

## Psychosocial Meanings of Life Experiences of Patients with Non-Oncologic Chronic Pain: A Literature Review

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### Abstract

Chronic pain (CP) is currently seen as a multidetermined phenomenon involving the interaction of physical, social, cultural, and psychological factors. This makes clear how important it is for scientific research related to this matter to go beyond isolated reflections on body, mind, and social environment to be able to provide an integrated view of the meanings of CP patients' lived experiences. Among the research methodologies in use, those that offer qualitative perspectives bring about a suitable way to explore the meanings of life experiences. Our work aimed to provide an overview of reflections on the life experiences of individuals with CP based on qualitative research studies published as scientific articles over a five-year period. A bibliographic survey of the database PubMed was conducted associating the terms chronic pain, life experience, and qualitative, considering articles published between October 2008 and October 2013. After this survey, we could confirm the impact the onset of CP has on patients' lives, which may result in a total life restructuring that includes even the individual's own identity. Among the difficulties patients faced in this restructuring process, reported in the articles under analysis, we perceived as fundamental their attempts to adapt to their new condition, as well as their suffering for not feeling understood by family members and healthcare teams. We also observed the articles analyzed tend to focus on certain aspects of CP patients' life experiences and fail to understand these individuals' actual and complete experience.

**Keywords:** Review Literature; Chronic Pain; Psychology; Psychosocial Effects of Disease; Life Experiences; Psychological Stress; Psychological Adaptation; Social Environment

### Introduction

The concept of the mechanism of pain as a stimulus-response reaction was first proposed by René Descartes in the seventeenth century. Since then, it has contributed significantly to the evolution of the treatment of patients with chronic pain (CP). For decades, this theory has laid the foundation for interventions with a biomedical focus and been responsible for the introduction of several surgical methods to manipulate chronic pain and for the development of drug therapies still used to block painful sensations [1,2]. However, this concept of pain as a specific sensation, with its own sensory equipment, independent of other senses, was not able to handle the complexity of CP patients' experiences [3].

As the biomedical sciences evolved and the perspective on the sick changed, favored by the gaps left by the previous proposition, a new theory arose in the beginning of the twentieth century, bringing a revolutionary view: the theory of the Gate Control [4]. This theory brought to light other elements at play in the process of pain, such as the individual's emotional state and the inclusion of new therapeutic approaches, instead of explaining pain as a predominantly afferent sensory experience [5].

Thus, the International Association for the Study of Pain (IASP) defines pain as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage [6].

Although some authors regard it as a proposition that does not demonstrate a satisfactory understanding about a person with CP [4], pain is now seen as a multidetermined phenomenon that involves the interaction of physical, social, cultural, and psychological factors [7,8]. This relationship between psychological factors and CP has been extensively discussed over the past decades [9,10]. Therefore, psychological and social factors are implicated in the etiology, persistence, and aggravation of pain conditions [11,12].

Consequently, CP as a process of falling ill cannot be understood as necessarily situated in a certain part of the body. It is related to a series of physical, psychosocial, spiritual, and social struggles [13,14] and affects people as a whole, calling their attention, assailing them with doubts, making them suffer, altering their family roles, changing their ability to work, limiting their chances of leisure. As Leder [15] emphasizes, pain calls people's attention to the affected part of the body and may control them as no other bodily experience. Pain is so intense that it is not possible to understand its process without understanding the patient's individual context as well. To understand CP, we need to give voice to the patient's experience [16].

Considering that, we perceived how important it is for scientific research related to this topic to go beyond the isolated interferences from the psychological and social spheres – encompassing more than symptoms and physical effects – to provide an integrated view of the meanings of these individuals' life experiences. Based on investigations which use qualitative methodologies, we can explore these aspects, given that one of the main characteristics of such methodologies is searching for meanings in what individuals say about the experiences they lived.

Research demonstrates the value of describing pain verbally [17,18] as opposed to studies which classify diseases more linearly, according to pain assessment scales. This methodological approach, characteristic of biomedicine, is limited, because it does not capture the intensity of the experience this type of patient undergoes [19].

The relevance of qualitative studies on patients' life experiences also points to conclusions whose aim is to improve therapy. Knowing who the patients with CP are may produce more effective therapies [20]. An example is that of drug interventions only partially efficient to relieve pain. They often lead patients to use non-pharmacological strategies developed individually in their search for what they think is adequate to their cases [21,22]. Thus, knowing who these individuals are and how they manage their own pain may enrich healthcare service strategies [20].

Taking into account the mentioned scientific relevance of studies on the life experiences of individuals with CP, this paper aims to provide an overview of what has been produced and published about the topic over a five-year period. We intend to present the researchers interested in the subject with organized information about the complexity of CP patients' life experiences reported in the literature.

## **Material and Method**

This is a literature review carried out using PubMed, a database that covers leading journals in the field of biomedical and allied sciences. To conduct our survey of Pubmed, we combined the search terms "chronic pain", "life experience" and "qualitative", considering the five-year period from October 2008 to October 2013. The steps taken were the following:

- First, we combined the terms "chronic pain" and "life experience" to focus on the theoretical aspect of our project on the lived experiences of CP patients; then, in a parallel subproject, the results of this first search will be used to contextualize our field research with CP patients. As mentioned in the Introduction, the term "qualitative" was chosen because it represents the methodology we believe to be adequate to an investigation into individuals' life experiences. This is the methodology used in our field study, in line with the approach adopted by the research group to which the authors of this article are affiliated.

- Second, we critically examined 51 articles. Of this total, we excluded 37 for one the following reasons: they explored life experiences focusing either on the process of falling ill or on treatments, and not on the CP experience itself; their participants were health professionals or patients' relatives, and not patients themselves; or they applied mixed qualitative and quantitative methodologies.
- Third, we read the fourteen remaining articles carefully, focusing on their findings and looking, at the same time, for thematic similarities among them.
- Finally, we faced the methodological challenge of establishing relationships among the similarities found in the material we extracted from the articles, organizing these similarities in topics to be discussed, and building a harmonious relationship among them.

Although the researchers of the Laboratory of Clinical-Qualitative Research, to which the authors are affiliated, have monitored all four steps, the last one, that of classifying the results in topics, required several debates and rounds of peer-reviewing.

### Results

The articles chosen for our study are from different countries: two from the United States; two from New Zealand; one from Spain; one from Ireland; two from Sweden; three from the United Kingdom; two from Australia; and one from Canada. All have been published in English, except for the one from Spain, which was published in Spanish. These articles focus on individuals with CP, independently of the type of the pain they have or of specific types of CP, such as fibromyalgia, neuropathic pain, chronic low back pain, chronic knee pain, or chronic pelvic pain.

Regarding their objectives, the studies by Soklaridis, *et al.* (2011) [31], Persson, *et al.* (2011) [30], Ong, *et al.* (2011) [28], Löfgren and Norrbrink (2012) [20], Traska, *et al.* (2012) [29], Dow, *et al.* (2012) [23], West, *et al.* (2012) [33], and Robinson (2013) [26] intend to explore a particular aspect of life experiences, for example: type of patients' discourses; strategies used to cope with pain; the frustration experienced; the meaning of resilience; or how individuals reconstruct their biographies after experiencing chronic pain. The research by Clarke, *et al.* (2012) [17], Budge, *et al.* (2012) [25], and Ferrer and Pera (2013) [32], besides investigating life experiences, aim to provide information to healthcare professionals. The others – Denny (2009) [19], Crowe (2010) [24], and Lin, *et al.* (2012) [27] – have as their only purpose to explore life experiences. Table 1 details this information.

The results of these studies make clear for us that the onset of pain in the life of an individual has an impact that can produce a total life change. This process of change is marked by patients' attempts to adapt and by their suffering, caused by lack of empathy on the part of family and healthcare providers.

Our understanding resulted from our readings, and we introduce it here as four categories: (1) The impact; (2) The coping, (3) Non-legitimate suffering; and (4) Identity change.

Reference	Year	Results
26	2013	Participants rejected a biomedical discourse by proposing their own explanatory models of pain, resisting psychosocial understandings of pain, criticizing medical professionals and healthcare services, and challenging medical expertise, professionalism, and power.
32	2013	Highlight the stress generated in the waiting time to diagnosis and the vital break which means the disease, the difficulty of sharing with family and friends, the conflict with health system and the limited presence of nurses, the interest to remain active at work and personal life although tightly constrained by the pain and discomfort, treatment adherence, aids association representing, and thinking the present and little for the future.
20	2012	Four categories emerged: "Pain is my main problem" explained the impact of pain in the informants' everyday life; "Drugs: the healthcare solution" described the informants' experiences of pain management; "The gap in my meeting with healthcare" described the discrepancy between what the informants wanted and what health care could offer. "But... this works for me" described treatments and strategies, which the informants found helpful for pain control and pain relief.
27	2012	The experience of CLBP was found to be multidimensional, impacting on activities of daily life, employment, sport and family participation, emotional and cultural well-being.
17	2012	Qualitative individual interviews and one group interview were undertaken with 23 older adults. Following analysis, the following main themes emerged: diversity in conceptualizing pain using a simple numerical score; personalizing the meaning of pain by way of stories, similes and metaphors; and, contextualizing pain in relation to its impact on activities.
25	2012	Three main themes are presented and discussed: 'medication concerns', which encompasses side-effects, reluctance to take pills and pain medication as a choice; 'coping with pain', including acceptance, pacing yourself and non-pharmaceutical pain relief; and 'seeking help for pain', which included negative and positive experiences and lack of care continuity.
29	2012	Participants reported many strategies to cope with fibromyalgia symptoms and manage their lives. Main strategies included: 'pacing/planning', 'distraction techniques', 'coping with touch sensitivity', 'putting on the mask' and 'medications'. In addition, 'social support' from others with fibromyalgia and from family members was reported to be very important.
23	2012	Frustration is a multi-faceted emotion and its effects are cumulative. Sources of frustration include interference with everyday activities, the interruption of life goals and roles and the unpredictability of pain; here we focus on the frustrations associated with the invisibility of chronic pain and the perceived limitations of diagnosis and pain management.
33	2012	The findings from this study revealed that while living with chronic pain is generally a negative experience, the participants also told positive stories around the following themes: (i) Recognizing individual strength; (ii) Looking for the positives in life; (iii) Accepting the pain; and (iv) Learning to accept help.
31	2011	Analysis of the focus groups revealed the impact that chronic pain has on the social components of an injured worker's life; particularly their sense of self, their relationship to others and how they perceive themselves in social situations.
30	2011	The findings showed that along with the grief of having to abandon jobs and former social networks, the participants coped with their everyday lives in ways that opened up the use of imagination and improvisation and the valuing of non-material and altruistic behavior.
28	2011	It emerged that self-management could be based on implicit and incremental learning from experience or on explicit evaluation of actions.
24	2010	Four main themes were identified: the unpredictability of the pain, the need for vigilance, the externalization/objectification of the body and the alteration to sense of self.
19	2009	Uncertainty exists around diagnosis, the course of the disease, and the future. It is argued that the way in which the pain of endometriosis is interpreted and managed by women and health professionals is integral to this uncertainty.

Table 1: List of articles analyzed.

### The Impact

The literature analyzed mentions that the onset of pain in the life of individuals may impact the simplest everyday activities, and eventually make them permanently unable to accomplish their daily activities or fulfill their social roles, causing emotional damages. This impact is emphasized and refers to CP traits from the beginning: invisibility, unpredictability, limiting character, and negative feelings.

CP invisibility make it hard to be communicated to and recognized by others [23]. In one of the studies analyzed [19], the authors identified the struggle of female patients with chronic pelvic pain, often mistaken for a common period pain.

Other study points out that, for its female participants, one of the major impacts of pain is related to the fact that they do not know when or how it will come and which actions will exacerbate it [24]. This confirms CP unpredictability, supposedly a life experience so significant that one of the studies focuses on the uncertainty that involves the experiences of patients with endometriosis [19]. The authors discuss their patients' uncertainties about diagnosis, the course of the disease, and the future.

One of the articles calls attention for the fact that their interviewees' stories often focus on the restrictive or totally disabling character of CP [17]. Pain invariably affects the daily activities of the interviewees, restricting or disabling them completely. For the participants, the severity of pain is related to gains and losses in physical and social activities. Other studies also discuss how the everyday life – activities and relationships – of an individual with CP is affected [17,25-30]. Löfgren and Norrbrink's interviewees consider pain as the worst problem in their lives [20].

The feeling of frustration is the subject matter of one of the articles under discussion [23]. The authors perceive in participants' discourses that life experiences associated to CP processes, such as those described before, trigger a frequent feeling of frustration. These authors identify frustration in the narratives of their interviewees about CP invisibility and diagnosis and management limitations. They state that frustration, in these cases, is cumulative. Other studies also identify the feeling of frustration in their interviewees' accounts [27,31].

The emotional cost, although little explored, is apparent. Lin., *et al.* (2012) mention that CP emotional consequences are widespread among their subjects, especially the most debilitated [27]. The authors describe what they call negative feelings in these individuals, for instance: anger, depression, fear, or anxiety. Mood swings, irritability, worthlessness, fear, shame, inadequacy, and emasculation are also feelings identified and discussed by Soklaridis (2011) [31].

### The Coping

The authors of the studies under analysis mention that research subjects try to develop means to adapt to their reality and remain active. They develop their own ways to relieve pain and accomplish their activities, in an attempt to adapt to increasing pain in their lives. The studies we analyzed discuss this type of action separately, addressing either the action related to coping with pain itself or the action related to coping with daily activities.

Concerning actions to relieve painful sensations, these studies state that it is while experiencing pain that people find out and/or create alternatives to cope with it. The adjustments individuals make in their lives are based on what they have learned through experience and experimentation [19,28,29]. Individuals with CP develop their skills by "trial and error", and become experts at dealing with their problem [19,20,26]. Therefore, each individual develops his/her own treatment.

One of the studies identifies amusement and holistic techniques as some of the resources to relieve pain. Listening to music or white noise, taking a bath or shower, relaxing the muscles, taking a leisurely walk, singing, etc. are resources used by this study's participants as a way of taking the focus off of pain and discomfort [29]. In the same vein, other study points out that its interviewees found and used non-pharmaceutical methods [25]. Having good ergonomic furniture, such as a good chair to rest, is considered very important; the warmth derived from a bath or shower, from a blanket, mattress or heat package is also often mentioned, as well as massages, physiotherapy, lying down, and listening to music.

Other authors observed in their patients' narratives a strategy they call daydreaming as another way of getting distracted from pain [30]. Daydreaming concerns thinking of desired occupations for the future, such as a trip. Reading a book is an activity some individuals consider positive, whereas others speak only of the value of "doing something" to not focus on their pain, without referring to any particular occupation. Using equipment, music, and movement techniques, changing position, taking breaks, stretching, amusing themselves, and resting are aspects mentioned in another study [26].

The importance of getting distracted from pain to relieve it is clear; however, some pleasant activities – which take the focus off of pain – are mentioned as potential aggravators, for example: taking care of grandchildren, doing sport activities, and going on vacation [28,30].

According to this literature, for some individuals pain is so severe and limiting that getting through the day is a challenge and requires detailed planning. Pacing activities is considered in these studies as another way of mitigating pain derived from physical exertion. This is a strategy frequently used by the participants of one of the studies analyzed, as well as reducing speed when walking, getting up, and doing daily activities [28].

About coping with practical daily living, one of the studies draws attention to the fact that the daily presence of pain forces individuals to think about the implications of all their actions. It illustrates this understanding with the story of one of its interviewees, who stated that simply parking his car would become a worry for him, because of his chronic knee pain [28].

Frequent or occasional difficulties in self-care, such as getting dressed and looking after personal hygiene, as well as doing household tasks, are often stressed in the studies analyzed. In some cases, the individual cannot get out of bed because of the severity of pain, which varies from day to day [27]. Research participants also state that there are days when they cannot bathe or even move [29]. They say they are sensitive to touch and that even the contact of clothes with their skin can be painful [29]. Therefore, routine activities become challenges, and patients report difficulties walking, cycling, walking the dog, going to the post office or to the mall, cleaning the house, cooking, washing clothes, gardening [17,30]. Becoming unable to work can also be a consequence for those living with CP [27].

Some studies [25,26,29,30] identify countless research participants who attempt to remain productive. Their main way to manage daily living and increase chances of accomplish important tasks, with the aim of mitigating pain, is described by one of the studies as pacing their activities [29]: "Pacing has involved consistently planning ahead, balancing activities over time, and allowing others to assist them in completing important tasks". The authors explain that individuals become cautious about the amount of effort dedicated to an activity and about the amount of activities they can do. The authors consider it a learning process, because, on the days the pain is not so intense, the individuals tends to do more, and the more they do, the more intense the pain comes back, making them suffer for days afterwards. Therefore, even when patients feel better, they remember that there is a limit for their actions.

This strategy was also reported in other study as slower pace and performance of daily doing [30]. In this study, women – who are in general responsible for household tasks – tell they split up their duties over the week, doing a task a day or an activity at a time, with no hurry. This attitude of moderation is also reported by other study's participant, who says he does everything he used to do, but it takes him longer [25]. Along the same lines, the following strategies for accomplishing activities are highlighted: using medication, resting, taking breaks, changing position, prioritizing, having targets, doing things differently, and getting assistance [26].

### **Non-legitimate suffering**

The studies analyzed here discuss the difficulty CP patients have to communicate their suffering and to see it recognized by their families and healthcare teams. One of the studies stresses that these individuals report they are seen by others as whiners, hungry for privilege or attention. They perceive that other people doubt their problems and are not interested in them [26].

The participants of another study complain that CP is an invisible condition. They point out that this fact makes pain difficult to communicate and prove [23]. Patients say they wish pain were visible (identifiable by others), making them look bluish or showing a letter “P” on their foreheads. In this way, others would not doubt the pain is there. These participants also complain that family and friends do not believe in them or seem to forget they have a problem.

The interviewees of other study state that the only people able to understand those who live with CP are other CP victims [29]. Another research, whose subjects are women with chronic pelvic pain, highlights that both family and healthcare professionals are perceived as those who make patients think they have some kind of moral flaw, since they cannot face their period pain as other women do [19]. One of the participants reports being accused by her doctor of overstating her pain when the site of her endometriosis was taken into account. Such accusation derives from the fact that this kind of CP is associated with a tissue lesion that can be seen through imaging tests.

As to healthcare professionals, patients complain that healthcare teams are not interested in their experiences, nor in the knowledge they have acquired of their own pain, nor in the way they cope with it. Patients say there is no interest and no support for any issue besides medication [20].

The relationship between healthcare professionals and patients with fibromyalgia is highlighted as often frustrating in one of the studies [32]. The authors report that the participants complain that their healthcare teams do not believe in them. These patients state that healthcare professionals do not recognize their diseases and do not give them adequate attention. Complaints also appear frequently in another study, which points out that patients are not heard by their doctors, who are not interested in patients with pain. From patients’ perspective, health professionals get tired of frequent complaints and give up on treatments, as they no longer know which procedures to adopt. The article also discusses the participants’ suspicion that their doctors assume patients pretend to feel pain [25]. One patient describes the double challenge of coping with her problem and making an effort to legitimate it before her doctors [23].

### **Identity change**

According to the studies analyzed, after significant life changes that alter activities, feelings, perspectives, and relationships, individuals with CP start to perceive themselves differently, and may eventually come to the conclusion that they are no longer who they used to be.

The new situation of these individuals’ existence is understood in one of these studies as an alteration to sense of self [24]. The authors highlight in their research subjects’ discourses how their “sense of self” had altered since they had experienced chronic pain problems. The researchers state that the experience of chronic pain altered not only lifestyles, but also the way their patients used to see themselves.

Other authors have also identified the alteration to sense of self as something relevant in their interviewees’ reports. Soklaridis, *et al.* observed their subjects – workers with CP – had lost the sense of who they were [31]. These patients compared who they were before and after the lesion that triggered the chronic pain and perceived that their “real” selves have been interrupted at some point before the onset of CP. They report difficulties in knowing their identities and understanding who they are now and who they will be in the future. In another study, the authors draw attention to a biographical interruption in their subjects’ lives: the difficulties they face to adapt to the limits of a formerly active time at work and at home, in which disease represents a rupture with their previous lives [32].

Other studies analyzed here also point to an alteration in participants’ values [30,33]. A revision of values or the adoption of new values may happen as a result of changes in patients’ lives. The new values come as a way of resignifying a lifestyle that became more restrict. Doing things on their own, as well as enjoying moments of more independence, are examples of how some people start to face the social restrictions of which they are victims. Finding meanings in non-material values, enjoying what is simple, learning to see the funny side of things, imagining that the situation could be worse, and hoping it improves are also aspects derived from CP experience considered as positive in many studies.

Therefore, changes of perspective that culminate in the acceptance of a new condition may improve well-being and quality of life. The acceptance of pain is identified by Budge, *et al.* in their interviewees' stories as an adjuvant aspect in coping with the problem [25]. The authors observe pain becomes, for some people, an important part of who they are. In the same vein, West, *et al.* address the tolerance to pain described by their patients as a learning process, a way of adapting to pain as part of their lives [33]. Accepting pain, for many of their interviewees, was a long process that involved assimilating the changes that occurred in their lives and redefining their identities.

## Discussion

We think our findings point to the importance of understanding CP as inseparable of individual contexts: who the subjects who experience CP are; with whom they relate; and what the environment where they live is. This helps us understand the origin of this process of falling ill, the way it is expressed, and how it is managed. The studies analyzed have reports that go beyond the mere complaint about the physical discomfort of pain. In their narratives, patients emphasize how pain spreads, affecting negatively their whole existence. Pain is not situated in the organ attacked; it affects the whole life of a human being.

According to these research studies, the impact of CP experience seems to exceed the uncomfortable feeling of frequent pain. It is aggravated by its effects in individual contexts and it is not merely the single impact of living with the frequent feeling of pain, but, rather, of pain plus the difficulty of communicating it, the unpredictable way it affects everyday life, and the limitations to accomplish daily activities. The intensity of these events generates a series of negative feelings expressed by the individuals who experience them.

Therefore, the impact of CP on the life of an individual can be so significant that it is compared to devastating events such as the death of loved ones, and can even be considered the worst event ever in someone's life [34].

The literature analyzed states that individuals with chronic illnesses face moments of crisis because they experience adverse situations related to their illnesses [35-37]. A disease affects the dynamics of a person's development, generating an inner disagreement. The disease breaks people's dynamics and relationships with themselves and the world, emerging as an enemy to be found, studied, and fought [38].

A permanent disease makes individuals experience loss in social and financial relations, physical abilities, leisure, and so on. These losses derived from the constant presence of pain may result in low self-esteem and lead to social isolation. In addition, constant challenges to individuals' integrity, such as the feeling of being stigmatized, the loosening of social bonds, and personality changes may lead individuals to experience negative emotions that are difficult to eliminate and that can hinder their rehabilitation processes [39].

The impact of these new life experiences causes the whirlwind of emotions described in the studies discussed. The whole of the negative experiences interfering with the practical and emotional life of patients may cause mental health problems. Maybe this is one of the reasons why anxiety and depression are so common in CP patients [40].

The results of the studies analyzed highlight patients' limitations caused by CP and patients' attempts to not let these restrictions affect their daily activities. The narratives of research subjects often focus on attempts to overcome pain and its limiting character. Some studies focus specifically on aspects of their participants' discourses that show the methods they use to change the situation in which they are living, caused either by pain or by the limitation pain imposes.

As to coping with painful sensations, other studies confirm the idea discussed in the articles analyzed. These studies conclude that through experimentation individuals develop specific ways – alternative to traditional medicine – to relieve their pain [41-43]. Similarly, with regard to coping with daily activities, it is already known how important work and autonomy are for an individual's health and well-being [44,45]. In some studies on CP, patients' accounts stress how important it is for them to remain engaged in their occupations, despite the pain [46-48], in an attempt to not give up to CP.



In a study on women with CP, there are narratives based on metaphors for fighting, describing how these women carry on despite their pain and how they complete what they perceive as their duties or social obligations [49]. May, *et al.* underline the notion of “hard work” related to the effort individuals have to make to remain active in spite of their disease [50,51]. According to Belgrave, for CP patients, their struggle can be time-consuming and requires effort, leaving them with little time and inclination to do other things [52]. Yet, pain patients do not consider this focus on daily activities as something extraordinary or deserving special attention. On the contrary, “hard work” does not even emerge as something planned [53], it tends to be obscured.

On the other hand, in the studies analyzed, patients do not report any kind of benefit derived from their processes of falling ill, such as financial gain or change in family roles. Likewise, there are no stories of specific aspects of individual suffering and failure without a subsequent description of attempts to change the situation.

Robinson, *et al.* identify a moral aspect in their interviewees’ narratives, related to the effort they make to show they behave properly. According to these authors, an immoral behavior for people with CP would be to pretend, to overstate, or to give up to pain to obtain “rewards” such as financial help, leaves of absence from work, or attention. These individuals describe themselves as honest people going through real pain, with no intention to burden others, trying to accomplish their activities and fulfill the requirements of their social roles, despite the pain [26]. The emphasis on this moral aspect is also highlighted in other qualitative studies, in which participants describe their attempts to demonstrate how efficiently they fulfill their obligations in order to be considered people of high moral standards. They reject the idea that the onset of pain is related to personality or individual weakness, or that pain is a call for attention or an excuse to avoid working [54,55].

The studies analyzed do not include subjects’ narratives about the possibility of getting something from their processes of falling ill, nor show stories of suffering itself. Similarly, they do not favor these aspects as the core of their investigation. Their interest is invariably focused on how individuals cope with and try to overcome pain and not on how they suffer from it.

Concerning patients’ narratives about the difficulty of having their suffering recognized by others, we observed that aspects related to family involvement in CP patients’ disease processes are mentioned in various other studies besides those discussed in this review. It is known that CP consequences affect not only patients’ lives, but also the lives of their partners and family [56]. This interference can be so significant in the family environment that it may produce affective and sexual changes in family relationships. Family roles change, as well as family perspectives for the future, which eventually can change the family dynamics completely [57,58].

Nevertheless, we did not find in any study on families reports showing they do not believe in the sick family member. Quite the reverse, when these studies stress the negative feelings expressed by CP patients’ relatives, these feelings are pacified by their feeling of guilty and their responsibility for the family member who is sick [58,59]. West, *et al.* identify anger when addressing the negative feelings of families toward an individual with CP. However, anger is described as related to CP and not to the sick family member [58]. Consequently, these studies approach aspects of the stoic and committed attitude of families and partners. Some families even exhibit a symbiotic dynamics, in which family functioning focuses on the individual with CP [59,60].

Similarly, theoretical discussions about the perception of individuals with CP concerning lack of understanding on the part of families are rare. Smith and Friedemann discuss this topic briefly and conclude that the perception of these individuals may be related to a supposed difficulty of people with CP to express and share their feelings [59].

Even rarer are studies on how healthcare professionals perceive patients with CP. It seems that little has been explained about the lack of understanding on the part of healthcare professionals mentioned by CP patients. This unfavorable and stereotyped view of certain types of CP emerges only in patients’ complaints reported in studies such as the ones analyzed in this review, but it is still little discussed [61].

However, we question whether this event is related to the well-known difficulty of biomedical model in understanding and managing CP. Lima, *et al.* state that, because of cultural influences and isolated scientific evidence, it is a characteristic of the biomedical model to direct attention specifically to that “part of the body” affected by the disease. It means that this type of intervention can be successful, even when no attention is given to the patient’s identity [4]. Because the situation opposes to this one and is complex in terms of physiopathology, diagnosis, and therapeutic management, the process to treat CP is extremely consuming not only for patients, but also for the professionals who take care of them [62].

Lima and Trad (2008) explain that, in many senses, CP escapes the biomedical paradigm and creates situations that threaten knowledge and practice in the field of professional healthcare. For these authors, CP transgresses the background of empiricist rationality, because it is not necessarily situated in a “part of the body” and because it is not simply a problem of nervous transmission. It then becomes an enigma [63]. Moreover, CP victims hardly improve, independently of the therapeutic resources used, putting in check doctors’ knowledge and patience [62].

The data discussed here show how appalling is the lack of studies on families and healthcare teams addressing their negative feelings toward individuals with CP. These feelings are clearly perceived by the participants of several investigations, and the studies that intend to examine families and healthcare teams specifically are emphatic when they mention the difficulties both of them face in the care of a CP patient. However, these difficulties are not expressed as something that affects the professional or the family negatively, but as something that motivates caregivers to change themselves and to be more efficient in the care they provide. The focus of discourses and investigations turns to morally appreciated aspects of life experience meanings.

Another aspect identified in the studies analyzed refers to the possible identity change individuals go through. Living with a chronic condition is an experience in which daily life structures and its guarantees are deeply disturbed and require a fundamental rethinking of a person’s biography. The onset of a chronic illness in someone’s life can be understood as a “disruptive event”, since it affects personal life, its meanings and expectations, that is, one’s personal “biography” [64-66].

Corbin and Strauss use the expression biographical work when they refer to patients’ struggle to adapt to their new condition after being diagnosed with a chronic illness [67]. Several studies have demonstrated that individuals with chronic illnesses become innovators in the face of their condition, because they have to create new meanings and values for their lives. Besides managing their illness, these individuals have to negotiate their social roles actively, face the problem of stigma every day, and try to resume their lives, which have been interrupted by a fatality [68,69].

Changing the routine according to their limitations and the feelings aroused in the process of falling ill generates modifications not only in the way people organize their practical lives, but also in the way they start to perceive themselves while they go through the process. Thus, it is expected that chronic illnesses will alter the self; it is expected that an individual’s identity will change.

The ability of CP to change one’s identity is addressed in some studies [70-72]. For Aldrich and Eccleston [70], one of the defining characteristics of pain is its intrinsic ability to modify the self. In other study, Eccleston [55] states that the fundamental and threatening challenge to the identity is central in the experience of prolonged suffering.

### Final Considerations

From a general perspective, the studies analyzed here show the impact of pain on people’s lives, depending on its magnitude, can affect their most basic daily activities to the point of preventing individuals from working and fulfilling their social roles and changing their way of behaving and thinking.

The impact of the onset of pain is marked by generalized losses and causes intense suffering. The constant presence of pain ends up affecting directly the accomplishment of everyday activities. Pain constrains its victims to think about the implication of all their acts.

However, it seems these people, despite the pain, insist on remaining active and try, also despite the pain, to adapt to the tasks to be accomplished. Moreover, they make an effort to show they can be successful and try to keep their functioning as close as possible to what it used to be.

As part of this process, patients also suffer for not feeling understood by their families and healthcare providers. In face of such a significant life change, which alters activities, feelings, perspectives, and relationships, the individuals start to perceive themselves differently and see they are no longer who they used to be. At this point, they stop asking for help and believing in treatments. It is then that frustration yields to resignation and a change of identity occurs.

We also confirmed that the scientific literature related to the topic is not scarce. However, we observed in this literature a tendency to narrow the focus of investigation, thus missing what might be understood about the real and integral experience of an individual with CP. These studies, despite valuing patients' narratives, instead of collecting data through instruments, maintain a perspective subordinate to the biomedical model, which emphasizes limited aspects of life experiences, such as patients' type of discourse; the strategies they use to cope with pain; the presence of certain feelings; the way they reconstruct their biographies after the experience, etc. These studies' methodology and understanding do not reflect an integral view of the human being. They seem to focus less on what patients suffer or experience in general and more on their chances of improvement.

On the other hand, the moral aspect identified in patients' accounts can make them co-responsible for this research focus. Not only do individuals with pain direct their narratives towards morally appreciated aspects, but also probably their families and healthcare teams, since we did not find discussions about personal difficulties related to coping with CP.

Therefore, patients, families, professional healthcare teams, and researchers seem to focus on what is understood as positive by common sense, making a tacit agreement to take only a superficial look at what they propose to discuss. Narratives and investigations focus on morally valued aspects, giving up on a real contact with patients' life experiences and, consequently, ongoing more deeply into their meanings.

### **Institutional Level of the Research; and Roles in Co-Authorship**

This article presents part of the results of the doctoral research developed by the first author at the Graduate Program of the Faculty of Medical Sciences of the State University of Campinas (Unicamp), Brazil. Daniela Dantas Lima conceived and designed the study, collected and interpreted the data, and drafted the article. Vera Lucia Pereira Alves conceived and designed the study, analyzed the data, and revised it critically. Cristina Aparecida Arrivabene Caruy and Egberto Ribeiro Turato conceived and designed the study and revised it critically.

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### **Conflict of Interest**

We declare we do not have any kind of conflict of interest related to this material.

### **Bibliography**

1. Bonica JJ. "The management of pain". 2<sup>nd</sup> edition Malvern: Lea & Febiger (1990).

2. Turk DC., *et al.* "Chronic pain and depression - Role of perceived impact and perceived control in different age cohorts". *Pain* 61.1 (1995): 93-101.
3. Novy DM., *et al.* "Perspectives of chronic pain: an evaluative comparison of restrictive and comprehensive models". *Psychological Bulletin* 118.2 (1995): 238-247.
4. Lima DD., *et al.* "The phenomenological-existential comprehension of chronic pain: going beyond the standing healthcare models". *Philosophy, Ethics and Humanities in Medicine* 9.2 (2014).
5. Kelly D. "Somatic sensory system IV: Central representations of pain and analgesia". In: Schwartz ERKJH, editor. *Principles of Neural Science*. New York: Elsevier (1981): 199-204.
6. IASP TFoT. "Classification of Chronic Pain: Descriptions of Chronic Pain Syndromes and Definitions of Pain Terms". In: Merskey H, Bogduk N, editors. *Seattle: IASP Press* (1994): 209-214.
7. Bial E and Cope DK. "Introduction to pain management, historical perspectives, and careers in pain management. In: N V, editor". *Essentials of pain management* New York: Springer Science Business Media (2011): 3-16.
8. Turk DC. 'Monarch ES. Biopsychosocial perspective on chronic pain". In: Turk DC, Gatchel RJ, editors. *Psychological approaches to pain management: a practitioner's handbook*. 2<sup>nd</sup> edition. New York: Guilford Press (2002): 3-29.
9. Campbell P., *et al.* "Conceptual overlap of psychological constructs in low back pain". *Pain* 154.9 (2013): 1783-1791.
10. Osborne TL., *et al.* "Psychologic Interventions for Chronic Pain". *Physical Medicine and Rehabilitation Clinics of North America* (2006): 17.
11. Thibodeau MA., *et al.* "Pain-related anxiety influences pain perception differently in men and women: a quantitative sensory test across thermal pain modalities". *Pain* 154.3 (2013): 419-426.
12. Wollaars M., *et al.* "Spinal cord injury pain: the influence of psychologic factors and impact on quality of life". *Clinical Journal of Pain* 23.5 (2007): 383-391.
13. Ong CK and Forbes D. "Embracing Cicely Saunders's concept of total pain". *British Medical Journal* 10331.7516 (2005): 576-577.
14. Baron R. "An introduction to medical phenomenology: I can't hear you while I'm listening". *Annals of Internal Medicine* 103.4 (1985): 606-611.
15. Leder D. "The dys-appearing body". In: Leder D, editor. *The absent body*. Chicago: The University of Chicago Press (1990): 69-99.
16. Madjar I. "The lived experience of pain in the context of clinical practice". In: Toombs S, editor. *Handbook of phenomenology and medicine*. Dordrecht: Kluwer Academic Publishers (2011): 263-277.
17. Clarke A., *et al.* "I feel so stupid because I can't give a proper answer.". How older adults describe chronic pain: a qualitative study. *BMC Geriatrics* 12 (2012): 78.
18. Gooberman-Hill R., *et al.* "Assessing chronic joint pain: lessons from a focus group study". *Arthritis Care and Research* 57.4 (2007): 666-671.

19. Denny E. "I never know from one day to another how I will feel: pain and uncertainty in women with endometriosis". *Qualitative Health Research* 19.7 (2009): 985-995.
20. Löfgren M and Norrbrink C. "But I know what works" - patients' experience of spinal cord injury neuropathic pain management. *Disability and Rehabilitation* 34.25 (2012): 2139-2147.
21. Heutink M., et al. "Chronic spinal cord injury pain: pharmacological and non-pharmacological treatments and treatment effectiveness". *Disability and Rehabilitation* 33.5 (2011): 433-440.
22. Norrbrink C and Lundeberg T. "Non-pharmacological pain-relieving therapies in individuals with spinal cord injury: a patient perspective". *Complementary Therapies in Medicine* 12.4 (2004): 189-197.
23. Dow CM., et al. "Talk of frustration in the narratives of people with chronic pain". *Chronic Illness* 8.3 (2012): 176-191.
24. Crowe M., et al. "Listening to the body and talking to myself - the impact of chronic lower back pain: a qualitative study". *International Journal of Nursing Studies* 47.5 (2010): 586-592.
25. Budge C., et al. "Learning from people with chronic pain: messages for primary care practitioners". *Journal of Primary Health Care* 4.4 (2012): 306-312.
26. Robinson K., et al. "Constructing the experience of chronic pain through discourse". *Scandinavian Journal of Occupational Therapy* 20.2 (2013): 93-100.
27. Lin IB., et al. "'I am absolutely shattered': the impact of chronic low back pain on Australian Aboriginal people". *European Journal of Pain* 16.9 (2012): 1331-1341.
28. Ong BN., et al. "The hard work of self-management: Living with chronic knee pain". *International Journal of Qualitative Studies on Health and Well-Being* 6.3 (2011).
29. Traska KT., et al. "Strategies used for managing symptoms by women with fibromyalgia". *Journal of Clinical Nursing* 21.5-6 (2012): 626-635.
30. Persson D., et al. "Defying aches and reevaluating daily doing: occupational perspectives on adjusting to chronic pain". *Scandinavian Journal of Occupational Therapy* 18.3 (2011): 188-197.
31. Soklaridis S., et al. "Biographical disruption of injured workers in chronic pain". *Disability and Rehabilitation* 33.23-24 (2011): 2372-2380.
32. Ferrer MCO and Pera MPI. "[Experience of fibromyalgia]". *Revista De Enfermeria* 36.7-8 (2013): 16-26.
33. West C., et al. "The meaning of resilience to persons living with chronic pain: an interpretive qualitative inquiry". *Journal of Clinical Nursing* 21.9-10 (2012): 1284-1292.
34. Loduca A., et al. "Chronic pain portrait: pain perception through the eyes of sufferers". *Revista Dor* 15.1 (2014).
35. Larsen PD. "The illness experience". In: Lubkin IM, Larsen PD, editors. *Chronic illness: impact and intervention*. 8<sup>th</sup> edition. Burlington Jones and Bartlett Learning (2013): 26-42.

36. Bury M. "Health and illness in a changing society". New York Routledge (1997): 240.
37. Corbin J and Strauss A. "A nursing model for chronic illness management based upon the trajectory framework". In: Woog P, editor. The chronic illness trajectory framework: the Corbin and Strauss nursing model. New York Springer Publishing (1992): 9-27.
38. Santos CT and Sebastiani RW. "Acompanhamento psicológico a pessoa portadora de doença crônica". In: Angemioni-Camon WA, editor. E a psicologia entrou no hospital. São Paulo: Pioneira (1996): 147-176.
39. Snelgrove S and Lioffi C. "Living with chronic low back pain: a metasynthesis of qualitative research". *Chronic Illness* 9.4 (2013): 283-301.
40. Malmgren-Olsson EB and Armelius BA. "Physical and psychological health and social relations in patients with prolonged musculoskeletal disorders". *Scandinavian Journal of Caring Sciences* 15.2 (2001): 181-189.
41. Bennett R., et al. "An internet based survey of 2,596 fibromyalgia people with fibromyalgia". *BMC Musculoskeletal Disorders* 8 (2007): 27.
42. Neill J., et al. "Effectiveness of non-pharmacological interventions for fatigue in adults with multiple sclerosis, rheumatoid arthritis, or systemic lupus erythematosus: a systematic review". *Journal of Advanced Nursing* 56 (2006): 617-635.
43. Lempp HK., et al. "Patients' experiences of living with and receiving treatment for fibromyalgia syndrome: a qualitative study". *BMC Musculoskeletal Disorders* 10 (2009): 24.
44. Cote D and Coutu MF. "A critical review of gender issues in understanding prolonged disability related to musculoskeletal pain: how are they relevant to rehabilitation"? *Disability and Rehabilitation* 32 (2010): 87-102.
45. Waddell G and Burton K. "Is work good for your health and well-being?" In: Pensions DfWa, editor. London: The Stationery Office (2006).
46. Aegler B and Satink T. "Performing occupations under pain: The experience of persons with chronic pain". *Scandinavian Journal of Occupational Therapy* 16.1 (2009): 49-56.
47. Van Huet H., et al. "Living and doing with chronic pain: Narratives of pain program participants". *Disability and Rehabilitation* 31.24 (2009): 2031-2040.
48. Crowe M., et al. "Self-management and chronic low back pain: a qualitative study". *Journal of Advanced Nursing* 66 (2010): 1478-1486.
49. Keponen R and Kielhofner G. "Occupation and meaning in the lives of women with chronic pain". *Scandinavian Journal of Occupational Therapy* 13.4 (2006): 211-220.
50. May C. "The hard work of being ill". *Chronic Illness* 2.3 (2006): 161-162.
51. May C., et al. "We need minimally disruptive medicine". *British Medical Journal* 339 (2009): b2803.
52. Belgrave L. "The relevance of chronic conditions in the everyday lives of elderly women". *Journal of Aging and Health* 2.4 (1990): 475-500.

53. Morden A., et al. "Lay models of self-management: How do people manage knee osteoarthritis in context"? *Chronic Illness* 7.3 (2011): 185-200.
54. Ong BN., et al. "Establishing self and meaning in low back pain narratives". *Sociological Review* 52.4 (2004): 532-549.
55. Eccleston C., et al. "Patients' and professionals' understandings of the causes of chronic pain: blame, responsibility and identity protection". *Social Science and Medicine* 45.5 (1997): 699-709.
56. Evans S and de Souza L. "Dealing with chronic pain: giving voice to the experience of mothers with chronic pain and their children". *Qualitative Health Research* 18.4 (2008): 489-500.
57. Blanchard A., et al. "Lived experiences of adult children who have a parent diagnosed with Parkinson's disease". *The Qualitative Report* 14.1 (2009): 61-80.
58. West C., et al. "Chronic pain and the family: the experience of the partners of people living with chronic pain". *Journal of Clinical Nursing* 21.23-24 (2012): 3352-3360.
59. Smith AA and Friedemann M. "Perceived family dynamics of persons with chronic pain". *Journal of Advanced Nursing* 30.3 (1999): 543-551.
60. Lewandowski W., et al. "Chronic pain and the family: theory-driven treatment approaches". *Issues in Mental Health Nursing* 28 (2007): 1019-1044.
61. Nguyen RHN., et al. "Perceived stereotyping and seeking care for chronic vulvar pain". *Pain Medicine* 14.10 (2013): 1461-1467.
62. Apkarian AV., et al. "Towards a theory of chronic pain". *Progress in Neurobiology* 87.2 (2009): 81-97.
63. Lima M., et al. "Dor crônica: objeto insubordinado". *História, Ciências, Saúde – Manguinhos* 15.1 (2008): 117-133.
64. Pierret J. "The illness experience: state of knowledge and perspectives for research". *Sociology of Health and Illness* 25 (2003): 4-22.
65. Bury M. "Meanings at risk: the experience of arthritis". In: Anderson R, Bury M, editors. *Living with chronic illness: the experience of patients and their families*. London: Unwin Hyman (1988).
66. Arnold LM., et al. "Patient perspectives on the impact of fibromyalgia". *Patient Education and Counseling* 73.1 (2008): 114-120.
67. Corbin J and Strauss A. "Managing chronic illness at home: three lines of work". *Qualitative Sociology* 8.3 (1985): 224-247.
68. Coutu MF., et al. "Transforming the meaning of pain: an important step for the return to work". *Work* 35.2 (2010): 209-219.
69. Toye F and Barker K. "'Could I be imagining this?' – the dialectic struggles of people with persistent unexplained back pain". *Disability and Rehabilitation* 32.21 (2010): 1722-1732.
70. Aldrich S and Eccleston C. "Making sense of everyday pain". *Social Science and Medicine* 50.11 (2000): 1631-1641.
71. Morley S. "Psychology of pain". *British Journal of Anaesthesia* 101.1 (2008): 25-31.

72. Tukker A., *et al.* "Overweight and health problems of the lower extremities: osteoarthritis, pain and disability". *Public Health Nutrition* 12.3 (2008): 359-368.

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