

Verbal and physical abuse experienced by family caregivers of adults with severe disabilities

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Abstract

Objective: To examine reports of verbal and physical abuse from family caregivers of adults with severe physical, neurological and developmental disabilities, and examine possible associations of abuse with family caregiver adjustment.

Design: Cross-sectional.

Participants: 147 community-residing caregivers (129 women, 18 men) of adults with disabilities (66 men, 81 women).

Measures: Caregiver burden, life satisfaction, depression, health complaints, supervision provided to a family member with a disability, and care-recipient agitation and functional impairment. A brief measure of verbal and physical abuse experienced over the previous year was administered to the caregiver.

Results: 51% of the sample reported some form of abuse in the twelve months prior to assessment. Caregivers who reported some form of abuse reported significantly greater distress and burden than caregivers who did not report any abuse.

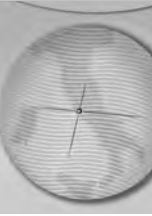
Conclusions: Caregivers who experience verbal and physical abuse may be at risk for increased emotional difficulties and have a greater sense of caregiver burden than caregivers who do not experience abuse. These data indicate that clinicians should attend to incidents of verbal and physical abuse that may occur between caregiver - care-recipient dyads. Further research is required to determine the conditions under which such abuse is likely to occur.

Key words: caregivers, abuse, adjustment, family, disability

Family caregivers provide the majority of long-term, community-based care in the United States for persons with severe, chronic and disabling conditions [1,2], and the market value of their work exceeds that spent on nursing home care and formal health care [3]. Yet family caregivers operate as *de facto* health care providers without formal training or support, often without routine access to health care systems that rely on their ability to perform complex medical and therapeutic tasks [4,5]. Adults with severe developmental and acquired physical disabilities may have considerable life expectancies that often necessitate life-long commitments from a family member to assume a caregiver role [6]. Consequently, the health and well-being of family caregivers is a priority in public health [7] and mental health policy [8].

Although subsequent declines in caregiver health, quality of life, and financial status are

now well documented [9-11], many aspects of the caregiver experience have not been systematically investigated, particularly among family caregivers of adults who live with severe physical and developmental disabilities. Family caregivers' experience of verbal and physical abuse, for example, has been largely ignored in the extant literature. We know from the gerontology literature that care-recipient displays of combativeness, verbal or physical aggression, disruptive behaviors, embarrassing public behaviors and lack of impulse control are very stressful to caregivers [12,13]. Many adults with severe disabilities have recurring problems with poor impulse control, agitation, irritability, and emotional instability [14]. Traumatic brain injury, in particular, has been associated with incidents of domestic abuse and violence in several studies [15-18]. Qualitative data are rare, but family caregivers of persons with spinal cord injuries in



a focus group reported problems with “hateful attitudes,” a lack of appreciation and “demanding and bossy” behaviors from care-recipients as the most stressful problems encountered in their caregiving roles [19].

We conducted the present study to examine reports of verbal and physical abuse from family caregivers of adults with severe physical, neurological, and developmental disabilities. Because many family caregivers may meet criteria for depressive disorders [20, 21] and caregiver distress is associated with dysfunctional family patterns and prior history of poor interpersonal relations with the care-recipient [22], we also examined possible differences in adjustment between caregivers who reported abuse and those who did not. In this manner, we hoped to obtain information about the nature of verbal and physical abuse that caregivers may experience and examine possible emotional correlates of abuse. Such information could provide valuable insights into the caregiver experience, and assist in developing instruments and services responsive to the needs and issues of certain caregiver - care-recipient dyads.

Methods

Recruitment and procedure

Caregivers volunteering to participate in a randomized clinical trial of a home-based problem-solving intervention for family caregivers of persons with severe disabilities [23, 24] completed a brief assessment of verbal and physical abuse that may have occurred in the year prior to participation. Prospective participants were recruited from posters, flyers, newspaper advertisements, public service announcements on local radio stations, home-health agency referrals and mailings throughout Alabama, Georgia, Mississippi, Southern Tennessee, and the Florida Panhandle. Families were also informed of the study during visits at rehabilitation hospitals located in Birmingham, AL, Tupelo, MS, and Warm Springs, GA. Coordinated efforts (including mailings, flyers) were also arranged with the United Cerebral Palsy office in Birmingham, AL, and with a home health agency in Atlanta, GA.

One project was strategically developed for family caregivers of women with disabilities (of any kind), and advertisements were developed with these criteria clearly stated. Another project was developed for (and restricted to) caregivers of persons with traumatically acquired brain injuries and advertisements and flyers contained this language. A third project was designed to recruit family caregivers of persons with “brain injuries”

(broadly defined), so caregivers of persons with other neurological conditions (such as stroke, dementia, Alzheimer’s disease) could participate. Each project reflected the interests and guidelines of each respective funding agency.

Interested individuals contacted project staff via a toll-free telephone number to discuss specific eligibility requirements. After making a basic determination of eligibility, the project coordinator then arranged a visit to the interested participant’s home to provide details about the study, to confirm eligibility, and to obtain signed consent from both the caregiver and care-recipient. To be eligible to participate, individuals had to be at least 18 years or older, have a family member (or “fictive kin”) who was clearly identified as a caregiver (by the caregiver and the care-recipient) and the care-recipient had a diagnosed disability. Participants had to have a telephone at home to be able to participate in the project, and the caregiver agreed to random assignment to one of two groups (problem-solving training, education-only control group). Caregivers also had to live in the same household as the care-recipient, and provide either part-time or full-time care.

As part of the screening process, dyads were informed prior to consent that the research team would ask specific questions about possible abuse experienced by the care-recipient, and that the research team was legally required to report any observed or reported abuse of vulnerable, dependent individuals (elderly, disabled, or children). In the first home visit, informed consent was obtained and an assessment was conducted about possible verbal or physical abuse to the care-recipient. Study instruments were then administered during the second home visit in which a trained data collection specialist administered the various measures to the caregiver and care-recipient separately. At this time, the caregiver completed an assessment of verbal and physical abuse they may have encountered in the year prior to participation.

Caregivers were interviewed for abuse with the questionnaire presented below. Caregivers also completed the CES-D (to assess depression), a subscale of the Caregiver Burden Scale, the Satisfaction with Life scale, and a measure of health complaints. The Functional Independence Measure (FIM) and a measure of agitation were completed with care-recipients. To ensure consenting caregivers could understand the verbal instructions and written materials, we administered the Folstein mental status examination [25].

Measures

Assessment of verbal and physical abuse. A brief questionnaire of verbal and physical abuse was used in this study. The four items from the Abuse Assessment Screen-Disability (AAS-D) [26] were reworded for use with caregivers to assess threats and acts of abuse. Caregivers were asked how many times in the past year they had experienced specific types of verbal and physical abuse (see Appendix A). For each positive response, caregivers were asked to identify who committed that particular act. For purposes of this study, we categorized caregivers who gave a positive response to any item as abused, and we examined the specific types of abuse experienced. We also tallied the identified perpetrators of each act of abuse.

Caregiver depression. The Center for Epidemiological Studies Depression Scale (CESD) [27] was used to assess caregiver depression. The CESD contains 20 items that assess various symptoms associated with depression. Items are scored on a 4-point scale to indicate how often symptoms are experienced in the preceding week. Scores range from 0 to 60. Higher scores indicate higher levels of depression. Alpha coefficients have ranged from .84 to .90 [27].

Caregiver life satisfaction. The Satisfaction with Life Scale (SWLS) [28] was used to evaluate subjective life satisfaction of caregivers and care-recipients. The SWLS is a 5-item instrument with items rated on a Likert type response format ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). Higher scores indicate greater life satisfaction. Psychometric studies of the SWLS have evidenced internal consistency ($\alpha = .87$) and reliability (2 month test-retest coefficient = .82) [28].

Caregiver health. The general form of the Pennebaker Inventory of Limbic Languidness scale (PILL) [29] was used to assess caregiver health. The PILL contains 54 items that are rated in a yes-no format and measures health problems experienced by the individual over the preceding three weeks. Higher scores reflect more health complaints. The PILL general form has adequate internal consistency (.88) and test-retest reliabilities over a two-month period have ranged from .79 to .83 [29]. PILL scores have been correlated with physician visits, aspirin use within the past month, days of restricted activities due to illness, drug and caffeine use, sleep and eating patterns, and with scores on related measures [29].

Caregiver burden. A subset of the Caregiver Burden Scale (CBS) [30] was used to assess

caregivers' perceptions of burden. The difficulty subscale measures the difficulty associated with 14 direct, instrumental and interpersonal demands common to family caregivers. The difficulty of performing specific activities is rated on a 5-point Likert scale (1 = none to 5 = a great deal). The subscale possesses high reliability (.91) and good internal consistency (Cronbach's $\alpha = .87 - .91$).

Care-recipient functional deficits. The severity of disability of each care-recipient was measured with the Functional Independence Measure (FIMSM) [31]. The FIMSM contains 13 items that assess motor function (eating, grooming, bathing, dressing, toileting, bowel and bladder control, transfers, and locomotion) and 5 items that measure cognitive function (communication and social cognition). Each item on the scale ranges from 1 (total assistance) to 7 (complete independence). Lower scores indicate more functional deficits. The FIMSM has evidenced adequate validity and reliability [32-34].

Care-recipient agitation. The Agitated Behavior Scale (ABS) [35] was used to assess agitation. The ABS is a 14-item scale designed to objectively assess agitation among persons with TBI. At the end of each observation period, raters assign a number ranging from 1 ("absent") to 4 ("present to an extreme degree") for each item, representing the frequency of the agitated behavior and/or the severity of a given incident. Total scores range from 14 (no agitation) to 56 (extremely severe agitation). In previous studies, the ABS has demonstrated adequate reliability and validity [35].

Data analysis

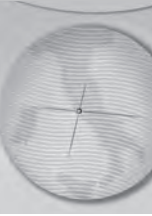
To examine potential differences in adjustment between caregivers who reported abuse and those who did not a series of one-way ANOVAs were conducted for each of the dependent variables (caregiver burden, depression, health complaints, and satisfaction with life; care-recipient functional impairment and agitation). Significant tests were determined by *p* values < .05.

Results

Participants

Consenting participants included 18 men and 129 women in caregiver roles. The sample was comprised of 110 White, 35 Black, and two Hispanic/Latino individuals.

Caregivers averaged 56.6 years of age and 13.5 years of formal education (see Table 1 for complete information). Ninety-two caregivers were married, 28 were divorced, 18 were



widowed, four were separated and five reported their marital status as single. The sample averaged 132 months in a caregiver role for the family member. The majority of caregivers were mothers ($n = 74$) of the care-recipient; 14 caregivers were categorized as husbands, two were fathers, three were grandparents, two were daughters, four were wives, two were aunts, and seven were sisters. Thirty-nine individuals were categorized as "other." In addition, consenting caregivers averaged 28.7 on the Folstein mental status examination ($SD = 1.7$).

Care-recipients who consented to participate had a variety of disabilities including traumatic

brain injury ($n = 67$), cerebral palsy ($n = 16$), and stroke ($n = 26$). Several care-recipients had a chronic debilitating disease (Alzheimer's disease, $n = 4$; multiple sclerosis, $n = 1$; arthritis, $n = 1$; chronic pain, $n = 1$) and others had a developmental disability (mental retardation, $n = 12$; Down's syndrome, Angelman's syndrome, autism, Prader-Willi syndrome, Rett's syndrome, fetal hydantoin, $n = 1$ each). Other care-recipients had various neurological conditions (dementia, $n = 3$; scoliosis, polio, tubular sclerosis, muscular dystrophy, seizure disorder, spinal cord injury, spinal meningitis, aneurysm, $n = 1$ each). Care-recipients averaged 44.9 years of age ($SD = 21.2$).

Table 1. Demographic information and self-report data for caregivers and care-recipients.

	<i>Caregivers</i>		M	SD
	<i>N</i>	%		
Men	18	12.24	--	--
Women	129	87.76	--	--
Caucasian	110	74.83	--	--
Black	35	23.81	--	--
Hispanic/Latino	2	1.36	--	--
Age	--	--	56.6	12.5
Years of education	--	--	13.5	2.7
Months caregiving	--	--	132.0	158.5
MMSE	--	--	28.7	1.7
Burden	--	--	31.1	11.9
Depression	--	--	15.8	12.4
Health complaints	--	--	12.2	8.4
Satisfaction w/ life	--	--	21.2	8.8
	<i>Care recipients</i>		M	SD
	<i>N</i>	%		
Men	66	44.90	--	--
Women	81	55.10	--	--
Caucasian	113	76.87	--	--
Black	33	22.45	--	--
Hispanic/Latino	1	0.68	--	--
Age	--	--	44.9	21.2
Years of education	--	--	12.1	3.6
MMSE	--	--	20.0	9.3
Agitated behavior	--	--	15.3	2.7

Table 2. Most frequently endorsed items by caregivers who reported abuse.

Yelled at or insulted	45.6%
Threatened to hit	12.9%
Actually hit	12.9%
Threatened to withhold assistance or equipment	4.8%
Actually withheld assistance or equipment	3.4%
Took something by force or threat of force	2.7%
Took something by force or threat of force using a weapon	0.7%
Raped or sexually assaulted	0.0%

Reports of abuse

To our knowledge and according to written records kept by research staff, no prospective participant expressed disinterest in the study after being informed of the legal requirement to report any observed or reported abuse of dependent individuals. There were no observed or reported incidents of care-recipient abuse. Responses to the abuse questionnaire revealed that 75 caregivers reported at least one experience of verbal or physical abuse in the year prior to participation; 71 caregivers reported no experience of verbal or physical abuse. As depicted in Table 2, 45.6% of the abuse experiences were described as being "yelled at or insulted." 12.9% of the experiences were described as receiving "threats to hit" and another 12.9% were described as actually being hit by a perpetrator in the previous 12 months. The majority of the perpetrators were care-recipients, who accounted for many incidents of yelling and insults, and for the majority of threats of hitting and for being hit. Members of the family collectively accounted for the remaining incidents of verbal and physical abuse reported by the caregivers (see Table 3).

Differences between caregivers who did and did not report abuse

Mean comparisons between caregivers who reported abuse and those who did not revealed that the abused caregivers had significantly higher levels of depression, burden, and health

complaints than caregivers who did not report any abuse (all p 's < .05; see Figure 1). Caregivers who experienced no abuse also reported greater life satisfaction than caregivers who reported an experience of verbal or physical abuse. No differences were found between the two groups in terms of care-recipient functional impairment (i.e., FIM scores), care-recipient agitation, caregiver or care-recipient age, gender, education, or length of time in the caregiver role.

Inspection of the care-recipient diagnostic conditions revealed that the group of caregivers reporting some experience of abuse included nine more care-recipients with a traumatic brain injury than the group reporting no experience of abuse in the previous year (see Table 4). There were no other apparent differences in the distribution of care-recipient conditions between the two groups.

Discussion

Of the family caregivers consenting to participate in a randomized clinical trial of a psychoeducational intervention, 51% reported having experienced some form of verbal or physical abuse in the previous 12 months. Subsequent inspection revealed that the majority of these incidents were attributed to care-recipients and family members. Furthermore, these data revealed that caregivers who experienced abuse were significantly more depressed, burdened, and had more health complaints than family caregivers who reported no incidents of verbal or physical abuse.

To our knowledge, this is the first study to document the kinds of verbal and physical abuse experienced by family caregivers of adults with severe disabilities. The present data imply that a relatively large percentage of family caregivers may experience abusive interpersonal conflict and others may be at risk for verbal threats and physical abuse. These interpersonal aggressions, tensions, threats and insults have an adverse, deleterious effect on family caregiver well-being and psychological adjustment.

The unique focus of the present study on abuse reported by family caregivers is in contrast with the existing literature on the abuse experienced by persons with severe disabilities. Available data suggest that persons with disabilities are at higher risk to experience abuse or neglect than persons without disabilities [36], and close family members are frequently guilty of abusive behaviors (e.g., husbands, parents) [37,38].

Parallel research in the gerontological literature suggests that care-recipients may be at risk to encounter abuse from caregivers when care-

Figure 1. Mean differences in adjustment between caregivers who did and did not report abuse.

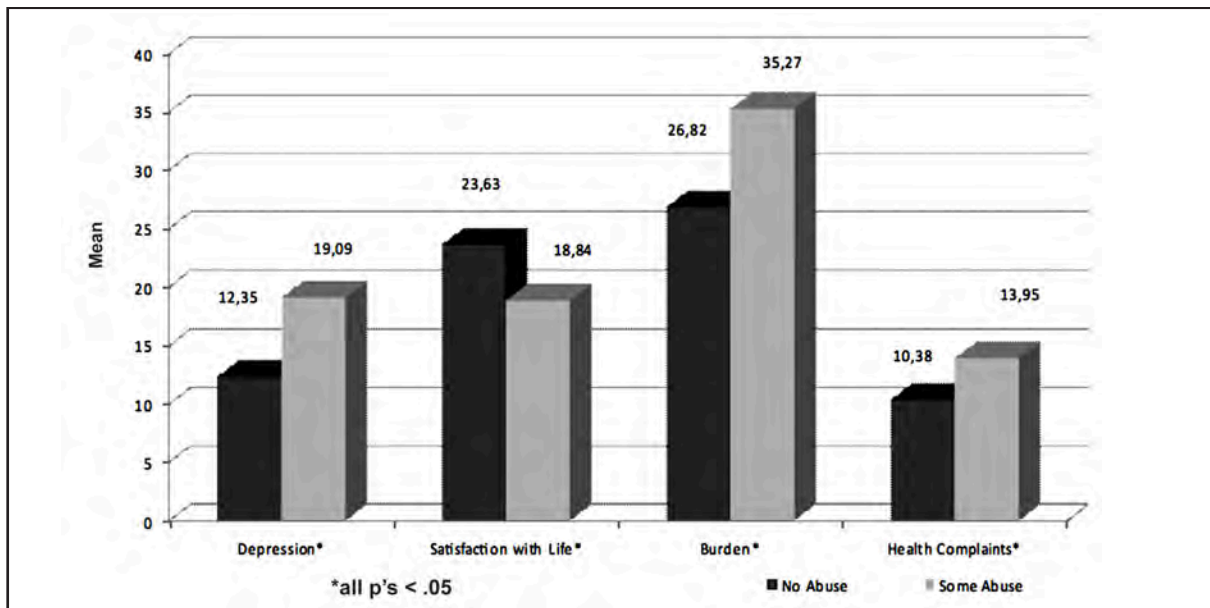


Table 3. Reported perpetrators of verbal and physical abuse to family caregivers.

	Yelled/insulted	Threat to hit	Actually hit	Threat to withhold assistance or equipment	Actually withheld assistance or equipment	Took something by force or threat of force	Took something by force or threat of force using weapon	Raped or sexually assaulted
Care recipient	23	10	8	--	--	2	1	--
Husband	8	--	--	--	--	--	--	--
Ex-husband	2	--	--	--	--	--	--	--
Mother	2	1	--	--	--	--	--	--
Son	5	1	1	--	--	--	--	--
Daughter	2	--	--	--	--	--	--	--
Sister	3	--	1	1	--	--	--	--
Niece	1	--	--	--	--	--	--	--
Grandson	1	--	--	--	--	--	--	--
In-laws	3	--	--	--	--	--	--	--
Other family*	3	--	--	--	--	--	--	--
Friends	3	--	--	--	--	--	--	--
Church members	--	--	--	--	1	--	--	--
Insurance companies	--	--	--	4	2	--	--	--
Doctors	--	--	--	1	--	--	--	--
Physical therapist	1	--	1	--	--	--	--	--
Co-workers	5	1	1	--	--	1	--	--
Employer (i.e., boss)	4	--	--	--	--	--	--	--
Acquaintances	3	--	--	--	--	--	--	--
Strangers	5	2	--	--	--	--	--	--
Not identified	15	4	5	1	1	2	--	--

*Other family indicates extended family members.

Table 4. Care-recipient diagnostic conditions among caregivers who report verbal or physical abuse and those who reported none.

<i>Caregivers Reporting Abuse</i>	
Traumatic Brain Injury	38
Stroke	13
Mental Retardation	4
Other Developmental Disabilities	6
Cerebral Palsy	5
Chronic Disease	4
Alzheimer's Disease	2
Dementia	2
Spinal Cord Injury	1
<i>Caregivers Who Reported No Abuse</i>	
Traumatic Brain Injury	29
Stroke	14
Mental Retardation	8
Other Developmental Disabilities	2
Cerebral Palsy	11
Chronic Disease	3
Alzheimer's Disease	2
Dementia	1
Multiple Sclerosis	1

recipients have pronounced needs for assistance, and when caregivers have pronounced levels of depression, ill health, and distress [39,40]. A history of interpersonal conflict and a poor relationship prior to caregiving are also associated with potentially harmful behaviors among caregivers [40, 41].

The present study reveals that a significant percentage of family caregivers may experience a pattern of conflict, tension and interpersonal hostilities that can potentially jeopardize the health and well-being of caregivers and, by extension, the safety and well-being of their care-recipients. Among the elderly population it has been shown that caregivers who are stressed and undergoing mental health problems such as anger, anxiety, and depression are at a higher risk of engaging in potentially harmful behavior against their care-recipients [42]. In fact, caregivers experiencing depression have been shown to be more likely to be investigated by social service agencies for possible mistreatment towards their care-recipients [43]. Although we found no evidence for similar problems in the current sample, service programs and interventions for these dyads should be attentive to the stress, burden and conflicts reported by both caregiver and care-recipient.

A comprehensive plan, in conjunction with professional health care providers, should be developed in order to better assist family caregivers

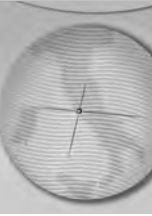
in their role. This additional support has the potential to ease the stress and burden experienced by family caregivers by effectively providing them an outlet to express their questions and concerns. By working closely with family caregivers and being attentive to the stressors and issues they face, professional health care providers have the opportunity to effectively prevent unnecessary conflicts and health related problems among the caregiver-care-recipient dyads. With proper health related and interpersonal training, family caregivers have the potential to help reduce and prevent early or unnecessary entrance into assisted living facilities and nursing homes, which could reduce the high costs of formal health care over time [44].

Several limitations of the present study should be considered. The cross-sectional analyses relied on self-report data. We do not have information about the nature of the caregiver-care-recipient relationships prior to the interview, nor do we have any information to corroborate caregiver reports of abuse. More importantly, the sample was a very exclusive group of individuals who expressed interest in participating in a randomized clinical trial of a psychoeducational intervention that could have potentially alleviated personal distress. We do not know the degree to which the sample may be representative of the larger community of family caregivers in similar scenarios, and we do not know the degree to which results of the present study may apply to caregiving experiences in the community, generally. We do not know the degree to which demand characteristics of the interview may have affected caregiver reports of abuse. Further research is needed to determine the extent and the nature of caregiver experiences of verbal and physical abuse in this area.

Acknowledgements

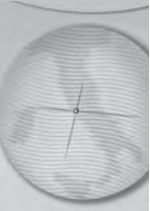
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Appendix A. Assessment of verbal and physical abuse.

In the past year how many times did you experience the following?

Someone yelled at or insulted you?

For each positive response ask: By whom?

Someone threatened to withhold assistance or equipment?

For each positive response ask: By whom?

Someone actually withheld assistance or equipment?

For each positive response ask: By whom?

Someone threatened to hit you?

For each positive response ask: By whom?

Someone actually hit you?

For each positive response ask: By whom?

Someone actually raped or sexually assaulted you?

For each positive response ask: By whom?

Someone took something from you by force or threat of force?

For each positive response ask: By whom?

Someone took something from you by force or threat of force using a weapon?

For each positive response ask: By whom?