Dimension-specific burden of caregiving among partners of rheumatoid arthritis patients

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Objectives. To assess subjective caregiver burden among partners of rheumatoid arthritis (RA) patients and to identify partner and patient variables and objective caregiver burden related to subjective caregiver burden.

Methods. In 2001, 134 patients diagnosed with RA and their caregiving partners participated in a postal questionnaire survey. Information was gathered on age, gender and health problems of patient and partner, disease duration of the patient, objective caregiver burden and subjective caregiver burden of the partner (using the multidimensional Caregiver Reaction Assessment). Correlation coefficients were computed between the subjective caregiver burden dimensions. Multivariate analyses were performed to identify variables that explained the variation in subjective burden.

Results. Partners of RA patients derived, on average, a high level of self-esteem from giving care. Negative subjective caregiver burden was to a large degree caused by a disrupted schedule and to a smaller degree by a lack of family support, financial problems and loss of physical strength. Problems of the partner with mobility or with pain/discomfort and problems of the patient with self-care activities and activities of daily life had the largest impact on negative levels of subjective caregiver burden.

Conclusions. Health parameters of the patient and partner have a considerable predictive value for the development of high levels of subjective burden in partners of RA patients. Support strategies should be developed for partners of RA patients, and should focus especially on reducing the burden caused by a disrupted schedule, and simultaneously on increasing the focus of caregivers on the positive aspects of caregiving.

KEY WORDS: Rheumatoid arthritis, Partners, Caregiver burden, Impact of caregiving, Informal care, Multidimensional burden of caregiving.
The physical impairments and disabilities of patients with RA often impede the performance of activities of daily living (ADL), resulting in the use of a wide variety of health-care services. Additionally, many RA patients need care and help at home, which is mostly provided by informal caregivers. The slow, progressive nature of the disease creates long-term dependency on family and friends. Spouses or partners, in particular, are expected to bear a large proportion of the burden of caregiving.

The concept of caregiver burden has been investigated widely, both in general and among caregivers of specific groups of patients. Studies in this field reveal that caring for an individual with disability is burdensome and stressful, which contributes to lower quality of life, psychiatric morbidity and early mortality of the caregiver.

Previous studies have investigated variables that could explain or predict the burden as perceived by caregivers. It has been shown that caregiver burden can be explained or predicted by three types of factor: patient characteristics, caregiver characteristics and objective caregiver burden, e.g. the number of care tasks to perform. The relation between caregiver burden and these factors has been studied for caregivers of mentally ill patients, stroke patients, cancer patients and RA patients. The association between caregivers’ age and caregiver burden yielded mixed findings. Some studies found that younger caregivers experienced a greater burden than older caregivers, while in others no association between caregivers’ age and caregiver burden could be determined. Regarding caregivers’ gender, educational level and family income, no relation with caregiver burden was found for informal caregivers of mental patients and stroke patients, while among informal caregivers of cancer patients high caregiver burden was associated with low family income. Furthermore, higher caregiver burden was associated with decreased physical health of the patients, caregivers’ depression, and the amount of care provided. It was found that caregiver burden was lower if professional support was received.

Regarding caregiver burden in RA, a greater caregiver burden was associated with worse mental health of both the patient and the caregiver, and lower health status of the patient, with worse expectancies of arthritis-related symptom control. Furthermore, higher caregiver burden was associated with decreased physical health of the patients, caregivers’ depression, and the amount of care provided. It was found that caregiver burden was lower if professional support was received.

The disease duration of the patient was identical to that for the partner. Disease duration. The disease duration of the patient was abstracted from the patient’s file.

Data collection

Data were collected by two self-report questionnaires, one for the partner and one for the patient. Information on disease duration was abstracted from the patients’ files.

Partner variables

Sociodemographic characteristics. Sociodemographic characteristics were age and gender.

Health status. Health was assessed with the EuroQoL questionnaire, which consists of five dimensions of health (mobility, self-care activities, ADL, pain/discomfort, and anxiety/depression), each with three answers: ‘no problems’, ‘moderate problems’ and ‘extreme problems’. Because of low numbers in the ‘extreme problems’ category, the answering categories of each of the dimensions were recoded for analyses into 0 (no problems) and 1 (moderate or extreme problems).

Patient variables

Sociodemographic characteristics and health status. The assessment of the sociodemographic characteristics and health status of the patient was identical to that for the partner.

Disease duration. The disease duration of the patient was abstracted from the patient’s file.

Professional home care. Patients were asked whether they received professional home care (yes/no), and whether they were on a waiting list for professional home care (yes/no).
Objective caregiver burden

The objective caregiver burden consisted of the tasks required to care for the patient (care tasks, home tasks, help tasks), time spend on these tasks, care duration and the number of care days a week.

Care tasks comprised ‘help with personal care’, ‘help with toilet care’, ‘help with moving indoors’ and ‘help with eating/drinking’. Home tasks included ‘fixing food or drinks’, ‘house cleaning’, ‘doing laundry/ironing/sewing’ and ‘shopping’. Help tasks were ‘help with moving outdoors’, ‘accompanying or helping with visits or day trips’, ‘accompanying or helping with health-care visits’, ‘taking care of adaptations in the home’, and ‘financial business’. Partners were asked whether they performed any care tasks (yes/no), any home tasks (yes/no) or any help tasks (yes/no) and how much time they spent on these tasks. Time per type of task was summed to compute a total time score. Care tasks were determined in minutes per day, and home tasks and help tasks in hours per day.

Care duration was defined as the total time in years for which the partner gave care to the patient. Care days referred to the number of days per week on which the partner performed care tasks, home tasks or help tasks.

Subjective caregiver burden

Subjective caregiver burden was assessed with the Dutch version of the CRA [16, 20]. The CRA was developed and validated in the USA among caregivers of persons with all types of chronic physical and mental impairments [16], and the Dutch version was also found to be valid among caregivers of colorectal cancer patients [20]. The CRA consists of 24 items on five dimensions that assess both the positive (‘care-derived self-esteem’) and the negative (‘lack of family support’, ‘financial problems’, ‘disrupted schedule’ and ‘loss of physical strength’) burden of caregiving, as described in Table 1. Each item is rated on a five-point scale, ranging from ‘strongly disagree’ to ‘strongly agree’. For each dimension, a total score was computed as the average of the item scores, ranging from 1.0 to 5.0. A score of 1.0 represents ‘no derived self-esteem’ on the positive dimension, and ‘no burden’ on the negative dimensions.

Statistics

All analyses were performed using SPSS 10.0 for Windows (SPSS, Chicago, IL, USA). Frequency tables and descriptive statistics were assessed for all variables. To determine the relation between each of the five dimensions of subjective caregiver burden, the Spearman correlation statistic (\(\rho\)) was computed. We defined correlations of \(\rho \geq 0.4\) as being relevant for reporting in the text.

To be able to interpret the absolute outcome values of the CRA, these values were compared with those of informal caregivers of patients with other chronic illnesses, namely cancer patients [21] and patients with dementia [22]. These other CRA values were abstracted from the literature.

To identify the effect of the variables mentioned above on subjective caregiver burden, a multivariate linear regression model was built for each of the five dimensions of subjective caregiver burden. By stepwise regression, partner variables, patient variables and objective caregiver burden variables were selected as the independent variables. Variables were included in the model if their contribution to the model was statistically significant (if \(P < 0.05\)). A maximum of six variables was accepted in each model. The effect sizes are expressed as the beta (\(\beta\)) value, i.e. the regression coefficient of the linear model, and the 95% confidence interval (CI).

Results

Study population

Of the 683 eligible patients, 33 were lost because of relocation to an unknown address (\(n = 12\)) and death (\(n = 21\)). Of the remaining 650 patients, 242 (37.2%) received informal care from their partner. Of these caregiving partners, 134 (55.4%) responded. No significant differences regarding age and disease duration were found between patients for whom the partner had responded and patients for whom the partner had not responded. Partners of female patients were more likely to respond than partners of male patients (\(\chi^2 = 39.3, P < 0.001\)). Patients for whom the partner had responded significantly more often had problems with mobility (\(\chi^2 = 32.6, P < 0.001\)), self-care activities (\(\chi^2 = 27.3, P < 0.001\)) and ADL (\(\chi^2 = 31.9, P < 0.001\)), and suffered more often from pain/discomfort (\(\chi^2 = 18.2, P < 0.001\)) than patients for whom the partner had not responded. No differences could be found for anxiety/depression between these two patient groups (\(\chi^2 = 2.9, P = 0.089\)).

Table 1. Dimensions of the Caregiver Reaction Assessment (CRA) [16]

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Type</th>
<th>No. of items</th>
<th>Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care-derived self-esteem(a)</td>
<td>Positive</td>
<td>7</td>
<td>The extent to which caregiving imparts individual self-esteem</td>
</tr>
<tr>
<td>Lack of family support(a)</td>
<td>Negative</td>
<td>5</td>
<td>The extent to which the family supports and works together with the caregiver</td>
</tr>
<tr>
<td>Financial problems(a)</td>
<td>Negative</td>
<td>3</td>
<td>The adequacy, difficulty and strain of the financial situation for the caregiver and the family</td>
</tr>
<tr>
<td>Disrupted schedule(a)</td>
<td>Negative</td>
<td>5</td>
<td>The extent to which caregiving interrupts usual activities, causes the elimination of some activities and interferes with relaxation time</td>
</tr>
<tr>
<td>Loss of physical strength(a)</td>
<td>Negative</td>
<td>4</td>
<td>The caregiver’s physical capability and energy to provide care</td>
</tr>
</tbody>
</table>

\(a\)Scores range from 1 to 5 on each dimension. Higher scores represent higher derived self-esteem on the positive dimension and higher burden on the negative dimensions.
The characteristics of patients and their partners are shown in Table 2. The mean age of the patients (n = 134) was 61.9 yr (range 28.1–87.0 yr; s.d. 13.0) and that of their partners was 62.7 yr (range 32.5–86.8; s.d. 12.9). Women constituted 84.3% of the patients (n = 113). The mean disease duration of the patients was 12.7 yr (range 3.0–59.8; s.d. 9.0). Only three patients (3.8%) were on a waiting list for this service.

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Table 4. Subjective caregiver burden (CRA) among partners of RA patients (n = 134), partners of patients with colorectal cancer (n = 148) [21] and informal caregivers of patients with dementia (n = 93) [22]; data are mean (95% CI)

<table>
<thead>
<tr>
<th>CRA dimension</th>
<th>RA (n = 134)</th>
<th>Dementia (n = 93)</th>
<th>Colorectal cancer (n = 148)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-esteem (+)</td>
<td>4.21 (4.10–4.32)</td>
<td>3.73 (3.61–3.85)</td>
<td>4.19 (4.12–4.26)</td>
</tr>
<tr>
<td>Lack of family support</td>
<td>2.50 (2.32–2.68)</td>
<td>n.a.</td>
<td>2.10 (2.00–2.20)</td>
</tr>
<tr>
<td>Financial problems</td>
<td>2.36 (2.15–2.57)</td>
<td>n.a.</td>
<td>1.82 (1.74–1.90)</td>
</tr>
<tr>
<td>Disrupted schedule</td>
<td>3.28 (3.19–3.37)</td>
<td>3.21 (3.00–3.42)</td>
<td>1.88 (1.78–1.98)</td>
</tr>
<tr>
<td>Loss of physical strength</td>
<td>2.27 (2.08–2.46)</td>
<td>2.68 (2.48–2.88)</td>
<td>1.98 (1.88–2.08)</td>
</tr>
</tbody>
</table>

(+), positive dimension.  
n.a., not assessed.

Impact of partner, patient and objective burden variables on subjective caregiver burden

The amount of variance explained ($R^2$) by the multivariate regression models varied from 21.5% for self-esteem to 49.5% for loss of physical strength (Table 5). Giving care to a patient with RA decreased the self-esteem of the partner if the patient had problems with ADL ($\beta = -0.534$; 95% CI -0.770, -0.297) and if the patient received home care ($\beta = -0.330$; 95% CI -0.575, -0.086) (Table 5).

Lack of family support caused a greater burden if the partner had problems with mobility ($\beta = 0.803$; 95% CI 0.402, 1.204), if the partner had problems with self-care activities ($\beta = 0.709$; 95% CI 0.334, 1.085), if the partner performed help tasks ($\beta = 0.542$; 95% CI 0.030, 1.053), and as the number of care days a week was higher ($\beta = 0.150$; 95% CI 0.057, 0.242). This burden was lower if more time was spent on home tasks ($\beta = 0.115$; 95% CI 0.192, -0.038).

Financial problems resulted in a greater subjective burden if the partner reported problems with mobility ($\beta = 1.012$; 95% CI 0.524, 1.500) and if the patient had problems with self-care activities ($\beta = 0.755$; 95% CI 0.336, 1.174). The scores on this dimension, however, decreased as the age of the patient increased ($\beta = -0.026$; 95% CI -0.043, -0.010).

The schedule of the partner was more disrupted with lower age of the patient ($\beta = -0.008$; 95% CI -0.015, -0.001), if the partner performed care tasks ($\beta = 0.310$; 95% CI 0.122, 0.497) and help tasks ($\beta = 0.479$; 95% CI 0.210, 0.748) and with increasing number of care days per week ($\beta = 0.083$; 95% CI 0.037, 0.130).

Loss of physical strength of the caregiver was higher if the partner had problems with mobility ($\beta = 0.835$; 95% CI 0.403, 1.267) or suffered from pain/discomfort ($\beta = 0.722$; 95% CI 0.335, 1.110), if the patient had problems with self-care activities ($\beta = 0.474$; 95% CI 0.127, 0.820) or ADL ($\beta = 0.596$; 95% CI 0.068, 1.124), and if the partner performed help tasks ($\beta = 0.516$; 95% CI 0.032, 1.000).

Discussion

We investigated the extent of subjective burden among partners of patients with RA on various dimensions. We found that caregiver burden is common among partners of patients with RA, and we identified partner and patient variables and objective caregiver burden variables that explained the variation in subjective caregiver burden.

Partners derived, on average, high self-esteem as a result of giving care. The dimension ‘self-esteem’ measures the extent to which caregiving imparts self-esteem, which implies that partners found, to a large extent, positive aspects in providing care. Negative aspects of subjective caregiver burden were to a large degree caused by a disrupted schedule and to a smaller degree by a lack of family support, financial problems and loss of physical strength. Given the results of the correlation analyses, patients who reported higher self-esteem perceived fewer financial problems and less loss of physical strength.

In comparison with caregivers of patients with dementia [22], partners in our study experienced higher levels of self-esteem and loss of physical strength, but a similar level of burden as a result of disrupted schedule. The relatively high levels of burden on the ‘loss of physical strength’ dimension among partners of RA patients could be caused by the way caregiver and patient were related. Our study focused on the partners of patients with RA, whereas in the study among caregivers of dementia patients the caregivers were related to the patient in various ways, such as partner, adult offspring, other family member and friend, and only 24% lived with the patient. Not living with the patient might result in less loss of physical strength, which is in concordance with previous results that caregivers who live with the patient experience a greater burden than caregivers who do not [23]. Nijboer et al. [21] studied burden levels of caregiving partners of colorectal cancer patients up to 6 months after discharge of the patient from hospital. Compared with the burden levels of the partners of these cancer patients, partners of RA patients derived a similar level of self-esteem but higher levels on all four negative burden dimensions. Partners in our study provided care for a longer period than the partners of the cancer patients (i.e. 11.4 yr vs a maximum of 6 months). Negative experiences resulting from giving care may increase as the duration of care provision increases.

We found that health variables of partner and patient, as measured with the EuroQoL questionnaire [19], and objective burden variables could explain a
Table 5. Impact of partner and patient variables and objective caregiver burden on the subjective caregiver burden among caregiving partners (n = 134) of patients with RA (multivariate stepwise regression)

<table>
<thead>
<tr>
<th></th>
<th>Subjective caregiver burden</th>
<th>Lack of family support</th>
<th>Financial problems</th>
<th>Disrupted schedule</th>
<th>Loss of physical strength</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>β (95% CI)*</td>
<td>β (95% CI)*</td>
<td>β (95% CI)*</td>
<td>β (95% CI)*</td>
<td>β (95% CI)*</td>
</tr>
<tr>
<td>Variance explained (R²)</td>
<td>21.5%</td>
<td>36.6%</td>
<td>27.5%</td>
<td>32.0%</td>
<td>49.5%</td>
</tr>
<tr>
<td>Partner variables**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EuroQoL Mobility: problems</td>
<td>-0.534 (–0.770, –0.297)$</td>
<td>0.803 (0.402, 1.204)$</td>
<td>1.012 (0.524, 1.500)$</td>
<td>0.835 (0.403, 1.267)$</td>
<td></td>
</tr>
<tr>
<td>ADL: problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Pain/discomfort: present</td>
<td>-0.008 (–0.015, –0.001)§</td>
<td>0.722 (0.335, 1.110)$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient variables**</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-0.026 (–0.043, –0.010)‡</td>
<td>-0.008 (–0.015, –0.001)§</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EuroQoL Self-care: problems</td>
<td>0.709 (0.334, 1.085)$</td>
<td>0.755 (0.336, 1.174)$</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>ADL: problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Receiving professional home care</td>
<td>-0.330 (–0.575, –0.086)‡</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Objective burden**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregivers performing care tasks</td>
<td></td>
<td></td>
<td>0.310 (0.122, 0.497)$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time spent on home tasks</td>
<td>-0.115 (–0.192, –0.038)‡</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregivers performing help tasks</td>
<td>0.542 (0.030, 1.053)$</td>
<td>0.479 (0.210, 0.748)$§</td>
<td>0.516 (0.032, 1.000)$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care days per week</td>
<td>0.150 (0.057, 0.242)$</td>
<td>0.083 (0.037, 0.130)$§</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(+) positive dimension.
*β, coefficient of linear regression model; 95% CI, 95% confidence interval of regression coefficient.
**Variables that were not accepted in any of the models are not shown in the table.
***P ≤ 0.05; ‡P ≤ 0.01; $P ≤ 0.001.
considerable part of the variance (21.5–49.5%) of all five dimensions of subjective caregiver burden, as assessed with the CRA. Problems of the patient with self-care activities and ADL and problems of the partner with mobility or pain/discomfort had a very large impact on negative levels of subjective caregiver burden. It is to be expected, therefore, that these health parameters of both patient and partner will have a considerable predictive value for the development of high levels of subjective caregiver burden in partners of RA patients. These findings are in concordance with the results of Chenier [24], who has shown in a review that decreased functional abilities of the patient was positively correlated with caregiver burden. Moreover, in our study group, more than 20% of the partners suffered from moderate or extreme anxiety/depression and almost 50% suffered from moderate or extreme pain/discomfort, which might, at least partly, indicate the straining effect of providing long-term care.

Age and gender of the partner had no influence on subjective caregiver burden. Previously, it was shown that younger caregivers experience greater burden than older caregivers [25] and that women exhibit greater burden than men [25–27]. Our results, however, could not confirm these findings. It is notable that we had relatively more male caregivers in our study than the other studies had.

In general, studies investigating caregiver burden among partners, adult children, other relatives and friends, each caring for elderly or chronically ill patients, have shown considerable burden levels in these caregivers. If we apply our findings to the general Dutch population [28], informal caregiving would concern almost 80 000 informal caregivers in the Netherlands, for RA only. It is expected that caregiver burden will increase significantly in the years to come, due to the ageing of the population, the ensuing rise of chronic patients and the shortage of personnel in nursing and caring professions in The Netherlands [29].

The shift of health-care to the ambulatory care setting has resulted in a dramatic increase in the burden placed on a patient’s family. Despite this, caregiver burden is greatly underidentified by, for instance, primary care physicians [30]. Although researchers have not reached consensus on the effect of caregiving on the caregiver’s long-term health [31], it was shown that informal caregivers who report a burden are at greater risk of adverse health outcomes [8, 10–13, 15]. Family physicians should, therefore, be aware of negative signals from informal caregivers to prevent them becoming patients themselves. As an example of an initiative to support informal caregivers, several years ago a new organization was founded in The Netherlands as a support group for informal caregivers [32]. This organization [Landelijke Organisatie van Mantelzorgers (LOT)] was founded to support informal caregivers and help them when problems arise, exist or increase.

Some remarks on our results are necessary. First, because most of the caregiving partners in our study were male (82.1%) and some studies have shown that female caregivers perceive greater burden [10–12], our results might present an underestimation of the caregiver burden. Secondly, many caregiving partners did not respond, while the patients they cared for did respond. On the one hand, these partners might have perceived high levels of caregiver burden and, hence, could not find the time or strength to participate in the questionnaire survey. This might have led to underestimation in our results. On the other hand, these non-responding partners might have perceived caregiving to the patient as self-evident, which might have led to overestimation in our results. Thirdly, the CRA provides no overall burden score, which makes it difficult to reach a conclusion regarding overall caregiver burden. Moreover, no cut-off point for substantial burden is available for the CRA, which makes it difficult to distinguish between groups of informal caregivers with and without substantial burden. Fourthly, the RA patients included in this study might have suffered from comorbidity, as many patients with RA report comorbidity [33–35]. We are, therefore, unable to conclude that the levels of caregiver burden observed among the partners of these RA patients are solely attributable to RA and not also to other illnesses. Fifthly, previous studies on informal care in RA have shown that various psychological factors, such as self-efficacy, coping and feelings of optimism and pessimism, influence caregiver burden [14, 15]. In this study we did not elaborate on these psychological factors, but focused on more objective variables in relation to subjective caregiver burden.

In conclusion, partners found, to a large extent, positive aspects of providing care to the RA patient. Negative aspects of subjective caregiver burden were predominantly caused by a disrupted schedule and to a smaller degree by a lack of family support, financial problems and loss of physical strength. In addition, partners who derived greater self-esteem from caregiving perceived fewer financial problems and less loss of physical strength. Problems of RA patients in self-care or ADL are to a large extent related to higher negative levels of caregiver burden among partners.

The results of this study could be used for identifying partners at risk of high negative burden and may lead to the development of support strategies to prevent or decrease high levels of negative caregiver burden and to increase the focus of caregivers on the positive aspects of caregiving. Preventing or decreasing high levels of negative caregiver burden is necessary, because caregiver burden contributes to adverse health outcomes [8, 10–13, 15]. Changing the focus of caregivers towards positive aspects of caregiving results in lower levels of depression, lower levels of negative caregiver burden and better self-assessed health in the caregiver [36]. Further research may help to establish evidence-based interventions by developing either specific support strategies for caregiving partners of patients with RA or specific care programmes for RA patients. Such interventions may strengthen the sustainable care provided at home.
Acknowledgements

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Conflict of interest

The authors have declared no conflicts of interest.

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31. Given B. If caring for a spouse with disabilities involved self reported strain, caregiver mortality was increased: commentary. Evid Based Nurs 2000;3:90.