



ORIGINAL RESEARCH

Subjective Caregiver Burden and Caregiver Satisfaction: The Role of Partner Relationship Quality and Reciprocity

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Abstract

Objective: To explore the effect of relationship quality and reciprocity in partnership on subjective caregiver burden and caregiver satisfaction in partners of persons with a severe physical disability (spinal cord injury).

Design: Cross-sectional, observational.

Setting: Community setting.

Participants: Caregiving partners of persons with spinal cord injury (N=118).

Interventions: Not applicable.

Main Outcome Measures: Subjective caregiver burden measured by the Zarit Burden Interview (short form) and caregiver satisfaction measured by a single item on feelings of satisfaction resulting from the caregiving role.

Results: Caregiving partners who rated their relationship quality as high encountered less subjective caregiver burden ($\beta = -1.10$; 95% confidence interval [CI], -1.47 to -0.72 ; $P < .001$) and more caregiver satisfaction (odds ratio [OR], 1.18; 95% CI, 1.01–1.45; $P = .049$). These associations persisted even after controlling for sociodemographic characteristics, lesion severity of the care receiver, and objective caregiver burden. Partners who indicated high reciprocity in their relationship to the care receiver indicated less subjective caregiver burden and more caregiver satisfaction when relationship quality was excluded from the final models; however, the effect of reciprocity on subjective burden ($\beta = -.38$; 95% CI, -3.71 to 2.95; $P = .82$) and caregiver satisfaction (OR, 1.21; 95% CI, 0.28–5.22; $P = .80$) disappeared when including relationship quality.

Conclusions: Results highlight the importance of relationship quality as a target for couple interventions aimed at reducing subjective caregiver burden and increasing satisfaction in the caregiving role.

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Caring for a person with physical disability may present a chronic stress experience that puts informal caregivers at increased risk of reduced well-being and enhanced morbidity and mortality.¹⁻³ In contrast with professional caregivers, informal caregivers provide care for a person without being compensated or specifically trained.³ This group of caregivers is steadily increasing as a consequence of a high burden of chronic disease in the aging

population and an extended life expectancy for persons living with chronic disabling conditions.^{4,5}

Theoretical models of the caregiving experience have identified social relationship constructs (eg, relationship quality, social support) within the caregiver–care receiver dyad as potential risk or protective factors for caregiver burden.^{6,7} There are a number of potential pathways through which social relationships may exert their influence on caregiver burden and health.⁸ Qualitative aspects of the caregiver–care receiver relationship may directly effect on the subjective perception of burden.^{9,10} Several studies observed an association between relationship satisfaction and caregiver burden, positing that social resources, such as those provided by intimate partner relations, can prevent the perception

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of caregiver burden.⁹⁻¹¹ Reciprocity within relationships (ie, the sense of equal and fair exchange of give and take)¹² is also an important factor and one which is closely related to relationship quality.¹⁰ The potential imbalance of give and take within caregiving relations may lead to a change in dyad dynamics,¹³ distress for both partners,^{14,15} and poorer relationship satisfaction and quality.¹⁶ Interventions to improve relationship quality and equity in caregiver–care receiver dyads have proved successful in couples affected by chronic illness, and by identifying the specific areas of relationships linked to caregiver burden, interventions can be better targeted.¹⁷

It is important to distinguish between subjective and objective burden when evaluating the effect of social relationships on caregiver burden. The subjective burden refers to the emotional or psychological effect that performing caregiving tasks has on the caregiver.¹⁸ In turn, the objective burden refers to the number of activities for which the care receiver requires assistance, and the time burden in providing support for these tasks. Several studies have not only found that objective and subjective burdens are influenced by different factors, but that the subjective burden is a stronger predictor of health and well-being than the objective burden.^{1,18,19} Although caregiving is frequently linked to negative outcomes, positive experiences (eg, sense of satisfaction, deeper sense of meaning to life) may also occur and need to be considered in research.^{20,21}

To our knowledge, this is the first study to investigate the effect of partner relationship quality on the subjective caregiver burden and caregiver satisfaction in caregivers of persons with spinal cord injury (SCI). SCI offers an informative case in point because it is a chronic condition which has an extensive effect on an individual's functioning, often leading to major disability and dependencies on informal caregivers.²² The objective of the article is to describe the correlates of subjective caregiver burden and caregiver satisfaction in the partners of persons with SCI, with a specific focus on relationship quality and reciprocity in partner relationships.

Methods

Sampling frame and participants

Data for this analysis came from the pro-WELL study.²³ Participants for the pro-WELL study were recruited from the community survey of the Swiss Spinal Cord Injury Cohort Study, which was performed between September 2011 and March 2013. This sampling frame included a representative study population of 1922 persons living in Switzerland, aged ≥ 16 years, with newly acquired traumatic or nontraumatic SCI.^{24,25} The eligibility criterion for the pro-WELL study were as follows: aged 30 to 65 years, fluent in German or French, living in a stable partnership, and agreement of the partner to also participate because only couples were included.²³ In total, 676 persons with SCI were deemed eligible. Of this eligible population, 133 persons with SCI and their partners participated in the baseline assessment of the pro-WELL study (N=266), resulting in a response rate of 19.7% (details on calculation reported elsewhere²³). A comprehensive

nonresponse analysis demonstrated good representation of the source population, with insignificant selection bias regarding sociodemographic and lesion characteristics.²³ In this analysis, only the partners of persons with SCI who indicated providing support in activities of daily living (ADL) or in instrumental activities of daily living (IADL) for their partners were included (N=118).

Study design

The pro-WELL study is a longitudinal community-based survey with 3 measurement waves (baseline, month 6, and month 12). Data were collected using computer-assisted telephone interviews and questionnaires (paper-pencil or online). This study used cross-sectional data from the baseline assessment that was carried out between May 2015 and January 2016. The study protocol and all measures were approved by the Ethical Committee of Northwest and Central Switzerland (no. EKNZ 2014-285). The pro-WELL study strictly observed all regulations concerning informed consent and data protection and conforms to the Helsinki Declaration.

Measures

Outcome: subjective caregiver burden

The emotional and psychological effect of caregiving was assessed using the Zarit Burden Interview²⁶ (short form),²⁷ previously validated in SCI caregivers.²⁸ The instrument consists of 12 items measured on a 5-point Likert scale. A sum score was computed ranging from 0 to 48, where a higher score indicated a higher perceived subjective burden. The standardized Cronbach α for the sum score was .88.

Outcome: caregiver satisfaction

Caregiver satisfaction was assessed by a single item asking participants on the degree of agreement with the statement that taking care of their partner gives them a sense of satisfaction. Response options were disagree, slightly disagree, slightly agree, and agree.

Predictor: sociodemographic characteristics

Level of education, net equivalence household income, and perceived financial hardship were used as indicators of individual-level socioeconomic circumstances. Education level was captured as total years of formal education. Income was measured by net equivalent household income in Swiss francs, including information on disposable income, weighted by number of adults and children according to Organisation for Economic Co-operation and Development criteria.²⁹ Financial hardship was assessed with a single item on how subjects get along with their available financial resources. Response options included very scarce, scarce, just lasts, lasts well, and lasts very well. Basic sociodemographic characteristics included age, sex, engagement in paid work, and whether the partnership existed before or after the partners' diagnosis of SCI.

Predictor: lesion characteristics of care receiver

Lesion characteristics included the level (paraplegia or tetraplegia) and completeness (complete or incomplete) of lesion and whether the SCI was traumatic or non-traumatic in etiology.

Predictor: objective caregiver burden

To assess the quantity of caregiving, caregivers were asked to what extent they provided help in 6 ADL and 5 IADL (table 1).

List of abbreviations:

ADL	activities of daily living
IADL	instrumental activities of daily living
OR	odds ratio
SCI	spinal cord injury

Response options were no help needed, some help needed, and much help needed, giving a sum score of 0 to 12 for ADL and 0 to 10 for IADL.³⁰ Standardized Cronbach α was 0.84 for the ADL and 0.72 for the IADL scale, respectively. Furthermore, information on the daily hours of caregiving, the involvement of external persons or institutions in caregiving activities, and support in caregiving activities from the social network was gathered. Duration of caregiving was calculated based on information on the time since SCI of the care receiver and the length of partnership.

Predictor: relationship quality

The Quality of Relationship Inventory assesses social support, conflict, and depth of any kind of close social relationship.³¹ For the purpose of this study, items were adapted accordingly (eg, "How much do you depend on this person?" was replaced by "How much do you depend on your partner?"). Two items from the social support and 6 items from the depth subscales of the Quality of Relationship Inventory were used. The 2 social support items included information on the amount of emotional and informational support available from the partner, and the 6 depth items evaluated the significance and importance of the partner relationship. All items were rated on a 4-point Likert scale ranging from not true to almost always true.³² A sum score ranging from 0 to 24 was calculated, with higher scores indicating higher relationship quality. The standardized Cronbach α across all 8 items was .84, demonstrating satisfactory internal consistency in our sample.

Predictor: reciprocity

Reciprocity in partner relationship was examined with an item previously used in established cohort studies (ie, GAZEL,⁸ Whitehall II¹²). Caregiving partners were asked whether they have always been satisfied with the balance between what they have given their partner and what they have received in turn on a 4-point Likert scale (no, a little, quite a lot, and very much). As only few participants selected the lowest category, the variable was dichotomized for multivariable analysis (no and a little: low reciprocity; quite a lot and very much: high reciprocity).

Statistical analysis

Analyses were conducted using Stata 14.1 for Windows.^a A descriptive analysis of sociodemographic characteristics, attributes of objective and subjective caregiving, and social relationship characteristics for the caregivers and the lesion characteristics of the care receiver were provided. Bivariable analyses were performed to identify correlates of subjective caregiver burden and caregiver satisfaction to be included in multivariable models. Items were entered into multivariable models if significant at the .05 level for either one of the outcomes.

Hierarchical multiple regression was conducted for both outcomes (subjective caregiver burden and caregiver satisfaction), whereby predictors were entered cumulatively according to a prespecified order; therefore, we could account for the influence of each block of variables on the outcome. As previously described, we included only variables which were significant at the .05 level in bivariable analysis. In addition, lesion severity of the care receiver was included in both models because the level of physical disability has previously been found to directly affect the caregiver burden.³³ To account for intrinsic floor effects of the Zarit Burden Interview (short form), we used tobit regression³⁴ to investigate the association of subjective caregiver burden with

sociodemographic characteristics, caregiving parameters, and social relationship constructs. Logistic regression was similarly used to investigate caregiver satisfaction as dichotomous outcome. Block 1 of the regression analysis included sociodemographic characteristics of the caregiver and lesion characteristics of the care receiver. Block 2 added caregiving characteristics of the objective caregiver burden. Block 3 isolated the unique contribution of relationship quality and reciprocity. To explore any potential relation between relationship quality and reciprocity in the final model, a post hoc analysis was undertaken whereby both variables were entered independently into the model. This enabled an evaluation of potential mediating effects.³⁵

Regression diagnostics were conducted to ensure that multicollinearity between predictors did not affect the models, and that all other necessary assumptions were fulfilled. Variance inflation factors were <10 for all variables in both models, indicating limited or minimal multicollinearity. To assess the increase in model fit with the addition of new variables, a pseudo R^2 was computed.³⁶

Item nonresponse was addressed using multiple imputation. Multiple imputation by chained equations was applied to derive 20 imputed datasets, imputing all predictors but no outcomes.³⁷ Results from multiple imputed datasets were combined using the Rubin rules.³⁸

Results

Basic characteristics of the 118 caregiving partners are displayed in table 1. Most of them were women (72.9%), and mean age was 50 years. About one-third of caregivers were not in paid employment, and the average duration of caregiving was 19 years, ranging from 0 to 45 years. The average daily care provided was 2h, ranging from 0 to 24 hours. Regarding ADL tasks, daily partner assistance with toileting, dressing, or washing was reported by more than one-third of caregivers. Support in IADL tasks was more frequent than support in ADL tasks, and among IADL tasks support with housework, shopping, or cooking was indicated by 60% to 80%. Roughly one-quarter of all caregivers reported receiving external help in caregiving activities, and 64% received support from their social network.

Correlates of subjective caregiver burden

Univariable correlates of subjective caregiver burden can be found in table 2. Sociodemographic characteristics of the caregiver and lesion characteristics of the care receiver were not associated with subjective caregiver burden. Subjective caregiver burden was positively associated with most objective caregiver burden indicators, with the exception of social support in caregiving and the duration of caregiving, which appeared unrelated in univariable analysis. In contrast, relationship quality and reciprocity were negatively associated with subjective caregiver burden, indicating that partners who reported good relationship quality and reciprocity reported lower subjective burden.

The final multivariable model, which included all variables on sociodemographics, lesion characteristics of the care receiver, objective caregiver burden, and partner relationship quality, had a pseudo R^2 of .11, and showed a better model fit than the models including only block 1 and block 2 variables (table 3). The positive association of number of IADL tasks ($\beta = .77$, $P = .013$) and negative association of relationship quality ($\beta = -1.10$, $P < .001$) with subjective caregiver burden persisted after controlling for all

Table 1 Basic characteristics of the study population (N=118)

Characteristic	n (%; 95% CI)*	Mean ± SD	Missing, n (%)
Sociodemographic characteristics			
Age, y	NA	50.7±10.0	NA
Sex			
Male	32 (27.1, 19.8–36.0)	NA	NA
Female	86 (72.9, 64.0–80.2)	NA	NA
Education, y	NA	14.0±3.2	7 (5.9)
Net equivalence household income (Swiss Francs)	NA	4333±1560	17 (14.4)
Financial hardship			5 (4.2)
Some financial hardship	39 (34.5, 26.2–43.9)	NA	NA
No financial hardship	74 (65.5, 56.1–73.8)	NA	NA
Paid work			7 (5.9)
Not in paid employment	37 (33.3, 25.1–42.7)	NA	NA
<20h/wk paid employment	25 (22.5, 15.6–31.3)	NA	NA
≥20h/wk paid employment	49 (44.1, 35.1–53.6)	NA	NA
Partnership before SCI	50 (45.0, 35.9–54.5)	NA	7 (5.9)
Lesion characteristics of care receiver			
Lesion severity			2 (1.7)
Incomplete paraplegia	36 (31.0, 23.2–40.1)	NA	NA
Complete paraplegia	45 (38.8, 30.3–48.1)	NA	NA
Incomplete tetraplegia	22 (19.0, 12.7–27.3)	NA	NA
Complete tetraplegia	13 (11.2, 6.6–18.5)	NA	NA
Etiology			3 (2.5)
Traumatic	97 (84.3, 76.4–90.0)	NA	NA
Nontraumatic	18 (15.7, 10.0–23.6)	NA	NA
Objective caregiver burden			
Duration of daily care, h	NA	2.0±3.5	12 (10.2)
External help in caregiving	28 (24.8, 17.6–33.7)	NA	5 (4.2)
Social support in caregiving	72 (64.3, 54.9–72.7)	NA	6 (5.1)
Duration of caregiving, y	NA	18.8±11.0	7 (5.9)
No. of ADL tasks (range, 0–12)		2.3±2.8	7 (5.9)
Receives help in going to bed or getting up in the morning	33 (30.3, 22.3–39.7)	NA	9 (7.6)
Receives help with using toilet	38 (34.2, 25.9–43.7)	NA	7 (5.9)
Receives help with dressing	38 (34.9, 26.4–44.4)	NA	9 (7.6)
Receives help with washing	43 (41.0, 31.8–50.7)	NA	13 (11.0)
Receives help with eating	18 (16.2, 10.4–24.4)	NA	7 (5.9)
Receives help with mobility indoors	24 (21.1, 14.4–29.6)	NA	4 (3.4)
No. of IADL tasks (range, 0–10)	NA	4.1±2.7	10 (8.5)
Receives help with shopping	74 (69.2, 59.6–77.3)	NA	11 (9.3)
Receives help with housework	86 (80.4, 71.6–86.9)	NA	11 (9.3)
Receives help with administrative issues	23 (20.7, 14.1–29.4)	NA	7 (5.9)
Receives help with cooking	65 (59.6, 49.1–57.5)	NA	7 (5.9)
Receives help with transfers	50 (44.6, 35.6–54.1)	NA	6 (5.1)
Subjective caregiver burden			
Zarit Burden Interview (short form) (range, 0–48)	NA	7.4±7.2	5 (4.2)
Satisfaction with caregiving			17 (14.4)
Satisfied	50 (49.5, 39.7–59.3)	NA	NA
Dissatisfied	51 (50.5, 40.7–60.3)	NA	NA
Partner relationship			
Partner relationship quality (range, 0–24)	NA	20.2±3.7	3 (2.5)
Reciprocity in partnership			3 (2.5)
None	6 (5.2, 2.3–11.3)	NA	NA
A little	17 (14.8, 9.3–22.6)	NA	NA
Quite a lot	50 (43.4, 34.6–52.8)	NA	NA
Very much	42 (36.5, 28.1–45.8)	NA	NA

Abbreviations: CI, confidence interval; NA, not applicable.

* Percentages excluding missing values.

Table 2 Results from univariable regression showing unadjusted effect sizes with 95% CIs for potential correlates of subjective caregiver burden and caregiver satisfaction

Correlates	Regression Model	Subjective Caregiver Burden		Caregiver Satisfaction	
		Tobit (0–48)*	P	Logistic (0,1) [†]	P
Subjective caregiver burden and caregiver satisfaction	ZBI-S sum score	NA		0.97 (0.92–1.03)	.34
	Caregiver satisfaction		<.001	NA	NA
	No satisfaction	0.00 (reference)		NA	NA
	Satisfaction	–1.67 (–2.34 to –0.99)		NA	NA
Sociodemographic characteristics	Age, per 10 y	1.01 (–0.40 to 2.42)	.16	1.52 (0.10–2.25)	.039
	Sex		.98		.014
	Male	0.00 (reference)		1.00 (reference)	
	Female	0.04 (–3.37 to 3.44)		0.30 (0.12–0.78)	
	Education, y	–0.06 (–0.53 to 0.41)	.81	0.96 (0.84–1.08)	.51
	Net equivalence household income (Swiss Francs)	0.00 (0.00 to 0.00)	.84	0.99 (0.99–1.00)	.83
	Financial hardship		.066		.85
	No financial hardship	0.00 (reference)		1.00 (reference)	
	Some financial hardship	2.92 (–0.20 to 6.04)		1.44 (0.62–3.33)	
	Paid work		.99		.061
	Not in paid employment	0.00 (reference)		1.00 (reference)	
	<20h/wk paid employment	0.31 (–3.97 to 4.58)		0.22 (0.06–0.72)	
	≥20h/wk paid employment	0.12 (–3.54 to 3.78)		0.61 (0.23–1.57)	
	Partnership before SCI		.35		.002
	No	0.00 (reference)		1.00 (reference)	
Yes	1.41 (–1.58 to 4.42)		3.89 (1.68–9.02)		
Lesion characteristics of care receiver	Lesion severity		.16		.55
	Incomplete paraplegia	0.00 (reference)		1.00 (reference)	
	Complete paraplegia	–1.35 (–4.81 to 2.11)		0.72 (0.28–1.87)	
	Incomplete tetraplegia	2.83 (–1.58 to 7.24)		1.34 (0.41–4.43)	
	Complete tetraplegia	1.80 (–3.17 to 6.77)		0.80 (0.22–2.94)	
	Lesion aetiology		.55		.21
Nontraumatic	0.00 (reference)		1.00 (reference)		
Traumatic	–1.25 (–5.37 to 2.86)		0.47 (0.15–1.52)		
Objective caregiver burden	No. of ADL tasks	1.01 (0.52 to 1.50)	<.001	1.03 (0.90–1.17)	.72
	No. of IADL tasks	1.39 (0.90 to 1.88)	<.001	1.11 (0.96–1.29)	.17
	Hours of caregiving	0.62 (0.18 to 1.05)	.006	1.11 (0.96–1.29)	.15
	External help in caregiving		<.001		.012
	No	0.00 (reference)		1.00 (reference)	
	Yes	5.70 (2.34 to 9.07)		3.54 (1.32–9.46)	
	Social support in caregiving		.33		.90
	No	0.00 (reference)		1.00 (reference)	
	Yes	0.89 (–0.91 to 2.69)		0.10 (0.65–1.64)	
	Duration of caregiving, y	–0.02 (–0.15 to 0.12)	.80	1.02 (0.98–1.06)	.27

(continued on next page)

Table 2 (continued)

Correlates	Regression Model	Subjective Caregiver Burden		Caregiver Satisfaction	
		Tobit (0–48)*	P	Logistic (0,1)†	P
Partner relationship	Partner relationship quality	–1.17 (–1.51 to –0.83)	<.001	1.09 (1.01–1.22)	.049
	Reciprocity in partnership	0.00 (reference)	<.001	1.00 (reference)	.17
	None	–6.25 (–12.94 to 0.45)		1.20 (0.17–5.66)	
	A little	–9.98 (–16.10 to –3.87)		1.91 (0.32–11.54)	
	Quite a lot	–13.22 (–19.41 to –7.03)		2.80 (0.45–17.31)	
Very much					

NOTE. Only complete cases are included in this analysis.
Abbreviations: CI, confidence interval; NA, not applicable; ZBI-S, Zarit Burden Interview (short form).

* Values are coefficients (95% CIs).

† Values are ORs (95% CIs).

other variables. Reciprocity was also negatively associated with subjective caregiver burden when relationship quality was excluded from the final model. The effect of reciprocity on subjective burden was $\beta = -.38$ ($P = .82$) when relationship quality was included and $\beta = -6.43$ ($P < .001$) when relationship quality was excluded.

Correlates of caregiver satisfaction

Caregiver satisfaction was positively associated with male sex, partnership before SCI, external help in caregiving, and higher relationship quality both in the univariable (see table 2) and multivariable analysis (table 4). The odds ratios (OR) for established partnership before SCI (OR, 5.34; $P = .004$), receiving professional help in caregiving activities (OR, 5.24; $P = .023$), and relationship quality (OR, 1.18; $P = .049$) were slightly increased in the multivariable model. The pseudo R^2 value increased with the addition of each block of variables, showing that the final model had the greatest likelihood. Age showed a marginal univariable association with caregiver satisfaction (see table 2 compared with table 4).

Discussion

This study provides evidence that the quality of the relationship between care receiver and caregiver influenced both the perception of subjective caregiver burden and caregiver satisfaction, independent of sociodemographic and caregiving characteristics. Reciprocity in partner relationships was not related to subjective caregiver burden or caregiver satisfaction in fully adjusted models. However, we observed higher subjective caregiver burden in partners who rated their reciprocity as low when relationship quality was not introduced as covariate. Besides relationship quality and reciprocity, indicators of objective caregiver burden (number of ADL and IADL tasks and receiving external help in caregiving) were positively associated with subjective caregiver burden. Being a man, being in an established partnership before SCI, and receiving external help in caregiving were positively linked to caregiver satisfaction.

Relationship quality

Our study suggests that high-quality intimate relationships provide resources which may reduce the stress, and therefore the burden, experienced by long-term caregivers. Although the negative association between relationship quality and caregiver burden has been identified in other studies,^{9–11} it has not yet been explored in caregivers for persons with physical disabilities such as SCI. However, it remains difficult to evaluate the direction of the association between relationship quality and caregiver burden. To clarify causal associations, it would be necessary to follow couples throughout transition into disability. Research which has retrospectively addressed this topic suggests that both past and present relationship quality exert some effect on caregiver burden.³⁹ The finding that higher relationship quality is also linked to satisfaction with the caregiving experience is novel to this study, and given the association between caregiver satisfaction and burden, this is an important link to establish.

Reciprocity

It has been suggested that the effect of relationship quality on subjective caregiver burden is solely down to the negative effects

Table 3 Adjusted coefficients (95% CIs) from tobit regression analyses of subjective caregiver burden* sequentially including sociodemographic characteristics and lesion characteristics of the care receiver, objective caregiver burden, and partner relationship quality

Predictors	Block 1: Sociodemographic and Lesion Characteristics	<i>P</i>	Block 2: Block 1 Plus Objective Caregiver Burden	<i>P</i>	Block 3: Blocks 1 and 2 Plus Partner Relationship Quality	<i>P</i>
Sociodemographic characteristics						
Age, per 10 y	0.82 (−0.64 to 2.27)	.27	−0.12 (1.48 to 1.23)	.86	0.51 (−0.60 to 1.61)	.37
Sex		.95		.37		.19
Male	0.00 (reference)		0.00 (reference)		0.00 (reference)	
Female	0.11 (−3.25 to 3.48)		1.37 (−1.64 to 4.38)		1.65 (−0.82 to 4.12)	
In partnership before SCI		.46		.86		.78
No	0.00 (reference)		0.00 (reference)		0.00 (reference)	
Yes	1.22 (−2.03 to 4.47)		0.26 (−2.68 to 3.19)		0.33 (−2.03 to 2.68)	
Lesion characteristics of care receiver						
Lesion severity		.24		.67		.24
Incomplete paraplegia	0.00 (reference)		0.00 (reference)		0.00 (reference)	
Complete paraplegia	−0.95 (−3.25 to 3.48)		−1.21 (−4.46 to 2.05)		−0.02 (−2.67 to 2.63)	
Incomplete tetraplegia	3.25 (−1.34 to 7.85)		−1.16 (−5.55 to 3.24)		−0.57 (−4.11 to 2.98)	
Complete tetraplegia	1.87 (−3.19 to 6.93)		−3.51 (−9.20 to 2.18)		−4.41 (−9.02 to 0.20)	
Objective caregiver burden	NA					
No. of ADL tasks (0–12)			0.24 (−0.56 to 1.04)	.56	0.65 (−0.01 to 1.31)	.052
No. of IADL tasks (0–10)			1.14 (0.41 to 1.87)	.003	0.77 (0.17 to 1.36)	.013
Hours of caregiving			−0.01 (−0.48 to 0.44)	.95	−0.18 (−0.55 to 0.19)	.34
External help in caregiving				.032		.076
No			0.00 (reference)		0.00 (reference)	
Yes			3.96 (0.35 to 7.58)		2.69 (−0.29 to 5.68)	
Partner relationship	NA		NA			
Partner relationship quality (0–24)					−1.10 (−1.47 to −0.72)	<.001
Reciprocity in partnership						.82
None, a little					0.00 (reference)	
Quite a lot, very much					−0.38 (−3.71 to 2.95)	
Pseudo <i>R</i> ²	.01		.05		.11	

NOTE. Values are coefficients (95% CIs) or as otherwise indicated. The *P* values are from equal-fraction-missing information test. Missing values were imputed by multiple imputation. Abbreviations: CI, confidence interval; NA, not applicable.

* Subjective caregiver burden measured with the Zarit Burden Interview (short form) (score range, 0–48).

Table 4 Adjusted ORs (95% CIs) from logistic regression analyses of caregiver satisfaction, sequentially including sociodemographic characteristics and lesion characteristics of the care receiver, objective caregiver burden, and partner relationship quality

Predictors	Block 1: Sociodemographic and Lesion Characteristics	<i>P</i>	Block 2: Block 1 Plus Objective Caregiver Burden	<i>P</i>	Block 3: Blocks 1 and 2 Plus Partner Relationship Quality	<i>P</i>
Sociodemographic characteristics						
Age, per 10 y	1.36 (0.87–2.14)	.181	1.31 (0.79–2.16)	.29	1.21 (0.73–2.00)	.46
Sex		.010		.023		.017
Male	1.00 (reference)		1.00 (reference)		1.00 (reference)	
Female	0.24 (0.08–0.73)		0.28 (0.09–0.84)		0.23 (0.07–0.77)	
In partnership before SCI		.004		.007		.004
No	1.00 (reference)		1.00 (reference)		1.00 (reference)	
Yes	4.45 (1.61–12.32)		4.39 (1.49–12.91)		5.34 (1.73–16.55)	
Lesion characteristics of care receiver						
Lesion severity		.44		.77		.75
Incomplete paraplegia	1.00 (reference)		1.00 (reference)		1.00 (reference)	
Complete paraplegia	1.23 (0.39–3.89)		1.06 (0.32–3.46)		0.97 (0.28–3.33)	
Incomplete tetraplegia	3.33 (0.74–14.94)		2.22 (0.43–11.52)		2.27 (0.40–12.72)	
Complete tetraplegia	1.32 (0.30–5.76)		1.14 (0.16–8.04)		1.23 (0.78–5.58)	
Objective caregiver burden	NA					
No. of ADL tasks (0–12)			0.90 (0.69–1.19)	.47	0.86 (0.64–1.14)	.28
No. of IADL tasks (0–10)			1.02 (0.78–1.32)	.90	1.04 (0.79–1.38)	.76
Hours of caregiving			1.03 (0.87–1.21)	.76	1.05 (0.88–1.25)	.57
External help in caregiving				.049		.023
No			1.00 (reference)		1.00 (reference)	
Yes			3.85 (1.01–14.77)		5.24 (1.26–21.89)	
Partner relationship	NA		NA			
Partner relationship quality (0–24)					1.18 (1.01–1.45)	.049
Reciprocity in partnership						.80
None, a little					1.00 (reference)	
Quite a lot, very much					1.21 (0.28–5.22)	
Pseudo <i>R</i> ²	.16		.20		.25	

NOTE. Values are ORs (95% CIs) or as otherwise indicated. The *P* values from equal-fraction-missing information test. Missing values were imputed by multiple imputation. Abbreviations: CI, confidence interval; NA, not applicable.

of inequality within relationships, arguing that this inequality or imbalance in the relationship results in poor quality and distress.⁹ Another study however failed to find a direct association between reciprocity and subjective caregiver burden.⁴⁰ This may be explained by the fact that the negative feelings of imbalance and inequality in relationships are experienced by care receivers more than caregivers because of a certain expectation by caregivers that imbalance is present.¹⁴ Our study is one of the first which offers the opportunity of analyzing reciprocity in this context. Our findings suggest that reciprocity is indeed associated with subjective caregiver burden. However, given that the effect of reciprocity is reduced when introduced into a model with relationship quality, it can be concluded that relationship quality mediates this association, therefore accounting for the observed association.

Sociodemographic and caregiving characteristics

We found that sociodemographic characteristics were unrelated to subjective caregiver burden, but were associated with caregiver satisfaction. The finding that caregivers who had an established relationship before SCI showed higher satisfaction with the caregiving situation seems to contradict social psychological theories claiming that individuals with prior knowledge of the nature of disability, and therefore the amount of care required, would cope better than individuals with no previous knowledge.^{13,41} This contradiction may be explained by the nature of our study, which includes community-dwelling couples a relatively long time after initial disability onset. It is therefore expected that those couples who did not survive through the initial phase of adaptation to injury, and to the caregiving role, were not represented in our sample. Future research which follows couples shortly after injury may be able to better understand this association. Our study also found that women had lower levels of caregiver satisfaction than men. In contrast with our findings, other investigations observed that women perceived a lower burden than men, which may be related to the different levels of support provided,^{42,43} or to gender role differences in reacting and responding to distress.⁴²

Indicators of objective caregiver burden were associated with subjective caregiver burden more so than with caregiver satisfaction. The findings that the more support the caregiver provided in both ADL and IADL tasks, the higher the subjective burden, have been reported previously.³³ Rather more striking was the effect of receiving external support in caregiving on both subjective caregiver burden and caregiver satisfaction. Receiving this kind of support was associated with both a higher burden and higher levels of satisfaction, results which suggest that receiving external support reflects a poorer functional status of the care receiver and therefore an increase in objective caregiver burden.⁴⁴ It also suggests that caregivers who are well supported by professionals gain more feelings of satisfaction from their caregiving role.

Study limitations and strengths

Several study limitations should be considered. First, because the study findings are based on cross-sectional data, no causal interpretation of the results can be made. It may also be the case that individuals with a high caregiver burden experience their partner relationship more negatively. Second, the small sample size precluded a more sophisticated analysis, and the detection of interaction effects. Third, because our sample only included couples who have been in a relationship for many years, it is possible that those

relationships which failed to cope well with the adjustment to the caregiving relationship have been missed. Finally, the provision of emotional support was not documented, despite research suggesting that this caregiving task was among the most challenging.⁴⁵

These limitations are balanced by several strengths. First, this is one of the first studies to analyze the relation between relationship quality, reciprocity, and caregiver burden in the partners of persons with SCI. Second, all associations of partner relationship quality and reciprocity with subjective caregiver burden and caregiver satisfaction were adjusted for relevant confounders, therefore minimizing the risk of reporting spurious associations. Finally, this study not only focused on the negative outcomes of caregiving but also assessed a positive effect of engagement in informal caregiving.

Conclusions

This study provides evidence for the protective effect of high relationship quality on subjective caregiver burden in the caregiving partners of persons with SCI. It also highlights the positive effect that high relationship quality has on the partner's satisfaction with the caregiving experience. It is therefore recommended that interventions targeted to reduce the subjective caregiver burden and to enhance caregiver satisfaction should strengthen the relationship between the care receiver and the caregiving partner.

Supplier

a. Stata 14.1 for Windows; StataCorp.

Keywords

Caregivers; Rehabilitation; Spinal cord injuries

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References

- Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *J Am Med Assoc* 1999;282:2215-9.
- Schulz R, Visintainer P, Williamson GM. Psychiatric and physical morbidity effects of caregiving. *J Gerontol* 1990;45:P181-91.
- Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. *Am J Nurs* 2008;108(9 Suppl):23.
- Houser A, Gibson MJ. Valuing the invaluable: the economic value of family caregiving, 2008 update. Washington (DC): AARP Public Policy Institute; 2008.

5. Kasselbaum NJ, Arora M, Barber RM, et al. Global, regional, and national disability-adjusted life-years (DALYs) for 315 diseases and injuries and healthy life expectancy (HALE), 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet* 2016; 388:1603-58.
6. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990;30:583-94.
7. McCubbin HI, Patterson JM. The family stress process: the double ABCX model of adjustment and adaptation. *Marriage Fam Rev* 1983;6:7-37.
8. Wahrendorf M, Ribet C, Zins M, Goldberg M, Siegrist J. Perceived reciprocity in social exchange and health functioning in early old age: prospective findings from the GAZEL study. *Aging Ment Health* 2010; 14:425-32.
9. Cairo Notari S, Favez N, Notari L, Charvoz L, Delaloye JF. The caregiver burden in male romantic partners of women with non-metastatic breast cancer: the protective role of couple satisfaction. *J Health Psychol.* 2016 Mar 3. [Epub ahead of print].
10. Quinn C, Clare L, Woods B. The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: a systematic review. *Aging Ment Health* 2009;13:143-54.
11. Steadman PL, Tremont G, Davis JD. Premorbid relationship satisfaction and caregiver burden in dementia caregivers. *J Geriatr Psychiatry Neurol* 2007;20:115-9.
12. Chandola T, Marmot M, Siegrist J. Failed reciprocity in close social relationships and health: findings from the Whitehall II study. *J Psychosom Res* 2007;63:403-11.
13. Schulz R, Tompkins CA, Wood D, Decker S. The social psychology of caregiving: physical and psychological costs of providing support to the disabled. *J Appl Soc Psychol* 1987;17:401-28.
14. Kuijter RG, Buunk BP, Ybema JF. Are equity concerns important in the intimate relationship when one partner of a couple has cancer? *Soc Psychol Quart* 2001;64:267-82.
15. Walster E, Walster G, William B. Equity: theory and research. Boston: Allyn and Bacon; 1978.
16. Kulik L. Marital equality and the quality of long-term marriage in later life. *Ageing Soc* 2002;22:459-81.
17. Kuijter RG, Buunk BP, De Jong GM, Ybema JF, Sanderman R. Effects of a brief intervention program for patients with cancer and their partners on feelings of inequity, relationship quality and psychological distress. *Psychooncology* 2004;13:321-34.
18. Montgomery RJ, Gonyea JG, Hooyman NR. Caregiving and the experience of subjective and objective burden. *Fam Rel* 1985:19-26.
19. Haley WE, LaMonde LA, Han B, Burton AM, Schonwetter R. Predictors of depression and life satisfaction among spousal caregivers in hospice: application of a stress process model. *J Palliat Med* 2003;6:215-24.
20. Cohen CA, Colantonio A, Vernich L. Positive aspects of caregiving: rounding out the caregiver experience. *Int J Geriatr Psychiatry* 2002; 17:184-8.
21. Noonan AE, Tennstedt SL. Meaning in caregiving and its contribution to caregiver well-being. *Gerontologist* 1997;37:785-94.
22. Bickenbach J, Officer A, Shakespeare T, Von Groote P, editors. International perspectives on spinal cord injury. Geneva: World Health Organization; 2013.
23. Fekete C, Brinkhof MW, Tough H, Siegrist J. Cohort profile: a longitudinal study of social participation and wellbeing among persons with spinal cord injury and their partners (pro-WELL). *BMJ Open* 2017;7:e011597.
24. Brinkhof MW, Fekete C, Chamberlain JD, Post MW, Gemperli A. Swiss national community survey on functioning after spinal cord injury: protocol, characteristics of participants and determinants of non-response. *J Rehabil Med* 2016;48:120-30.
25. Fekete C, Segerer W, Gemperli A, Brinkhof MW. Participation rates, response bias and response behaviours in the community survey of the Swiss Spinal Cord Injury Cohort Study (SwiSCI). *BMC Med Res Methodol* 2015;15:80.
26. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20: 649-55.
27. Bedard M, Molloy DW, Squire L, Dubois S, Lever JA, O'Donnell M. The Zarit Burden Interview: a new short version and screening version. *Gerontologist* 2001;41:652-7.
28. Rajabi-Mashhadi MT, Mashhadinejad H, Ebrahimzadeh MH, Golhasani-Keshtan F, Ebrahimi H, Zarei Z. The Zarit Caregiver Burden Interview Short Form (ZBI-12) in spouses of veterans with chronic spinal cord injury, validity and reliability of the Persian version. *Arch Bone Jt Surg* 2015;3:56-63.
29. Hagenaars AK, de Vos K, Zaidi MA, editors. Poverty statistics in the late 1980s: research based on micro-data. Luxembourg: Office for Official Publications of the European Communities; 1994.
30. Schofield HL, Murphy B, Herrman HE, Bloch S, Singh B. Family caregiving: measurement of emotional well-being and various aspects of the caregiving role. *Psychol Med* 1997;27:647-57.
31. Pierce GR, Sarason IG, Sarason BR. General and relationship-based perceptions of social support: are two constructs better than one? *J Pers Soc Psychol* 1991;61:1028-39.
32. Reiner I, Beutel M, Skaletz C, Braehler E, Stobel-Richter Y. Validating the German version of the Quality of Relationship Inventory: confirming the three-factor structure and report of psychometric properties. *PLoS One* 2012;7:e37380.
33. Post MW, Bloemen J, de Witte LP. Burden of support for partners of persons with spinal cord injuries. *Spinal Cord* 2005;43:311-9.
34. Tobin J. Estimation of relationships for limited dependent variables. *Econometrica* 1958;26:24-36.
35. Baron RM, Kenny DA. The moderator—mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. *J Pers Soc Psychol* 1986;51:1173.
36. Cameron AC, Windmeijer FA. An R-squared measure of goodness of fit for some common nonlinear regression models. *J Econom* 1997;77: 329-42.
37. White I, Royston P, Wood A. Multiple imputation using chained equations: issues and guidance for practice. *Stat Med* 2011;30:377-99.
38. Rubin DB. Multiple imputation for nonresponse in surveys. Hoboken: John Wiley & Sons; 2004.
39. Snyder JR. Impact of caregiver-receiver relationship quality on burden and satisfaction. *J Women Aging* 2000;12:147-67.
40. Horowitz A, Shindelman LW. Reciprocity and affection: past influences on current caregiving. *J Gerontol Soc Work* 1983;5:5-20.
41. Kiesler CA. The psychology of commitment. New York: Academic Press; 1971.
42. Holicky R, Charlifue S. Ageing with spinal cord injury: the impact of spousal support. *Disabil Rehabil* 1999;21:250-7.
43. Shackelford M, Farley T, Vines CL. A comparison of women and men with spinal cord injury. *Spinal Cord* 1998;36:337-9.
44. Rodakowski J, Skidmore ER, Rogers JC, Schulz R. Role of social support in predicting caregiver burden. *Arch Phys Med Rehabil* 2012; 93:2229-36.
45. Bakas T, Lewis RR, Parsons JE. Caregiving tasks among family caregivers of patients with lung cancer. *Oncol Nurs Forum* 2001;28: 847-54.