

Vulnerabilities for Abuse Among Women with Disabilities*

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Research findings reveal that women with disabilities experience rates of emotional, physical, and sexual abuse that are comparable to, if not greater than, women without disabilities. Disability specialists propose that women with disabilities experience specific vulnerabilities to abuse. The question in the present study was, "What types of abuse experienced by women with physical disabilities are directly related to their disability?" Of the 504 women with disabilities who responded to a questionnaire assessing sexuality and relationships, 181 of the women completed open-ended questions about abuse. Using qualitative techniques, we analyzed their responses and identified disability-specific types of emotional, physical, and sexual abuse. Certain disability-related settings increased vulnerability for abuse. The need for personal assistance with daily living created additional vulnerability. We conclude that disability is not a protective factor against abuse; indeed, it often serves to reduce a woman's emotional and physical defenses. These findings indicate a need for the development of disability-sensitive abuse screening instruments, and development and testing of interventions to assist women with disabilities in recognizing abuse, protecting themselves in abusive situations, and removing themselves from potentially abusive relationships and situations.

KEY WORDS: women; disability; abuse; domestic violence; qualitative research.

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The reaction of the general public, medical professionals, and disability-related service providers to information about abuse of women with disabilities is often one of shock and disbelief, as if they believe that disability is somehow a protective factor against this epidemic social problem. Advocates and researchers in the field of disability, on the other hand, are bringing to light case studies and statistics that point to disability as a risk factor for abuse. Although estimates vary widely on the prevalence of lifetime and current abuse experienced by women with disabilities, there is general agreement that disability introduces additional vulnerability for abuse in women's lives. The purpose of this paper is to examine vulnerability for abuse that is specifically related to physical disability in women.

There has been some analysis of why women with disabilities might experience a greater vulnerability to abuse. Andrews and Veronen (1993) cited eight reasons for increased vulnerability to victimization among persons with disabilities, including 1) increased dependency on others for long-term care, 2) denial of human rights that results in perceptions of powerlessness, 3) less risk of discovery as perceived by the perpetrator, 4) difficulty some survivors have in being believed, 5) less education about appropriate and inappropriate sexuality, 6) social isolation and increased risk of manipulation, 7) physical helplessness and vulnerability in public places, and 8) "values and attitudes within the field of disabilities toward mainstreaming and integration without consideration for each individual's capacity for self-protection" (p. 148). A qualitative interview study ($n = 31$) conducted by the Center for Research on Women with Disabilities identified several disability-related vulnerability factors: inability to escape a situation due to architectural inaccessibility, lack of adaptive equipment, social stereotypes of vulnerability, increased risk in institutional settings, increased exposure to medical settings, and dependence on perpetrators for daily survival activities, such as transferring from bed to wheelchair, eating, using essential orthotic equipment, and taking medications (Nosek, 1996).

Additional analyses seek to explain why women with disabilities might experience increased vulnerability to abuse. Five risk factors have been identified. First is the combined cultural devaluation of women and persons with disabilities (Belsky, 1980). Analysis of the policy implications of abuse of women with disabilities, Nosek, Howland, and Young (1997) has shown a stereotypic vulnerability factor that includes the belief that women with disabilities are asexual, passive, unaware, and therefore, easy prey. Many women who have been victims of abuse for most of their lives may accept it as normal behavior.

Second, overprotection in addition to both internalized social stereotypes and reduced societal expectations are other significant contributors. The large majority of persons who have activity limitations depend on family for personal assistance (Rutgers University, n.d.). Whether or not the person providing the assistance is the perpetrator of abuse, the woman with a disability may perceive

that this is her only living option, that no one else would take care of her, and that abuse is the price she must pay for survival. Difficulty financing and obtaining adaptive equipment leaves many women trapped in immobility and unnecessarily dependent on abusers.

Third, sexuality in women with disabilities has been denied. Womendez and Schneiderman (1991) characterized the experience of women with disabilities as having fewer opportunities to learn sexual likes and dislikes and to set pleasing boundaries. Due to frequent rejection or overprotection, they may not date, go to parties, or engage in age appropriate sexual activity. Their first sexual experience may come much later in life. Women with disabilities often perceive celibacy or violent sexual encounters as their only choices, believing no loving person would be attracted to them. Some believe that fate proclaims they deserve what they get, and that bad feelings (such as pain) are better than none. There is often dissociation of the self from the parts of the body being assaulted, rooted in frequent pain inflicted by doctors and "helpers," where privacy is denied, nakedness is the norm, and women are treated as if they are inhuman.

Fourth, certain types of disabilities that have associated cognitive impairments, such as traumatic brain injury, mental illness, and mental retardation, may limit the woman's ability to recognize abuse. These impairments also interfere with her understanding that she should seek help and how she could go about seeking help.

A fifth critical risk factor for increasing the vulnerability of women to abuse is lack of economic independence. Farmer and Tiefenthaler (1996) propose that improved economic opportunities for women decrease the level of violence in abusive relationships. Women with disabilities share the problems of low wages and occupational segregation faced by women without disabilities (Schaller & DeLaGarza, 1995). However, compared to women without disabilities and men with disabilities, economic disadvantage is greater for women with disabilities, increasing their susceptibility to entering and remaining in abusive relationships. Participation in the labor market is 33% for women with disabilities, dropping to 13% for full-time work, compared with 69% for men (Danek, 1992; U.S. Bureau of the Census, 1989). Their employability is also impaired by a lower educational level than for women without disabilities. Even college-educated women with disabilities are less successful in obtaining employment than college-educated men with disabilities or non-college-educated women without disabilities (Fine & Asch, 1988). Contrary to societal expectations that women with disabilities are considered asexual and thus exempt from sexual harassment in the workplace, sexual harassment may also lead to job loss, demotion, and interrupted education for women with disabilities (Murphy, 1992, 1993).

Individuals in the battered women's movement, while acknowledging the

seriousness of abuse of women with disabilities, believe that the nature of this abuse is a variation of the abuse experienced by women in general, that it shares the same roots in the need among men to exert power and control over women. While this commonality of essence may exist, it does not overshadow the importance of context. This paper seeks to explore the unique vulnerabilities for abuse that occur in the context of disability. The primary research question that guided the qualitative analysis presented below was, "What types of abuse experienced by women with physical disabilities are directly related to their disability?"

METHOD

In 1992, the Center for Research on Women with Disabilities (CROWD) was funded by the National Institutes of Health (NIH) to study the broad range of sexuality issues facing women with physical disabilities. The study began with a qualitative interview study of 31 women with physical disabilities. The theme of abuse arose so often and with such intensity that it was impossible to ignore it as a factor that substantially affected the sexual functioning and self-esteem of the women with disabilities. It is obvious from these examples in our study that women with disabilities face some unique risk factors that make them susceptible to physical or sexual abuse. These risk factors included inability to leave an abusive situation because of mobility impairments or dependency on a caregiver, and increased perceived vulnerability due to physical, mental, and emotional limitations (Nosek, 1995).

The second phase of the NIH study was an extensive quantitative assessment of the sexuality of women with disabilities, covering multiple areas of concern, such as sexual functioning, reproductive health care, dating, marriage, and parenting issues, and developmental issues, including family influences and a woman's sense of self as a sexual person. Data were collected by means of a national survey based on the findings from the qualitative study. With the assistance of national and local advisors, including consumers, researchers, medical professionals, social workers, and educators, the research team developed a questionnaire that represented all the primary themes from the qualitative study and issues raised in the literature. The final version of the questionnaire consisted of 311 items containing 1011 variables. Two pages of the survey were devoted to abuse issues, encompassing more than 80 variables and including two open-ended questions. Women were asked if they had ever experienced emotional, physical, or sexual abuse. Emotional abuse was defined as being threatened, terrorized, corrupted, or severely rejected, isolated, ignored, or verbally attacked (Finkelhor & Korbin, 1988; Claussen & Crittenden, 1991). Physical abuse was defined as any form of violence against her body, such as being

hit, kicked, restrained, or deprived of food or water (Soeken, McFarlane, Parker, & Campbell, 1997). Sexual abuse was defined as being forced, threatened, or deceived into sexual activities ranging from looking or touching to intercourse or rape (Cole, 1984; Soeken et al., 1997). If the woman responded positively to the abuse question, she was asked to indicate the type(s) of abuse, who the perpetrator was, and at what age the abuse began and ended.

Criteria for participation in this survey required being a woman who: 1) was between the ages of 18 and 65 years old, 2) had a self-reported physical disability that limits mobility and/or self care, and 3) had no known cognitive impairments or mental health problems or problems understanding English that would significantly impair her ability to understand the survey and respond to the survey items as directed. The sample was recruited from independent living centers in each federal region and women who responded to announcements of the study asking for participants.

Questionnaires and postage-paid return envelopes were thus mailed to 1,150 women with physical disabilities. Each woman was also sent a similar questionnaire (minus all disability-related questions) and a postage-paid return envelope to give to one of her nondisabled female friends. A total of 946 completed questionnaires were received, 504 from women with disabilities and 442 from members of the comparison groups, and 45% response rate. Analyses were run on a subset of 860 women, 439 with disabilities and 421 without disabilities, after eliminating those who did not meet the age criterion, did not respond to the abuse questions, or experienced abuse before the onset of disability.

Women with disabilities who responded to the survey had the following characteristics. The most common primary disability type was spinal cord injury (23.9%), followed by polio (19.8%), muscular dystrophy (11.8%), cerebral palsy (10.7%), multiple sclerosis (9.1%), and joint and connective tissue disorders (6.6%). Severe disability was reported by 24.2%, moderate disability by 50.8%, and mild disability by 24.4%. The average age was 40 years. Eighteen percent were minorities, 51% were college graduates, and 58% were employed. About a third had never married and another third were currently married; 37% had children. The mean household income was \$32,000; 32% were below the poverty level.

After indicating in a chart the type of abuse experienced, the perpetrator, and the age at which the abuse began and ended, participants were given space to describe their experiences in their own words. The stimulus questions were 1) "Please describe each experience indicated in the previous question, including how often it occurred and how long it lasted, whether or not anything was done about it, and if so, what. Please use as much space as you need to answer," and 2) "At the time it occurred, did you know the experience was abusive or exploitative? Please explain."

One hundred eighty-one women with disabilities reported that they had experienced some type of emotional, physical, or sexual abuse, and completed the open-ended questions. Responses to these open-ended items were transcribed, checked for accuracy, and listed with the participant's identification number, disability type, and age at onset of disability. Narratives about abuse that occurred before the onset of disability were eliminated from the analysis. The remaining narratives were coded independently by three investigators for thematic content. Codings were compared and any discrepancies were discussed in meetings of the team of investigators.

Data analysis employed the methods of analytic induction and constant comparison described by Glaser and Strauss (1967). Analysis began with a team of three researchers reading each of the transcriptions and discussing the major themes and issues. As key concepts emerged from these discussions, they were listed and grouped into major thematic areas. Five thematic domains were identified: 1) disability-related emotional abuse, 2) disability-related physical abuse, 3) disability-related sexual abuse, 4) abuse related to disability-related settings, and 5) abuse related to helping relationships. After the development of these major themes, all responses were coded by at least two researchers by bracketing the thematic passages on the transcripts and recording the appropriate code or codes for that passage. Disagreements about coding were resolved in team meetings and the coding scheme itself was refined when needed. The major themes were validated by the lack of modifications required as the last responses were analyzed.

RESULTS

Aspects of abuse that were specifically related to disability fell into two broad categories, 1) variations on common forms of emotional, physical, and sexual abuse that would not be as likely if the women did not have a disability, and 2) abuse that occurred in a disability-related health care or service setting or relationship. Although the nature of the abuse revolves around the dynamics of power and control, the presence of disability or the context of a disability-related setting or relationship opens new channels for the expression of those dynamics.

Disability-Related Emotional Abuse

In situations of disability-related emotional abuse perpetrators use the presence of disability as a reason for emotional abandonment and rejection. In some families, there are high expectations for conformity in appearance and behavior.

When a disabled daughter is born, there can be expressions of shame, anger, and hostility over abnormal appearance, an inability to perform tasks such as walking or talking in a normal manner, or the need for more time to perform such tasks. Family members can become so intolerant of these special needs that they reject the child and there is a total collapse of the parent/child relationship. One participant reported,

My mother didn't seem to know how to relate to me. My dad usually ignored me. He got so if I was in a room or at the dining table, he wouldn't or couldn't see me . . . I was told he would talk about his five kids; he had six.

In families where the mother and father already have a relationship that lacks intimacy and acceptance, a disabled daughter may provide a convenient excuse for their relationship problems. Sometimes abusive mothers repeatedly blame the daughter for causing her own disability as a transference of the mother's inability to cope with the disability or other problematic relationships. This is evident on the statement by a participant that "Mother was divorced and unhappy, and blamed me because of my disability." Other types of disability-related emotional abuse are threats of abandonment or withholding of care, denial of disability, accusation of faking, and belittling based on disability characteristics.

Just as dysfunctional families may project blame for their relationship problems on the disability of one of their children, so husbands perpetrate emotional abuse by blaming their marital problems on the disability of their wives. There were many cases of husbands refusing to acknowledge their wives' disabilities, particularly in disabilities that are less visible, such as lupus and early stages of multiple sclerosis. The belittling and threats of abandonment seen in families of origin were also reported by women discussing their husbands. One woman said her husband told her, "I would never have married you if I had known you were going to be disabled." In some cases the abandonment is carried out, as in the following report:

I experienced emotional abuse from my first husband after my wreck. He told me that I wasn't sick. He left me and my 18-month-old baby to 'show me' he could. He carried me to my parents and told me that he was tired of babying me and said 'bye.'

Disability-Related Physical Abuse

Disability-related physical abuse can take the form of various types of confinement and physical restraint, which is often easier to perpetrate against a woman whose disability affects her strength or coordination, making self-defense or escape more difficult. Physical abuse can also take place in the helping relationship. A parent, sibling, or spouse may express anger, impatience, frustration, or resentment by handling the girl or woman with a disabili-

ity roughly while dressing, bathing, transferring, or performing other types of assistance with activities of daily living. One participant wrote, "My spouse is my attendant and was abusive in his helper capacity." Another woman reported that when she was a child, her sisters would tire of having to assist her and would punish her for making them miss time with their friends; "My sisters would slap me and shut me in my room." By withholding or otherwise preventing the use of orthotic devices or medication, a woman can be rendered helpless. One woman with multiple sclerosis wrote, "Once he pushed me out of my wheelchair and left the house; I laid on the floor for five hours until a neighbor came to help." Another woman reported:

After my child was born, he [spouse] became jealous and didn't want me to get up and take care of her. He would take away my chair from me and tied me up when I pulled myself out of bed . . . He was also physically abuse while I was pregnant.

Some women told of parents who would force excessive compliance with medical recommendations, such a exercise, to the point of injuring the child.

Disability-Related Sexual Abuse

Disability-related sexual abuse can take the form of fondling or forcing sexual activity in return for accepting help. "The father of a girlfriend kissed and fondled me. This was in exchange for helping me up and down steps and the like . . ." Perpetrators may take advantage of physical weakness and inaccessible environments (such as a car or an upstairs apartment) to force sexual activities. One woman thought her disability would have a protective effect in a long term abusive situation; "It [sexual abuse by brother-in-law] began when I was about 12; I sustained an SCI [spinal cord injury] at age 15, and even thought it would stop; it didn't." Spousal rape is a problem for women in general who have abusive husbands; however, for women with disabilities, there is a reduced ability to defend themselves. A woman with rheumatoid arthritis wrote, "My first husband raped me when I could neither spread my legs or lift them four inches."

Abuse Related to Disability-Related Settings

Certain disability-related settings create an environment of isolation and diminish the defenses of disabled children and adults. Examples of these settings include special education classrooms or special schools for disabled children, residential facilities, hospitals, clinics, and paratransit vehicles. Segregated schools for students with disabilities magnify the vulnerability of children who may not be able to communicate easily, have limited mobility, and may

have cognitive impairments that prevent them from understanding inappropriate touch. One woman wrote:

When I was in 4th grade (at the crippled children's school), a man began to trap me in the hall and say sexual things as well as touch me inappropriately. This happened maybe two to three times a week for the duration of a school year.

Abuse-Related to Helping Relationships

Medical settings are particularly restricting and often remove from girls and women what defense mechanisms they may have, such as putting their wheelchairs or other mobility devices out of reach, and separating them from the parent or attendant who brought them. One woman reported, "At the clinic, my neurologist once made me take all my clothes off and began fondling me." Another wrote, "The orthotist told me he had to put his finger in my vagina to be sure the (artificial) leg fit right."

Residential facilities for people with disabilities are often plagued with problems of turnover and recruitment of qualified care staff. Incidents of rape, physical maltreatment, and neglect are legend. Due to poor wages for support staff, understaffing, and lack of supervision, residents are not able to receive quality services from direct care workers, and mechanisms exist within the bureaucracy that discourage or actively punish residents or other staff who complain about such conditions or incidents. One participant who had spent some time in such a facility wrote, "I was [abused] . . . on and off for 8 months by an attendant at an unlicensed group home."

Women who have severe functional limitations and need assistance with activities of daily living are at increased risk for emotional, physical, and sexual abuse. For assistance received both from family and non-family paid workers, participants described abuses of the helping relationship, including threats of withholding assistance, physically rough treatment, inappropriate touch during hygiene care, refusal to honor the woman's choices and preferences, and stealing money and property. Often these abuses are perpetrated when the woman is in a particularly vulnerable situation where she cannot defend herself, such as in bed or on the toilet, when she is ill or experiencing an exacerbation of disability symptoms, or in public and needing assistance. Some examples of reports include, "[My] attendant sexually abused me three times." "[My] caregiver had an affair with my husband when I got sick." "She (my attendant) smeared food in my hair and face three times; she would hold me down in the bed and say horrible things to me. I would cry a lot." The need for personal assistance and the difficulty of locating and retaining persons outside the family to provide that assistance can make women with disabilities more tolerant of abuse behaviors.

DISCUSSION

The reports of abuse experiences that women offered in this study indicate that disability is not a protective factor; indeed, women with disabilities are vulnerable to the same types of abuse as are all women. Emotional, physical, and sexual abuse are rooted in the need for perpetrators to exert power and control over their victims. All women, whether disabled or nondisabled, have vulnerabilities that can be used as avenues for the exertion of power and control; disability serves as an additional vulnerability factor. The stigma and social isolation that often accompany physical disability may reduce a woman's emotional defenses by lowering self-esteem and removing the emotional and instrumental support from others that can serve as protective factors. Disability reduces physical defenses by limiting escape options and creating the need for assistance with essential activities of daily living, thereby allowing opportunities for emotional, physical, and sexual abuse, and neglect in ways that most women do not experience.

There is a host of tactics for abusing women that are directly related to physical disability, such as withholding orthotic devices, medications, and essential personal assistance, and confinement in inaccessible locations. Without ever touching the woman, a perpetrator can use these tactics as a means of coercion and punishment, with resulting physical injury that could be as serious as battering.

Traditional techniques for determining abuse prevalence are not sensitive to abuse that is specifically disability-related. The most commonly used abuse screening instrument in the literature is the Abuse Assessment Screen (AAS) (Soeken, McFarlane, Parker, Campbell, 1997). The AAS consists of two questions to determine the frequency, severity, perpetrator, and body site of injuries that occurred within the past year. The AAS evaluates two forms of abuse: 1) physical abuse (being hit, slapped, kicked, or otherwise physically hurt), and 2) sexual abuse (being forced into sexual activities). Like women in general, women with disabilities experience these types of abuse as well as disability-specific types of abuse which are not typically recognized as abusive. Two examples illustrate this phenomenon which can lead to decreased levels of detecting and reporting abuse and violence against women with disabilities. A woman with post polio who had been left on the toilet for hours and had her diabetes medication moved out of her reach may indeed suffer intentional physical injury as a result, but would not be likely to label it as physical abuse. A woman with spinal cord injury whose attendant fondles her while helping her get dressed may not consider that being forced into sexual activity and would probably not label it as sexual abuse. The forms of intentional and unintentional neglect that many women with disabilities experience, such as having no one able or willing to turn them at night or help them with personal hygiene, can be

physically very injurious, yet are not considered by most researchers as falling within the realm of abuse and are not included in abuse screening efforts.

The findings of this study demand that we develop disability-sensitive abuse screening instruments and techniques for determining the vulnerability for abuse that can be attributed to disability, beyond the vulnerability experienced by women in general. Questions must be asked about any treatment that leads to humiliation or injury, whether or not it fits within the traditional definitions of emotional, physical, or sexual abuse. In some cases, the distinction of disability-relatedness will be clear, as in the withholding of orthotic equipment. In other cases, however, it will be more difficult to determine, such as being fondled by a medical professional in a clinical setting. All women face this risk, but does it make a difference if the woman is first rendered helpless by removing access to her mobility devices?

Nosek and colleagues, in collaboration with McFarlane, developed the Abuse Assessment Screen-Disability (AAS-D) and tested it among 511 women seen in speciality clinics for women with disabilities (e.g., MS clinic, rheumatology clinic) (McFarlane, Hughes, Nosek, Groff, Swedlund, & Mullen, submitted). This tool adds two questions about 1) preventing the woman with a disability from using a wheelchair, respirator, or other assistive device, and 2) refusal to assist with an essential personal need such as taking medicine, going to the bathroom, getting out of bed, getting dressed, and getting food or drink. Twenty percent of the abuse detected would not have been discovered without the addition of these two questions (McFarlane, Hughes, Nosek, Groff, Swedlund, & Mullen, submitted). This type of screening tool should be used in medical clinics, battered women's programs, and independent living centers, in order to fully identify types of abuse experienced by women with disabilities. Moreover, other tools should be developed and validated that are designed to assess emotional abuse perpetrated against women with disabilities.

Women with disabilities whose safety is jeopardized by a severely abusive caregiver often cannot go to a battered women's shelter because the shelter is not able to accommodate women who need assistance with daily self-care or medications. A survey conducted in 1998 by the Center for Research on Women with Disabilities targeting 598 battered women's programs found that only 6% of programs are able to provide personal assistance services to women who need assistance with personal care (Howland, Nosek, & Young, submitted). Every battered women's program should have on hand an extensive network of community referrals and contact numbers, including volunteers or other community resources for obtaining personal assistance with personal care. Networking with local independent living centers may provide a source of personal assistance referral as well as disability sensitivity training.

There is a strong need to develop and test interventions to assist women with disabilities in recognizing abuse, protecting themselves in abusive situa-

tions, and removing themselves from potentially abusive relationships and situations. Because of the many social factors that lead to the personal devaluation and isolation of women with disabilities, they often do not have the opportunity to learn about self-defense and safety planning in ways that are relevant to their physical limitations and living situations. Battered women's programs, independent living centers, rehabilitation counseling services, and other disability-related service providers must acknowledge the increased vulnerability to abuse that is experienced by women with disabilities and expand their programming to include awareness raising and educational activities that will enable women with disabilities to learn skills and strategies that will reduce their vulnerability and increase their power to protect themselves. No victims of abuse and violence are ever responsible for the actions of their perpetrators. Those programs, then, must also extend their community outreach programming to educate and raise awareness among potential perpetrators (e.g., family members, caregivers, health care providers) of behaviors that constitute emotional, physical, and sexual abuse against women with disabilities.

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