

## Introduction

- More than 3.4 million Americans forty years and older are legally blind or visually impaired (CDC, 2019).
- Incidence of visual impairment is projected to increase due to high prevalence of diabetes mellitus.
  - 1 in 3 people with diabetes mellitus develop diabetic retinopathy.
  - 4.2 million adults have diabetic retinopathy and 655,000 people have vision threatening retinopathy.
- Evidence shows that legally blind older adults (over 65) are more likely to have breathing problems, depression, diabetes, hearing impairment, heart problems, hypertension, joint symptoms, back pain, and stroke (Crews, Jones, & Kim, 2006).
- While the healthcare needs of the legally blind are large, they continue to encounter barriers throughout their health care experiences.
- Limited research has been conducted to address the healthcare needs and experiences of legally blind patients.

## Purpose

The purpose of this project is to describe the healthcare needs and experiences of legally blind adults in the Chicagoland area.

## Sample

- Study participants were 4 legally blind adults:
- 2 female; 2 male
  - Age range 48-56
  - Not born legally blind
  - Able to speak and understand English
  - Live in the Chicagoland area
  - Have had sufficient experience with the healthcare system

## Methods/Procedures

**Design:** Cross-sectional, qualitative design using in-depth interviews through a semi-structured question guide.

### Recruitment:

- Social networking within the blind community
- Chain sampling technique

### Data Collection

- Semi-structured open ended questions were used in the interviews

### Analysis

- Interviews were transcribed verbatim
- Coding was done after reading through the transcripts
- Repeating ideas were put into categories, themes, and subthemes



## Findings

### Loss of Self-Dignity

#### Lack of Privacy:

*"When I went in for a mammogram they would not give me a gown and that was the last straw. I do not know the thinking behind it. I do not get the same privacy as anybody else."*

#### Loss of Independence:

*"Quite often you are required to fill out paperwork when you come to any doctor's appointment. If it is a new situation I do not always want my husband to be the one to help me do all of that. Of course he knows it, but he does not need to come to all of my doctor's appointments. That is ridiculous."*

#### Underestimation of the Blind Population's Abilities:

*"The doctor had the expectation that because I was blind I was incapable of doing anything. You got here by yourself really? Oh my god what an inspiration. The expectation is low."*

### Safety and Quality Issues

#### Inadequate Technology:

- Inaccessible Health Information:
  - *"Their whole portal for accessing my healthcare information and managing my own healthcare is totally inaccessible to a blind person. It does not work with the screen reading software that I have at all."*
- Absence of Braille on Healthcare Technology:
  - *"I know I was in the hospital with my mother at one point and they had them put band-aids over the nurse call button so that if I pushed the soft part of the bandaid then I was pushing the nurse call button."*

#### Susceptible to Medication Errors:

- Access to Prescription Labels on Bottles:
  - *"So you can put a braille label on there but what I really want is an abbreviated version of the name of the pill like maybe the first three letters and I can figure it out from there."*
- Inaccuracy of Using Other Senses to Take Medication:
  - *"It was like I was taking 40 mg of a medication when I was only supposed to be taking 4 mg of. And I did it over the span of three or four days at a point I started to feel something was wrong."*
  - *"I will say that there was one very good nurse who taught me how to tactically feel the difference between one syringe and the other for insulin."*

### Disability Competency

#### Disability Education for New and Experienced Providers:

*"So incorporating it into the education and changing the mind set when students are going through education and exposing them to disability studies and disability awareness will have a bigger impact than making it an annual class for staff."*

#### Sighted Guide:

*"I think that when you have to go to the doctor's office and they have to call your name someone should come out and guide you in. Because if you are just sitting in a room full of people you have no idea and are banging people around."*

### Empowerment

#### Self-Advocacy:

*"And if you let that go like it is okay then people are just reinforced to think that it is okay. Self-advocacy stuff is so important."*

## Discussion

### Conclusion

- In this sample, themes that describe the healthcare needs and experiences of legally blind adults include loss of self-dignity, safety and quality issues, disability competency, and empowerment.
- Participants indicate that lack of privacy and independence in the healthcare setting lowers their sense of self-dignity.
- Providers underestimating their abilities factored into this loss of self-dignity as well.
- Quality of care issues arise from inadequate technology that impedes blind patients from accessing health information.
- Safety becomes a concern when blind patients cannot access prescription labels on bottles and are using other senses to differentiate between medications.
- Participants claim it is important that providers are educated on how to provide disability competent care.
- Participants feel empowerment and self-advocacy skills are necessary in order to receive high quality healthcare.

### Implications

- Medical and nursing schools should include disability workshops into their curriculum.
- Healthcare systems need to make their online portals accessible to blind patients who use screen reading software.
- Hospitals should examine the technology in their rooms to ensure it is accessible.
- Providers need to ensure that their patients know how to take their medications correctly and potentially teach blind patients different tactics to reduce medication errors.
- Continue to empower blind patients and actively listen to their concerns.

## Future Research

- Larger sample size
- Study newly blind individuals who do not have self-advocacy skills yet
- Utilize focus groups
- Examine medication errors and recommend ways to limit them

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