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The Impact of Chronic Diseases: the Partner's Perspective

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A chronic physical disease not only has direct consequences for the chronically ill person but can also distort the life of the healthy partner. This study of a representative sample of chronically ill persons and their partners in the Netherlands presents quantitative information on the proportion of partners who experience consequences in 4 distinguished areas (personal life strain, social relations, financial burden, and intrinsic rewards) and provides insight into the factors related to this. Data were derived from a subsample (N=1,093) of participants in the Dutch Panel of Patients With Chronic Diseases. Linear regression analysis was used to determine the relative effect of caregiving and of disease characteristics to explain the variance in the 4 impact factors. The most prevailing consequences, experienced by more than half of the partners, were related to personal life strain and intrinsic rewards. An impact on social relations and financial situation was reported by 20% of the partners. The regression analyses showed that the time spent on caregiving is the main predictor for all 4 impact measures in this study. However, the findings also make clear that the impact on the partner's life does not arise entirely from the amount of caregiving. An independent effect of specific disease characteristics is observed in addition to the effect of caregiving; that is, we found that physical impairments in the patient are related to higher personal life strain and higher financial burden whereas social impairments are related to higher impact on all 4 factors. When the patient's disease is accompanied with fatigue, the partner reports higher impact on personal life, on social relations, and on intrinsic rewards, and pain significantly affects the partner's social relations. Partners of patients with cancer, musculoskeletal, or digestive disorders are more vulnerable for the consequences of the chronic disease. The impact on female partners is higher

for all 4 impact factors. The findings make clear that living with a chronically ill person has an impact on the partner's life that goes beyond the consequences of caregiving.

It is increasingly recognized that a chronic somatic disease not only has various consequences for the patient's life but also has implications for those who live with the chronically ill, particularly the partner. Several studies have been conducted to identify the areas in which the partner's life may be affected. Aspects frequently mentioned include consequences for social relations, financial position, recreational and leisure activities, working arrangements, flexibility, as well as positive aspects such as increased self-esteem and feelings of closeness.

Most studies conducted in this area are exploratory and descriptive in nature, aimed at identifying a broad spectrum of possible consequences.¹⁻⁵ They do not indicate how many of the partners are actually confronted with the identified consequences, thus leaving unclear whether it is pressing for many or for relatively few people. On the other hand, there are numerous psychologic studies that investigate more distal outcome measures, such as the physical or psychological well-being of the partner or quality of life.⁶⁻¹³ These, however, do not specify in what respects the lives of partners are challenged or affected.

In addition, there is a line of existing literature that specifically focuses on the burden of care as the main consequence for partners of a chronically ill person. The underlying viewpoint is that partners of chronically ill people are directly affected because they face an increase in caregiving responsibilities toward the chronically ill person, which, in contrast to acute illnesses, is long-lasting and often progressive in nature. Most of these studies have investigated how specific disease characteristics, such as type and stage of the disease or the resulting functional disabilities, define the burden of care.^{11,12,14,15} However, they do not explore consecutively in what ways the burden of care actually changes the lives of the caregiving partners. Moreover, it can be argued that a chronic somatic disease may have an additional independent effect on the partner's life that cannot be retraced to the burden of giving care (Fig 1). After all, certain manifestations of a chronic disease may not necessarily lead to more caregiving, but are certainly likely to interfere with the partner's life. For instance, the unpredictability of the patient's condition or the anticipation of possibly bad days may force partners to set aside their own needs, reorganize their lives in advance, or it may hinder personal achievements. Such direct effects on the partner's lives remain unobserved when focusing on the role of caregiving only, whereas they may call for other solutions to support the partner.

The aims of this study were 2-fold. The first aim was to investigate in what areas and to what extent partners of persons with a chronic somatic disease are confronted with specific consequences in daily life. The second aim was to investigate what factors are related to the prevalence of these consequences.

More specifically, analyses were aimed at revealing to what extent the impact on the partner's life could be attributed mainly to the amount of caregiving (which is influenced by disease characteristics) and to what extent certain disease characteristics exert an additional independent factor when the effect of caregiving is controlled for. Insight into these relationships will provide information about the elements that determine the impact on a partner, as well as help us identify patient-partner dyads that are most vulnerable for the consequences of a chronic disease.

This also gives an indication of the factors that should be addressed to prevent the risk of increasing health disparities between households due to a chronic disease. This study focused on chronic physical diseases and did not include chronic mental diseases.

DATA AND MEASUREMENTS

Data

The data for this study were collected within the framework of the Panel of Patients with Chronic Diseases, a longitudinal study of persons 15 years and older, diagnosed by a medical practitioner with a chronic (ie, noncurable or long-lasting) physical disease.¹⁶ Respondents for the panel, who were invited to participate via a random sample of 51 general practices in the Netherlands, applied in 2001 by sending in a written consent to participate in the research program. Twice a year, participants of the panel received postal questionnaires. In April 2003, an additional questionnaire was sent to be handed out to the partner of the participant or, in case no partner was present, to someone else close to the participant. Of the 1,750 respondents returning their questionnaire (response rate=83%), 1,364 indicated living with a partner.

Of these, 214 (16%) did not return the partner-questionnaire and 57 questionnaires were filled out by someone other than the partner. Therefore, data for 1,093 patient– partner dyads were included in this study.

[FIGURE 1]

With respect to gender, age, diagnosis, disease duration, comorbidity, and subjective health of the patient, the sample does not differ from the total panel sample of respondents with a partner. The sample can therefore be considered representative for the Dutch population of chronically ill with a partner.

Independent variables

Information on the independent variables for this study was derived both from the questionnaires for panel participants and the questionnaires for their partners. First of all, with respect to the background variables, questions to the partners regarding their age, gender, highest level of education, and engagement in paid labor were included. The latter aspect was also available for the chronically ill person. Information on the labor market participation of both the patient and the partner was then combined to assess the socioeconomic position of the household. Five categories were distinguished: both employed, just the partner employed, just the patient employed, neither employed, and both or partner retired.

Partners were also asked about their involvement in specific caregiving tasks, using a standard list of daily living activities and household tasks.¹⁴ Objective burden of care was assessed by summing the number of hours per week the partner is engaged in providing either personal or domestic care to the patient or both. Missing data for hours of caregiving per week were calculated by the mean number of hours found for groups with a similar amount of tasks. Personal care activities and domestic care activities were calculated separately.

To investigate the effect of the chronic disease, variables pertaining to the type and characteristics of the disease were included as independent variables. Disease diagnosis and duration since diagnosis were registered by the general practitioner, and could thus be considered objective reliable measures for the chronic illness. Diagnosis has been classified according to the official International Classification of Primary Care codes.¹⁷ In the case of comorbidity, the disease first diagnosed was used as the index disease.¹⁸ In the following analyses, several International Classification of Primary Care categories have been merged, resulting in a classification of 8 diagnostic categories.

Several rare diseases that do not fall into each of the 8 main disease categories have been combined under the category of “other diseases.” Disease characteristics as perceived by the chronically ill person are measured by means of a validated list of 8 items, reflecting the consequences or “disease stressors” one has to cope with when having a chronic disease.^{19,20} The 8 variables relate to stressful physical and mental consequences of the chronic disease that may occur: (1) threat of life, (2) progressive or (3) fluctuating course of the disease, (4) fatigue or (5) pain, and to stressful consequences of the disease in terms of impaired (6) physical, (7) mental, and (8) social functioning.

Construction of the dependent variables

To measure the dependent variables in this study—that is, the areas in which the partner's life is affected—an adjusted version of the validated Impact on Family Scale²¹ was adopted.

Some items were omitted from the original scale because they typically refer to the presence of a chronically ill child in the family.

On the other hand, some items were added to cover aspects that are relevant in an adult relationship (such as responsibility for household chores). The resulting Impact-on-Partner Scale comprised 25 items. Respondents were asked to indicate on a 4-point Likert-type scale (ranging from strongly agree to strongly disagree) to what extent they feel that the stated consequence applies to them. Considering that specific items were irrelevant to some respondents (eg, the items concerning paid work), the response category “not applicable” was added in the questionnaire. In the analyses, this category was merged with the disagree category, since obviously an illness cannot have an impact in an area that is not encountered. Furthermore, as the frequency distribution of the items was skewed, the items were dichotomized to reflect the presence or absence of the impact, that is, the response categories “(strongly) disagree” reflect absence and “(strongly) agree” reflects presence.

To construct intrinsically meaningful variables reflecting the areas in which partners experience an impact on their lives, explorative factor analysis with varimax rotation was performed on the dichotomized variables in 2 steps. The first step, including all 25 items, found 4 factors. Two items with factor loadings below 0.50 (fatigue and time lost from work) and 1 item cross-loading on 2 factors (less social contacts) were removed.

Then factor analysis was performed once again, which produced 4 factors explaining 56% of the variance. The resulting factor structure and factor loadings are given in Table 1. The internal reliability of each scale (Cronbach's α) is sufficient. The first factor, termed personal life strain, reflects limitations in time and restricted flexibility in personal life. The second factor, social relations, refers to the disruption of social relationships and social interaction. The third factor concerns the intrinsically positive aspects that partners experience. And the fourth factor, financial burden, refers to the economic consequences the partner perceives. These factors constitute the 4 dependent variables. The underlying dimensions are comparable to the original Impact on Family Scale factors, which support the validity of the impact variables. For the analyses, factor scores were computed for each of the 4 dependent variables by summing the item scores (0 or 1) and dividing it by the number of items constituting that factor.

A score higher than zero implies that the partner is affected by the chronic disease in this area; a score of zero implies that the chronic disease does not affect the partner in this area.

Analysis

To meet the first aim of this study and to identify to what extent partners of chronically ill persons experience an impact on their lives, the prevalence of each impact variable was determined separately by computing the percentage of partners with a score higher than zero on the impact variable relative to the ones with score zero.

With regard to the second research question, which aimed to assess the relative independent effects of disease characteristics, background variables, and the time spent on caregiving on the impact variables, multiple linear regression analyses were performed with the 4 impact variables as separate outcome variables. In the regression analyses, the summed score on the respective impact variables was used (interval scale). Categorical predictor variables were included as dummy variables. Standardized β -coefficients were presented to allow comparison of the relative effect of the predictor variables. As we aimed to disentangle the effect of caregiving and possibly the additional independent effect of disease characteristics, 2 consecutive models were assessed. In the first model, disease characteristics were included to assess their effect on the impact variables when the role of caregiving is not explicitly accounted for. In the second model, amount of time spent on caregiving was also added as predictor variable so as to find out to what extent the effect of disease characteristics is absorbed in the effect of caregiving (or, in other words, actually reflect an effect of caregiving) and to what extent disease characteristics exert an independent effect in addition to the effect of caregiving. If the effect of disease characteristics disappears when caregiving is included, this is interpreted as an indication that the impact of a chronic disease on the partner primarily stems from caregiving and that the effect of disease characteristics only operates through their effect on caregiving. If, however, the β -coefficient for a disease characteristic in the second model remains practically similar to that in the first model, it can be concluded that this characteristic has an additional independent effect that has nothing to do with caregiving. In both models, sociodemographic characteristics of the partner were included to control for the confounding effect of these covariates. Sociodemographic characteristics of the patient were not entered as separate predictors, because they were almost fully correlated to those of the partner.

[TABLE 1]

RESULTS

[TABLE 2]

Table 2 presents the description of the study sample for the main independent variables.

Informal care was provided on an average of 11 hours per week for the majority of the sample. Half of the partners giving care were involved in care activities for less than 6 hours a week. The informal care

predominantly concerned domestic care (60%) or a combination of both domestic and personal care (36%), whereas providing just personal care was rare (4%).

Table 3 presents consequences resulting from living with a chronically ill person. More than half of the partners felt that the chronic disease of their mate puts a strain on their personal life in one way or the other. Consequences for their social relations or financial situation were reported less frequently.

[TABLE 3.]

About 1 of 5 partners indicated that they encounter implications in these areas as a result of their mate's chronic disease. On the other hand, it is striking to see that as much as two thirds of the partners discovered intrinsically rewarding aspects in living with a chronically ill person. In general, for those with positive scores on a certain impact factor, the impact appears to be rather mild. But for some of the partners, the consequences pertaining to a specific domain manifest themselves in numerous ways; that is, they responded affirmative to several items of the factor. Moreover, the results in the last 3 columns of Table 3 show that the perceived impact is not always confined to one domain only. About one fifth of the partners who reported an impact on their personal life also encountered changes in their social relations (19.7%), or experienced financial consequences (17.9%), and 1 in 10 encountered a combination of both social and financial consequences. Almost 9% reported consequences in personal, social, and financial aspects. However, most partners did not meet negative consequences only. Most of them simultaneously experienced intrinsically positive effects. For instance, more than 40% not only did experience a strain on their personal life but, at the same time, also felt intrinsic rewards. The proportion of partners reporting no consequences in any of the identified areas is limited to 23%.

To identify to what extent the strength of the impact variables is mainly attributable to caregiving or to disease characteristics as well, regression analyses were then performed.

A higher score on the impact variable implies that the partner reported an impact on this dimension in several ways, and thus experienced a stronger impact. The results for the impact variables "personal life strain" and "social relation" are given in Table 4, and results for "financial burden" and "intrinsic rewards" in Table 5.

The results of the first regression model show that personal strain is significantly increased when the patient's disease is lifethreatening or is accompanied by physical, social, or mental impairments or by fatigue. The personal life strain is also significantly higher for partners of patients with cancer and for women and for couples who are both unemployed.

When the number of hours of caregiving is added as the predictor variable (model 2), it becomes clear that caregiving is the most decisive variable determining the personal life strain, but that most of the above-mentioned disease characteristics also maintain an additional independent effect. Yet, the relative effect size of physical impairments decreases when caregiving is controlled for in the second model and the effects of life threat and mental impairments are no longer significant.

This implies that basically the effect of these 3 variables rests on more caregiving activities.

This, however, is not the case for social impairments and fatigue. Their effect on the partner's life does not run via increased caregiving.

[TABLE 4]

In general, the same can be concluded about variables related to the impact on social relations (Table 4, last 2 columns). Here, too, caregiving demands exert the strongest influence, but some of the disease characteristics have an independent effect in addition to that of caregiving. That is, the impact on the social relations of the partner significantly increases when the ill mate has social impairments, or suffers from pain or fatigue.

[TABLE 5].

Also, the social impact is significantly higher for women and for partners with labor market obligations. What is more, as the β -coefficients of these variables in the first and second models are comparable, it can be concluded that their effect does not stem from caregiving tasks.

The financial burden appears to be higher for partners of patients with physical impairments and with social impairments (Table 5).

For this impact variable, diagnosis also emerges as a significant predictor: partners of patients with cancer, musculoskeletal disorder, or digestive disorder experience a significantly stronger financial burden than for other chronic diseases. When the patient has more than one disease, the perceived financial burden is significantly smaller. The observed effects of the disease characteristics persist when caregiving is included in the model, although the β -coefficient for the effect of physical impairments decreases when caregiving is controlled for. Again, gender and socioeconomic position are significant predictors. In households where only the partner is employed or both are unemployed, the perceived financial burden is higher.

However, the partners did not experience negative effects only, as many of them reported feeling intrinsic rewards. The strength of intrinsic rewards for the partner is also determined by caregiving responsibilities, although the effect is not very strong (Table 5, last 2 columns). In addition to that, intrinsic rewards were significantly higher among partners whose mate has a life-threatening disease or a disease accompanied by social impairments or fatigue. It must be noted, however, that the variables in the model explained only 16% of the variance in this impact measure, thus the intrinsic rewards are related mostly to variables not measured here.

CONCLUSION

This study aimed to provide quantitative information with regard to the degree that partners of chronically ill persons experience an impact on their lives and in what respect.

The results show that the impact on the partners varies and that not all partners have the feeling that their lives are affected in the domains that are distinguished in this study.

The most disruptive factor appears to result from the strain on personal life, which is mentioned by more than half of the partners.

About 1 in 5 partners reported changes in social relations, like significant others having turned away or having less time for social contacts. The proportion experiencing financial implications is also limited to about one fifth of the partners (or probably more precisely, the households). On the other hand, as much as 65% of the partners experienced intrinsically positive feelings, but we cannot conclude from this study to what extent these compensate for the negative sides that have been detected.

Our findings justify the emphasis that is usually put on the burden of caregiving for partners.

First, the results showed that providing informal care is, indeed, rather common among partners living with a chronically ill person. Almost three quarters of the partners were involved in taking care of their ill mate.

What is more, they mostly did so without getting help from professional home healthcare, because in the Netherlands, only 12% of the chronically ill receive professional assistance from a home care center.²² Second, the objective burden of caregiving appears to be the main predictor for all impact variables in this study. The fact that one has to take substantial care certainly impinges on the partner's life, mostly in a negative way, a majority felt an intrinsically positive side of the coin as well.

This endorses the importance of professional home care as a means to support the partner and alleviate the burden.^{15,23} The fact that coresident partners are available to provide care must not be an argument to withhold home care health services, without considering the negative impact on the caregiver.

However, the findings also make clear that the consequences for the partner do not arise entirely from the amount of caregiving required by the patient's condition. An independent effect of specific disease characteristics is observed in addition to the effect of caregiving.

This implies that the implications of a chronic disease are reflected on the partner irrespective of the burden of care that is required. Especially, when the patient's disease is accompanied by social impairments, the impact on the partner's life is profound.

The results of the regression analyses show that social impairments in the patient affect the partners in all 4 areas. Physical impairments are also quite intrusive as they put a strain on the partner's personal life and on the financial position. Fatigue in the patient has a far-reaching effect on the partner's life as well. It is related to higher personal life strain and poorer social relations, but, on the other hand, also to deeper intrinsic fulfillment. Although pain can be very probing for a patient,^{24,25} it does not affect the partner in the areas studied here, except for an observed impact on social relations. Mental impairments due to the chronic disease do not touch upon the lives of the partners in any of the ways under investigation here, neither do progressiveness of a disease or fluctuations in the patient's condition. Considering these outcomes, it would be interesting to find out in future research whether these disease characteristics affect the life of the patient

in the same way as was found for the partner, or differently. This will provide more complete knowledge of the implications of a chronic disease and the vulnerability of households of chronically ill persons.

Another important indicator determining the vulnerability of partners is the socioeconomic position of the household. The results show that involvement in paid employment of both partner and patient protects the partner from increased personal life strain as well as from financial burden. For retired couples, the financial impact is lower, which is consistent with the findings of Covinsky et al,²⁶ that at younger age the chronically ill person is more often confronted with the loss of the major income source and the loss of family savings. And, apparently, employment of the partner is not enough to reverse the financial impact, particularly because partners sometimes have to cut back their working hours. These findings also make clear that—because the consequences of a chronic illness reflect on the partner as well—health problems intensify existing social inequalities at the household level.

It is remarkable that female partners report a higher burden in all respects than male partners.

A difference in impact on healthy men and women was previously found with respect to psychologic distress,¹¹ as well as caregiver distress in general.²⁷ Our findings show that in the aspects of daily life that were considered here, male partners feel less consequences of their mate's chronic disease than female partners. For women, the chronic disease of their mate thus seems more disturbing than for men. It may be that by nature women are more sensitive to the well-being of others,²⁸ but it is also known that healthy men more often receive professional home care for their ill partner,²² and this may free them from some of the burden.

The size of this study, which includes a variety of somatic diagnoses, makes it possible to compare the impact of different physical chronic diseases. In general, it can be said that the perceived impact is not dependent on the type of chronic disease. That is, when the effect of specific disease characteristics is controlled for, the perceived impact is not significantly higher for some diagnoses than for others.

This implies that for most diagnoses the impact is mainly related to consequences that are common to a chronic physical illness. This is not the case, however, for partners of patients with cancer, who report more personal life strain and more financial impact, and for partners of patients with musculoskeletal or digestive disorder, who encounter a higher financial burden as well. Which typical features of these diseases, not common to other diseases, are responsible for this may be further investigated. For now, it is clear that partners of these patients with a chronic physical disease are in a relatively more vulnerable position.

Whether this applies in the same way to partners of persons with chronic mental diseases should be investigated in a next study.

It has been pointed out repeatedly that the partner's well-being is an important issue to consider, because the potential impact on the partner of a chronically ill person may be detrimental to the health of both partner and patient.^{1,6,29,30} This study has shown in what respects a chronic disease affects the partner's life and in what circumstances the consequences are more severe. What has not been addressed here, however, is how much the consequences in these areas, in turn, affect the partner's well-being; in other words, which consequences are more harmful to the partner's physical or psychological well-being than others. Further research on this relation may render more specific directions for interventions to support the families of chronically ill and avert the negative consequences that may give rise to increasing health disparities between households.

[FIGURE AND TABLES]

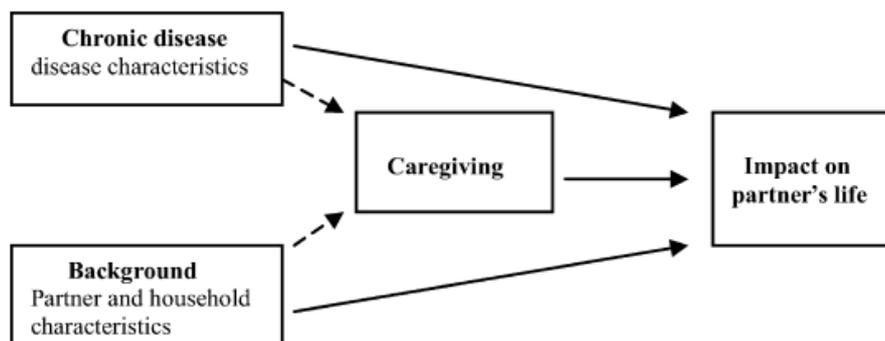


Figure 1. Model of the relations to be investigated in explaining the impact on the partner of a chronically ill person.

Table 1. Impact on the partner: Percentage agreeing to the items (column 1); factor structure plus factor loadings for the Impact-on-Partner Scale (columns 2 to 5)

Because of my partner's chronic disease...	% Saying yes	Factor loadings*			
		Factor 1	Factor 2	Factor 3	Factor 4
.. I had to give up hobbies	8.2	0.547	0.230	0.086	0.213
.. I go on holidays less frequently	18.1	0.727	0.104	0.093	0.294
.. I have less recreational opportunities	16.8	0.694	0.263	-0.017	0.207
.. I go out less often	20.7	0.607	0.239	0.106	0.194
.. I cannot go on distant trips	26.7	0.667	0.050	0.250	0.148
.. I have to change plans at the last minute	23.4	0.650	0.228	0.270	0.062
.. going somewhere puts a strain on me	15.9	0.614	0.340	0.110	0.102
.. I have to do more household chores	33.3	0.562	0.018	0.200	0.114
.. I cannot plan for the future	25.8	0.661	0.192	0.229	0.153
.. I have little time for myself	3.1	0.597	0.448	0.025	0.092
.. I cannot do things spontaneously	11.9	0.650	0.315	0.119	0.075
.. important others have turned away	5.5	0.134	0.704	0.065	0.257
.. I have less time for other family members	4.1	0.241	0.547	-0.004	0.349
.. I am treated differently by neighbors and friends	9.1	0.131	0.720	0.126	0.225
.. I encounter much misunderstanding	14.7	0.304	0.670	0.182	0.028
.. I feel like living on a roller coaster	11.6	0.373	0.655	0.024	0.006
.. we have become closer	40.9	0.111	0.013	0.774	0.131
.. I appreciate things in life more	55.2	0.188	0.067	0.837	0.051
.. I look at life differently	48.9	0.196	0.205	0.794	0.071
.. there is less financial latitude	19.0	0.327	0.147	0.231	0.701
.. I had to cut down working hours	5.4	0.182	0.216	0.021	0.534
.. we encounter financial problems	9.9	0.175	0.146	0.094	0.777
Eigenvalue		8.03	1.85	1.35	1.11
Cronbach's α		.89	.76	.77	.64

*Factor 1 indicates personal life strain; factor 2, social relations; factor 3, intrinsic rewards; and factor 4, financial burden. The factor loadings in bold indicate that these items score highest on that factor, and thus constitute the underlying dimension.

Table 2. Characteristics of the study group by variables of interest ($N = 1,093$)

	%	Mean		%	Mean
<i>Partner characteristics</i>					
Age		57.8	Intermediate	24.0	
Women	49.3		High school	15.8	
Educational level			Involved in paid work (<65)	49.9	
Basic	58.1		<i>Diagnosis</i>		
Intermediate	24.3		Cardiovascular disease	9.9	
High school	17.5		Asthma	9.5	
Involved in paid work (<65)	61.2		Chronic obstructive pulmonary disease	9.3	
Objective burden of care			Musculoskeletal disease	14.6	
Providing care	71.5		Cancer	4.4	
Hours per week		11.0	Diabetes mellitus	15.3	
<i>Household characteristics</i>					
Socioeconomic position			Neurological disease	7.9	
Both employed	27.2		Digestive disorder	3.5	
Partner employed	12.7		Other	25.6	
Patient employed	8.4		Disease duration, y		11.4
Neither one employed	10.5		Comorbidity	32.3	
Retired (partner or both)	41.2		<i>Disease characteristics</i>		
Household composition			Life-threatening	20.0	
Children present	24.6		Progressive	57.0	
No children present	74.4		Fluctuating course	71.3	
<i>Patient characteristics</i>					
Age		58.5	Visible physical changes	42.0	
Women	51.2		Physical impairments	52.9	
Educational level			Social impairments	45.5	
Basic	60.2		Mental impairments	46.8	
			Accompanied by pain	56.9	
			Accompanied by fatigue	77.3	

Table 3. Prevalence of the impact variables on the partners of chronically ill persons: Percentage experiencing consequences in 4 domains*

	%	Prevalence of combination of factors		
		Personal life strain	Social relations	Financial burden
Personal life strain	53.1			
Social relations	22.3	19.7		
Financial burden	21.3	17.9	10.8	
Intrinsic rewards	64.5	43.7	20.4	19.6

*Percentage saying "yes" to one or more of the items of the factor concerned (ie, factor score > 0).

Table 4. Regression analyses with personal life strain and impact on social relations as dependent variables; standardized β -coefficients and significance levels

	Personal life strain		Social relations	
	Model 1	Model 2	Model 1	Model 2
Gender of partner (female vs male)	0.10*	0.12†	0.16†	0.17†
Age of partner				
<45 y (reference)	0.00	0.00	0.00	0.00
45-64	0.04	0.03	0.08	0.08
≥65	0.11	0.12	0.08	0.09
Socioeconomic position				
Both employed	-0.11*	-0.05	-0.01	0.05
Partner employed	-0.01	0.02	0.09	0.13*
Patient employed	0.01	0.04	0.03	0.06
Neither one employed	0.10	0.11†	0.04	0.06
Retired (partner or both) (reference)	0.00	0.00	0.00	0.00
Presence of children (yes vs no)	0.00	0.00	-0.01	-0.01
Diagnosis				
Cardiovascular disease	0.02	0.01	0.07	0.06
Asthma	0.01	0.02	0.05	0.06
Chronic obstructive pulmonary disease	0.02	0.02	0.03	0.03
Musculoskeletal disease	0.03	0.03	0.00	0.00
Cancer	0.07*	0.07*	0.05	0.06
Diabetes mellitus	-0.02	-0.03	0.04	0.04
Neurological disease	0.05	0.04	0.01	-0.01
Digestive disorder	0.05	0.05	0.02	0.04
Other (reference)	0.00	0.00	0.00	0.00
Comorbidity (yes vs no)	-0.01	-0.01	-0.01	-0.01
Disease duration	0.01	0.00	0.00	-0.01
Disease characteristics				
Life-threatening	0.08†	0.04	-0.04	-0.07
Progressive	0.03	0.02	-0.04	-0.05
Fluctuating course	-0.01	0.00	0.04	0.05
Visible physical changes	0.00	-0.01	0.02	0.01
Physical impairments	0.17†	0.11†	0.04	0.01
Social impairments	0.26†	0.23†	0.21†	0.18†
Mental impairments	0.08*	0.05	0.05	0.02
Accompanied by pain	-0.03	-0.06	0.14†	0.11*
Accompanied by fatigue	0.12†	0.13†	0.10*	0.10*
Caregiving, h/wk		0.34†		0.27†
Variance explained, R^2	0.35	0.45	0.20	0.25

* $P < 0.05$.

† $P < 0.01$.

Table 5. Regression analyses with financial burden and intrinsic rewards as dependent variables; standardized β -coefficients and significance levels

	Financial burden		Intrinsic rewards	
	Model 1	Model 2	Model 1	Model 2
Gender of partner (female vs male)	0.09*	0.12 [†]	0.04	0.05
Age of partner				
<45 y (reference)	0.00	0.00	0.00	0.00
45-64	0.06	0.00	0.10	0.10
≥65	-0.01	0.00	0.06	0.09
Socioeconomic position				
Both employed	-0.13*	-0.07	-0.02	0.02
Partner employed	0.12*	0.15 [†]	0.05	0.08
Patient employed	-0.05	-0.02	0.04	0.05
Neither one employed	0.15 [†]	0.18 [†]	0.06	0.06
Retired (partner or both) (reference)	0.00	0.00	0.00	0.00
Presence of children (yes vs no)	0.06	0.07	-0.06	-0.07
Diagnosis				
Cardiovascular disease	0.03	0.03	0.03	0.03
Asthma	0.03	0.03	-0.08	-0.08
Chronic obstructive pulmonary disease	0.01	0.01	-0.03	-0.03
Musculoskeletal disease	0.10 [†]	0.11 [†]	0.05	0.05
Cancer	0.07	0.07*	0.07	0.07
Diabetes mellitus	0.03	0.01	-0.01	-0.01
Neurological disease	-0.02	-0.03	-0.02	-0.05
Digestive disorder	0.06	0.07*	0.03	0.03
Other (reference)	0.00	0.00	0.00	0.00
Comorbidity (yes)	-0.11 [†]	-0.11 [†]	0.01	0.01
Disease duration	0.03	0.02	0.03	0.02
Disease characteristics				
Life-threatening	0.02	0.00	0.10 [†]	0.09*
Progressive	0.01	0.02	0.01	0.00
Fluctuating course	0.02	0.02	0.05	0.05
Visible physical changes	0.06	0.03	-0.01	-0.01
Physical impairments	0.19 [†]	0.14 [†]	0.03	-0.01
Social impairments	0.13 [†]	0.12 [†]	0.09*	0.10*
Mental impairments	0.00	0.00	0.05	0.04
Accompanied by pain	0.05	0.02	-0.04	-0.05
Accompanied by fatigue	0.00	0.01	0.13 [†]	0.12 [†]
Caregiving, h/wk		0.25 [†]		0.14 [†]
Variance explained, R^2	0.27	0.33	0.15	0.16

* $P < 0.05$.

[†] $P < 0.01$.

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