

Original Article

The Impact of Chronic Pain on Life in the Household

Marius A. Kemler, MD, PhD and Carina A. Furnée, PhD

*Department of Plastic Surgery (M.A.K.), Free University Hospital, Amsterdam, The Netherlands; and Chapin Hall Center for Children (C.A.F.), University of Chicago, Chicago, Illinois, USA***Abstract**

To study what happens in a family where one member suffers from chronic pain, we quantitatively assessed the effect of chronic pain resulting from complex regional pain syndrome type 1 (CRPS) on 1) employment status, 2) time allocation, 3) additional domestic help, and 4) out-of-pocket expenses of Dutch patients ($n = 50$) and their spouses ($n = 43$). This study is the first to measure the effect of chronic pain on time allocation by means of a diary assessment technique. The results were compared with normative values for the Dutch population overall. In households containing a male patient, the total employment full time equivalent (FTE) decreased by 47% ($P = 0.05$), with the result that the mean household income decreased by \$4,000 ($P = 0.01$). In those with a female patient, there was a reduction in FTE of 29% ($P < 0.05$), causing a decrease of the mean household income by \$2,000 ($p < 0.001$). As compared with controls, patients were found to spend less time on paid employment, and to invest more time in household maintenance and housekeeping. Of 50 patients, 35 received a mean of 4.5 hours per week of domestic help. The mean out-of-pocket expenses related to CRPS amounted \$1,350 per patient per year. Spouses were forced to invest more time on housekeeping and household maintenance, which resulted in less time for personal needs and leisure activities. There were only small differences in time allocation between cases where the sufferer was male or female and, similarly, only minor variation between hand-affected or foot-affected patients. Households with either male or hand-affected patients did prove to have higher out-of-pocket expenses as compared with households containing female or foot-affected patients. Those containing female or hand-affected patients required more domestic help than households either with male or foot-affected patients. The present study demonstrates that chronic pain due to CRPS has a profound impact on many aspects of the lives of both patients and their spouses. *J Pain Symptom Manage* 2002;23: 433–441 © Cancer Pain Relief Committee, 2002.

Key Words*Methodology, questionnaire, reflex sympathetic dystrophy*

Address reprint requests to: Marius A. Kemler, MD, PhD, Department of Surgery, Martini Hospital, P.O. Box 30033, 9700 RM Groningen, The Netherlands. E-mail: M.A.Kemler@mzh.nl

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Introduction

Chronic pain resulting from bodily trauma, disease, injury or unknown etiology may have considerable effect on patients' lives. Many individuals may have to give up work permanently, eliminate potentially satisfying physical and social activities, and withdraw from contact

with friends and family.¹⁻³ In addition to the problems created for the patients themselves, chronic pain is likely to alter traditional family roles, result in deterioration of the sexual and marital relationships, cause financial difficulties, and create distress for other family members.^{1,4} When one person suffers from chronic pain, the couple is required to manage not only the typical conflicts and stress factors that arise in all marriages, but also those stemming from adjustments that the marital system needs to make to adapt to the chronic pain problem.⁵ Apart from dealing with altered roles and responsibilities, spouses of chronic pain patients often must deal with the patient's psychological distress and physical limitations.⁶ It can be expected that chronic pain has effects not only on the spouse, but also on the children and any members of the extended family living with the patient.¹ Because of the profound implications on the entire household, it has been acknowledged that the major responsibility for the management of chronic health conditions rests with the individual and his family rather than with the health professional.⁷

To study the consequences of chronic pain, we evaluated patients suffering from chronic refractory complex regional pain syndrome (CRPS) Type 1 in an extremity. This condition causes pain and impaired function in the affected arm or leg. It virtually always starts abruptly after a noxious event, such as a trauma or an operation.⁸ The pathogenesis of CRPS is only partly understood,⁹ and there are no treatments that can guarantee improvement. As a consequence, only 20 to 30% of CRPS patients return full-time to their previous employment.¹⁰ All patients in this study had one affected arm or leg that caused them both severe pain and functional impairment.

Although several studies have attempted to improve understanding of the consequences of chronic pain on family life, it is extremely difficult to assess what exactly happens in a family when one member suffers from chronic pain. Previous investigations mostly determined the scores of patients and their spouses on standard self-report tests measuring factors like physical disability, marital and sexual relationship, cognitive appraisal, depression, and pain.^{1,6,11} Financial consequences, role changes, and alterations in time allocation in the marital dyad after chronic pain have not been assessed. The

present study quantitatively investigated the effects of chronic pain due to CRPS on employment status, time allocation, additional domestic help, and out-of-pocket expenses within the household, i.e., for patients and their spouses. The study is the first to demonstrate the actual consequences of chronic pain on life in the household with use of a diary assessment technique.

Methods

Patients

All medical specialists known to treat CRPS patients (such as anesthesiologists, surgeons, neurologists, and others) working in hospitals in the south of the Netherlands were asked to refer patients fulfilling the study criteria to the Department of Surgery of Maastricht University Hospital. Upon arrival in our institution the final decision whether patients could enroll the study was based on re-checking these criteria. To ensure the diagnosis of CRPS and its chronicity in our consecutive patient group, the subjects had to meet the following criteria:

- CRPS according to diagnostic criteria of the International Association for the Study of Pain (IASP);¹²
- CRPS clinically restricted to one extremity, but at least affecting the whole hand or the whole foot;
- duration of CRPS of at least six months, during which period there was no lasting benefit of standard therapies, including nonsteroidal antiinflammatory drugs, opioids, antidepressants, anticonvulsants, sympathetic blocks, transcutaneous electrical nerve stimulation and physical therapy, and;
- a mean pain intensity of at least 5, as measured on a visual analogue scale (VAS) ranging from 0 (no pain) to 10 (very severe pain).¹³

Patients with neurological abnormalities not related to CRPS, or conditions affecting function of the diseased or the contralateral extremity other than CRPS were excluded. Written informed consent was obtained from all patients according to the Declaration of Helsinki. The study protocol had been approved by the Ethical Committee of our institution.

Employment Status

Patients and their spouses were asked to provide information on their employment status before and after the onset of CRPS. Employment of 36 hours per week or more was classified as full-time; 10–36 hours per week was classified as half-time; and employment less than 10 hours per week was classified as minimally employed.

The household income before and after CRPS was expressed as net yearly income. Disabled persons in the Netherlands continue to receive 70% of their last salary. The exact figures on patients' change of income owing to CRPS were obtained from the authorities responsible for the payment of disability benefits; information on the income of spouses was provided by the subjects themselves.

Time Allocation

Time allocation was measured by means of a questionnaire that was developed by the Social and Cultural Planning Office (SCP), a research organisation which provides information for policy formulation by the Dutch Government in social and cultural areas.¹⁴ Patients and spouses were asked to list prospectively on a prepared form the average number of hours spent per week on the following pursuits:

- Personal needs (washing, dressing, eating, going to the lavatory, visiting a doctor, dentist or therapist, sleep, afternoon nap)
- Housekeeping (preparing meals, laundry and upkeep of clothes, tidying and cleaning the house, and other household chores)
- Shopping (not only day-to-day shopping but also purchase of special items such as clothes, furniture and household appliances, transport to shops, visits to post office, bank, etc.)
- Care of children (caring for children, baby sitting, help with homework, playing games with children)
- Education (education and transport to and from place of education)
- Paid employment (paid employment and transport to and from place of work)
- Social participation (participation in political and social organizations, corporate life, church communities, works council)
- Household maintenance (household repairs, jobs around the house, maintaining

car/bicycles; care of pets, gardening and care of house plants; handicrafts)

- Social contacts (meeting family or friends, visiting bars, social clubs, going out to eat)
- Leisure activities (watching TV, reading, listening to/making music, walking, biking, playing sports and games)
- Remainder

At the start of the week, patients and their spouses received the form by mail. During the week, they listed their time allocation, and at the end of the 7-day period, they came to the hospital and handed in the forms to the researcher. During the week, the researcher was available by telephone to answer questions. During the visit, all forms were checked to determine whether they were completed correctly.

The results of patients and their spouses were compared with the normative values for the Dutch population overall. This information was obtained from the SCP. The technique of assessment conducted in the present study was identical to the technique conducted by the SCP; thus, the normative values are valid as controls. The normative values of the SCP are presented separately for different types of households, each characterized by either one full-time wage earner (Category 1), one full-time and one half-time wage earner (Category 2), two full-time wage earners (Category 3), one half-time wage earner (Category 4), or no single wage earners (Category 5). In order to obtain control values, all patients and spouses were matched on the basis of gender and the household category that applied to their situation prior to the start of CRPS. The seven patients who were single were matched on the basis of their employment status prior to CRPS. Note that no normative values for children's time allocation are presently available; consequently, in our project it was decided not to gather data for children.

Domestic Help

Patients were asked whether they were getting domestic help from a person not belonging to the household as a consequence of their health status. Domestic help based on grounds other than CRPS was disregarded. All patients getting domestic help listed the number of hours of help received per week.

Out-of-Pocket Expenses

In order to estimate the households' out-of-pocket expenses resulting from CRPS, patients were asked to complete a cost diary for one month of the study. The exact financial expenditures, as reported by the patients, were then used. Journeys made were rated at \$0.30 per kilometer, as is normal practice in The Netherlands.¹⁵ Recorded costs were multiplied by 12 to obtain the estimated CRPS related out-of-pocket expenses per year.

Statistical Analysis

Fisher's exact tests were used to compare proportions of employment status for patients and spouses before and after CRPS. Time allocation results of patients or spouses and controls were compared using an independent samples t-test. Hours of domestic help and out-of-pocket expenses were compared (a) as between male and female patients; and (b) as between patients with an affected hand or foot using an independent samples t-test. Two-sided *P*-values < 0.05, after Bonferroni correction for multiple significance testing, were considered to indicate statistical significance.

Results

The study included 50 consecutive white, Dutch-speaking adults—15 males and 35 females—suffering from chronic CRPS of one hand or foot. The mean age (SD) was 39 ± 11 years; the mean duration of CRPS (SD) was 36 ± 25 months. In 32 cases, an arm was affected, and in 18 cases, a leg was involved. Since standard therapies had all been shown to be ineffective for their CRPS, the current treatment regimen of these patients was variable. In an attempt to control the pain, most patients continued to try nonsteroidal antiinflammatory drugs, opioids, antidepressants and anticonvulsants; 24 used spinal cord stimulation and 23 still underwent physical therapy. Five of the women and two of the men were single, with no children, and lived independently. Their income prior to the onset of CRPS ranged from zero to \$19,000 (mean \$8,500). The remaining 43 patients (13 male, 30 female) were all living with their spouses; 23 of the households were families with children (seven families had one child, 12 had two children, two had three children, and the remaining two families had four

and six children respectively). The mean (SD) family income prior to the onset of CRPS was \$25,000 ± \$8,500.

Effect of CRPS on the Employment Status of Patients and Spouses

Of the seven patients who were single, both men had held full-time tenured positions, four women held half-time tenured positions, and one woman was unemployed prior to CRPS. After the onset of CRPS, none of these patients were able to continue in their employment. As a result, their mean income decreased from \$8,500 to \$5,500 (*P* > 0.05).

Of the patients who were living with their spouses, separate results have been calculated for male and female patients, and their respective spouses.

Male Patients (n = 13). Prior to CRPS, 11 male patients had full-time tenured positions; one male patient had a half-time tenured position and one patient was unemployed (11.5 full time equivalents, FTE). After CRPS, only one patient remained a full-time wage earner, while the others were unable to continue in their employment (1 FTE). This was a significant decrease in FTE (*P* < 0.001). Of their spouses, four held full-time, and three held half-time positions prior to CRPS of their husbands (5.5 FTE). After CRPS, six spouses held full-time positions, while four spouses worked half-time (8 FTE); this is a non-significant increase (*P* = 0.43). The total FTE within households with male patients decreased significantly from 17 to 9 (47%) as a result of CRPS (*P* = 0.05). As a consequence, the mean household income decreased significantly from \$26,000 to \$22,000 (*P* = 0.01).

Female Patients (n = 30). Ten female patients had held full-time tenured positions and eight patients had half-time positions prior to CRPS; the remaining 12 patients had no wage earnings (14 FTE). After CRPS, one patient remained in half-time employment, another remained in full-time employment, and one full-time wage earner was reduced to half-time work. All other female patients lost their incomes as a result of CRPS (2 FTE); the loss of 12 FTE was significant (*P* < 0.001).

Of their male spouses, 27 held full-time positions which did not change as a consequence

of CRPS (27 FTE). Hence, as a result of CRPS, the total FTE among households with female patients suffered a significant decrease from 41 to 29 (29%; $P < 0.05$), causing the mean household income to decrease significantly from \$24,500 to \$22,500 ($P < 0.001$).

Time Allocation, Domestic Help and Out-of-Pocket Expenses

CRPS Patients and Their Spouses versus Controls. Results of time allocation measurements in patients and their spouses versus controls are presented in Figure 1. Significant divergences between CRPS patients ($n = 50$) and controls were found for time spent on: (1) housekeeping (21h vs. 14h; $P = 0.03$); (2) paid employment (3h vs. 22h; $P < 0.001$); and (3) household maintenance (9h vs. 3h; $P < 0.001$).

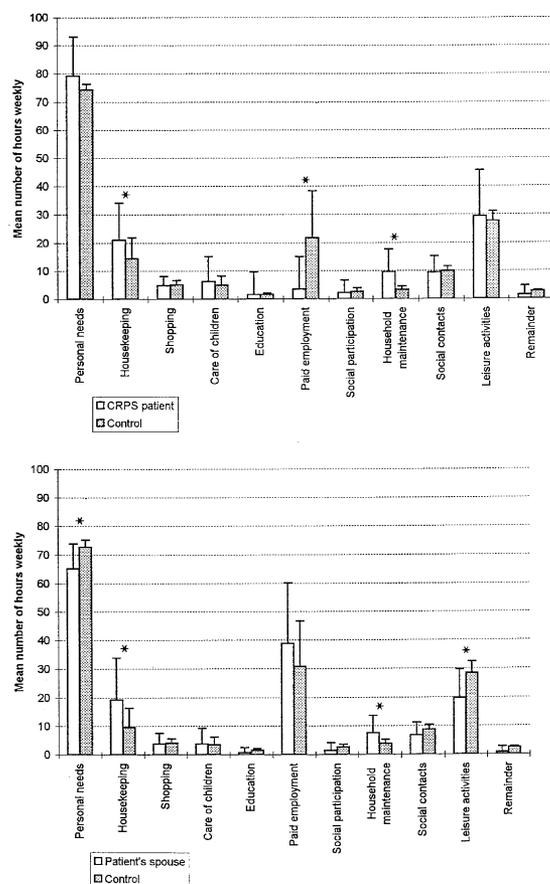


Fig. 1. Time allocation to various activities in hours per week (SD) for 50 patients with matched controls (a), and for 43 spouses with matched controls (b). Asterisks indicate significant results.

Figures for the remaining categories were not significantly different than those of controls. Significant divergences for time allocation between spouses of CRPS patients ($n = 43$) and controls were found for time spent on: (1) personal needs (65h vs. 73h; $P < 0.001$); (2) housekeeping (19h vs. 10h; $P = 0.002$); (3) household maintenance (8h vs. 4h; $P = 0.005$); and (4) leisure activities (20h vs. 28h; $P < 0.001$).

As a consequence of CRPS, 35 households obtained domestic help (mean: 4.5 hours per week). The mean out-of-pocket expenses related to CRPS were \$1,350 per patient per year.

Male CRPS Patients and Female Spouses versus Controls. Results for time allocation of male patients and their female spouses versus controls are shown in Figure 2. Significant divergences between male CRPS patients ($n = 15$) and controls were only found for time spent on paid employment (6h vs. 36h; $P < 0.001$). Scores on all remaining categories were comparable to those of controls. Significant divergences between female spouses of male CRPS patients ($n = 13$) and controls were found for time spent on: (1) personal needs (67h vs. 75h; $P = 0.008$); (2) housekeeping (33h vs. 18h; $P = 0.02$); and (3) leisure activities (16h vs. 27h; $P < 0.001$). Remaining categories were comparable to those of controls.

As a consequence of CRPS, nine households with a male CRPS patient received domestic help (mean: 3.5 hours per week). The mean out-of-pocket expenses related to CRPS were \$1,600 patient per year.

Female CRPS Patients and Male Spouses versus Controls. Results for time allocation of female patients and their male spouses versus controls are illustrated in Figure 3. Significant divergences between female CRPS patients ($n = 35$) and controls were found for time spent on: (1) education (0h vs. 1h; $P < 0.001$); (2) paid employment (2h vs. 15h; $P < 0.001$); and (3) household maintenance (9h vs. 3h; $P < 0.001$). Remaining categories were comparable to those of controls. Significant divergences between male spouses of female CRPS patients ($n = 30$) and controls were found for time spent on: (1) personal needs (64h vs. 72h; $P = 0.003$); (2) housekeeping (13h vs. 6h; $P = 0.02$); and (3) leisure activities (22h vs. 29h; $P = 0.02$).

Remaining categories were comparable to those of controls.

Twenty-six of the households with a female CRPS patient were obtaining domestic help (mean: 5 hours per week) and the out-of-pocket expenses related to CRPS were \$1,250. Figures for domestic help and out-of-pocket expenses showed no significant differences between households with male as opposed to female patients.

Patients with CRPS of the Hand Versus Controls. Results for time allocation of hand-affected and foot-affected patients versus controls are illustrated in Figure 4. Patients with an affected hand ($n = 32$) differed from their controls for time spent on: (1) paid employment (4h vs. 23h; $P < 0.001$); and (2) household maintenance

(9h vs. 3h; $P = 0.01$). All other categories were comparable to those of controls.

Of the households, 26 were receiving domestic help (mean: 5 hours per week). The out-of-pocket expenses related to CRPS totalled \$1,550 per patient per year.

Patients with CRPS of the Foot versus Controls. Patients with an affected foot ($n = 18$) differed from their controls for time spent on: (1) education (0h vs. 2h; $P < 0.001$); (2) paid employment (3h vs. 20h; $P = 0.009$); and (3) household maintenance (11h vs. 3h; $P = 0.009$). All other categories were comparable to those of controls.

Nine of the households were obtaining domestic help (mean: 3.5 hours per week). The out-of-pocket expenses related to CRPS were \$950 per patient per year. Only the figures for

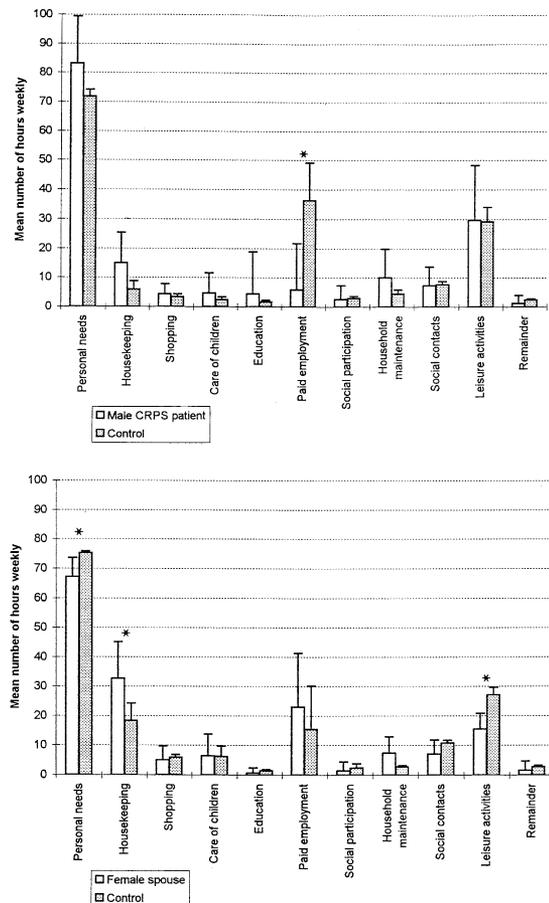


Fig. 2. Time allocation to various activities in hours per week (SD) for 15 male patients with matched controls (a), and for 13 female spouses with matched controls (b). Asterisks indicate significant results.

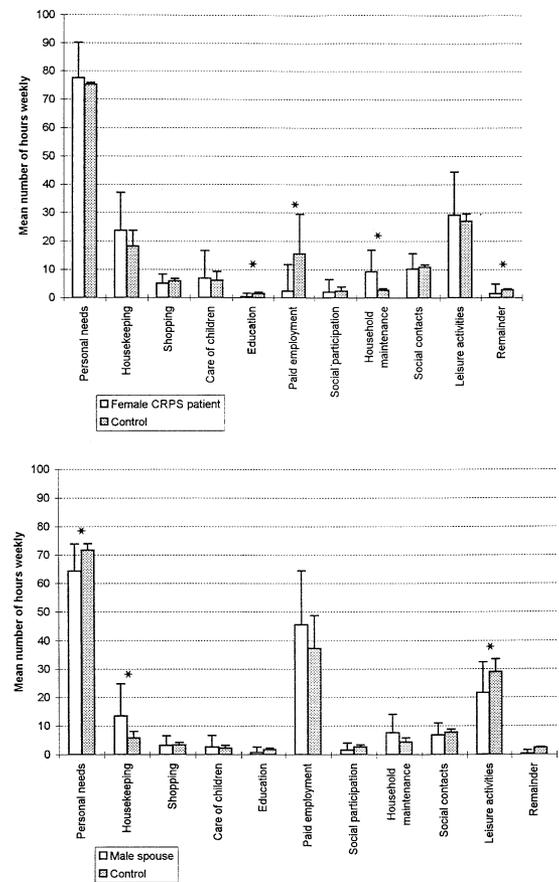


Fig. 3. Time allocation to various activities in hours per week (SD) for 35 female patients with matched controls (a), and for 30 male spouses with matched controls (b). Asterisks indicate significant results.

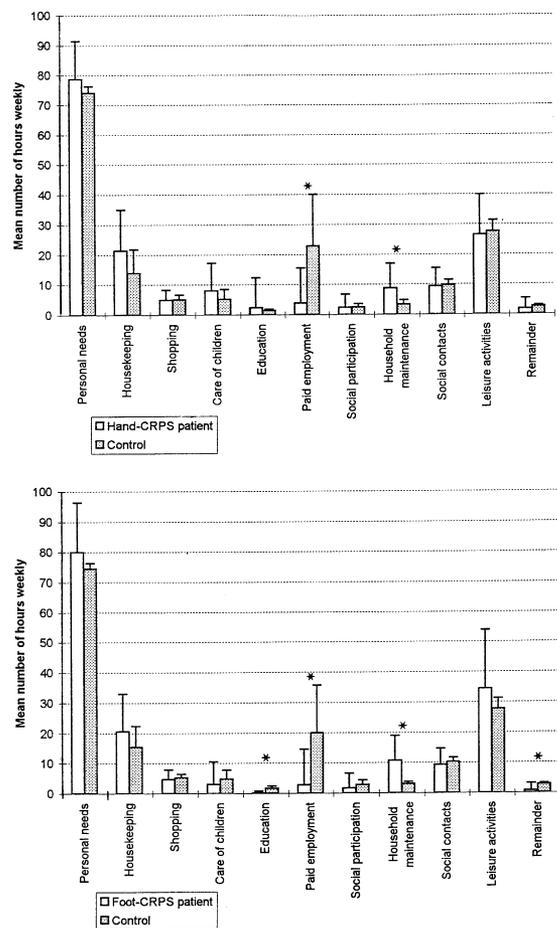


Fig. 4. Time allocation to various activities in hours per week (SD) for 32 hand-affected patients with matched controls (a), and for 18 foot-affected patients with matched controls (b). Asterisks indicate significant results.

out-of-pocket expenses showed a significant difference between households with patients in whom either the hand or the foot was affected ($P < 0.05$).

Discussion

This study explored the effect of CRPS on finances, role changes and weekly activities of male and female patients with CRPS and their spouses. This is an important area that deserves investigation. Although several population-based studies have examined the effect of pain on finances and behavior of patients and their families,¹⁶ the present study is different in that it attempts more exact quantification of the effect of pain. With use of a diary assess-

ment technique, our study is the first to provide quantitatively the exact impact of chronic pain on the economics and life in households.

Nevertheless, it is important to note that the data are preliminary, assess a particular pain syndrome (CRPS) in a particular society (The Netherlands), and derives from a small sample ($n = 50$). Thus, the findings cannot be generalized to all pain patients.

To test this new approach to measurement, we purposely studied the pain syndrome of CRPS, which is a significant clinical problem.¹⁷ There is certainly a clear possibility that having CRPS can have an impact on one's spouse. We applied strict criteria for chronic CRPS. By doing so, we avoided doubts about the diagnosis or the severity of suffering. The resulting rather small sample size was taken for granted.

The results of this study indicate that CRPS produces important reductions in family income, even within a society that provides disability compensation at 70% of the claimants pre-illness income. Moreover, both patients and their spouses undergo important changes in their weekly activities.

In Dutch families with male CRPS patients—who had also typically been the household's main wage earner before CRPS—the loss of employment due to the disabling effect of CRPS was found to affect the household to a considerable extent. Although the spouses increased their participation in the labor market, these households experienced a 47% FTE decrease. Because only a small proportion of female patients were the household's main income providers, the effects of CRPS in these households were less extreme. The total loss of FTE in these households was 29%. The employment status of male spouses of CRPS patients was not influenced by CRPS at all, and no compensation was observed for the job loss of female patients in the household. Our study was conducted in The Netherlands; the paid employment market participation of women is likely to be different in other countries.

Family income and expenditures were found to be greatly affected by CRPS. Our study showed significant reductions in family income in households either with male (\$4,000) or female (\$2,000) CRPS patients. Furthermore, owing to disease, out-of-pocket expenses rose by \$1,250 for female patients and \$1,600 for male patients, thereby considerably increasing

the overall financial burden. Again, note that these figures are influenced by the fact that our study was conducted in the Netherlands, where disabled persons continue to receive 70% of their last salary, which prevents even greater financial losses. In addition, health insurance is a legal requirement for all citizens,¹⁸ as a consequence of which no patients ever had to pay health care expenses themselves, significantly reducing their financial loss. Different conditions obviously apply from one country to another.

The most noteworthy divergences in time allocation as compared to normal healthy Dutch individuals were recorded for spouses rather than for the sufferers themselves. The patients in general showed increases in time spent on housekeeping, household maintenance, and, of course, a considerable loss in time spent on paid employment and therefore in income. Spouses of CRPS patients showed increases in housekeeping and household maintenance. However, in addition, as far as spouses were concerned, the extra demands for care of the sufferer led to a significant decrease in time spent on personal needs and leisure activities. These quantitative results confirm the general presumption that chronic pain of a patient has a profound impact on the entire family.^{1,4}

Although the time allocation of patients appears to differ only slightly from controls, it is questionable whether their time spent on household tasks (housekeeping, household maintenance) was used efficiently—especially when taking their pain and functional impairment into account. Matched control households, on average, required 24 hours for housekeeping (subjects 14.5; spouses 9.5 hours) and 7 hours for household maintenance (subjects 3, spouses 4 hours). Patient households, on average, spent 40 hours on housekeeping (patients 21; spouses 19 hours) and 17 hours for household maintenance (patients 9.5; spouses 7.5 hours). Assuming that spouses of CRPS patients continue to use their time efficiently, this implies that spouses supply most of the households' requirements. On the other hand, this also means that patients had to spend 21 hours (housekeeping) and 9.5 hours (household maintenance) to generate 5 and 0 efficient hours, respectively. These figures show the enormous efforts that CRPS patients need to put into daily household chores. Because the

patients spend no more time on leisure activities than controls, we may assume that the increase in time devoted to household tasks is indispensable to their families.

In general, there were no differences between male and female patients with regard to time allocation. However, male patients showed a more extended increase in time spent on personal needs and a more obvious decrease in time spent on paid employment. Patients with CRPS of the hand expended more time on personal needs and housekeeping (not statistically significant), while these factors were less important for CRPS patients with an affected foot. Both types of patients showed a reduction in time spent on paid employment compared with an increase in time spent on household maintenance.

For male spouses, a higher time expenditure was devoted to paid employment (not statistically significant) and housekeeping. Female spouses, on the other hand, showed significant increased time expenditure for housekeeping and household maintenance. With regard to paid employment this appears to be a contradictory result, since our study found a notable increase in employment status of female spouses and an unchanged state for male spouses after CRPS. This apparent contradiction may be explained by the fact that employment changes were calculated from figures before and after CRPS, while time allocation data were computed from divergences between patients or spouses versus controls. Apparently, even after the observed increase in paid employment among female spouses, they only reach the control average in time spent in this way. It seems reasonable to assume that the number of working hours was below the control average prior to CRPS. For male spouses, we observed no change in the number with paid employment, but we did observe a score for time spent at work that was significantly higher than for the controls. This appears to imply that although they remained full-time wage earners, they increased their number of working hours.

Thus, both male and female spouses increased their working hours after CRPS. Given the financial consequences of CRPS, it is reasonable to assume that spouses were forced to increase the number of hours devoted to paid employment (1) to overcome loss of household income due to CRPS and (2) to cover the

costs of expenditure on treatment and other out-of-pocket expenses. Another explanation might be that the demands of patients on their spouses are high, and in order to escape these demands the spouses increase the time spent away from home in paid work.

It must be emphasized that this study is intended as an inventory and does not pretend to provide any explanation of these data. Further research along the lines set out in this study, and the development of appropriate measurement instruments, will greatly enhance insight into the management of chronic health conditions by the patient and his family.

Acknowledgments

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