

Chapter II

Development of the Abuse Assessment Screen-Disability (AAS-D)

An earlier national study conducted by CROWD (Nosek, Howland, Rintala, Young, & Chanpong, 1997) showed that, in addition to the physical and sexual abuse experienced by women in general, women with physical disabilities are vulnerable for disability-related abuse. This type of abuse includes withholding needed orthotic equipment, medications, or transportation, and refusing to provide essential assistance with personal tasks (Nosek, Foley, Hughes, & Howland, 2001). Many individuals who have functional limitations may depend on family or others for personal assistance. In the event that the person providing the assistance is the perpetrator of abuse, the woman with a disability may perceive that this assistance is her only option, that no one else would provide her care, and that abuse is the price she must pay for survival. Our national study suggested that the prevalence of emotional, physical, and sexual abuse was not significantly different between women

with disabilities compared to women without disabilities. The same percentage (62%) of women with and without disabilities had experienced emotional, physical, or sexual abuse. There was, however, a significant difference in the duration of the abuse. Women who had disabilities experienced all three types of abuse for significantly longer periods of time compared to women without disabilities. When comparing women with and without disabilities, the two groups appear to experience the same amount of abuse. However, this prevalence study did not evaluate abuse stemming from disability-related factors. Disability-related abuse may add to the prevalence of abuse experienced by women with disabilities over and above the physical, sexual, and emotional abuse experienced by women in general. Abuse screening measures identified in the literature were unable to detect women with disabilities who are experiencing disability-related abuse, leaving such abuse unidentified and untreated.

DESIGNING THE “ABUSE ASSESSMENT SCREEN-DISABILITY” (AAS-D)

As a result, we determined that it was clinically important to develop an instrument that would be responsive to disability issues. We began the construction of this instrument by studying and incorporating the results from the qualitative study reported in Chapter I of this report, and the findings from our previous research and other investigations reported in the literature. Our work was greatly enhanced with expert input from the national and local advisors consisting of consumers, researchers, health care and other service providers, legal advisors, and law enforcement representa-

tives. As proposed, we modified the Abuse Assessment Screen (AAS) (Soeken, McFarlane, Parker, & Campbell, 1998), a well-researched instrument that evaluates physical and sexual abuse and consists of two questions to determine the frequency, severity, perpetrator, and body site of injuries that occurred within the year prior to the evaluation. Modifications to the AAS included the addition of two items focusing on disability-related abuse, including the assessment of being denied (a) medications or access to assistive devices, and (b) personal assistance needed for essential activities of daily living. The draft of the modified instrument, which is entitled the Abuse Assessment Screen-Disability (AAS-D) (McFarlane et al., 2001), was reviewed by our advisors and consumers whose suggestions and feedback were considered during the refinement of the instrument. While their feedback did not necessitate substantive modifications, it did provide helpful information on the overall appeal and appropriateness of this instrument. Intensive reviews by experts suggested that the instrument had content validity, meeting the objective of this phase of the study. The experts were positive in their reviews. Dr. Judith Cook (Cook, 1999), University of Illinois at Chicago, stated: “Overall, I think that the AAS-D would be quite applicable for clinical and service delivery settings. It is concise and user-friendly, addressing physical and sexual abuse and neglect experienced by adult women...” The AAS-D consists of four items as shown in Table 2.1.

Table 2.1 ABUSE ASSESSMENT SCREEN-DISABILITY (AAS-D)

1. **WITHIN THE LAST YEAR**, HAVE YOU BEEN HIT, SLAPPED, KICKED, PUSHED, SHOVED OR OTHERWISE PHYSICALLY HURT BY SOMEONE? **YES** **NO**

If **YES**, WHO? (CIRCLE ALL THAT APPLY)

Intimate Partner	Care Provider	Health Professional	Family Member	Other (e.g., stranger, clergy)
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PLEASE DESCRIBE: _____

2. **WITHIN THE LAST YEAR**, HAS ANYONE FORCED YOU TO HAVE SEXUAL ACTIVITIES? **YES** **NO**

If **YES**, WHO? (CIRCLE ALL THAT APPLY)

Intimate Partner	Care Provider	Health Professional	Family Member	Other (e.g., stranger, clergy)
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Please describe: _____

3. **WITHIN THE LAST YEAR**, HAS ANYONE PREVENTED YOU FROM USING A WHEELCHAIR, CANE, RESPIRATOR, OR OTHER ASSISTIVE DEVICES? **YES** **NO**

If **YES**, who? (Circle all that apply)

Intimate Partner	Care Provider	Health Professional	Family Member	Other (e.g., stranger, clergy)
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Please describe: _____

4. **WITHIN THE LAST YEAR**, HAS ANYONE YOU DEPEND ON REFUSED TO HELP YOU WITH AN IMPORTANT PERSONAL NEED, SUCH AS TAKING YOUR MEDICINE, GETTING TO THE BATHROOM, GETTING OUT OF BED, BATHING, GETTING DRESSED, OR GETTING FOOD OR DRINK? **YES** **NO**

If **YES**, WHO? (CIRCLE ALL THAT APPLY)

Intimate Partner	Care Provider	Health Professional	Family Member	Other (e.g., stranger, clergy)
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Please describe: _____

MEASURES

This section includes an overview of most of the measures involved in the studies as reported in Chapters II through V of this document. In each chapter, we briefly identify the measures used in the study being reported, referring back to this summary for more detailed information.

Data were collected by means of a survey questionnaire developed for this study and administered orally by project staff in the clinics. The survey questionnaire assessed demographic information including age, race, education level, household and personal income, and marital status, plus the following instruments.

Disability Status was assessed according to the paradigm of the WHO International Classification of Functioning and Disability (World Health Organization, 1997): impairment, activity, and participation.

For *impairment*, we used age at onset and duration of disability, and the pain scale from the Medical Outcomes Study Short Form-36 (SF-36); the two-item pain scale asks about severity of pain and the extent to which it interferes with functioning. The SF-36 is a self-administered indicator of health status and includes multi-item scales to measure eight dimensions including bodily pain and physical functioning (Stewart & Ware, 1992). The median across many studies of the alpha internal consistency coefficients exceeded .76. Test-retest correlations are .60 - .90 for six months. Scores on the SF-36 scales are standardized, ranging from 0 (worst) to 100 (best) (Stewart et al., 1989).

Activity was determined by three measures of physical functioning, 1) the physical functioning subscale of the SF-36 (10 items rated on a scale

from one [limited a lot] to three [not limited at all]); 2) the mobility subscale of the Craig Handicap Assessment & Reporting Technique (CHART) (Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1988), which is a measure of handicap or the inability to fulfill expected social roles. Items are scored on a standardized scale ranging from 0 (most limited) to 100 (least limited). The mobility subscale of the CHART assesses hours out of bed, days out of the house, nights spent away from home, and access to transportation; and, 3) a two-item measure of the need for personal assistance with activities of daily living and instrumental activities of daily living that had been used in our previous studies.

Participation was measured in terms of social isolation, which was assessed by three items asking about contacts with friends and relatives. The items were taken from an index previously used in the Human Population Laboratory study of Alameda County (Roberts, Kaplan, Shema, & Strawbridge, 1997). Respondents are asked to indicate how many close friends and relatives they have, and how many of these they see at least once a month. The upper limit for each item is 10 or more. Total score ranges from 0 to 30. Reliability for the three-item social isolation index in the current study was high ($\alpha = .82$).

Social Support. The availability of social support was assessed by the Medical Outcomes Study Social Support Scale (Sherbourne & Stewart, 1991), consisting of 19 items grouped into four subscales: tangible support, affectionate support, positive social interaction, and emotional or informational support. Internal consistency is high at .97. Questions ask how often each type of support is available, on a scale from 0 (none of the time) to 4 (all of the time). An additional item with a three-point scale asks about

overall satisfaction with social relationships. Total score ranges from 1 to 79, with higher scores indicating greater social support. For this study an eight-item subset of the full scale was used, including two items from each subscale (Groff, 1999). Score range for this subset is 1 to 35. Reliability for the eight-item version in our sample was high ($\alpha = .82$).

Abuse. Information on abuse experiences was gathered using the Abuse Assessment Screen-Disability (AAS-D) (McFarlane et al., 2001) which was developed by this study (see Table 2.1).

Health Status was assessed using the vitality (4 items) and mental health (5 items) subscales of the SF-36 (please refer to psychometric information above).

MANDATORY REPORTING ISSUES

The recruitment phase of this study was delayed due to the consideration of the State of Texas mandatory reporting law for abuse of persons who are elderly or disabled (1995). We believed that being required to inform the women that we would report abuse would potentially increase the number of false negatives. Due to the sensitive nature of the study and its inherent risk of retaliatory violence, the safety of each participating woman was paramount in our procedures. An application to the CDC for a Certificate of Confidentiality was considered until it was clarified that such a certificate would not serve as a waiver for the mandatory reporting law. Consultations were conducted with various legal and compliance offices. An attorney from Adult Protective Services interpreted the mandatory reporting requirement to apply to persons with disabilities who are not legally compe-

tent or who cannot speak for themselves (i.e., cannot seek help without assistance). This attorney interpreted the word "disabled" in the relevant code to mean a person who has both severe physical and cognitive impairments. However, our concern related to the confidentiality of disclosure of current abuse by a research participant who has a physical disability but who does not have a severe cognitive impairment. Our informed consent form, therefore, stated that we were required to report the current abuse of persons with disabilities who could not speak for themselves. After in-depth consultation with the study advisors, consultants, and other experts, we determined that obtaining verbal and witnessed consent was indicated. This procedure was intended to minimize the risk that could result if the names of the study participants were ever to be revealed. Thus, we requested and were granted by the Baylor IRB a waiver of the regulatory requirement of written documentation of consent in order that the research could be practically executed. To assure that the woman's participation in the study could never be discovered by the perpetrator or through subpoena of records, we conducted the screenings anonymously and thus did not schedule appointments or document the woman's name in other ways. Not scheduling interviews necessitated that the project staff were on-site in the clinics for many more hours than just those necessary to conduct the interviews. Our procedures included asking that each participant mark an 'x' on the signature line, and having two members of the research staff sign that they obtained consent. Although this procedure was cumbersome and staff-intensive, we determined that it was a protective alternative to the possibility that the identity of the woman could ever be revealed or reported without her expressed consent. Additionally, the \$10 cash payment was made without the woman's

signature. We thereby necessarily forfeited our opportunity to make follow-up contact with the study participants.

PILOT STUDY

The AAS-D was pilot-tested with 10 women with physical disabilities including one woman who screened positive for abuse. Each woman was offered resources for assistance, information on safety planning, and referrals to community services as needed. At the completion of the pilot study, the instrument and assessment protocol were reviewed by project staff and consultants. No substantive changes were indicated.

ENROLLMENT AND SCREENING

The recruitment and screening occurred in specialty outpatient clinics, including the rheumatology clinic of the county's Ben Taub General Hospital (n=199), Baylor-Methodist International Multiple Sclerosis Clinic (n=131), the outpatient physical medicine and rehabilitation clinic of the county's Quentin Mease Community Hospital (n=32), the outpatient clinic of The Institute for Rehabilitation and Research (n=127), and the rheumatology clinic of the county's People's Health Center (n=18); other (n=4). Recruitment of study participants in each clinic began by visiting the clinic medical staff who were asked to in-

**511 WOMEN WITH
PHYSICAL
DISABILITIES
PARTICIPATED IN
THIS STUDY**

form their female patients about the study. Women who were interested in participating and met the eligibility requirements were directed to the project staff. Interviews were conducted while the women were waiting for their appointments or before they left the clinic. The project staff escorted interested women to a confidential area where the study was explained. A sample of 511 women met the study criteria and gave informed consent.

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Approximately twenty women refused to participate and be screened. Lack of time was the most common reason for not participating. Basic demographic information and disability-related information was gathered preceding administration of the AAS-D and other study instruments. The

interviews averaged 20 minutes in length. All women were offered written information on the cycle of violence and community resources for law enforcement, safe shelter, and legal aid. Data collection spanned a nine-month period. We conducted the interviews in English (86.9%) and Spanish (13.1%), as preferred by the women participating.

We experienced several challenges to optimal recruitment: 1) Time delays related to busy medical staff who did or did not have the interest and willingness to refer women to a study on violence, or who did not identify a woman as having a physical disability; 2) A general lack of private and accessible space arrangements to assure participant comfort and foster a sense of safety in disclosing sensitive issues; 3) Disability-related fatigue

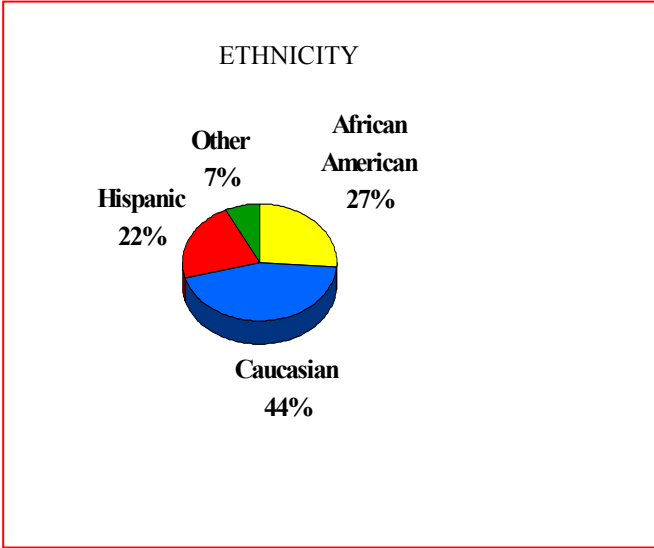
discouraged women from participating in an interview after completing a lengthy physician consultation; 4) The women's first priority was to obtain a physician consultation, which was their reason for coming to the clinic; this consultation may have interrupted or ended the interview (Nosek, Howland, & Hughes, 2001).

In addition to the recruitment issues, our experience in conducting the actual interviews in the clinic setting yielded several potential pitfalls. First, the brevity of the interviews sometimes reduced the necessary rapport building and may have inhibited the full disclosure of abuse-related information, especially in cases where the abuse was being disclosed for the first time. Dilemmas related to the participants' perception of the interviewer as "expert" or "peer" had to be resolved so as not to create false expectations. Therefore, part-time project staff were trained to adhere to their assigned roles, to recognize their limitations, and to offer appropriate referrals for psychological support and other issues. The project director, a licensed psychologist, or another mental health counselor provided psychological back-up at all times. The part-time screening staff were instructed to contact these professionals for consultation, referral assistance, crisis intervention, and/or debriefing following a difficult interview. This debriefing process was always given a priority at the end of a long day in the clinics to lessen the emotional burden on the part-time staff.

RESULTS

The sample was predominantly unemployed (78%), members of ethnic minority groups (52%), unmarried (58%), with secondary (38.6%) and

post-secondary (38%) education. The mean age was 45.9 (SD=11.07, range 18-64). The median personal income was \$6,550 with a median household income of \$14,000. The primary disability type was joint and connective tissue (34.6%), followed by multiple sclerosis (23.7%), spinal cord injury



(14.7%), polio (9.2%), neurologic disorders (9.0), and others (8.9%). The majority of the women used assistive devices including a power (14.5%) or manual (32.7%) wheelchair, cane (36%), walker (26.4%) or other assistive device. The mean age of

disability onset was 32.6 years, and the mean for disability duration was 13.3 years. Approximately 70% of the women reported moderate to severe pain within the past week, and 85% reported that they required assistance with instrumental activities of daily living.

Using the four-question AAS-D, 9.8% of the women (50/511) reported abuse. Using only the two original questions of the AAS (#1

**50 OF 511 WOMEN
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DURING THE
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physical, and #2 sexual), only 7.8% of the women (40/511) reported abuse. When the two disability-related questions (#3 and #4) were added, they identified an additional 20% who screened positive for abuse.

Women who identified themselves as other than African American, Caucasian, or Hispanic (i.e., Asian or mixed ethnic background) were more likely to report physical and/or sexual abuse. Disability-related abuse was reported almost exclusively by Caucasian women. An intimate partner was the primary perpetrator of physical or sexual abuse.

CONCLUSION

It is necessary to use both traditional abuse and disability-specific questions to obtain an accurate estimate of abuse and violence against women with physical disabilities. Although the level of abuse measured with questions 1 and 2 of the AAS-D is similar to prevalence rates among women in primary care settings (Elliott & Johnson, 1995; McCauley, Kern, Kolodner, Derogatis, & Bass, 1998), no study was uncovered in the literature for comparison of the findings on disability-related abuse. Using a traditional two-question screening tool, only 80% of the abused women with disabilities would have been detected. The generalizability of the findings from this study is limited by the cross-sectional and convenience sample of predominantly urban clinic female patients with disabilities. Replication studies of the AAS-D are needed in rural geographic areas, as well as with more severely disabled women who lack outpatient clinic access. Furthermore, the study relies entirely on self-report, which may influence the amount of disclosure. Despite these limitations, this study documents the

utility of a simple, four-question abuse screening tool designed for women with physical disabilities and the necessity of assessing disability-related abuse. It is recommended that assessment for physical, sexual, and disability-related abuse be standard care for women with disabilities.

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