

Original article

Title: The impact of chronic pain on patients and spouses: Consequences on occupational status, distribution of household chores and caregiving burden

Running title: Chronic pain impact on patients and spouses

^aCarlos Suso-Ribera, Ph.D.

^bEsther Yakobov, Ph.D.

^cJunie S Carriere, Ph.D. ^aAzucena García-Palacios, Ph.D.

^aDepartment of Basic and Clinical Psychology and Psychobiology, Universitat Jaume I, Castelló de la Plana, Spain.

^bDepartment of Psychology, McGill University, Montreal, Quebec, Canada.

^cDepartment of Anesthesiology, Brigham and Women's Hospital Pain Management Center, Harvard Medical School, Chestnut Hill, Massachusetts.

Correspondence: Carlos Suso-Ribera. Avenida de Vicent Sos Baynat, s/n. 12071. Castellón de la Plana (Spain). Tel: 0034 964 387 737. Fax: 0034 964 729 267. E-mail: susor@uji.com

Manuscript contains 3 Tables, 1 Figure, and 42 references.

Funding: Preparation of this manuscript was supported by grant POSDOC/2016/15 from the Universitat Jaume I and a research agreement with McGill University.

Conflicts of interest disclosures: The authors have no conflicts of interest to disclosure.

Significance: Research has shown that chronic pain poses a significant burden on individuals, which increases their reliance on others for assistance. However, the burden of informal caregiving assumed by spouses of patients with chronic pain has not been

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the <u>Version of Record</u>. Please cite this article as <u>doi:</u> 10.1002/EJP.1616

systematically investigated. This study offers new insights into the impact of chronic pain on patients and their spouses, which might provide empirical foundation for the development of new avenues for intervention aimed at promoting adjustment in patients with chronic pain and spouses who act as informal caregivers.

Abstract

Background. Informal caregiving by spouses has become frequent in chronic pain settings. However, the impact of pain on occupational, functional, and health outcomes in spouses has not been systematically investigated. Aims: The goal of the present study was to examine the impact of pain on both patient and spousal outcomes. **Methods.** In the present study, the impact of chronic pain on 114 heterosexual dyads was explored (patients: 59% females, average age = 57.81 years, SD = 11.85; spouses: 41% females, average age = 57.32 years, SD = 12.15). **Results.** Overall, both patients and spouses reported important consequences of pain on outcomes, including occupational status distribution of household chores and marital satisfaction). Almost 52% of spouses indicated a high-to-severe burden. A multivariate model with spouse and patient factors accounted for 37.8% of the variance of this burden. In the model, patient disability ($\beta =$ 0.36, p = .002), spouses' change in occupational status ($\beta = 0.26$, p = .002), and spousal perception of marital adjustment ($\beta = -0.36$, p < .001) were uniquely associated with burden. **Conclusions.** The results indicate that the impact of chronic pain should be evaluated both for patients and spouses and point to patient and spouse factors that might contribute to spousal burden, which might help guide family interventions in a more effective manner.

Introduction

Chronic pain is a worldwide problem that poses significant economic and social challenges on individuals, their relatives, employers, healthcare systems, and society. Importantly, chronic pain poses a significant physical and mental burden on those with the condition (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006; Breivik, Eisenberg, & O'Brien, 2013; Geurts, Willems, Kallewaard, van Kleef, & Dirksen, 2018). Indeed, chronic pain limits patients' ability to participate in valued life activities and increases psychological distress (Miller & Cano, 2009; C Suso-Ribera, Camacho-Guerrero, Osma, Suso-Vergara, & Gallardo-Pujol, 2019; Wetherell et al., 2011), and reliance on others for assistance with activities of daily living (Abbasi et al., 2012; Dueñas, Ojeda, Salazar, Mico, & Failde, 2016). The burden of chronic pain on those who provide routine assistance to patients has called for increased awareness and research on impact of chronic pain on caregivers (Abbasi et al., 2012).

Informal caregivers have been described as individuals who provide assistance to those in need without receiving economic compensations (Bastawrous, 2013). With the increase of life expectancy, the informal caregiving role assumed by a relative has become a frequent, and even a normative practice. For example, the European Quality of Life Survey conducted in 18 European countries revealed that approximately one quarter of Europeans provide informal caregiving to disabled or elderly relatives (Verbakel, 2014).

In the scientific literature, studies on caregiver burden (i.e., stress perceived by caregivers due to responsibilities of providing care) have been primarily conducted in older populations in the context of dementia, and in populations with cancer (Verbakel, 2014; Winblad et al., 2016). For example, Hunt and colleagues reported that up to 70% of caregivers in the United States felt forced to either reduce their working hours, change employment, take a leave of absence, or quit work entirely due to caregiving (Hunt, Barrett, & Lutz, 2009). Research in Europe also exists to suggest that informal caregivers of older adults are at a greater risk for adverse physical and mental health outcomes when compared to demographically similar non-caregivers (Hiel et al., 2015).

Systematic research on caregiving of younger populations with chronic pain that is not due to terminal illness is lacking. Most research in this area has focused on the influence of spouse behavior on patient health status only (Forsythe, Romano, Jensen, & Thorn, 2012; Raichle, Romano, & Jensen, 2011; Seibert, Miller, Pryor, Reidy, & Zeichner, 2010). While acknowledging the importance of the previous studies that explored the impact of spousal factors on patient outcomes, it is important to note that research on the impact of chronic pain on the spousal factors is scarce. With the ageing of the population, the burden of chronic conditions on health care and other support systems is likely to increase substantially (Busse, Blümel, Scheller-Kreinsen, & Zentner, 2010; Hiel et al., 2015). The impact of chronic pain on proximal support systems comprised of relatives, friends and spouses has been largely ignored in pain literature.

Previous research has indicated that spouses of individuals with chronic illness tend to be the most frequent informal caregivers (Bastawrous, 2013; Suso-Ribera, Yakobov, & Ribera-Canudas, 2016). The goal of the present study was to fill the gap in literature on the impact of informal caregiving on several life domains of spouses of patients with chronic pain. First, we aimed to investigate the impact of pain on several patient outcomes. We also examined the relationship between patients' pain and spousal outcomes (caregiving burden), as well as outcomes for both patients and spouses (i.e., marital adjustment, changes in occupational status, and changes in the distribution of household chores). We hypothesized that patients and their spouses would report changes in occupational status and household chores after the onset of patients' pain, with more pronounced changes in patients, relative to their spouses. We also anticipated that patients' pain severity, pain interference, and painrelated disability would be associated with perceived burden for their spouses and poorer marital adjustment.

Methods

Participants

The sample was comprised of 114 heterosexual couples (59% of patients and 41% of spouses were females). The average age of patients and spouses was 57.81 years (SD = 11.85, age range = 35 to 82 years) and 57.32 years (SD = 12.15, age range 25 to 82 years), respectively. Almost all participants were born in Spain. More than half of the participants completed less than 12 years of education. Approximately 24% of patients and 40% of spouses were employed at the time of assessment.

Procedure

Recruitment was conducted by the physicians during medical consultations at the Vall d'Hebron Hospital, a tertiary pain clinic. Over the course of 12 months (from January to December 2017), all patients attending the clinic with their spouses were offered to participate in this study. Five couples refused to participate due to time restrictions and 3 couples were excluded due very low literacy either in the patient or in the spouse. There was no participant selection in terms of the type of pain, as such patients in this study can be considered as a representative sample of the type of pain population attending the pain clinic.

All participants provided written informed consent as a condition of participation and received 15 EUR as compensation for completing the questionnaires. The research was approved by the Research Ethics Boards of the Vall d'Hebron Hospital. The procedures followed were also in accordance with the ethical standards of the Helsinki Declaration of 1975, as revised in 1983. Patients and their spouses were informed that their answers would not be shared with their partner. Participants completed a set of questionnaires in two separate rooms. All participants were asked to provide demographic information and complete measures of pain severity, pain interference, pain-related disability, marital satisfaction, and pre and post pain onset household activity distribution and occupational status. Spouses were also asked to complete a measure of perceived burden associated with caregiving. The inclusion criterion for informal caregiver was drawn from the definition provided by the Family Caregiver Alliance (2019), "an unpaid individual (i.e., a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks". All spouses in the present study have met the requirements for assuming the role of an informal caregiver. Patients with chronic pain attending the clinic were considered recipients of care. Even though approximately 53% of spouses also reported a degree of chronic pain, the levels of pain were significantly lower than those of patients.

Measures

Pain intensity and interference

Pain intensity and interference were measured with the Brief Pain Inventory (Cleeland & Ryan, 1994). Participants were asked to assess their pain intensity using a single numerical rating scale ranging from 0 = "No pain" to 10 = "Worst pain imaginable". Participants also reported the extent to which pain interfered with several life domains that include daily activities, mood, ability to walk, occupational or household activities, interpersonal relationships, sleep, and satisfaction with life. All interference items use an 11-point Likert scale with responses ranging from 0 = "Does not interfere" and 10 = "Completely interferes". The ratings for the seven areas were averaged to obtain an overall interference score. The internal consistency of the Brief Pain Inventory and its subscales (i.e., pain interference) has been demonstrated repeatedly in the literature (Atkinson et al., 2010).

Physical disability

The Pain Disability Index (Tait, Pollard, Margolis, Duckro, & Krause, 1987) was used to assess the degree to which pain-related disability disrupts function across seven domains of daily living that include home/family responsibilities, interpersonal, leisure, occupational, sexual, self-care, and life support activities. For each domain, participants indicated their pain-related disability on an 11-point Likert scale ranging from 0 = "No disability" 10 = "Total disability". The Pain Disability Index has shown to have high internal consistency, and to be associated with objective indices of disability (Tait, Chibnall, & Krause, 1990). Marital satisfaction

Marital satisfaction was assessed with the Revised Dyadic Adjustment Scale (Busby, Christensen, Crane, & Larson, 1995). The scale consists of 14 items that are grouped into three subscales: Consensus, Satisfaction, and Cohesion. A total score for overall dyadic adjustment can also be calculated by summing all subscales. The total score was used in the present study to reduce the number of statistical comparisons. The total score ranges from 0 to 69. Items in the Revised Dyadic Adjustment Scale use a Likert-type response scale. The response labels and the number of response points differ across items (i.e., some items have a 6-point agreement response scale, while other items use a 5-point frequency rating scale). The questionnaire has been shown to have high internal consistency and test-retest reliability (Anderson et al., 2014).

Impact of the patients' pain on occupational status

Change in occupational status and household activities

A list of the most frequent changes in occupational status was created *ad hoc* by the authors of the present study after a series of meetings with physicians, nurses, and patients at the tertiary pain clinic where the study was conducted. Participants were asked to select one of the options listed in Figure 1.

A list of 22 household activities was compiled *ad hoc* by the authors of the present study after a discussion with physicians, nurses, and patients at our tertiary pain clinic. Participants were asked to report who was responsible for each of the activities before and after the onset of the patients' pain using "*mostly me*", "*mostly my spouse*", "*equally shared*", or "*does not apply*" as response options (see Appendix I).

Caregiver burden

Spouses completed the short version of the Zarit Burden Interview to report their perceived caregiving burden (Zarit, Orr, & Zarit, 1985). This self-report questionnaire is comprised of 22 items and uses a 5-point Likert-type response scale with endpoints 0 = "Never" and 4 = "Always". The overall burden score ranges from a 0 to 88. The Zarit Burden Interview recommended cut-offs are 0 to 8 for low burden, 9 to 17 for moderate burden, 18 to 32 for high burden, and 33 and over for severe burden (Hébert, Bravo, & Préville, 2000). The questionnaire has been shown to have excellent psychometric properties (Bédard et al., 2001).

Data analysis

All data analyses were conducted with SPSS version 22 (IBM Corp., 2013). Descriptive data (means, standard deviations, and percentages) were computed for all study variables. Independent sample *t*-tests were computed to compare patients' and spouses' ratings of pain severity, disability, and pain interference.

Impact of the patients' pain on occupational status and household activities

Raw change scores were calculated for changes in household activities and occupational status pre and post pain onset for patients and their spouses.

Change in occupational status and household activities

For the purpose of the analyses described below, a "change in household activities" variable was calculated by subtracting household activities performed alone or with the partner before the onset of pain from household activities performed alone or with the partner after pain onset. This resulted in a continuous variable ranging from -22 (the responder gained 22 activities after pain onset) to 22 (the responder lost 22 activities after pain onset). The "change in occupational status" variable used in the correlations was set as binary (0 = no, 1 = yes), where "yes" represented a change in occupational status experienced by the responder.

Association between the patients' and the spouses' factors

Pearson correlations were used to examine the associations between patients' pain-related outcomes (pain intensity, pain-interference, and pain-related disability) and patients' and spouses' outcomes (changes in occupational status and household activities, marital satisfaction, and caregiver burden). Pearson correlations were also used to examine the associations between patients' and spouses' outcomes with sociodemographic factors (i.e., age, sex, duration of pain, hours spent caregiving, household income, and educational level). As a final step, a multivariate regression analysis was conducted to explore the contribution of both patient and spousal factors on spouse burden associated with caregiving. In a first block, demographic characteristics (i.e., age and sex) of dyads were entered. The second block included patient status, and the third block included spouse psychosocial factors. The variables to be included in blocks 2 and 3 were those that significantly correlated with caregiving burden in the bivariate analyses to reduce the risk of collinearity problems and suppression effects when including irrelevant predictors. To reduce the risk of type I errors, analyses used a restrictive alpha level of .001.

Results

Sample characteristics

Demographic information as well as means and standard deviations of study measures are summarized in Table 1. Most patients presented with chronic musculoskeletal pain with mixed etiology (both neuropathic and somatic characteristics). Most frequent pain locations for patients and spouses were low back (79.8% and 30.7%, respectively), neck (46.5% and 29.8%, respectively), and knee (15.8% and 17.5%, respectively).

On average, spouses reported caring for the patient for 1.57 hours every day (SD = 1.55, range = 0-4). More than half of spouses (52.6%) also indicated experiencing chronic pain at the time of assessment (> 6 months in duration). Compared to patients, spouses reported lower scores on pain intensity (M = 4.1, SD = 2.1, t = 6.3, p < .001), pain interference (M = 3.5, SD = 2.4, t = 7.4, p < .001), and disability (M = 2.8, SD = 2.5, t = 7.5, p < .001). Even though the pain reported by spouses was significantly lower than that of patients', we included a new dichotomous variable ("with chronic pain") in the correlation analyses (Table 2).

Occupational-status changes due to the patients' pain

In total, 65.8% of patients and 27.2% of spouses reported changes in occupational status due to the patient's pain-related condition (Fig. 1). The most frequent changes for patients included obtaining permanent disability compensation (17.5%), quitting a job without compensation (16.7%), early retirement (15.8%), and reducing the number of working hours (7.0%). Even though approximately 34% of patients with chronic pain maintained their full time occupational status, as revealed during an interview, patients who maintained full time status revealed that they significantly reduced their participation in household chores. For spouses, most frequent changes included anticipating their retirement (8.8%), quitting job without compensation (5.3%), increasing the number of working hours (4.4%), or being fired due to difficulties in combining work and the caregiving role (2.6%).

Changes in household chores due to the patients' pain

Of the 22 household chores, patients reported performing a median of 18 activities before pain onset (M = 16.75, SD = 5.86), which decreased to 12 activities at the time of assessment (M = 11.75, SD = 5.94, t = 9.25, p < .001, 95% IC = 3.93, 6.07). For spouses, the median number of activities before pain onset was 15 (M = 14.44, SD = 6.33), and at the time of the assessment increased to 17 (M = 16.16, SD = 5.00, t = -3.91, p < .001, 95% IC = -2.59, -3.91), respectively. Changes in household chores were dependent on sex characteristics, but only when assessed by patients (female patients perceived that they lost twice the number of activities than males, t = -2.42, p = .017, 95% CI = -4.74, -0.48). These changes were

independent of sex, when considering the spouses' appraisal, and the age of patients and spouses (all p > .05).

Marital adjustment and caregiving burden

According to the Zarit Burden Interview recommended cut-offs (Hébert et al., 2000), 25 spouses (21.9%) reported low burden (0 to 8 range), 30 spouses (26.3%) reported moderate burden (9 to 17 range), 41 spouses (36.0%) reported high burden (18 to 32 range), and 18 spouses (15.8%) reported severe burden (scores of 33 and over). According to the recommended cut-off score of 47.31 on the Revised Dyadic Adjustment Scale (Hébert et al., 2000), 27.2% of patients and 22.8% of spouses reported experiencing a distressed relationship.

The relationship between patient factors and patients' and spouses' outcomes

Patients' perceived disability and pain interference were associated with patients' and spouses' outcomes (Table 2). Specifically, pain-related disability was associated with greater changes in patient (r = .25, p < .001) and spouse occupational status (r = .30, p = .001), a decrease in patients' participation in household activities (r = .38, p = .001; note that positive scores in "change in household activities" should be interpreted as a decrease in the number of performed activities after pain onset), and spouses' caregiving burden (r = .33, p < .001).

Pain-interference was also associated with greater changes in patient (r = .25, p < .001) and spouse occupational status (r = .30, p = .001), a decrease in patients' participation in household activities (r = .38, p = .001), and an increase in caregiving burden (r = .33, p < .001).

Association between patients' and spouses' outcomes

In addition to the aforementioned patient factors, we investigated the associations between patients' change in occupational status, changes in household activities, and perceived marital adjustment with spouses' outcomes (change in occupational status and household activities, caregiving burden, perceived marital adjustment, and chronic pain). Zero-order correlation analyses revealed a negative association between patients' and spouses' changes in household activities (r = -.26, p = .006), and a positive association between patients' and spouses' reports of change in occupational status (r = .19, p = .041). Patients' and spouses' perceptions of marital adjustment were also significantly positively associated (r = .56, p < .001).

Analyses also indicated that marital maladjustment, reported by patients and spouses, as well as spouses' report of change in occupation due to the patients' pain were associated with caregiving burden. Spouses' perception of marital maladjustment and caregiving burden were higher in spouses who had chronic pain (r = -.22, p < .016 and r = .22, p < .017, respectively).

Predicting spouse burden from patient and spousal factors

Table 3 shows the results of the multivariate regression predicting spouse burden. As indicated earlier, candidate predictors were patient and spouse age and sex (block 1) and patient and spouse status factors that significantly correlated with spouse caregiving burden in the bivariate analyses reported in Table 2 (i.e., patient pain interference and physical disability and spouse change in occupational status, perceived marital adjustment, and chronic pain status). Both spousal and patient perceived marital adjustment were associated with spousal caregiving burden. However, only spouse perception of adjustment was included as a predictor of spouse burden. This decision was motivated by the fact that both measures of adjustment refer to the same construct and were strongly intercorrelated (r = .56, p < .001) and because spouse perception of marital adjustment (r = -.47, p < .001 vs. r = -.22, p < .05).

The overall model was significant and accounted for 37.8% of the variance. The results of the multivariate regression revealed an overall significant contribution of patient (block 2, R^2 change = 11.8%, p < .001) and spousal factors (block 3, R^2 change = 24.5%, p < .001) on spousal caregiving burden. Specifically, patient disability ($\beta = 0.36$, p = .002), spouses' change in occupational status ($\beta = 0.26$, p = .002), and spousal perception of marital adjustment ($\beta = -0.36$, p < .001) uniquely contributed to caregiving burden after controlling for patient and spouse demographic characteristics.

Discussion

The goal of the present study was to assess the influence of chronic pain on patients' and spouses' outcomes. As anticipated, both patients and spouses perceived that the patient's pain onset and chronification had impacted several life domains. For example, over 65% of patients and 25% of spouses reported occupational changes due to the patient's pain (most frequently discontinuation of employment). Changes also occurred at home in the form of household chore distribution (patients reported a decrease in responsibilities, whereas spouses reported an increase). Also, more than half of spouses reported a high-to-severe burden associated with caregiving of the patients with chronic pain. Both patient (physical disability) and spouse factors (perceived marital adjustment and, to a lesser extent, age) were found to be independently associated with spouse burden. Overall, these findings suggest that pain

onset and chronification affects not only patients, but also spouses, and points to patient and spouse factors as potential screening and therapeutic targets in clinical settings addressing spouse burden. The results of our study indicate that occupational changes occur in both patients with chronic pain and in their spouses. Specifically, we found that temporary or permanent occupational discontinuations following pain onset occurred in up to 62.3% of patients and in up to 20.2% of spouses. Our findings are consistent with previous research showing that both temporary and permanent work discontinuation are frequent in patients with chronic pain (De Sola, Salazar, Dueñas, Ojeda, & Failde, 2016). The present study findings suggest that permanent changes, such as anticipating retirement, obtaining permanent disability compensation, or discontinuing work without any compensation are frequent. It is possible, however, that this finding is biased as participants of this study were attending specialized pain clinics, and data may differ for community samples (De Sola et al., 2016). A significant contribution of the present investigation to existing research was the exploration of occupational consequences on spouses of patients with chronic pain. As anticipated, occupational changes were less frequent in spouses compared to patients. Yet, more than 27% of spouses reported experiencing occupational changes as a result of the patients' pain onset. Previous research elaborated on the negative impact of the patient's pain in a number of life areas of the spouses, including leisure time and sleep quality (Kemler & Furnée, 2002; Martire, Keefe, Schulz, Parris Stephens, & Mogle, 2013; Ojeda et al., 2014). Extending previous research, the present study evidenced the negative impact on the occupational status in at least 25% of spouses. An important finding was that 5.3% of spouses started working or increased the number of working hours, arguably to compensate for the loss of income associated with the patients' change in occupational status (Kemler & Furnée, 2002). This increase in working hours did not occur in any of the patients. Interestingly, though, discontinuing or reducing work (i.e., early retirement, stop working, obtaining a temporary sick leave, getting fired, or reducing the number of working hours) occurred in 20.3% of spouses, which may be explained by the need for informal care experienced in the chronic pain context.

In relation to the impact of pain on occupational status, it is important to note that, while the direct costs of chronic pain have become a matter of public concern in Europe and worldwide (Allegri, Lucioni, Mazzi, & Serra, 2018; Breivik et al., 2013; Phillips, 2009), these direct costs are insignificant when compared to indirect costs that include loss of productivity and costs of informal care for the family (Geurts et al., 2018; Tymecka-Woszczerowicz, Wrona, Kowalski, & Hermanowski, 2015). Considering this and the large

number of patients and spouses who reported having to change their occupational situation (frequently by discontinuing work), greater governmental efforts should be made to address the problem of job discontinuation in patients (i.e., adapting jobs to their condition) and spouses (i.e., providing some formal caregiving support).

Another important contribution of the present investigation was the examination of changes in the distribution of household activities. Previous research had revealed that, when compared to controls, patients with chronic pain invest more time in household activities (Kemler & Furnée, 2002). This same study also indicated that patients with chronic pain spend less time in paid employment when compared to controls, which might explain why they spend more time in household activities (i.e., they spend more time at home). In this study, we found the opposite change in household chores distribution. Specifically, spouses reported that they took on additional responsibilities at home following the onset of the patient's pain, while patients reported that they discontinued doing a significant number of tasks at home due to pain.

In relation to these changes in household activities, our bivariate analyses revealed an association between patient disability and decreased participation in household activities. This may be due to the inability of patients to keep up with the daily activities at home is, at least in part, due to the disability associated with pain. Alternatively, it is possible that decreased participation in household activities contributes to increased disability (i.e., physical deconditioning may favor loss of functioning and fatigue, which often contributes to a negative view of oneself (Olver & Hopwood, 2012). In both cases, the current findings findings are in line with previous research suggesting that the impact of pain on the family should not be overlooked (Dueñas et al., 2016; Flor, Turk, & Berndt Scholz, 1987; Schwartz, Slater, Birchler, & Atkinson, 1991; Strunin & Boden, 2004).

The results of the present study revealed that spouse burden was frequent, with less than 25% of spouses reporting low perceived burden, and more than 50% of the spouses reporting high-to-severe burden levels. Factors associated with spouse burden included patients' reports of disability and pain interference, as well as spousal report of change in occupational status and marital adjustment. In a previous study, patients' pain intensity was associated with poor outcomes in the spouse in the form of poor sleep quality (Martire et al., 2013). The present study provides further evidence showing that patient status variables are important factors associated with spouse burden. Thus, patient status variables may allow clinicians or policy makers to prioritize assistance for the spouses at risk (i.e., psychological support or economic compensation).

In addition to the impact of the patient's pain on patient and spouse status, we found that chronic pain is also common in spouses of patients with chronic pain (Leonard & Cano, 2006). Extending previous research, the present investigation revealed that chronic pain in spouses is associated with poorer marital adjustment and increased burden associated with caregiving. Moreover, this study revealed that the onset and chronicity of pain is not only associated with significant occupational and household-related activity changes for the patient (Dueñas et al., 2016; Strunin & Boden, 2004), but also has significant impact on changes in occupational and household activities of the spouses. As anticipated, patient status variables (i.e., pain-related disability and pain interference and disability) were associated with spousal outcomes (i.e., perceived burden and change in occupational status). Finally, the results from regression equation revealed that patient's physical disability, spousal change in occupational status, and perceived marital adjustment emerged as unique contributors to burden associated with caregiving. Contrary to our expectations, pain intensity was not associated with perceived spouse burden. This finding is line with research that showed that pain intensity is not unequivocally associated with patient functioning, and has indicated that patient's appraisals are important in the prediction of the impact of pain on disability (Suso-Ribera, Sullivan, & Suso-Vergara, 2018). Consistent with this idea, patient disability, which does not necessarily correspond with patient pain levels, was the key patient factor associated with spouse burden.

There are several limitations in the present investigation. First, causality cannot be established due to the cross-sectional and non-experimental nature of the study. For instance, we cannot establish whether change in caregiver occupational status might be a reflection of burden or a potential factor contributing to it. While our findings suggest that changes in spousal occupational status should receive more attention in pain research, a qualitative or, preferably, a prospective longitudinal study would be needed to reach a more robust conclusion about the direction of associations. Additionally, in the present study we only examined the caregiving role of the spouses which prevents from generalizing the present study findings to other informal caregivers (i.e., children, other relatives, friends who also act as informal caregivers). Finally, the strength of the associations between the study variables ranged between small to moderate; and replication of study findings is needed to bolster confidence in these findings.

Conclusions

The present study is among the first to examine the impact of patients' chronic pain on spousal outcomes. While the impact of pain on a number of spousal outcomes, such as emotional well-being and sleep quality, have been previously reported (Dueñas et al., 2016; Flor et al., 1987; Schwartz et al., 1991; Strunin & Boden, 2004), the present findings suggest that more attention should be paid to occupational, household, and burden-related outcomes of spouses of patients with chronic pain. The present study calls for increased awareness and management of the burden associated with informal caregiving in the context of chronic pain. Our results lay a foundation for the development and implementation of policies that change the provision of health care to include both the patient and caregivers in treatment. Future studies are needed to provide additional information relevant to the impact of pain on caregivers on the family. Some of the avenues of research should focus on the impact of pain on caregivers other than spouses. Other lines of research are necessary to explore the costeffectiveness of different policies that aim at minimizing the impact of pain on occupational status and household chores (i.e., adapting the home and the work environment), as well as conducting trials to investigate the effectiveness of stress and burden management programs for informal caregivers of patients with chronic pain.

Acknowledgments: We would like to thank the staff at the Pain Clinic of the Vall d'Hebron Hospital, especially Dr. M.V. Ribera Canudas, for their support during recruitment, as well as Dr. Michael J.L. Sullivan for his insights during study conceptualization.

Data Availability: The data underlying the manuscript will be made available upon reasonable request.

Author Contributions: CSR and EY conceptualized and designed the study. The initial analyses were conducted by CSR with the support of EY, AGP, and JSC, who provided insights and helped in the interpretation of data. CSR and EY prepared the first draft of the manuscript, which was then revised critically by AGP and JSC. After a series of revisions, this final version was approved by all authors.

References

Abbasi, M., Dehghani, M., Keefe, F. J., Jafari, H., Behtash, H., & Shams, J. (2012). Spouse-

assisted training in pain coping skills and the outcome of multidisciplinary pain management for chronic low back pain treatment: A 1-year randomized controlled trial. *European Journal of Pain*, *16*(7), 1033–1043. https://doi.org/10.1002/j.1532-2149.2011.00097.x

- Allegri, M., Lucioni, C., Mazzi, S., & Serra, G. (2018). Social cost of chronic pain in Italy. Global & Regional Health Technology Assessment: Italian; Northern Europe and Spanish, 2(1), GRHTA.5000187. https://doi.org/10.5301/grhta.5000187
- Anderson, S. R., Tambling, R. B., Huff, S. C., Heafner, J., Johnson, L. N., & Ketring, S. A. (2014). The Development of a Reliable Change Index and Cutoff for the Revised Dyadic Adjustment Scale. *Journal of Marital and Family Therapy*, 40(4), 525–534. https://doi.org/10.1111/jmft.12095
- Atkinson, T. M., Mendoza, T. R., Sit, L., Passik, S., Scher, H. I., Cleeland, C., & Basch, E. (2010). The Brief Pain Inventory and Its "Pain At Its Worst in the Last 24 Hours" Item: Clinical Trial Endpoint Considerations. *Pain Medicine*, *11*(3), 337–346. https://doi.org/10.1111/j.1526-4637.2009.00774.x
- Bastawrous, M. (2013). Caregiver burden--a critical discussion. International Journal of Nursing Studies, 50(3), 431–441. https://doi.org/10.1016/j.ijnurstu.2012.10.005
- Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. a, & O'Donnell, M. (2001). The Zarit Burden Interview: a new short version and screening version. *The Gerontologist*, 41(5), 652–657. https://doi.org/10.1093/geront/41.5.652

Breivik, H., Collett, B., Ventafridda, V., Cohen, R., & Gallacher, D. (2006). Survey of chronic pain in Europe: Prevalence, impact on daily life, and treatment. *European Journal of Pain*, *10*(4), 287–287. https://doi.org/10.1016/j.ejpain.2005.06.009

- Breivik, H., Eisenberg, E., & O'Brien, T. (2013). The individual and societal burden of chronic pain in Europe: The case for strategic prioritisation and action to improve knowledge and availability of appropriate care. *BMC Public Health*, *13*(1). https://doi.org/10.1186/1471-2458-13-1229
- Busby, D. M., Christensen, C., Crane, D. R., & Larson, J. H. (1995). A revision of the Dyadic Adjustment Scale for use with distressed and nondistressed couples: Construct hierarchy and multidimensional scales. *Journal of Marital and Family Therapy*, 21(3), 289–308. https://doi.org/10.1111/j.1752-0606.1995.tb00163.x
- Busse, R., Blümel, M., Scheller-Kreinsen, D., & Zentner, A. (2010). Tackling chronic disease in Europe: Strategies, interventions and challenges. In *Observatory Studies* (Vol. 20). https://doi.org/10.1558/poth.v0i4.65

- Cleeland, C. S., & Ryan, K. M. (1994). Pain assessment: global use of the Brief Pain Inventory. *Annals of the Academy of Medicine, Singapore*, 23(2), 129–138. Retrieved from http://europepmc.org/abstract/MED/8080219
- De Sola, H., Salazar, A., Dueñas, M., Ojeda, B., & Failde, I. (2016). Nationwide cross-sectional study of the impact of chronic pain on an individual's employment:
 Relationship with the family and the social support. *BMJ Open*, 6(12).
 https://doi.org/10.1136/bmjopen-2016-012246
- Dueñas, M., Ojeda, B., Salazar, A., Mico, J. A., & Failde, I. (2016). A review of chronic pain impact on patients, their social environment and the health care system. *Journal of Pain Research*, 9, 457–467. https://doi.org/10.2147/JPR.S105892
- Family Caregiver Alliance. (2019). National Center on Caregiving. Retrieved October 4, 2019, from https://www.caregiver.org
- Flor, H., Turk, D. C., & Berndt Scholz, O. (1987). Impact of chronic pain on the spouse:
 Marital, emotional and physical consequences. *Journal of Psychosomatic Research*, *31*(1), 63–71. https://doi.org/10.1016/0022-3999(87)90099-7
- Forsythe, L. P., Romano, J. M., Jensen, M. P., & Thorn, B. E. (2012). Attachment style is associated with perceived spouse responses and pain-related outcomes. *Rehabilitation Psychology*, 57(4), 290–300. https://doi.org/10.1037/a0030083
- Geurts, J. W., Willems, P. C., Kallewaard, J.-W., van Kleef, M., & Dirksen, C. (2018). The Impact of Chronic Discogenic Low Back Pain: Costs and Patients' Burden. *Pain Research and Management*, 2018, 1–8. https://doi.org/10.1155/2018/4696180
- Hébert, R., Bravo, G., & Préville, M. (2000). Reliability, validity and reference values of the zarit burden interview for assessing informal caregivers of community-dwelling older persons with dementia. *Canadian Journal on Aging*, *19*(4), 494–507. https://doi.org/10.1017/S0714980800012484
- Hiel, L., Beenackers, M. A., Renders, C. M., Robroek, S. J. W., Burdorf, A., & Croezen, S. (2015). Providing personal informal care to older European adults: Should we care about the caregivers' health? *Preventive Medicine*, 70, 64–68. https://doi.org/10.1016/j.ypmed.2014.10.028

Hunt, G. G., Barrett, L., & Lutz, S. (2009). *Caregiving in the U*. S. IBM Corp. (2013). *IBM SPSS Statistics for Windows, Version 22.0*. Armonk, NY: IBM Corp.

Kemler, M. A., & Furnée, C. A. (2002). The impact of chronic pain on life in the household. *Journal of Pain and Symptom Management*, 23(5), 433–441. https://doi.org/10.1016/S0885-3924(02)00386-X

- Leonard, M. T., & Cano, A. (2006). Pain affects spouses too: personal experience with pain and catastrophizing as correlates of spouse distress. *Pain*, *126*(1–3), 139–146. https://doi.org/10.1016/j.pain.2006.06.022
- Martire, L. M., Keefe, F. J., Schulz, R., Parris Stephens, M. A., & Mogle, J. a. (2013). The impact of daily arthritis pain on spouse sleep. *Pain*, 154(9), 1725–1731. https://doi.org/10.1016/j.pain.2013.05.020
- Miller, L. R., & Cano, A. (2009). Comorbid chronic pain and depression: who is at risk? *The Journal of Pain*, 10(6), 619–627. https://doi.org/10.1016/j.jpain.2008.12.007
- Ojeda, B., Salazar, A., Dueñas, M., Torres, L. M., Micó, J. A., & Failde, I. (2014). The impact of chronic pain: The perspective of patients, relatives, and caregivers. *Families*, *Systems, & Health*, 32(4), 399–407. https://doi.org/10.1037/fsh0000069
- Olver, J. S., & Hopwood, M. J. (2012). Depression and physical illness. *Medical Journal of Australia*, 1(October), 9–12. https://doi.org/10.5694/mjao12.10597
- Phillips, C. J. (2009). The Cost and Burden of Chronic Pain. *Reviews in Pain*, *3*(1), 2–5. https://doi.org/10.1177/204946370900300102
- Raichle, K. A., Romano, J. M., & Jensen, M. P. (2011). Partner responses to patient pain and well behaviors and their relationship to patient pain behavior, functioning, and depression. *Pain*, 152(1), 82–88. https://doi.org/10.1016/j.pain.2010.09.015
- Schwartz, L., Slater, M., Birchler, G., & Atkinson, J. (1991). Depression in spouses of chronic pain patients: the role of patient pain and anger, and marital satisfaction. *Pain*, 44(1), 61–67.
- Seibert, L. A., Miller, J. D., Pryor, L. R., Reidy, D. E., & Zeichner, A. (2010). Personality and laboratory-based aggression: Comparing the predictive power of the Five-Factor Model, BIS/BAS, and impulsivity across context. *Journal of Research in Personality*, 44(1), 13–21. https://doi.org/10.1016/j.jrp.2009.09.003
- Strunin, L., & Boden, L. I. (2004). Family consequences of chronic back pain. Social Science and Medicine, 58(7), 1385–1393. https://doi.org/10.1016/S0277-9536(03)00333-2
- Suso-Ribera, C, Camacho-Guerrero, L., Osma, J., Suso-Vergara, S., & Gallardo-Pujol, D. (2019). A reduction in pain intensity is more strongly associated with improved physical functioning in frustration tolerant individuals: A longitudinal moderation study in chronic pain patients. *Frontiers in Psychology*, *10*(APR), 1–12. https://doi.org/10.3389/fpsyg.2019.00907
- Suso-Ribera, C, Yakobov, E., & Ribera-Canudas, M. V. (2016). Coping is Important for Spouses Too: Impulsive coping moderates the relationship between spouses' perception

of the patients' pain intensity and spouses' physical health. *Clinical Journal of Pain*, 32(9), 1. https://doi.org/10.1097/AJP.00000000000328

- Suso-Ribera, Carlos, Sullivan, M. J. L., & Suso-Vergara, S. (2018). Pain Intensity Is Not
 Always Associated with Poorer Health Status: Exploring the Moderating Role of Spouse
 Personality. *Pain Research and Management*, 2018, 1–9.
 https://doi.org/10.1155/2018/7927656
- Tait, R. C., Chibnall, J. T., & Krause, S. (1990). The Pain Disability Index: psychometric properties. *Pain*, 40(2), 171–182. https://doi.org/10.1016/0304-3959(90)90068-O
- Tait, R. C., Pollard, C. A., Margolis, R. B., Duckro, P. N., & Krause, S. J. (1987). The Pain Disability Index: psychometric and validity data. *Archives of Physical Medicine & Rehabilitation*, 68(7), 438–441. https://doi.org/10.1016/0304-3959(90)90068-O
- Tymecka-Woszczerowicz, A., Wrona, W., Kowalski, P. M., & Hermanowski, T. (2015). Indirect costs of back pain - Review. *Polish Annals of Medicine*, 22(2), 143–148. https://doi.org/10.1016/j.poamed.2015.07.003
- Verbakel, E. (2014). Informal caregiving and well-being in Europe: What can ease the negative consequences for caregivers? *Journal of European Social Policy*, 24(5), 424– 441. https://doi.org/10.1177/0958928714543902
- Wetherell, J. L., Afari, N., Rutledge, T., Sorrell, J. T., Stoddard, J. A., Petkus, A. J., ...
 Atkinson, J. H. (2011). A randomized, controlled trial of acceptance and commitment therapy and cognitive-behavioral therapy for chronic pain. *Pain*, *152*(9), 2098–2107. https://doi.org/10.1016/j.pain.2011.05.016
- Winblad, B., Amouyel, P., Andrieu, S., Ballard, C., Brayne, C., Brodaty, H., ... Zetterberg,
 H. (2016). Defeating Alzheimer's disease and other dementias: A priority for European science and society. *The Lancet Neurology*, *15*(5), 455–532.
 https://doi.org/10.1016/S1474-4422(16)00062-4
- Zarit, S. H., Orr, N. K., & Zarit, J. M. (1985). *The hidden victims of Alzheimer's disease: Families under stress*. New York: New York University Press.

Table 1. Sample sociodemographic characteristics

Table 2. Means, standard deviations, and bivariate associations between patient pain and disability factors and patient and spouse outcomes

Note. Change in household activities was calculated by subtracting household activities performed alone or with the partner before the onset of pain from household activities performed alone or with the partner after pain onset. Items "change in occupational status" and "has chronic pain" are binary (0 = no, 1 = yes) and reported percentages correspond to "yes".

* p < .05, ** p < .01, *** p < .001

Table 3. Predicting spousal caregiving burden from patient and spouse factors *Note.* "change in occupational status" and "has chronic pain" are binary (0 = no, 1 = yes). Beta is standardized. R^2 is adjusted

Figure 1. Changes in occupational status attributed to pain onset. Numbers represent percentages.

Appendix I. List of household chores

Instructions (before pain onset version): *Listed below are various household activities.* **Prior to the onset of your** (patient version) / **your partner's** (spouse version) **pain condition**, who had the primary responsibility for each of the activities listed below?

	Mostly me	Mostly my	Equally shared	Doesn't apply		
		spouse				
Cleaning the kitchen						
Vacuuming/sweeping floors						
Mopping floors						
Cleaning bathrooms						
Laundry						
Shopping for groceries						
Shopping for clothes						
Paying bills						
Organizing recreational outings						
Organizing social outings						
Washing dishes						
Making beds						
Putting out the garbage						
Washing windows						
Dusting furniture						
Folding clothes						
Preparing breakfast						
Preparing lunch						
Preparing dinner						
Ironing						
Setting the table						
Caring for a sick relative other						

than spouse		

Instructions (after pain onset version): Who has **now** the primary responsibility for each of the activities listed below?

. .

	Mostly me	Mostly my	Equally shared	Doesn't apply
		spouse		
Cleaning the kitchen				
Vacuuming/sweeping floors				
Mopping floors				
Cleaning bathrooms				
Laundry				
Shopping for groceries				
Shopping for clothes				
Paying bills				
Organizing recreational outings				
Organizing social outings				
Washing dishes				
Making beds				
Putting out the garbage				
Washing windows				
Dusting furniture				
Folding clothes				
Preparing breakfast				
Preparing lunch				
Preparing dinner				
Ironing				
Setting the table				
Caring for a sick relative other				
than spouse				

Table 1. Sample sociodemographic characteristics

	Patients	Spouses			
Educational level					
No studies/Primary Education	42 (36.8%)	41 (36.0%)			
Secondary Education	23 (20.2%)	22 (19.3%)			
Technical Studies	25 (21.9%)	25 (21.9%)			
University Studies or higher	24 (21.1%)	26 (22.8%)			
Yearly household income					
< 17,500 euros	00 euros 42 (36.8%)				
17,501 to 24,000 euros	28 (24.6%)				
> 24,000 euros	44 (38.6%)				
Current occupational status					
Active worker	27 (23.7%)	45 (39.5%)			
Unemployed / homemaker	12 (10.5%)	19 (16.7%)			
Temporary sick leave	12 (10.5%)	1 (0.9%)			
Permanent disability compensation	25 (21.9%)	9 (7.9%)			
Retired	38 (33.3%)	40 (35.1%)			

	Mean (SD) / %	2	3	4	5	6	7	8	9	10	11
Patient factors											
1. Pain intensity	5.9 (1.7)	.39***	.35***	.09	.07	01	.10	03	.15	.03	.12
2. Pain interference	6.2 (2.1)		.73***	.19*	.36***	11	.23*	12	.19*	09	.01
3. Disability	43.0 (16.0)			.25**	.38***	15	.30**	09	.33***	07	.01
Patient outcomes											
4. Change in occupational status	65.8%				.15	20*	.19*	<.01	.10	12	.02
5. Change in household activities	5.0 (5.8)					.11	.13	26**	.09	.08	15
6. Marital adjustment	50.8 (8.9)						08	01	22*	.56***	17
Spouse outcomes											
7. Change in occupational status	27.2%							02	.42***	20*	.07
8. Change in household activities	-1.7 (4.7)								03	.12	.08
9. Caregiving burden	41.7 (12.1)									47***	.22*
10. Marital adjustment	51.9 (7.2)										22*
11. Has chronic pain	52.6%										

Table 2. Means, standard deviations, and bivariate associations between patient pain and disability factors and patient and spouse outcomes

Note. Change in household activities was calculated by subtracting household activities performed alone or with the partner before the onset of pain from household activities performed alone or with the partner after pain onset. Items "change in job status" and "has chronic pain" are binary (0 = no, 1 = yes) and reported percentages correspond to "yes".

* p < .05, ** p < .01, *** p < .001

	β	р	95% CI	R^2 change	F change	р
Patient and spouse demographics				.033	1.95	.108
Age spouse	-0.38	.049	-0.76, -0.01			
Sex spouse	0.09	.763	-11.77, 16.01			
Age patient	0.34	.070	-0.03, 0.73			
Sex patient	0.02	.936	-13.84, 15.01			
Patient status				.118	7.83	<.001
Patient pain interference	-0.16	.143	-2.19, 0.32			
Patient physical disability	0.36	.002	0.76, 3.18			
Spouse factors				.245	15.07	<.001
Spouse occupational change	0.26	.002	2.68, 11.36			
Spousal marital adjustment	-0.36	<.001	-0.87, -0.34			
Spouse has chronic pain	.0.12	.133	-0.87, 6.52			

Table 3. Predicting spousal caregiving burden from patient and spouse factors

Note. "change in occupational status" and "has chronic pain" are binary (0 = no, 1 = yes). Beta is standardized. R^2 is adjusted



