

“I Thought I was Less Worthy”: Low Sexual and Body Esteem and Increased Vulnerability to Intimate Partner Abuse in Women with Physical Disabilities

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Several studies have documented disproportionately low sexual and body esteem in women with high degrees of physical impairment. Moreover, other studies have begun to examine the problem of intimate partner and other forms of abuse in women with physical disabilities. In this article we examine the link between low sexual and body esteem and intimate partner abuse in women with physical disabilities based on findings obtained from an in-depth qualitative study. Findings indicate that women with high degrees of physical impairment are more likely to perceive themselves as sexually inadequate and unattractive than women with mild impairment. These negative perceptions, when combined with a strong desire to be partnered, increased women's vulnerability to getting into and staying in abusive relationships over time. Major themes presented in the article include: societal devaluation, low sexual and body esteem, preference for non-disabled men, desire to be partnered, and relationship decision-making. We depict the relationships between each of these themes in a simple model to further aid the reader's understanding.

KEY WORDS: intimate partner violence; sexual esteem; body esteem; women with physical disabilities.

Sexual and body esteem in women with physical disabilities are important factors that affect self-esteem and mental health. Sexual esteem refers to one's sense of self as a sexual being, ranging from sexually

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appealing to unappealing and sexually competent to incompetent (1), and body esteem denotes an overall positive or negative evaluation of one's body (2). Several studies have examined sexual and body esteem in people with physical disabilities generally (3,4–8) and a few have examined related concepts in women with physical disabilities specifically (9,10). Findings from some of these studies indicate that high degrees of physical impairment are associated with lower sexual and body esteem in women with physical disabilities (3,9). These findings are consistent with findings from our recently completed qualitative study of abuse of women with physical disabilities. In this study we found that women with high degrees of impairment were more likely to perceive themselves as sexually inadequate and unattractive than women with mild impairment (11). This finding was particularly pronounced in women with acquired disabilities such as spinal cord injury. In turn, these negative perceptions, when combined with a strong desire to be partnered, increased women's vulnerability to getting into and staying in abusive relationships over time (11). The purpose of this article is to review findings related to sexual esteem, body esteem, and women's vulnerability to abuse from this larger qualitative study. In doing so we hope to contribute to the knowledge base about factors that may increase women with physical disabilities' vulnerability to abuse.

REVIEW OF LITERATURE

Sexual and Body Esteem in Women with High Degrees of Physical Impairment

Women with physical disabilities have greater difficulty forming and maintaining intimate partner relationships than non-disabled women (12,13). Moreover, women with physical disabilities are more likely to have problems with sexual functioning (7) and/or low sexual confidence, and greater body dissatisfaction than non-disabled women (14–17). Because they tend to be furthest away from cultural constructions of ideal feminine beauty (13,18,19), and are more likely to experience difficulties with sexual functioning than women with mild physical impairment, the problems of negative body and sexual esteem are likely magnified in women with high degrees of impairment.

It is known that women with high degrees of impairment are less likely to marry than other women with disabilities (20). Moreover, women with high degrees of impairment experience significantly lower levels of sexual esteem and sexual satisfaction, and engage in mutual sexual activity less often than women with mild impairment (3,9). Women with high degrees of impairment are also more likely to be dissatisfied with

their bodies (9). For some women, these disadvantages translate into an increased tolerance of abuse in intimate partner relationships out of fear that no one else will want or care for them (11). This is a major concern since abuse poses a significant threat to the health and safety of women with physical disabilities (11,21–23).

Abuse of Women with Physical Disabilities

Women with physical disabilities experience abuse at high rates and are often victimized by multiple perpetrators (20, 21, 24, 25). Studies of abuse of women with physical disabilities indicate that 40–72% have been abused by an intimate partner, family member, caregiver, health care provider, or other service provider (23,25–27). The effects of abuse on the health and functional ability of women with physical disabilities, while largely unknown, are likely to be severe. Findings from our larger qualitative study indicate that abuse negatively impacts women's ability to manage their primary physical disabilities and leads to the onset of debilitating secondary conditions. The significance of the problem has been highlighted by women with physical disabilities themselves who identified abuse as the most important health issue they face (28).

Despite the significance of the problem, little is known about abuse of women with physical disabilities. Information about what factors increase women's vulnerability to abuse is particularly lacking. The majority of published studies have focused on the prevalence of abuse of women with physical disabilities, types of abuse, and types of perpetrators. Only two published studies have specifically examined vulnerability factors and/or correlates of abuse in women with physical disabilities. In the first study, Nosek and colleagues explored sexuality and relationships in women with disabilities using a cross-sectional survey design (29). As part of this investigation, Nosek and colleagues analyzed open-ended responses from 181 women who reported that they had experienced some type of emotional, physical, or sexual abuse. Findings indicated that having a disability increased women's vulnerability to abuse. The social stigma and isolation that often accompany physical disability reduced women's emotional defenses by lowering self-esteem and removing emotional and instrumental support from others. Moreover, disability reduced physical defenses by limiting escape options and creating the need for assistance with essential personal care, opening up opportunities for emotional, physical, and sexual abuse and neglect in ways that most women do not experience. In a second study, Milberger and colleagues explored correlates of abuse in a sample 177 women with physical disabilities (26). Findings indicated a positive relationship between abuse history and being unemployed. Abused women

in the study were also more likely to have been divorced and less likely to be single at the time of the study compared to non-abused women.

METHOD

Critical disability research seeks to locate problems affecting the lives of people with disabilities in the broader cultural and societal contexts in which they occur and attend to the ways in which race, class, gender, disability and other social constructions shape experience (30). This critical disability research study examined the abuse experiences of community-dwelling women with physical disabilities in order to:

1. Describe their lived experiences of abuse in the context of society.
2. Describe their concerns and background meanings with regard to the influence of abuse on their emotional, social, and physical well-being; and
3. Recommend abuse assessment and intervention strategies to prevent and end the problem of abuse as it occurs among with women physical disabilities.

A total of 72 individual in-depth interviews were completed. Each woman participated in up to three interviews. Initial interviews combined life history and focused interviewing approaches. All participants signed consent forms approved by the Oregon Health & Science University institutional review board prior to initiation of interviews. After reviewing the purpose of the research, each participant was asked to tell her life story beginning with early childhood. Next, information was sought about abuse experiences. This part of the interview focused on the concrete details of women's abuse experiences. During the final interview component, participants were asked to reflect on the meaning of the experiences they had shared with the interviewer (31). Follow-up interviews were used to explore emerging themes and clarify gaps noted in first interview narratives.

Analysis

The goal of data analysis was to uncover themes of commonality and difference among women with physical disabilities with regard to their lived experiences with abuse and ultimately to place emerging themes in a larger social context. Analysis occurred concurrently with data collection. Analytic strategies employed included thematic analysis, exemplars, biographical comparisons, and paradigm cases (32). Thematic analysis was

performed using an iterative process of developing and refining codes. Exemplars were interpreted by looking at the parts and the whole of the text within and across cases as well as through comparison with other exemplars within each thematic category. Throughout the analytic process, biographical comparisons were used to frame lived experience narratives by contextualizing locale, identity, and personal history. Finally, paradigm cases were used as a perceptual strategy to aid in understanding how sub-themes were inter-related. Each of these analytic strategies was supported by NVivo 2.0, (33) a qualitative research analysis and data management tool. Measures to protect the safety of participants taken throughout the study followed the Nursing Research Consortium on Violence and Abuse (NRCV)(34). Measures to promote qualitative reliability and validity included peer review and debriefing, external audit, and member checking (35). Rich thick description was used to enhance transferability (36).

Sample

Purposive sampling was used to recruit 37 women age 19–60 with physical disabilities who had experienced abuse as a woman with a physical disability into this study. Recruitment strategies included flyers, word of mouth, and snowball sampling. Tables 1 and 2 display the ethnic and disability characteristics of the sample. Of the 37 women, 34 were heterosexual. Although abuse adversely affected participants’ health, it was not the cause of their physical disabilities. Because the nature of intellectual and physical impairment is quite different, women with intellectual disabilities were excluded from the study. Because there is a high rate of co-morbidity between psychiatric disorders and abuse, women with physical disabilities who had co-morbid psychiatric conditions were included. Of note, the majority of participants perceived that their psychiatric and substance abuse problems were caused directly or indirectly by the abuse they had experienced. As Table 2 indicates, women had a variety of physical disabilities. Of the 37 women, 9 had multiple physical disabilities.

Table 1. Ethnic Composition of the Sample

White	African-American	Asian	Hispanic	Native American	Multi-racial
25	4	1	1	1	5

Table 2. Disability Composition of the Sample

SCI	Other Spinal Cord ^a	Deaf/HOH	Arthritis ^b	Vision	Seizure D/O	Cancer	HIV	Hep. C	COPD
13	9	5	5	2	2	1	1	1	1

^aIncludes five women with Cerebral Palsy and four with other non-injury related Spinal Cord Impairment.

^bIncludes one woman with Rheumatoid Arthritis, three with Osteoarthritis, and one with Fibromyalgia.

RESULTS

Because all but two of the women in our sample were heterosexual, the findings presented here represent an analysis of women with physical disabilities' heterosexual relationships. We found that pervasive societal devaluation, low body and sexual esteem, a perceived need to be partnered, a preference for being with non-disabled men, and limited options for forming and maintaining intimate partner relationships influenced women's decision making as they entered into and stayed in abusive relationships. Figure 1 below depicts the relationships between these concepts.

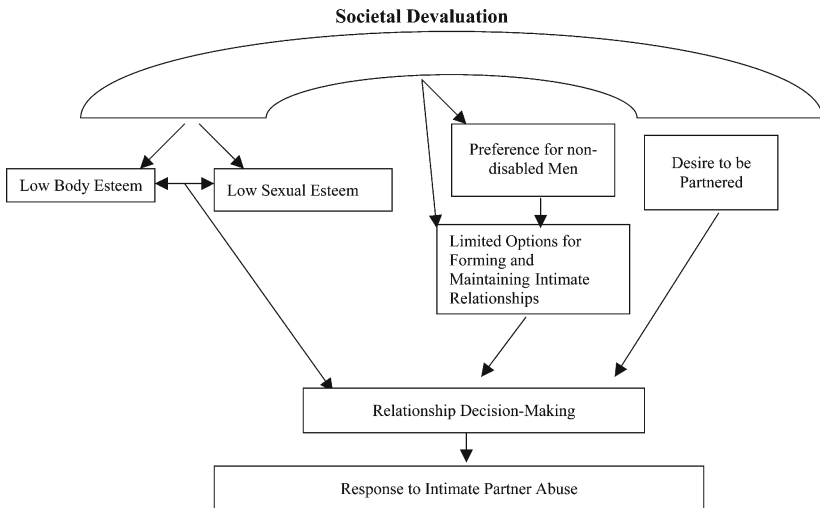


Fig. 1. Relationships between themes.

Societal Devaluation

Stereotyping of women with physical disabilities as asexual and undesirable is pervasive in dominant Western culture. Moreover, cultural constructions of feminine beauty that emphasize thinness, youth, and athleticism and male-to-female sexual intercourse as the sexual norm, have resulted in standards that many women with physical disabilities cannot meet. Tilley emphasized the pressure women experience to have the “perfect” body and to fit into their gender role, which is “. . . defined by a traditional, heterosexual marriage. . .” (37) (p. 140) and Wendell cited the “rejection” of disabled women’s bodies as a major obstacle to wellbeing. In this study, the effects of negative stereotyping and narrow societal constructions of beauty and sexuality in society most profoundly impacted women with high degrees of physical impairment. This is consistent with findings from other studies indicating that persons with high degrees of impairment suffer from poorer body image than those with mild impairment.

Low Body and Sexual Esteem

Given the societal context of pervasive devaluation that women with physical disabilities experience, it is not surprising that members of this population tend to have lower body esteem than non-disabled women. In our study we found that the more visible and impairing women’s physical disabilities were, the more likely they were to perceive themselves as unattractive. The following exemplars illustrate this phenomenon:

Exemplar #1

Disabled women are less likely to marry just because guys see us differently and guys tend to look at women in a certain way. . . guys are into bodies, making themselves look good if they have got a nice looking chick and that kind of thing.

Exemplar #2

I have to be in this body, so I have to be there. Even I find it unpleasant to be with me.

The next two exemplars illustrate the impact negative body image had on participants’ sexuality:

Exemplar #1

I haven’t had an intimate partner since I’ve been injured and stuff and I just can’t picture it because of all the bags I wear now and all the things that happened. I just don’t feel like a sexual being. I mean I’ve shut down that part of my body.

Exemplar #2

I think that 99% of it [no sex post-injury], is because of my body image. Because all my life before my husband, my body image was you know the main focus. And even with my husband it was... And being in Nevada and working the Casinos, it's body image.

As the above exemplars illustrate, women's negative evaluation of their bodies was closely tied to perceptions that others viewed them as sexually undesirable. This perceived undesirability was often related to mobility impairment and the accompanying fear that they would be unable to satisfy their sexual partners. The following exemplar comes from a woman whose intimate partner left her for another woman:

I remember feeling really inadequate because I was thinking that well, partially he was leaving me because he could have better sex with her [his new non-disabled girlfriend] then he could with me, because I couldn't move... but I could do it orally and manually so that was the only way I could think of doing it, um because I felt very inadequate. Because I just physically can't move that much being a quad... um, I didn't see after the accident, I didn't see myself and sensual anymore, or sexual. Um, I still have problems with that so I didn't think I could please him physically.

Despite having limited mobility, many women preferred sexual intercourse to other forms of sexual activity. The following exemplar illustrates the meaning sexual intercourse has for some women:

He [her husband] kept telling me we were going to make the marriage work [after her injury] that it was just a matter of getting a house and getting moved in together. And yet in the meantime he would give me a peck kiss and that was it when he got there and when he left... Before I ever left the rehab center and moved to the nursing home we spent the night in a motel one night to see if we were going to be able to handle it supposedly. And to give him the idea of what it was going to be like and the nurses taught him how to change my bag and transfer me all that kind of stuff so that he could do that for that night—and he would not make love to me. He would not have intercourse with me, he would allow me to pleasure him and he would try to pleasure me in the areas where I could feel. *But there was no intercourse and I kind of knew in the core of my being at that point that we were not going to be able to make it work, that he really did not want me anymore* [emphasis added].

Consistent with the exemplar above, several women with high degrees of impairment indicated that their male partners preferred oral sex and displayed a lack of interest in intercourse. This finding was particularly common in women with spinal cord injury. Women tended to interpret their partners' lack of interest both as a way of neglecting their needs and as a disconfirmation of their womanhood.

Preference for Non-Disabled Men

Consistent with pervasive societal devaluation of people with physical disabilities, many women expressed a preference for being with non-disabled

men. Partners who had traits such as youth and athleticism were described with great pride:

Exemplar #1

Participant. I don't know if it is a privilege, but I have been with able-bodied men. And my husband now is very popular. Um, he was a wrestler, very good-looking, um, senior president in college and also in his high school. And so I felt very honored. In fact, people could not believe he was marrying a disabled woman.

Interviewer. Why do you think that?

Participant. He was very well known in the community. Because he dated very, you know, I mean he was um, just really, dated a lot of great-looking women, you know, and people with disabilities just are, are thought about as inferior, you know.

Exemplar #2

He was young, able-bodied, and good looking and I was very proud to be his girlfriend.

Exemplar #3

And after John moved out I met somebody else. And he was very athletic.

Intimate partner relationships with men with disabilities tended to be viewed less favorably:

Exemplar #1

I have had one person with a disability that I have had a sexual relationship with, and I really would be more involved with him but he didn't have arms. And I realized, I went with this guy and it got kind of serious. And I had to tell him—to cut him off, and said, you know we can't continue because I like arms, I mean, that is something I, I like to be held and stuff.

Exemplar #2

I met this guy there and we dated for a while...He has got this terrible head injury and he has expressive dysphagia where he can talk and he understands exactly what is going on but he cannot find the right words to express himself and would not say a lot...Although I felt romantic toward him when we first started dating over time, because of the inability to communicate and provide any intellectual stimulation, I got to the point where I felt like I was using him to take me out to dinner and to the movie and I was not really romantically interested in him anymore and...I said no I don't think so I don't want to be your girlfriend anymore.

Because non-disabled men tend to have higher social status than men with disabilities, many participants felt that being with non-disabled men was a means of affirming their worth and desirability as women. When this dynamic was in place, the power imbalance between women with physical disabilities and their non-disabled male partners was magnified.

Desire to Be Partnered

Those women who were most vulnerable to abuse were those who had a strong desire to be partnered and feared being alone:

Participant. I think I'm totally different as a person and have experienced this stuff [abusive intimate partner relationships] I have because of my disability. Because of the insecurity and wanting to be in relationships like normal and looked at as a person who can be a sexual person, you know... Who is attractive.

Interviewer. Uh huh. What about responding to the abuse as it occurred?. Do you think that it was pretty much the same as it would have been whether you had a disability or not, or do you think that your disability influenced your response?

Participant. I think it did. I mean, I think, well I, I guess it would depend why people stay in relationships, but I really think I stayed in my relationships, um, one is, one is because I want to be married. I want a relationship... So the abuse to me is secondary.

Exemplar #2

You know, that [getting married] was the focus of my life until I found somebody. And then after George and I split up, it was like I really needed somebody... and then I met somebody else... and he did not want to be seen with me because of my disability.

When women were afraid of being alone and also thought that they would have great difficulty replacing an abusive intimate partner, they tended to stay in abusive relationships. In these instances, women tolerated abuse in exchange for companionship and intimacy.

Relationship Decision-Making

Women in our study with poor body and sexual esteem who also wanted to be in intimate partner relationships explicitly stated that they had lowered their expectations and standards with regard to selection of intimate partners and were willing to tolerate a certain level of abuse rather than be alone:

Exemplar #1

There were a couple of times I settled for people that I would pre-injury never even considered getting involved with... because I felt so much well, as a quad that a woman I wasn't worthy, I wasn't desirable, I would never you know... so I lowered my standards, my criteria changed. I might have allowed myself to be part of something that I really didn't want to be a part of.

Exemplar #2

I've had relationships with people that I really wasn't all that attracted to and probably wouldn't have before my accident... setting my standards lower thinking that as a woman with a disability, I would not be a partner or seen as a

woman who is worthy...there were times when I was involved with people that had criminal histories and stuff or were just, just not somebody I would have been involved with before my accident. I think that had a lot to do with some of the abuse.

Exemplar #3

I don't know that they [women with physical disabilities] thought it was all they deserved but they thought it was all they could get; better than nothing...I think that is why I was with John that's why I was with George.

Once they were in relationships, negative sexual esteem also played a role in shifting the balance of power between women and their abusive partners:

I think if you can't sexually please a man...I mean, you know, like be very, um, what do you call it, um, be physical in the sense of doing sports and things like that, I mean I'm limited to what I can do in my wheelchair. So my main thing that I think my relationship with my men is to please my man...and so I do everything that I can do to please. Because it's constantly in my head - am I pleasing him sexually?

Women's low body and sexual esteem, their desire to be partnered, and the perception that if they ended abusive relationships they would be left alone, contributed to a tendency among women to "hang on" to abusive relationships. The following exemplar is from a woman whose intimate partner had repeatedly stolen from her and assaulted her emotionally and physically:

I could have gotten out of it a lot sooner. But I kept hanging on and hanging on and really almost begging, you know not to split up, for him not to move. You know because we had really good, fun times...I mean we had some wonderful adventures...and I guess that was the prize, and um the outcome I wanted, I was willing to sacrifice a lot.

In this case, the fact that the abuser was a young able bodied attractive male added to this woman's reluctance to let go. Sadly, even though the abuse had severely affected her health, the relationship did not end until the abuser had been sent to jail. This is concerning since prolonged abuse exposure increases women's risk for negative health outcomes including injury, chronic pain, depression, post traumatic stress disorder, substance abuse, homicide and suicide (38–44).

CONCLUSION

This qualitative study found that women with high degrees of physical impairment often internalized negative societal messages about the desirability of people with physical disabilities as sexual partners. This was particularly pronounced in women with acquired physical impairment

such as spinal cord injury. This pervasive societal devaluation also had an influence on potential partners, limiting to some extent women's options for forming and maintaining intimate partner relationships. When women feared being alone and had a strong desire to be partnered, low body and sexual esteem and the problem of limited relationship options influenced their decision-making. In these instances, rather than be alone, women often lowered their standards, entering into relationships that were not their first choice. Moreover, once in relationships, these women were more likely to tolerate a certain level of abuse rather than face being alone. Thus, findings from our study indicate that low body and sexual esteem may increase the likelihood that women with physical disabilities will enter into and stay in abusive relationships. Understanding that women with low body and sexual esteem who strongly desire an intimate partner relationship may be vulnerable to abuse is an important first step toward addressing this serious problem.

LIMITATIONS OF THE STUDY

The social context of disability described in our findings is based on women's experience with disability in dominant Western culture. Because disability is culturally bound it may be that women with physical disabilities belonging to specific ethnic or religious groups experience abuse differently. Because the study sample was heterogeneous, in-depth analysis of specific cultural groups was not possible. Research is needed to begin to address this gap in knowledge.

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