

Development of An Abuse Screening Tool for Women with Disabilities

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Abstract

Women with disabilities are at increased risk for violence and abuse, including forms of abuse experienced by all women and forms unique to women with disabilities, such as abuse by personal assistants. The purpose of this study was to develop an abuse screening tool unique to women with disabilities that could be self-administered by women as well as used by providers and advocates to identify women at risk for abuse. Derived from previous research findings, the tool was field-tested with 47 women who experienced physical and physical and cognitive disabilities. Further refinement of the tool's wording and formatting was accomplished through 2 focus groups and several individual interviews. Findings indicated that use of the screening tool facilitated the identification of abuse and risk factors, and that women with disabilities were receptive to participating in screening. Recommendations for abuse screening and risk assessment with women who have disabilities are presented.

Violence and abuse pose significant risks for women with disabilities, who are more likely to experience abuse than nondisabled women (Furey, 1994; Gill, 1996; Nosek, Howland, Rintala, Young & Chanpong, 1997; Powers, Curry, Oschwald, Maley, Saxton, & Eckels, 2002; Sobsey & Doe, 1991; Stimpson & Best, 1991). These risks include those experienced by nondisabled women such as physical injury, sexual abuse, emotional trauma, and financial abuse. However, women with disabilities also experience unique forms of abuse, such as disabling equipment, manipulating medications, or refusal to provide essential personal care. They are at risk for experiencing health complications, loss of independence, and the inability to work as a result of the abuse (Saxton, Curry, Powers, Maley, Eckels & Gross, 2001; Powers, et al 2002). The purpose of this study was to develop an abuse screening tool unique to women with disabilities that could be self-administered by women with disabilities as well as used by health and social service providers, domestic violence and disability advocates to identify women at risk for abuse.

Background

According to the 1992 Census, over 26 million women were reported to have physical disabilities, representing approximately 20 percent of the total female population (ref). This large and diverse population of women unfortunately experience the social context of disability, including factors such as discrimination, inaccessibility, poverty and isolation, which are crucial for understanding their increased risk for abuse. Like women without disabilities, disabled women are at risk for experiencing intimate partner and/or family violence. However, reliance on both paid and unpaid personal assistance from family members, intimate partners, friends, or strangers creates additional and unique exposure to risks for abuse among women with disabilities. Approximately 25 percent of women with disabilities use personal assistance

services, which are defined as “One or more persons assisting another person with tasks which the individual would typically do if they did not have a disability” (Litvak, Zukas & Heumann, 1987). Abuse by personal assistance providers has been identified by women with disabilities as a significant problem and is integrally related to the capacity of disabled women to live independently. When personal assistance abuse occurs, women’s abilities to engage in daily life activities are compromised along with their personal health and safety.

The few studies that have examined abuse among women with disabilities have found a high or higher incidence of abuse compared to women without disabilities. Nosek, Young & Rintala (1995) found the incidence of abuse among 439 women with physical disabilities and 421 women without physical disabilities was similar; 62% of both groups reported some type of lifetime abuse. However, women with disabilities were more likely to experience abuse by personal assistants and health providers and they were more likely to experience a longer duration of abuse than nondisabled women. Similarly, Powers, et al (2002) in their study of 200 women with physical and physical and cognitive disabilities found that 67% of the women had experienced physical abuse and 53% had experienced sexual abuse during their lifetimes.

Saxton, et al (2001) conducted a qualitative study of 72 women with disabilities who used personal assistance in order to describe and understand the nature and management of personal assistance abuse. Focus groups and individual interviews were conducted to determine how women defined abuse, the barriers they faced in handling abuse, and strategies they recommended for preventing or stopping abuse. Participants described many forms of abuse common to all women such as physical, sexual, emotional and financial abuse. They also described numerous forms of disability-specific abuse such as medication manipulation, destruction of equipment, threats or actual refusal to provide essential personal care and

abandonment. The women identified many barriers to addressing abuse, including: difficulty recognizing and having abuse validated; feelings of shame; lack of back-up personal assistance providers; fear of institutionalization or loss of children if they reported the abuse; and lack of access to resources such as crisis lines or domestic violence shelters. Strategies they suggested for preventing or ending the abuse included: support groups; access to emergency or back-up personal assistance providers; information about domestic violence resources; and support in hiring, training and supervising personal assistance providers.

Findings from the qualitative study just described were used to conduct a survey study aimed at determining women with disabilities' experience of, and perception of the harmfulness of, various forms of abuse behavior (Powers, et al, 2002). The study also examined the severity of barriers to ending abuse experienced by participants as well as which strategies they perceived as most helpful for preventing or ending abuse. A total of 200 adult women with physical disabilities or physical and cognitive disabilities were recruited through centers for independent living and disability services agencies in four urban areas. All participants were living in non-congregate community residences and used personal assistance services provided by family members, friends, or paid personnel (or some combination of these). Personal experience of abuse was not a requisite for participation.

As previously reported, 67% of the women reported a lifetime history of physical abuse and 53% reported experiencing sexual abuse during their lifetimes. When asked whether they had ever experienced any one of the 31 forms of abuse behavior from a personal assistance provider, at least 20% of the women reported experiencing some type of abuse. The most common were poor job performance, threatened or actual neglect, verbal abuse, exerting control or denying the women's choices, threatened physical abuse, rough treatment, and financial

abuse. The inappropriate administration of medication was reported by 14% of the participants while inappropriate touching was reported by 11% of the women.

The women were asked to rate how hurtful the 31 behaviors would be to them or a woman with a similar disability. All of the behaviors were rated within the moderately to very hurtful range. The most hurtful behaviors were clustered into categories that included: a) physical, sexual, verbal and financial abuse or threat of abuse; b) neglect; c) withholding or destruction of equipment; d) inappropriate administration of medication; e) providing personal care while intoxicated or high on drugs; and f) inappropriate exertion of physical or verbal control. The behaviors that were identified as most hurtful and had an incidence rate of 20% or higher included financial abuse, threatening physical harm, being drunk or high on the job, verbal abuse, making decisions without asking and/or denying choices, handling roughly, snooping in belongings, and ignoring requests.

The participants ranked all of the 16 barriers to ending or stopping abuse as moderate or very severe. The most critical barriers related to personal assistance provider factors such as low wages, shortage of qualified providers and lack of back-up providers. These were followed in importance by lack of knowledge about abuse resources and fear of provider backlash if they reported the abuse. Not surprisingly, the most important strategies for preventing or stopping abuse endorsed by participants included having a back-up personal assistance provider and being able to choose their own provider. Other strategies that were positively rated focused on accessing resources (e.g. crisis line, shelters) and learning to successfully manage their relationships with personal assistance providers. While the participants strongly endorsed being screened for abuse as very important, only 21% reported that their health provider had ever asked them about abuse. The women reported the following preferences for the person who should

conduct abuse screening: a) 53% by a therapist; b) 62.3% by a nurse; c) 64.1% by a physician; d) 68% by a case manager; e) 69% by an independent living staff person; f) 75.9% by a religious person; and g) 76.5% by a counselor.

Overall, the study findings validated the extent of abuse experienced by women with disabilities, both in terms of the high incidence as well as the many unique types of abuse they encountered. These data, along with the findings related to barriers and strategies, were used to develop the screening questionnaire and risk assessment questions evaluated in this study.

Method

The development of the final version of the screening and risk assessment tool required three distinct steps. The first step involved creating a draft instrument based on the findings from the focus group and survey studies just described. The second step consisted of a field-test of the revised instrument and the third step consisted of holding several focus groups and individual interviews to refine the final instrument. All procedures involving the participation of human subjects were approved by appropriate Institutional Review Boards.

Initial Draft of Abuse Screening and Risk Assessment Questions

The initial draft of the screening questions included 8 questions. Five questions were developed with language that women had used in the focus groups to describe abusive behaviors unique to women with disabilities and 3 questions were selected from established abuse screening tools for women without disabilities. The initial draft of the risk assessment questions included items we thought might place women who screened positive for abuse at additional risk.

Abuse Screening Questions. The 5 questions that were unique to women with disabilities included examples of abusive behaviors that were endorsed as very hurtful and/or

common in the survey study. These behaviors included manipulation of medication, financial exploitation, destruction of or withholding of assistive devices, threat of or actual neglect to help with an important personal need, and consistent emotional abuse. Developing the language for the first 4 of these questions was fairly straight-forward. For example, the question regarding medication was: “Within the last year has anyone refused to give you your medication, kept you from taking your medication, or given you too much or too little?”

However, the question regarding emotional abuse was very difficult to construct. Participants in the focus groups described being yelled at and put down as common, painful, and demoralizing. Likewise, participants in the survey study ranked being yelled and screamed at and being put down by personal assistant providers as both common and hurtful. Because women in the focus groups identified strangers as well as intimate others and personal assistance providers as the source of these personal attacks, we decided to limit the perpetrator in the screening question to someone close. Furthermore, we wanted the question to reflect a repetitive pattern, rather than an episodic event. Thus, the question asked: “Within the last year has anyone close to you over and over again yelled at you or said things to put you down or hurt your feelings?”

The 3 questions from established instruments asked about physical abuse, sexual abuse, and feeling unsafe with someone. The question about physical abuse asked: “Within the last year, has anyone threatened or actually hit, slapped, kicked, shoved, handled you roughly, or otherwise physically hurt you?” It was modified from the typical way in which it is usually asked with the inclusion of language about being threatened and handled roughly. This came from the participants in the focus groups who consistently described how controlling and abusive the threat of being physically hurt was for them. Likewise, being handled roughly, which could

result in a serious injury, was also frequently described as very abusive. The question about sexual abuse asked: "Within the last year, has anyone touched you in a sexual way that you did not want or forced you to have sexual activities?" It was also modified from the way it is typically asked with the inclusion of language about being touched in an unwanted sexual way. Women in the focus groups repeatedly described how common and hurtful these unwanted touches were to them. They were frequently described as ways that were used to control their access to services, such as transportation drivers insisting on fondling their breasts before being allowed onto a lift. The final question from existing instruments: "Do you feel unsafe with anyone?" was not modified in the way it is typically asked.

Risk Assessment Questions. The model for the risk assessment questions was the Danger Assessment tool developed by Campbell (1995). The purpose of the Danger Assessment is to determine which women who screen positive for abuse are also at increased risk for severe violence and/or homicide. The items for our risk assessment questions were based on the Danger Assessment, our focus group and survey data, and the clinical expertise of domestic violence and disability advocates. Our initial draft intentionally included a broad range of questions as our goal was to begin to understand what factors might place women with disabilities at greater risk for making their situations worse. Examples of these questions were: "Does the person abusing you keep you from getting needed health care?"; "Do you have a health problem that can be come dangerous if neglected such as diabetes, epilepsy, skin sores, or heart disease?"; and "If you depend on caregivers, do you have emergency back-up caregivers?"

Focus Group Refinement. A focus group of women with physical and cognitive disabilities reviewed and refined the 8 abuse screening questions and the risk assessment questions. Their contributions were invaluable in improving the clarity of the questions and

adding important content. Examples of the latter included adding telephones to the abuse screening question that asked about restricting the use of or damaging assistive devices and including a risk assessment question about whether the person abusing them had a lot of personal pressures. This turned out to be the third most common risk factor, which was not surprising given the low wages and high-turnover of personal assistance providers that women in this and the previous focus groups described.

Field Test of Screening and Risk Assessment Questions

Women living in Oregon or California who had participated in the survey study were sent
a packet including a letter inviting them to participate in the field-testing of the screening questionnaire. Oregon and California participants were selected because they lived in the same geographic area as the investigators and would be available for interviews. Interested women were asked to return an enclosed postcard indicating they might like to participate. A total of 167 packets were mailed; 12 were returned because of changes of address without forwarding information. Postcards indicating interest in the study were received from 59 women. Of those, 47 agreed to participate in the field-test after being contacted by an investigator. Of the remainder, some could not be contacted while others declined to participate once contacted.

All initial contacts were by telephone. After explaining the purpose of the study and obtaining informed consent, an investigator asked a few basic demographic questions including the participant's age, ethnic identity, type of disability, and type of personal assistance they used. Then, all participants were asked the following abuse screening question "Some disabled women report that they have had things happen to them like medications manipulated, equipment destroyed, sexual or physical abuse, or repeated verbal abuse by somebody close to them. Have you personally experienced any one of these things in the last year? Please answer by saying

'yes' or 'no'." The investigator would then confirm the participant's answer with the following statement: "So you have/have not experienced one or more of these things in the last year?"

Next, an appointment was made to complete the abuse screening and risk assessment questionnaire in-person at a safe and convenient location. A trained interviewer who did not know the woman's response to the telephone abuse screening question completed all the interviews. The following script was used to introduce the 8 abuse screening questions: "Women with disabilities, like all women, are at risk of being abused by their intimate partners. However, women with disabilities are also at risk for being abused by persons who provide them

with assistance. Some examples of persons, paid or unpaid, who may give assistance are family members, friends, intimate partners, health providers, bus and van drivers, and physical therapists. Can you think of anyone who you get assistance from? (*Pause for answer*). When you think about all of these people..." Then, the first abuse screening question was asked. Participants who answered yes to one or more of the 8 questions were then introduced to the risk assessment questions with the following script: "These are some things that may place women with disabilities who are being abused at risk for making her situation worse. Please answer yes or no to the following questions."

No problems were experienced administering the abuse screening questions, which took an average of 5 minutes to complete or the risk assessment questions, which took an average of 7 minutes to complete. Participants repeatedly expressed how grateful they were that someone was concerned about the issue of violence among women with disabilities and typically thanked the interviewer. Several offered detailed descriptions of their own past and current abuse experiences. All participants were offered printed information regarding local resources for women with disabilities who are experiencing abuse and were financially compensated for their

time.

Description of participants. The average age of the 47 participants was 51, with a range of 25 to 87 years. The majority were Caucasian (70%) followed by African-American (17%), Hispanic (9%), and Asian (4%). Participants had completed an average of 14 years of education, with a range of 4 to 21 years. Nearly half (47%) described their level of disability as severe, followed by 43% who reported it was moderate and 11% who reported it was mild. All used some type of personal assistance.

Response to abuse screening questions. A total of 33 participants (70%) reported experiencing abuse in the past year. Thirteen of these women initially answered "yes" to the single telephone abuse screening question and subsequently also answered "yes" to one or more of the 8 screening questions. An additional 20 women, who had initially reported no abuse to the telephone screening question, answered "yes" to one or more of the 8 screening questions when interviewed in person. This was a significant increase in abuse disclosure (Chi-Square 11.37, 1, $p < .01$). Seventeen participants (52%) reported experiencing only one type of abuse in the past year. The two most common types of abuse were financial (N=7) and emotional (N=4). Of the remaining participants, 7 reported 2 types of abuse, 6 reported 3 types, 1 reported 4 types and 2 reported 5 types of abuse. The response to all 8 questions can be seen in Table 1. The most common type of abuse was emotional abuse, followed by financial abuse and feeling unsafe with someone.

Response to risk assessment questions. Twenty-five of the 33 women who screened positive for abuse were asked the 14 risk assessment questions. The incidence of positive responses can be seen in Table 2. The most common positive response was having a serious health problem that could become dangerous if neglected. Twenty women (80%) answered

“yes” to this question. Examples of health conditions women reported included diabetes, heart disease, seizures, and skin sores. The next most common response was not having an emergency back-up care giver (60%) followed by their abuser having a lot of personal pressures (48%) and their abuser being responsible for providing their personal care (44%).

Final Refinement of Abuse Screening and Risk Assessment Questions

The last step in developing the abuse screening tool utilized two focus groups and several individual interviews to refine the wording, sequential placement, and formatting of the abuse and risk assessment questions. The over-riding goal was to have a final product that women with physical and cognitive disabilities could understand and self-administer.

The first focus group consisted of women with physical and/or cognitive disabilities. The participants were told that the purpose of the group was to help us put the original 8 abuse screening questions into language that women like themselves could understand. The women were also asked to consider the order in which they thought the questions should be asked. Several changes were made to clarify and/or simplify the language. For example, in the question regarding whether someone had refused or neglected to help with an important personal need, the example “toileting” was changed to “using the bathroom”. In the question regarding financial abuse, the example of using credit/debit cards without permission was expanded to include the phrase “or information” in response to the prevalence of identity theft among disabled women. The ordering of the questions was changed so that questions increased in sensitivity from the least sensitive “do you feel unsafe” to the last question which asked about sexual abuse. These suggested revisions were then discussed with several individual women, who had been unable to attend the focus groups.

Next, the investigators met to review this input and carefully analyze the response to the

risk assessment questions. We recognized that some questions contained more than one issue and needed to be put into separate questions. For example, the question that asked if the abuse had increased in severity and/or a weapon had been used was made into two individual questions. On the other hand, for brevity's sake, there were some questions we decided to combine. An example was to combine the questions regarding increased frequency and severity of the abuse. Finally, we decided to conceptually cluster the risk assessment questions into a set of items that asked about the abuser and a set of items that pertained to the woman herself. Items that asked about the abuser included whether he/she had access to a gun, controlled most of the woman's activities, was drunk often, or was someone the woman depended on for care. Items that pertained to the woman herself asked if she had a serious health problem or had access to a back-up caregiver.

A second focus group was held that included some, but not all of the members who had attended the first focus group. Again, women with physical and/or cognitive disabilities were represented. The participants were asked to review the revised and re-ordered abuse screening and risk assessment questions for clarity of language. They were also asked to help us format the questions into a brochure that could be given to women, providers and advocates. They had many very useful and pragmatic suggestions that were incorporated into the final product, which is available at www.ohsu.selfdetermination/brochure3.html.

Discussion

Findings from this preliminary validation of an abuse screening tool for women with disabilities are consistent with preceding research that highlights the high rates and diverse forms of abuse experienced by women with disabilities (Furey, 1994; Gill, 1996; Nosek, Howland, Rintala, Young & Chanpong, 1997; Powers, Curry, Oschwald, Maley, Saxton, & Eckels, 2002;

Sobsey & Doe, 1991; Stimpson & Best, 1991). Our experience in administering this screening tool to 47 women with physical and physical and cognitive disabilities suggests that women welcome participating in abuse screening and that the use of the tool and associated screening procedures facilitate the identification of abuse and risk factors.

A number of methodological limitations, such as small sample size, recruitment of participants from those who had already elected to participate in an abuse survey and the absence of documentation of self-reported abuse, must be recognized as they may constrain the interpretation and generalization of the findings. However, given these limitations, the study findings and the resulting abuse screening tool provide the basis for one of the first systematic approaches to abuse screening for women with disabilities. This is critical as traditional abuse screening tools do not include forms of abuse facing many women with disabilities and abuse screening is typically not conducted with this population. As a result, many women with disabilities lack validation that what they are experiencing constitutes abuse and they are not provided with information, support and resources to address it. Screening is essential if we are to bring the abuse of women with disabilities out of the closet.

Consistent with other findings related to the abuse of women with disabilities, results from this screening validation study suggest that a high proportion of women with disabilities are being abused and that many are facing more than one type of abuse. Assisting women to identify these multiple forms of abuse, which could have different implications for their level of risk and safety, requires the discussion of specific abuse behaviors and risks factors rather than offering one or two broad screening questions. Although this type of screening requires additional time, it appears to be essential for helping women to sort out exposure to abusive treatment from their often complex experiences.

Recommendations for Abuse Screening

In addition to refining the screening questions, the focus group and interview participants also assisted in the articulation of an abuse screening procedure for women with disabilities. Their suggestions were considered in association with the research team's experiences in developing the following list of recommended procedures.

- 1) Offer support to a women in completing the screening tool, including assistance with reading or clarifying the questions.
- 2) ~~When administering the screening tool, be sure to be alone with the woman in a~~ confidential location, not accompanied by her personal assistant, guardian, driver, spouse, parent, or other support person.
- 3) Talking with the woman without her personal assistant may bring about suspicion, anger, or resentment from the assistant, thereby increasing the risk of harm for the woman. Though it is essential the woman is alone during the screening procedure, it is important to understand the dynamics of asking the support person to leave the room. Discuss these dynamics with her.
- 4) Tell the woman if you are a mandated reporter before beginning the screening process, and explain the reporting procedures if she discloses abuse.
- 5) Pause during the screening procedures to ask the woman how she is doing; check in with how she is feeling.
- 6) Following the screening, offer all women supports, resources, and domestic violence referrals, regardless of abuse disclosure. Explain that this information is important to all women, and encourage them to share these resources with others.

Abuse screening provides an opportunity for women with disabilities to access

information, support and resources that are needed to address the problem. However, obstacles such as the lack of accessible shelters, back-up personal assistance services and advocates trained in disability issues, often make it difficult for women with disabilities and those assisting women with abuse to adequately respond. Ultimately, addressing these system gaps is essential if we are to effectively support women with disabilities to manage abuse. Regular abuse screening by health and social service providers, staff from centers for independent living and others that regularly interact with women with disabilities will both help women to identify abuse in their lives and focus attention on the resources needed by women to promote their safety.

Table 1. Incidence of positive responses to the abuse screening questions (n=47).

Screening Question	Number of Respondents	Percent of Total
Constantly yelled or screamed at	17	36%
Had valuables stolen	14	30%
Felt unsafe with someone	12	25%
Had personal needs neglected	9	19%
Kept from or had equipment disabled	5	11%
Physically abused	4	9%
Medication abuse	1	2%
Sexual abuse	1	2%

Table 2. Incidence of positive responses to the risk assessment questions (n=25).

Risk Assessment Question	Number of Respondents	Percent of Total
Has serious health problem that could become dangerous, if neglected	20	80%
No back-up care giver in an emergency	15	60%
Abuser has personal pressures & stresses	12	48%
Abuser responsible for giving personal care	11	44%
Abuser controls most of daily activities	9	36%
Abuse has increased in frequency over past year	8	32%
Abuse is interfering with taking care of health needs	6	24%
Abuser keeps from needed services, such as health care	5	20%
Abuser regularly uses alcohol and/or drugs	5	20%
Believes could harm self and/or abuser might harm self	4	16%
Abuse has increased in severity over past year	3	12%
Abuser has hurt or threatened to hurt pets	2	8%
Abuser has destroyed personal property	1	4%
Abuser has hurt or threatened to hurt children	0	0%

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