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## Family Caregivers of Women with Physical Disabilities

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### Abstract

Cross-sectional, correlational analyses of data from two separate studies were conducted to examine the correlates of adjustment among family caregivers of women with disabilities. Participants included 40 caregivers of women with spinal cord injuries in the first study and 53 caregivers of women with cerebral palsy, traumatic brain injury, and other neuromuscular disabilities in the second study. It was hypothesized that a negative problem-solving style would be associated with greater caregiver distress in both studies, and that caregiver adjustment would be associated with care recipient depression in the second study. As expected, results indicated that a higher negative orientation toward solving problems was associated with caregiver depression and lower well-being. However, in the second study, caregiver characteristics were not associated with care recipient depression. These data indicate that considerable variability exists in caregiver adjustment. Methodological limitations and the implications for research, service, and policy formation are! discussed.

### Keywords

Caregiver; Women; Disability

## Family caregivers of women with physical disabilities

As health care programs continue to circumscribe their service to persons with chronic, debilitating health conditions, many family members are compelled to assume caregiving roles (Hoffman, Rice, & Sung, 1996). In fact, available data indicate that family caregivers “... constitute the largest group of care providers” in the United States (Parish, Pomeranz-Essley, & Braddock, 2003, p. 174), and as they provide the majority of long-term care in this country, the market value of their activity far exceeds that spent on formal health care and nursing home care (Vitaliano, Young, & Zhang, 2004, p. 13). Yet family caregivers function as *de facto* healthcare providers without adequate training or appropriate remuneration (Shewchuk & Elliott, 2000): They are expected to operate competently as extensions of health care systems, often performing complex medical and therapeutic tasks, helping a loved one perform and adhere to therapeutic regimens (Donelan et al., 2002).

Caregiving is often associated with many deleterious effects on the caregiver (Donelan, Falik, & DesRoaches, 2001; Vitaliano, Zhang, & Scanlan, 2003). However, this work has been largely

restricted to studies of care recipients who have degenerative diseases (e.g., Alzheimer's disease, dementias). These experiences are ultimately time-limited, contingent upon the eventual progression of the disease. The stress of these caregiving scenarios is unlike that associated with assisting individuals with permanently and severely disabling conditions, in which the care recipient is impaired but has a considerable life expectancy. To date, little research has addressed the impact of caregiving for people with severe physical disabilities who now have considerable life expectancies, and the research that has been conducted has been confined to predominately male samples, with no attention to the unique issues that face caregivers of women with physical disability who are typically underserved by traditional health care programs.

Women are more likely to assume caregiver roles for individuals who live with severely disabling conditions (Moen, Robison, & Dempster-McClain, 1995) and constitute as much as two-thirds of primary family caregivers, generally (Donelan et al., 2001). The preponderance of women in caregiving roles poses an intriguing, unstudied concern: Women with disabilities are likely to be single, divorced or living with parents (Fine & Asch, 1988; Hanna & Rogovsky, 1991). Given the historical inattention to the needs and experiences of women with disability in medical and psychological research (Nosek & Hughes, 2003), we do not know the characteristics of family members who assume a caregiver role for a woman with disability.

We know that women with disability report a higher rate of depression and other secondary complications than observed among men (Hughes, Robinson-Whelen, Taylor, Petersen, & Nosek, 2005; Nosek, Howland, Rintala, Young, & Chanpong, 2001) and these problems appear to be imposed primarily by social and physical barriers to integration and access (Nosek & Hughes, 2003). Personal resources, such as self-esteem, are also compromised by social isolation and the quality of intimate relationships (among other factors; Nosek, Hughes, Swedlund, Taylor & Swank, 2003). Women with disabilities appear to be as likely to be abused at rate observed among women in general (and the most frequent perpetrators of this abuse were husbands and parents; Nosek et al., 2001).

It is important that we examine the characteristics of individuals who assume caregiver roles for women with disabilities, and further, it is important that we examine characteristics of those who adjust optimally and those who appear to have difficulty. Individuals who have difficulty adjusting to the caregiver role may be unable to adequately assist a woman with a disability, and in turn jeopardize the health of the care recipient and contribute to the development of secondary complications. Prospective research has shown that caregivers who have ineffective problem solving abilities at the time a family member incurs a physical disability are more likely to experience higher levels of depression, anxiety, and ill health throughout the initial year of caregiving (Elliott, Shewchuk, & Richards, 2001). When a caregiver has difficulty solving problems of everyday life, the health of the care recipient may be at risk: Ineffective problem-solving abilities among caregivers have been significantly associated with higher depression and lower life satisfaction among persons with congestive heart failure (Kurylo, Elliott, DeVivo, & Dreer, 2004). Moreover, an impulsive and careless problem-solving style among caregivers has been prospectively and significantly predictive of pressure sores occurrence among persons with SCI over the course of a year (Elliott, Shewchuk, & Richards, 1999).

In this paper, we report analyses of data from two studies of family caregivers of women with physical disabilities. We have defined a family caregiver as one who provided ongoing assistance, support, and service for a woman with a physical disability. Attendants who are employed by agencies or who are on private hire were not considered eligible caregivers for the purpose of either of these studies. In the first study, we examined baseline data obtained from family caregivers who consented to participate in clinical trials of the effects of a brief

problem-solving intervention for family caregivers of persons with spinal cord injury. This permitted a thorough examination of the characteristics of individuals who assume caregiver roles for women with SCI. We also examined the degree to which caregiver social problem-solving abilities would be predictive of their self-reported depression and psychosocial adjustment. Based on our prior research, we expected a negative problem-solving style would be associated with higher depression and impairment scores. In the second study, we analyzed baseline data collected from caregivers who consented to participate in a clinical trial of the effects of monthly problem-solving training for family caregivers. This study allowed us to examine the characteristics of family caregivers of women with a variety of disabilities, including traumatic brain injury, cerebral palsy, and other disabilities. We also examined the relations of caregiver problem-solving abilities to caregiver depression and care-recipient disability severity, and the possible relations of caregiver burden and care-recipient disability severity with caregiver problem-solving abilities and adjustment.

## Study 1

### Method

**Participants**—Participants included 28 women ( $M$  age = 45.9 years,  $SD$  = 9.30 years,  $M$  years of education = 12.1,  $SD$  = 2.58) and 12 men ( $M$  age = 51.1,  $SD$  = 4.02 years;  $M$  years of education = 14.2,  $SD$  = 4.15) who were identified as the family member caring for a woman with a SCI.

Some caregivers learned of the study while their family member was participating in therapies at a rehabilitation hospital. Community-residing caregivers learned of the project through advertisements, flyers at various community agencies, and through outreach programs. Once interested individuals expressed interest, a trained research staff member provided information about the project and obtained informed consent. The baseline measures were then administered at a time convenient to the participant and the research staff member. Measures were administered in a random order.

The women with SCI averaged 39.9 years of age ( $SD$  = 18.86). Twenty-three women had incomplete lesions to the cord and 17 had incomplete lesions; 20 women had paraplegia, 18 had tetraplegia, and two had other cord-related injuries (e.g., spinal stenosis, cauda equina).

### Measures

**Social problem solving abilities**—The Social Problem Solving Inventory-Revised (SPSI-R; D'Zurilla, Nezu, & Maydeu-Olivares, 2002) has 52 items that are rated on a 5-point Likert-type scale ranging from *not very true of me* (0) to *extremely true of me* (4). Higher scores on each scale indicate a greater propensity in that facet of problem solving. The SPSI-R has five scales. Two scales measure the problem orientation dimensions of the social problem solving model: positive orientation (PO) and negative orientation (NO). The remaining three scales assess different problem solving styles, including rational problem solving (RPS), impulsivity/carelessness style (IC), and avoidance style (AV).

The Positive Orientation scale (PO) assesses a general cognitive set which includes the tendency to view problems in a positive light, to see them as challenges rather than threats, and to be optimistic about one's ability to detect and implement effective solutions. The Negative Orientation scale (NO) assesses a cognitive-emotional set indicative of a greater pessimism, a lack of motivation toward problem solving, and a proclivity for negative moods that hinders effective problem solving. The Rational Problem Solving scale (RPS) assesses the tendency to systematically and deliberately employ effective problem solving techniques by defining the problem, generating alternatives, evaluating alternatives, and implementing solutions and

evaluating outcomes. The Impulsivity/Carelessness Style scale (IC) measures the tendency to solve problems in an impulsive, incomplete and haphazard manner. The Avoidance Style scale (AV) assesses dysfunctional patterns of problem solving characterized by putting the problem off and waiting for problems to solve themselves.

Internal consistency estimates for the scales with college students range from alphas of .76 for PO to .92 for RPS and test-retest (3 weeks) reliability ranges from .72 for PO to .88 for NO for the same sample (D'Zurilla et al., 2002).

**Depressive behavior**—The Inventory to Diagnose Depression (IDD; Zimmerman & Coryell, 1987) is a 22-item measure of depressive behavior and each item is rated on a five point scale ranging from no presence of the symptoms (0) to severe symptomology (4) (Zimmerman, Coryell, Corenthal, & Wilson, 1986). The IDD is a sensitive indicator of depression among community-residing adults and persons with a variety of health problems (Frank et al., 1992). Acceptable test-retest reliabilities (.98 over days) and internal consistency (.92) coefficients have been reported; correlations with other self-report measures of depression have been adequate (ranging from .80 to .87; Zimmerman & Coryell, 1987; Zimmerman, Coryell, Corenthal & Wilson, 1986; Zimmerman, Coryell, Wilson, & Corenthal, 1986). Higher scores reflect greater depressive behavior.

**Distress and health**—Aspects of personal health and general distress were assessed with the omnibus Medical Outcomes Study Short Form Health Survey (SF-36; Ware, Snow, Kosinski, & Gandek, 1993). The SF-36 features eight scales: physical functioning, physical role functioning, pain, general health, energy/fatigue, social functioning, emotional role functioning and mental health. Higher scores on each scale denote positive and optimal responses on each respective dimension.

Raw scores for each scale are transformed with an algorithm to a 0–100 scale (Ware et al., 1993). Considerable evidence supports the basic psychometric properties of the SF-36 scales. Internal consistency reliabilities have ranged from .62 (energy/fatigue) to .96 (emotional role functioning) and test-retest coefficients have ranged from .43 (pain) to .90 (physical functioning; Ware et al., 1993).

### Statistical analysis

We expected a negative orientation would significantly predict caregiver depression, personal health, and distress. Therefore, separate regression equations were conducted to examine the relation of the problem orientation component to each of these criterion variables after controlling for any possible variance attributable to the problem solving styles. This conservative procedure has been used to test hypothesized properties of the social problem-solving model among caregivers (e.g., Grant, Elliott, Giger, & Bartolucci, 2001).

### Results

Table 1 presents descriptive statistics, by gender, for demographic and self-report variables for the sample of caregivers. Seventy percent of the caregivers were women. The majority of caregivers were mothers of the care recipient (60.7%). The majority of male caregivers were husbands of the care recipient (66.7%). A higher rate of daughters (21.4%) and sisters (10.7%) were observed among female caregivers; no brothers or sons were in caregiver roles. One significant difference (determined by a  $\chi^2$  statistic) was observed in the race of the caregiver by gender: The rate of black men among caregivers was less than expected by chance for this distribution.

Table 2 presents zero-order Pearson correlations among the caregiver self-report variables. We hypothesized that caregiver social problem-solving strategies would remain significantly associated with caregiver adjustment (depression, distress, and health variables) after statistically controlling for caregiver demographic variables and care recipient level of disability. To reduce the number of health-related outcomes, we computed a principal components analysis with varimax rotation on the eight subscales of the SF-36. Two components with eigenvalues greater than 1 were extracted, which accounted for 64.8 percent of the original measurement variance. The first component (eigenvalue 3.9; 49.9 % variance) had high loadings from the Physical Functioning (.92), Role Physical (.85), General Health (.64), and Pain (.60) scales. We labeled this component the “Physical Health Factor.” The second component (eigenvalue 1.2; 14.9% variance) had high loadings from the Mental Health (.95), Energy (.83), Social Functioning (.53), and Role Emotional (.49) scales. We labeled this the “Mental/Social Functioning Factor.” Factor scores were computed for all participants and were used as criterion variables in hierarchical regressions.

For each regression, we entered caregiver age, gender (1 = women, 0 = men), and ethnicity (1 = European American, 0 = African American) at the first step. At step 2, we entered level of care recipient disability (6 = tetraplegic, complete; 5 = tetraplegic, incomplete; 4 = paraplegic, complete; 3 = paraplegic, incomplete; 2 = Other, complete; 1 = Other, incomplete). At step 3, we entered the PO and RPS subscales of the SPSI, and at the final step we entered the NO, AV, and IC subscales of the SPSI. This would test our assumption that a negative problem-solving style would be predictive of each criterion variable.

### Social problem-solving and depression

In predicting caregiver depression, the block of demographic variables at step 1 was not statistically significant,  $F(3,36) = 1.11, ns$ . At step 2, level of disability ( $\beta = .33$ ) yielded a significant increase in prediction ( $R_{inc}^2 = .11$ ),  $F_{inc}(1,35) = 4.72, p < .05$ . Greater disability severity was associated with higher depression scores. At step 3, the block of positive problem-solving variables added significantly to the prediction ( $R_{inc}^2 = .21$ ),  $F_{inc}(2,33) = 5.94, p < .01$ . Higher PO ( $\beta = -.42; t = -2.99, p < .01$ ) and RPS ( $\beta = .33; t = 2.28, p < .05$ ) subscales were significantly associated with lower depression scores. At the final step the block of negative problem-solving strategies added significantly to the equation ( $R_{inc}^2 = .17$ ),  $F_{inc}(3,30) = 3.90, p < .05$ . A higher negative problem orientation ( $\beta = .59, t = 2.54, p < .05$ ) was significantly associated with higher depression scores.

### Social problem-solving and mental/social functioning

Neither the demographic [ $F(3,36) = 1.25, ns$ ], severity of disability [ $F_{inc}(1,35) = 3.86, ns$ ], nor positive problem-solving blocks [ $F_{inc}(2,33) = 2.58, ns$ ] produced a significant prediction of Mental/Social Functioning factor scores. However, the block of negative problem-solving variables yielded a significant increase in prediction at the final step,  $F_{inc}(3,30) = 3.61, R_{inc}^2 = .19, p < .05$ . Higher negative orientation scores ( $\beta = -.58, t = -2.27, p < .05$ ) were associated with lower mental/social functioning scores.

### Social problem-solving and physical health

Physical health factor scores were significantly predicted by the block of demographic variables ( $R^2 = .44$ ),  $F(3,36) = 2.86, p < .05$ . Not unexpectedly, older age ( $\beta = -.42, t = -2.70, p < .01$ ) was associated with lower health ratings. Neither severity of disability,  $F_{inc}(1,35) = .61, ns$ , positive problem-solving,  $F_{inc}(2,33) = 1.03, ns$ , nor the negative problem-solving blocks,  $F_{inc}(3,30) = .73, ns$ , significantly augmented the prediction of physical health.

## Discussion

Consistent with the extant literature, these data indicate that mothers, sisters, and daughters often assume a caregiver role for a woman with an acquired SCI. Our analyses show that a negative problem-solving style is associated with emotional distress (and, more specifically, a lower negative style is associated with a higher level of mental health) among these caregivers. Caregiver gender was not a significant factor in the prediction of any criterion variable. Older caregiver age was associated with more health problems. However, this study was limited in focus to caregiver adjustment: We do not know the association between caregiver adjustment—or caregiver problem-solving abilities—to care recipient adjustment. Furthermore, we do not know if these results would generalize to a sample of family members who assume a caregiver role for women with other disabilities. These issues were addressed in the second study.

## Study 2

### Overview

Similar to the first study, some caregivers learned of the study while their family member was participating in inpatient and outpatient therapies at a rehabilitation hospital. Community-residing caregivers learned of the project through letters describing the study that were mailed throughout the state by United Cerebral Palsy or by the Alabama Head Injury Foundation. Other caregivers responded to advertisements, flyers at community agencies, and upon learning of the project in programs conducted by the research staff. Interested individuals contacted project staff and basic eligibility requirements were discussed in a telephone conversation. The project coordinator then arranged a visit in the interested participant's home and further details were presented. Informed consent was then obtained. A second appointment was set for a trained examiner to visit with the caregiver and care recipient to individually administer the baseline measures. Measures were administered in a random order.

### Participants

Participants included 48 women ( $M$  age = 56.7 years,  $SD$  = 9.37 years,  $M$  years of education = 13.2,  $SD$  = 2.90) and 5 men ( $M$  age = 48.4,  $SD$  = 5.18 years;  $M$  years of education = 15.8,  $SD$  = 3.63) who were identified as the family member caring for a woman with a disability.

Eligible care-recipients were 19 years or older and had a diagnosed physical disability for 6 months duration or longer. Caregivers who were less than 19 years of age and those who obtained a Folstein Mini-Mental Status Examination score (Folstein, Folstein, & McHugh, 1975) of 24 or less were also excluded from the study. Eligible participants were providing care to a person who requires active part-time care, full-time direct care, or full-time direct supervision.

Over 69% of these caregivers were Caucasian, and 30.2% were Black. Of the care recipients, 15 women with cerebral palsy were in the study. Fourteen women had a diagnosis of traumatic brain injury (TBI) and 24 women had various disabilities (e.g., other developmental or congenital disabilities, stroke). The majority of the care recipients were Caucasian (71.6%) and 28.3% were Black.

### Measures

**Social problem-solving abilities**—The SPSI-R was used to assess caregiver problem-solving abilities.

**Caregiver depression**—The Center for Epidemiological Studies Depression Scale (CESD; Radloff, 1977) was used to obtain an index of caregiver depression. The CESD contains 20

items that assess current levels of depressive behavior, with a particular emphasis on the impact of depressed mood. 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 depressive behavior; scores greater than 16 have been found to differentiate depressed from nondepressed community-residing adults (Craig & Van Natta, 1978). Alpha coefficients have ranged from .84 to .90 (Radloff, 1977).

**Caregiver life satisfaction**—The Satisfaction with Life scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985) is a five-item instrument; each item is rated on a Likert-type response format ranging from 1 (strongly disagree) to 7 (strongly agree). Sample items on the SWLS include: “In most ways my life is close to my ideal,” “The conditions of my life are excellent,” and “I am satisfied with my life.” Higher scores reflect greater subjective well being. The SWLS has evidenced internal consistency ( $\alpha = .87$ ) and reliability (two month test-retest coefficient = .82; Diener et al., 1985). Correlates with other instruments indicate that the scale is relatively independent of social desirability effects and psychopathology, and it is favorably associated with other measures of life satisfaction (Diener et al., 1985).

**Caregiver health**—The general form of the Pennebaker Inventory of Limbic Languidness scale (PILL; Pennebaker, 1982) 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 (Pennebaker, 1982). PILL scores have been positively correlated with physician visits, aspirin use within the past month, days of restricted activities due to illness, exercise habits, drug and caffeine use, sleep and eating patterns, and with scores on several symptom inventories (Pennebaker, 1982).

**Caregiver burden**—Caregiving burden perceptions were measured with the difficulty subscale of the Caregiving Burden Scale (CBS), a 14-item rating scale that measures difficulty associated with doing direct, instrumental, and interpersonal care tasks by family caregivers. There is support for content and construct validity of the measure with acceptable reliability coefficients for family members of chronically ill populations ( $\alpha = .91$ ; Carey, Oberst, McCubbin, & Hughes, 1991; Oberst, Thomas, Gass, & Ward, 1989). Higher scores indicate greater caregiver burden.

**Functional deficits**—The severity of disability of the stroke survivor was measured with the Functional Independence Measure (FIM<sup>SM</sup>; Uniform Data Set for Medical Rehabilitation, 1996). The FIM<sup>SM</sup> has been used as a measure of functional ability in numerous studies that span various populations and data support the measure has adequate validity and reliability (Chau, Daler, & Andre, 1994; Dodds, Martin, Stolov, & Deyo, 1993; Granger, Cotter, Hamilton, & Granger, 1993). The instrument contains 13 items that address 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), with lower numbers indicating more functional deficits.

**Care recipient depression**—We used a 6-item short form of the Hamilton Depression Rating Scale (HAM-D) to assess care recipient depression. The six-item HAM-D was developed to improve measurement consistency across depression subtypes by focusing on the core symptoms of depression (O’Sullivan, Fava, Agustin, Baer, & Rosenbaum, 1997) while minimizing sensitivity to somatic morbidity. Because it is a unidimensional measure of core depressive symptoms, this version has been shown to have adequate statistical power to detect

changes in depression in a multicenter clinical trial involving over 2,600 patients (Stein, Sliwinski, Gordon, & Hibbard, 1996). The decreased somatic focus is consistent with recommendations of Stein et al. for assessing depression in individuals with behavioral or neurological impairment.

### Statistical analysis

To determine the associations between caregiver characteristics and care recipient adjustment (represented by HAM-D scores), we examined correlations between these variables. In the event of any significant associations, we would then conduct a regression equation to determine the best predictors of care recipient depression. We then conducted separate regressions to predict caregiver depression, life satisfaction, and health complaints. For each regression, we entered age, gender (1 = female, 0 = male), and ethnicity (1 = European American, 0 = African American) at the first step. At step 2, we entered caregiver burden, care recipient depression (HAM-D), and care recipient functional ability (FIM). We then entered the elements of positive and negative problem-solving styles at the last two blocks of each equation.

### Results

Table 3 contains the demographic and self-report information for caregivers; Table 4 contains similar information for the care recipients. Women constituted 90.5% of the family caregivers; mothers were frequently represented (83.3%). Four husbands were caregivers. Twenty-six women were employed full-time outside the home, and 16 were working part-time. Over half of these women were unmarried. Although the low sample sizes preclude meaningful interpretations, women had more negative scores on each self-report adjustment measure than men (CESD, SWL, CBS, PILL).

As depicted in Table 4, women with CP had greater disability severity (FIM score) and considerable variation was observed in the HAM-D scores. Care recipient depression was not statistically associated with any caregiver self-report variable or with FIM scores (see Table 5). Therefore, we did not conduct any prediction of care recipient depression in subsequent analyses.

### Social problem-solving and caregiver depression

The block of demographic variables at step 1 did not significantly predict CESD scores,  $F(3,48) = 1.36, ns$ . At step 2, the block of caregiver burden and care recipient variables resulted in a significant increase in prediction ( $R_{inc}^2 = .22$ ),  $F_{inc}(3,45) = 4.72, p < .01$ ; greater burden was associated with higher depression ( $\beta = .51, t = 3.73, p < .01$ ). At step 3, the block of positive problem-solving variables did not significantly augment the equation,  $F_{inc}(2,43) = 1.26, ns$ . At step 4, the block of negative problem-solving strategies added significantly to the prediction of depression ( $R_{inc}^2 = .23$ ),  $F_{inc}(3,40) = 6.84, p < .01$ . A greater negative orientation was associated with higher depression scores ( $\beta = .70, t = 3.97, p < .001$ ).

### Social problem-solving and caregiver life satisfaction

The demographic variables were not significantly associated with caregiver life satisfaction,  $F(3,48) = .71, ns$ . The block of burden and care recipient variables significantly improved prediction ( $R_{inc}^2 = .18$ ),  $F_{inc}(3,45) = 3.35, p < .05$ . Greater burden was associated with lower life satisfaction ( $\beta = -.41, t = -2.82, p < .01$ ). The block of positive problem-solving scales did not significantly increase prediction,  $F_{inc}(2,43) = 2.71, ns$ . Finally, the block of negative problem-solving variables accounted for significant variance in the criterion variable ( $R_{inc}^2 = .20$ ),  $F_{inc}(3,40) = 5.35, p < .01$ . A lower negative orientation ( $\beta = -.67, t = -3.57, p < .$



01) and higher avoidant scores ( $\beta = .40, t = 2.24, p < .05$ ) were independently associated with higher caregiver life satisfaction.

### Social problem-solving and caregiver health

PILL scores were not significantly predicted by the block of demographic variables,  $F(3,48) = 1.76, ns$ . The block of caregiver burden and care recipient variables did yield a significant increase in prediction ( $R_{inc}^2 = .17, F_{inc}(3,45) = 3.39, p < .05$ ; greater caregiver burden was associated with more health complaints ( $\beta = .43, t = 3.07, p < .01$ ). Neither the positive problem-solving block,  $F_{inc}(2,43) = 1.66, ns$ , nor the negative problem-solving block,  $F_{inc}(3,40) = 1.47, ns$ , was significantly predictive of caregiver health.

### Overall discussion

Collectively, these data provide evidence that women are likely to assume a caregiver role for a woman with a severe disability. More specifically, it appears that mothers are more likely than other members to be family caregivers. This pattern was observed among women with acquired (SCI, TBI) and developmental (CP) disabilities. These data raise concern, then, about the unique needs and vulnerabilities of older women who assume physically and emotionally demanding activities that accompany caring for a person with mobility restrictions. Older individuals have a higher incidence of chronic health conditions (Vitaliano et al., 2003), and older caregivers in poor health are especially vulnerable to the strains of caregiving (Navaie-Waliser et al., 2002). Aging caregivers also face problems with social isolation and declining resources, and they have lingering worries about who will care for their loved one if they are unable to provide care (Braddock, 1999). Older age was associated with higher depression in our first study of caregivers of persons with SCI.

Our data provide additional evidence that considerable variability in adjustment can be observed between family caregivers. Caregivers who harbor pessimism about their ability to solve problems, regulate their emotions, and be motivated to handle complex challenges often report greater distress and depression in cross-sectional (Grant et al., 2001) and prospective (Elliott et al., 2001) studies. The present findings also suggest that this component of problem solving is implicated in caregiver well-being. Many caregivers thrive in their role and experience personal fulfillment (Kramer, 1997). Perhaps caregivers who have a lower negative orientation are more inclined to find personal meaning in their activities, or alternatively, their caregiver experience (and their relationship with the care recipient) is not compromised by the distress and pessimism that typically characterizes a negative orientation. Furthermore, we observe that higher levels of caregiver burden are particularly detrimental to family caregiver adjustment, and burden may represent a more subjective process with little association to disability severity or instrumental tasks (Chwalisz, 1996).

These studies illustrate the need to consider the health and well-being of family caregivers as matters germane to the health care of women with disabilities (Aneshenel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Although we failed to find any associations between caregiver characteristics and care recipient adjustment in our second study, this may reflect the difficulties inherent in measuring adjustment of persons with severe physical and neurological disabilities, generally (as evident in the degree of impairment among the women with disabilities in the second sample). Future research should consider the study of other secondary complications with more objective methods. But these data indicate that there are characteristics of caregivers who are more inclined to experience difficulties in their role, and these individuals may benefit from community-based services that nurture collaborative partnerships, addressing the unique needs of the individual caregiver.

Unfortunately, the available evidence concerning interventions for family caregivers is “... intellectually Balkanized into disjointed literatures that are associated with specific disabilities” (Elliott & Parker, in press). This situation precludes the development of any informed, overarching policy across caregiving scenarios and effectively relegates the utility of available research to the discretion of various medical specialties and associated providers that restrict their focus to the medical management of acute episodes of care. Research that demonstrates the effectiveness and benefits of interventions and services to caregivers is needed to influence a reasonable and informed policy for caregivers across caregiving scenarios and over the lifespan.

There are several limitations to the current research. These cross-sectional data do not reflect the dynamic trajectory of the caregiver career, and we understand that considerable variability exists within each caregiver experience. Relatedly, we did not systematically take into account the length of time in each caregiver experience (although we noted few significant differences between caregiver self-report data across the specific categories in the second study). Nevertheless, caregivers risk social isolation and significant declines in support over time, and further research is needed to determine the rates of depression among those women who provide a lifetime of assistance to adult children with severe disabilities.

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**Table 1**

Demographic and self-report data from family caregivers of women with SCI in study 1

	Women ( <i>n</i> = 28)	Men ( <i>n</i> = 12)
Demographics		
Age	45.9 (9.30)	51.1 (4.02)
Education (Years)	12.1 (2.58)	14.2 (4.15)
Race		
European American	11	11
African American	17	1
Relationship to care recipient		
Parent	17	3
Spouse/Partner	2	8
Sibling	3	—
Child	6	—
Other	—	1
Outcome variables		
IDD	12.2 (12.30)	8.1 (10.41)
SF-36		
Physical functioning	78.8 (19.56)	88.3 (12.67)
Social functioning	78.1 (28.38)	94.8 (14.56)
Role-physical	76.8 (35.95)	97.9 (7.22)
Role-emotional	77.4 (38.55)	88.9 (29.59)
Mental health	64.9 (26.36)	82.0 (12.36)
Energy/Fatigue	48.9 (29.61)	62.9 (23.79)
Pain	74.6 (27.43)	78.9 (18.17)
General health	70.6 (24.58)	72.6 (22.66)
SPSI-R		
PO	14.9 (2.92)	14.4 (2.39)
RPS	55.0 (9.10)	48.5 (10.68)
NO	9.8 (10.14)	3.4 (4.70)
AV	7.4 (6.29)	3.5 (3.99)
IC	6.9 (7.21)	5.5 (5.05)

*Note.* Standard deviations for averages in parentheses. IDD = Inventory to Diagnose Depression, PO = Positive Orientation, RPS = Rational Problem Solving Style, NO = Negative Orientation, AV = Avoidant Style IC = Impulsive/Careless Style.

**Table 2**  
Correlations between self-report measures obtained from family caregivers in study 1

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. IDD	—	—	-.39	-.13	-.29	-.10	-.80	-.43	-.34	-.19	.33	.55	.33	.24
2. Physical functioning		.02	.42	.75	.36	.13	.42	.50	.54	-.15	.09	-.17	-.15	.01
3. Social functioning		—	—	.41	.30	.48	.39	.33	.37	-.11	-.04	-.41	-.23	-.29
4. Role-physical				—	.31	.22	.46	.45	.47	-.04	-.13	-.16	-.03	.11
5. Role-emotional					—	.34	.43	.06	.32	-.06	.05	-.45	-.23	-.28
6. Mental health						—	.75	.46	.39	.24	-.16	-.61	-.39	-.33
7. Energy/Fatigue							—	.58	.50	.16	-.22	-.46	-.30	-.13
8. Pain								—	.66	.15	.10	-.16	.03	.21
9. General health									—	.33	.28	-.29	-.14	-.07
10. PO										—	.25	-.16	-.12	-.08
11. RPS											—	.20	.24	.03
12. NO												—	.77	.67
13. AV													—	.71
14. IC														—

Note.  $N = 40$ . All correlations of magnitude  $> .32$  or  $< - .32$ ,  $p < .05$ ; IDD = Inventory to Diagnose Depression, PO = Positive Problem Orientation, NO = Negative Problem Orientation, RPS = Rational Problem Solving Style, IC = Impulsive/Careless Style, AV = Avoidant Style.

**Table 3**

Demographic and self-report data from family caregivers of women with disabilities in study 2

	Women ( <i>n</i> = 48)	Men ( <i>n</i> = 5)
Demographics		
Age	56.7 (9.37)	48.4 (5.18)
Education (Years)	13.2 (2.90)	15.8 (3.63)
Race		
European American	33	4
African American	15	1
Relationship to care recipient		
Parent	40	1
Spouse/Partner	—	4
Sister	3	—
Aunt	2	—
Other	3	—
Employment		
Full time	26	1
Part time	16	4
Unemployed	6	—
Marital status		
Married	22	4
Divorced	14	1
Widowed	9	—
Separated	2	—
Single	1	—
Self-report variables		
MMSE	28.6 (1.99)	29.4 (.89)
CESD	14.2 (10.53)	9.4 (7.89)
SWL	21.3 (8.58)	27.0 (4.85)
CBS	33.7 (11.38)	26.8 (10.92)
PILL	13.6 (8.74)	5.8 (5.72)
SPSI-R		
PO	13.8 (3.59)	13.4 (3.91)
RPS	48.9 (13.05)	52.2 (9.60)
NO	11.8 (9.62)	10.8 (6.61)
AV	7.4 (4.69)	4.6 (1.82)
IC	10.6 (8.36)	9.6 (3.36)

*Note.* Standard deviations in parentheses. MMSE = Mini-Mental Status Examination, CESD = Center for Epidemiological Studies—Depression scale; SWL = Satisfaction with Life, CBS = Caregiver Burden Scale, PILL = Pennebaker Inventory for Limbic Languidness, PO = Positive Orientation, RPS = Rational Problem Solving Style, NO = Negative Orientation, AV = Avoidant Style IC = Impulsive/Careless Style.

**Table 4**  
Demographic and self-report data from women with disabilities in study 2

	CP ( <i>n</i> = 15)	TBI ( <i>n</i> = 14)	Other ( <i>n</i> = 24)
<b>Demographics</b>			
Age	32.4 (10.38)	36.8 (13.95)	32.8 (13.89)
Education (Years)	12.1 (1.79)	12.6 (2.31)	11.7 (6.59)
<b>Race</b>			
European American	10	12	16
African American	5	2	8
<b>Employment</b>			
Full Time	—	—	1
Part Time	2	—	2
Unemployed	13	14	21
<b>Marital Status</b>			
Married	1	4	2
Divorced	—	1	—
Widowed	—	1	—
Separated	—	1	—
Single	14	7	22
<b>Self-report Variables</b>			
MMSE	11.7 (9.77)	20.9 (10.19)	12.2 (11.16)
FIM	83.6 (36.16)	111.9 (37.99)	96.9 (39.05)
HAM-D	2.0 (2.45)	2.7 (3.52)	1.4 (2.60)

*Note.* MMSE = Mini-Mental Status Examination, FIM = Functional Independence Measure, HAM-D = Hamilton Depression Rating Scale—Six Item.



**Table 5**  
Correlations between self-report measures used in regression analyses in study 2

Variable	1	2	3	4	5	6	7	8	9	10	11
1. CESD	—										
2. SWL		-.65									
3. CBS			.53								
4. PILL			-.42	.60							
5. PO				-.44	-.25						
6. RPS				.38	.31	-.10	.63	.25	.34	-.06	.01
7. NO					-.16	.11	-.52	-.16	-.21	.11	-.12
8. AV					-.02	-.21	.36	.23	.30	-.26	.04
9. IC						.12	.30	.07	.01	.05	-.02
10. FIM						.51	-.56	-.44	-.36	-.07	.01
11. HAM-D							-.26	-.37	-.55	.09	-.05
								.62	.60	.01	-.07
									.66	-.05	-.25
										-.03	-.21
											-.07

Note.  $N = 53$ . All correlations of magnitude  $>.27$  or  $<-.27$ ,  $p < .05$ . CESD = Center for Epidemiological Studies—Depression scale, SWL = Satisfaction with Life, PO = Positive Problem Orientation, NO = Negative Problem Orientation, RPS = Rational Problem Solving Style, IC = Impulsive/Careless Style, AV = Avoidant Style, FIM = Functional Independence Measure, HAM-D = Hamilton Depression Rating Scale—Six Item.