UNIVERSITY OF OKLAHOMA

GRADUATE COLLEGE

HEALTHCARE PROVIDERS' MOTIVATIONS AND CHALLENGES WHEN COMMUNICATING ABOUT SEXUAL HEALTH WITH INDIVIDUALS WITH INTELLECTUAL DISABILITIES

A THESIS

SUBMITTED TO THE GRADUATE FACULTY

in partial fulfillment of the requirements for the

Degree of

MASTER OF ARTS

By

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Norman, Oklahoma
2023

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HEALTHCARE PROVIDERS' MOTIVATORS AND CONTEXTUAL FACOTRS WHEN COMMUNICATING ABOUT SEXUAL HEALTH WITH INDIVIDUALS WITH INTELLECTUAL DISABILITIES

A THESIS APPROVED FOR THE

DEPARTMENT OF COMMUNICATION

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Dedication

To my fiancé, Rose, for believing in me even when I didn't believe in myself.

Acknowledgments

I could not have accomplished so much in the last two years without the constant support and encouragement from the people I love, who are constantly rooting for my success.

To my advisor, Dr. Elaine Hsieh, I cannot thank you enough for everything you have done through my program. You believed in my potential and invested your time in me to help me grow to reach that potential. Thank you for providing me with an abundance of knowledge and wisdom that I will utilize for the rest of my life.

To my best friend, Nate, no matter how far away you were, you always had my back, and I could always count on you for a laugh. Thanks for being there and pushing me to be better. My friends who have been there to listen and offer words of wisdom, you are a massive part of my success. Believing in each other is how we all succeeded together.

Lastly, I want to thank my partner, Rose; I would not be here without your belief in me. Our time in Oklahoma had many obstacles and challenges to conquer; you were there every step of the way with love and support, and I could not have done it without you. Having you as my family means everything to me, and I know I can do anything with you by my side. Thank you for putting up with me and my crazy dreams.

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Abstract

Patients with intellectual disabilities face additional challenges due to fears of health literacy (i.e., the ability to seek, understand, and utilize health information) and communicative competence. The taboo nature of sex has limited the communication surrounding sex for individuals with intellectual disabilities, including education, prevention, biological components, disease, and more. The limited communication about sexual health and the more significant challenges present when communicating have placed individuals with intellectual disabilities at a higher risk for sexual consequences. The current study examines providers' motivations and motivators when communicating with individuals with intellectual disabilities about sexual health to understand the role healthcare providers contribute.

Nine healthcare providers were recruited for the current study; participants included OBGYN, family medicine, and women's healthcare physicians. Data was collected from semi-structured interviews lasting 30-45 minutes, asking participants about their experiences in the clinic while communicating with patients with intellectual disabilities. Data was gathered using audio recording and transcribed to be coded using grounded theory methods presented by Charmaz (2014).

Findings suggest that providers communicate with patients with intellectual disabilities about sexual health when one of three motivations exists within a clinical. The motivators for providers are patient initiation, provider observation, and normative practices, which initiate the conversation about sexual health. After initiating the conversation, five contextual factors exist to determine how the provider communicates with patients with intellectual disabilities. The four motivators are patient cognitive abilities, patient verification, third-party verification, and provider interpretation. Potential future directions for the current findings are continued research

examining patients with intellectual disabilities, the ability to initiate the conversation the motivators when enacted by individuals with intellectual disabilities.

Healthcare Providers' Motivations and Contextual Factors when Communicating about Sexual Health with Individuals with Intellectual Disabilities

Discussing sexual health in medical encounters can be challenging for both the provider and the patient, as the topic can raise concerns about personal privacy, relational intimacy, and moral judgment. Patients with intellectual disabilities may face additional challenges due to fears of health literacy (i.e., the ability to seek, understand, and utilize health information) and communicative competence. The additional challenges faced by patients with intellectual disabilities contribute to their ability to communicate with their providers about sexual health. The United States has the highest rate of STD/ STI and unwanted pregnancies for individuals with and without intellectual disabilities than any other developed country (Satcher et al., 2015). Researchers have argued that improving the system in the U.S. for approaching sexual health could reduce the adverse effects of sexual activity (Fuzzell et al., 2016; Rohleder & Swartz, 2012; Satcher et al., 2015). Providers in the United States are not directly educated on addressing sexual health with patients with intellectual disabilities (Criniti et al., 2014; Faulder et al., 2004). There is minimal consistency among medical schools in educating providers on how to communicate with patients with intellectual disabilities about sexual health, resulting in a gap within the healthcare system that leaves individuals with intellectual disabilities at a disadvantage for their health needs (Criniti et al., 2014). Current research has created a gap in understanding the current motivations determining how a provider addresses sexual health.

Historically, individuals with intellectual disabilities have not had equal opportunities in life because these individuals were dismissed and seen as nothing, which progressed to a general belittlement of the culture. The result of cultural belittlement happened because few alternatives were offered to individuals with intellectual disabilities. Individuals with intellectual disabilities

can fight back for their rights and be heard and seen as equally valuable individuals and members of society; however, it is an uphill battle that has been historically lost (Jones, 1996). Individuals with an intellectual disability can also choose to let how the nation they live in control their lives and how they live (Ellis & Kent, 2016). These alternatives may seem extreme; however, fighting back against the stigma of disability and what individuals with an intellectual disability can do with their life has been the only alternative presented to this cultural group. Existing is not a life, and it is not an equal life. Individuals with intellectual disabilities have been fighting for their rights as individuals, and to be seen as equals have pushed the general population into a new age of better understanding of disability. An increase in accessibility for these individuals has happened over time, creating more options for the culture to break the molds of society and fight for a life that fits their unique needs instead of being controlled.

Disability and Sex

Individuals with intellectual disabilities have been around for a long time; it was not a recent occurrence that individuals developed intellectual disabilities. The reason for the appearance that intellectual disabilities are a recent phenomenon is that medical technology has improved (Cutler, 2005). As people discovered themselves as a species and learned medicine, they noticed the distinct qualities and named the different intellectual disabilities, not simply shun or outcast members of society (Davies, 2011). The current medical definition of an intellectual disability is a disability that effects accusation of knowledge and skills, effecting intellectual processing, educational attainment necessary for independent and social functioning (Harris & Greenspan, 2016). Medical technology has done more than allow for the identification of intellectual disabilities; it has improved the ability of these individuals to live in the world (Sand-Jecklin, 2007). Before many modern technological advances, individuals with an

intellectual disabilities did not survive because of the level of dependence required to accommodate their disability (Davies, 2011). Our ability as a species has developed to accommodate these differences in many ways, many of which started with keeping individuals with intellectual disabilities alive and so much more.

To begin to understand that an individual with an intellectual disability has the ability to be a sexual being, societal assumptions need to be deconstructed to develop an understanding of their sexual desires and needs. McRuer and Mollow (2012) present the argument that disability studies allow for a deeper understanding of the normalization of disabled bodies by extending awareness of the capabilities of the body, extending past what might be seen. The current drive for research is toward inclusion for individuals with intellectual disabilities; exploration of disability through sexuality has the potential to offer a unique ideal of normalization of disability. (Wilkerson, 2012). Normalization of disability through sexuality occurs when the acceptance of the reality that individuals with an intellectual disability have the ability to be sexual beings (Gill, 2015; Wilkerson, 2012). Gill (2015) continues the argument that for individuals with and intellectual disability to be seen as sexual individuals, the conversation cannot include an individual's intellectual competency as the only determination of who can be sexually active. When discussing an individual's ability to be sexual, exclusion of other sexual factors and hyper-fixating on competency drives the conversation of disability and sexuality in a different direction. To begin the conversation about disability and sexuality requires a conceptual framework that pushes past the current assumptions to break down the basics of being a sexual being and who falls under that category.

Individuals with an intellectual disability, whether intellectual or physical, can reproduce, meaning their reproductive organs, hormones, and desires are present with their ability to have

sex and be sexually active. Murphy and Young (2005) detail how children and adolescents with intellectual disabilities still go through puberty and have levels of sexual development similar to their nondisabled counterparts. The current research reports that an individual's intellectual disability does not impact their ability to be sexual activity and continues to mention findings of similar sexual activity levels as their peers (Murphy & Young, 2005). Nancy Murphy, M.D. examined children with intellectual disabilities and found results suggesting children with intellectual disabilities are sexual beings and mature with sexual desires (Murphy et al., 2006). Kijak (2011) echoed similar findings of individuals with an intellectual disability having both physical and psychological desires for sexual activity. The argument about who can and cannot be sexually active has been present without including the individual's sexual desires limiting the inclusion of individuals with an intellectual disability as sexual beings. Having a disability does not limit an individual's ability to be sexually active and participate as a sexual being because they go through the same developmental change of becoming sexual mature to develop into having the desire to be sexually active.

When considered who is a sexual being, an important variable to consider is if the individual desires to be sexually active. Sexual activity and the desire to consent to sexual activities is at the discretion of the individual and the control they possess of their body. The desire for sexual activity develops in a variety of ways, from the general interest to the interest at the moment for sexual activity. Kijak (2011) states that individuals with an intellectual disability possess the hormonal develop to contribute to the psychological desire for sexual activity. McRuer and Mollow (2012) mention examples of individuals with intellectual disabilities desiring sexual activity from desiring the connection that is gained with a person during an intimate moment as well as the personal physical pleasures sexual activity can produce. Results

from interviews of women with intellectual disabilities found that they have a strong desire for sexual activity, suggesting a need to recognize that sex is for individuals with an intellectual disability (Dotson et al., 2003). The desire for sexual activity and to be recognized as sexual beings is present in individuals with an intellectual disability (Kim, 2011; Loeser et al., 2018). The desire to be sexually active and a sexual being is just as important as the ability to have sex and has the potential to create a new lens to view who is sexually active. Having the desire to be sexually active plays a crucial role in having sexual relations; examining an individual without the knowledge of their desire to be sexually active limits our understanding of who is sexual.

To continue conceptualizing who is a sexual being, it is necessary to consider an individual's ability to consent to sexual activity. The ability to consent is crucial because it creates the foundation for a safe sexual interaction to limit the potential of someone being taken advantage of in a sexual situation or unwanted sexual advances. Individuals with intellectual disabilities can be recognized as sexual beings if their ability to consent to sexual activity is accepted and protected (Onstot, 2019). Without accepting an individual with an intellectual disability capacity to consent to sexual activity, all sexual encounters are then seen as sexual assault of their inability to consent (Gill, 2010; Murphy, 2003; Murphy & O'Callaghan, 2004). While an individual with an intellectual disability is at a greater risk for assault, not every sexual encounter is a sexual assault (Gill, 2015). Individuals with an intellectual disability have been recognized by law as having the ability to consent to sexual activity (Murphy & O'Callaghan, 2004; Onstot, 2019). Meaning that it is up to the individual with an intellectual disability to determine their willingness to consent and partake in sexual activity. Having a higher educational understanding and knowledge of sexual encounters can give individuals with intellectual disabilities more control in sexual scenarios to consent but does not affect their ability to consent

(Eastgate, 2005). With more education, an individual can know more about their decision to consent to sexual activity, but a disability does not effect this ability. Recognizing that individuals with intellectual disabilities can consent to sexual activity allows for the recognition that they are sexual beings that possess the ability to consent, have sex and have the desire for sexual activity is the start. Understanding how history has created a social stigma that individuals with intellectual disabilities are not sexual plays a critical role in understanding the discrepancies that exist within sexuality and sexual health for individuals with an intellectual disability.

Individuals with intellectual disabilities experience more social stigmas related to their disability and have throughout the years. While gaining more awareness and rights, they are still not viewed as equal in the sheets. Based on the understanding of disability, society has, historically, created a shift in thinking around social stigmas related to an individual with an intellectual disabilities' sexuality. The current system oppresses individuals with intellectual disabilities through societal stereotypes(viewing them as burdens, weak, and childlike) and has developed the current social stigmas, myths, and understanding of an individual with intellectual disabilities' sexual lives (Albrecht, 2016; Albrecht et al., 2001; Rohleder & Swartz, 2012). In the early 1990s, individuals with intellectual disabilities were routinely sterilized to avoid being sexual and potentially passing on their faulty genes (Hubbard & Davis, 1997; Rowlands & Amy, 2019). This historical act of sterilizing individuals with an intellectual disability is part of the current assumption that individuals with an intellectual disability are asexual or that sex is not meant for these individuals (Rowlands & Amy, 2019; Tilley et al., 2012). The effects of forced sterilization are just beginning to surface and suggest a larger issue of sexuality for individuals with intellectual disabilities (Stubblefield, 2007; Tilley et al., 2012). The routine sterilization of individuals with intellectual disabilities and the assumptions that developed from this action has

affected the perceptions and social stigmas around individuals with intellectual disabilities as sexual beings. The historical understanding of disability and actions of forced sterilization have developed overtime into a societal understanding of individuals not being sexual.

The effects of the historical sterilization of individuals with an intellectual disability contributed to the stereotypical ideal that these individuals are asexual or do not desire or cannot have sex. The effect of this ideal resulted in a lack of sexual health education, mistreatment of individuals with an intellectual disabilities towards being sexual, and left them with the risk of being exploited or raped. Sterilizing individuals with an intellectual disability has direct links to creating the stigma that these individuals are not sexual beings because, historically, they could not be due to forced sterilization (Milligan & Neufeldt, 2001; Rowlands & Amy, 2019). Individuals responsible for educating individuals about sexual education and helping them to develop during adolescents view sexual activity as something to be feared, and discussing any topic related to sex is off limits for fear of potential dangers resulting from education (Rohleder & Swartz, 2012; Wilson et al., 2011). Gagnon (2004) suggests that sexual scripts such as the ones developed from forced sterilization offer the framework for considering the effects of these scripts on individuals with intellectual disabilities leading to feelings of being othered, low sexual esteem, and sexual depression (McCabe & Taleporos, 2003). The effects of forced sterilization are staring us right in the face as individuals with intellectual disabilities continue to believe that being sexual is not for them, even when they have desires and questions about being sexually active. The societal image of individuals with intellectual disabilities' sexuality has othered them into becoming a sexual minority group because they have been overlooked and stereotyped into not being able to have sex.

While not being seen has sexual beings has placed individuals with an intellectual disability into a sexual minority group that suffers from stereotyping, not being heard from their viewpoint, lack of access to healthcare, and other consequences that an individual has to suffer when placed in a minority group, especially one related to sex and sexual activity. The current research about individuals with intellectual disabilities as a sexual minority is relatively limited because it focuses on outside sources of information, not research that is developed from research that includes the individual's perspective of their life (Shuttleworth, 2012). Researchers have started to interview individuals about their experiences they have found evidence of their sexual minority and the individual's identity with this minority through their narratives about sex (Eliason et al., 2015; Herrick & Datti, 2022). The effects of being part of a sexual minority are echoed throughout research that interviewed individuals with intellectual disabilities about their specific and unique experiences. (Bush, 2019; Herrick & Datti, 2022). For this community, the social scripts that have played in conjunction with the idea of sexual minorities have resulted in nondisabled individuals viewing disabled individuals as nonsexual, asexual, sex is a detriment to their health and other scripts to encourage low communication about sexuality, and sexual health. Further exploration into the effects of being typed into a sexual minority, as individuals with intellectual disabilities have been, is the first step in making progress towards more affirmative and inclusive sexual scripts for individuals with intellectual disabilities.

Disability Culture and Health

Exclusion into this sexual minority has resulted in a lack of sexual health for individuals with intellectual disabilities, as sexual health encompasses the mental, physical, emotional, and social wellbeing of the individual regarding sexuality (Services, 2019). The current literature on individuals with intellectual disabilities as a sexual minority leans toward a large discrepancy in

the overall sexual health of these individuals, such as higher rates of assault, increased occurrences of STD/ STI, and unwanted pregnancies. (Bush, 2019; Eliason et al., 2015; Herrick & Datti, 2022; Shuttleworth, 2012). Not being considered sexual limited the education and overall awareness of sexual activity for individuals with intellectual disabilities. Researchers claim that further exploration into the physical and psychological sexual health of individuals with intellectual disabilities is the next step in disability and sexuality research (Bush, 2019; Eliason et al., 2015). Herrick and Datti (2022) had participants mention their desires for more healthcare, education, and respect as a sexual beings from their providers and feel they have not been heard about their sexual health needs. This call to action in the current research encompasses a large subject area, and a large number of individuals, as roughly 16% of the world population has a disability, has developed the need to identify a theoretical lens to operate under (World Health Organization, 2023). To begin to understand the potential discrepancy based on the current research, a perspective, and framework to examine the discrepancy is vital for examining the behaviors in healthcare towards individuals with intellectual disabilities.

The current literature has presented an area of research that has begun to be studied but sexuality and disability are still too broad. Taking a health communication perspective to the understanding of disability and sexuality will have the potential to aid in understanding the nuances of sexual health and disability. Sexual health at the core is emotion, physical, social, and psychological welfare related to sex and sexuality; this core understanding of sexual health continuing from a health perspective will aid in understanding the effects of the minority group (Engelen et al., 2020; World Health Organization, 2023). Sandfort and Ehrhardt (2004) have found benefits in examining and explaining sexual health as a public health initiative to promote positive sexual health. Understanding sexual health as a public health concern aids in examining

sexual health form a health communication perspective because researchers have found benefits in examining health communication within public health (Ivankovich et al., 2013; Rimal & Lapinski, 2009). The current relationship in the research suggests a successful outcome for research by examining sexuality and disability as a public health issues that can be examined under health communication theories. Theories in health communication have been designed to aid and facilitate positive outcomes from different effects, such as aiding in sexual health for individuals within a minority group (Schiavo, 2013). Taking a health communication perspective to the current call to action addressing the effects of being part of a sexual minority group can explain the current literature by expanding our understanding of the impacts being typed into a sexual minority has played on individuals with intellectual disabilities' health.

When examining health communication, it is important to understand the individuals involved in the scenario being studied. By studying health communication through a cultural lens, researchers can begin to understand the nuances around certain behaviors that affect individuals' healthcare. When examining situations for an entire group of individuals in the healthcare setting, examining culture becomes and essential factor in understanding behaviors within healthcare (Hsieh & Kramer, 2021; Kreuter & McClure, 2004). Hsieh and Kramer (2021) explained that much of the current public health and health communication reflects a Western-centered cultural understanding, resulting in a lack of information on the effects of culture on healthcare. Continuing to elaborate that examining culture in a health communication context provides contextual factors, serving as a resource, shaping responses, and institutional structures that understanding culture within health is for everyone (Hsieh & Kramer, 2021). Being inclusive within healthcare is to challenge the current conceptions of culture and push past, current cultural understanding as racial and ethnic groups to include everyone. Fundamental

differences in values, believes, attitudes, and worldviews can be attributed to an individual's cultural background, leading to significant differences in their realities (Hsieh & Kramer, 2021; Kramer et al., 2013). Examining culture from a healthcare perspective can aid in the understanding of the connection between social stigmas(generally utilized to control individuals in other cultural groups) and behaviors attributing to healthcare being received are utilized (Hsieh & Kramer, 2021). Contextualizing culture within health offers a deeper understanding of complications that can arise when treating in a healthcare environment because of the high impact culture has on how an individual interprets and responds to the world.

Culture has been conceptualized to understand the different characteristics that unite individuals into a cultural group by racial and ethnic identity, speech, worldviews, and the living process. Culture as an ethnic group pertains to a race or nation that is a group of individuals connected by common descent; researchers have become wary of utilizing this understanding of culture because of the potential to overemphasis genetic components in culture (Hsieh & Kramer, 2021; Lee & Bean, 2007). Gumperz (2009) defined culture as a speech community employing speech variants within the group, defining the group based on their communicative practices (Hsieh & Kramer, 2021). Culture as a worldview utilizes social worlds constructed by social norms to construct and sustain a cultural reality (Hiebert, 2008). As a living process defines the aspects of culture that evolve, humans never stop learning and interpreting the world around us, affecting how we respond in the future; as a living process, culture evolves with the integration of past and present experiences (Hsieh & Kramer, 2021). Culture creates a shared reality and sensemaking developed from cultural characteristics that define the group, often sharing nontransferable primary and secondary characteristics that unite the cultural group (Kramer et al., 2013; Taylor, 2017). A shared reality and sensemaking develop from having the

same foundation of self and values that unites the group (Kramer et al., 2013). Individuals with a shared disability also share a standard way of interpreting the world around them. Culture cannot be a catch-all for grouping individuals with similarities, the conceptualization of culture is vital to understanding how communities of individuals qualify as a culture or a group that shares similar interests and experiences.

To begin to further understand individuals with an intellectual disability and what they experience together, we must examine and conceptualize the parameters of what creates a community into a culture instead of a group. Individuals with intellectual disabilities have the ability to relate to each other, and there is more than one singular disability or individual with an intellectual disability. The current issues being examined around sexuality effect more than just one individual; examining the group as a singular entity, such as a culture, can aid in our understanding of individuals with intellectual disabilities and their sexual lives. Gill (1995) began conceptualizing disability as a culture by breaking down the connections made within the disability community and the cultural definitions offered at the time, finding that individuals with an intellectual disability are a culture because of their shared core values, social oppression, and through speech used to communicate with each other. Years later (Peters, 2000) preformed a detail examination challenging that deaf culture exists, but disability culture does not find a syncretized understanding of disability culture that exists as a cross-cultural phenomenon. Further conceptualization has been performed to understand how disability can be a culture and if it meets the set forth guidelines to be considered a culture. Brown (2002) created a reflection of the current work at the time on disability and culture to create an encompassing idea of disability culture, finding that research suggests that culture can be used to describe disability. More recent research has gone into more detail, examining the nuances of culture and how

disability culture connects to meeting a culture's contextual requirements (Brueggemann, 2013; Riddell & Watson, 2014). When individuals have the same individualistic foundation, it becomes easier to connect because the beliefs, values, emotions, attitudes, and needs of the individuals match the group has the same ideas and values because they have the shared needs from their shared reality that unites them as a culture (Kramer et al., 2013). Conceptualizing the individuals as a cultural group allows for the use and examination of disability under cultural theories and assumptions as the community does function as a culture (Couser, 2005; Kleege, 2005; Riddell & Watson, 2014). Individuals with an intellectual disability as a culture value their disability and what it provides them instead of the alternative of what they do not have—examining a group of individuals with a similar value of how their interpretations of their world better their lives because their performance is so varied from other cultures.

Health Disparities

Discussing sexual health in medical encounters can be challenging for both the provider and the patient, as the topic can raise concerns about personal privacy, relational intimacy, and moral judgment. The taboo nature of sex and disability has limited the communication received by individuals with an intellectual disability surrounding sex, including education, prevention, biological components, disease, and more (Luker, 2007; Nusbaum & Hamilton, 2002). Many individuals with intellectual disabilities grow up believing that sex and relationships are not for them (Rohleder & Swartz, 2012). Individuals with an intellectual disabilities are sexual and have been told that they should not have sexual thoughts, are not sexual beings, and that sex is not for them (Gill, 2015; Rohleder & Swartz, 2012). Even if individuals with an intellectual disability have ideas, fantasies, or curiosities about sex, they tend to ignore those feelings or discourage themselves from further inquiring and exploration (Gill, 2010, 2015). Sterilization has become

less common and is only performed when it is medically necessary to perform the procedure; however, the historical effect has already damaged the societal view of this culture. Combined with the awareness of sexual activity, societal scripts and opinions on individuals with intellectual disabilities have developed an environment lacking knowledge and education, resulting in serious sexual health consequences (Milligan & Neufeldt, 2001).

The U.S. provides school-aged children with units of sexual health in their general health classes within their primary education to aid in understanding biological development (Luker, 2007; Oakley et al., 1995). Children and adolescents are taught about sexual health (including body parts, body functions, safe sex, condom use for STI/STD prevention, and birth control); this education provides the knowledge and tools to communicate with their healthcare providers about sexual health (Oakley et al., 1995). During the younger times of sexual education, children learn the boundaries of their bodies and how to protect themselves and consent to touch. Ownership of an individual's self develops into a solid relational foundation for self and sexual consent (Harris, 2018). Knowing the identification in parts allows individuals to communicate about their body when things happen or have been violated. Sexual education is the foundation of this level of awareness of oneself and how to identify their body correctly (Landry et al., 2000). However, minimal information has been provided to the American public through the public-school educational programs and other sources (e.g., television, social media, and peer groups), providing unreliable information to youth (Eisenberg et al., 2008; Luker, 2007). The information received in the sexual health classes provided aids in adolescents knowledge about their bodies and provides information to continue the sexual health conversation with parents or healthcare providers.

However, individuals with intellectual disabilities are removed from different educational classes within the school systems, contributing to the gap in their knowledge about sexual health due to not receiving any formative education or other information about their bodies (McCabe & Taleporos, 2003). Individuals with an intellectual disability are placed on a modified learning program to accommodate their intellectual disability; as part of being in this program, they are excluded from receiving sexual health education from their teachers (Esmail et al., 2010). Sexual education has the ability to lay the framework for understanding the repercussions of sexual activity and has been found to lower the rates of sexual consequences in teens (Breuner et al., 2016; Eisenberg et al., 2008). A sexual health class provides no benefit when the individual never attends the class to receive the information mitigating the purpose of the class (Breuner et al., 2016; Landry et al., 1999). The removal of students with intellectual disabilities from adolescent sexual health classes and included in the curriculum has placed these students at a disadvantage, and a higher risk for sexual consequences due to vulnerability and lack of knowledge (Breuner et al., 2016; Eisenberg et al., 2008; Esmail et al., 2010) The limited access to sexual education for children and adolescents with an intellectual disability has contributed to the gap in their knowledge about their bodies as a collective while their peers receive formative education to provide the foundation.

The United States has the highest rates of STD/ STI, unwanted/teen pregnancies, and assault rates among adolescents and young adults than any other developed country suggesting an issue with the sexual health and education provided to the American population (Fuzzell et al., 2016; Services, 2019). The hushed tones of sex and disability have masked a massive problem with sexually transmitted diseases and infections while also increasing the occurrences of sexual assault for an entire cultural population (Humphreys & Brousseau, 2010; McRuer &

Mollow, 2012; Reiter et al., 2007). As a vulnerable population, individuals with an intellectual disability are at a higher risk for assault and have a higher infection rate than the average American (Breuner et al., 2016; Esmail et al., 2010; Fuzzell et al., 2016; Zhang et al., 2020). Rohleder and Swartz (2012) found that individuals with intellectual disabilities are more likely to contract a sexual infection because they have limited knowledge about safe sex. Mailhot Amborski et al. (2022) reviewed 68 studies from 1975- 2018 surveying 12,427 participants and found significant evidence that individuals with an intellectual disability are at a significantly higher rate of sexual assault showing an increase in rates when the individual is in adulthood. It is estimated that roughly 16% of the population has been a victim of sexual assault, while it is estimated that 39% of individuals with a disability have been a victim of assault (Basile et al., 2016; Dworkin et al., 2021). The removal from educational classes has taken a detrimental effect on individuals with intellectual disabilities, putting them in danger. Societal stereotypes and past ideations about their sexuality have placed this culture in a position to be unable to protect themselves. Society adjusting the responsibility of educating youth about sexual health and determining who can attend the classes on sexual health has placed a reliance and assumption on healthcare providers to fill the void in the knowledge of sexual health for individuals with an intellectual disability.

Patients with intellectual disabilities face additional challenges when communicating with their providers because of difficulty communicating based on their disability (Fuzzell et al., 2016). Many individuals with an intellectual disability share similar communicative issues with providers, such as; impediments, impairments, intellectual understanding, and many other reasons specific to the individual and others specific to the individual's disability (Ryan et al., 2005). Communicating with healthcare providers is increasingly difficult for individuals with

intellectual disabilities to advocate for their sexual health needs because their disability impact patient cognitive ability to communicate electively (Reiter et al., 2007). The struggle when communicating with healthcare providers is only heightened when other factors contribute to the conversation such as bias or health literacy, and the issue is not just communicative ability is due to their needs not being met within the appointment and treatment from their healthcare provider (Duggan et al., 2012). The complexity of health information has been known to be overly complex for individuals without disabilities and even more so for individuals who share in communicative disadvantages (Rowlands et al., 2015). A provider can over-correct and under-accommodate an individual with an intellectual disability, not understanding the full extent of their disability, impacting the effectiveness of the patient's understanding of the health information (French & Swain, 2004). Communicating with a healthcare provider can be challenging that addressing complex topics such as sexual health with limited knowledge continues to hinder the patient and enforce sexual consequences for this population (Gill, 2010; Reiter et al., 2007).

Individuals with intellectual disabilities face significant barriers to having a healthy sex life, including receiving limited knowledge about sexual health, safe sex, reproductive considerations, and the connection between sexual health and overall well-being (Gill, 2015; Rohleder & Swartz, 2012). The barrier present in the culture is maintained when individuals with an intellectual disability are viewed as asexual or unable to have sex resulting in a modified action when interacting with nondisabled individuals (Rohleder & Swartz, 2012). Individuals with intellectual disabilities are often overlooked and spoken for when only they can speak for their bodies (Cunningham & Glenn, 2004; Okoro et al., 2018). Routinely individuals with intellectual disabilities end up in this circle of misinformation from people about sexual

education instead of creating opportunities and communicating with them about sexual health (Fuzzell et al., 2016; Zhang et al., 2020). The parents of children with intellectual disabilities do not want to approach the subject of sexual health and rely on the teachers and providers for this information (Zhang et al., 2020). Individuals with an intellectual disability can speak for themselves, and their needs must meet within the conversation for them to be able to effectively communicate and advocate for themselves (Cunningham & Glenn, 2004). The human body is subjective; only the individual can know exactly what is happening within them. A third individual cannot accurately describe what the individual may be going through to the healthcare provider, requiring direct communication between the patient and the provider.

Individuals with intellectual disabilities often desire and rely on their healthcare providers to initiate the topics of sexual health based on the inability to receive educational information form parents and educators; providers tend to neglect the subject of sexual health in their medical encounters (Fuzzell et al., 2016). Individuals with intellectual disabilities have a desire for their healthcare provider to discuss sexual health with them and have reported that they wish providers would communicate with them (Fuzzell et al., 2016; Kijak, 2011). Healthcare providers have become vital sources of information for patients with intellectual disabilities because they possess fewer skills than providers to initiate conversation and communicate about sexual health (Albrecht et al., 2001; Zhang et al., 2020). Individuals with an intellectual disability desire to be seen as a sexual individuals that can have intimacy and be sexually active, and they want to be seen this way when in the presence of their healthcare provider to feel accepted, and it is their place to have a conversation about sexual health (Albrecht et al., 2001; Kijak, 2011; McRuer & Mollow, 2012). Healthcare providers offer a medical perspective that can contribute any knowledge to the patient about their disability and sexual encounters; aiding in the sexual

education for their patient can be beneficial to the patient seeking the education. Individuals with intellectual disabilities desire to have a conversation about sexual health and rely on the provider for initiation because they have been given no alternative skills or knowledge to assume a different approach to receiving sexual health. Reliance on the provider has contributed to the lack of discussion seen for the community around sexual health information contributing to occurrences of sexual consequences.

Bias developed from societal stereotypes of individuals with intellectual disability and their sexual lives has attributed to the lack of initiation of communication about sexual health with patients with an intellectual disabilities from their healthcare provider. Assumptions that have been made about the disability community have effected their healthcare and the assumptions their healthcare providers make about their sex lives (Azzopardi Lane et al., 2019; Engelen et al., 2020). The current social script is that individuals with intellectual disabilities are not having sexual activity and do not need to discuss clinics (Albrecht et al., 2001; Mona et al., 2017). Providers' personal bias of if an individual with an intellectual disability is sexually active or desiring to engage in sexual activity has been found to influence the discussion of sexual health with patients (Albrecht et al., 2001). The assumption made by the healthcare provider based on a bias that individuals with intellectual disabilities are not having sexual relations impacts the patient’s ability to be treated for their sexual health. Healthcare providers are individuals, and bias impacts individuals understanding of other cultures, which impacts treatment and initiation of the conversation of sexual health.

There is no consistency among medical schools in educating providers on how to communicate with patients with an intellectual disabilities resulting in a gap within the healthcare system that leaves individuals with intellectual disabilities at a disadvantage in their

health needs (Criniti et al., 2014). When a healthcare provider sees a patient, they typically see them for an ailment and have been trained to clinically assess their patient to provide the best care (Albrecht et al., 2001). Healthcare providers are trained in the biological workings of the body and hospital procedures and functioning (Albrecht et al., 2001). Providers are specifically trained to diagnosis patients and have had limited educated about sexual health to help facilitate communication between them and the patient (Criniti et al., 2014; Faulder et al., 2004; Zhang et al., 2020). During medical school, providers are trained about the human body and its ideal function and how to treat possible conditions and disabilities that could occur (Faulder et al., 2004). Healthcare providers are also taught how to communicate with patients about their medical conditions and be the bridge that communicates to patients about their bodies while providing their expertise to the situation (Baylor et al., 2019). Providers are not trained in communicating with patients with an intellectual disabilities (increasing their need to see a provider), affecting their communication ability (Criniti et al., 2014). The current education model for healthcare providers does not allow education to be specifically geared towards education on a certain medical topic, such as sexual health, or to focus on a specific cultural group and how to address their care (Albrecht et al., 2001). This relative gap in a provider's knowledge has not left providers at a disadvantage for treating their patients. However, it has left individuals with an intellectual disability at a disadvantage because patients with an intellectual disability are not receiving the necessary and desired care from their providers.

Providers are in a position of authority between themselves and their patients and have control over the clinical visit to aid and guide their patients through the visit to reach the best decision to meet the patient's needs. Individuals with an intellectual disability tend to receive more health information pertaining specifically to care for their disability receiving even less

information about preventative and general self-care from their providers (McRuer & Mollow, 2012). The doctors' visits are surrounded by how to care for their disability, leading to routinely receive limited information about diet, exercise, preventive care, and sexual education (Baylor et al., 2019). Inquiry into the motivations for a provider to communicate with a patient about sexual health is vital to begin to understand the cultural health disparities individuals with intellectual disabilities face when receiving sexual health.

The current situation in healthcare is known from a few different angles so that we can begin to assume a picture of what is happening during a clinical visit (Iezzoni & Agaronnik, 2020). However, this is just an assumption to be able to create a theoretical solution for practical application; evidence about the situation from all angles is required (Peacock et al., 2015). The challenges present for individuals with an intellectual disability are known for expressing their struggles directly from the community (Iezzoni, 2011; Iezzoni et al., 2021). This even includes the assumptions of the provider's side of the interactions developed from their perspective. The current research consists of the challenges in healthcare for all patients and a limited knowledge of the population's challenges.

The provider is vital in educating patients with intellectual disabilities about sexual health and well-being. Further research into how a provider communicates about sexual health with patients with intellectual disabilities can improve the quality of communication between providers and patients with intellectual disabilities—serving as a bridge between understanding sexual health and communicating with intellectual disabilities. The knowledge gained by examining the complete picture of the reasons, causes, motivations, and challenges that contribute to the sexual health disparities present in the disability culture can be applied to develop improved healthcare. The challenges for individuals with intellectual disabilities go

beyond sexual health; however, a specific topic must be examined in depth to understand all the dimensions of cultural health disparities. This in-depth examination can allow for a theoretical framework of an innovative solution to the health problems present in the disability culture.

Researchers have argued that improving the system in the U.S. for approaching sexual health could reduce the adverse effects of sexual activity (Fuzzell et al., 2016; Rohleder & Swartz, 2012). Understanding the current motivations and how a provider addresses sexual health is essential in addressing barriers and challenges to sexual health faced by individuals with intellectual disabilities.

Research Questions

1) What motivates a provider to initiate a conversation about sexual health with a patient with an intellectual disability?
2) What factors influence providers' motivations to discuss sexual health with a patient with an intellectual disability?

Method

Providers create the link between our bodies and our knowledge about those bodies, with the most accurate information about how the body interacts with sexual health and disability. The intent of the study is to further explore the motivations and challenges of providers when communicating with individuals with intellectual disabilities. With limited research on sexual health communication with patients with intellectual disabilities the study calls for a more exploratory approach to data analysis. The current research design has been created to accompany the research questions through snowball sampling, semi structured interviews, and analysis utilizing grounded theory.

Study Participants

The principal investigator has a research focus and experience with individuals with intellectual disabilities. The study was conducted under direct supervision of their advisor during the completion of master thesis credits. The researcher was trained in institutional review board policies, data collection and analysis prior to the conduction of this study. Findings have been reported ethically, respectfully, to protect the participants while accurately reporting the results. The researcher had not prior relationship with participants prior to recruitment and interviewing participants.

Nine participants were recruited (from a southern city) and interviewed during Spring of 2022. Four family medicine or primary care providers and five OBGYNs or gynecologists participated in this study. Three participants were pediatric providers or treated pediatrics and adults in their practice. Two of the participants were male, and seven of the participants were female.

For this study, the ideal participant is a healthcare provider that includes sexual health in their practice (Bryant & Charmaz, 2007). Selecting healthcare providers that have a greater chance at communicating about sexual health patients increases the encounters and experience the participants can draw from within the interview (Bryant & Charmaz, 2007). Participants for this study are healthcare providers such as primary care physicians, nurse practitioners, and women's healthcare providers. Sexual health is typically communicated during appointments with physicians that specialize on the reproductive anatomy or overall health of the body because they have a larger more specialized focus that is relevant to sexual health (Schiavo, 2013). Providing participants with direct experiences to reference for the study on communicating about sexual health because it is part of why a patient would seek their medical aid.

Participants for this study were required to have some prior experience treating patients with intellectual disabilities. Considering the number of individuals, they do treat with an intellectual disability to get a general idea of their clinic and the relevance within their practice. Providers without prior or current experience of treatment of the cultural population are disqualified to participate in this study because they have no direct experience treating and communicating with patients with intellectual disabilities. Without prior experience communicating with the specific patient population being explored the results could be skewed because the participant would be drawing from experiences with a different patient population with different communicative needs and abilities.

Having relevant experience treating patients with intellectual disabilities and discussing sexual health is vital to the study because it gives the interview questions the best potential for ideal results to answer the focused research questions. Without working with individuals with intellectual disabilities and discussing sexual health, a participant would not be able to accurately portray treating this culture and their motivations around the type of conversation currently being explored. With the relatively limited information on this genre of cultural health, it is important to be specific while remaining vague to allow participants to share their stories in-depth for the best results and detailed understanding of the phenomena occurring.

Participant Recruitment

Prior to participant recruitment the study received approval of the Institutional Review Board at the University of Oklahoma to conduct this research with human subjects. Participants were recruited through convivence sampling by visiting clinics(in a southern state) to recruit providers. Flyers were left at the clinics for providers to reach out to participate in the study. Other recruitment methods included emails to providers based on tier contact information

publicly posted on hospital and clinic websites. Prior to reaching out to potential participants it was verified by the researcher that each provider specialized in the desired specialties for the study. Key words such as family medicine, primary health, OGBYN, or gynecology on their profile were utilized to verify providers specialties prior to initial contact for recruitment.

Data Collection

Each participated in in-depth, one-on-one semi-structured interviews over the phone or utilizing the Zoom platform. The duration of the interviews ranged from 17.15 minutes to 30.36 minutes (std. 2.55 minutes, avg. 24.8 minutes). Participants consent to voluntary participation and audio recording in the study with no expected compensation prior to participation. Following the completion of the consent participants answered a series of open-ended questions according to the interview protocol developed by the principal investigator. Each participant was given a description of the study and the intent with instructions to answer the questions based on their experiences with the desired patient population. The interview questions were designed for the participant to go into detail about how they communicate with patients with intellectual disabilities within their clinic.

The audio recordings were recorded through zoom and preserved for data analysis after the interviews. After the interview, a mix of self-transcription and transcription software called Descript was used to transcribe the interview recordings. Each transcript was reviewed for accuracy prior to use in data analysis. Participants' identities and other identifying information were removed from the transcriptions during the transcription process. Transcriptions and audio files were then used for analysis. Upon initial reflection, transcripts were reviewed for accuracy. After accuracy was confirmed, the transcripts (68 single spaced, Times New Roman, 12pt typed pages) could be used as data during analysis.

Analysis

After the completion of analyzed the transcripts keeping an unbiased opinion and perspective when creating the analysis (Briggs, 1986; Sciarra, 1999). Grounded theory was developed as a way for researchers to explore and understand research topics that do not have a theoretical backing behind them to develop a working theory of the phenomenon being studied (Charmaz, 2014). Ground theory is a beneficial analysis method when there is little information on a phenomenon being studied and was selected (Bryant & Charmaz, 2007; Charmaz, 2014). Utilizing grounded theory for analysis will allow the researcher to analyze each interview separately and collectively to understand the providers' motivations to develop the different factors that go into a provider's decision to communicate with their patient about sexual health. This study follows Charmaz's approach to the grounded theory presented in Charmaz (2014). The grounded theory allows the researcher to analyze and develop and look back to continue developing an understanding of a phenomenon's motivators (Bryant & Charmaz, 2007; Charmaz, 2014).

To move forward with the research, one must understand why the phenomenon occurs. The coding process was conducted with careful examination of the evidence. Accomplishing this started with phase one of coding: line by line coding (Charmaz, 2014). The process of line-by-line coding was conducted and repeated to develop the units used for open coding (Charmaz, 2014). The codes were examined in detail to connect the data with the claims answering the questions to provide the claims with evidence. This process of line-by-line coding was repeated until a list of finalized codes was created. The process of line-by-line coding was conducted until all data could be categorized into specific topics that emerged from the data. Creating the units of data to develop results based on the interviews to answer the research questions.

Following the completion of line-by-line coding, open coding was conducted. Audio was listened to during review for heightened clarification for brainstorming on potential categories when conducting the open coding (Charmaz, 2014). To recognize moments when information repeats to develop the initial codes to then function and develop into the final categories. This enhanced the ability to find any categorical evidence to answer the research questions. Open coding was used as an attempt to develop initial categories within the data. Allowing development of codes suggested by the data to reach a statistical understanding of the research grounded in the data. After open coding was conducted the codes were analyzed to be placed into topics and themes to represent the data (Charmaz, 2014). Grouping the codes into themes allowed for further exploration into the data.

The second phase relates the list of codes to a connection between the codes and the research questions. Initial codes were examined and related to the factors influencing a provider's motivations to discuss sexual health. Focused coding was used to determine the data phenomenon concerning the research questions. During this process, the codes were considered related to the questions for coding all data (Bryant & Charmaz, 2007; Charmaz, 2014). Codes were interpreted, reorganized, and adapted during this process to conceptualize a finalized list of codes that identifies the provider's factors and motivations for initiating sexual health conversations with patients. During this process, the categories were evaluated, and subcategories were developed and related to each other. During this process the categories were examined for their theoretical connection with each other to ground the data into itself. The data was examined to connect through one logical train that represented the data categorically and with relation to each category in the data (Bryant & Charmaz, 2007; Charmaz, 2014). The author developed each category's specific aspects and identified the dimensions within the categories.

This process will allow the author to develop a deep analysis of the categories and develop accurate results to represent the data through categorical evaluation.

Results-Motivators

Three factors were discovered during data analysis that motivate providers to initiate communication about sexual health with patients with intellectual disabilities. The motivators are normative practices, patient initiation, provider observation. Motivators are the beginning of the conversation between healthcare providers and patients with intellectual disabilities. The motivators are designed to initiate the conversation of sexual health between patient and provider. Without the existence of one of the three motivators, communication about sexual health does not occur. These three factors motivate providers to initiate conversations about sexual health that are appropriate for their patients with intellectual disabilities.

Patient Initiation

Patient initiation was found to be a motivator influencing providers to communicate about sexual health based on the patient's desires and needs for the appointment. Patient initiation is usually communicated through the patient seeking education (e.g., questions, concerns for personal health, symptom reporting) and trust between patient and provider. Patients come to appointments with questions they have for their provider, guiding the conversation and seeking their answers. Providers tend to have guidelines for the appointment but will alter their communication to accommodate the patient's questions. The patient's concerns establish the visit, and the relevance to sexual health is determined, allowing providers to focus on their concerns. For example, Ophelia mentioned their approach to patient concerns "Anytime a patient comes in; obviously, it is either a complaint or a concern, and I try to educate about what is happening, and why, how to prevent it and have healthy body functions."

Penelope echoed, “I usually focus on their concern, like the patient's concern.". Providers will then determine the level of appropriateness for a conversation about sexual health based on the patient’s initial concerns. For example, Phyllis said, "If someone comes in for a discharge or for pain in the pelvic region […], it's appropriate and necessary for me to address their sexual health”. Concerns are a primary motivator for patient initiation; however, continuity between the provider and patient was found to be a factor in patients initiating conversations about sexual health.

The trust a patient has with their healthcare provider will influence the initiation of communication with providers. Patients with intellectual disabilities develop trust with their providers over time, contributing to the initiation of sexual health conversations. Sexual health can be a hard subject for patients with intellectual disabilities to communicate about, and an increased level of continuity with their providers helps to motivate patients to communicate with their providers. Providers build trusting relationships with their patients through methods of applied confidentiality, leading to increased trust from a young age. For example, Phyllis mentioned their approach to developing trust "I use gradual autonomy for the child during the office visit, increasing privacy of the physician-patient interaction. Begging about the age of 13, I provide a few moments where the parent leaves the room […] I offer them the opportunity to ask any pressing questions that they may have”. The provider can help build confidential trust with their patient prior to a concern developing. Phyllis continued, "We spend time talking about whom you talk to and who do ask questions of. The doctor is always a good person to ask”. Phoebe mentioned, "It's difficult to talk about those things in front of your parents. Um, so we're going to separate you, and so we can talk with your child just by themselves"(Phoebe). The level of continuity a patient has with their provider correlates to their level of motivation to initiate

conversations about sexual health. For example, Penny said, "The biggest thing is gaining that confidentiality. So, they know that they can talk freely with me". Without continuity, patients won't initiate intimate conversations with providers. Ophelia mentioned their experience, "I don't think people feel comfortable with their healthcare providers, in general, to bring up those things, especially with someone or someone that may think they are going to be judged." Penny ended with creating "the depth of trust" with patients can lead to an increase in questions from the patient.

Trust is developed over time between a patient and the provider. The level of trust a provider has with their patient will influence how a provider communicates with a patient. Often times results in a challenge to receive information accurate information. With a lower level of trust, a provider will have a harder time with the patient opening up and asking questions about sexual health and feeling comfortable discussing their sexual lives with the provider. Ophelia relayed their perspective "I don't think people feel comfortable with their healthcare providers, in general, to bring up those things, especially with someone or someone that may think they are going to be judged or being told because they are not able or smart enough or whatever or because we do make a judgment on people with disability". The Provider can only discuss sexual health with a patient to the level that the patient wants to discuss the topic. Penny mentioned "I think they're more willing to talk to you and tell you those things, just being a little bit older, and you can be a little more direct about those things and ask more specific questions". After initiating the conversation, of sexual health, a patient can choose to not share information or say they have no questions or needs while possibly desiring that conversation but not having the trust with their provider to have those conversations. Penny continued "it's when you ask those open-

ended questions in a nonjudgmental way, typically they're willing to talk to you so you can start talking about some safety things".

Providers desire patients to be involved with their health choices and ask questions to understand their treatment options and sexual health. Patient involvement promotes patient initiation through the initiation of communication of sexual health with a question based on their firsthand experiences of their body. For example, Ophelia said, "you want people to be involved with their healthcare even if there is an intellectual disability and they are able to truly comprehend they can still have that, they can still be involved in that as much as possible." Patients with intellectual disabilities will initiate conversations with providers about sexual health if they have questions. Ophelia talked about an educational conversation with a past patient "Wanted to have an intimate relationship, not necessarily sex but have a boyfriend, and they didn't know what that meant and why. Just really wanted to have a conversation about what a vagina is and what is kissing?". While providers desire questions from their patients, many do not receive questions and are unable to have as open of a conversation about sexual health.

Provider Observation

Providers' observations factor into providers' motivations for initiating conversations about sexual health with patients with intellectual disabilities. During the clinical visit, providers will make observations about the patient's lifestyle (e.g., independence, abilities, sexual activity level, multiple homes) and cues presented during the visit to develop a medical recommendation to educate their patients about sexual health. The observations made by the healthcare provider motivate them to initiate a conversation of sexual health with their patient with an intellectual disability. Phoebe made the conclusion about ability and treatment "It depends on the patient and the level of ability. Especially if a patient is going to be out in the world, acting on their own,

then they need to have information to make good decisions about themselves". Based on the lifestyle and abilities, providers have been found to make a different determination on how they communicate about sexual health. For example, Penny said the following, "Depending on their independence, their lifestyle kind of would change how I talk about their options. Someone who is completely non-verbal is not as sexually active, but needs something". Paula echoed, "Their ability to either take a pill daily or come in and get a shot every three months. We vary their treatment and individualized treatment plan based on all those things". Modifying their communication to meet the needs of the patient while still considering their lifestyle, Phyllis mentioned if "They are living independently; I don't believe I treat them any differently." Providers can suffer from bias regarding the patient's lifestyle and their potential needs. "If the patient is living with their parent, um, even as they reach maturity, depending on their level of dependence, I probably do suffer from some bias that they are probably not engaging in sexual exploration"(Phyllis).

During the visit, a provider will observe the patients' cues (e.g., body language, speech hesitation) to initiate and guide the conversation about sexual health. For example, Ophelia said, "I can usually tell with body language and get a feel for how they are answering or not answering." Phoebe mentioned modifications to her speech based on their patient:

"I take my cues from them and see how far along they are. I don't want to pile a whole lot of information on them that they're not ready for. I try to gauge their developmental level and make it appropriate for where they are".

Paula mentioned how they continue to remind patients about the conversation "A lot of times they are shy, they don't wanna talk about it sometimes you can see they wanna talk about it, but they don't wanna push very hard." Sexual health is a difficult subject that can be

intimidating to communicate about. Providers initiate a conversation based on subjectively interpreted cues to provide appropriate healthcare. However, Paula did admit a gap in care "The reality is doctors need to do this better because we don't do a good job and patients won't initiate, but they do want to talk about it." Providers are an important resource for patients with intellectual disabilities receiving education about sexual health.

The final aspect of provider observations is their consultation (e.g., medical education, recommendations, and observations based on lifestyle and cues), providing medical advice sought by the patient. If a healthcare provider makes the observation about their patient and the level of consultation they need will motivate a provider to communicate with their patient about sexual health. For example, Olivia mentioned their perspectives "Education is the reason ultimately [for the patient visit]. Whenever they come to see us, probably the most, the biggest thing, the most memorable thing that patients will walk away with". Oscar echoed, "Yea, I think it is driven in large part by what they are coming to me for. Are there risk factors from other medical conditions that could drive that. We talk about possible options." Giving patients the power of autonomy while offering medical advice Phoebe mentioned "I'm trying to get them, information so they can make good decisions and encourage them to know that they have a choice, and they get to be the ones to decide what happens and make good decisions about themselves." Phyllis continued "You have to filter everything through your medical assessment of the patient, the social, intellectual aspects of their care." Paula elaborated how they provide their medical opinion to patients "I kinda if I have a concern, I usually tell them if I if I think about it we should do it because that's usually something that comes back to bite us if we don't do it.". Phoebe echoed, "So if I have a concern that I usually suggested and say, you know what?

I think it's probably a good idea. Let's go ahead and check". Creating an open dialogue between the provider and the patient based on the observations the provider has been trained to make.

Normative Practices

When normative practices motivate providers to initiate discussions, such discussions are usually structured through the standards of care within the clinic. Normative practices can include guidelines and instruments used during a wellness check, a screening session (e.g., sexual health risks), or medical history-taking (e.g., symptoms to be reported). For example, Phoebe reported, "We do have a template in our electronic medical record that can guide the visits." Oscar echoed, “[there are] some standardized questions that we offer all of our patients." The normative practices of annual wellness visits also guaranteed sexual health are discussed. Such practices allow all providers to maintain uniformity of care, regardless of providers’ and patients’ preferences, differences, or circumstances. As part of the routine practice, Ophelia noted, “I will just ask matter-of-fact questions about their sexual activity. Single partner, multiple partners, male or female?”

Standards of practice allow providers to distance themselves from potentially awkward, insensitive, or discriminatory information-seeking conversations during the engagement of difficult and sensitive topics such as sexual health. Penelope explained, "There's a recommendation for everyone between fifteen and sixty-five to be screened once in their lifetime for HIV and Hepatitis C." Olivia affirmed, "Every patient that walks in my door is offered STD testing." Whereas discussions about and testing of HIV, STD, or Hep C can entail negative connotations of sexual activities or drug use, as a part of standardized practice, both providers and patients can engage in these discussions without potentially face threats. Alternatively Paula mentioned “wellness exams have changed like pap-smears we don’t do them every year we do

them every five years, so it kinda sucks because like that was a really good place to touch base frequently on a lot of things um so I still do them its just the frequency level has changed based on recommendation" ultimately effecting the frequency at which a provider ahs the opportunity to communicate with their patients. Penny describes their experiences "I don't have that, like follow-up that I would love to see and have, you know, people come in yearly from 12 to 17." (Penelope). Provider echoed, "I feel at 11, and they're there at 16 because they know they need immunizations. Right. Even if you ask them to come back, but those patients who do come every year, and we do talk about this, I mean". Limited exposure to patients has presented as a challenge to providers in their ability to communicate with patients about sexual health.

The standards of care are indicated by the specific nature of the medical encounter, a provider's routine is structured and limited by the cause of the visit (e.g., annual visit versus emergency). As part of the screening, Oscar used "standardized questionaries at the new patient encounter very briefly asking about [whether they are] sexually active, and […] have pain with intercourse." However, when a patient reports a different reason for an appointment, the standardized routine may not include such questions. Phyllis explained, "If an individual is coming in for a fever and a cough. It's not appropriate for me to address anything related to their sexual health."

Providers will adapt their communication during a good visit to the age of the patient for appropriate communication between the provider and patient. For example, Phyllis explained, "I usually begin the conversation about body parts, the names of the parts, when children are in elementary school." However, Age-appropriate conversations do not mean "dumbing" down the conversation, obfuscating topics, or creating euphemisms. Ophelia noted, "Use the name of the body parts appropriately. Don't give them nicknames — that can be confusing" As body parts are

named, boundaries are identified. For example, Phyllis said, "We talk about safe touch, who can touch, who cannot touch, we talk about ownership of one's private body parts." The type of visit and the age of the patient alters the communication that is initiated during the examination. Following guidelines set forth about when to discuss certain topics to make sure the conversation age appropriate.

As a child gets older, providers contemplate more complex, nuanced topics while considering the child's ability to process such information. Phyllis noted, "Then as the child gets older and we anticipate changes to the child's body to the child's intellectual, emotional, sexual development, we begin the conversation usually preadolescent." Physical maturity and mental and psychological development do not always go in sync for this particular patient population. As a result, for our providers, age-appropriate conversations are not solely determined by the actual age. Paula mentioned, "With intellectual disabilities, you have a lot more issues, but it depends on their level of comprehension and that particular day." Providers will continue the conversation with patients as an echoing of their body's developmental stages. For example, Phoebe mentioned, "By the time the kid is 13, 14, usually they are in the middle or later stages of sexual development, they're pubertal development, and so we continue to talk". As the patients develop and mature, providers can modify their communication about sexual health. Penny mentioned, "You can be a little more direct at 17 or 18 because you can look at a 17 or 18 and you say one of the questions". The use of direct questions has become more of a central practice within normative practices to unify information given to patients.

Alternatively, clinics may also routinely provide specific resources (e.g., education pamphlets and caregiver workshops) during the practice of care. The use of handouts produced

by their clinic is common to offer patients further education (e.g., sexual health education, treatment options, appointment summary) at the end of the appointment. For example, Oscar uses "Concrete education and handouts and one sheet of notes that they take and reference." Penelope echoed, "I have some handouts that I've given about just sexual health. I offer that in like a well-child check as well". The use of a handout is to continue the conversation initiated during visits when a sensitive and extensive topic like sexual health is initiated during the clinical setting. Normative practices allow providers to have a structure to their appointments and provide uniform education to their patients.

Results-Contextual Factors

There are five contextual factors that have been found to influence and direct a provider's motivations to discuss sexual health with a patient. Sexual health is a large topic, and providers need to have the ability to navigate the conversation about sexual health. Providers have initial motivations; however, the contextual factors provide an understanding in how healthcare providers modify their communication to fit the specific needs of their patient. The following contextual factors determine how a provider will continue a conversation about sexual health with their patients with intellectual disabilities. The four influencing factors have been found to be patient cognitive ability, patient verification, third-party verification, and provider interpretation.

Patient Cognitive ability

Patient cognitive ability is the first contextual factor to the provider's motivations to discuss sexual health with a patient with an intellectual disability. Including the patient's cognition, comprehension, and communication abilities with the patient is a potential influencing factor to providers' motivations. Patient cognitive ability is a passive influencing factor for

providers because both the provider and the patient have no control over the patient cognitive ability of the patient. The contextual factor cannot be influenced by alternative forces, determine that the provider modify their communication to meet the needs of the patient with an intellectual disability.

The patient's level of cognition in relevance to patient cognitive ability is the action of the provider understanding the patient's disability and the limits that accompany their disability. Understanding a patient's disability and level of cognition has the potential to impact the patient's ability to understand and comprehend the conversation. Intellectual disabilities manifest differently for each specific disability and one patient may have the cognitive ability to understand the conversation if adapted appropriately for effective communication. However, some patients with intellectual disabilities cognitive ability will not respond to modified communication that altering how one communicates may not impact the outcome of the conversation. Paula mentioned, "depends on the again with intellectual disabilities you have a lot more issues, but it depends on their level of comprehension and that particular day" when discussing sexual health with individuals with intellectual disabilities. Ophelia echoed, "I just have to judge their maturity level and the reason we are doing something like that, but as far as the act of having sex using birth control and talking about periods". The topic of sexual health can be brought up, but it is up to the provider to determine how the conversation will unfold. "They were that was significant, so we didn't have so we were able to not have a lot of discussions with the patient, and they were much more severe with their disability" (Phyllis). Phoebe echoed, "with patients with intellectual abilities, it varies in terms of the autonomy of the patient and how much they can make their own decisions and think critically and more abstractly. If they don't have that capability, then oftentimes we're talking about sexual health

with the parents included, um, patients who are severely limited". Oscar agreed "I think it would be deponed upon the patient's age as well as their um medical discussion-making capabilities" about a patient's cognitive ability being determined by cognition; they suggested that developmental age seemed to play a part in a patient's cognitive ability. A patient with an intellectual disability typically matures at different rates; this development directly influences the patient's ability to understand their provider and have conversations about sexual health.

Comprehension plays a direct role in a patient's cognitive ability and influences providers' motivations to discuss sexual health. The level at which a patient can comprehend a conversation about sexual health influences how a provider communicates with the patient about sexual health. Phyllis mentioned their approach to sexual health with this patient population: "Individuals with intellectual disabilities clearly are successfully partnered with individuals they successfully have a sex life they can successfully bare and raise children. So, it's a matter of having the conversation in a way that the individuals can best understand it". Paula echoed Phyllis when continuing the conversation of sexual health once it began "it depends on it depends on the patient's age comprehension and their yea intellectual ability to kinda have that conversation I mean if they I f yea I feel like ya know you should treat the person first and talk to the persona". Phyllis also mentioned, "To some extent, again, it's a matter of trying to have a conversation with the patient in a way that the patient can understand. So, it varies greatly based the where they sit on a spectrum of intellectual disability". If the patient is unable to comprehend specific language, a provider will modify their communication with their patient by using simple language to describe and go into detail about sexual health. Ophelia practiced, "but if they don't understand, um, I will try to clarify it a little bit more or to clarify what I mean by sex or sexually transmitted infections". While providers modify their communication to be more simplistic, they

do not shy away from using anatomical and medically accurate language with the patient, so they can develop their knowledge and level of comprehension after years of development. Phyllis stated their approach to developing with the patient "But the patient who may be in their 20s but has the intellectual capacity of an 8-year-old, I'm still having those meaningful conversations about body ownership, body safety, um, we do need to have conversations how the adult body is functioning."

Based on patient's current cognitive level determines the level of depth a provider can give their patient about sexual health. Patient cognitive abilities are discussed with the providers during initial visits and tracked through medical records and the healthcare providers relationship with the patient. Phoebe said, "It depends on the patient and the level of ability. When possible, and especially if a patient is going to be out in the world, if a kid is going to be out in the world, acting on their own, then they need to have information to make good decisions about themselves." with details about meeting the patient where they were and what was best for their life and ability, Penelope echoed "It depends on the level that intellectual disability and cognitive impairment or understanding of what that would be. Um, so depending on their independence, their lifestyle kind of would change how we would, um, How, how I talk about their options." Each patient is an individual who needs to meet at the level they are at in their life and ability or even desire to have a lifestyle that needs a discussion with a provider. Providers utilize the information about their patient's cognition and their intents to influence their approaches to sexual health communication. The cognition of the patient is included when a provider examines a patient's cognitive ability and ability to consent and understand treatment. However, their cognition is not the only part of cognitive ability that may influence a provider's discussion about sexuality; comprehension is another important part of cognitive ability.

Patient cognitive ability influences how a provider will communicate with their patient with an intellectual disability. If an individual is deaf, then they would need an interpreter to communicate with a patient influencing their communication. A provider has to analyze how they want to continue the conversation about sexual health with their patient based on the initial motivators for the discussion. The initial motivators are influenced by patient cognitive ability, and many providers respond with modified communication to aid the patient. Ophelia mentioned their approach to discussing sexual health with a patient with an intellectual disability after the conversation of sexual health has started "I'll alter it based on how I feel like their comprehension is". While altering communication is a result of patients' autonomy, Oliver shared their approach to these discussions, "boiling it down to the actual activity itself and just some very plain simple descriptions of what they expect when they put this pill in their mouth every day and take it and things like this will make it so that, you know, lead as much or we won't bleed at all so that, you know, your mom and dad can take care of anymore". Modifications in the communication of how providers communicate with patients are determined by the initial motivators to discuss sexual health and the patient's cognitive ability.

Patient Verification

Patient verification is the second contextual factor and serves as an active factor which can continually change during a single clinical visit for influencing providers' motivations to discuss sexual health with a patient with an intellectual disability. When a provider is with a patient, providers are actively interpreting the patient's answers in response to any probing that may have been conducted to examine the desires of the patient. Providers utilize patient verification as a way to determine the patient's knowledge, understanding, and treatment desires to modify their communication about sexual health during the clinical visit.

Checking for knowledge of sexual health is an action utilized to develop an initial understand of the patient's comprehension and understanding of sexual health with patients with an intellectual disability. A knowledge check is performed by the provider asking a question to the patient about what they know after the conversation of sexual health has been initiated. Based on the answer the patient gives to the knowledge check influences how the provider continues the conversation. Phoebe discussed their approach to knowledge-checking a patient, "So I ask them the questions and see where they are. And then I try to ask more specific questions to see how much they know, like, um, what are two things that can happen if you have sex.". When asking knowledge check questions, it is important for the provider to meet the patient where they are and to continue the conversation in a way, they can gain the most valuable information from their provider. Ophelia mentioned their approach to continuing the conversation of sexual health after the initiation of the conversation.

"I try to ask it more simply, or more elementary do you know what sex is? Do you ever have sex? Have you ever had an infection from having sex? Do you do anything to keep from getting pregnant? You know, I try to just based on what I think their understanding is; a lot of times, I'll have them repeat it back to me so if we come up with a plan, okay, what are we gonna do? When are you going to do that"(Ophelia)

Providers have adapted more to the use of verification questions because of the evolution of social media. The access to sexually related content has increased, and prior exposure to this content happens more frequently. For example, Phyllis said, "I just assume everybody has already heard some of this stuff. You can't open TikTok without having some conversation pop into your face; half the Instagram posts can border on soft porn depending on what you're looking for". After establishing the patient's level of understanding about sex and sexual health

providers will initiate a conversation about their treatment desires. For example, Paula continues "let's talk about what we can do, what you interested in, what have you tried? What have you heard about? Go from there?". Aftercare is established, providers will initiate a comprehension check of the plan with their patients with intellectual disabilities. Ophelia said the following: "I'll have them repeat it back to me if we come up with a plan. What are we gonna do? When are you going to do that?"

Providers are aware that patients have mixed feelings about healthcare providers asking knowledge check questions to develop an understanding of their knowledge and activity. Penelope shared their experience of having a mixed result from asking follow-up questions from patients, "I've definitely asked, which I mean, people are probably annoyed with me, but it's a lot more in-depth questions However these questions have become critical to a provider and the role they can play in the discussion of sexual health. The knowledge check questions play a large part in patient verification because the provider can modify the conversation to their needs; as Olivia mentioned, "Yeah, absolutely. As you readdress their reproductive goals, then you, um, then the conversation will certainly change" The conversation can be continued by repeating what was said in an alternative form for clarification or to continue to the next part of the conversation because verification was successful.

A patient's desires are used to influence a provider's motivation for discussing sexual health. Suppose a patient does not desire to have a period because they are in a wheelchair, then the provider will have a conversation about options related to sex and their desire not to have a period. The desire of the patient influences the specific topic of sexual health that is discussed. Paula mentioned "so what motivating it and kinda go from there because what's motivating is what going to drive the conversation". Ophelia utilized the patient's desires and leans into

including the patient in the discussion about their treatment “include patients even if they don’t fully understand or you know to know it is about them and if I see they have a preference or a want or a question in that as much as possible”. Providers' use of following up on the desires of the patient to verify where they are at is utilized just to not assume the patient's desires and learn from the patient about their needs. Phyllis mentioned, “I don’t want to make any assumptions about anyone”. Without the follow-up questions asking about the patient's desires, a provider can assume a small or large aspect and then not provide the treatment the patient came for because their desires have not been met. Penelope addressed their approach to avoiding the dilemma of assumptions in a clinical visit.

> “I try to make it as individualized as possible. My patients with intellectual disabilities, I often find that, um, They don't have a lot of questions, or they're from comfortable talking to me about things. So I've been comfortable. I offer to have the care aid staff out. Um, if they want to talk to me privately, and sometimes people will, sometimes they will accept that. And then talk to me a little bit more after, but sometimes they're not comfortable talking to me at all” (Penelope)

Sexual health is learned in developmental stages, and providers gauge the patient's desire for more information on the subject, which has an influence on what and how healthcare providers discuss sexual health with their patients with intellectual disabilities. “I try to gauge off of patient responses, how comfortable they are with me asking the questions, depending on how much further I go into detail.” (Penelope). Patients with intellectual disabilities have adjusted desires based on their unique needs, and this influences how a provider will discuss sexual health with a patient.

The questions that the patients ask their provider after initial discussions about the sexual influence the direction of the continued conversation of sexual health. “That is also a good time to ask questions related to their sexual identity, their sexual activity, um, their sexual exploration, and any questions they may have that they don’t want to ask the parents about.”(Phyllis). The questions are also utilized to know where the patient is, asking about periods is a different conversation from STD or even pregnancy.

> “Um, are you sexually active? When do you think you're going to become sexually active? What kind of plans do you have for yourself? What values are important to you, and how you can incorporate that into, you know when you decide to do that and if they are sexually healthy, I mean, active, then we'll talk about, okay. Are you ready to have a baby? Do you know how you are going to prevent pregnancy? How are you going to prevent infection? Do we need to check for infection today? You know, let's check, and S, you know, have you missed periods? Are you pregnant?” (Phoebe)

In some cases, this may be the end of the conversation because the patient has no further questions on the subject on which the conversation ends. If a patient has no more questions or desires to continue the conversation, then the conversation about sexual health ends, and providers will either move on to other patient concerns or finish their visit with the patient.

Third-Party Verification

Third-party (e.g., guardian, caregiver, POA) verification can occur naturally by the third-party such as a parent or caregiver sitting in on the appointment. The individual present may join in silence simply observing the interaction or the provider may request them to add to the conversation for a better understanding of the whole picture and the needs of the patient. Having a deeper understanding can influence how in-depth a provider can go or to what level of

knowledge the individual may require. At times the third party can confirm that the individual with an intellectual disability is not sexually active, and that information will influence how the provider communicates with the patient about sexual health. Penny asked “Do you think they understand this? And at that point, we try to talk to about like sexual health and safety and private parts and those types of concerns based on like, um, like the intellectual understanding.” Helping to form and shape the appointment to the specific needs of the patient to reach the desired outcome. Penelope mentioned how they utilize a guardian present in clinic “then if the guardian and the patient needed to make the decision together, but I, you know, I usually let that be their choice.”

Providers will utilize comprehension-seeking questions and treatment plan verification questions to verify the patient’s understanding while engaging the third party to verify the patient's understanding and develop treatment plans. For example, Paula directed baseline questions to the third party present, " have you ever thought about [sexual activity]? Can they understand the word sexual activity? Have they even thought about being sexually active? Have you ever thought about do you think romantically about other people". Phyllis mentioned their verification conversation they have with caregivers, "talking with them very specifically about the need to protect the patient and potential partners from pregnancy, from disease, that sort of thing. Always reemphasizing if I have had this opportunity". Providers will seek patients’ responses before advancing the conversation.

The use of a third party to verify the patient’s understanding and comfort is a common practice as patients with intellectual disability come in with either a guardian or a caregiver who has the potential to provide further insight on the patient that could benefit the provider’s ability to treat. Providers' use of third-party verification is subtle in comparison to patient verification by

setting up individuals in a way to be able to glance at the third party for verification during the appointment. Paula mentioned how she utilizes a third party for verification:

" I still talk to the person, and then I'll get a side glance over the other direction. Sometimes I line them up, so I don't have to move my eyes to be able to see them, and I can see them in the background or out of the corner of my eye nodding or shaking their head."

The use of a third party in the room helps providers to initiate information about sexual health so that the patient can understand and feel in control of their medical decisions. Penny mentioned, "I talk to the guardian; what do you think they understand this? Do you think they understand this? At that point, we try to talk about sexual health, safety, private parts, and those types of concerns". These conversations with the third party can evolve into conversations about treatment plans. Depending on the medical power the patient possesses can alter the motivations of the provider for the type of conversation. Penelope allowed mutual choice with the third party "if the guardian and the patient needed to make the decision together, but I, you know, I usually let that be their choice."

Alternatively, if a patient has a higher level of impairment, the provider will change their initiation of the conversation to the other party and adapt the language being used. Providers will initiate an alternative conversation about sexual health with the guardian depending on the patient's ability to comprehend and communicate. For example, Phyllis mentioned, "Usually, the people with intellectual disabilities have their guardian with them, particularly if their disability is significant enough that they cannot consent to their own treatment. Usually, it is a simultaneous conversation, and I do usually address the caregiver ". Establishing medical care, safety, and concerns for the patient with the guardian becomes more important with patients with severe disabilities. Oscar initiated different conversations depending on the medical power status

of the patient; for example, " It would be deponed upon the patient's age as well as their um medical discussion making capabilities if the patient does not have a decision for medical power of attorney for making decisions." While Phoebe echoed similar practices with patients with intellectual disabilities "Varies in terms of the autonomy of the patient, how much they can make their own decisions and think critically and more abstractly. If they don't have that capability, oftentimes we're talking about sexual health with the parents included". The provider plays a vital role in the discussion-making process of treatment for patients and is their resource for sexual health.

Providers Interpretation

Providers interpretation is the influencing factor that is determined solely based on the provider and their medical knowledge. A patient goes to a healthcare provider for their medical interpretation about something happening with their body or for the potential education they can provide. The healthcare providers interpretation also controls what type of sexual health information is provided based on the conversation. Providers presented an increased motivation for their desire to educate and inform their patient about the best options based on their medical opinion helping to reach the patients goal of the appointment. When a patient is in the clinic, it becomes the perfect opportunity to educate the patient, provide medical knowledge, and make recommendations based on the patient's lifestyle and desires. Healthcare providers routinely view a "provider's interpretation" as the main reason a patient seeks out their medical opinion and is in their clinic being treated.

> "Education is the reason really ultimately right. Whenever they come to see us, probably the most, biggest thing, the most memorable thing that patients will walk away with. Um,

and so I like to make sure they feel like they have a really good grasp on, um, everything that we've talked about in the visit" (Olivia)

Providers view their medical advice and education as the reason for the patient to be in their office to begin with because the medical education a provider is able to give the individual is vital to the individual understanding their body. Without the aid of a healthcare provider, individuals would not have the medical help and attention that is received. Medical education influences how a provider communicates about sexual health because their education has also taught them how to eliminate choices presented to patients based on the desires of the patient. Phyllis mentioned the standard for physicians "part of the global assessment and recommendation process not simply exclusive to sexual health but um yea you have to filter everything through your medical assessment of the patient, the social, intellectual aspects of their care.". Many of the providers described the steps they take to provide their interpretation to the patients. Many of them balance the different influencing factors to provide the best medical advice to their patients. Phyllis established the basic level of assessment generally used in medicine;

"We use a technique in medicine called the five A's. I don't know if you guys talk about that in communications or not, but it asks, advises, uh as, what is it ask to advise, asses, ya, assist and then arrange to follow up, and the idea is that you are asking all these questions and then you develop the recommendation and walk them through it and so that second piece is where I tend to get pretty blunt"(Phyllis)

Others suggested a similar routine in providing their medical advice based on their interpretation as a trained healthcare provider. Olivia said "I keep in mind any potential limitations they might have or inability to receive birth control.". Oscar continued the conversation and the information

that is provided to aid their patient in making medical decisions. “I always try and lay out all the options that are available to them risks, pros and cons, and help them with the best decision”. Providers have gone through extensive training to memorize the interactions between the body and medications and other potential medical solutions to a myriad of medical problems. Olivia provided examples of how they process their patient's information to provide the best recommendation to the patient based on what is discussed during the visit, “For example, if they have trouble swallowing the pill, then we're probably going to start talking, options that are not pill based. If they really have a needle phobia, we're going to probably talk about options that don't require shots every three months”.

The provider's role to their patients influences a provider’s communication with their patients about sexual health by manipulating how they have to relate to the patient and communicate necessary information. A provider is influenced by the topic of sexual health needs to be addressed with the patient because the topic of sexual health is very encompassing. It would be impossible for a provider to hit on every subtopic of sexual health with one patient in one visit. “Yea, I think it is driven in large part by what they are coming to me for. Are their risk factors for stuff, ya know, from their other medical conditions that could drive that, and as we talk about possible surgical options or medical therapies, making sure we don’t have any conflicting contraindications or anything like that.” (Oscar). If a provider has to diagnose a patient with a sexual infection their motivations around the conversation are completely different causing a switch in their communication with the patient. “I make a recommendation, and then I give them a category of two to three different options, and I walk through what’s a most likely side effect, good or bad, what the dangerous side effect would be, and then assess what their, what their choice would be” (Phyllis). A provider may also have to address the patient about

sexual assault and the provider's role evolves in these situations influencing their motivations to talk about sexual health and how sexual health is communicated with their patients with an intellectual disability. “It's my responsibility, our responsibility, to take them down that road and happen. Think about those possibilities and do everything we can to ensure that their child is safe in all situations”. (Phoebe)

> “I tried to be as open with her about what you feel would make you safe. And then I talked to her. The future of screenings that we would still want to do. You know, she was tested once for a couple, you know, for routine screenings for STDs, but they wanted to make sure that in the future, I, you know, we need to retest her.” (Penelope)

Interpretations made by the healthcare provider about the patient’s lifestyle influence what aspects of sexual health are discussed because the patient’s lifestyle has a large impact on the recommendations made based off of the providers interpretation. If an individual with an intellectual disability is unable to remember to take a medication every day, then a provider will not discuss those options with the patient. Wheelchair users have different lifestyle needs than other individuals with an intellectual disability and their providers have the ability to address and make recommendation based off of those needs “we have lots of ways to get to the ultimate end and let’s go in a direction the person can appreciate and accept” (Paula). Penelope continued the conversation “It's just, whatever's going to work best for, you know, the patient and their lifestyle and how they're going to be able to make sure that it is consistent”. However, the medical options for an individual’s sexual health are vast with the intention that a patient would never be able to make a choice of what to do without their Paula recommended. “she also has cerebral palsy, she can’t she’s a total care and so ya know the concept for that yes obviously pregnancy but also just having to deal with menses when you are a total care is a big deal so I, I actually

think that was a really smart thing to do." Lifestyle recommendations are an important part of the providers interpretation and how their recommendation to patients is influenced by their disability needs and the needs of the visit. The patient needs to determine and influence how and what aspects of sexual health are discussed with the patients from the interpretation of the provider. Ophelia offered their interpretation "just talk about wellness and what is happening based on the time in your life, whether it be conception or perimenopause menopause or all of the changes that happen throughout a woman's lifetime, puberty ya know" Echoed by Oscar, "the conversation is going to be vastly different if you know the average age of my population is about 55 years old, so uhh that's a much different conversation than ah a 19-year-old population who is trying to decide if they are going to become pregnant in the near future or a 13-year-old whose trying to decide if she's going to become sexually active".

Table 1

Summary of Findings

	Definition	Example quote
Motivators		
Patient Initiation	Influencing providers to communicate about sexual health based on the patient's desires and needs for the appointment	"you want people to be involved with their healthcare even if there is an intellectual disability and they are able to truly comprehend they can still have that, they can still be involved in that as much as possible."(Ophelia)
Provider Observation	Initiating conversations about sexual health with patients with intellectual disabilities	"I take my cues from them and see how far along they are. I don't want to pile a whole lot of information on them that they're not ready for. I try to gauge their developmental level and make it appropriate for where they are". (Phoebe)
Normative Practices	Discussions structured through the standards of care within the clinic	Phoebe reported, "We do have a template in our electronic medical record that can guide the visits." Oscar echoed, "[there are] some standardized

		questions that we offer all of our patients.“
Contextual Factors		
Patient cognitive Ability	patient’s cognition, comprehension, and communication abilities	It depends on the level of intellectual disability and cognitive impairment or understanding of what that would be. Um, so depending on their independence, their lifestyle kind of would change how we would, um, How, how I talk about their options.”(Penelope)
Patient Verification	patient’s knowledge, understanding, and treatment desires	“So I ask them the questions and see where they are. And then I try to ask more specific questions to see how much they know, like, um, what are two things that can happen if you have sex.”(Phoebe)
Third-Party Verification	Guardian, caregiver, POA’s verification of patient’s knowledge and understanding	Penny asked “Do you think they understand this? And at that point, we try to talk to about like sexual health and safety and private parts and those types of concerns based on like, um, like the intellectual understanding.”
Providers Interpretation	Educate the patient, provide medical knowledge, and make recommendations based on medical knowledge and opinion	“part of the global assessment and recommendation process not simply exclusive to sexual health but um yea you have to filter everything through your medical assessment of the patient, the social, intellectual aspects of their care.”.(Phyllis)

Discussion

The study's results examining healthcare providers' motivations when communicating with patients with an intellectual disability about sexual health revealed the start of a deeper understanding of a health disparity in the culture. Establishing that providers have communicated with their patients with an intellectual disability about sexual health when one of the three motivators occurs and is influenced by the four contextual factors that control how healthcare provider communicate about sexual health. When a clinical visit occurs, and if the initial

motivators occur; then a conversation about sexual health can begin. Without a motivator being present, healthcare providers will not discuss sexual health with their patients with intellectual disabilities because it may be unwanted or inappropriate based on the patient's current needs. The contextual factors were found to control the communication after the motivators had been established, dictating the specific nuances of a healthcare provider when communicating with a patient with intellectual disabilities. Providers have a clear pathway to establishing a conversation about sexual health and communicating it with their patients with intellectual disabilities by addressing the topic when normative practice, patient initiation, and provider observation occur. Then determining the directions of the conversation based on patient cognitive ability, patient verification, third-party verification, and providers interpretation.

When a patient arrives at the clinic, they have made the appointment for a specific reason and potentially gone through some initial screening questions. This is a normative practice of the clinic to establish what the patient needs from the provider. The human body is very complex and cannot be covered in one visit, and the United States has a more segmented healthcare system referring patients to specific providers based on their needs that establishing the need prior to the visit is important. The healthcare system has also established patterns and routines for physicians to check on their patients based on the potential development of unknown ailments before it gets to a not treatable level. A provider relies on motivators to start the conversation about any medical topic, especially sexual health. A provider must judge the initial reason for the visit to determine if a conversation about sexual health is warranted, if the clinical recommendations require the conversation to occur, and if the patient initiates the conversation.

The providers' observations are a culmination of many little bits of information collected from the patient during the visit, from prescreening to the provider being present with the patient.

General practitioners have the potential to see a patient for a myriad of reasons, and many of those reasons do not warrant a conversation about their sexual health. Often providers wait to initiate the conversation until a further visit for new clientele or a sick patient visits. The provider is there to be the delivery method of health information about the patient's body and how to take care of their body at the current moment. Suppose a potential reason arises that the providers feel the need to address their sexual health based on the preestablished needs of the patient or any symptoms mentioned during conversations with their patient. Then the provider will mention if they are worried; however, if someone is coming in for an unrelated issue, the conversation about sexual health will not begin. After the conversation of sexual health has been initiated, the provider will control the conversation based on contextual factors as to how the topic of sexual health is communicated with the patient.

The initiation of a motivator needs to occur before a healthcare provider will communicate about sexual health with a patient with an intellectual disability. Providers address all concerns or scenarios that may occur while targeting how best to communicate the knowledge to their patients based on the influencing factors. The contextual factors are patient cognitive ability, patient verification, third-party verification, provider interpretation. The providers use patient cognitive ability to gauge at what level the health information needs to be addressed. Patient verification is the process of understanding where the patient is at with the information provided to them during the conversation. Third-party verification is the use of any other party in the room that comes with the patient to verify any additional details or confirmation of the patient's response and understanding. The provider will then utilize their interpretation of the information given and any challenges that may occur to achieve the best outcome for the patient.

However, if the conversation never starts, the patient never receives any information or inquires about the subject matter. Providers have ways to navigate the conversation, state the conversation is occurring, and evaluate every patient based on their motivations and influences. The contextual factors can determine the differences in how a provider communicates with an individual with an intellectual disability, that patient's specific needs, and how the factors interact in the conversation. The conversation needs to start and only start with one of three motivators. Individuals with an intellectual disability are known not to receive any primary education from parents or educators as their non-disabled counterparts. Their nondisabled counterparts are provided with primary education and knowledge to seek further education from their provider on sexual health. Limiting one motivator for patients with an intellectual disability without the knowledge to discuss sexual health with their provider, they will not create a visit that would trigger a series of normative practices to discuss sexual health—continuing to eliminate another motivator leaving the initiation of the conversation on the provider and their medical observation of the situation. If an individual with an intellectual disability does not see a general practitioner or a reproductive health physician, the provider will not have those conversations based on their medical scope. The patient could see a primary care or a generalist; however, the patient's disability will have a focus in the clinical visit that the provider may not observe or think about starting the conversation. If the conversation is never started, there is no communication about sexual health.

Providers do have a lot on their workload, an overabundance of patients, and their ability to educate is limited to the specific needs of the visit. The high workload has resulted in limited timeframes to treat and visit patients to accommodate the abundance of patients. Many providers spend an average of 15 minutes with each patient, and more time would allow a provider to give

well-rounded patient care (Tai-Seale et al., 2007). Over time the limited access has forced the education of self onto other individuals, such as teachers and parents, to aid in compensation for their knowledge under the assumption that education about the care of yourself would be provided and healthcare officials can give further advice when expressly warranted through the clinical visit (Andersen et al., 2007; Fuzzell et al., 2016). The combination of clinical reasons, time restraints, and special needs as a priority in treatment has created a gap for patients with an intellectual disability because they do not receive the primary education to care for themselves. Providers are at the discretion of what to discuss with their patients based on why the patient is present for a visit and what the providers believe to be the ideal recommendation for the patient (Legere et al., 2017). Often there must be more time to cover anything than the initial reason for the visit. If a provider believes a conversation about preventative medicine or education is irrelevant or a concern for the patient, it will be overlooked. This control over the appointments has the potential for a cultural bias to control how a provider approaches work with a patient from a disability culture. Often in the clinic, a provider may only have a small percentage, between 1 and 5 percent of their patients with some form of disability (Mapou, 2022). While another provider will have almost an entire clinic of patients with an intellectual disability. Daily disadvantages and social stigmas produced by society creates a viewpoint that individuals with an intellectual disability are a burden.

Limitations and Future Directions

The current study presented a few limitations that could improve for further exploration into sexual health disparities for individuals with intellectual disabilities. The initial limitation was the number of interviewed participants; the study had nine participants. The interviewed participants ranged from a few different types of healthcare providers who discuss sexual health.

Across all interviews, that data was categorized appropriately and are grounded in the data. A larger participant pool would allow further saturation of the data. All the participants had patients with an intellectual disability but only had a 5% patient cliental limiting their experiences. A few providers stated having a higher saturation of patients with an intellectual disability in their clinic. Interviewing providers with more experience working with patients with an intellectual disability could give richer data to aid in the data saturation.

Further exploration into the start of the conversation and how the motivators occur could aid in understanding the present health disparity. Individuals with an intellectual disability have more challenges in starting the conversation of sexual health to receive knowledge about their bodies and be able to communicate with their providers about sexual health. The current study focused on identifying providers' motivation and influencing factors in communicating with their patients with intellectual disabilities. The providers have those factors and utilize them with their patients; however, a discrepancy still exists because they claim from the provider is it is communicated when appropriate, and individuals with an intellectual disability claim sexual health is not communicated with them. Based on the findings, exploration in the start of the conversation of sexual health is the next step in understanding the health disparity present to have the potential to create a target solution for the existing cultural health disparity.

Conclusion

The health disparities for individuals with an intellectual disability potentially rest in the start of the conversation. If the conversation begins, a provider will have a reasonably appropriate conversation with their patient with intellectual disabilities. However, the conversation will never occur if the initial motivator does not occur. The cultural health disparity exists, and further exploration into the details of the disparity is required to establish a complete

understanding of the phenomena occurring between individuals with intellectual disabilities and their sexual health. The current findings contribute a detailed understanding of how healthcare providers communicate with patients with intellectual disabilities to the current research. Explaining the discrepancies that exist in the research about medical providers do not communicating with patients with intellectual disabilities. Discovering that healthcare providers are communicating about sexual health with patients with intellectual disabilities and the current problems do not reside with the motivations of the provider.

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