [healthcare provider]?
- Were you dissatisfied with how much information the [healthcare provider] shared with you? Why or why not?

**What kind of lasting impact do you think this experience had on you if any?**

- Do you see these positive experiences with your healthcare providers impacting your motivation to follow doctor's prescriptions or recommended treatment?
  - As a result of this positive experience, how do you feel going into a doctor's appointment now?
- Has the positive experience impacted you in any other way?

Think about a time when you had a **bad or negative experience** with a healthcare provider.

- **What was it like?** [if not specified by participant] Could you tell me what kind of healthcare provider this was? How many times/long had you been seeing this care provider?
- **How did you respond to this experience in the moment?**
- **What do you think the healthcare provider thought of you as a person? How could you tell?**
- Have there been times when you felt that the [healthcare provider] asked inappropriate questions about you/your blindness? How did this make you feel?
- Have you ever had to direct the doctor's attention back to the reason you came in to see them? How did the healthcare provider respond to this? Did they continue to treat you this way throughout the visit?
- Have you ever had to demonstrate your assertiveness to make sure that your medical information was kept confidential? How did the healthcare provider respond to this?
- Did the [healthcare provider] seem not to care about you as a person? How could you tell?
- Did the healthcare provider treat you like you didn't understand what was going on? Unable to take care of your own health? Unable to carry on every-day tasks? Why do you think this was the case?
- Did the healthcare provider seem uncomfortable interacting with you? Treating you? Why do you think this was the case?
- Did they seem to not believe/mistrust the information you gave?
- **How did you feel about the outcome of the visit?**
- In this negative situation, what kind of language did the [healthcare provider] use to communicate with you about your health concern(s)? Did they use other ways of communication? Did they seem to consider what you had to say? Did the HCP seem to disrespect you? How could you tell?

- Did you feel that your [healthcare provider] made assumptions about your blindness or about you because of your blindness? What kinds of assumptions did the HCP make?
- Did you feel comfortable raising all of your health concerns with this [healthcare provider]? Why or why not?
- Do you think that the [healthcare provider] made a good decision? Why?
- Do you think that the [healthcare provider] made a bad decision? Why?
- Were you satisfied with how much information the [healthcare provider] shared with you? Why or why not?
- Did you feel uncomfortable raising all of your health concerns with this [healthcare provider]?
- Were you dissatisfied with how much information the [healthcare provider] shared with you? Why or why not?
- As a result of this negative experience, did you search for another provider? [frequency of visits with particular HCP] why or why not?
- As a result of this negative experience, how do you feel going into a doctor's appointment now?
- Do you see this negative experiences with your [healthcare provider] impacting your motivation to follow doctor's prescriptions or recommended treatment?
- Has the negative experience impacted you in any other way?

#### Questions about other, related experiences

- How have your interactions with receptionists and other patients been?
- How have you managed completing paperwork for visits? Has this felt comfortable to you? How did it make you feel?
- Do you see your experience with your healthcare provider impacting the way you interact with other authority figures?

#### Closing remarks

- Imagine that you are given the opportunity to give advice to healthcare providers in training (e.g., medical students). **What advice would you give them?**
- **What further comments do you have?**

## Appendix E

### Pre focus group checklist

- Screening form
- Schedule appointment
- Schedule time for informed consent and Qualtrics survey (takes about 20 minutes)
- Read informed consent document
- Record informed consent authorization statement (be sure to ask participant to state their first and last name on the recording)
- Complete Qualtrics survey
- Generate pseudonym/nickname
- In the schedule Google doc, replace their real name with their pseudonym/nickname
- Call participant one day prior to scheduled session (you can call them on weekends if they are scheduled for a Monday session).

### Appointment Information

Date of appointment (e.g., MM/DD/YYYY):

Day of the week (e.g., Monday, Tuesday, etc...):

Time of interview (e.g., 12:00PM MST):

Your nickname: \_\_\_\_\_

Please plan to call in **FIVE MINUTES BEFORE** your scheduled time.

On the day of your call, you will dial this toll-free phone number (1-844-801-6666). You will use the following conference code to enter the interview meeting (863921). Once you have entered the meeting, you will be prompted to say your name. Please use the nickname that you created for yourself so that your responses may remain anonymous. Throughout the interview, if you have something to contribute, please state your nickname first and then say what you would like to say. This helps the researcher to keep information organized when she goes back to analyze the data.

What questions do you have?

PI Nazanin Heydarian [nmheydarian@miners.utep.edu](mailto:nmheydarian@miners.utep.edu)

Thank you for taking the time to speak with me. Have a nice day. Goodbye.

## Appendix F

### Screening Form with Inclusion Criteria

RA Initials: \_\_\_\_\_  
Participant Name: \_\_\_\_\_  
Participant Phone: \_\_\_\_\_  
Participant Email: \_\_\_\_\_  
Preferred method of contact \_\_\_\_\_  
Date of call: \_\_\_\_\_  
Message:

---

Hello, Judgment and Decision-Making lab. This is \_\_\_\_\_. How may I help you?

I am going to ask you a few questions to determine whether this study is a good fit for you.

What is your age in years? : **must be 18 years or older** \_\_\_\_\_

Would you consider yourself to be fluent in English? **YES** NO

**Response of “YES” or must demonstrate ease of communicating in English with you.**

Do you consider yourself to be blind or visually impaired? **YES** NO

Do you use a mobility aid such as a white cane or guide dog? YES NO

Describe your visual acuity:

**Must be at 20/200 or less in the better eye after correction (e.g., while wearing glasses and/or contacts) and/OR visual field of 20 degrees or less**

Have you ever been diagnosed with...

Albinism?	YES	NO
Cataracts?	YES	NO
Diabetic retinopathy?	YES	NO
Glaucoma?	YES	NO
Head injury?	YES	NO
Hypertensive retinopathy?	YES	NO
Macular degeneration?	YES	NO
Optic neuritis?	YES	NO
Retinal detachment?	YES	NO
Retinal vascular occlusion?	YES	NO
Retinitis pigmentosa?	YES	NO
Strabismus?	YES	NO
Other? _____		

Have you ever been diagnosed with a hearing impairment? YES NO

Please specify \_\_\_\_\_

**If NO, they qualify according to this criteria. If YES, make sure that they have the technology to access a telephone call. If they have the technology to access a phonecall, than they may be eligible for this study.**

Have you ever been diagnosed with a cognitive impairment? YES **NO**

Please specify \_\_\_\_\_



Do you have problems with your memory?

YES **NO**

Please specify \_\_\_\_\_

**\*IF QUALIFIES\*** It looks like this study might be a good fit for you. Do you have time now to schedule an interview time?

*\*USE SCHEDULING SPREADSHEET TO SCHEDULE PARTICIPANT FOR A FOCUS GROUP\**

**\*IF DOES NOT QUALIFY\*** Thank you for taking the time to answer these questions. Unfortunately it doesn't appear that this study would be a good fit for you. Would you be interested in remaining on a list and be contacted for future studies that might be a good fit for you?

**\*\*AFTER SCHEDULING OR AFTER GETTING THEIR INFORMATION FOR PARTICIPANT REGISTRY\*\***

What questions do you have?

**\*IF YOU DON'T HAVE AN ANSWER, DIRECT THEM TO NAZANIN HEYDARIAN, THE PRINCIPLE INVESTIGATOR FOR THIS STUDY.**

**([NMHEYDARIAN@MINERS.UTEP.EDU](mailto:NMHEYDARIAN@MINERS.UTEP.EDU))\***

Thank you for taking the time to call today. You will receive the phone number for the conference call and the conference code for your appointment at your preferred contact (email, phone). On the day and time of your appointment (remind them of the day and time), you will be instructed to call in at the phone number, prompted to enter the code for your conference call, and you will be asked to come up with a nickname to use on the call so that your responses remain anonymous. A research assistant will call you back to remind you of your appointment the day before your appointment. Have a nice day. Goodbye.

## Appendix G

### Health and Activities Questionnaire

1) Compared to other people your own age, how would you rate your physical health?

- 1 = much worse
- 2 = worse than average
- 3 = average
- 4 = Better than average
- 5 = Much better than average

2) How satisfied are you with your present health?

- 1 = Not at all satisfied
- 2 = Not very satisfied
- 3 = Neither satisfied nor dissatisfied
- 4 = Somewhat satisfied
- 5 = Extremely satisfied

3) How often do health problems stand in the way of your doing the things you want to do?

- 1 = Never
- 2 = Seldom
- 3 = Sometimes
- 4 = Often
- 5 = Always

4) Have you ever lost consciousness for more than 10 minutes because of a head injury?

- 1 = Yes
- 2 = No

5) Do you participate in any regular form of exercise or activity (e.g., climbing stairs, walking, other forms of exercise)?

- 1 = Yes
- 2 = No

If YES, please list the activities below and the approximate number of hours per week spent engaging in each activity.

6) Are you on post-menopausal estrogen replacement therapy?

- 1 = Yes
- 2 = No

7) Do you take any other medication (prescription or nonprescription) on a regular basis (at least once a week)?

- 1 = Yes – Please answer question 9
- 2 = No – Skip to question 10

8) List all prescription and nonprescription medications you use at least once a week.

9) Please check which of the following conditions you have now or have had in the past.

Condition	In your lifetime	Now
Chronic migraine headaches		
Diabetes		
Encephalitis of Meningitis		
Epilepsy		
Heart attack or bypass surgery		
Multiple sclerosis		
Parkinson's disease		
Rheumatoid arthritis or other autoimmune disorders		
Osteoarthritis		
Stroke		
Alzheimer's disease		
Dementia or other memory disorder		
Other significant illnesses or medical diagnoses (please list)		

10) How many BONE FRACTURES have you had in the LAST FIVE YEARS?

- 1 = none
- 2 = 1
- 3 = 2
- 4 = 3-5
- 5 = More than 5

11) How many SURGERIES have you had in the LAST FIVE YEARS?

- 1 = None
- 2 = 1
- 3 = 2
- 4 = 3-5
- 5 = More than 5

12) How many times have you been HOSPITALIZED in the LAST FIVE YEARS?

- 1 = None
- 2 = 1
- 3 = 2
- 4 = 3-5
- 5 = 6-10
- 6 = More than 10

13) Please list any other impairments or disabilities that you have.

#### Demographics

Age (in years) \_\_\_\_

Gender \_\_\_\_\_

Ethnicity \_\_\_\_\_

Education (in years, not including before first grade) \_\_\_\_\_

Occupation \_\_\_\_\_

Pseudonym/nickname \_\_\_\_\_

Abbreviated Stereotype Content Questionnaire

Each item is rated on a scale of how much participants feel that society in general would agree or disagree with each statement, on a scale of 1 = not at all, to 5=extremely.

How confident are blind people?	
How competent are blind people?	
How sincere are blind people?	
How warm are blind people?	
How well educated are blind people?	
How economically successful are blind people?	
If blind people get special breaks, this is likely to make things more difficult for other people.	
Resources that go to blind people are likely to take away from other people.	

## Appendix H

### Transcription Assignments

	Transcribe & Time Stamps	Double Check	Triple Check
RA1	FG4	FG2	FG1, FG3, FG5, FG6, FG7
RA2	FG1, FG		
RA3	FG2	FG1, FG3, FG5, FG6	
RA4	FG3	FG4	FG2
RA5	FG5, FG6	FG7	FG4

Note. RA = Research assistant, FG = Focus group

## **Appendix I**

### **Themes from Study 1 and items written based on those themes**

#### **Accommodating**

- Healthcare providers are accepting of my guide dog
- Healthcare providers write my prescriptions in a format that is accessible to me
- Healthcare providers ask how I prefer to be accommodated
- Healthcare providers explain what they will do before they do it
- Healthcare providers provide reasonable accommodations
- *RC* Healthcare providers are usually unaware of accommodations for blind people
- *RC* I feel healthcare providers are often in a rush to finish with my appointment

#### **Accommodating RC/respect**

- *RC* Healthcare providers touch me without a warning

#### **Preparation**

- I have friends/family who assist with healthcare visits

#### **Attributions**

- Compared to other patients, I am more likely to be treated unfairly in the healthcare setting
- Healthcare providers treat me the way that they do because of my gender/sex more than based on my blindness/visual impairment
- My personality influences how healthcare providers treat me more than my blindness does
- *RC* Healthcare providers treat me the same as other patients

#### **Warmth**

- *RC* Sometimes, I may come off as cold to the healthcare provider
- *RC* At times, I may come off as aggressive to the healthcare provider
- *RC* At times, healthcare providers may think that I am intimidating

#### **Competence**

- Healthcare providers recognize that I can take care of myself
- Healthcare providers treat me like a whole person
- Healthcare providers listen to what I say about my health
- *RC* When I come to an appointment with a sighted person, healthcare providers address them instead of me

#### **HCP competence/accommodating**

- With proper training, healthcare providers can learn how to better interact with blind patients

#### **Respect**

- *RC* Healthcare providers often ask me irrelevant questions about my blindness

- RC My privacy is not respected when I get help with filling out forms
- RC Healthcare providers are often uncomfortable when I am around

### **Pity**

- I often think that healthcare providers feel sorry for me

### **Support**

- Healthcare providers support me in pursuing activities I enjoy

### **HCP Warmth**

- I usually enjoy when healthcare providers use humor
- Most healthcare providers treat me with kindness
- My healthcare provider listens carefully to my concerns
- Healthcare providers take time to know me
- RC My limited/lack of eye contact makes some healthcare providers uncomfortable

### **Demonstrating competence**

- I think the key to a positive experience with a healthcare provider is clearly stating my needs
- I consider it my responsibility to educate healthcare providers about blindness
- I must appear confident in front of healthcare providers
- I often need to demonstrate my intelligence for healthcare providers
- Sometimes, I need to prove to healthcare providers that I am capable

### **Positive/Negative**

- Overall, my interactions with healthcare providers have been positive

## Appendix J

### Categories and themes associated with open-ended questions

Question 1. Categories and themes associated with the open-ended question “How clear was the language of the items in the measure that you just completed?”

Row Labels	#	Definition	Example Quote
Feedback (81.714%) <i>When participants made comments about the scale, what they felt was a strength of the scale, and what they felt could be improved about the scale</i>			
Clarify Attention Check	9	<i>When participants refer to any confusion surrounding the attention check item “Please select ‘strongly disagree”</i>	<i>A clear question is one that asks specifically about a particular kind of behavior, and has a definite answer available within a range of possibilities. There was one puzzling page. It said, “Please select “Strongly disagree.”” WHY? But I did as directed, because I wanted to continue with the survey.</i>
Clarify Language	7	<i>When participants indicate that they had difficulty understanding a question</i>	<i>...Sometimes it is slightly abstract, ...</i>
Clarify Scale	1	<i>When participants have a comment on the response options or scaling of questions</i>	<i>Sometimes the scale is strange all different levels of agreement.</i>
Clear Instructions	1	<i>The guidance given to participants about answering the questions was sufficient</i>	<i>And they were giving good instruction as to how I needed to respond.</i>
Clear Language	47	<i>Questions are written in a way that makes them easy to understand</i>	<i>...and questions are specific.</i>
Clear Scale	3	<i>When participants make a comment about how the response options for the items was written in language that was easily understandable</i>	<i>Questions that had the strongly agree, agree, neither agree or disagree, disagree, strongly disagree were good, some other questions that had always, mostly, sometimes, hardly at all, never, some of those did not have not apply. ...</i>
Clearer Instructions	1	<i>When participants want more guidance as to how to answer questions</i>	<i>I think it would be helpful if there was somewhere a reminder that healthcare professionals include everybody associated with doctor's office.</i>
Comprehensive	2	<i>The items in the measure cover a satisfactory breadth of topics</i>	<i>...and they included questions more than me being blind and more about my experience.</i>
Concise	6	<i>Questions are long enough to convey the intended message</i>	<i>All questions were concise and clear</i>
Define Reasonable Accommodations	4	<i>Provide an operational definition of reasonable accommodations for those participants who may be unaware of what the term refers to</i>	<i>and do they provide prescription in accessible format what are the different formats.</i>
Demographics	4	<i>When participants make a comment that pertains to the part of the survey that comes before the measure we are developing.</i>	<i>When asking for list of medication</i>



Differentiate Between HCPs	4	<i>Have separate set of items or otherwise indicate which kind of HCP an item refers to OR some comment about how participants would rate items differently depending on which kind of HCP the item was referring to (e.g., staff, medical support staff, primary care provider, nurse, doctor, technician, therapist)</i>	<i>broad field when saying health providers be more specific. Cause a doctor's responsibilities are so different from a receptionist for example</i>
Example	4	<i>When participants refer to a specific items from the measure that were eliminated after inspecting response frequencies</i>	<i>For instance, healthcare providers can learn how to better interact with blind people with proper training.</i>
Example 6 & 9, 16, 18, 21, 22, 3, 5, 7, 8, 9	8	<i>When participants give specific examples of items from the measure that were not eliminated after inspecting response frequencies</i>	<i>I think health care providers feel sorry for me -- clear.</i>
Example Unclear	7	<i>When participants give a specific example of an item that was not clear and was eliminated after inspecting response frequencies</i>	<i>Question, I must appear confident in front of my healthcare provider. Intent is unclear. "I do?" or "I need to."</i>
Example Unclear 6, 7, 9, 12, 13, 15, 16, 21	14	<i>When participants give a specific example of an item that was not clear</i>	<i>Sometimes I come off as intimidating to the healthcare provider, not sure what the point was</i>
Good	6	<i>A generally positive comment about the scale</i>	<i>...but since you are just asking our opinions, this is probably ok.</i>
Provide Open-ended Prompts	4	<i>When participants indicate that they want more opportunities to share their experiences in a freer form than multiple choice questions</i>	<i>I think that you should have a space to hear some stories we have to tell!</i>
Scaling Suggestion	5	<i>When participant makes a recommendation about response options or additional space to include reactions to items.</i>	<i>Have an answer choice as neither agree nor disagree</i>
Survey Attributes	3	<i>When participants comment on other aspects of the survey besides the content in general and scaling of the measure items. For example, if they comment on survey flow, text size/font/etc...</i>	<i>Text needs to be bigger and. Bolder.</i>
<b>Remark (18.286%) When participants made a comment directly about or inspired by the content of the scale and how it relates to them, and share examples from their experiences</b>			
Comment	3	<i>When participant makes a remark about something that isn't a specific experience that anyone had related to the scale, could be an opinion or perspective about how the world works in general or how healthcare works in general</i>	<i>My current situation is the best Ive ever been in but in the past it was terrible</i>
Experience	4	<i>When participants describe an experience that they had and do not clearly tie it in with the measure or any item from the measure</i>	<i>...Most of my bad experiences happened in the past, and I am currently very happy with my experiences.</i>
No Comment	3	<i>When participants indicate that they have no feedback or any contribution such as comments, observations, examples, etc...</i>	<i>I can't think of anything</i>
Observation	5	<i>A general comment about how participants think the scale is set up or organized, or what participants think that the scale is measuring without referring to any specific item and without drawing a personal connection with the measure</i>	<i>Sometimes interpretation of experiences would be more likely to influence outcome rather than question language.</i>
Other	3	<i>When participant does not give enough information for the coder to sort the response into any existing theme</i>	<i>Not hearing was the only unclear thing</i>

Relates to Example	3	<i>Remark about how the participant relates to a specific item from the measure that was eliminated after inspecting response frequencies. They may mention that the example resonates with them or not and may elaborate on how or why. They may even relate the example to experiences in their own life by using similar wording to the example.</i>	<i>For example, initially a healthcare provider may see me as intimidating. I work hard to diffuse that impression, often using humor - the grease of awkward encounters. If that does not work, I find a new doctor because we are not going to get along.</i>
Relates to Example 1, 10, 22	5	<i>Remark about how the participant relates to a specific example. They may mention that the example resonates with them or not and may elaborate on how or why. They may even relate the example to experiences in their own life by using similar wording to the example.</i>	<i>asking if need to prove intelligence to provider. This was very clear and something I've often felt I needed to do.</i>
Relates to Measure	4	<i>Remark about how the participant relates to the measure or any item from the measure. They may mention that the item resonates with them or not and may elaborate on how or why or give an example from their life that is related to an item from the survey by using similar wording to an item from the survey.</i>	<i>Some of the questions did not apply to me.</i>
Thought Provoking	2	<i>When participants explicitly state that the scale item caused them to think/reflect</i>	<i>Thought provoking one about eye contact</i>

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Note. # = the count of the number of responses coded within a given theme. Total coded responses = 175, Raw percent agreement = 68.000%, lenient percent agreement = 73.714%.

Question 2. Categories and themes associated with the open-ended question “Please give specific examples of questions that sounded natural or unnatural.”

Theme	#	Definition	Example Quote
Feedback (76.230%) <i>When participants made comments about the scale, what they felt was a strength of the scale, and what they felt could be improved about the scale</i>			
Clear Language	8	<i>Questions are written in a way that makes them easy to understand</i>	<i>I like the fact that it was plain language, straightforward and easy understand.</i>
Clearer Instructions	2	<i>When participants want more guidance as to how to answer questions</i>	<i>Maybe add in: When thinking about your experience as a patient with a visual impairment"? I think you should have asked if we have ever given suggestions to health care providers on how to treat us differently, and if so if it caused the situation to improve. ... You didn't ask if we ever filed a complaint with the medical facility or the DOJ.</i>
Content Suggestion	1	<i>When participants make suggestions for topics that they think the scale should cover</i>	<i>I also would have liked to have questions that clarify what accommodations were not provided. Most of the ones that were not provided currently are accessible paperwork. While in the past it was doctors not providing quality services.</i>
Define Reasonable Accommodations	2	<i>Provide an operational definition of reasonable accommodations for those participants who may be unaware of what the term refers to</i>	<i>List of major illnesses could be longer. Example: nerves of heart instead of just muscle which is heart attack. With my heart nerves not working, my heart will not beat on it's own, so I have a pacemaker. You did not ask about such things as: lungs, gastro.</i>
Demographics	3	<i>When participants make a comment that pertains to the part of the survey that comes before the measure we are developing.</i>	<i>The questions ask about a health care provider but there are many and their responses can be varied from the doctor, to the clerical staff, to the nurse practitioner and we have different doctors specialists for different things such as a dermatologist, dentist, internist and screeners for mammograms. there can be a lot of variety among the different health care professionals.</i>
Differentiate Between HCPs	5	<i>Have separate set of items or otherwise indicate which kind of HCP an item refers to OR some comment about how participants would rate items differently depending on which kind of HCP the item was referring to (e.g., staff, medical support staff, primary care provider, nurse, doctor, technician, therapist)</i>	
Example	4	<i>When participants refer to a specific items from the measure that were eliminated after inspecting response frequencies</i>	<i>The question about the guide dog.</i>
Example 2, 3, 5, 8, 9, 10, 12, 16, 17, 24	16	<i>When participants give specific examples of items from the measure that were not eliminated after inspecting response frequencies</i>	<i>The questions about whether I feel that I am treated differently because I am blind seem very natural to ask.</i>
Example Unclear	1	<i>When participants give a specific example of an item (that was eliminated after inspecting response frequencies) that was not clear</i>	<i>Must appear confident, the must could be too different things. Should I appear confident, do I have to appear.</i>

Example Unclear 13	1	<i>When participants give a specific example of an item that was not clear</i>	<i>the question about am i treated as a whole question, kind of murky because what is the definition of a whole question</i>
Example Unnatural	3	<i>When participant give a specific example of an item (that was eliminated after inspecting response frequencies) that was not natural</i>	<i>The confidence in front of health care providers is unnatural</i>
Example Unnatural 7, 10, 11, 12, 21	4	<i>When participant give a specific example of an item that was not natural</i>	<i>THE question I referred to previously about the eye contact seemed fairly unnatural.</i>
Natural Language	32	<i>Participants indicate that the language of the survey is not colloquial and in line with everyday speech</i>	<i>Well, I think all of them sound natural.</i>
Provide Open-ended Prompts	2	<i>When participants indicate that they want more opportunities to share their experiences in a freer form than multiple choice questions</i>	<i>I also would would have liked to tell some stories about some major experiences with health care providers.</i>
Relevant question	4	<i>When participants state that a question is relatable, timely, relevant, is the topic of conversation within the blind community, etc...</i>	<i>Scenarios were very relatable and natural</i>
Scaling Comment	1	<i>When participants make a comment regarding the response options/scaling of the items</i>	<i>...that is why I did not pick an answer that's worded strongly before agree or disagree, ...</i>
Scaling Suggestion	1	<i>When participant makes a recommendation about response options or additional space to include reactions to items</i>	<i>more questions need the NA selection</i>
Survey Attributes	3	<i>When participants comment on other aspects of the survey besides the content in general and scaling of the measure items. For example, if they comment on survey flow, text size/font/etc...</i>	<i>Too difficult to differentiate between questions.</i>
<b>Remark (23.770%) <i>When participants made a comment directly about or inspired by the content of the scale and how it relates to them, and share examples from their experiences</i></b>			
Comment	2	<i>When participant makes a remark about something that isn't a specific experience that anyone had related to the scale, could be an opinion or perspective about how the world works in general or how healthcare works in general</i>	<i>When we have an issue as bind people, it may not always is the fault of the sighted person...</i>
Diabetes Management	1	<i>When participants remark on their experiences regarding their diabetes and disease management efforts and techniques</i>	<i>I found that staff while in the hospital were clueless on how to manage my diabetes; doctors I see outside a hospital environment are much more receptive to me and my management techniques. ...I become annoyed w hen I can hear in their voice that they are totally floored that I have a graduate degree. Admittedly, library science is a weird degree for a blind person to have though some blind have done amazingly well with this degree, partly through luck, and partly though just plain hard work and smarts, though I could wish some of these hard-working luckies would share it a little. ...</i>
Experience	1	<i>When participants describe an experience that they had and do not clearly tie it in with the measure or any item from the measure</i>	<i>See examples for previous question on clarity.</i>
No Comment	6	<i>When participants indicate that they have no feedback or any contribution such as comments, observations, examples, etc...</i>	

Observation	7	<i>A general comment about how participants think the scale is set up or organized, or what participants think that the scale is measuring without referring to any specific item and without drawing a personal connection with the measure</i>	<i>Usually you can see a pattern in which a survey is trying to extract a specific outcome. I did not sense that with this one.</i>
Other	1	<i>When participant does not give enough information for the coder to sort the response into any existing theme</i>	<i>Oh come on! That's asking for too much work.</i>
Relates to Example	4	<i>Remark about how the participant relates to a specific item from the measure that was eliminated after inspecting response frequencies. They may mention that the example resonates with them or not and may elaborate on how or why. They may even relate the example to experiences in their own life by using similar wording to the example.</i>	<i>Many of these situations occur regularly so all questions sounded natural. ...and one related to how comfortable health care providers seemed to be with ... guide dogs.</i>
Relates to Example 4, 11, 15, 17, 22	6	<i>Remark about how the participant relates to a specific example. They may mention that the example resonates with them or not and may elaborate on how or why. They may even relate the example to experiences in their own life by using similar wording to the example.</i>	<i>Sometimes I feel I have to be aggressive with my healthcare provider.</i>
Thought Provoking	1	<i>When participants explicitly state that the scale item caused them to think/reflect</i>	<i>They are honest questions that need to be thought about.</i>

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Note. # = the count of the number of responses coded within a given theme. Total coded responses = 122, Raw percent agreement = 63.033%, lenient percent agreement = 79.508%.

Question 3. Categories and Themes that Emerged from the analysis of Responses to the Prompt “Please give specific examples of relevant or irrelevant questions. Elaborate”

Row Labels	#	Definition	Example Quote
Feedback (43.976%) <b><i>When participants made comments about the scale, what they felt was a strength of the scale, and what they felt could be improved about the scale</i></b>			
Address Accessibility	3	<i>When participants call researchers to assess how well healthcare providers consider accessibility and provide accommodations for the blind patient</i>	<i>though I wish you would target information accessibility more specifically.</i>  <i>Meeting accommodations needs more attention. I don't recall being asked about completing history or consent forms, etc. Eye physicians especially should have private assistance and larger print when requesting patient history or consent. With kiosk /digital information gathering, formats must be accessible and often are not. I prefer to complete forms myself in writing. This is also a problem with the older population in general, not just the blind or visually impaired.</i>
Address Accessibility-Written Materials	3	<i>When participants call researchers to assess how well healthcare providers consider accessibility and provide accommodations for the blind patient, particularly when it pertains to written documents such as information sheets and prescriptions.</i>	<i>To be honest, I expected more questions about health insurance companies - I think they need an academic audit!</i>
Content Suggestion	1	<i>When participants make suggestions for topics that they think the scale should cover</i>	<i>asking things like do you read braille or use magnifiers</i>
Demographics	8	<i>When participants make a comment that pertains to the part of the survey that comes before the measure we are developing.</i>	
Differentiate Between HCPs	5	<i>Have separate set of items or otherwise indicate which kind of HCP an item refers to OR some comment about how participants would rate items differently depending on which kind of HCP the item was referring to (e.g., staff, medical support staff, primary care provider, nurse, doctor, technician, therapist)</i>	<i>Again, the differences I've experienced were in-hospital vs. doctor visits outside a hospital environment</i>
Example	7	<i>When participants refer to a specific items from the measure that were eliminated after inspecting response frequencies</i>	<i>A relevant question is do you think it is your responsibility to educate the health care professional. The question pertaining to if my health care provider provided documents in an accessible format was very relevant because this rarely happens for individuals.</i>
Example Relevant 1, 2, 5, 7, 8, 9, 12, 13, 14, 16, 18, 21, 22, 24	34	<i>When participants give specific examples of items from the measure that were not eliminated after inspecting response frequencies</i>	<i>Not relevant to use the word, "cold" in dealing with health care providers, in my experience.</i>
Example Irrelevant 7, 10, 11, 19, 20, 21	8	<i>When participant give a specific example of an item that was not relatable, timely, relevant, is the topic of conversation within the blind community, etc...</i>	<i>...This one and the humor one I don't know how to answer. ...</i>
Example Unclear	1	<i>When participants give a specific example of an item that was not clear and was eliminated after inspecting response frequencies</i>	

Example unclear	6	1	<i>When participants give a specific example of an item that was not clear</i>	<i>...Have no way of knowing how sighted patients are treated in respect to fairness. ...</i>
Scaling Suggestion	1	1	<i>When participant makes a recommendation about response options or additional space to include reactions to items</i>	<i>some didn't apply to me, so needed a NA selection</i>
Survey Attributes	1	1	<i>When participants comment on other aspects of the survey besides the content in general and scaling of the measure items. For example, if they comment on survey flow, text size/font/etc...</i>	<i>...I wonder if each category of questions should have this relevant question as th at way question groups would be fresh in your mind. ...</i>
<b>Remark (56.024%) <i>When participants made a comment directly about or inspired by the content of the scale and how it relates to them, and share examples from their experiences</i></b>				
Comment	6	6	<i>When participant makes a remark about something that isn't a specific experience that anyone had related to the scale, could be an opinion or perspective about how the world works in general or how healthcare works in general</i>	<i>...The discrimination-based method of asking questions overlooks the fact that medical providers off make assumptions about all of the patients. The worst experiences I've had with doctors would not be rendered with training about how to work with blind people, but let her training on how to relate better to patients, and two if you patients about their goals related to treatment rather than assuming that everybody wants the same thing. If you are gathering opinions of how I experience a medical appointment, then I believe all aspects were covered.</i>
Comprehensive	1	1	<i>The items in the measure cover a satisfactory breadth of topics</i>	<i>It seems that you asked excellent questions,...</i>
Good	1	1	<i>A generally positive comment about the scale</i>	
Irrelevant	3	3	<i>When participants state that a question is not relatable, timely, relevant, is the topic of conversation within the blind community, etc...</i>	<i>They didn't feel relevant to me....</i>
No Comment	4	4	<i>When participants indicate that they have no feedback or any contribution such as comments, observations, examples, not sure of what to say</i>	<i>Not sure</i>
Not Comprehensive	1	1	<i>When participants make a general statement about how there is more to the experience of interacting with healthcare providers that is not captured in this survey.</i>	<i>...however it does not include the whole scale of the healthcare experience</i>
Not Written by Blind Person	1	1	<i>Participants remark that they do not think that the measure was written by someone who has experience with blindness/low vision</i>	<i>...don't think that a blind person wrote it</i>
Observation	9	9	<i>A general comment about how participants think the scale is set up or organized, or what participants think that the scale is measuring without referring to any specific item and without drawing a personal connection with the measure</i>	<i>...some of the time I misunderstand the categories they went into.</i>
Other	4	4	<i>When participant does not give enough information for the coder to sort the response into any existing theme</i>	<i>Again, if you don't know what types of questions aer relevant, then you don't need to be designing surveys. Noone has time for that unless you pay them.</i>

Praise/appreciation	4	<i>When a participant makes a remark such that they are showing their appreciation for the study or praising the efforts of the research team. Also if they express an interest of knowing the study's results Remark about how the participant relates to a specific item from the measure that was eliminated after inspecting response frequencies.</i>	<i>Good job.</i>
Relates to Example	4	<i>They may mention that the example resonates with them or not and may elaborate on how or why. They may even relate the example to experiences in their own life by using similar wording to the example. Remark about how the participant relates to a specific example. They may mention that the example resonates with them or not and may elaborate on how or why. They may even relate the example to experiences in their own life by using similar wording to the example.</i>	<i>...however, a lot of the time healthcare professionals are too interested in my guide dog to focus on me</i>
Relates to Example 8, 10, 11, 13, 14, 16, 17, 19, 21	11	<i>Remark about how the participant relates to the measure or any item from the measure. They may mention that the item resonates with them or not and may elaborate on how or why or give an example from their life that is related to an item from the survey by using similar wording to an item from the survey.</i>	<i>...the part that is most relevant to me is interaction with the actual healthcare providers and how I might influence the interaction: like the question about ...aggressive,</i>
Relates to Measure	1		<i>...the part that is most relevant to me is interaction with the actual healthcare providers and how I might influence the interaction: like the question about ... How professionals viewed me or how I viewed myself.</i>
Relevant	43	<i>When participants state that a question is relatable, timely, relevant, is the topic of conversation within the blind community, etc...</i>	<i>...Most of them are relevant but those stood out to me.</i>

Notes. # = the count of the number of responses coded within a given theme. Total coded responses = 166, Raw percent agreement = 62.874%, lenient percent agreement = 76.048%.



Question 4. Summary of Themes and Categories that emerged from the Open-ended Prompt “How would you describe the tone of the survey?”

Theme	#	Definition	Example Quote
<b>Feedback (47.727%)</b> <i>When participants made comments about the scale, what they felt was a strength of the scale, and what they felt could be improved about the scale</i>			
Clear Language	6	<i>Questions are written in a way that makes them easy to understand</i>	<i>It was very clear ...</i>
Comprehensive	6	<i>The items in the measure cover a satisfactory breadth of topics</i>	<i>Very thorough...</i>
Demographics	2	<i>When participants make a comment that pertains to the part of the survey that comes before the measure we are developing.</i> <i>A generally positive comment about the scale that does not fit within other themes of positive connotation. Also when participants say that</i>	<i>...the demographic questions took too long. Some of the consent form items were too long. ...</i>
Good	42	<i>the survey was “okay” or “fine” because although these terms are slightly less strong than calling the survey “good”, they are still on the positive side of neutral</i>	<i>...I enjoyed it</i>  <i>...I think some more specific questions might be helpful: How often do providers know how to offer assistance when signing a form or receipt? How knowledgeable are providers about accessible medical devices like scales &amp; thermometers, not just diabetes tools.</i>
More Survey Questions	3	<i>When participants indicate that they want more questions related to their experiences with healthcare providers</i>	
Precise	13	<i>When participants describe the survey as concise, structured, etc...</i> <i>and their comment has a positive sound to it</i>	<i>Direct ...</i>
RA Positive	1	<i>When the participant makes a positive comment about the research assistant who administered the survey</i>	<i>...and the survey administrator was patient and made sure I understood the question</i>
Relevant	7	<i>When participants state that a question is relatable, timely, relevant, is the topic of conversation within the blind community, etc...</i>	<i>...I feel that the questions were very real and very relevant to my experience</i>
Scaling Comment	1	<i>When participants make a comment regarding the response options/scaling of the items</i>	<i>... with enough choices to make the correct answer.</i>
Survey Attributes	1	<i>When participants comment on other aspects of the survey besides the content in general and scaling of the measure items. For example, if they comment on survey flow, text size/font/etc...</i>	<i>... however I feel that there were some redundant questions.</i>
Voice Experiences	1	<i>When participants note that participating in this survey provided them with an opportunity to express and discuss experiences with HCPs</i>	<i>...it gave me a chance to explain my experiences with health care providers.</i>

Well Written	1	Participants make positive comments regarding how the scale was written. This could include comments regarding the level of insight of the author	Well written...
<b>Remark (8.523%) When participants made a comment directly about or inspired by the content of the scale and how it relates to them, and share examples from their experiences</b>			
Comment	2	When participant makes a remark about something that isn't a specific experience that anyone had related to the scale, could be an opinion or perspective about how the world works in general or how healthcare works in general	...Vision loss isn't pleasant, but it is just a fact of life like so many others. There is no need to avoid mentioning the word "blind" as if I am unaware I can't see where I am going half the time. How silly people can be!
No Comment	1	When participants indicate that they have no feedback or any contribution such as comments, observations, examples, not sure of what to say	Can't say.
Observation	4	A general comment about how participants think the scale is set up or organized, or what participants think that the scale is measuring without referring to any specific item and without drawing a personal connection with the measure information from the participant's response to determine where else to sort their response.	Questions are valid - they do suggest you're looking for a lack of understanding about blindness in the medical community. It most definitely exists.
Other	2	When participant does not give enough information for the coder to sort the response into any existing theme	?
Relates to Example	1	Remark about how the participant relates to a specific item from the measure that was eliminated after inspecting response frequencies. They may mention that the example resonates with them or not and may elaborate on how or why. They may even relate the example to experiences in their own life by using similar wording to the example.	...I noticed there was a question related to if the health care provider thought I could take care of myself and I thought this was a very good one because it usually seems that professionals think I have a caregiver even though I have five children I take care of.
Relates to Example 13	1	Remark about how the participant relates to a specific example. They may mention that the example resonates with them or not and may elaborate on how or why. They may even relate the example to experiences in their own life by using similar wording to the example.	...I don't see it that way that healthcare providers look at blind people as less than half the person. It is my duty to make it a comfortable and productive interaction. Maybe the idea of it is to focus on the problem i encounter in any situations. ...
Thought Provoking	4	When participants explicitly state that the scale item caused them to think/reflect	It was thought provoking...
<b>Tone (43.750%) When participants comment on tone of the survey and what impression they got from it</b>			
Accusatory	2	Participants state that the language used in the survey is confrontational, aggressive, defensive, blaming, etc...	There were times where I felt defensive,...
Appropriate	3	The tone is in line with the purpose of the study	about right for the perceived purpose of the study which would appear to be the treatment and perceived abilities of blind individuals by their health care providers

Comfortable	15	<i>When participants describe the tone as comfortable or putting them at ease, easy going, etc...</i>	<i>...non-invasive</i>
Inquisitive	9	<i>When participant notes that the questions have a tone of genuine curiosity and/or that the author of the questions wrote them in a spirit of genuine and respectful curiosity</i>	<i>Inquiring</i>
Negative Tone	7	<i>The participant notes that the questions have a pessimistic or otherwise negative tone to them.</i>	<i>Somewhat negative towards health professionals, ...</i>
Neutral	15	<i>The participants not that the tone of the survey is neither positive nor negative</i>	<i>I would describe the tone of the survey as impartial. Some questions assumed a positive tone while others assumed a negative tone.</i>
Not Unusual	6	<i>The survey is a typical survey and doesn't violate participants' expectations of what they were getting themselves into by participating in this survey</i>	<i>Nice just a survey</i>
Professional	8	<i>When participants describe the survey as professional, elevated level of discussion (as opposed to overly simple language)</i>	<i>Professional</i>
Respectful	6	<i>When participants note that the tone regards the perspectives of participants as valuable, respectful tone</i>	<i>Respectful of what a low vision/blind individual experiences.</i>
Rigid	2	<i>The language used in the survey sounds cold, mechanical, highly structured, machine like, not human like. When the participant describes the language in this way and their description is inherently negative sounding</i>	<i>A little rigid and mechanical</i>
Sensitive	3	<i>Participants describe tone of the survey as considerate of the needs and concerns of participants, pertaining to feelings</i>	<i>touchy feely.</i>
Serious	1	<i>When participants describe the tone of the survey as considering topics that require careful and immediate consideration</i>	<i>serious</i>

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Note. # = the number of responses coded within a given theme. Total coded responses = 176, Raw percent agreement = 83.051%, lenient percent agreement = 84.746%.

Question 5. Summary of Themes and Categories that emerged from the Open-ended Prompt “Please give specific examples of items where the tone of the question stood out to you.”

Themes	#	Definition	Example Quote
<b>Feedback (54.348%) <i>When participants made comments about the scale, what they felt was a strength of the scale, and what they felt could be improved about the scale</i></b>			
All Questions	10	<i>When participants make a remark about all of the questions, usually in a positive sense</i>	<i>I think all the questions were awesome.</i>
Demographics	4	<i>When participants make a comment that pertains to the part of the survey that comes before the measure we are developing.</i>	<i>What kinds of Meds &amp; supplements do you take?</i>
Example	4	<i>When participants refer to a specific item from the measure that were eliminated after inspecting response frequencies</i>	<i>The question regarding how one is or is not heard in by the medical professional.</i>
Example 1, 2, 3, 4, 5, 6, 8, 10,11, 13, 16, 17, 18, 24	23	<i>When participants give specific examples of items from the measure that were not eliminated after inspecting response frequencies</i>	<i>Nothing jumps to mind at the moment. Possibly the one about the degree of aggression.</i>
Good	3	<i>A generally positive comment about the scale that does not fit within other themes of positive connotation. Also when participants say that the survey was “okay” or “fine” because although these terms are slightly less strong than calling the survey “good”, they are still on the positive side of neutral</i>	<i>...Positive</i>
RA Positive	3	<i>When the participant makes a positive comment about the research assistant who administered the survey</i>	<i>You were very helpful and you are not pushy and I understand why this person is asking these questions for their research. When I had a question or comment you would listen and you were helpful and relaxed</i>
Relevant	1	<i>When participants state that a question is relatable, timely, relevant, is the topic of conversation within the blind community, etc...</i>	<i>I thought most of the questions were relevant</i>
Word Usage	2	<i>When participants make a comment about the wording of items, positive or negative.</i>	<i>worded well</i>
<b>Remark (39.130%) <i>When participants made a comment directly about or inspired by the content of the scale and how it relates to them, and share examples from their experiences</i></b>			
Comment	3	<i>When participant makes a remark about something that isn’t a specific experience that anyone had related to the scale, could be an opinion or perspective about how the world works in general or how healthcare works in general</i>	<i>Not sure how to answer this other than to say than it is a fact that ignorance in our world exists and it is each of our jobs to educate the public as well as to expect progress to be made.</i>
No Comment	22	<i>When participants indicate that they have no feedback or any contribution such as comments, observations, examples, etc...</i>	<i>I can't think of anything</i>
Observation	3	<i>A general comment about how participants think the scale is set up or organized, or what participants think that the scale is measuring without referring to any specific item and without drawing a personal</i>	<i>It was a survey that were looking for how individuals are being treated. ...</i>

		<i>connection with the measure information from the participant's response to determine where else to sort their response. Remark about how the participant relates to a specific item from the measure that was eliminated after inspecting response frequencies.</i>	
Relates to Example	1	<i>They may mention that the example resonates with them or not and may elaborate on how or why. They may even relate the example to experiences in their own life by using similar wording to the example. Remark about how the participant relates to a specific example. They may mention that the example resonates with them or not and may elaborate on how or why. They may even relate the example to experiences in their own life by using similar wording to the example. Remark about how the participant relates to the measure or any item from the measure. They may mention that the item resonates with them or not and may elaborate on how or why or give an example from their life that is related to an item from the survey by using similar wording to an item from the survey.</i>	<i>The question about training providers felt hopeful to me.</i>
Relates to Example 1, 3, 5, 7, 11	5		<i>Do people touch you without warning stood out to me because unless the blind person communicates to the doctor, the doctor will just come at them with their routine. It is up to the blind person to communicate</i>
Relates to Measure	2		<i>Questions relating to the actions of professionals, that is my biggest issue, that and the lack of disability awareness or education</i>
<b>Tone (6.522%) When participants comment on tone of the survey and what impression they got from it</b>			
Neutral Tone	4	<i>The participants not that the tone of the survey is neither positive nor negative</i>	<i>No significant difference in the tone of the questions.</i>
Not Unusual	2	<i>The survey is a typical survey and doesn't violate participants' expectations of what they were getting themselves into by participating in this survey</i>	<i>I think the questions were fine. They sounded like regular questions that might be asked in a medical survey and a behavior survey of those that provide services.</i>

Note. # = the number of responses coded within a given theme. Total coded responses = 92, Raw percent agreement = 70.968%, lenient percent agreement = 78.495%.

Question 6. Summary of Themes and Categories that emerged from the Open-ended Prompt “Do you get the feeling that the people who wrote these questions have an accurate idea of the experience of blind and low vision patients? Please explain why or why not.”

Themes	#	Definition	Example Quote
<b>Accurate Representation (64.390%) <i>When participants express to what degree they believe that the author of the measure understands the experiences of blind patients interacting with their healthcare providers</i></b>			
Blindness Spectrum	3	<i>The participants reply that they think the author of the items understand the experiences of certain people on a particular spot on the blindness spectrum better than they understood the experiences of other blind people on different places of the blindness spectrum</i>	<i>More for totally blind than those low vision</i>
No	7	<i>When participants indicate that they think the author of the items does not have an accurate idea of the experiences of blind people in the healthcare setting</i>	<i>I did not get the idea that the researchers have a full idea of challenges faced by persons who have vision impairments in navigating the healthcare systems. ...</i>
Not Sure	3	<i>Participants are not sure whether the author of the items has an accurate idea of the experiences of blind patients</i>	<i>m not sure. ...</i>
On the Right Track	4	<i>When participants respond that they do not believe the author has an accurate idea of the experience of blind adults, but that they are on the right track to gaining these insights</i>	<i>Hard to tell, I can't really perceive if they are doing a survey or thinking about the population they are addressing. I don't think they have a lot of experience with blind people. The intent is good</i>
Somewhat Valid	14	<i>Participants state that they believe that the authors of the scale items have a fair idea of the nature of the experiences of blind patients</i>	<i>A little. ...</i>
Yes	80	<i>Participants indicate that they think the author of the items has an accurate idea of the experiences of blind people in the healthcare setting</i>	<i>Absolutely, oh yes they do.</i>
Yes Relatable	21	<i>When participants say that they do think that the author of the questions had an accurate idea of the experiences of blind patients and go on to state that they themselves have experienced situations similar to what the measure gets at or know of others who have had such experiences.</i>	<i>I think so; I have friends who've had some of the problems asked about.</i>
<b>Feedback (18.049%) <i>When participants made comments about the scale, what they felt was a strength of the scale, and what they felt could be improved about the scale</i></b>			
Accessibility Comment	2	<i>When participants remark on the accessibility or inaccessibility of the survey</i>	<i>...The online form should have been coded for automatic form text-box fill-in with JAWS.... ...but I think a question asking participants to say what they appreciate about their health care providers would have been nice. Perhaps it could have been paired with a question asking specifically what they don't like about the health care providers they deal with.</i>
Content suggestion	10	<i>When participants make suggestions for topics that they think the scale should cover</i>	

Example	5	<i>When participants refer to a specific item from the measure that were eliminated after inspecting response frequencies</i>	<i>...as they asked about guide dogs,...</i>
Example 1, 5, 12, 14,15, 16, 17, 22	13	<i>When participants give specific examples of items from the measure that were not eliminated after inspecting response frequencies</i> <i>A generally positive comment about the scale that does not fit within other themes of positive connotation. Also when participants say that the survey was “okay” or “fine” because although these terms are slightly less strong than calling the survey “good”, they are still on the positive side of neutral</i>	<i>...There is mention of intimidation, ...</i>  <i>...I mean that there was sensitivity to both patients and healthcare provider</i>
Good	2	<i>When a participant makes a remark such that they are showing their appreciation for the study or praising the efforts of the research team</i>	<i>...Thank you for doing this. I hope this is the beginning of a much needed eye-opening to the healthcare providers of our country.</i>
Praise/appreciation	3	<i>When participant makes a recommendation about response options or additional space to include reactions to items</i>	<i>...Some of the questions are not applicable so the choices could had been there more &amp; I never go into an office with a sighted person so I could had used that choice there.</i>
Scaling Suggestion	1	<i>When participants comment on other aspects of the survey besides the content in general and scaling of the measure items. For example, if they comment on survey flow, text size/font/etc...</i>	<i>...The survey questions should have responded with another set of sub questions.</i>
Survey Attributes	1	<b>Remark (17.561%) <i>When participants made a comment directly about or inspired by the content of the scale and how it relates to them, and share examples from their experiences</i></b>	
Comment	13	<i>When participant makes a remark about something that isn't a specific experience that anyone had related to the scale, could be an opinion or perspective about how the world works in general or how healthcare works in general</i>	<i>...Are we perceived as good &amp; accurate reporters? Do we ask relevant questions? This seems to depend more on our cognitive and linguistic skills than our vision. Everyone with or without a disability needs to be proactive regarding medical care. I have found that asking questions about my care in a direct and friendly manner is very helpful and gets desired results. ...although my blindness does not dictate my interactions with docs; in the hospital I had to be overly assertive, as they did not know the concept of carb-counting and, worse, said they could not customize the treatment of my diabetes because they had some many diabetic patients to treat?!? The "hospitalists" were generally clueless, did not listen to me as a well-controlled diabetic and treated me as insignificant and irrelevant. However my docs on the outside treat me with dignity and respect because they see how well I manage my diabetes, even with no</i>
Diabetes Management	1	<i>When participants remark on their experiences regarding their diabetes and disease management efforts and techniques</i>	

			<i>vision. So, my experience crosses the spectrum from excellent to horrific!</i>
Observation	5	<i>A general comment about how participants think the scale is set up or organized, or what participants think that the scale is measuring without referring to any specific item and without drawing a personal connection with the measure information from the participant's response to determine where else to sort their response.</i>	<i>...but possibly a bit negative to health care providers.</i>
Other	2	<i>When participant does not give enough information for the coder to sort the response into any existing theme</i>	<i>...because of the perception of an inferior status directed toward the disabled patient</i>
Relates to Example 1, 5, 8, 13, 14, 16, 22	9	<i>Remark about how the participant relates to a specific example. They may mention that the example resonates with them or not and may elaborate on how or why. They may even relate the example to experiences in their own life by using similar wording to the example.</i>	<i>...but I feel it really depends on the personality of the individual as to how the doctors are going to treat them.</i>
Relates to Measure	6	<i>Remark about how the participant relates to the measure or any item from the measure. They may mention that the item resonates with them or not and may elaborate on how or why or give an example from their life that is related to an item from the survey by using similar wording to an item from the survey.</i>	<i>...Some things, i.e. help with appointments is more complicated. We may need help to get there, and/or help with forms, but not with talking with the techs and doctors.</i>

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Note. # = the number of responses coded within a given theme. Total coded responses = 205, Raw percent agreement = 65.700%, lenient percent agreement = 79.710%.



Question 7. Summary of Themes and Categories that emerged from the Open-ended Prompt “Please share your thoughts about the survey that you just completed.”

Theme	#	Definition	Example Quote
<b>Feedback (21.951%)</b> <i>When participants made comments about the scale, what they felt was a strength of the scale, and what they felt could be improved about the scale</i>			
Accessibility Comment	6	<i>When participants remark on the accessibility or inaccessibility of the survey</i>	<i>There are people that are not that don't have screen readers i think its good to do it over phone accessible These questions about clarity and relevance etc should be mentioned in the beginning so we can prepare throughout the survey then at the end do them.</i>
Clearer Instructions	2	<i>When participants want more guidance as to how to answer questions</i>	<i>...One area I forgot mention is adding a question about how often providers use appropriate sighted guide techniques - still so many that try to grab my arm - this is so easy to fix in basic training!</i>
Content Suggestion	7	<i>When participants make suggestions for topics that they think the scale should cover</i>	<i>I was surprised by the request for my Meds list.</i>
Demographics	4	<i>When participants make a comment that pertains to the part of the survey that comes before the measure we are developing.</i>	<i>...I will reiterate that there are many levels of health care professionals so it is difficult to generalize across the lines. For example, a physical therapist I had was very understandind and sensitive and so is my internist who knows me but someone that is filling out forms and talking to the sighted person who comes with you might be in a different category.</i>
Differentiate Between HCPs	4	<i>Have separate set of items or otherwise indicate which kind of HCP an item refers to OR some comment about how participants would rate items differently depending on which kind of HCP the item was referring to (e.g., staff, medical support staff, primary care provider, nurse, doctor, technician, therapist)</i>	<i>...I really do feel as if that question needs to be restated, about how family should interact with us if they accompany us to a medical appointment. I think maybe that question needs to be reworded or addressed differently.</i>
Example	1	<i>When participants refer to a specific items from the measure that were eliminated after inspecting response frequencies</i>	<i>The question about the touching without knowing maybe rephrase it to say say inappropriately like cuz doctors have to touch but without warning. ...</i>
Example 5	1	<i>When participants give specific examples of items from the measure that were not eliminated after inspecting response frequencies</i>	<i>As previously stated, for some reason, I expected more questions about the insurance side of healthcare....</i>
Insurance	1	<i>When participants make a comment about including information about the participants' insurance in the survey</i>	<i>...wish there were places to give specific anecdotes though.</i>
Provide Open-ended Prompts	8	<i>When participants indicate that they want more opportunities to share their experiences in a freer form than multiple choice questions</i>	
Survey Attributes	2	<i>When participants comment on other aspects of the survey besides the content in general and scaling of the measure items. For example, if they comment on survey flow, text size/font/etc...</i>	<i>It seemed too long.</i>
<b>General Sense (39.534%)</b> <i>When participants give feedback about their overall impression or experience of the measure</i>			

Comprehensive	6	<i>The items in the measure cover a satisfactory breadth of topics</i>	<i>I thought it was very thorough ...</i>
Concise	1	<i>Questions are long enough to convey the intended message</i>	<i>I thought it was a good length.</i>
Dissatisfied	2	<i>When participants express complaints and/or annoyances with more than one aspects of the survey taking experience</i>	<i>It wasn't accurate and thorough surveyed. I have never had to give so much feedback and a survey that I have completed for a study!</i>
Good	29	<i>A generally positive comment about the scale that does not fit within other themes of positive connotation. Also when participants say that the survey was "okay" or "fine" because although these terms are slightly less strong than calling the survey "good", they are still on the positive side of neutral</i>	<i>Good.</i>
Praise/appreciation	16	<i>When a participant makes a remark such that they are showing their appreciation for the study or praising the efforts of the research team</i>	<i>I think it's an interesting survey. I appreciate the opportunity to participate in it. ...Thank you and best of luck with this project and with your graduate studies at UTEP. ...</i>
RA Positive	2	<i>When the participant makes a positive comment about the research assistant who administered the survey</i>	<i>The person that read the questions to me was patient and kind. We were not hurried and I tried to make it as accurate as I could.</i>
Relevant	4	<i>When participants state that a question is relatable, timely, relevant, is the topic of conversation within the blind community, etc...</i>	<i>I think the survey is relevant ...</i>
Somewhat Valid	1	<i>Participants state that they believe that the authors of the scale items have a fair idea of the nature of the experiences of blind patients</i>	<i>...I think that it was written by professionals who deal with visually impaired....</i>
Thought Provoking	4	<i>When participants explicitly state that the scale item caused them to think/reflect</i>	<i>I thought the survey was very thought provoking ...</i>
<b>Remark (38.415%) <i>When participants made a comment directly about or inspired by the content of the scale and how it relates to them, and share examples from their experiences</i></b>			
Comment	13	<i>When participant makes a remark about something that isn't a specific experience that anyone had related to the scale, could be an opinion or perspective about how the world works in general or how healthcare works in general</i>	<i>...In the past 5 years, it seems that more healthcare providers have knowledge about appropriate interaction and assistance techniques when working with blind patients, but there is much work to do especially in rural areas. ...</i>
Diabetes Management	1	<i>When participants remark on their experiences regarding their diabetes and disease management efforts and techniques</i>	<i>...As indicated, in-hospital docs were clueless and I had to really aggressively assert myself and the management of my diabetes.</i>
Interest/hope about Results	29	<i>When participants express an interest about the results from this study and/or future, related studies and/or express their hope for the implications of the research findings</i>	<i>...and I hope that my participation will help in the research</i>
No Comment	6	<i>When participants indicate that they have no feedback or any contribution such as comments, observations, examples, not sure of what to say</i>	<i>None. Just trying to help.</i>

Observation	1	<i>A general comment about how participants think the scale is set up or organized, or what participants think that the scale is measuring without referring to any specific item and without drawing a personal connection with the measure information from the participant's response to determine where else to sort their response.</i>	<i>...and I think it assess more than the patient's experience, but also the preconceived notions of the healthcare provider that they bring to when they interact with blind patients. ...</i>
Other	6	<i>When participant does not give enough information for the coder to sort the response into any existing theme Remark about how the participant relates to a specific item from the measure that was eliminated after inspecting response frequencies.</i>	<i>Dr explains/reads prescription, etc rathe</i>
Relates to Example	1	<i>They may mention that the example resonates with them or not and may elaborate on how or why. They may even relate the example to experiences in their own life by using similar wording to the example. Remark about how the participant relates to a specific example. They</i>	<i>...but I have good experiences with health care providers; a positive attitude as a blind person relaxes sighted people.</i>
Relates to Example 13, 21, 22	4	<i>may mention that the example resonates with them or not and may elaborate on how or why. They may even relate the example to experiences in their own life by using similar wording to the example. Remark about how the participant relates to the measure or any item</i>	<i>The limited/lack of eye contact I do not know how to answer.</i>
Relates to Measure	2	<i>from the measure. They may mention that the item resonates with them or not and may elaborate on how or why or give an example from their life that is related to an item from the survey by using similar wording to an item from the survey.</i>	<i>...I think it touched on the issues that a lot of us face at the doctor and the hospital.</i>

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Note. # = the number of responses coded within a given theme. Total coded responses = 164, Raw percent agreement = 70.909%, lenient percent agreement = 72.121%.

Question 8. Summary of Themes and Categories that emerged from the Open-ended Prompt “Are there any topics that you think should be mentioned that were not mentioned in the survey? Please specify in the space provided.”

Theme	#	Definition	Example Quote
<b>Accommodations and Accessibility (19.697%) <i>When participants make comments about adding items related to the assessment of accommodations and accessibility to the measure</i></b>			
Address Accessibility	7	When participants call researchers to assess how well healthcare providers consider accessibility and provide accommodations for the blind patient	...Look into what format would be beneficial, Where would an accommodation be helpful for scheduling, rescheduling, discharging forms, best outcome of this survey would be to see if they would be able to recommend what accommodations would be helpful directly from the blind people so that we can present it to the doctors. ...
Address Accessibility-Orientation and Mobility	4	When participants call researchers to assess how well healthcare providers consider accessibility and provide accommodations for the blind patient, when it pertains to healthcare providers or support staff orienting blind patients, giving directions, or providing sighted guide	When leading me from one place to another the assistance or the lack there of.
Address Accessibility-Transportation	3	When participants call researchers to assess how well healthcare providers consider accessibility and provide accommodations for the blind patient, particularly when it pertains to transportation for medical related travel	Transportation to inflexible suggested arrival times for some Doc's offices.
Address Accessibility-Written Materials	10	When participants call researchers to assess how well healthcare providers consider accessibility and provide accommodations for the blind patient, particularly when it pertains to written documents such as information sheets and prescriptions.	It might be helpful to know about accessibility of patient record systems. It is much easier when I am able to complete health information paperwork independently on-line. This keeps my information more private and eliminates the time it takes to complete a form in the office with someone reading it to me.
Define Reasonable Accommodations	2	Provide an operational definition of reasonable accommodations for those participants who may be unaware of what the term refers to	What reasonable accommodations are. I would have to say that it was a reasonable accommodation that they allowed me to dictate my answers on the health forms, but it still violated my privacy since they did in front of everyone in the waiting room.
<b>Content-related Comments (35.606%) <i>When participants make suggestions to add items addressing specific content topics to the measure</i></b>			
Content Suggestion	18	When participants make suggestions for topics that they think the scale should cover	More about privacy and confidentiality
Demographics	4	When participants make a comment that pertains to the part of the survey that comes before the measure we are developing.	for the question about technology aids please list screen readers. I use one of this e
Differentiate Between HCPs	7	Have separate set of items or otherwise indicate which kind of HCP an item refers to OR some comment about how participants would	... Experience with office staff. Experience with medical assistants. ...

		rate items differently depending on which kind of HCP the item was referring to (e.g., staff, medical support staff, primary care provider, nurse, doctor, technician, therapist)	
HCP Vocal Characteristics	4	When participants state that healthcare providers change their tone or speed of speech when addressing the participant, when the participant reports that they are being talked to “like a child”	...Did they talk to you like an adult. ...
Insurance	3	When participants make a comment about including information about the participants’ insurance in the survey	...insurance.
Intersectionality	6	When participants make suggestions for the research team to examine the role of combinations of identities such as age, gender, ethnicity with blindness and considering the effects these combinations will have on the way healthcare providers treat them.	...And gender especially to those from the LGBTQ community.
Privacy issues	1	When participants make suggestions regarding assessing how HCPs handle privacy and confidentiality of their medical information.	Privacy regarding for example blood test info being sent via mail in a manner that I cannot read, and I don't want my husband reading it. Send via e-mail. I want to put this consideration out there. Touch boundaries some people may have been abused. Good for patients to say that they have touch boundary issues. Patient should be able to say this and doctor should be open about this. Lots of equipment with no touch. I am equally bothered that palpation is a piece I would want doctors to do that. If they are reading from a digital screen and I can't.
Touch Issues	4	When participants make suggestions for assessing how healthcare providers use touch with the participant. They may use it too much, inappropriately such as without proper informed consent from patient, or not enough when the patient feels like they need it to understand what the HCP is describing to them	
<b>Feedback (17.424%) When participants made comments about the scale, what they felt was a strength of the scale, and what they felt could be improved about the scale</b>			
Comprehensive	8	The items in the measure cover a satisfactory breadth of topics	All topics I can think of were covered. ...
Provide Open-ended Prompts	3	When participants indicate that they want more opportunities to share their experiences in a freer form than multiple choice questions	...Maybe adding experiences for blind parents with health care professionals could follow this.
Suggestion for Improving Care	12	When participants make a suggestion, usually directed towards healthcare providers, about improving care for blind patients. When participants make suggestions that these findings be shared with healthcare providers or that trainings should be developed to develop skills in healthcare providers to more effectively engage with and work with blind patients.	...but maybe having workshops with healthcare providers.
<b>Remark (27.273%) When participants made a comment directly about or inspired by the content of the scale and how it relates to them, and share examples from their experiences</b>			
Comment	6	When participant makes a remark about something that isn't a specific experience that anyone had related to the scale, could be an opinion or perspective about how the world works in general or how healthcare works in general	sometimes healthcare providers forget that I have limited vision when I come back for a follow-up. ...

Interest/hope about Results	1	<i>When participants express an interest about the results from this study and/or future, related studies and/or express their hope for the implications of the research findings</i>	<i>curious as to see this given to anyone with a disability to see if they are facing similar disabilities. ...</i>
No Comment	27	<i>When participants indicate that they have no feedback or any contribution such as comments, observations, examples, not sure of what to say</i>	<i>No</i>
Other	1	<i>When participant does not give enough information for the coder to sort the response into any existing theme</i>	<i>Facial cues.</i>
Relates to Example 16	1	<i>Remark about how the participant relates to a specific example. They may mention that the example resonates with them or not and may elaborate on how or why. They may even relate the example to experiences in their own life by using similar wording to the example.</i>	<i>...I like the question about if they revealed private information during checkin or when filling out paperwork, because in more than one situation people did not provide a private place to fill out paperwork, and I had to complain to get them to change.<sup>8</sup></i>

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Note. # = the number of responses coded within a given theme. Total coded responses = 132, Raw percent agreement = 73.684%, lenient percent agreement = 74.436%.

## Appendix K

### Patient Satisfaction Questionnaire - 18

*On the following pages are some things people say about medical care. Please read each one carefully, keeping in mind the medical care you are receiving now. (If you have not received care recently, think about what you would expect if you needed care today.) We are interested in your feelings, good and bad, about the medical care you have received.*

#### **General Satisfaction**

- 11. The medical care I have been receiving is just about perfect.
- 49. I am dissatisfied with some things about the medical care I receive.

#### **Technical Quality**

- 15. When I go for medical care, they are careful to check everything when treating and examining me.
- 8. I think my doctor's office has everything needed to provide complete care.
- 12. Sometimes doctors make me wonder if their diagnosis is correct.
- 45. I have some doubts about the ability of the doctors who treat me.

#### **Interpersonal Aspects**

- 29. Doctors act too businesslike and impersonal toward me.
- 34. My doctors treat me in a very friendly and courteous manner.

#### **Communication**

- 6. Doctors are good about explaining the reason for medical tests.

#### **Financial Aspects**

- 14. I feel confident that I can get the medical care I need without being set back financially.
- 24. I have to pay for more of my medical care than I can afford.

#### **Time Spent With Doctor**

- 46. Doctors usually spend plenty of time with me.
- 35. Those who provide my medical care sometimes hurry too much when they treat me.

#### **Accessibility and Convenience**

- 28. Where I get medical care, people have to wait too long for emergency treatment.
- 48. I find it hard to get an appointment for medical care right away.
- 25. I have easy access to the medical specialists I need.
- 51. I am able to get medical care whenever I need it.

*Note.* Item number reflects order as presented in the Medical Outcomes Study baseline questionnaire. Scale and instructions from Marshall and Hays (1994). The highlighted items comprise the PSQ-18, the validated short form of the PSQ III (Marshall & Hays, 1994).

## **Appendix L**

### **Wake Forest Trust in Physicians Scale**

Rate items on a scale of 1 – Strongly Disagree to 5 – Strongly Agree

1. Your healthcare provider cares about your health just as much or more than you do.
2. Your healthcare provider will do whatever it takes to get you all the care you need.
3. RC Your healthcare provider's medical decisions are based on how much money he or she can make.
4. Your healthcare provider is the kind of person who would fight hard to get your health insurance to pay for your treatment.
5. RC Sometimes, you worry that your healthcare provider's medical decisions are wrong.
6. RC Sometimes, your healthcare provider cares more about what is convenient for him or her than about your medical needs.
7. RC If your healthcare provider asked you to be in a medical research study, you would worry that he or she cares more about the research than what is best for you.
8. No matter what health problem you might have, your healthcare provider will always be able to figure out exactly what is wrong.
9. RC Your healthcare provider's medical skills are not as good as they should be.
10. You think your healthcare provider can handle any medical situation in his or her field, even a very serious one.
11. RC Your healthcare provider does not always give you a chance to say everything you think he or she needs to know.
12. Your healthcare provider is extremely thorough and careful.
13. You completely trust your healthcare provider's decisions about what medical treatments are best for you.
14. Your healthcare provider will listen with care and concern to any problem you might have, even problems that are small and silly.
15. Your healthcare provider would never prescribe the wrong medicine for you.
16. Your healthcare provider is totally honest in telling you about all of the different treatment options available for your condition.
17. Your healthcare provider has better medical skills than most other healthcare providers in his or her field.
18. RC Your healthcare provider sometimes pretends to know things when he or she is really not sure.
19. Your healthcare provider only thinks about what is best for you.
20. RC Sometimes, your healthcare provider does not pay full attention to what you are trying to tell him or her.
21. RC You worry that your healthcare provider may share embarrassing information about you with people who have no business knowing it.
22. Your healthcare provider always uses his or her very best skill and effort on your behalf.
23. You have no worries about putting your life in your healthcare provider's hands.
24. Your healthcare provider would never mislead you about anything.



25. Your healthcare provider is the kind of person who would take care of you even if you could not afford to pay.
26. All in all, you have complete trust in your healthcare provider.

## **Appendix M**

### **Discrimination in the Medical setting Scale**

Rated on a scale from 1 – Never to 5 – Always.

1. You are treated with less courtesy than other people.
2. You are treated with less respect than other people.
3. You receive poorer service than others.
4. A doctor or nurse acts as if he or she thinks that you are not smart.
5. A doctor or nurse acts as if he or she is afraid of you.
6. A doctor or nurse acts as if he or she is better than you.
7. You feel like a doctor or nurse is not listening to what you are saying.

## **Appendix N**

### **Marlowe-Crowne Social Desirability Scale**

Answer true or false to the following items:

1. It is sometimes hard for me to go on with my work if I am not encouraged.
2. I sometimes feel resentful when I don't get my way.
3. On a few occasions, I have given up doing something because I thought too little of my ability.
4. There have been times when I felt like rebelling against people in authority even though I knew they were right.
5. No matter who I'm talking to, I'm always a good listener.
6. There have been occasions when I took advantage of someone.
7. I'm always willing to admit it when I make a mistake.
8. I sometimes try to get even rather than forgive and forget.
9. I am always courteous, even to people who are disagreeable.
10. I have never been irked when people expressed ideas very different from my own.
11. There have been times when I was quite jealous of the good fortune of others.
12. I am sometimes irritated by people who ask favors of me.
13. I have never deliberately said something that hurt someone's feelings.

## Curriculum Vitae

Nazanin Mina Heydarian earned her Bachelor of Arts degree in Psychology from The University of Texas at El Paso (UTEP) in 20010. She joined UTEP's Health Psychology doctoral program in 2012. In 2015, she received her Master of Arts degree in Clinical Psychology from UTEP. Dr. Heydarian was the recipient of National Federation of the Blind National and Texas state scholarships. Dr. Heydarian has presented her research at several meetings including the 2018 Society of Behavioral Medicine Conference and the 2018 National Federation of the Blind Texas State Convention. Her work has appeared in the proceedings of these conferences as well as *Behavior Research Methods* and *Association for Psychological Science Observer*. She is preparing a manuscript for *Health Psychology* based on the first study of her dissertation. While pursuing her degree, Dr. Heydarian worked as a Research Associate for the Department of Psychology and for the Research Evaluations and Assessment Services division of the Office of Research and Sponsored Projects. She also work as a Teaching Assistant and Assistant Instructor for various classes in the Department of Psychology, and taught Clinical Psychology to high school students of Duke University's Talent Identification Program. Dr. Heydarian's dissertation, "The Development and Validation of a Measure Assessing Blind Patients' Perceptions of the Stereotype Content of their Healthcare Providers," was supervised by Dr. Osvaldo Morera.