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Intimate partner violence, reproductive coercion, and unintended pregnancy in women with disabilities

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Abstract

Background: Women with disabilities experience higher rates of intimate partner violence (IPV) than the general population. Reproductive coercion, a type of intimate partner violence, is associated with an increased risk of unintended pregnancy (UIP), yet little is known about this relationship among women with disabilities.

Objective: This qualitative descriptive study explored perspectives of women with disabilities who had experienced an UIP as a result of reproductive coercion.

Method: In-depth, semi-structured telephone interviews were conducted with nine women living with diverse disabilities across the United States as part of a larger study examining facilitators and barriers to UIP among women with disabilities.

Results: Analysis revealed three broad themes related to the ways in which physical violence and reproductive coercion elevated women's risk of UIP. They included (1) inadequate health care provider or system response, (2) disability-related risks for IPV, and (3) resource needs to optimize safety.

Conclusions: This is the first in-depth exploration of ways in which reproductive coercion may lead to an increased risk of UIP among women with disabilities. Health care providers must screen for IPV and reproductive coercion and provide the necessary supports and resources for women with disabilities experiencing unintended pregnancy as a result of violence.

Keywords

Intimate partner violence; Reproductive coercion; Disability; Unintended pregnancy

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Declaration of competing interest

The authors report no conflict of interest.

Introduction

The incidence of unintended pregnancy (UIP) is a key indicator of a population's reproductive health.¹ In the United States, nearly half of all pregnancies are unintended.² Unintended pregnancy can have serious health, economic, and social consequences for women and their families. Women reporting unintended pregnancies have poorer mental health^{3,4} are more likely to delay the initiation of prenatal care^{5,6} and are more likely to report increased use of alcohol and other substances during pregnancy.⁷⁻⁹ The consequences of UIP extend to the neonate with an increased risk of preterm birth^{10,11} and a meta-analyses demonstrating a higher risk of low birthweight.¹² Yet, the mechanisms for these relationships is poorly understood.

Unintended pregnancy may be particularly salient for the approximately 11% of U.S. women of childbearing age with disabilities who are more likely to be single, of low socioeconomic status, to lack health insurance, and to have less education¹³⁻¹⁸ all risk factors associated with UIP.^{2,19,20} Further, women with disabilities are at an increased risk of intimate partner violence (IPV) which is a well-established risk factor for UIP.²¹ Indeed, unintended pregnancies are two-to three-times more likely to be associated with violence than planned pregnancies, with an increasing recognition of the role of behaviors of male partners in this association.²²⁻²⁶ Reproductive coercion, which is a type of IPV, includes behaviors that interfere with the autonomous decision making of a woman around her reproductive health. Reproductive coercion may include pregnancy coercion as well as active interference with birth control (e.g., purposely breaking condoms, destroying oral contraceptives).^{22,27} Reproductive coercion can occur in conjunction with or independent of physical or sexual violence.

The earliest studies of reproductive coercion have estimated prevalence rates from 8% to 25% in populations studied.²⁸⁻³⁰ Researchers have demonstrated that those women with a previous or current history of physical violence by an intimate partner are at an increased risk of reproductive coercion.^{28,30,31} Limited research has examined the associations between reproductive coercion and UIP. In a large sample of young women, Miller and colleagues found that IPV and reproductive coercion were associated with nearly twice the risk of UIP.²⁸ Using PRAMS data, researchers found a significant association between reproductive coercion and UIP in unadjusted models yet after adjusting for relevant sociodemographic characteristics (i.e., age, race/ethnicity, education, marital status, income), the association was no longer significant.²⁶

Despite demonstrated associations between reproductive coercion and UIP among women of reproductive age in the general population, little is known about these associations among women with disability. Thus, the purpose of this study was to explore associations between experiences of reproductive coercion and UIP among women with disabilities.

Methods

Participants

As part of a larger mixed method study on the risks and protective factors for UIP among women with disabilities, we conducted individual, semi-structured interviews with women with diverse disabilities, including limitations in hearing, vision, cognition, mobility, self-care, and independent living, from across the United States. Women were eligible who had experienced an UIP after the onset of a disability, had a disability or were Deaf or hard-of-hearing for at least two years, and were between the ages of 18 and 44 years of age at the time of the interview. Women were excluded if they were unable to answer simple questions demonstrative of understanding of the informed consent, did not understand and express themselves in English or American Sign Language, lived in a nursing home or other institution, reported severe misuse of alcohol or other drugs, or had a suicidal plan. The study was approved by the University of Virginia Institutional Review Board.

Our team aimed to capture the experiences of women living with disabilities across the United States, thus multiple dissemination methods were used to best reach a diverse group of women in terms of geography as well as disability type. We disseminated information about the study through social media, disability-related websites, community-based organizations, and blogs and social media of individuals who were actively engaged in the disability community. Additionally, as part of the parent study, we partnered closely with our community advisory board (CAB) comprised of nine women living with diverse disabilities throughout the United States. In addition to working closely with us throughout the development phase, our CAB also supported our recruitment efforts.

For the qualitative component of the parent study, 31 women with disabilities participated. Four women were deemed ineligible due to having a planned pregnancy (n = 1) or disability onset after an unintended pregnancy (n = 3). The parent study examined risks and protective factors for UIP among women with disabilities. The interviews were guided by a semistructured interview guide developed by the researchers in close collaboration with our CAB. To develop the interview guide, we drew upon findings generated from the quantitative findings in the parent study.⁴⁹⁻⁵¹ Questions explored included participants' knowledge of contraceptive choices, where they learned about contraception, and health care providers' advice around sexual and reproductive health including experiences of discrimination within the health care environment. Given the demonstrated associations between experiences of violence and UIP^{28,30} we also asked participants about their desire to become pregnant and their perceived control over their pregnancy intentions, any acts of violence or coercive methods, their partners' reactions to their pregnancies, and their autonomy in the decision to continue a pregnancy. In an effort to use optimally accessible language and to reflect the unique lived experiences of women with disabilities, we partnered closely with our CAB on the wording, language, experiences, and behaviors representative of women with disabilities in all questions.

The focus of the current analyses is on experiences of violence and any association with UIP; therefore, we report findings from nine participants who reported an UIP as the result of violence including reproductive coercion, and forced sex by an intimate partner. While the

remaining participants experienced an unintended pregnancy, they did not attribute violence as the cause. Further, one participant experienced an UIP due to stranger rape, and her experience is not included in the current analyses given all other participants were in intimate relationships.

Data collection

The first author conducted interviews in English over the phone that lasted, on average, 60 minutes. The interviews were conducted over the phone given women from throughout the United States participated. The entire study team has extensive experience working clinically and using a community-based participatory research approach with women with and without disabilities experiencing violence. Prior to the start of each interview, the interviewer reminded participants that they could skip questions or refuse to answer any questions or ask that the recording be turned off during any portion of the interview. Additionally, each participant was given a code word that they could use if they felt that their privacy was in jeopardy from either the perpetrator or anyone else that they did not want to risk hearing their interview. If the code word was relayed, the interviewer would thank the woman for her time, and end the call with the understanding that the participant would re-contact the interviewer at her convenience when her privacy could be maintained. Although this precaution was enacted, the code word was never invoked. Two participants asked that their voices not be recorded and allowed ample time for the interviewer to take copious notes.

Data analysis

Seven of the nine interviews were audio-recorded and transcribed verbatim. The two remaining interviews included detailed notes of the interview, including verbatim responses. ATLAS.ti software was used to facilitate data analysis. All transcripts were analyzed using content analysis with the purpose of being descriptive rather than generating a grounded theory. This analysis was conducted through a four-step process.³² Initially, all research team members independently read all of the transcribed interviews, and notes from the two interviews that were not recorded, to immerse ourselves in the participants' experiences. Next, two authors (JA, TB) coded the individual interview transcripts and notes with attention focused on any discussion of violence. During this phase, notes regarding the authors' first impressions as well as initial analyses were maintained. Next, the authors discussed emerging categories, and themes in an iterative manner. Codes were revised as themes and patterns emerged. Finally, using identified themes or categories, interviews were independently reanalyzed by two authors (JA, TB). If any instances of contradiction arose, discussion among the authors took place until consensus was reached. To ensure consistency of findings, an audit trail was maintained for transparency in the analysis.

Results

Participant characteristics

The sociodemographic characteristics of the sample are shown in Table 1. Women reported diverse disabilities with physical disabilities including spinal cord injury, cerebral palsy, and muscular dystrophy the most commonly reported. With regards to demographics, the women ranged from 19 to 44 years of age at the time of interview, and over half were Non-Hispanic

White. The majority of women reported being unemployed, and a total household income of less than \$40,000 per year.

Our analysis generated three themes related to the experience of reproductive coercion and UIP among women with disabilities. These findings are described below and case examples with exemplars from participants are included.

Lack of health care provider or system response "they never asked"

All participants were asked about their experiences with screening for violence during pregnancy or any discussions around healthy relationships by members of the health care team (i.e., nurses, physicians, nurse practitioners, certified nurse midwives). Eight of the nine participants (89%) noted that they were never asked about violence during pregnancy. One participant recalled, "They never asked. No one ever asked. I even made a comment when my [gestational] weight [gain] was going in the wrong direction about having a lot of stress, and the doctor just offered some deep breathing exercises. Like deep breathing is going to help when you're getting the shit beat out of you. I had visible bruises, no way no one saw them. No one asked." Another participant stated, "I mean they gave me a depression screen, and my score was apparently high because they gave me some resources. They didn't once ask why I might be so depressed. I guess they chalked it up to being in a wheelchair and being pregnant." Similarly, another participant didn't feel heard stating, "in my opinion [they] missed every red flag I was trying so desperately to wave. I felt like they couldn't get out of the room fast enough. I was never asked. I feel lucky to be alive ... but it didn't have to be this difficult." For these participants, physical abuse occurred in conjunction with reproductive coercion ultimately leading to unintended pregnancies. Two-thirds of participants experienced both reproductive coercion and physical violence while three participants reported reproductive coercion without physical violence.

When participants were asked if they would have been comfortable disclosing abuse to a health care provider, six of the nine participants stated they would be comfortable while the remaining three noted it would depend on their trust in their provider and perceived supports in place with such a disclosure. One participant noted, "I think at the time I was scared about what could happen to my daughter [if abuse disclosed]. I feared they would take her away, and that would have killed me. If someone had offered me things like resources, I definitely would have been more comfortable. There were too many unknowns or what ifs." Another participant noted that she likely wouldn't have been comfortable talking about violence in her relationship because of "fears of being judged," stating "I mean the system is meant to help women like me, but I think the disability piece makes it that it could be a problem for me. Sometimes I wonder if that's why I have never been asked about the abuse. If they don't know, they don't have to do anything, right?"

For those participants that would have been comfortable discussing reproductive coercion with their health care provider, all remarked that the assurance of being asked in a respectful, confidential manner was paramount. One participant said, "it's hard because I rely on him [partner] for help with getting undressed or getting on [exam] table so no, don't ask me when he's sitting right there." Related, another participant explained how trust in her health care provider would be critical stating, "I would need to know that she [health care provider]

had my best interests in mind. I can't worry that he'd somehow find out or the violence would just end up much worse." She went on to describe that she would have been comfortable talking about the fact that the pregnancy was not planned, and would have assumed that any "reasonable" health care provider would have posed further questions to uncover reproductive coercion. Similarly, another participant stated "there needs to be mutual trust there, and that doesn't come easy. But, yeah, I would have trusted her [health care provider] to help me confidentially ... I was desperate for information but they never asked."

Disability-related risks "we're vulnerable to violence"

Participants were asked how they felt living with a disability was related to their experiences with violence. Every participant described how they felt their disability elevated their risk of violence. Each participant described varied ways in which their partner "used their disability" to take advantage of them. The majority of participants described being pressured into sex when they did not want to with partners explicitly discussing their own desires to have them become pregnant. One participant living with cerebral palsy stated, "I felt terrible, I was on a new medication for the spasms and he was like, 'you're not going to tell me no' so I couldn't say no or I knew it'd get physical." Another participant living with multiple sclerosis described that her partner refused to believe her when she was not feeling well stating, "I felt so tired and I had no energy but he wasn't going to take no for an answer so I didn't feel like I had a choice." She went on to state, "he knows I can't fight back. I mean what can I do? Women like me [in a wheelchair], we're vulnerable to violence." Similarly, a participant with a spinal cord injury felt as if her partner "specifically chose" her given her limitations in "fighting back." She described multiple episodes of forced sex, stating "he knew exactly what he was doing when he 'picked' me. After awhile you realize saying no is only going to make things worse so you just let him do it ... it's an indescribable feeling ... you feel so trapped but there's no way out."

Reproductive coercion was also a common experience for participants, ultimately leading to an UIP. Participants described not wanting to get pregnant at that time due to concerns about cooccurring experiences of physical or sexual violence, how a pregnancy might impact their disability, not feeling ready for a child from a financial perspective, and wanting to optimize their health prior to becoming pregnant. Yet, these concerns were dismissed by partners. One participant had been advised by her health care provider that she should delay pregnancy until her pressure ulcers were adequately treated. She wanted to start birth control remarking "I wasn't ready ... I really did want my health to be as good as it could be but he [abusive partner] wasn't willing to wait. He forbid me from even filling the prescription. Literally, he said 'I forbid you.' I didn't see any other choice." Similarly, another participant did not feel financially prepared to care for a baby and wanted to finish school yet her partner was not supportive. "It was his way or his way. They talk about negotiation. There was no negotiation ... he was like 'you're not going to deny me a baby' and he ended up being right."

Resource needs "how to be safe is an important first step"

At the end of each interview, participants were asked what types of resources they wished they had access to or supports needed to optimize their health. For each of the participants reporting sexual violence, there was mention of a lack of information and resources unique for women with disability specific to violence. Five of the participants specifically mentioned that components of safety planning would have been helpful. One participant stated "I would have taken anything I could have safely accessed. And I guess information on how to safely access those resources. That was my biggest fear ... him finding out that I wanted to leave." Several participants discussed the unique needs around safety planning given their disability. One stated, "after the fact I learned about safety planning ... that would have been really helpful ... though we have unique needs, like how will I have all my medical supplies or even get to a shelter." Similarly, another participant said "I knew I needed to get out ... but that's easier said than done when you're reliant on [abusive partner] to get you everywhere. I needed to know where I could go, and not worry that it would be worse." Finally, participants discussed informational needs around long-acting reversible contraception with one participant commenting that she did not want to be pregnant, but was concerned her abusive partner would be able to tell that she was using contraception. Four other participants recalled that birth control options were not discussed in the postpartum period, all noting the need for information on contraceptive choices specific to their disability.

Discussion

Taken together, the results of our qualitative study further the understanding of the experiences of women with disabilities and the contribution of disability-related barriers to an increased risk of UIP. These barriers include a lack of screening for violence, coupled with a lack of provision of resources and information. Previous research has demonstrated that women with disabilities are three to four times more likely to experience physical abuse both before and during their pregnancy.³³ Specific to sexual abuse, the evidence is clear that women with disabilities experience disproportionately high rates of sexual victimization.³⁴ For example, according to one population-based study³⁵ women with disabilities that severely limited activities of daily living were four times more likely to be sexually assaulted than women without disabilities after controlling for demographics and household characteristics.

Screening for interpersonal violence among women with disabilities is an important first step. McFarlane and colleagues noted that such screenings should involve traditional abuse questions as well as disability-specific questions.³⁶ Two abuse screening tools have been developed specifically for women with disabilities are both are based on the widely used Abuse Assessment Screen (AAS)³⁷ which assesses sexual and physical abuse. The AAS was modified to create the Abuse Assessment Screen-Disability (AAS-D) by adding two items assessing disability-related abuse (i.e., the refusal to provide assistance with essential daily activities such as getting out of bed and the withholding of assistive devices such as a wheelchair) to the original two items on sexual and physical abuse.³⁶ Research demonstrates that this screening tool performed significantly better than the AAS when administered to

women with physical disabilities. The second abuse screening tool, developed by Curry et al., was tested with women living with physical and/or cognitive disabilities.³⁸ This tool includes eight items that ask the questions from the AAS about being physically abused and experiencing sexually abuse and includes additional items assessing emotional abuse, having money or valuables stolen, feeling unsafe with someone, having personal needs neglected, and having adaptive equipment withheld or disabled. Both tools represent important steps in measuring violence against women with disabilities.³⁸

In the current study, reproductive coercion, including pregnancy coercion and birth control sabotage, was an important type of IPV leading to UIP. Similar to screening for IPV, screening for reproductive coercion is a critical element of comprehensive care. The American College of Obstetricians and Gynecologists (ACOG) released a practice bulletin highlighting the associations between reproductive and sexual coercion and poor reproductive health. Not surprisingly, reproductive coercion is associated with significantly higher rates of UIP. Given these links, ACOG provided examples of screening questions to be incorporated into routine care including annual examinations, new patient visits, and during prenatal care (i.e., at the initial prenatal visit, at least once per trimester, and at the postpartum checkup). Examples of these questions include "Has your partner ever tried to get you pregnant when you did not want to be pregnant?," "Are you worried your partner will hurt you if you do not do what he wants with the pregnancy?," and "Does your partner support your decision about when or if you want to become pregnant?"³⁹ Screening for IPV or reproductive coercion should be done in a private area, ensuring the woman can communicate freely without interference from her partner. As voiced by participants in our study, this may require additional supports from health care providers as women may be relying on potentially abusive partners for assistance with undressing, transferring onto a table, or communicating.

There are numerous vulnerabilities that increase the risk for violence among women with disabilities including the characteristics of the abuser.⁴⁰ According to the often cited study on male partner violence by Brownridge, patriarchal domination and sexually proprietary behaviors of the perpetrator explained the difference in violence rates between women with disabilities and without disabilities living in a marital or common law union. In that study, patriarchal domination was defined as a male partner preventing his female partner from knowing about or having access to the family income, and sexually proprietary behavior was defined as a male partner demanding to know who his female partner was with and where she was at all times.²¹ When their perpetrator is an intimate partner, women with disabilities may remain in the relationship due to a desire to be partnered, reliance on partners for a multitude of resources (e.g., financial, housing, transportation, personal assistance), need to survive, fear of being left alone, and low body and sexual esteem.²¹ Consistent with those findings, women in our study shared the vulnerability related to dependence on an abusive partner for care needs and economic survival, which increased risk of staying in an abusive relationship. As one participant stated, "I mean my options are limited ... who else would be able to take care of me?"

Participants talked about the barriers in accessing resources for safety planning, contraceptive options, and leaving an abusive relationship. Contraceptive options should be

discussed during antenatal care, and ideally initiated as soon as possible in the postpartum period to reduce the risk of repeat pregnancy within the first year postpartum as well as reduce the risk of unintended pregnancy. Resources specific to contraception were not provided to the majority of participants, and represent a missed opportunity to identify reproductive coercion. With regards to leaving an abusive relationship, women with disabilities may encounter architectural and other environmental barriers that may prevent them from accessing a shelter for women who have been abused such as lack of proper assistive technology, policies against service animals, or restrictions on children remaining in the facility.⁴¹

Based on the tenets of empowerment, safety planning, including education to increase women's awareness about IPV, the provisions of tailored support to identify options for reducing the risk of violence, and support for accessing resources, is an intervention intended to support abused women's decision making around the relationship, relocation, and other safety concerns. Safety planning is one of the most widely recommended IPV intervention.⁴² Safety planning that is individualized, with careful attention to women's unique priorities, level of risk, and available resources, has been shown to be effective in reducing a woman's exposure to violence and, ultimately, improves health outcomes. Our findings demonstrated that women with disabilities were not aware of safety planning, or how it could be used in their unique situations. Research has shown that the many (48.7%– 67.8%) abused women do not access safety planning resources, elevating their risk of serious injury or even death.⁴³⁻⁴⁵ Individual⁴⁶ and group safety awareness including disability-specific safety planning^{47,48} programs designed to meet the unique needs of women with diverse disabilities are described in the literature. For individuals, safety planning focuses on abused women's priorities, often includes an assessment of their level of risk for lethal violence, and includes tailored resources. Safety planning recognizes that a woman's safety decisions for herself, and family are not linear, often changing throughout the course of a relationship. In group settings, individuals often progress through a specified number of sessions addressing violence, in general, with focused content on safety and safety planning.⁴⁸ In addition, it is critical that safety planning interventions for women in the general population include disability-specific information and resources for accessing safety.

Limitations

There are several limitations that need to be acknowledged. First, our sample was limited to participants who could demonstrate capacity to consent. Thus, we were not able to include women with moderate to severe intellectual disabilities, a group known to be at a significantly increased risk for violence. Second, while consistency across interviews was reached suggesting data saturation, further research is needed to determine if our findings are consistent across larger, and more diverse samples of women with disabilities. Finally, the qualitative interviews were conducted at a single time point, and future studies should incorporate longitudinal designs to better understand risk patterns associated with UIP.

Conclusions

Our qualitative study offered several ways in which IPV may lead to an increased risk of unintended pregnancy among women with disabilities. Health care providers must not wait for women to disclose IPV. Importantly, physicians, nurses and other clinicians must be equipped with the education and requisite skills to screen for violence and provide adequate and accessible resources for women with disabilities. Beyond the clinical arena, researchers must continue to examine ways in which IPV can be prevented before it occurs. These may include community- and societal-level prevention strategies that recognize social determinants of health, and extend beyond the treatment of individuals. Our findings also point to the significant need for safety planning resources that address and respond to the unique needs of this population so that reproductive health outcomes can be optimized in women with disabilities.

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Table 1

Characteristics of women with disabilities experiencing an unintended pregnancy as a result of reproductive coercion (N = 9).

Characteristic	N (%)
Age, mean (range)	30.2 (19-44)
18-24	2 (22)
25-34	4 (44)
35-44	3 (33)
Race	
Non-Hispanic White	5 (56)
African American	3 (33)
Other	1 (11)
Marital Status	
Single	3 (33)
Partnered/not married	3 (33)
Married	3 (33)
Employment Status	
Unemployed	5 (56)
Employed part-time	2 (22)
Employed full-time	2 (22)
Total household income	
Under \$20,000	2 (22)
\$20,001 - \$30,000	2 (22)
\$30,001 - \$40,000	2 (22)
>\$40,000	1 (11)
Did not answer	2 (22)
Disability Type	
Physical Disability	7 (78)
Intellectual Disability	2 (22)