

Families, Systems, and Health

The Impact of Chronic Pain: the Perspective of Patients, Relatives and Caregivers. --Manuscript Draft--

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Abstract:	<p>Objective. To assess the impact of chronic pain on the family environment from the patient's, relative's and caregiver's perspective.</p> <p>Methods. A cross-sectional study on a representative sample of Spanish adults that suffered pain at least 4 days a week for ≥ 3 months. The relatives and caregivers of patients that fulfilled these criteria were also studied. Data was gathered on the characteristics of pain and the perception of its impact on the family environment. Logistic regression models were used to reveal the variables associated to the impact of pain on the family.</p> <p>Results. From a total of 1,957 subjects, 325 suffered chronic pain and 34.6% of them perceived that their pain affected their family environment. These patients recognized a stronger impact when their relatives were sad (OR=3.61;CI:1.57,8.27) and had modified the leisure activities because of the pain (OR=3.62;CI:1.56,8.38). Among the 131 relatives, 51.2% perceived that pain was affecting the family, causing changes in their leisure activities (OR=1.17;CI:1.04,9.94) and sleep disturbance (OR=1.40;CI:1.32,12.58). Among the 36 caregivers, mainly women over 50 years of age, 66.7% indicated that pain affected the family, although 72.8% were satisfied with the help they provided.</p> <p>Conclusion. The impact of chronic pain on the family is very strong, although it is perceived distinctly by patients, relatives and caregivers. Recognition that factors related to pain affect the family's well-being, and adopting a global approach to pain that takes into consideration the family's experiences, could improve the effective pain-related outcome, and enhance the patient's and relative's quality of life.</p>
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	<p>We are really hopeful that you are satisfied with the work done. I am looking forward to hearing from you. Ojeda B.</p>
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Colleen T. Fogarty & Larry Mauksch

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Dear Dr. Fogarty and Dr. Mauksch,

We would like to thank you for offering us the opportunity to revise and resubmit our article “The Impact of Chronic Pain: the Perspective of Patients, Relatives and Caregivers” (FSH-2013-1106R1) to Family, Systems & Health. We also appreciate the suggestions and comments made by the reviewers and the editor during the review process.

In light of this, most of the required modifications have been made to the manuscript, as reflected in our point by point responses to the issues raised.

This paper addresses the topics related to the biopsychosocial model of pain whose significance has been demonstrated to improve strategies in research and management of patients with chronic pain. The study is part of a nationwide epidemiological study on the prevalence of chronic pain in the Spanish general population, submitted to Pain Medicine currently under review. We inform you in advance that we attached a table as supplementary material because we consider this information as a relevant part of the study.

Neither the entire paper nor any part of its content has been published or has been accepted by another journal. The paper is not being submitted to any other journal. All the authors have made substantial contributions to the conception and design of the study and have been involved in drafting the manuscript. The authors declare that they have no conflicts of interest.

Once again we would like to take this opportunity to thank you in advance for your time and consideration.

Yours sincerely,

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The Impact of Chronic Pain: the Perspective of Patients, Relatives and Caregivers.

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The Impact of Chronic pain: the perspective of Patients, Relatives and Caregivers

Abstract

Objective. To assess the impact of chronic pain on the family environment from the patient's, relative's and caregiver's perspective.

Methods. A cross-sectional study on a representative sample of Spanish adults that suffered pain at least 4 days a week for ≥ 3 months, and on relatives and caregivers of patients that fulfilled these criteria. The characteristics of pain and the perception of its impact on the family environment was assessed, using logistic regression models to reveal the variables associated with the impact of pain on the family.

Results. From a total of 1,957 subjects, 325 suffered chronic pain and 34.6% of them perceived that their pain affected their family environment. These patients recognized a stronger impact when their relatives were sad (OR=3.61; CI:1.57, 8.27) and had modified the leisure activities because of the pain (OR=3.62; CI:1.56, 8.38). Among the 131 relatives, 51.2% perceived that pain was affecting the family, causing changes in their leisure activities (OR=1.17; CI:1.04, 9.94) and sleep disturbance (OR=1.40; CI:1.32, 12.58). Of the 36 caregivers, mainly women over 50 years of age, 66.7% indicated that pain affected the family, although 72.8% were satisfied with the help they provided.

Conclusion. Chronic pain has a very strong impact on the family, although this is perceived distinctly by patients, relatives and caregivers. Recognising that factors related to pain affect the family's well-being, and adopting a global approach to pain that takes into consideration the family's experiences, should improve the therapeutic response, and enhance the patient's and relative's quality of life.

Key words. Chronic pain; Family; Caregivers; Pain impact; Mood changes

Introduction

Chronic pain is a common condition, and a worldwide source of suffering and disability (Goldberg & McGee, 2011). Yet pain not only has a strongly impact on a patient's quality of life (Azevedo, Costa-Pereira, Mendonça, Dias, & Castro-Lopes, 2012; Langley, Ruiz-Iban, Molina, De Andres, & Castellón, 2011) but it is also a major concern for their relatives and caregivers. Relatives and caregivers of patients with pain often have to carry out tasks they are not used to (e.g. monitoring pain, giving medication and dealing with side effects) and they often feel some uncertainty about performing these tasks adequately (Bigatti & Cronan, 2002; Greene Bush & Pargament, 1997; Meeker, Finnell, & Othman, 2011; Neumann & Buskila, 1997; Söderberg, Strand, Haapala, & Lundman, 2003). This may negatively affect the caregivers, generating feelings of sadness, burden, frustration and helplessness (Ferrell, Cohen, Rhiner, & Rozek, 1991). Indeed, greater pain intensity has been associated with depression in the caregiver (Redinbaugh, Baum, DeMoss, Fello, & Arnold, 2002), and caregivers' discomfort may even be greater than the pain reported by the patient (Yeager, Miaskowski, Dibble, & Wallhagen, 1995). However, despite recognizing the damaging effects of pain, inconsistent results have been obtained when comparing the impact of pain on relatives and patients (Kemler & Furnée, 2002; Miaskowski, Zimmer, Barrett, Dibble, & Wallhagen, 1997).

In broadly accepted biopsychosocial models, many factors influence the outcome of chronic pain, including the family environment, which also influences the maintenance of the perpetuating problems associated with pain. Theoretical models to assess the impact of chronic pain on the family, such as the systems theory, operant conditioning and cognitive-behavioural transactional models (Fordyce, 1976; Lewandowski, Morris, Draucker, & Risko, 2007), positioned informal support provided by the family as a focal point for policies, as reflected by the platform "Societal Impact of Pain" of the European Federation of IASP

Chapters (Kress, 2012). Nevertheless, more studies should evaluate the factors affecting the family's well-being from the patient's, relative's and caregiver's point of view.

Accordingly, this study assessed the impact of chronic pain on the family environment from the perspective of the patient, relatives and caregivers, evaluating the factors that produced the strongest impact on the family. It was hypothesized that the effect of pain would be perceived more strongly by relatives than by patients, especially by those acting as caregivers. Moreover, it was expected that feeling sad and/or anxious, suffering disturbed sleep and a loss or decrease in social activities, would produce the strongest impact on the family. The recognition of these factors could guide interventions that might improve the family environment and reduce the overall severity of pain.

Methods

Sample design and subjects

This cross-sectional study was carried out on a representative sample of the general Spanish adult population (≥ 18 years of age) obtained by multistage stratified sampling and designed to determine the prevalence of chronic pain in Spain.

In the first sampling phase, the aging criterion was calculated from the ratio of the population older than 65 years and those younger than 15 in function of the geographic area, given the effect of these factors on pain prevalence (Carmona, Ballina, Gabriel, & Laffon, 2001; Catala et al., 2002; Miro et al., 2007), generating four strata (ratios: ≤ 1.0 ; 1.0-1.5; 1.5-2.0; > 2.0). In the second phase, the number of towns within each stratum was determined, classifying them into four groups in function of size and selecting the towns randomly but proportional to the total number of towns in the group.

In the third phase, sampling units (telephone numbers) were randomly selected from each town using the telephone numbers in the InfobelEspaña Office v.7.1 directory. Thus, the target population represented approximately 80.6% of all Spanish homes and 72.5% of the eligible Spanish population. Based on the overall prevalence data, and that according to sex and age (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006; Catala et al., 2002), and considering a response rate of 42% based on other studies using telephone interviews (Davern et al., 2010), the final number of sampling units required was estimated to be 4,595.

In a fourth sampling phase, the subjects interviewed were selected randomly according to established sex and age quotas. After a maximum of three attempts, calling at different times of the day, the phone number was substituted by another from the corresponding sex and age quota in that population if no contact was established.

Three different groups of subjects were interviewed (Fig. 1):

1. Chronic pain patients who suffered pain at any site at least 4 days a week in the previous 3 months.
2. A relative living with a patient who fulfils criterion 1.
3. The caregiver an individual who fulfils criterion 2, and provides most of the care and attention to the patient while not belonging to any formal network of carers (del Mar García-Calvente, Mateo-Rodríguez, & Maroto-Navarro, 2004; Ferrell, 2001). These subjects were identified through the question: *Are you the family member who is undertaking most of the care of a relative with pain at home?*

All subjects provided their informed consent before participating in the study.

Instruments and procedure

Sociodemographic data (age, sex and academic level) and information regarding the perceived impact of pain on the family was collected between February and June 2011 by

trained interviewers using structured computer assisted telephone interviews (CATIs) drawn up on the basis of information from other qualitative research studies and distinct surveys carried out in Spain (Closs, Staples, Reid, Bennett, & Briggs, 2009; García, Mateo, & Gutierrez, 1999; Instituto Nacional de Estadística (INE), 2006; Instituto Nacional de Estadística (INE), 2008; Strunin & Boden, 2004; Zarit, Reeve, & Bach-Peterson, 1980). The interviewee assessed the global impact of pain on the family (Q1), coded as not at all, little, moderate, quite a lot and a lot. The effect of pain on sadness (Q2), nervousness (Q3), sleep disturbances (Q4), work changes (Q5), leisure activities (Q6) and family economy (Q7) was also assessed when the response to Q1 was from “moderate” to “a lot”.

Patients were also asked to characterise their pain (duration and intensity, measured as: mild, moderate, severe and unbearable pain: (Poulain, Langlade, & Goldberg, 1997), and to define the number and location of painful areas. How pain limited the subject’s daily activities, the effect of pain on their mood, changes in their working environment, and their level of satisfaction with the help provided by their family was recorded. Likewise, relatives were questioned about the patient’s capacity to deal with pain, and caregivers were asked about the consequences of caring on their own health, mood, social life and time they dedicated to themselves.

Statistical analysis

The frequency, the central tendency and the dispersion of the results was analyzed. Differences between the groups were detected with the χ^2 , U Mann-Whitney or H Kruskal-Wallis tests, applying a Bonferroni correction to multiple comparisons where appropriate. To identify factors associated with the impact of pain on the family environment, two logistic regression models were constructed: one targeting patient perceptions (Model 1), and the other the relative’s perceptions (Model 2). In both models the dependent variable was the

global impact of pain by the patient or relative (Q1), grouped as “A little/Moderate” vs “Quite a Lot/A Lot” to increase the number of subjects in each group and to build binary logistic regression models.

Model 1 included explanatory variables directly related to the patient (age, sex, academic level, pain characteristics, limitations on daily life, effect of pain on mood and changes in the working environment) and variables related to their perception of sadness (Q2), nervousness (Q3), sleep disturbances (Q4), work (Q5), leisure activities (Q6) and economic change in the family environment due to pain (Q7). Model 1 also included the patient’s level of satisfaction with the help provided by the family. Model 2 (relative perception) included the explanatory variables of age, sex, academic level, perception of sadness (Q2), nervousness (Q3), sleep disturbances (Q4), work (Q5), leisure activities (Q6) and economic change in the family due to pain (Q7), and their opinion about the patient’s capacity to cope with their pain.

There were too few caregivers to construct a logistic regression model.

Results

General characteristics of patients suffering from chronic pain

Of 1,957 subjects surveyed, 325 (16.6%) suffered from chronic pain (Table 1) with a mean duration of approximately 10 years, and 45.4% of them experienced pain at multiple locations. The intensity of pain was considered to be moderate to severe by 78.4% of the patients and while 32.2% felt quite or very sad, 29.3% felt quite or very anxious. Likewise, 50 to 64% of the patients indicated that pain limited their daily activities to some extent and 12% referred to having left or lost their job because of their pain (data not shown).

The patient’s perspective of the effects of pain

Almost 35% of the chronic pain patients considered that their pain affected the family environment moderately or a lot, indicating that their relatives were sad (67%), nervous (46.5%), suffered sleep disturbances (37%) or that they had abandoned or modified their leisure activities due to their pain (42.7%: Table 2). However, patients were generally satisfied or very satisfied (77.4%) with the help received from their relatives.

Men more often indicated that their relatives were nervous (52.4% vs. 45.0%), suffered altered sleep patterns (56.5% vs. 31.2%), or had lost or left their jobs (29.2% vs. 13.3%), and that the family was experiencing economic problems due to the pain condition (26.1% vs. 13.6%: Table S1). Similarly, opinions were influenced by the age and academic level of the subjects, whereby younger patients more often stated that their relatives were nervous because of their pain than older ones (58.1% vs. 30.3%), and middle-age patients more frequently stated that the family's leisure activities had been modified as a consequence of their pain than older ones (54.5% vs. 28.2%: Table S1). Generally, patients with only primary or secondary education (PE and SE) more negatively viewed the effect of pain on the family than those with university studies (US), particularly in terms of the perception that their relatives were sad (PE 88.9% vs. US 41.7%) and nervous (PE 70.8% vs. US 23.1%: Supplementary Table 1S).

The relative's perspective

Of 131 relatives surveyed (Table 1), only 12 were relatives of patients previously interviewed, yet as no differences were evident in the impact of pain they reported these 131 subjects were analyzed together. Relatives considered that pain was affecting their family environment moderately or a lot more often than patients (51.2% vs. 34.6%; $p < 0.001$), while 63.2% of them perceived sadness and 47.5% reported changes in their leisure activities

(Table 2). Moreover, and unlike patients, sex, age or educational level did not influence their perceived impact of pain on the family environment.

In terms of the impact of pain on the family (Q2-Q7), patients more frequently indicated that members of their families had left or lost their jobs (patients 16.8% vs. relatives 6.0%: $p=0.063$) and that they were experiencing economic problems due to their pain (patients 16.3% vs. relatives 7.6%: $p=0.154$).

The caregiver's perspective

Of the relatives interviewed, 21.6% were the main caregivers (Table 1), 66.7% of whom considered that pain affected the family moderately or a lot, more than patients (34.6%) and relatives (51.2%, $p<0.001$: Table 2). Sadness (95.8%), sleep disturbances (65.2%) and abandonment or changes in leisure activities (75%), were the most frequent complaints (Table 2). In terms of sex, age and educational level, only the youngest age group (18-44 years of age) differed in their reference to the influence of pain on employment ($p<0.05$).

Notably, 22.2% of caregivers believed their health had worsened quite a lot or a lot through caring for a chronic pain patient (Table 3), while 41.6% indicated that their mood had deteriorated and 33.4% indicated their social life had been affected quite a lot or a lot. Similarly, 33.3% of these caregivers indicated that frequently or always they did not have time for themselves, although most were satisfied or very satisfied (72.8%) with the help they provided.

Factors associated with the impact of pain on the family environment

The factors identified by patients with the strongest impact on the family environment (*Model 1*) were sadness in the family and altered leisure activities of their relatives due to pain. By

contrast, the relatives (*Model 2*) considered the modification of leisure activities and sleep disturbances as the factors most strongly associated to pain (Table 4).

Discussion

Chronic pain significantly affects the family environment, both through the experiences of the patient and those of the family as a whole. This is the first study to analyse the impact of pain on the family, comparing the perceptions of patients, family members and caregivers, and demonstrating that chronic pain is perceived more intensely by relatives and caregivers than by the patients themselves. Likewise, the perception of sadness and the modification of leisure activities, together with sleep disturbances, are factors related to pain that patients and relatives identify as having a strong impact on the family.

Problems associated with pain extend beyond the individual and have profound and reciprocal consequences for social networks involving family, friends and work colleagues (De Souza & Frank, 2011). Different theoretical models explain the relationship between family members of chronic pain patients, with operant conditioning and cognitive-behavioural transactional models among those most extensively analysed (Kerns & Otis, 2003; Lewandowski et al., 2007; Turk, Flor, & Rudy, 1987). These models helped develop therapeutic strategies involving relatives of patients experiencing pain, although their efficacy has been poorly evaluated to date (Campbell, Wynne-Jones, & Dunn, 2011). We found a high percentage of relatives who perceived nervousness or sadness, and who had their social activities limited due to the patient's pain, although they feel satisfied with the help they provide. Relatives might share the emotional experiences of patients with pain, including tension and distress, and the emotional impact of chronic pain can affect the entire family (Feinauer & Steele, 1992). Similarly, family life is restricted by pain, with family members

becoming progressively isolated from their friends and community (Smith, 2003). Relatives become less involved in recreational activities, not only because their family life becomes centred on pain and illness but also, due to the lack of time and/or financial constraints (Söderberg et al., 2003). Moreover, a reduction in the quality of the relationship with their partners, relatives and pain management professionals has been shown in patients with neuropathic pain, conditioning a negative impact on treatment outcomes (Closs et al., 2009).

A substantial proportion of the relatives who cared for patients indicated that their physical, mental and social health deteriorated as a consequence of the attention they provided, consistent with an earlier study in which caring involves fulfilling a variety of roles, often alone and often complicated (del Mar García-Calvente et al., 2004). Pain adversely affects the mood of caregivers, in particular their level of depression and anxiety (Miaskowski, Kragness, Dibble, & Wallhagen, 1997), with caregivers reporting overwhelming feelings of grief, burden, frustration and helplessness when their relatives experienced pain, with greater patient pain associated with depression among caregivers (Redinbaugh et al., 2002). Moreover, family members overestimate cancer patient's pain (Elliott, Elliott, Murray, Braun, & Johnson, 1996), which appears to inflate their own distress.

Some limitations of the present study must be taken into account. While the validity of information collected through telephone interviews may be questioned, such interviews do appear to produce comparable results to face to face interviews for health issues, while improving access to subjects (Groves et al., 1988; Thornberry Jr., 1987). While the interviewer might be another potential bias, this was anticipated by training the interviewers and providing them with clear guidelines to follow during the data collection process.

The origin of pain was not taken into account here as it could not be accurately ascertained through a telephone survey and such information could not be contrasted with a medical

diagnosis. Furthermore, no validated instruments to assess the degree of dependence on the carer were used to keep the relatives' and carers' information as uniform as possible, and to keep the interviews as brief as possible. Conversely, this study benefits from accessing information from the general population rather than health centre patients and their relatives. Moreover, comparing the impact of pain on patients and relatives allows us to better define the factors associated with the influence of pain on the family.

In conclusion, chronic pain negatively affects the family environment, an impact perceived to be more intense by relatives than by patients and particularly, by those who are caregivers. Recognising the factors that affect family well-being and adopting a more global approach to pain should improve pain-related therapeutic outcomes, thereby improving the patients' and relatives' quality of life.

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*Table 1***Sample characteristics**

	Patients	Relatives	Caregivers
	N=325	N=131	N=36
Sex (%)			
Male	24.6	53.4	33.3
Female	75.4	46.6	66.7
Age			
Mean (SD)	56.5 (15.23)	47.33 (17.05)	53.4 (20.1)
Age group (years) (%)			
18 - 44	28	50.4	36.1
45 - 64	37.5	30.5	36.1
65 or more	34.5	19.1	27.8
Academic level (%)			
No education	19.2	7.4	13.1
Primary education	26.4	19.8	25
Secondary education	25.5	31.4	27.8
Vocational training	12.6	14	5.6
University studies	16.3	27.3	27.8
Standard deviation (SD)			

Table 2

Perceptions of patients, relatives and informal caregivers of the impact of chronic pain on the family.

	Patients	Relatives	Caregivers	¹ p	² p	³ p	⁴ p
Q1. How does pain affect the family environment?	N=324	N=131	N=36				
Not at all	52.8	23.7	16.7				
A little	12.7	25.2	16.7	<.001	<.001	<.001	<.001
Moderate	16.4	34.4	8.3				
Quite a lot	14.8	12.2	41.7				
A lot	3.4	4.6	16.7				
Q2. Do you consider that your relatives feel sad due to the presence of pain in the home?	N=97	N=57	N=24				
Yes	67.0	63.2	95.8	.001	.756	.010	.006
Q3. Do you consider that your relatives are nervous, and that there are frequent discussions due to the presence of pain in the home?	N=101	N=65	N=24				
Yes	46.5	44.6	62.5	.300	.934	.238	.208
Q4. Do you consider that your relatives have altered sleep patterns due to the presence of pain in the home?	N=100	N=63	N=23				
Yes	37.0	38.1	65.2	.039	.979	.025	.046
Q5. Do you consider that your relatives have abandoned or modified their leisure activities (such as meetings with friends) due to the							
				.017	.675	.009	.041

presence of pain in the home?	N=103	N=59	N=24				
Yes	42.7	47.5	75.0				
Q6. Do you consider that your relatives have had to leave or have lost their jobs due to the presence of pain in the home?	N=107	N=67	N=23				
Yes	16.8	6.0	39.1	.001	.063	.035	<.001
Q7. Do you consider that economic problems have arisen in the family due to the presence of pain in the home?	N=104	N=66	N=24				
Yes	16.3	7.6	29.2	.033	.154	.246	.021

¹p-value: Patients vs. Relative vs. Informal Caregiver.

POST-HOC: ²p-value: Patients vs. Relatives

³p-value: Patients vs. Informal Caregivers

⁴p-value: Relatives vs. Informal Caregivers

Table 3

Distribution of the responses to the informal caregiver's questionnaire

	%
Do you believe your health has worsened as a consequence of caring for your relative? N=36	
Not at all	44.5
A little	33.3
Quite a lot	19.4
A lot	2.8
Do you believe your mood has deteriorated as a consequence of caring for your relative N=36	
Not at all	30.6
A little	27.8
Quite a lot	33.3
A lot	8.3
Do you believe their social life has been affected by caring for your relative N=36	
Not at all	33.3
A little	33.3
Quite a lot	22.3
A lot	11.1
How often do you think that you do not have time for yourself because of having to care for your relative? N=36	
Never	25
Almost never	19.5
Sometimes	22.2
Frequently	19.4
Always	13.9
How do you evaluate the help that you give your relative? N=33	
Very unsatisfied	3
Unsatisfied	3
Not satisfied nor unsatisfied	21.2
Satisfied	39.5
Very satisfied	33.3

Table 4

Factors associated with the impact of chronic pain on the family environment

Perception that the relatives...	Model 1 ¹			Model 2 ²		
	OR	95% CI	p-value	OR	95% CI	p-value
...are sad because of the pain.						
No*	1					
Yes	3.615	(1.579;8.273)	.002			
... have abandoned or modified their leisure activities because of the pain.						
No*	1			1		
Yes	3.621	(1.564;8.381)	.003	1.171	(1.047; 9.940)	.041
... have altered sleep patterns because of the pain.						
No*				1		
Yes				1.406	(1.323; 12.582)	.014

¹Hosmer-Lemeshow: .051; p-value=.975.²Hosmer-Lemeshow: .275; p-value=.871.

*Reference category

Supplemental Material (Additional) Table S1

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Figure 1

Flowchart of participants in the study

