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The DeafBlind Epistemology Scale: Experience, Language, and Identity

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Abstract

The DeafBlind Episteme Scale was used to examine the perspectives of DeafBlind individuals regarding their identities, lived experiences, and language attitudes. Exploratory factor analysis was applied to analyze the data. Findings revealed that DeafBlind individuals rely on touch to access information through tactile languages. However, barriers to this access can result in communication breakdowns and negative experiences, limiting their ability to navigate audio-visual-centered societies. These challenges shape DeafBlind individuals' perceptions of their positionalities within society, which were identified as tactile modality, distantism, vidism, and acceptance.

Keywords

DeafBlind Identity, Tactile Communication, Language Attitudes, Everyday Experiences, Exploratory Factor Analysis

1. Introduction

Each of us lives in a cognitive ecology that shapes our knowledge (Hutchins, 2010). Cognitive ecology explores the interactive relationship between organism-environment interactions and its impact on cognitive phenomena. We may assume everyone with all five senses shares this ecology, but this assumption is incorrect. For example, some individuals do not notice that they are hearing until they interact with a Deaf or Hard of hearing person (DHH; Bauman & Murray, 2017). Others take vision for granted and are referred to as Sighted people regardless of their hearing status. Nevertheless, there is a group of individuals who are DeafBlind, with extremely different sensory world experiences.

The process of understanding these various cognitive ecologies (Hutchins, 2010) is heightening and many Deaf and disabled individuals now reject the disability

label (Cue et al., 2019); however, there is no comparable research that uses an emic perspective on DeafBlind epistemology and their lived experiences. Therefore, this project's research questions were used to explore a DeafBlind epistemology as each individual has their own cultural episteme, a concept that refers to the implicit rules that govern what is considered legitimate knowledge in a particular culture and time period (Hauser et al., 2010; Cue et al., 2019).

1.1. Etiology

Individuals who acquire a DeafBlind identity later in life (Arndt & Parker, 2016; Graves, 2022) will go through a new identity journey once they start to transition from their Deaf identity to a DeafBlind identity (Yunashko, 2015). During their transitions, they learn to adjust with constant changes in their senses and adopting new ways to navigate. As Yunashko (2015) mentioned, a new DeafBlind identity transition does not mean to detach from the Deaf identity but to discover a new part of oneself. Hence, DeafBlind individuals could have intersectional identities (Gordon, 2016), which means an individual can have more than one identity (Crenshaw, 2013). Thus, identifying what a DeafBlind epistemology entails is critical as this group of people is highly diverse and DeafBlind individuals are often rejected from the Deaf community (Morrison & Johnson, 2020; Wolsey, 2018; Wright, 2020).

During this transition process from a Deaf identity to a DeafBlind identity can have an impact on language preferences by transitioning from a visual to tactile way of communicating. Wimberly (2023) translated Glickman's Deaf Identity Scale to represent the DeafBlind population and incorporated language preferences as the transition goes on based on the research done by Morrison & Johnson (2020); "culturally sighted...culturally marginal...immersion identity...bicultural DeafBlind" (Wimberly, 2023). Glickman's identity scale can be fluid along with transition, without any static limitations (Morrison & Johnson, 2020), which means individuals can have a mixture of language preferences. The transition between Deaf and DeafBlind identities influences language preferences, particularly for individuals with Usher Syndrome (USH). Those who identify as culturally sighted may unconsciously prioritize visual communication due to dysconscious vidism and distantism (Clark, 2017; Danermark & Moller, 2008; Gertz, 2003; Glickman, 1993; Wimberly, 2023; Wright, 2020; Yunashko, 2015). Individuals in a culturally marginal phase may struggle with shifting from Deaf to DeafBlind identity while navigating deafnormativity, leading to fluctuating language choices. Those fully immersed in a DeafBlind identity often embrace tactile communication, viewing it as essential to their cultural and personal identity (Wimberly, 2023). This evolution highlights how language preferences are shaped by identity development and societal influences.

Deafblindness is caused by a variety of etiologies, as 50% of DeafBlind individuals have Usher syndrome, while the others become DeafBlind from glaucoma, optic nerve damage, trauma related to the eye, or birth defects (AADB, 2009).

These varied etiologies and their changes throughout the lifespan, point to the changes that occur during a DeafBlind person's life. DeafBlind people are likely to grapple with their identities as their sensorium changes through time. Huddy (2001) wrote, "the fixed subject of liberal humanistic thinking is an anachronism that should be replaced by a more flexible individual whose identity is fluid, contingent, and socially constructed" (p. 127). This view of a fluid identity applies to DeafBlind individuals across their lifespan as prior to their transition, they were part of either a DHH community and identified as a Deaf person or part of the hearing community and identified with hearing culture (Hersh, 2013; Miller, 2015; Wolsey, 2018).

DeafBlind individuals attend many kinds of educational institutions based on their individual etiology and family choice. Some attend mainstream schools while others enroll in Deaf residential schools. These placements tend to determine their first language (L1), as well as levels of hearing, such as those who experience a visual condition early with some hearing abilities in life tend to have English as an L1 while those who are Deaf and Hard of Hearing may have ASL as their L1 (Wolsey, 2018). These cognitive ecologies are influenced by educational placements (Hutchins, 2010) and shape identities until their sensorium changes. DeafBlind individuals are likely to experience a significant change in their sensorium during their adolescence years and encounter communication barriers with Deaf and/or blind people (Hersh, 2013; Wolsey, 2018). During this time, DeafBlind individuals must decide if they are comfortable relying on other Sighted people for visual information (Wright, 2017) using close vision or if they are ready to move to the tactile dimension using either Tactile ASL or Protactile Language.

1.2. Language Preferences

During this transition process from a Deaf identity to a DeafBlind identity can have an impact on language preferences by transitioning from a visual to tactile way of communicating. Wimberly (2023) translated Glickman's Deaf Identity Scale to represent the DeafBlind population and incorporated language preferences as the transition goes on based on the research done by Morrison & Johnson (2020); "culturally sighted... culturally marginal... immersion identity... bicultural DeafBlind" (Wimberly, 2023). Glickman's identity scale can be fluid along with transition, without any static limitations (Morrison & Johnson, 2020), which means individuals can have a mixture of language preferences. The transition between Deaf and DeafBlind identities influences language preferences, particularly for individuals with Usher Syndrome (USH). Those who identify as culturally sighted may unconsciously prioritize visual communication due to dysconscious vidism and distantism (Clark, 2007; Danermark & Moller, 2008; Gertz, 2003; Glickman, 1993; Wimberly, 2023; Wright, 2020; Yunashko, 2015). Individuals in a culturally marginal phase may struggle with shifting from Deaf to DeafBlind identity while navigating deafnormativity, leading to fluctuating language choices.

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This study focuses on participants who acquired American Sign Language as their first langauge (L1). With their changes in auditory and vision, some DeafBlind individuals find themselves needing to make decisions about changes in language access and use. Options include the use of American Sign Language (ASL), Tactile American Sign Language (TASL), and Protactile Language (PTL; Turner & Reynolds, 2010; Reynolds, 2015). However, some DeafBlind individuals mentioned that ASL is for Sighted people and here it is rebranded as Visual American Sign Language (VASL; Bauman & Murray, 2017; Edwards, 2014a; Edwards, 2014b; Edwards, 2015; Edwards, 2017; McAlpine, 2017; Quinto-Pozos, 2002; Wolsey, 2017; Wright, 2020). There are also other language preferences within the DeafBlind communities, which are elaborated more with some background information below.

Tactile reception of American Sign Language was the only available choice before PTL (Edwards, 2015) and is an effective method for some DeafBlind individuals (Quinto-Pozos, 2002). Some scholars claim that TASL (Bauman & Murray, 2017; Quinto-Pozos, 2002) is a modified communication mode of VASL that is based on air space (Checchetto et al., 2018; Petronio & Dively, 2006; Smith, 2002). TASL follows the structure of ASL but does not include grammatical facial markers, which are labelled non-manual markers [NMM] (Edwards, 2014a; Edwards, 2014b; Quinto-Pozos, 2002). Also, TASL is "accompanied by conventionalized tactile cues for visual signals, such as backchanneling one's responses and emphasizing whether something is a question, an affirmative, or a negative reaction" (Van Der Mark, 2023, p. 510) For instance, if a Sighted person wanted to explain cutting down a tree with an axe to a DeafBlind individual via TASL, they would be likely to produce signs in air space. While the latter touch their hands but it is likely to overlook NMMs nor may not understand whole thing (Quartz, 2016). Unless DeafBlind individuals have residual vision that will allow them to track some signs (Van Der Mark, 2023), TASL will not convey all of the necessary information. Therefore, using TASL is similar to lip reading skills (Edwards, 2014a, 2014b) as the grammar and lexicons are not clear to some DeafBlind individuals.

Moreover, TASL is ineffective for some DeafBlind individuals because there are many ASL signs that share overlapping phonemes related to handshapes, location, movement, orientation, and NMMs (Edwards, 2022; Quartz, 2016; Smith, 2002). VASL's deictic points are not completely distinct (Quinto-Pozos, 2002) because they are produced in air space without a tactile establishment (Checchetto et al., 2018; Smith, 2002). Some scholars called TASL a separate language from VASL that evolved to provide better access, but they also call for more research (Checchetto et al., 2018; Edwards, 2022; Van Der Mark, 2023).

Thus, some DeafBlind individuals frequently prefer more phonemes access to understand language, rejecting TASL (Edwards, 2014a, 2014b, 2022).

1.3. The Protactile Movement

In 2007, because TASL was unable to convey all linguistic content (Edwards, 2014a, 2014b) a new "socio-political movement known as the pro-tactile movement (that) has opened up new possibilities for direct communication between DeafBlind people" (Edwards, 2015: p. 2) emerged. It started with aj granda and Jelica Nuccio, along with the support from the Seattle DeafBlind community, and was based on touch (Edwards, 2014a, 2015, 2017; Granda & Nuccio, 2018). Communication through PTL may also allow DeafBlind individuals to be more social and to connect with other people (Arndt & Parker, 2016). PTL may be part of eliminating the stigma of being DeafBlind and its negative associations, leading to the development of the DeafBlind community that has its own identity (Edwards, 2018). However, it is imperative to note that some DeafBlind individuals are not fluent in PTL and prefer TASL as they are not comfortable with the focus on body contact (Willoughby et al., 2020).

PTL is currently being investigated as a new language that is diverged from VASL and TASL (Bradbury et al., 2019; Edwards, 2014a, 2014b; Fidrocki, 2018; Friedner & Kusters, 2020; McAlpine, 2017; Rocketship et al., 2022). Edwards and Brentari (2020) discuss the conventionalization of PTL phonology with the emergence of specific grammatical roles for four hands. Again, with cutting down a tree example, PTL users will describe the process on other people's hands and arms (Quartz, 2016) because it allows them to feel the movement within a contact space (Van Der Mark, 2023). PTL therefore is classified as an emerging sign language, following the typical trajectory of all emerging sign languages that occur when a community forms like signing villages or Deaf schools (e.g., Adamorobe Sign Language; Kusters, 2014; De Vos, 2012; Nicaraguan Sign Language; Senghas & Coppola, 2001; Zinacantec "Z" Signs; Haviland, 2013). Given that many are unaware that PTL is emerging as its own language. some DeafBlind individuals who use PTL must educate other individuals by explaining that they prefer to use PTL. Interestingly, for some this switch was easily accepted while others resisted, leading to the DeafBlind person needing to fight for their preferred language accommodation.

Struggles to gain full access from VASL or TASL may be one of the motivations for DeafBlind individuals' transition to a DeafBlind identity and the use of PTL (Edwards, 2017, 2018; Willoughby et al., 2020; Yunashko, 2015). Also, to have a support is a key for a new epistemic knowledge that shaped their beliefs of themselves (Ding et al., 2023). Episteme formulation is connected to identities, experiences, and language attitudes (Pizzolato et al., 2008, Edwards, 2022), but the transition process requires some time with adapting though bidirectional relationships between new epistemes and identities (Pizzolato et al., 2008).

1.4. Transition Experiences

Research has identified Deaf identity by using various measurement tools, such as the Deaf Identity Scale model (Glickman, 1993). However, there has been a struggle to define DeafBlind identity (Fischer & McWhiter, 2001; Glickman, 1993; Leigh et al., 1998). Wimberly (2023) attempted to align the Deaf Identity Scale to a possible DeafBlind Identity Scale depending on the person's journey. In the DeafBlind Identity Scale, there may be four categories proportional to Glickman's scale such as culturally sighted, culturally marginal, immersion identity, and biculturally DeafBlind (Wimberly, 2023). Noting the process of changes is important relying on the duration for each individual's transition varies (Turner & Reynolds, 2010 Yunashko, 2015). Transition in identity is a difficult journey for most DeafBlind individuals (Wright, 2017, 2021a). Given their early L1 and educational cognitive ecologies (Hutchins, 2010), DeafBlind individuals go through the process of giving up a comfortable identity to move to a DeafBlind identity. Each person accomplishes this change in their own time (Wright, 2017, 2021a). Accepting the change in their hearing and vision abilities (Morrison & Johnson, 2020) is the first step in transiting to a new identity that would acknowledge their current status and the need for a different way to access the environment (Maxwell-McCaw et al., 2000; Hersh, 2013; Chapman & Dammeyer, 2017).

This self-acceptance process leads some DeafBlind individuals to seek a support system from other DeafBlind individuals who expose them to resources, such as PTL (Granda & Nuccio, 2018). DeafBlind individuals who have a strong desire to obtain access to the environment, are likely to develop a DeafBlind identity via interactions (Maxwell-McCaw et al., 2000). Seemingly, the openness to use new identity labels as part of their identity journey develops as DeafBlind individuals seek a social space that accepts, accommodates, and provides for their needs. While looking for their space, DeafBlind individuals also become more comfortable as advocates for themselves (Granda & Nuccio, 2018; Wright, 2017, 2020; Van Der Mark, 2023).

During the development of a DeafBlind identity, rejections, denial, and exclusions from hearing and DHH Sighted communities are typical (Clark, 2017; Wright, 2020). These exclusions include audism which happens to DHH people and relates to phonocentrism and hearing society's insistence on spoken language (Cue, 2020; Humphries, 1975). Another example of audism is hearing people's unwillingness to use pencil and paper or texting with DHH signers. This behavior is even more problematic for DeafBlind people as it is difficult for them, as this writing typically is not visible enough for them to read. Some DeafBlind people prefer a black marker in these situations, as that writing is larger and more legible to them (Eckert & Rowley, 2013). The more accommodations a person needs, the more rejected they are by society (Emens, 2021). Predominately, there are other discrimination issues that are more specific to being DeafBlind, including vidism and distantism. These issues will be discussed below.

1.5. Vidism

As the vision level progresses, new complications for navigating within visually centered DHH communities become common for DeafBlind individuals because other Sighted people are not likely to provide visual information via the tactile dimension. "Vidism has historically been defined as a visual barrier to access" (Morrison & Johnson, 2020: p. 1). DHH Sighted people often converse without including DeafBlind individuals during get-togethers such as dinner; and still expect Deafblind individuals to accommodate to their sighted ways with VASL, which is defined as vidism (Yunashko, 2015). Some DeafBlind people have more access through touch than vision, however some DHH people value vision and expect DeafBlind people to be able to understand their signing through the air (Edwards, 2015; Yunashko, 2015). Yet, another example of vidism is when a person refuses to provide an image description or transcript on a video (Clark, 2017) as DeafBlind people prefer transcripts so that they can access the information at their own pace (Goodwin, 2020). Others argue that closed captions solve the problem, but frequently they go too fast for some DeafBlind individuals and cannot be slowed down or re-read (Nuccio, 2020). Vidism creates many communication breakdowns for DeafBlind people, leaving them feeling frustrated, misunderstood, and oppressed just because Sighted people want them to follow their visual ways (Yunashko, 2015).

In addition, there is another form of oppression for some DeafBlind individuals depending on their intersectionality, such as audvidism or vidaudism. Shariff (2014) defines audvidism as discrimination based on both senses, the ability to hear and see. Shariff (2014) explains that putting "aud" first focuses on Deaf first. The term "dysconcious vidaudism" also applies where DeafBlind individuals can internalize hearing and sighted beliefs about what is considered typical (Graves, 2022; Shariff, 2014). Dysconcious vidaudism can also apply to DeafBlind people internalizing the DHH community value of visual access (Shariff, 2014). DeafBlind individuals can also internalize vidism and deny their access needs by attempting to be sighted enough, therefore hiding communication breakdowns and missing important information, which can be termed as dysconcious vidism (Wimberly, 2023). Auditory oppression may not apply in dysconcious vidism because of the focus on the sense of sight and the acceptance of being Deaf and the knowledge of how to advocate for the Deaf part (Wimberly, 2023). Again, the type of oppression can depend on how the individual identifies in order within their intersectionality.

1.6. Distantism

Out of all kinds of oppression towards DeafBlind individuals, distantism seems to be the main issue for some DeafBlind individuals (Morrison & Johnson, 2020). Distantism is defined as "the privileging of the distance senses of hearing and vision" (Clark, 2017) as cited in Van Der Mark, 2023: p. 520). Clark (2017), who is a DeafBlind person, coined the term "distantism", which means fear of touch by

both hearing and DHH Sighed people (Van Der Mark, 2023). In addition, distantism is also associated with the phenomenon called "freezing" (Edwards, 2017). Whenever a DeafBlind individual touches a Sighted person during socialization, the likely response from a Sighted person is to pause or "freeze", which distorts the interpretation of the flow of information (Edwards, 2017). However, it is possible for some DeafBlind individuals to be a distantist (Van Der Mark, 2023) as it will require time for them to adjust to their new context. These experiences were the cornerstone for some DeafBlind individuals to start acquiring a new episteme of navigating in a society that is not designed for them (Edwards, 2022). The transition process is difficult because of the existing audiovisual society running on distantist norms. For example, the audiovisual society focuses on communication via sight and auditory, not touch which means closeness between persons.

These changes towards language attitudes, knowledge from experience, and identity development can lead to gaining autonomy (Clark, 2017). Avoiding distantism leaves DeafBlind individuals report feeling less frustrated as they then have a support system from their communities, their language usage may include a tactile communication system (Hersh, 2013). That occurs when DeafBlind individuals have their own space for their autonomy, language, culture, and norms to flourish (Van Der Mark, 2023).

1.7. DeafBlind Autonomy

Up to this point, DeafBlind communities have been described as diverse by including multimodal languages usage, including spoken, signed, and tactical languages, as well as the DeafBlind manual alphabets and Braille (Hersh, 2013; Van Der Mark, 2023). However, it was the access to the tactile modality that led to a DeafBlind individual becoming a member of the DeafBlind community with support from peers, which emboldens DeafBlind autonomy, and be a deliciated advocate for the community (Granda & Nuccio, 2018; Wright, 2017, Wright, 2020). Furthermore, DeafBlind identity, self-confidence, and independence are essential compounds of DeafBlind autonomy (Turner & Reynolds, 2010). Tactile modality is critical for some as it holds DeafBlind individuals together as a community and allows them to be autonomous with a sense of pride in being DeafBlind.

Based on our literature review and the research questions, the foundation of DeafBlind epistemology is hypothesized to be made up of themes of identity, experiences through audism, vidism, and distantism, as well as the valuing of tactile modality in terms of a preferred language (Clark, 2017; Edwards, 2014a, 2014b, 2015, 2017, 2018, 2022; Granda & Nuccio, 2018). DeafBlind individuals have experienced oppression, self-discovery, and developed attitudes towards language in a variety of ways, leading to the formation and shifting of their epistemology. However, due to the vary of experiences, there may not be one epistemology, but multiple epistemes and this study may be the first step to finding out the aspects of the DeafBlind epistemes. The Venn diagram below shows the three categories, experience, identity, and language while the epistemes are in the middle since the

epistemes can be developed by the overlap of all three categories. Due to so many different backgrounds among the DeafBlind population, the environmental interaction causes a ripple effect to the shifting of epistemes. As their experiences define the context (Cue et al., 2019) within which DeafBlind communities differ from other communities. This hypnotization led us to develop an ideal DeafBlind Epistemology Scale as shown below.

DeafBlind Epistemology Scale

The constructs were reviewed by DeafBlind members of this research team and the next step was to revise to reflect their experiences as a DeafBlind person. Once the review was completed, statistical validation was conducted to ensure the number of latent variables of subscales were included. In addition, models were evaluated to see if there were differences among DeafBlind, Deaf-Blind, Deaf with Usher syndrome, and Deaf people with visual conditions (See **Table 1**).

Table 1. Literature review organization and scale development support.

Constructs	Items	References
Identity	DeafBlind is a terrible disability	Morrison & Johnson (2020)
	The DeafBlind community has both a Cultural Identity and its own language	Edwards (2014, 2018)
	When I am with Deaf and hearing sighed people, I remember my pride as a DeafBlind person	Edwards (2014, 2018)
	PTL is an important part of my identity	Morrison & Johnson (2020)
Isms	Deaf and hearing sighted individuals do not like to touch other hands	Clark (2017), Edwards (2014b)
	which is called Distantism	
	Deaf and hearing sighted individuals practice Vidism	Yunashko (2015)
	Neither Deaf nor hearing individuals accept me	Wright (2020)
	Some Deaf and hearing sighted individuals genuinely support PT culture and DeafBlind ways	Hersch (2013), Wright (2020)
	It is possible for a DeafBlind person to prefer signing ASL and still proud to be DeafBlind	Yunashko (2015)
Language Attitude	PTL is a separate language from ASL	Edwards (2022)
	PTL is different from Tactile ASL	Granda & Nuccio (2018)
	I can switch between ASL, English, and PTL for efficient communication	Edwards (2017, 2018)
	DeafBlind awareness and PTL training for professionals is necessary	Wolsey (2017)
	ASL, PTL, and English are different languages of equal value	Willoughby et al. (2020)

2. Method

2.1. Hypothesis

The DeafBlind Scale development was based on three research questions. The research questions are: 1) Are members of the ProTactile community likely to identify themselves as DeafBlind over other labels such as Deafblind, Deaf-blind, and

deaf-blind? 2) Do most DeafBlind individuals prefer ProTacticle language over other languages? 3) What kind of everyday experiences will DeafBlind likely encounter with other communities? The hypothesis consists of three categories, Identities, Language Attitude, and Everyday Experiences. The DeafBlind Epistemology Scale's 14 items are created to represent a DeafBlind episteme or more (see Figure 1).

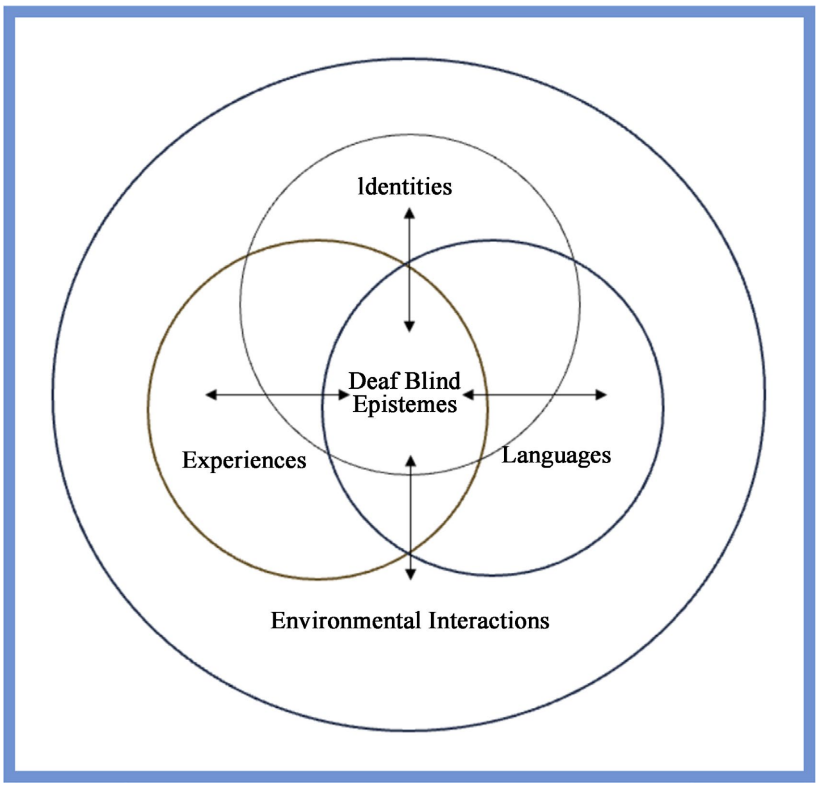

Figure 1. Venn diagram—DeafBlind Epistemes.

2.2. Research Design

A quantitative method was selected with survey design with the goal of investigating DeafBlind individuals' beliefs and attitudes towards PTL, TASL, ASL, and English. Additionally, the survey included sections on beliefs about DeafBlind identity and everyday experiences. The development of the survey was based on the ideas discussed above and used to investigate a potential DeafBlind epistemology. The authors created the questionnaire first based on the literature review and then reviewed it for accommodations to be a DeafBlind friendly survey.

2.3. Likert Scale

A Likert scale with five points was used for the convenience of DeafBlind people (Boone & Boone, 2012; Tavakol & Dennick, 2011). The scale was anchored with strongly agree (5), agree (4), neutral (3), disagree (2) and strongly disagree (1). The survey included 9 demographic questions that asked for age, gender, identity,

ethnicity, education, marital status, income, language use, and employment. In addition, there were three sections of five items each, for a total of 15 items related to Identity, the ISMs, and Language Attitudes. The survey questions were developed using Qualtrics software, Version 2022.

The first category focused on the statements related to Identity and there were five subscale items in this category. This category focused on if the DeafBlind community has both cultural identity and its own language, how that participant feels pride as DeafBlind person when around Deaf and hearing sighed people, and their view on PTL's role in identity. The second category focused on oppressions which were labeled as -Isms; Distantism, Vidism, acceptance by Deaf and hearing individuals, support from Deaf and hearing Sighted individuals related to PT culture and DeafBlind ways, and view on ASL and being proud as DeafBlind persons. Individuals who were impacted by the Isms had various experiences which led to being a part of common life experiences.

2.4. Procedures

As discussed earlier about the construction of proposed DeafBlind Epistemology Scale (Table 1), the DeafBlind research members reviewed and made suggestions, and the next step was to obtain an approval from the Institutional Review Board with Lamar University (IRBFY21-114). Once the IRB approval was obtained, the research team started to recruit participants through a QR code and an anonymous link to allow it to be shared. Criteria for inclusion were that participants must be eighteen years or older and DeafBlind. Before taking the survey, they had the opportunity to review the informed consent form through Qualtrics and if they agreed, they clicked on yes and the survey began. If any time during this research study, a participant stopped participating, their data was removed and deleted from Qualtrics.

2.5. Participants

A total of 102 participants took the survey, and opening with the first category which is identity; the highest number of participants identified as DeafBlind at 70% out of the group (n = 71) followed by Deaf with Usher Syndrome at 13% (n = 13) followed by Deaf-Blind (n = 9). The next group of participants identified as Deaf with Visual Condition (n = 6) followed by Other (n = 3). Moving into the next category of demographics; the largest number of participants selected White at 72% (n = 73) followed by these participants who preferred not to say (n = 8) followed by participants who identified as Black or African American at 7% (n = 7). The next smaller group of participants who had more than two ethnicities (n = 6) followed by Asian Americans (n = 4) followed by American Indian or Alaska Native (n = 3) closing with the smallest number of participants who identified as Native Hawaiian or Pacific Islander (n = 1).

The third category was gender, and female participants were the highest group at 64% of participants (n = 65) followed by participants who were male at 26% (n

= 26). Next group of participants who identified as non-binary (n = 5) followed by participants who were cross gender (n = 4). The last group of participants preferred not to say (n = 2). The next category was language usage, and the response that was frequently selected is ASL at 16% (n = 16) followed by participants who prefer to use multimodalities at 15% (n = 15). The next largest group of participants were these who selected ASL and English (n = 11) followed by participants who only used ProTactile (n = 8). The next smaller group is divided into two categories; these who use ASL and Tactile ASL (n = 7) and ASL, Tactile ASL and English (n = 7) followed by participants who used TASL and English (n = 5). The next group of participants used ASL, TASL and PT as their languages (n = 4) followed by the last group of participants with two categories that is split evenly; participants who used TASL and ProTactile (n = 2) and these who selected Other (n = 2).

The fifth category of characteristics was age and the highest number of participants who were between 36 and 45 years old at 36% (n = 36) followed by 46-55 years old at 27% (n = 27). The next group was participants who were between 18 and 35 years old (n = 19) followed by these whose age was between 56 to 65 years old (n = 13). The next smaller group of participants who were aged 66 and over (n = 5) followed by these who preferred not to share their age (n = 2). As for the highest level of education which is the sixth category, there were two groups of participants who achieved B.A. at 26% (n = 26) and these who earned M.A. (n = 26) followed by 28% of participants had some college experience however, no degree representing 23% of this group (n = 23). The next group representing participants who had a high school degree or equivalent e.g., GED (n = 14) followed by these who earned an associate degree (A.A. or A.S., n = 9). Next smaller group who earned less than a high school diploma (n = 3) followed by one participant who earned a doctorate degree (n = 1). Moving into the next category, which is marital status, the most common status that participants selected was single who never married at 45% (n = 46) followed by participants who were married or in a domestic relationship at 40% (n = 41) followed by these who was divorced (n = 10). The next group of participants who were separated (n = 3) followed by these whose were widowed (n = 2).

The employment status was the eighth category, and this was shown that participants who had a full-time job at 29% of participants (n = 29) being the largest group followed by participants who were unemployed and looking for work representing 13% of this group of participants (n = 13). The next group of participants were split evenly into three categories; participants who were employed part time (n = 10), unable to work (n = 10), and retired (n = 10). The next group of participants also were split into two groups; these who were students (n = 9) and self-employed (n = 9). The next smaller group of participants were these who were unemployed but not looking for a job (n = 7) followed by participants who were homemakers (n = 5). As for the ninth and last category which was income, the results showed the highest number of participants was these who made over

$50,000 and over at 34% (n = 34) followed by participants who earned less than $15,000 at 24% of this group of participants (n = 24). The next group of participants (n = 22) with the third largest number of responses was their income with $15,001 to 25,000 followed by two groups of participants who earned between $30,001 to $40,000 (n = 8) and these who earned between $40,0001 to $50,000 (n = 8) followed by participants who also were tied; these who earned between $25,001 and $30,000 (n = 3) and participants who prefer not to say (n = 3).

To sum up the characteristics of participants who took part of this study, they were single white women who was ASL user and educated with BA or MA degree. They also identified themselves as DeafBlind employed full-time earning over $50,000.

2.6. Data Treatment

Data was downloaded from Qualtrics into IBM SPSS v. 29. Analyses included Exploratory Factor Analysis (EFA), Cronbach Alpha, Item-Total Correlation were used to examine the data via 14 items. Principal Axis Factoring EFA analysis was chosen for EFA and the two different rotations, Varimax and Direct Oblimin, were utilized to see which one would produce a clear result (Fields, 2009). The team determined the correlation matrix with a Direct Oblimin rotation and was able to answer research questions. The team reviewed the Scree plot to determine the number of factors and decided to include all that had an eigenvector above 1.00, Items with Eigenvalues greater than.3, were selected on each eigenvector. The internal consistency of the scale was assessed using Cronbach's alpha. Alpha was set at.05 with a two tailed level of significance. The Item-Total correlation was checked for each item and items under.03 were removed. This approach helped to have a better internal consistency (see **Table 1**) before starting again with Exploratory Factor Analysis (EFA). The process was repetitive until the desired level of Kaiser-Meyer-Olkin (KMO) and Cronbach's Alpha were reached. Factors were given names, based on their factor loadings that related to the DeafBlind Epistemology Scale.

3. Results

Exploratory Factor Analysis

A Principal Axis Factor analysis was conducted on 9 items with Direct Oblimin rotation and the Kaiser-Meyer-Olkin (KMO), Measure of Sampling Adequacy, which yielded a value of 0.83, indicating a meritorious level of sampling adequacy (Fields, 2009). Bartlett's Test of Sphericity was significant, χ^2 (36) = 202.653, $p <$ 0.001, suggesting that the correlation matrix was suitable for factor analysis. The Matrix produced two distinct factors, the first factor, DeafBlind Episteme I with 9 items, (eigenvalue = 2.83, explaining 31.3% of the total variance) and the second factor, DeafBlind Episteme II with 6 items, (eigenvalue = 0.60, explaining 6.7% of the total variance).

The internal consistency of the scale was assessed using Cronbach's alpha. The

analysis yielded Cronbach's alpha of.79 for DeafBlind Episteme I (see Figure 2), indicating an acceptable level of reliability (α = 0.79, n = 9). While the second DeafBlind Episteme II (see Figure 3) had a slightly lower score but yielded an acceptable level of reliability (α = 0.76, n = 6). Thus, EFA results are sound and suggested DeafBlind communities does have more than one episteme and will be elaborated in discussion section.

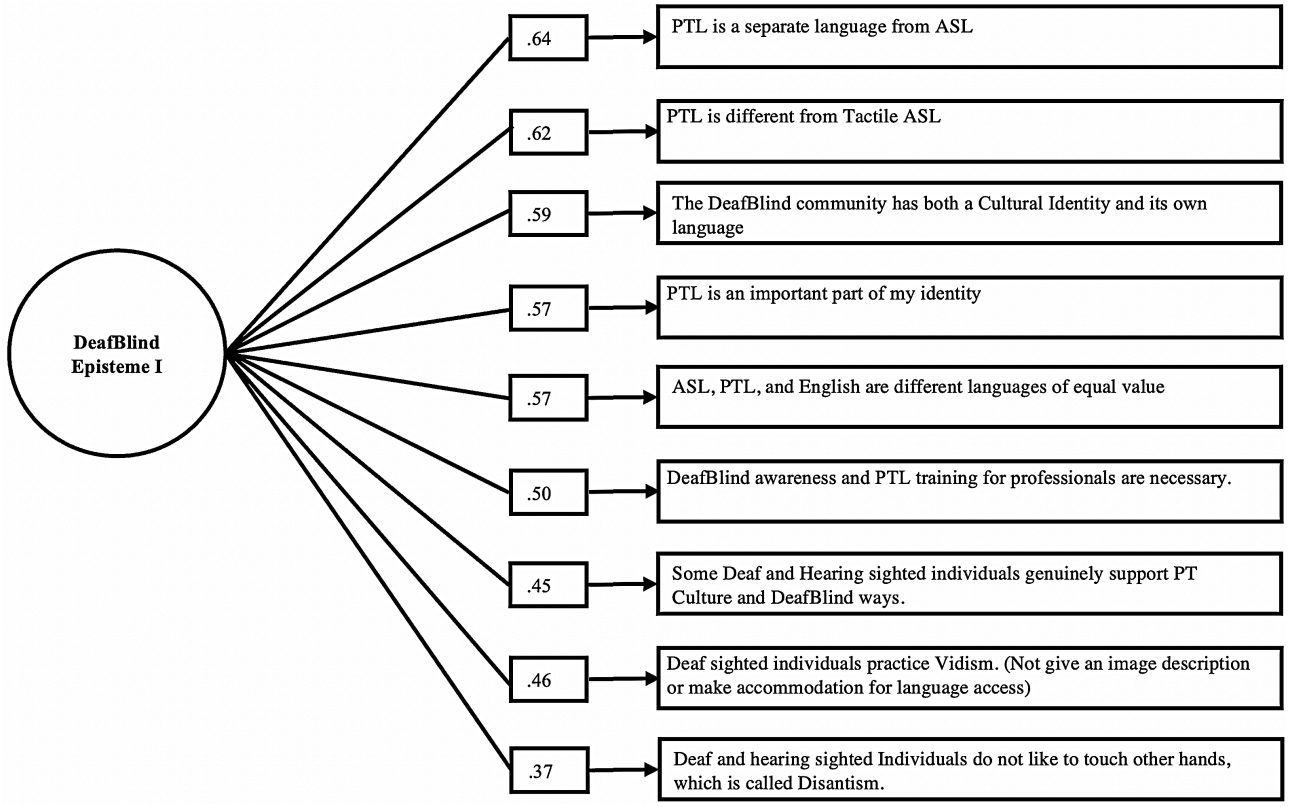

Figure 2. DeafBlind Episteme I.

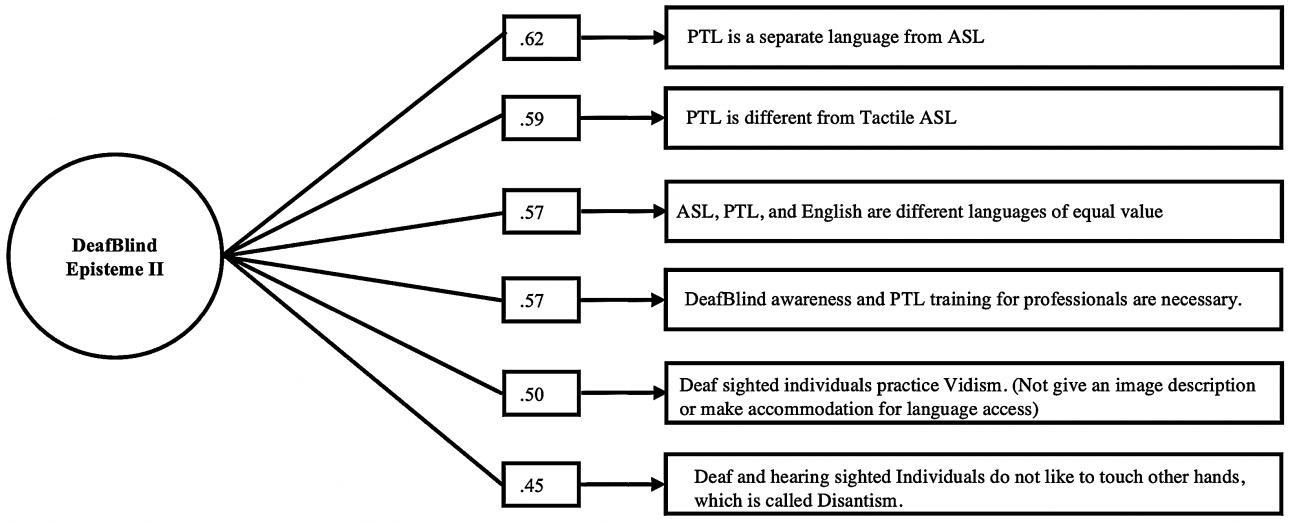

Figure 3. DeafBlind Episteme II.

4. Discussion

This study sought to explore the foundational elements of DeafBlind epistemology and its implications for identity, language attitude, and lived experiences. While DeafBlind epistemology is still emerging as a framework, this study highlights how environment, education, interactions, language usage, and perspectives shape the epistemological choices and identity development of DeafBlind individuals as shown on **Figure 1**. The findings provide critical insights into the complexities of DeafBlind identity, language preferences, and the societal barriers encountered by this community. The results of this factor analysis provided insight into the language attitudes, identity, and experiences of DeafBlind individuals regarding PTL and related communication practices. The two-factor structure identified in the analysis suggests that there are distinct yet interconnected themes in the way PTL is perceived and experienced within the DeafBlind community and among sighted Deaf and hearing individuals. Hence, this study has helped us to identify two different kinds of epistemes, which have many different layers or experiences, leading them to have different perspectives on communication modalities and identity development.

4.1. DeafBlind Identity Development

The data revealed that DeafBlind identity is strong, with 71 out of 102 participants identifying as DeafBlind. This indicates an inclination towards the term "DeafBlind" as a preferred identity label, possibly due to its cultural resonance and the double capitalization emphasizing the sensorium change and embrocation. However, the remaining participants chose alternative labels, and some of those remaining participants do use PTL, reflecting that the name of identity is not an important factor. These findings suggest that identity development in the DeafBlind community occurs within a complex interplay of personal experiences, interactions, and environmental factors. Notably, acceptance of the DeafBlind identity is influenced by factors such as language attitudes and societal oppression, echoing similar identity struggles faced by DHH individuals not fully aligned with a capital D identity (Pudans-Smith et al., 2019).

The idea of the DeafBlind community having both a cultural identity and its own language was strongly agreed by DeafBlind Episteme I while DeafBlind Episteme II reflected to be neutral. However, for the high resonation of DeafBlind Episteme I with a DeafBlind community having both a cultural and linguistic identity, multimodality can still be applicable in this cultural dynamic (Morrison & Johnson, 2020). This idea of having its own identity and language may mean that the DeafBlind community consists of multiple languages including ASL, TASL, English, and PTL and according to the various identities like explained above, the DeafBlind community may consist of multiple faceted identities. According to the demographics of the participants, ASL is shown as the primary language while the second largest group of participants are shown to be multimodalities.

4.2. Language Attitudes and Access

Language attitudes play a pivotal role in shaping DeafBlind identity and community dynamics. The study revealed significant correlations between language preferences and identity. For example, 8 participants reported using PTL as their primary language, and many agreed that PTL is a critical component of DeafBlind identity. However, the preference for PTL varies, and some participants indicated that they continue to use VASL, English or TASL, which puts emphasis on the two factors from the factor analysis focusing on multimodalism. These findings suggest that language choice is influenced by a combination of personal preference, accessibility, and the need for advocacy within diverse environments.

Some individuals may be exposed to PTL and could learn, while others who may not have been exposed to PTL use other kinds of communication methods. Once again, in the Deaf community where ASL has been evidenced as a rich, beneficial language (Caselli et al., 2021), the study's DeafBlind participants have shown a preference for various communication methods, leading to the interpretation that the DeafBlind community consists of multimodality.

DeafBlind Episteme I encompasses attitudes that affirm PTL as a distinct and valuable language, separate from both ASL and Tactile ASL. The high factor loadings on statements such as "PTL is a separate language from ASL" and "PTL is different from Tactile ASL" reinforce the idea that PTL is not simply an adaptation of ASL but rather a unique linguistic system developed by and for DeafBlind individuals. "TASL is often considered inferior by not only co-researchers, it has emerged in newer traditional academic research, as well as grey literature that such a view is found to be legitimate experience by a majority of Deaf-Blind individuals" (Edwards, 2014a; Nuccio & Granada, 2013; Shariff, 2014 as cited in Wright, 2020, p. 12-13). However, PTL "emphasizes the communication through ASL that occurs through touch among members of the DeafBlind community without the aid of sighted people to facilitate message exchanges" (Nuccio, 2008 as cited in Shariff, 2014). Essentially, PTL employs TASL alongside backchanneling techniques to provide immediate, direct feedback (Berge & Raanes, 2013 as cited in Shariff, 2014). Additionally, the inclusion of items that highlight PTL's role in personal and cultural identity, such as "The DeafBlind community has both a cultural identity and its own language" are deeply intertwined in the belief that the DeafBlind community has its own language. As Edwards (2014a) described the principles of PTL, that PTL is "not just for communication, but for a "way of life" (p. 141).

Conversely, DeafBlind Episteme II does not agree with "PTL is a separate language from ASL", "PTL is different from Tactile ASL", and "ASL, PTL, and English are different languages of equal value". DeafBlind Episteme II might consider PTL as a branch of ASL (Hauschildt, 2022). Therefore, the common denominator in those items is PTL, which may be a language that is not widely used with DeafBlind Episteme II, which is emphasized by the item where there is neutrality, "PTL is an important part of my identity", compared to DeafBlind Episteme I. While

Episteme II do not perceive a difference between PTL and TASL, it may be due to having the same perception as several publications that they are still able to communicate through TASL with the possible addition of backchanneling (Berge & Raanes, 2013, Nuccio, 2008). In addition, the strong loading of "DeafBlind awareness and PTL training for professionals is necessary" with DeafBlind Episteme I compared to DeafBlind Episteme II feeling like it is not necessary underscores the bidirectional influences based on language preference and community's recognition of systemic barriers and the need for increased education and training to ensure effective communication access.

Interestingly, some statements related to the importance of PTL, such as "ASL, PTL, and English are different languages of equal value" and "DeafBlind awareness and PTL training for professionals is necessary," show negative correlations with DeafBlind Episteme II. The negative correlations suggest that individuals who do not use PTL and tactile communication are also less likely to see these languages as equal or to support training initiatives, also lack of access of training with PTL exists. There are many possible factors to why DeafBlind Episteme II do not share the same perspectives as Episteme I, including fear of touch, lack of access to PTL, and internalized oppression. As for fear of touch, some DeafBlind individuals may have experienced fear or trauma to the point where they may not be comfortable with the degree of touch that comes with PTL. "If you have never been where protactile people are and you have no plans of going there, then you have never been in contact space, and you never will be (Edwards, 2014a: p. 141). In order to be immersed in using contact space, you would have to use touch, which some people can have the "fear of physical contact through TASL" (Wright, 2020, p. 9). As for learning how to use PTL, training courses are not widely offered and are only limited to a number of trainers and a training center (Tactile Communications, n.d.). Tactile Communications announced that they were closing on May 3rd, 2024, and were looking into new ways to spread PTL (Tactile Communication, 2024). Protactile Language Interpreting (PLI) also provides training, but only to interpreters (Protactile Language Interpreting National Education Program, n.d). Essentially, for a DeafBlind individual to learn PTL, "they tend to ask DeafBlind folks who are familiar with PTL or ask around in the DeafBlind community" (Goodwin, personal communication, March 2025).

4.3. Everyday Experiences: Acceptance and Oppression

DeafBlind Episteme I represents a whole that would experience Vidism and Distantism including exclusion, discrimination, and lack of access related to PTL and DeafBlind communication. The positive factor loadings on statements such as "Deaf sighted individuals practice Vidism (not giving image descriptions or making accommodations for language access)" and "Deaf and hearing sighted individuals do not like to touch other hands, which is called Disantism" reflect significant barriers faced by DeafBlind individuals. Vidism, or the privilege of visual communication without considering tactile access (Clark, 2017) and Disantism,

or the aversion to touch, present substantial obstacles to PTL's full acceptance and implementation in mainstream Deaf and hearing communities. However, DeafBlind Episteme I feels that some Deaf and Hearing sighted individuals genuinely support PT Culture and DeafBlind ways DeafBlind Episteme II group shows more of an opposite approach towards oppression and feels like they do not experience oppression. One theory is that DeafBlind Episteme II may not feel as much oppression because they do not use PTL, which includes a higher level of touch. However, another theory can be that you are about meeting a standard of being DeafBlind enough if you know PTL is also a form of oppression which may lead to the oppressed being the oppressors instead of accepting differences (Freire, 2018). A level of linguistic and cultural gatekeeping could be occurring where Episteme I may be conducting upon Episteme II. "Language is communication; communication is language. Binning, or separating language and communication creates hierarchies of languaging wherein specific kinds of languaging is devalued because they are seen as communication rather than languaging" (Henner & Robinson, 2023: p. 8). On the other hand, DeafBlind people may be internalizing oppression and practicing dsyconscious vidism (Gertz, 2003; Wimberly, 2023), or internalized distantism (Van Der Mark, 2023) as there are some DeafBlind members who would try to pass as a Deaf individual (Hauschildt, 2022; Wright, 2020).

Internalized oppression can influence identity development, particularly during the transition from a Deaf to a DeafBlind identity, as individuals may fear losing their place within the community—a phenomenon known as deafnormativity (Wright, 2020). To develop one's identity, a person needs to find their "agency, self-definition, and self-advocacy" (O'Brien et al., 2015: p. 106). Some view DeafBlind individuals as lacking a unique culture due to "hybridization" and being classified as "half-breeds" within a small population which may be a phenomena DeafBlind Episteme II is experiencing (Spear, 1994; Wright, 2020 as cited in Wimberly, 2023). While the Deaf community has a cultural identity, the DeafBlind community is under scrutinization to be recognized as a cultural community because of the additional loss of sense (Spear, 1994) which could be one factor leading to internalized oppression. However, the shared experiences of oppression, even internalized oppression, among multimodal DeafBlind individuals can contribute to the formation of a distinct cultural identity through language and lived experiences (Smith, 2002). Oppressive forces rooted in the social hegemony between the Deaf and DeafBlind communities create additional layers of marginalization and cultural conflict. These systemic barriers and dominant societal norms may push individuals associated with DeafBlind Episteme II to the lowest levels of the social hierarchy (Goffman, 2009; Scambler, 2009; Wright, 2020 as cited in Wimberly, 2023). For example, one of the creators of PTL, Jelica Nucco "called the "tunnel-vision people," clung to their dwindling eyesight, continuing to use visual A.S.L" (Leland, 2022). DeafBlind individuals are still practicing sighted ways such as bringing their own interpreter to DeafBlind events and using their interpreter to communicate with other DeafBlind individuals while that

could be happening directly (Van Der Mark, 2023). DeafBlind Episteme II could also be going through acculturative stress (Aldalur et al., 2021) and trying to find their "House of Being" (Cue et al., 2019). Therefore, the range of potentials of why Episteme II reports to not experience oppression ranges from not knowing PTL to self-denial.

DeafBlind individuals navigate a unique set of challenges shaped by both acceptance and oppression in their everyday lives. The study found that interactions with DHH and hearing sighted individuals significantly influence these experiences. While some DHH and hearing sighted individuals genuinely support PT culture and DeafBlind ways, others perpetuate exclusion through phenomena such as distantism and vidism. Distantism, a fear or aversion to touch, and vidism, the prioritization of visual information over tactile communication, create barriers to inclusion and reinforce societal marginalization (Clark, 2017; Yunashko, 2015). However, we note that the results show those who use PTL experience more distantism and vidism than others who use different communication methods. The reason why is unknown but could lead to the various amounts of touching in between different communication methods.

The exclusionary practices rooted in distantism and vidism are particularly damaging because they contradict the core value of touch within DeafBlind epistemology. For instance, DHH sighted individuals' reluctance to accommodate tactile communication needs reflects a broader societal bias toward visuo-photocentric norms. This bias not only hinders DeafBlind individuals' ability to navigate their environments but also delays their transition to adopting tactile-centric communication methods, such as PTL or TASL, during periods of sensory loss. These findings underscore the critical need for increased awareness and accommodations that prioritize tactile access to foster a more inclusive society.

4.4. Implications for DeafBlind Epistemology

These findings reinforce the notion that the DeafBlind community is inherently multimodal utilizing PTL, Tactile ASL, ASL, and English in various settings. However, this multimodalism exists within a sociolinguistic landscape marked by both recognition and resistance. While PTL is viewed as integral to DeafBlind identity and culture, it is also met with opposition or neglect, particularly by sighted Deaf and hearing individuals who may be unfamiliar with or unwilling to accommodate tactile-based communication.

The factor structure also points to the need for systemic change, particularly in raising awareness and providing training on PTL within Deaf and hearing communities. The strong support for professional training suggests that many DeafBlind individuals recognize the importance of increasing knowledge and acceptance of PTL to bridge communication gaps and reduce linguistic and social isolation.

This transition, often necessitated by progressive vision condition, requires individuals to relearn communication methods and navigate environments through touch. However, societal biases against touch and the slow adoption of PTL as a

recognized language hinder this process. Participants reported frustrations with miscommunications and the time required to adapt to tactile communication, reflecting the broader societal undervaluing of tactile modalities (Bradbury et al., 2019). ASL is widely accessible, from high school ASL classes to community classes, while PTL is not.

This study aimed to show the DeafBlind epistemology including the need for touch-centric community (Watharow & Wayland, 2024), however, the study ended up showing that there is not one DeafBlind epistemology but several DeafBlind epistemes and there is no one way to be DeafBlind. DeafBlind Episteme I views PTL as a distinct language and essential to DeafBlind identity, recognizing systemic oppression like vidism and distantism while advocating for PTL training and awareness. In contrast, DeafBlind Episteme II does not strongly differentiate PTL from ASL or Tactile ASL, remains neutral on DeafBlind language identity, and is less likely to perceive oppression, potentially due to limited exposure to PTL or internalized distantism. The hope is that DeafBlind individuals "allow space to be open and let DeafBlind people go on that journey and discover their identities themselves" (Morrison & Johnson, 2020, p. 7). These perspectives highlight the diversity within the DeafBlind community, emphasizing that identity and language attitudes are shaped by personal experiences, societal influences, and access to communication modalities. "To socially recognize a person is to acknowledge that the person is a human being with needs and wishes" (Danermark & Moller, 2008, p. 121). If the acknowledgement of DeafBlind individuals as human beings who have the right to develop their identity including language preference and self-advocacy skills becomes common knowledge, then society and sub-societies would be taking action to promote inclusion. Predominately, with the mixture of our participants into two epistemes, we should acknowledge that "no way of languaging is bad" (Henner and Robinson, 2023). The varying epistemes come from the bidirectional influences within the ecosystem where environmental interactions can have an impact on language attitudes, lived experiences, and identity development.

5. Conclusion

This study provides a foundational understanding of DeafBlind epistemology, emphasizing language attitudes, lived experiences, and daily experiences. While progress has been made in recognizing the cultural and linguistic contributions of the DeafBlind community, significant barriers remain. Addressing these barriers requires a multifaceted approach that includes raising awareness about multimodalism, making tactile communication more accessible, fostering identity development, and respecting various lived experiences. These findings underscore the need for advocacy and educational practices that recognize and celebrate the diverse journeys of DeafBlind identity development. Everyone's path to achieving ontological security, a secure sense of self, should be respected, with educational programs tailored to allow personal discovery and growth.

Acknowledging that DeafBlind individuals are multimodal, advocacy efforts should promote awareness that there is no singular or "correct" way to be DeafBlind. Instead of imposing a rigid, one-size-fits-all approach, educational practices must offer multiple communication resources, ranging from ASL and Tactile ASL to Protactile Language and other tactile communication methods, allowing individuals to choose what aligns best with their unique experiences and preferences. Protactile Language also should become more widely available.

By eliminating linguistic and cultural gatekeeping, advocates and educators can create inclusive environments that empower DeafBlind individuals to explore their identities without the pressure to conform to a prescribed model. This flexibility not only supports personal agencies but also enriches the broader community by valuing diverse modes of communication and expression.

Despite the differences in the heterogeneous community of DeafBlind individuals, there is an overlapping point where we are all faced with similar pain points and experiences as shown in the Venn diagram in **Figure 1**. By advancing our understanding of DeafBlind epistemology, we can contribute to a more equitable and accessible world for DeafBlind individuals.

6. Limitations

This research targeted DeafBlind individuals who were Deaf first before experiencing a visual condition. Thus, for future research, the team needs to modify questions to include other DeafBlind individuals who were blind first before losing their hearing ability or gradually losing both hearing and vision abilities. This change will help to validate the data about DeafBlind identity as DeafBlind individuals have their own journey before arriving at the point of self-acceptance as a DeafBlind person.

Furthermore, Qualtrics may not be accessible to all DeafBlind individuals who are using a braille display to read the survey, leading to the deletion of twenty participants. In addition, this feature can support more participants who rely on the usage of a braille display that is connected to a smartphone via Bluetooth.

Another limitation was that 73 out of 102 participants were white and 64% of women were part of the sample which showed the lack of diversity. The study needs to include more diversity for a fuller picture of this identity process. Some questions need to be broken down for example "Some Deaf and hearing sighted individuals genuinely support PT culture and DeafBlind ways" could be broken down between PT culture and DeafBlind ways.

7. Future Research

Future research should explore whether these factors reflect distinct groups of individuals, such as those who fully support PTL as being an important part of the DeafBlind identity versus those who are more fluid about the DeafBlind identity. Whether they represent: they have varying degrees of exposure and acceptance within the broader DeafBlind and Deaf communities. Additionally, studies could

investigate how these attitudes evolve over time as more institutions and professionals incorporate PTL into their communication frameworks. Moreover, there seems to be a need for research into language modalities used by DeafBlind people that incorporate linguistic frameworks to explore in depth how DeafBlind is being exposed to PTL including age of transition. Also, studies can be conducted on internalized distantism and dysconscious vidism.

The DeafBlind Episteme Scale needs to be revised by adding more items from Glickman (1993)'s Deaf Identity Development Scale (DIDS) and Wimberly (2023)'s DeafBlind Community Cultural Wealth (DBCCW) into the survey. This approach will allow the DeafBlind Episteme Scale to have subscales with a better internal consistency. Also, some DeafBlind individuals with Usher's Syndrome, type 1 are likely to identify as a visually orientated Deaf person first before adopting another identity. We need to know what their thoughts on Deaf Sighed people with their tactile orientated ideologies are. As when their identity transition begins and their process "is interdependent on what we absorb from our settings, either causing an obstacle or encouraging our embodiment of the DeafBlind identity" (Baumeister, 1997; Morrison & Johnson, 2020 as cited in Wimberly, 2023: p. 66). This upgraded scale survey needs to capture DeafBlind individuals via intersectional perspectives from past, present and future identities, language attitude and preference, and everyday challenges.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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