Redefining Abuse of Women With Disabilities: A Paradox of Limitation and Expansion

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Affilia 2001; 16; 220
DOI: 10.1177/08861090122094235

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The study presented here, which relied on naturalistic design and focus-group methodology, examined the experiences of abused women with disabilities and the women's use of and need for services and resources. The study found that although disabled and nondisabled women face many of the same forms of abuse, disabled women have unique experiences that require specialized services.

Women with disabilities are especially vulnerable to victimization because they are perceived to be less able to defend or care for themselves than are women without disabilities (Groce, 1988). Furthermore, they experience many forms of abuse: physical, sexual, and emotional assaults; threats and intimidation; withholding of food or medicine; and the removal or sabotage of their accessibility devices.

Adults with disabilities, particularly those who are dependent on others for care, are at risk for physical and sexual abuse in their homes, hospitals, and institutions. According to the Domestic Violence Initiative for Women with Disabilities (National Coalition Against Domestic Violence, 1996), approximately 60% of the women seeking help were disabled before

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they were abused, and 40% acquired a disability as a result of the abuse. In a study of 100 disabled women, protection from abuse and violence was ranked as their number one priority (Berkeley Planning Associates, 1992).

Disabled and nondisabled women experience the same rate of abuse. In a national study of 439 women with physical disabilities and 421 women without disabilities, the Center for Research on Women with Disabilities found that 62% of both groups of women had experienced emotional, physical, or sexual abuse at some point in their lives. For both the disabled and nondisabled women, their husbands or live-in partners were the most common perpetrators of physical or emotional abuse. Compared with the nondisabled women, the women with disabilities experienced the abuse for a longer duration, were more likely to be abused by a greater number of perpetrators, reported a higher number of health care workers and attendants as the perpetrators, and noted fewer options for escaping or resolving the abuse (Walter, 1998; Young, Nosek, Howland, Chanpong, & Rintala, 1997).

Despite the same rate of abuse in general as nondisabled women, women with disabilities and other chronic conditions are more likely to be victims of sexual assault than are women who do not have these conditions (Gill, Kirschner, & Reis, 1994; Golding, Stein, Siegal, Burnam, & Sorenson, 1988; Mullen, 1988). Moreover, abused women are at risk for developing permanent disabilities as a result of battering. Common injuries due to domestic violence that are treated in hospital emergency departments include fractures, dislocations, dental injuries, musculoskeletal injuries, head injuries, and gunshot wounds (Bureau of Justice Statistics, 1997).

The emotional battering, physical and sexual assault, intimidation, threats, isolation, economic control, degradation of the disability, immobilization-restriction, forced sterilization, harassment, chemical restraint, and neglect of physical care (Chenoweth, 1996; Groce, 1988; Nosek, 1995; Sobsey, 1994) that women with disabilities experience take many forms. Specific examples of such abuse include (a) moving a woman in a wheelchair somewhere that she does not want to go, (b) removing the

battery from an electric wheelchair, (c) removing the portable ramp from a home, (d) taking away or breaking a telecommunication device for the deaf (TDD), (e) threatening a woman with institutionalization, and (f) failing to assist a woman with daily living skills. Abuse also occurs when caregivers or personal assistants lack respect for disabled women and show neglect in how they handle personal hygiene issues.

Women with disabilities are often overprotected by family members, friends, and agency personnel and are taught to comply with the requests and demands of others. This overprotection, coupled with trained compliance, may leave a women unprepared to handle an abusive relationship or to advocate for herself with agency personnel (Chenoweth, 1996). Furthermore, women with disabilities may not be believed when they disclose their abuse to others because of societal myths that they are asexual and hence are unlikely to be in a relationship or would not be abused because others would take pity on them, rather than abuse them (Calvey, 1998). In addition, it is generally difficult for women with disabilities to receive help for abuse because domestic violence services (shelters and nonshelters) are typically located in physically inaccessible settings, lack materials in alternative formats, and do not have staff who are proficient in the use of American Sign Language or trained to provide services on multiple cognitive receptive and expressive levels.

For a woman who is living in an accessible home, leaving her home for reasons of personal safety may also mean leaving a physical environment in which her independence and autonomy are maximized. Because there is a shortage of reasonably priced, accessible housing, if the woman is unable to return to her home, her ability to continue to live in the community may be compromised. Finally, if the abuser happens to be her personal care assistant, she may have difficulty obtaining help with personal care if she leaves the abuser (National Coalition Against Domestic Violence, 1996).

In summary, women with disabilities are vulnerable to various types of abuse as a result of issues such as their socialization

and physical and attitudinal barriers to receiving services to prevent abuse or escape abusive relationships. Because the literature on the experiences of abused women with disabilities is scant, more information is needed to understand the types of abuse experienced by disabled women, as well as the women's interactions with service delivery systems. The study presented here examined disabled women's experiences of abuse and need for services and resources. This article focuses specifically on the forms of abuse that disabled women experience.

METHOD

Rationale

A naturalistic design that relied on focus group interviews and thematic and taxonomic data analyses (DePoy & Gitlin, 1998) was used to address the following research objectives:

1. To gain a better understanding of the types of abuse experienced by women with disabilities.
2. To explore the relationships between abusers and victims.
3. To identify victims' efforts to obtain services and victims' experiences with those services.
4. To inform health care practitioners, the criminal justice system, and personnel who work with abused women about the experiences and concerns of women with disabilities.
5. To assist policy makers in identifying gaps in services.

Because of the dearth of well-developed, tested theories on this topic of inquiry, a naturalistic design was selected to explore the problem and to provide information from which hypotheses could be induced and theory could be developed for future testing. Focus-group interviewing provides the context for group dynamics to stimulate participants to reflect on issues and hence yields additional data that may not have emerged in individual interviews (Frey & Fontana, 1993) and rich descriptions of process and meaning on which hypotheses

for future research can be built (Creswell, 1994). One type of naturalistic design is feminist interview research.

According to Reinharz (1992, pp. 18-19), open-ended feminist interview research allows "opportunities for clarification and discussion . . . explores people's views of reality and allows the researcher to generate theory . . . [and] produces nonstandard information that allows researchers to make full use of differences among people." This method appeals to feminists because it "offers researchers access to people's ideas, thoughts, and memories in their own words rather than in the words of the researcher" (p. 19). Given that dominant groups have historically spoken for people with disabilities, including women, this method allows these populations to tell and interpret their experiences in their own words. It also encourages such feminist notions as establishing rapport and relationships between the interviewees and the interviewers and the use of personal self-disclosure, both of which were used in this study. Although the authors used a semistructured data collection method in the form of four open-ended questions to guide the study, they allowed participant-guided discussions of the questions and included a broad question at the end that encouraged the participants to express their thoughts beyond the scope of the four guiding questions.

One reason for the emergence of feminist research was that women, like other disempowered groups, were often not included as participants or researchers in studies. Therefore, theories developed from positivist methodology are frequently developed on the basis of data that have omitted the lived experiences of all but those in the mainstream (Fonow & Cook, 1991). Thus, the study of a group of women (women with disabilities) who are often excluded from research on women, particularly research on abused women, was best accomplished with methods that are well accepted by feminist researchers. A fundamental premise of the authors' study was that disabled women who experience abuse have not been studied extensively, cannot be characterized by existing theories, and thus may have unique abuse experiences and needs for resources

and services that can be revealed only by naturalistic inquiry (DePoy & Gitlin, 1998).

Data Collection and Analysis

In spring 1998, the authors conducted two focus groups at centers for independent living (CILs) in a southeastern state, one in an urban setting and the other in a small, rural town. The following open-ended questions were asked to explore issues related to abused women with disabilities: What forms of abuse occur most often among women with disabilities? How can the woman with a disability or disabilities protect herself and her children? What could people and agencies in the community do to address the issue of abuse among women with disabilities and make reporting easier? To conduct further research on abused women with disabilities, what could researchers do to gain access to the women, and what questions should they ask?

The questions asked in both focus groups were provided in writing and orally. Because of the extensive discourse among the participants, few probes to expand the discussion were necessary. Each group session was audiotaped, and the tapes were subsequently transcribed verbatim by a graduate student.

Specific accommodations to ensure accessibility and full participation by women with hearing and/or sight impairments were used in both focus groups. Each focus group was facilitated by either the first or second author and a graduate student. The graduate student observed the participants' nonverbal communication and helped ensure that the participants were encouraged to offer comprehensive responses to the semistructured focus-group queries. Another graduate student also attended the focus groups to record field notes that described particular levels of intense response, anxiety, nonverbal mannerisms, and interactions among the participants. The first or second author ensured that refreshments were provided and that the participants' needs for assistance were met.

The authors analyzed the focus group data using the computer program QSR NUD*IST (1996). After they were trained in

the use of the program, they engaged in the conceptual task of developing a system for organizing the data. The coding system, based on the principles of grounded theory (Strauss & Corbin, 1990), allowed the generation of themes and a taxonomy of connections among themes on which to build theories. The two primary researchers read and reread the transcripts to develop themes or meaning categories and thus to ensure the trustworthiness of the analysis. This approach used what Anastas and MacDonald (1994) termed a mixed research design that included elements of both a flexible and a fixed method. The mixed design, which permitted inductive and deductive reasoning, allowed the authors to uncover and describe properties of the poorly understood phenomena of disabled women's experiences with domestic violence. The narrative descriptions of the experiences of the participants permitted the emergence of concepts and theoretical tenets presented later.

Participants

All the participants were volunteers who were recruited through CILs in their region. The intent of the study was to recruit participants from a population of physically disabled or nondisabled individuals with a history of or interest in abuse of women with disabilities. The CIL staff posted flyers with information, including the telephone numbers of the primary researchers, at the CILs and forwarded them to providers of disability and domestic violence services in their areas. As is characteristic of naturalistic boundary setting, initial conceptualizations are dynamic and frequently change (Depoy & Gitlin, 1998). Such was the case with the recruitment of participants, which resulted in a mix of disability categories and experiences. This flexibility (Anastas & MacDonald, 1994) provided the authors with information that they would not have otherwise collected with the narrow participant profile they first considered. The expansion of the participants beyond women with physical disabilities also yielded comparative information about nonphysical disabilities and childhood abuse.

Of the 10 women in the urban-based focus group, 9 had disabilities: 6 had physical disabilities (1 each had cerebral palsy, multiple sclerosis, muscular dystrophy, spina bifida, a degenerative neuromuscular disease, and a stroke-related disability), 2 had multiple disabilities (1 with a brain injury and 1 with multiple sclerosis and visual impairment), and 1 had a visual impairment. Nine of the 10 women (both those who had disabilities and those who did not) had been abused in childhood or adulthood or both. Four of the 10 women worked as professionals in the disability or medical services field. The other 6 women were receiving or had received services from the CIL. Two of these women had also received services from a domestic violence or sexual assault program.

Of the 6 participants in the rural focus group, 5 were women and 1 was a man; 4 of the women had disabilities: 1 with a hearing impairment, 1 with a spinal cord injury, 1 with a stroke-related disability, and 1 with a neurologic disability. Four of the 5 women had been abused in childhood, adulthood, or both. All 6 participants were professionals, 5 in the disability services field and 1 in a domestic violence program.

RESULTS

The thematic analysis revealed two major overarching themes: the nature of the abuse (types of abuse experienced) and responses to abuse. Three subthemes emerged that characterized the nature of the abuse for all the women, including the disabled women: assault, neglect, and control/restraint. Assault refers to direct emotional or physical battering, neglect refers to intended passive behavior by the perpetrator that resulted in harm to the woman, and control/restraint refers to the perpetrators' deliberate limitation of a woman's physical, emotional, financial, or social options, thereby resulting in harm (see Table 1).

Three categories of responses for all the women were evident in the transcripts: "bad self," "stuck," and "movement." Bad self refers to acceptance of responsibility for the abuse and attempts

TABLE 1: Thematic Analysis

Forms of Abuse Common to All Women			*Forms of Abuse Unique to Disabled Women*		
Physical and Emotional Assault	*Neglect*	*Control/Restraint*	*Physical and Emotional Assault*	*Neglect*	*Control/Restraint*
Physical, attacking her self-confidence, comparing her to others, making her feel like a nonperson, calling her names, treating her paternalistically, instilling fear and intimidation, threatening her safety, sexual abuse	Not listening, being judgmental, withholding emotional support, treating her like a child, making decisions for her	Needing to have everything perfect and in order, limiting or controlling her access to jobs, controlling her assets, making her totally dependent, assuming responsibility for all finances	Conveying judgmental attitudes based on her disability, threatening her with the loss of her children because of the disability, threatening to institutionalize her	Physical, withholding personal assistance, erecting or refusing to remove architectural barriers in the home, lifting a wheelchair out of the way with her in it, not contacting a physician when one is needed	Withholding medications; controlling access to needed items or persons; controlling assistive services; using disability to demean, discredit, or dismiss; refusing access to social support; refusing to communicate using assistive devices

Response to Abuse		
Bad Self	*Stuck*	*Movement*
Trying to be good, internalizing blame for the abuse, doubting oneself	Feeling that one cannot leave the relationship, feeling dependent on the abuser, not knowing where to go or what to do	Confronting the abuser, threatening to leave if the abuse continues, separating from or divorcing the abuser, finding role models, spending time with positive people, sharing stories with other abused women, developing a support system, connecting with service providers, volunteering to help other abused women

to change one's behavior as a preventive mechanism. Stuck was defined as resignation that the abusive situation would not change. Movement was described as the active response to abuse in which the victim intended to or actually sought help to leave the abusive situation (see Table 1).

Within each theme, commonalties of abuse, as well as clear distinctions between the disabled and nondisabled women, were revealed. Poverty and isolation factored into the lives of the participants, exacerbating the effect of abuse and influencing the participants' responses to ebuse. Table 2 presents examples from the transcripts that illuminate the unique nature of the abuse that the disabled women described.

DISCUSSION AND IMPLICATIONS

This study revealed important theoretical tenets for future examination, as well as some preliminary but immediate considerations. First, some types of abuse are common to all women, but other types of abuse are unique to disabled women because of the limitations that their disabilities present. What may not be an abusive phenomenon for nondisabled women, such as moving them against their wishes, may be extremely harmful for disabled women. Of particular note was the additive effect of demeaning or dismissive comments to women with disabilities who belong to a population that is devalued and marginalized by the mainstream culture.

It is particularly noteworthy that there was a disproportionately higher perception of abuse as restraint and control among the disabled women than among the nondisabled women. Moreover, because disabled women are frequently dependent on others for daily care, the perpetrators of intentional or indirect abuse may be the very people who are supposed to be helping the women: family members, friends, and providers of services. Furthermore, because the paternalistic attitudes of perpetrators diminish disabled women's sense of strength and resilience, the addition of abuse is exponentially harmful.

TABLE 2: Examples From the Transcripts

Assault	*Neglect*	*Control/Restraint*
"In a doctor's office, they grab my chair regardless of where my hands may be and push me out of the way."	"I've had people, nurses, carry on and engage in conversation, and if I happen to be in the way, just very casually come over and lift my chair out of the way with me in it."	"If you have a memory impairment, someone can say, 'That's not so; that did not happen.' "
"If I am able bodied, and my intimate partner makes me so afraid that I am forbidden to use the bathroom unless he says that's OK, it's probably emotional abuse. But if I'm physically incapable of providing that service to myself and at some given time, my intimate partner is the one . . . if let's say my aide is not there and that's my partner's thing to do during that time, it's physical abuse. I can't provide for my own physical needs. I think it's [the line between physical abuse and emotional abuse] blurrier."	"A lot of folks whom I talked to told about being dismissed or things that have been said to them that make them feel like nonpersons or less than other."	[As told to a woman by her ex-husband]: "Isn't it more practical for you disabled people to just take SSI [Supplemental Security Income], rather than having to worry about transportation and jobs?"
"A woman whose esteem has been totally destroyed by an emotionally abusive relationship. That's much more subtle. It can [be done by] caregivers, children, and your own adult children. It can [be done by] a boyfriend or significant other or a spouse. I think it can be much more	"It's withholding care, but it's [also] withholding connection. 'I can still give you your pill and dinner, but there will be a wall so I am not there, and I will not engage with you at all.' "	"They [medical professionals] still put you in a sick mold, which in their mind [means that] they're going to reach out. They're going to take care of you. They're going to make decisions for you."
	"Many people with physical disabilities or emotional and mental disability have been kept just as isolated and just as much away from communications and connection as people who are deaf or hard-of-hearing, and that's . . . [because] their caregivers or their significant others or [other] people in their lives are controlling and . . . don't provide for connection."	"[With] women with mental [or] emotional disability, the abuser [can] throw out the medications and deny access [to the medications]."
		"Her mother was intrusive in every aspect of her life down to the times she went to the bathroom."
		"You want a ride to go somewhere; they can, if they're mad at you, say, 'I'm not taking you.' And [if] you are really dependent and need a drink of water, they can walk out of the room. And if you need help

devastating. It keeps you from functioning."

"When we first married, he was the sweetest guy on earth; . . . he did give flowers and kindness and warmth and everything. But he had ways of cutting me down. . . . He would compare me to other women, 'You'd look so much better with black hair . . . so much better with large breasts . . . so much better with different clothes."

"Women with disabilities come up against that paternalistic attitude 'Oh, he means well; he's just trying to protect you and make sure that you're OK.' "

with toileting, they can look at you [and not help you], if they're mad at you."

"One of my aerobics students said to me, 'I think one of the reasons W [her husband] married you was because of your eyes. He wanted to take care of you.' . . . After the years went on, I realized, hey, that's why he's attracted to me. . . . He's attracted to women he can rescue."

Looking at the findings in total, the theoretical construct of limitation seems to be the major factor that transforms seemingly ordinary situations into harmful ones, placing disabled, abused women in cycles of poverty or isolation or both that then increase their vulnerability to even more abuse and limitations. Because of the current conceptualizations of the abuse of nondisabled women, providers and other community members may not recognize extremely harmful abuse that is unique to women with disabilities. Thus, it is critical to expand the definition of abuse of disabled women. Narrow definitions of physical abuse, such as a criminal justice definition of physical assault, may exclude many forms of abuse of disabled women and hence isolate these women from services and supports that could decrease or eliminate the abuse and provide a supportive environment in which the women could live safely and productively.

Given the exploratory nature and findings of the study, the implications for both immediate and future consideration are critical to address within the boundaries of exploratory findings. The immediate implications, although intended to be used to develop theory for further testing, revealed several essential guidelines for providers who work with disabled women. First, the application of traditional criminal justice models of abuse to identify disabled women who have been or are being abused is not sufficient. Therefore, the participants suggested that the following questions be used as probes to identify abuse that may not be identified with traditional assessment techniques:

- Has someone ever withheld something from you, such as medication or an assistive device, that you needed?
- Has someone ever said you cannot do something, such as get a job or find housing?
- Has someone ever just walked out of the room when you said to them you need to use the rest room or left you in your chair, knowing there was no way for you to transfer without assistance?
- What level of respect do you feel you get from people?
- Do you feel you are in control of your life?

- Who controls your activities? Your medication? Your health? Have you ever experienced anything that made you uncomfortable?

Second, although spouses or live-in partners have been found to be the most frequent perpetrators of the abuse of both disabled and nondisabled women (Young et al., 1997), the participants reinforced Young et al.'s findings that disabled women are likely to be abused by health care workers and attendants. Therefore, when asking a disabled woman about the perpetrator of her abuse, service providers should not assume that the relationship between victim and perpetrator is a romantic or familial one.

There are two main areas concerning future and long-term directions. First, it is essential to develop and test theories and apply empirically generated knowledge to the development and implementation of services, supports, and policies that will prevent abuse among disabled women and provide needed supports for this population.

Second, because the population of abused disabled women is not homogeneous, the participants suggested that researchers need to examine issues regarding the abuse of women with disabilities by type and onset of disability. One such issue is, Does a woman who has had a disability all her life gain a certain amount of confidence and knowledge about herself that gives her greater strength to leave an abusive relationship than the woman with a recent-onset disability who may still be adjusting to the disability and her sense of self as a disabled person? The participants also suggested that the causative factors related to the abuse of disabled women by health care providers that are specifically related to job stress need to be fully examined. A more complete understanding of the diversity of both disabled women who are abused and of perpetrators and the identification of correlates and predictors of the abuse of disabled women can provide the needed knowledge for developing and implementing responsive prevention and treatment programs and policies.

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