I WASN'T PREPARED FOR THAT: INTELLECTUAL DEVELOPMENTAL DISABILITIES UNTOLD STORY ABOUT INTIMATE PARTNER VIOLENCE

by

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Submitted in partial fulfillment of the

requirements for Departmental Honors in

the Department of Social Work

Texas Christian University

Fort Worth, Texas

May 2, 2022

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ABSTRACT

Individuals with intellectual or developmental disabilities (IDD) experience unjustly high rates of intimate partner violence (IPV) related to disability risks that often can be reduced through focused intervention. The purpose of this research is to investigate the victimization of intimate partner violence among individuals with intellectual or developmental disabilities with an emphasis on the level of preparedness an individual with IDD has after intimate partner violence victimization. This study utilized a qualitative, exploratory design; participants were individually interviewed and asked questions to gather their experiences, perspectives and knowledge regarding intimate partner violence safety planning and services provided within their communities. Three main themes emerged from the individual interviews: 1) awareness of safety planning, 2) awareness of intimate partner violence, 3) safety and resources. The results of this study revealed important insights about participants' experiences, perspectives and knowledge regarding intimate partner violence safety planning and services provided within their communities. Researchers learned ways to improve disability service programs by advocating for inclusive victim assistance programs to better serve the IDD community.

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Background

The American Association of Intellectual and Developmental Disabilities (AAIDD) defines intellectual disability as "a significant impairment in general cognitive functioning, social skills, and adaptive behavior." (AAIDD, 2021). The US Department of Health and Human Services (HHS) encompasses a much broader use of the term intellectual disability to include developmental challenges. The addition of developmental challenges includes the "lifelong challenges that can be intellectual, physical, or both" (HHS, 2021). IDD, or intellectual or developmental disabilities is the term often used to describe situations in which intellectual disability and other disabilities are present (HHS, 2021). According to the AAIDD (2021), this disability typically originates before the age of 22. Therefore, for the purpose of this research IDDs and or IDD will be used interchangeable throughout the study. Intimate partner violence (IPV) is a serious public health concern as well as a violation of human rights (Grande, Hickling, Taylor, & Woollacott, 2003; Uno, Ui, & Aoyama, 2004). Intimate partner violence, also referred to as domestic violence, is typically thought to include behaviors intended to exert power and control over another individual, including physical, sexual, verbal, emotional, or financial abuse (Robinson-Whelen, Hughes, Gabrielli, Lund, Abramson, & Swank, 2014).

Individuals with IDD are sexually assaulted at a rate seven times higher than those without disabilities (Shapiro, 2018). The general population has historically segregated individuals with IDD from their personal sexual interest by neglecting and denying them education resulting in the upholding of negative stereotypes regarding their sexual freedoms (Kempton & Kahn, 1991).

Sexual victimization occurs when there is opportunity for the perpetrator to exploit situations that give them power and control. Lightfoot and Williams (2009) state these instances are amplified when the vulnerability of their potential victims is increased, and the risk of their victim's exposing exploitation are diminished. For people with intellectual or developmental disabilities, this formula for becoming a target puts them directly into a high-risk category, as their vulnerability is directly related to their ability to discern and appropriately communicate in different social environments (2009). The more people with IDD lack these skills, the more vulnerable they become to sexual exploitation. In a 2018 radio series, the US National Public Radio cites recent studies that highlight the rates of sexual exploitation among people with intellectual disability is much higher than people without intellectual disabilities. This trend is even more alarmingly elevated among black women with intellectual disability for whom the rate is 12 times higher (National Public Radio, 2018).

As victimization typically occurs where opportunity exists, the dependent and sheltered nature of the lifestyles of most of the people with intellectual disability in our society exposes them high risk of exploitation within their normal social circles. This is classified as intimate partner violence (IPV) as people who are known and have contact with people with intellectual disability become the abusers. People with intellectual disability are naturally dependent, and often lack the social skills to detect, prevent and communicate threats of IPV before, during, and after abuse occurs. The nature of their disability renders these individuals especially vulnerable to high-risk IPV circumstances.

Study Purpose

The objective of this study was to gather qualitative data through individual interviews to learn participants' experiences, perspectives and knowledge regarding intimate partner violence

safety planning and services provided within their communities. Researchers expect to learn ways to improve disability service programs by advocating for inclusive victim assistance programs to better serve the IDD community. Our research question for this study is what are the participants' experiences, perspectives and knowledge regarding intimate partner violence safety planning and services provided within their communities?

Methods

Research Design

This study utilized a qualitative, exploratory design to gather participants' experiences, perspectives and knowledge regarding intimate partner violence safety planning and services provided within their communities. The study utilized a constructivist theoretical framework where themes and patterns in collected data were revealed rather than predetermined. Individual interviews were conducted to collect personal stories. Kruger and colleagues (2019, p. 245) state, "Individual interviews have traditionally been an important data collection method in qualitative research." This study was approved by a Texas Christian University institutional review board for human subject research.

Participant Recruitment

Participant recruitment began after the study protocol was approved by the Institutional Review Board at Texas Christian University. The researcher started recruitment with personal contacts who self-identify as an individual with an intellectual or developmental disability and self-identify as an individual who has experienced intimate partner violence. The researcher contacted personal contacts through text, email, facetime, or Facebook messenger to inform the m about the study and forwarded the recruitment message. Snowball sampling was used to find additional participants. The recruitment messages and flier were distributed by the researcher,

and sharable by others through social media including Instagram and Facebook. Each post contained the recruitment message to help reduce the possibility of undue influence or coercion.

Data Collection Procedures

Due to Covid-19, in-person interviews were not conducted. Interviews were conducted remotely through Zoom video conferencing software. Each individual interview was approximately 45 minutes. Consent documents were delivered electronically to participants 24 hours before the scheduled interview. The documents included the consent form and the media recording consent form to the participants or their legally authorized representative. Participants or their legally authorized representative reviewed the form and had the option to sign electronically before the interview took place. If a consent form was signed by a legally authorized representative, the participant was asked to complete an assent form. Participants or their legally authorized representative were given the option to receive a physical copy of their signed consent documents by mail. Participants also gave verbal consent stating they had read and understood consent to interview. The research study did not involve any procedures for which written consent is required outside the research context. Participants were informed that audio recording is necessary for transcription and analyses purposes. Personal identifying information was not collected. Individual participant data was not collected, reported, or published. Participation was completely voluntary, and the researcher informed participants that they can withdraw from the study at any time or choose to have their interview excluded. There was no penalty for withdrawing. To withdraw, participants had the option to contact the secondary researcher by email or phone. No incentive or payment was used to encourage participants, and participants receive no reward.

In addition, it is increasingly clear through past research that individuals with IDD not only can make decisions and provide informed consent so long as certain safeguards are in place, but they value the opportunity to participate in research, and their participation has clear social and scientific benefits (Boxall & Ralph 2010; Dalton & McVilly 2004; McDonald, 2012).

The researcher was trained to facilitate individual interviews by acquiring knowledge and skills in social work micro practice. The interviews were conducted following a 15-question guide created by the researcher (see appendix E). The guide opened the conversation to help facilitate conversation regarding the participants' experiences regarding intimate partner violence and safety planning. Follow up questions were also asked based on participant responses.

Inclusions and Exclusions

Participants self-identified as an individual with an intellectual or developmental disability and as an individual who has experienced intimate partner violence. Participants were over the age of 18, and capable of self-consent or had a legally authorized representative consent to research. The researcher recruited four (N=4) participants. Those who are under the age of 18, unable to consent to research, or identify as only having an IDD, or being a victim of intimate partner violence were excluded.

Data Analysis

Interviews were audio recorded and transcribed using the online transcription service Rev. Qualitative software program, Dedoose was used to break down the data into first level concepts and categories. Focused coding was then performed to condense and sharpen the themes and concepts that have emerged from the data. Focused coding requires looking at what the initial codes imply and reveal about the data. This coding is guided by concepts and categories identified during the initial coding process. A thematic analysis was then used to

identify participants' perceptions regarding intimate partner violence safety planning services within their community.

Results

Four participants self-identified as an individual with an intellectual or developmental disability and as an individual who has experienced intimate partner violence: three females and one male that were over the age of 18 years participated in this study.

Table 1. Sample Demographic Characteristics.

Variables	%
Gender	
Female	75.0
Male	25.0
Highest Level of Education	
High School	50.0
Some College	50.0
Cognitive Level- was self-reported by the participant	
Mild	25.0
Moderate	50.0
Moderate-Severe	25.0
Race	
White	50.0
Hispanic/Latino	50.0
Age	
35-45	75.0

45-55	25.0

Note. N=4.

Findings

Three themes emerged from the data which proved significant in gaining a better understanding of participants with IDD experiences, perspectives and knowledge regarding intimate partner violence safety planning and services provided within their communities. The three main themes evident from analyses of the individual interviews were 1) awareness of safety planning, 2) awareness of intimate partner violence, and 3) safety and resources. Each theme is substantiated by participant statements that were made during the individual interviews.

Theme 1. Awareness of Safety Planning was broken into two sub themes 1) lack of awareness, and 2) general idea of safety planning. The participants' overall knowledge regarding intimate partner violence and safety planning was no knowledge to minimal knowledge. The participants lack of awareness of safety planning lends to increased improvements in public awareness. Here are some thoughts shared by participants, "Not really." and "I guess I was too young to really even know about anything like that." Another participant shared, "The battered women shelter was the first time." the participant had previously been a victim of IPV. The participant's previous incidences were not taken seriously until she was hospitalized due to an attempt to leave the batterer. At the battered women's shelter was the first time she had been formally educated on safety planning procedures.

The second sub theme was the participants' general idea of safety planning after victimization. After victimization, a general awareness of IPV and safety planning was established but it too was very basic knowledge. The participants shared mixed feelings

regarding safety plans and its effectiveness. This participant had a safety plan in place but questioned its effectiveness, "Because no matter how much of a safety plan you have, they're not fail proof." Another participant used the safety plan as a navigation tool, "I just feel like it's something that helps you to guide you in the right direction." This participant used the safety plan to help inform their decisions on how to leave, "Maybe make more informed decisions about what you do and what you don't do." A feeling of safety was felt by this participant, "I started to create a plan to leave, to create a plan to feel safe." These statements can assist providers in using a strength based approached when assisting victims in creating their plan.

Theme 2. Awareness of IPV was broken into two sub themes 1) lack of awareness, and 2) general idea of safety planning. The participants lack of awareness of IPV highlights the need for healthy relationship education. Participants all shared a common feeling regarding IPV awareness, "I would say no, I was, not." and "Yeah. I'd never even heard of that." These participants had no educational awareness of identifying IPV. This participant knew about domestic violence but was unaware until seeking help she was a victim, "You mostly just hear domestic violence."

The participants general idea of IPV after victimization changed dramatically. Through counseling participants were then able to reflect and identify red flags within the relationship. Here are some thoughts shared by participants "The love bombing in the beginning." "You can be... by words, by actions, by manipulation, by control." "I feel like a lot of people don't think that they're in a domestic violent marriage because, if they were never hit, but now I know that that's not true." and "It's when you have been intimately involved with someone, and they abuse you or they neglect you or treat you very badly." These statements show that there is not one type of IPV but a variety of power and control tactics which batterers use.

Theme 3. Safety and Resources was broken into three sub themes 1) internet and media, 2) family and friends, and 3) counseling. Participants sought help through online resources for better clarity in developing a safety plan to best prepare for possibly future IPV victimization, and or to make a plan to leave. Victims put their resources in the palm of their hand with the use of a smartphone. “Look stuff up online.” participants quickly learned that the Internet and a variety of media platforms provide a wealthy of information. The information is safe to access and is available to them whenever they need it. IPV awareness is instantly raised in educating the community and providing a risk-free approach to gaining information. Internet and media fosters courage and community for victims. Awareness is critical in in the first steps of leaving or after victimization.

Overall, participants relied on family and friends to help them initiate the safety plan and to assist them in leaving the relationship. Participants also shared that their lack of knowledge made them more vulnerable to victimization and in getting help sooner. Family and friends were instrumental in providing ongoing support to participants. These participants shared that their success would not have been possible without their support. In their words participants shared, “I did turn to my parents, and they were able to help me get out.” “Support. Just having someone to listen and be there.” “My sister and two of my best friends, they can see my location.” and “_ knows about everything I've been through, and I tell him quite a bit.” The show of support from family and friends was key in validating the victim’s story. Another connection to family with these victims was that they had all witnessed a form of IPV in childhood and some felt it was normalized in relationships.

The participants all turned to counseling to process their trauma and to help sort out their lives. One participant shared, coping without counseling would have led them through a repeated

path of victimization. Each participant shared a similar voice; “I went to a marriage counselor and a counselor for myself.” “Therapist or a counselor online.” “I talk to my counselor.” and “Counseling and still do therapy sessions.” Through counseling participants learned that early education would have helped them to identify the red flags and to make a better decision before committing to a relationship.

Discussion

The results of this study uncovered insights about experiences, perspectives, and knowledge among participants with IDD regarding intimate partner violence safety planning and services provided within their communities. Participants’ stories aid in recommendations for improvements for inclusive programming and community resources. Based on the results, IDD individuals experiencing IPV share the same or similar feelings as neuro typical individuals. They process feelings and emotions equal to or perhaps a bit deeper due to their disability which makes them more vulnerable. Advocacy for equitable service programming for IDD individuals is imperative. The importance of opening the discussion to end the normalization of IPV through continued education of healthy relationships.

However, there are areas in which the vulnerability and risk to people with intellectual disabilities can be diminished. Paramount on this front is appropriate, preemptive sexual education for the individuals with IDD (Arrango et al., 2014; Senn et al., 2015). All humans are sexual and curious by nature, and it is no different for the people with intellectual disability. However, the societal approach to care for members of this community has been to ignore their sexuality, and completely deprive them of any education where their own sexuality is concerned due to lack of access to prevention programs (Fitzsimons, 2009, 2010). This increases their risk and exposure as it deprives them of the critical knowledge required to begin protecting themselves. Even the common knowledge of sexual education to include consenting procedures,

identifying body parts, and providing clear examples of healthy relationships for people with intellectual disability would reduce IPV risk, as awareness and attention to the problem elevates the potential for exposing abuse, and conversely decrease the vulnerability of potential victims.

Practice Implications

Practice related suggestions, based on the study results, include expanding accessibility of safety plans and sexual health education. The data showed that overall basic sexual health education and safety planning services were denied or inefficient. The material would benefit from including inclusive sexual health education language to address individuals with IDD regarding homosexuality, bisexuality, or transgender identity. For individuals that are visually impaired and hard of hearing provide materials in non-English alternate text formats.

Educators have an opportunity to play a leading role in the direction in which young adults transition from high school to independent living. This can be impacted by young adulthood sexual health transition education. Developing sexual health information for people with IDD that is individually suited to their level of knowledge and environment, utilizing language and materials that are appropriate for their skills. The development of peer-to-peer support groups would provide a safe space for individuals to practice what they have learned in a teach back method. This will provide a better retention rate and understanding of the materials.

Cross-training among service providers is important to engage in both IDD and IPV education. It is important that service providers break barriers to obtain adequate, accessible service outcomes (Lightfoot & Williams, 2009). Service providers can engage in sensitivity training regarding race and ethnicity to better address the needs of the community. Additionally, service providers can also engage in cognitively based abuse prevention programs in meeting the needs across the spectrum. An individual with IDD uses self-directed decision making which

was theorized as a confidence-building form of decision-making in which individuals with IDD make choices based on assessments of personal goals and potential outcomes (Khemka, 2000).

Limitations

There were several limitations in the study that may have impacted the results. The sample (N=4) was small and did not give clear representation of the IDD community. The sample size was smaller because the IDD community is challenging to reach and to locate. Due to Covid, the interviews were virtual versus in-person which may not provide an opportunity to develop a strong rapport with the participant to gather in-depth information. The topic of intimate partner violence is a sensitive topic, which can be challenging to discuss.

Future Research

This study highlights the need for increased advocacy and inclusive programming for individuals with intellectual and developmental disabilities and emphasizes the need for accessible interventions to facilitate safety and resources and community integration. In addition, Lightfoot and Williams highlight, individuals with IDD have unique experiences in accessing assistance for IPV in comparison with people without disabilities due to a lack of accessible services, differing manifestations of abuse, isolation, negative attitudes toward people with disabilities, and for Deaf and hard of hearing people, living within a small, tight-knit community (2009). Accessible interventions can be gathered through the perspectives of a broader, more diverse sample size—a comprehensive quantitative survey distributed nationally to understand the prevalence of IPV in IDD communities better. Finally, to follow up the survey with qualitative interviews to gather personal perspectives and stories.

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Appendix E

Interview Questions

Demographic Questions

1. What is your gender?
2. What is your race/ethnicity?
3. What is your age?
4. What is your disability?
5. What is your level of cognitive ability?
6. What is the highest level of education you have received?

Regular Individual Interview Questions

1. Do you understand what intimate partner violence is? If so, please explain.
2. Were you ever educated to identify intimate partner violence?
3. Have you been a victim of intimate partner violence?
4. How many times have you experienced intimate partner violence?
5. Who was the first person you reported to?
6. Do you feel like your report was appropriately addressed?
7. What was the result of the reporting?
8. Do you feel safe now?
9. Do you see yourself as a resilient victim? If so, please explain.
10. Do you have a safety plan in place? If so, please explain.
11. Who created the safety plan?
12. How do you access your safety plan?
13. Does having a safety plan make you feel safer? If so, please explain.
14. What is the most important thing you want others to know about a safety plan?
15. Can you teach others about red flags of intimate partner violence?
16. Can you identify one person in your life that you can share your experience with regarding intimate partner violence? If so, please explain.
17. What are things that make you feel the safest?
18. Do you have regular interaction with a counselor?
19. What access do you have to public health resources and programs?
20. Do you feel safe sharing details of your life with these agencies?
21. What future plans do you have for yourself?