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## Understanding Abuse of Women With Physical Disabilities An Overview of the Abuse Pathways Model

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The purpose of this article is to provide an overview of an empirically based theoretical model of abuse of women with physical disabilities. The Abuse Pathways model was developed from a critical disability life history research study conducted with 37 women who had simultaneously experienced abuse and physical disability. The model begins to address the complexity of abuse of women with physical disabilities by identifying the interactive components of the phenomenon. These components include (1) the social context of disability; (2) women's abuse trajectories; and (3) vulnerability factors for abuse. The article concludes by discussing potential applications and limitations of the model. Key words: abuse, caregiving, physical disability, theory, violence, women

OMEN with physical disabilities have identified abuse as the most important health issue they face. 1 Abuse of women with physical disabilities includes any intentional act that results in, or is likely to result in, harm or suffering, including threats of such acts, coercion, or arbitrary deprivations of liberty, whether occurring in public or private life. <sup>2,3</sup> To date, studies investigating the abuse of women with physical disabilities have reported a combined lifetime prevalence of up to 67% for all types of abuse.<sup>4,5</sup> Moreover, women with physical disabilities experience disability and care-related forms of abuse, are often victimized by multiple perpetrators, and experience abuse for longer periods of time than do nondisabled women. 4,6,7 Although re-

search investigating the effects of abuse on health of women with physical disabilities is in its infancy, what is known suggests that the effects are likely to be severe; abuse decreases the likelihood that women with disabilities can work, maintain their health, and live independently in the community.<sup>5</sup>

Despite the significance of abuse, no empirically based theory specific to abuse of women with physical disabilities is available and only 2 related theoretical articles have been published. The first article described an ecological model of abuse of women with disabilities generally.<sup>6</sup> Based on a review of literature pertaining to abuse of women with disabilities, this ecological model described environmental and cultural factors and victim and perpetrator characteristics that may increase women's risk for abuse. Factors relevant to women with physical disabilities included in the model were pervasive discrimination, stigma, and dependence on others for personal care. The second article, a grounded theory model of limitation, was derived from data obtained from women with and without disabilities as well as one man with disabilities.<sup>8</sup> In this grounded theory, limitation was cited as the single greatest factor

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that magnifies seemingly ordinary situations into harmful ones, placing people with disabilities at risk for poverty and social isolation. While each of these theoretical articles has made important contributions to understanding abuse of women with disabilities generally, they do not provide an in-depth theoretical understanding specific to physical disability. To begin to address this need, a critical disability life history study was conducted. The purpose of this article is to provide an overview of the Abuse Pathways model developed from study findings.

#### **METHODS**

Critical disability research seeks to locate problems affecting the lives of people with disabilities in the broader cultural and social contexts in which they occur and attend to the ways in which race, class, gender, disability, and other social constructions shape experience.<sup>9</sup> This critical disability research study examined the abuse experiences of community-dwelling women with physical disabilities 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 women with physical disabilities.

A total of 72 individual in-depth interviews were completed. Each woman participated in up to 3 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 a review of the purpose of the research, each participant was asked to tell his or 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. 10 Follow-up interviews were used to explore emerging themes and clarify gaps noted in first interview narratives.

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. 11 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 subthemes were interrelated. Each of these analytic strategies was supported by Nvivo 2.0,<sup>12</sup> 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 violence research guidelines. 13 Measures to promote qualitative reliability and validity included peer review and debriefing, external audit, and member checking.<sup>14</sup> Rich thick description was used to enhance transferability. 15

#### Sample

Purposive sampling was used to recruit 37 women aged 19 to 60 years with physical disabilities who had experienced abuse and disability simultaneously into this study. Of the

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**Table 1.** Ethnic composition of the sample

White	African American	Asian	Hispanic	Native American	Multiracial
25	25 4		1	1	5

37 women, 34 were heterosexual. Although abuse adversely affected participants' health, it was not the cause of their primary physical disabilities. Because the nature of intellectual and physical impairments is quite different, women with intellectual disabilities were excluded from the study. Moreover, because there is a high rate of comorbidity between psychiatric disorders and abuse, women with physical disabilities who had comorbid 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. Recruitment strategies included flyers, word of mouth, and snowball sampling. Tables 1 and 2 display the ethnic and disability characteristics of the sample. As Table 2 indicates, women had a variety of physical disabilities. Of the 37 women, 9 had multiple physical disabilities.

#### **FINDINGS**

#### Overview of the model

In the *Abuse Pathways* model, women go through several phases as they enter into and leave abusive relationships (during adulthood). These phases can be conceptualized as an abuse trajectory, occurring within, and influenced by, social and cultural contexts. The model also posits that there are vulnerability factors that increase the likelihood that women with physical disabilities will Get Into abusive relationships and Experience Abuse, thus increasing their negative Health Outcomes. Lack of Intervention increases the length of time women stay in abusive relationships, also negatively affecting health. When the Trade-offs involved in being in an abusive relationship become untenable, women reach a Breaking Point and decide to leave their abusers. This is followed by a period of Building Support and Gaining Strength in preparation for leaving. While leaving, the threat of abuse women face increases, as abusers attempt to maintain power and control. After Getting out, a woman may remain abuse-free, reenter the abusive relationship, or enter into a new relationship with a different abuser. Study findings related to each of these model components are briefly reviewed below (Fig 1).

# Description of model components The social context of disability

The social context of disability is characterized by the systematic oppression of women

**Table 2.** Disability composition of the sample\*

SCI	Other Spinal Cord <sup>†</sup>	Deaf/HOH	Arthritis <sup>‡</sup>	Vision	Seizure D/O	CA	HIV	Hepatitis C	COPD
13	9	5	5	2	2	1	1	1	1

<sup>\*</sup>SCI indicates spinal cord injury; HOH, hard of hearing; D/O, disorder; CA, cancer; HIV, human immunodeficiency virus; and COPD, chronic obstructive pulmonary disease.

 $<sup>^\</sup>dagger$ This includes 5 women with cerebral palsy and 4 women with other non-injury-related spinal cord impairment.

 $<sup>^{\</sup>ddagger}$ This includes 1 woman with rheumatoid arthritis, 3 women with osteoarthritis, and 1 woman with fibromyalgia.

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**Description of Model Components** 

Figure 1. Abuse Pathways model.

with disabilities in society. 16-20 Social devaluation of women with physical disabilities influenced participants' abuse trajectories as well as their vulnerability to abuse. This devaluation had a particularly detrimental impact on their ability to find and maintain intimate partner relationships. As one participant noted,

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.

The notion that women with physical disabilities are less attractive than nondisabled women, coupled with a concern expressed by participants that their mobility limitations decreased their desirability as sex partners contributed to feelings of inadequacy. Because they felt inadequate as intimate partners, many women lowered their standards, entering into high-risk intimate relationships. In this way, social devaluation of women with physical disabilities compounded participants' vulnerability to abuse.

Social devaluation also impacted women's relationships with service providers. An example of this was provided by a woman with a spinal cord injury:

One of the caregivers they had, he didn't last long, but he was the type that he would put your cushion in the chair backwards. He would put your pants on twisted and he goes, "what difference does it make? You're paralyzed it doesn't matter to you."

Unfortunately the kind of devaluation illustrated in the above exemplar was common and participants reported that frequent contact with the social and healthcare systems did little to help prevent or end abuse in their lives (D. Hassouneh-Phillips and E. McNeff, unpublished data, 2003). Thus, the larger social context of disability shaped participants' abuse experiences at multiple levels. Overall, social devaluation of women with physical disabilities increased their personal vulnerability to abuse while simultaneously decreasing access to safe and effective abuse prevention and response interventions.

### Abuse trajectory

Within- and across-case analysis revealed a common abuse trajectory composed of 7 stages (see Fig 1). Getting in describes the processes of entering into abusive relationships. Women who were vulnerable both psychosocially and physically were more likely to enter into abusive intimate partner and caregiver relationships and were more likely to experience repeated victimization over time. Experiencing Abuse refers to the

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Table 3. Types and forms of abuse experienced by women with physical disabilities

Type of Abuse	Forms
Care-related abuse	Coercing
	<ul> <li>Overmedicating or withholding medication to obtain compliance</li> </ul>
	<ul> <li>Removing access to assistive devices or telephone (during caregiving activities)</li> </ul>
	Disregarding and taking over care
	• Directing a woman's care against her will
	<ul> <li>Refusing to provide essential personal care</li> <li>Objectifying</li> </ul>
	,
	Endangering
	• Caregivers not showing up for work (with intent)
	• Caregivers showing up for work late (with intent)
	• Caregivers not doing a good job (with intent)
	• Injuries from transfers or falls (with intent)
	<ul> <li>Caregivers being drunk or high on the job</li> </ul>
	<ul> <li>Abandonment/walking out on the job</li> </ul>
	<ul> <li>Kept from taking care of physical needs</li> </ul>
	Invading
	<ul> <li>Invasion of privacy</li> </ul>
	<ul> <li>Gossiping</li> </ul>
	Refusing to leave
	Hurting
	<ul> <li>Rough handling (with intent)/forced physical examination</li> </ul>
	<ul> <li>Providing alcohol or drugs to women with physical disabilities younge than 18 years</li> </ul>
	<ul> <li>Touching inappropriately during bathing, dressing, or other caregiving activity</li> </ul>
Disability-related abuse	Blaming a woman for her disability
,	<ul> <li>Threatening or actually taking over, damaging, destroying, or taking away assistive devices</li> </ul>
Psychological abuse	<ul> <li>Threats/intimidation/harassment (ie, destruction of property for the purpose of intimidating, repeated unwanted phone calls, threats of</li> </ul>
	harm to a woman, her children, or her pets)
	Yelling/verbal abuse/humiliation/degradation
Physical abuse	Physical assault (any type)
Sexual abuse	• Forced sex
SCAUII UBUSC	Unwanted sexual touch
	<ul> <li>Psychological sexual violation (ie, use of obscene language, gestures o</li> </ul>
	innuendos, unwanted exposure to masturbation)
T. 1 1	Sexual exploitation  The Good Sexual exploitation explored the Good Sexual explore
Financial abuse	<ul> <li>Theft (of money, valuables, household goods, medications, and identity</li> <li>Keeping a woman from working or going to school</li> </ul>
	<ul> <li>Taking over a woman's money/finances against her wishes</li> </ul>

types of abuse women with physical disabilities experience including emotional, physical, sexual, financial, and care-related and disability-related forms of abuse (see Table 3). Care- and disability-related forms of abuse

are specific to people with disabilities. Carerelated abuse denotes abuse perpetrated in the context of caregiving activities. The following exemplars illustrate how abusive caregivers attempted to exert power and control over women by controlling their care and environments:

Exemplar 1. There was one girl, she was only with me for a couple of weeks before the real her came out. And so ah, she wouldn't let me use my phone when I was in bed. She got me in bed and she'd just, she just left me there. It was morning and she didn't want to get me up; she didn't feel like getting me up. She wasn't even going to try. She didn't want to come in and give me any water or my meds or anything. And I said, "Well would you give me the phone?" She goes, "No I ain't going to let you use your phone." So then I was really stuck. She actually came in my room and picked up the phone like she was going to give it to me. Then she goes "No I don't think we need to use the phone" and put it back on the dresser.

Exemplar 2. He [her caregiver] worked for a couple of hours and then, you know, he would have a 10 minute break. So he didn't want to listen to my rules. He was constantly saying, "well hire somebody else, I can leave right now." He'd say, "keep it up, keep it up, I'll leave" you know, so what do you do when you're stuck in bed and they say, "oh I can leave right now"? You feel like somebody's holding a gun at you, you've got to shut up.

Although care-related abuse was among the most common form of abuse reported by participants, disability-related abuse was also reported. Unlike care-related abuse, disability-related abuse did not necessarily occur within the context of caregiving relationships. The following exemplars describe incidents of disability-related abuse perpetrated by intimate partners:

Exemplar 1. There were times when he'd kick the chair, yeah kick the chair um, threw things at me... Because it is a part of me, yeah, and it was going to damage something that I needed to get around.

Exemplar 2. I had a boyfriend who would take a hold of the back of my chair and tip it back sometimes almost to the floor. And I would tell him not to do that to my chair. He thought it was funny.

As the above exemplars illustrate, disabilityrelated abuse often involved withholding or damaging assistive devices. Other forms of disability-related abuse commonly reported included blaming a woman for her disability or calling her names such as "crybaby quad."

When a woman experienced abuse, her ability to get help was often severely limited by the lack of available disability-appropriate interventions. *Lack of Intervention* refers to the inadequacy of care systems to identify and intervene with abused women with physical disabilities. The following 2 exemplars illustrate the ways in which *Lack of Intervention* severely limited women's ability to stay safe:

#### Exemplar 1.

Participant: I tried to get into a shelter, and I couldn't take a [nonabusive male] care provider with me. Um, I had to be out of there by 8 o'clock in the morning, and it's wintertime, you know.

*Interviewer*: And why couldn't you take a care provider with you?

Participant: Well, for one thing, the care provider that I had at the time was male, and so I couldn't do that. He could not even to come in for a couple of hours and then leave, couldn't do that. Um, and also taking my equipment with me and finding a place that was accessible. They didn't have accessible places.

#### Exemplar 2.

I was afraid she [her caregiver] was going to escalate to the point of hurting me. At that point she was just verbally abusing me and if I had someone to replace her with I would have immediately replaced her. As it was I was on the phone to my caseworker who did not help me... they don't have many options unless they got someone to step right in there. And if I had someone to step right in there I would replace them.

As the exemplars above illustrate, common barriers to help seeking identified by participants included lack of emergency backup caregivers, lack of availability of caregivers in general, inaccessible shelters, inaccessible social and health services, and lack of awareness on the part of law enforcement, healthcare, and social service providers.

Throughout the narratives, the idea that there were *Trade-offs* involved in *Staying in* relationships with abusive caregivers and/or intimate partners emerged. *Trade-offs* generally included putting up with a certain level

of abuse to maintain some benefit. These benefits sometimes included being in an intimate partner relationship with someone who could provide both intimacy and personal care. In caregiver relationships, these benefits might include reliable care, increased access to transportation, and the ability to engage in recreational activities. One woman described the *Trade-offs* involved in her relationship with a controlling caregiver:

My main caregiver he's younger than I am but he acts like my father at times, you know "You are going to go to bed at this time." I know he's looking out for my own good but he is also lazy...you know he wants me to go to bed at five o'clock, six o'clock every night and it's like wait a minute I have to have some life... But yet, I could trust him with my bankcard and he is a licensed massage therapist so there are perks, its almost... I am willing to trade-off some of the you know... definitely trade offs because I've never had the real horror stories that other people have about being ripped off by caregivers... but it is hard to know where to draw the line... so it is a constant battle.

When caregivers were also intimate partners, the *Trade-offs* involved in the relationship became even more complex. Of note, participants who received essential personal care from an intimate partner tended to *Stay In* abusive relationships longer. One woman whose intimate partner was also her caregiver described her experience as follows:

He could get me out of my chair, and I could participate in lots of different things. And so I felt it was a trade-off that I could probably handle, manage, and things would get better. That the abuse would... that the outbursts and the destruction, the destructive behavior, because as of yet it hadn't really gotten to me physically in terms of hands on, choking.

... 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.

The woman quoted in the above exemplar experienced severe psychological, physical, fi-

nancial, and care-related abuse in her relationship. Of note, she also had all of the vulnerability factors described later in this article.

As women *Stayed In* abusive relationships and made *Trade-offs*, there came a point at which the harm associated with staying outweighed any potential benefit. Often, this *Breaking Point* occurred after the abuse had escalated beyond tolerable levels. One woman reached the *Breaking Point* in her marriage after being hit:

It wasn't even until after we got married that things got steadily worse and he started getting physically violent, throwing things, breaking things, um, throwing things at me, um, calling me names, um, um, um, saying, you know, you can't get a job, you can't do anything. It just got worse and worse and worse. And I stayed for three years . . . He'd never actually-he'd pushed me, he'd thrown things at me but um, he'd never hit me until about  $2\frac{1}{2}$  years into the marriage, and then, and I'd always told him, if you, if you hit me the marriage is over. I'd always told him that, because I didn't like what was happening, and that was sort of the boundary. And I'd always said I want to go for counseling, and he would always refuse. And after he hit me, I said do you realize now that our marriage is over, and he, you know, he did the typical, he got down on, on his hands and knees and was just crying. And he said, I'll go for counseling, I'll go for counseling. That night—I told him, leave, you need to leave.

When participants reached a *Breaking Point*, they began to contemplate leaving. *Building Support and Gaining Strength* denotes a process of gaining strength and actively seeking safety in preparation for leaving. An example of this was described by a woman who took a course on caregiver management to help her deal with abusive caregivers more effectively:

They were having classes on how to be assertive, how to do your own, handle your attendants and how to fire and hire and write your program. And it was awesome. It gave me a backbone. It really did. I mean some of the training was really hard. Because we'd do role playing and they'd start hollering, you know, or saying, screaming at you, then I would just crumple into the corner until I could refocus... and I found that I didn't have to be a doormat. That really changed my life. It strengthened my resolve. It strengthened everything.

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Other examples of Building Support and Gaining Strength included obtaining alternate caregiver services, attending support groups, and building social networks. Getting out describes the process of leaving the relationship, either temporarily or permanently. This may mean refusing to utilize the services of a particular transportation worker or caregiver, leaving an abusive intimate partner for a few days, or obtaining a divorce. Once out of their abusive relationships, participants remained abuse-free (subsequently entering into nonabusive relationships or remaining alone), reentered the abusive relationship, or entered into a new relationship with a different abuser. It should be noted that when women reentered relationships with their abusers they tended to move through the abuse trajectory stages more rapidly. Because in most cases the abuse did not cease, all but 1 of the 37 women interviewed eventually left permanently. One woman who had been married for 20 years did report a resolution of the abuse after multiple separations and reunions. She attributed this improvement to her husband's sobriety, which he achieved after suffering from alcoholism for many years.

#### Vulnerability factors

Over the course of women's lives, a number of antecedents that increased their vulnerability to abuse were noted. These vulnerability factors tended to shift the balance of power in relationships in favor of actual or potential abusers. Vulnerability factors fell into 2 categories: (1) cumulative lifetime trauma and psychosocial vulnerabilities and (2) disability-related factors.

Cumulative lifetime trauma and psychosocial vulnerability factors included poor parental relationships, child abuse, previous intimate partner abuse, and alcohol or drug use. Individually and collectively, these factors undermined women's self-esteem and decision making, weakening their ability to protect themselves from abusers. The following exemplars illustrate the psychosocial impact of child and intimate partner abuse on participants:

#### Exemplar 1.

The abuse early on as a child really changed my, or altered my view and perspective about sex and intimacy, relationships...I'd be at risk because I was misinterpreting and not allowing myself to really—had I not really had that really twisted view or perspective or experience with sex and intimacy, it never would have gotten to the point of being...I mean feeling the need to be connected with this person and allowing myself to be subjected to abuse and stick around.

#### Exemplar 2.

Participant: I guess I held onto my husband because he was my only support system. And I didn't feel like I could live by myself. I didn't know I could live by myself. And of course he assured me that I couldn't you know.

Interviewer: Was he abusive?

Participant: He was very abusive, alcoholic, heavy drugs, and I mean he had that volatile... personality

Interviewer: What type of abuse did you experience with him?

Participant: Ah not so much physical as mental. He was very good at the mental game. And I was very fortunate that he married me and . . .

Interviewer: That's what he kept telling you?

Participant: Oh yeah and that nobody else would ever want me and ... my self-esteem level ... was nothing.

In addition to child and intimate partner abuse, alcohol and drug abuse also increased women's vulnerability to abuse. One participant who was a former substance abuser described this danger:

It was good at first, but it was also party hardy time and lifestyle we were living . . . it was like party until three, you know, sleep until three, get up and do it again. And I lost my job probably due to that [lifestyle] ... I could tell that I was starting to look worn and torn...while he was there [in her home] I quit drinking and quit doing drugs and he wanted to continue that lifestyle. And since he wasn't working and I had the income, you know, I just quit buying. So we fought a lot more . . . I've

got a few less doors in my house . . . he'd go shut me in a room and I'd go ram it in with my wheelchair. I'd get so mad, I mean because I couldn't scream, I couldn't get out.

Not surprisingly, intimate partners and/or caregivers who abused substances tended to be lower functioning, more violent, more likely to steal, and more likely to neglect their caregiving duties than those who did not abuse substances.

In addition to cumulative lifetime trauma and psychosocial vulnerability, vulnerability factors specifically related to physical disability were also identified. These factors are related to the social devaluation of women with physical disabilities described earlier and include feelings of sexual inadequacy and perceived need for an intimate partner, intimate partners as caregivers, and physical dependency. Like psychosocial vulnerabilities, disability-related factors influenced women's exposure to, and decision making about, abuse.

Sadly, many women put up with intimate partner abuse out of fear that no one else would love or care for them. One woman who had experienced repeated victimization talked about how her feelings of inferiority impacted her decision making:

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 . . . 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.

When intimate partners were also caregivers, women were doubly invested in their relationships, making it more difficult to combat abuse when it occurred. One participant fittingly coined the term *double jeopardy* to describe this dual investment.

In addition to shaping the context of intimate partner abuse, disability also placed many women at risk for caregiver abuse. This risk was most pronounced in women with high levels of physical dependence. As noted in the earlier description of *Lack of Intervention*, the absence of emergency backup caregivers left women who relied on caregivers for essential personal care such as eating and bathing with little choice but to endure abuse since replacement caregivers were often hard to find. Thus, women with high levels of physical dependence may be at particularly high risk for ongoing abuse and its associated negative health outcomes.

#### Negative bealth outcomes

While the detrimental effects of abuse on health have been well-documented among nondisabled women, very little is known about abuse and health in women with physical disabilities. For this reason participants were specifically asked about the impact of abuse on their psychological, physical, and social health. The health effects reported here were perceived by women to have been caused or exacerbated by the abuse they experienced. The psychological effects of abuse most commonly reported included stress, depression, anxiety, and suicidal ideation. Physical effects included worsening bowel and bladder control, poor nutrition, skin breakdown, and impaired mobility secondary to physical injury. In addition to psychological and physical abuse sequelae, significant social problems were also reported. Social consequences included distrust of others, social isolation, and homelessness.

One of the key health findings of this study was the ways in which disability and violence interact. Because women with physical disabilities have a narrower margin of health than do nondisabled women, injuries and other abuse sequelae have a great impact

on their functional ability and overall health. An example of the interactive effects of abuse and disability was provided by 1 of the participants. This woman, who had survived a spinal cord injury, suffered a rotator cuff sprain as a result of a physical assault. Because she had limited use of her upper extremities to begin with, the injury reduced her mobility and independence considerably. She lost her ability to use a manual wheelchair, open doors, and perform a number of other tasks:

Um, my shoulder's finally better. Oh it's been almost a year it's been about nine months. Nine months with this rotator cuff. Yeah I was laying on my side and he had a hold of my shoulder and he was just kind of pushing down like he would do, push down and push me down into the mattress on the bed and all of the sudden—pop. It affected my ability to do a lot of things. I couldn't, I mean I couldn't get the door you know, to open, I couldn't open the door, it sucked. Couldn't reach for things, oh man that messed me up.

The interactive effects of abuse and disability highlight the alarming health consequences of abuse in this population. Similar interactions were observed between abuserelated mental health comorbidities and physical disability. For example, one woman identified a relationship between the abuse she had experienced, anorexia nervosa, and her physical health status:

Oh, I was so unhealthy physically. I only weighed 90 pounds for the longest time. You know. Um because [the abuse] just affected every piece of me. You know um, I couldn't eat. Because when I get um, upset about things, or things bother me then I don't eat. You know and, and I lean towards anorexia anyway before, even before my accident. And um, and so then after, I lost a lot of weight after the accident you know, initially. You know I got, because I think I weighed 120, about 120 pounds before my accident. And I kept trying to lose weight and I couldn't. You know and I was fasting like for three days in a row and, and I wasn't eating and you know and it felt really good, and there was that whole control issue thing going. And, and I, and I felt it. I mean it was just such a power trip...I had control...Oh I was constantly getting pressure sores. Being, being so thin. You know I was so bony; my butt was so bony only weighing 90 pounds you know. That ah, yeah, I just kept getting sores...You know, and then they'd heal up and then maybe about a month or two later I'd get another one and so it was, it was a constant. You know really a constant.

Not surprisingly, participants with mental health comorbidities were also less able to effectively manage their primary physical disabilities and engage in health-promoting behaviors, resulting in increased vulnerability to the onset of comorbid physical conditions.

#### **SUMMARY**

Abuse of women with physical disabilities is shaped by the interaction between the social context of disability and biography. Because of the complexity of the phenomenon, careful and thoughtful responses to the problem are essential to effect change. The Abuse Pathways model, developed from an analysis of 72 life history interviews, begins to address the complexity of abuse of women with physical disabilities by identifying the interactive components of the phenomenon. After quantitative validation, the vulnerability factors identified in this study may be used to identify women with physical disabilities at risk, promoting preventative and/or early abuse intervention. Moreover, the abuse trajectory identified in this study may prove useful in developing disability-appropriate abuse interventions that are stage specific. In accordance with the model, such efforts must be framed within the social context of disability to avoid blaming women for their plight and to promote social policy change.

### LIMITATIONS OF THE MODEL

It should be noted that the heterogeneity of the study sample limits the applicability of the Abuse Pathways model. The social context of disability described in the model 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. Moreover, because the majority of participants in this study had major mobility impairment, it may be that women with less severe, hidden, or sensory disabilities may also have different abuse experiences. Because the study sample was heterogeneous,

the kind of in-depth analysis of specific cultural and physical disability groups was not possible. Research is needed to begin to address this gap in knowledge. The interactive effects of abuse and disability on health and the lack of disability-appropriate interventions currently available highlight the urgent need for this research.

#### REFERENCES

- 1. Berkeley Planning Associates. Priorities for Future Research: Results of BPA's Delphi Survey of Disabled Women. Oakland, Calif: Berkeley Planning Associates: 1996.
- 2. United Nations. Declaration on the elimination of violence against women. General Assembly Resolution 48/104. 1993. Available at: http://www.ohchr. org/english/law/eliminationvaw.htm. Accessed January 7, 2005.
- 3. World Health Organization. Violence against women. Fact Sheet No. 239. Available at: http://www.who. int/mediacentre/factsheets/Fs239/en/. October 12, 2004.
- 4. Young E, Nosek M, Howland C, Changpon G, Rintala D. Prevalence of abuse of women with physical disabilities. Arch Phys Med Rehabil Spec Issue. 1997:78:S34-S38.
- 5. Powers L, Curry MA, Oschwald M, Saxton M, Eckels K. Barriers and strategies in addressing abuse: a survey of disabled women's experiences. J Rehabil. 2002;68(1):4-13.
- 6. Curry MA, Hassouneh-Phillips D, Johnston-Silverberg A. Abuse of women with disabilities: an ecological model and review. Violence Against Women Int Interdiscip J. 2001;7(1):60-79.
- 7. Hassouneh-Phillips D, Curry MA. Abuse of women with disabilities: state of the science. Rehabil Counsel Bull. 2002;45(2):96-104
- 8. Gilson S, Cramer E, Depoy E. Redefining abuse of women with disabilities: a paradox of limitation and expansion. Affilia. 2001;16(2):220-235.
- 9. Mertens D. Mixed methods and the politics of human research: the transformative-emancipatory perspective. In: Tashakkori A, Teddlie C, eds. Handbook of Mixed Methods in Social and Behavioral Research. Thousand Oaks, Calif: Sage; 2003:135-164.

- 10. Seidman I. Interviewing as Qualitative Research: A Guide for Researchers in Education and the Social Sciences. New York: Teachers College Press; 1991.
- 11. Benner P. The tradition and skill of interpretive phenomenology in studying health, illness, and caring practices. In: Benner P, ed. Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness. Thousand Oaks, Calif: Sage; 1994:99-128.
- 12. Nvivo 2.0 [computer program]. Thousand Oaks, Calif: Sage; 2003.
- 13. Parker B, Ulrich Y, Bullock L, et al. A protocol of research on abuse of women. Nurs Res. 1990;39(4):248-250.
- 14. Creswell J. Qualitative Inquiry and Research Design: Choosing Among Five Traditions. Thousand Oaks, Calif: Sage: 1998.
- 15. Lincoln Y, Guba E. Naturalistic Inquiry. Thousand Oaks, Calif: Sage; 1985.
- 16. Gill C, ed. Dating and Relationship Issues. Baltimore: Paul Brooks: 1996.
- 17. Krotoski M, Nosek M, Turk M, eds. Women With Physical Disabilities—Achieving and Maintaining Health and Well-Being. Baltimore: Paul H. Brooks Publishers: 1996.
- 18. Wendell S. The Rejected Body—Feminist Philosophical Reflections on Disability. New York: Routledge;
- 19. Lonsdale S. Women and Disability—The Experience of Physical Disability Among Women. New York: St Martin's Press; 1990.
- 20. Thomas C. Female Forms-Experiencing and Understanding Disability. Philadelphia: Open University Press; 1998.