

RESEARCH PAPER

Chronic pain affects the whole person – a phenomenological study

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Abstract

Purpose: The aim of this qualitative study was to explore participants' perspectives on the effects of chronic pain on the psychophysical unity. **Methods:** Thirty-four chronic pain outpatients were interviewed, and the transcribed interviews were analysed with Giorgi's four-phase phenomenological method. The mean age of the participants was 48 years, and 19 of them were women. For 21 of the participants, the pain duration was more than 5 years, and most had degenerative spinal pain. **Results:** The results of this whole research project indicated that the phenomenon chronic pain consisted of four essential themes: Pain affects the whole person, invisibility, negativity, and dominance of pain. This study concentrates only on one theme "Chronic pain affects the whole person", in which were found eight subthemes in the interviews. The strongest argument made by the participants was not the physical pain itself but the psychosocial consequences, such as distress, loneliness, lost identity, and low quality of life which were their main problems. **Conclusions:** In multidisciplinary holistic rehabilitation, it is essential to take care of the patient's psychological distress. A potential source of psychosocial symptoms may be the subjective responses to experience of chronic pain due to the subjective meanings of pain.

► Implications for Rehabilitation

About chronic pain

- Pain is an experience, not only an aversive sensation. Intensity of pain describes only the sensation, not the experience of pain.
- In chronic pain, the main complaint may be not the physical pain, but the distress.
In rehabilitation, the patient needs to be taken as a whole person.
- Multidisciplinary rehabilitation, including patient counselling should be the fundamental part of treatment.
- In rehabilitation, the individual meaning of chronic pain needs to be disclosed.

Keywords

Chronic pain, psychosocial, quality of life

History

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Introduction

Despite multiple treatment advances and research progress, chronic pain remains poorly understood. Chronic back pain disability rates have increased from 1988 to 2004, despite modern technology and advances in pain treatment [1,2]. Waddell [3] states that back pain is a burden on society because it is the fastest-growing reason for work loss and sickness benefits. Additionally, health care professionals are expected to explain and diagnose back pain to offer proper help, but chronic pain is resistant to most of the treatments used in health care. One potential cause of the difficulty in pain diagnoses and treatment

may be the Cartesian legacy of thinking of chronic pain as a symptom of an underlying medical disease, although chronic pain is an illness in its own right [4]. Chronic pain is multifactorial and is associated with physical and psychosocial difficulties [5]. Therefore, there is no clear distinction between physical and psychological realms in chronic pain [6].

The shift from the traditional dualistic explanation to a holistic paradigm offers a better understanding and improved management of chronic pain, where a great concern in examinations and interventions are paid to the interplay between psychological, social, and contextual features as well as pain behaviour [7,8]. Although the biopsychosocial paradigm is well supported [9], it does not explain the phenomenon of pain and the subjective meanings of pain. Although the biopsychosocial paradigm is well known in health care, Sessle [10] in the recent review calls for more pain awareness and education for the crises and management of chronic pain.

Phenomenology has its scientific methodological foundations in Edmund Husserl's (1859–1938) work, and therefore, it is not only a method but also a philosophy and a theoretical framework. As a holistic paradigm, phenomenology rejects dualism and supports the idea that the mind and body are whole [11]. The body is both corporeal and mental, which means that the person does not just have a body but rather that he/she is the body; the consciousness is embodied [12]. In pain, the unity is disrupted and the painful part of the body becomes an object that the patient takes to a clinician to be fixed [13]. Therefore, the chronic pain patient should not be considered a patient with pain but a patient in pain, as one whole biopsychosocial unity without dualism to discriminate physical, psychological, and social aspects of the patient [11,12].

The aim of this study was to explore the effects of chronic pain from the participants' perspective and how the participants constitute their chronic pain.

Phenomenological method

Phenomenology is a science that studies experience and how a lived experience appears in the consciousness and what its meaning is. The phenomenological method is a qualitative method to study human experiences that are difficult to reach by any other method. In the analysis, an experience must be described as it presents itself to the person experiencing it [11,14–16]. Amadeo Giorgi is a psychologist who developed the method in the 1960s for use as a qualitative method in his field. Although the method he developed is primarily used in psychology, Giorgi has stated it is applicable to any social science that works with human beings. Nursing science is an example of how the method can be applied more broadly, e.g. Moi and Gjengedal [17]. Despite the flexibility of the method to be modified and used in a range of fields, the researcher has to assume the attitude of the specific discipline and show sensitivity to detect the phenomena of interest.

Giorgi's descriptive phenomenological method has four steps: Step 1 is to get a sense of the whole by reading the text provided to understand the language of the describer. Step 2 is to discriminate meaning units, the essential parts of the data sets that, in qualitative studies, are typically large. This step is needed in order to break the data down into smaller pieces. Step 3 involves collecting meaning units together into groups and the transformation of the subject's expressions into everyday language. Step 4 is the synthesis of all groups of meaning units by using related scientific language. For more on this method and its application see [14,15,27].

Giorgi's four-phase method was chosen and applied to this study to determine the essential meanings of chronic pain for the following reasons: (1) Giorgi's method employs a descriptive tradition; (2) phenomenology is a science of experiences; (3) experience consists of meanings; and (4) the aim in phenomenology is to analyse the meanings of the experience, describe the structure of the experience, and bracket previous knowledge of pain aside in analysis using *epoché* [14,15].

Study methods

Participants

The participants comprised 34 chronic pain patients who were recruited from four different sources in Finland fulfilled the aim of representing a heterogeneous group of chronic pain patients. Fifteen outpatients were from the Department of Physical and Rehabilitation Medicine, and six outpatients from the Pain Clinic at the same University Hospital. Four participants were obtained from the local Back Support, and nine of them

were obtained from the local Pain Support Group by the first author. In the beginning, the participants were given written information about the study.

The participants in this study had: (1) chronic pain of at least duration of 3 months as defined by the patient's own physician, (2) willingness to talk about the individual experience of chronic pain, (3) ability to read and write in Finnish, and (4) a minimum age of 18 years.

The ages of the participants varied from 26 to 73 years with a mean age of 48 years. Nineteen of the participants were women and 21 were married. Half of the participants were retired, and a fifth worked full-time. Each of the participants could walk without assistance but many needed help in tasks including household work. Most of the participants used a combination of medications. The individual characteristics of the participants and pain are presented in Table 1.

Ethical considerations

Ethical approval for the study was obtained from the University Hospital Ethical Committee. During the recruitment session, the first author or the doctor explained the nature of the study and an informed consent was obtained from each participant. In both the recruitment sessions, the voluntary natures of the participation the option to withdraw if desired, and a guarantee of confidence in the analysis of data where nobody could be identified, were clarified to the participants.

Data collection

The first author (T.O.) collected the data by using conversational interviews from May to November 2011 after contacting each participant by telephone to ensure his/her willingness to participate.

Every interview started with a short conversation. The same information of the study as was given in the recruitment session was repeated before recording the interview with an audio recorder. A copy of the signed informed consent was also given to the participant. The interviews were as conversational as possible by using open-ended questions [16] to allow the participant to tell about the experience of chronic pain as much as possible. The key statement was "Please, tell me about your chronic pain and how it started". Additional questions were used depending on how much he/she revealed. Figure 1 presents an example of questions that were used in one interview.

The length of the interviews ranged from 45 to 90 min in a supportive atmosphere and the interviews were transcribed by a professional transcriptionist. The complete collection of interviews consisted of 631 single-spaced transcribed A4 pages and ranged from 11 to 31 pages.

Meaning analysis

In the following section it is explained how the data of this study were analysed using Giorgi's [14,15] phenomenological method without any technical software.

- (1) The first author (T.O.) read each interview carefully several times and wrote a complete description of each participant's experience of chronic pain [14,15].
- (2) In the second phase, the first author discriminated meaning units of chronic pain from each participant's description, using the participant's own words and expressions to find the meaning units for pain [14,15]. A meaning unit could consist of a few words, a phrase, or an entire sentence, and were noted every time a participant referred to pain.

Table 1. The sociodemographic and clinical characteristics of the participants.

Participant	Gender	Age	Marital status			Work status			Pain duration			VAS			Medication	Diagnosis			
			F/M	years	Single	Married	Other	At work	Retired	Unemployed	Other	<1 year	1–3 years	3–5 years	>5 years	mm	Pain killers	Antidepressants	Combination
1	F	26			x					x		x	0	18	x				Sciatic syndrome
2	F	26			x				x			x	48	x					Causalgia
3	F	56	x			x				x		x	86	x					Cervical spinal stenosis
4	F	54			x					x		x	71	x					Fibromyalgia
5	F	50			x					x		x	47	x					Spondyarthrosis cervicis
6	F	64			x					x		x	90	x					Sciatic syndrome
7	F	31			x				x			x	62	x					Chronic LBP
8	F	29			x				x			x	6	x					Chronic LBP
9	F	58			x				x			x	64	x					Chronic LBP
10	F	53	x			x			x			x	18	x					Chronic LBP
11	F	31			x				x			x	80	x					Thoracic pain
12	F	60	x			x			x			x	23	x					Causalgia
13	F	60	x			x			x			x	45	x					Back pain
14	F	53	x			x			x			x	76	x					Chronic LBP
15	F	59	x			x			x			x	73	x					Sciatic syndrome
16	F	60	x			x			x			x	56	x					Lumbar spondylarthrosis
17	F	45	x			x			x			x	47	x					Pelvic pain
18	F	45	x			x			x			x	20	x					Fibromyalgia
19	F	26	x			x			x			x	83	x					CRPS
20	M	55	x			x			x			x	43	x					Sciatic syndrome
21	M	51	x			x			x			x	55	x					Sciatic syndrome
22	M	36	x			x			x			x	77	x					Cervical disc herniation
23	M	30	x			x			x			x	66	x					Chronic LBP
24	M	53	x			x			x			x	76	x					CRPS
25	M	50	x			x			x			x	83	x					Cervical spondylarthrosis
26	M	73	x			x			x			x	64	x					Polyneuropathy
27	M	47	x			x			x			x	68	x					Chronic neck pain
28	M	58	x			x			x			x	89	x					Sciatic syndrome
29	M	37	x			x			x			x	1	x					Spondylarthritis
30	M	33	x			x			x			x	77	x					Sciatic syndrome
31	M	60	x			x			x			x	40	x					Sciatic syndrome
32	M	58	x			x			x			x	23	x					Spondylarthritis
33	M	56	x			x			x			x	55	x					Sciatic syndrome
34	M	45	x			x			x			x	55	x					Spondylarthritis

CRPS, complex regional pain syndrome; LBP, low back pain.

(3) Each participant's meaning units which he/she used to describe, for example, the mood in pain were collected together, and a meaning structure, as we titled it, was formed. The number of meaning structures varied from five to ten for each participant. The meaning structures were arranged so that the most valuable meaning structure, from the participant's perspective was placed on top, and the others were placed below it and/or in parallel in an order that reflected how they were related to each other. The value of each of the meaning structure was defined by how the participant described the experience of it, and how he/she related or referred it to other meaning structures. The more valuable the meaning structure was, the more often the participant returned to it during his/her speech or used salience, indicating its subjective importance and

Please tell me about your chronic pain and how it started.
 How did you feel about it?
 What does the pain mean to you?
 What is the worst issue with living with chronic pain?
 Can you tell me something more about "a mess"?
 How do you explain it?
 What do you mean by saying "This is not human life"?
 Have you noticed if you ever forget your pain?
 What do you think your family thinks of your pain?
 How have you coped to live with pain?
 How is your mental well-being with chronic pain?
 What do you think your future will be like?

Figure 1. An example of questions used in one interview.

Figure 2. P28's meaning network of chronic pain. P28's meaning perspective "There is no sense in my life." P28 had to retire from his job due to burn out and low back pain. His symptoms were vague and he was never examined well. He thinks that his burn out was associated with his continuing back pain. Ever since his retirement, P28 has experienced depression and distress and he has felt himself to be a disabled man. P28 does not believe that his pain will ever be alleviated permanently and therefore he has lost his exuberance. If he had to choose between living and dying, he would choose the latter. P28 lives in his own house and due to his disability he has also had financial problems. His wife divorced him due to his pain by explaining that he was too ill for her. This point represented the ultimate collapse of his world. His depression, distress, and pain intensified and he felt he was all alone own because his friends had also abandoned him. They did not believe P28's pain to be real due to the lack of any visible trauma or injury and because P28 was active and maintained a good level of physical fitness, which he still does to the best of his ability. For this reason, a complete loss of ability to move is the worst scenario for him. P28's pain is dark and agonizing presence and he thinks that those who are married cope better with pain. His only friend is his dog, which understands him and helps alleviate his pain. P28 longs for the companionship of other men and a good friend to talk with and to engage in men's hobbies with. Physiotherapy has improved P28's quality of life. He prefers physiotherapy because it does not involve medication. For him good physiotherapy requires a supportive therapist.

significance. This organised collection of meaning structures constituted a subjective meaning network.

In addition, a meaning perspective was written from each participant's meaning network. The meaning perspective included everything that was included in the meaning structures and represented the entire experience of chronic pain for the participant. In this phase, the language was changed to reflect a third-person perspective [14,15]. Figure 2 presents the analysis of chronic pain of one of the participants (P28).

(4) In the synthesis, determining the essential themes of chronic pain, the essential meanings of chronic pain were extracted from the meaning structures of all 34 participants [14,15]. Initially, at least 10 themes and a number of subthemes with similarities were identified. Some meaning structures were combined and/or retitled to achieve a reasonable entity, precision and complexity in representing the experience of chronic pain.

Phases 1 and 2 of the meaning analysis were performed by the first author. The researcher wrote only what the participant told in the interview without subjective interpretations or opinions as the experience of chronic pain presented itself to the participants. Phases 3 and 4 were performed by the entire team under the direction of an author's (A.P.) expertise in phenomenology. Figure 3 presents the main points of the analysis.

Results

In the meaning analysis it was found that the experience of chronic pain consists of four essential themes or perspectives

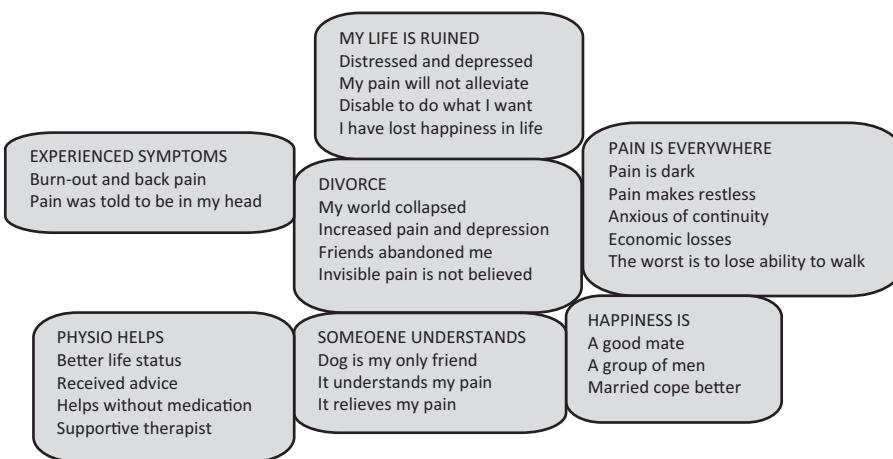


Figure 3. This figure illustrates the main points of the analysis.

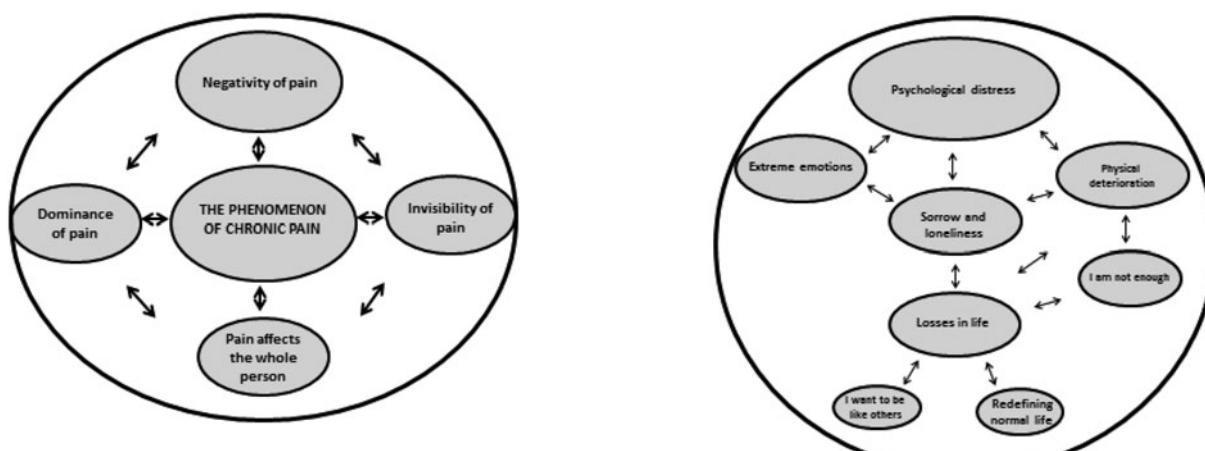
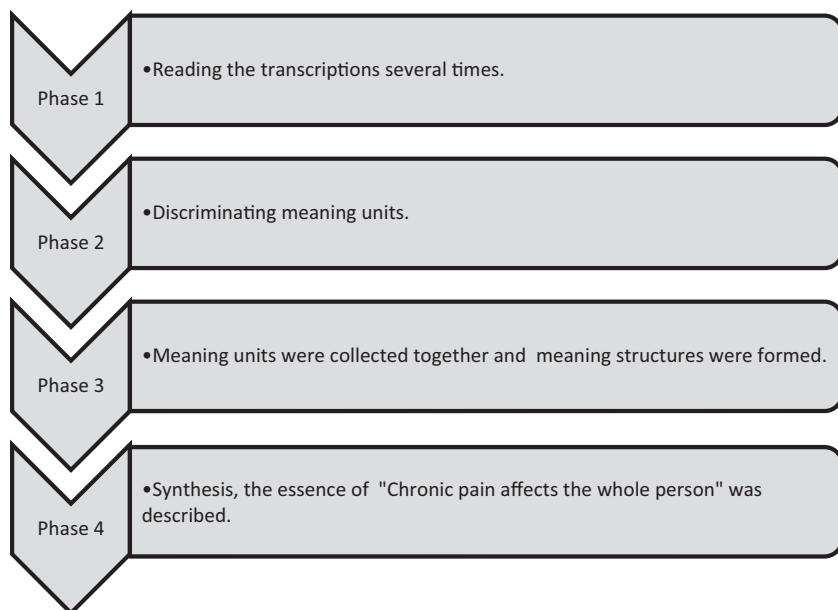


Figure 4. The phenomenon of chronic pain. This figure illustrates the four essential themes of chronic pain. In reality, the themes partly overlap, but they are presented separate for clarity.

of chronic pain: Pain affects the whole person, invisibility, negativity, and dominance of pain (Figure 4). In this article, we concentrate only on one essential theme; chronic pain affects the whole person (Figure 5).

The thematic meaning analysis of ‘‘Chronic pain affects the whole person’’ consists of eight subthemes that are described later in this section. The eidetic structure of the essential theme and how the subthemes are related to each other is presented in Figure 5. The most valuable subtheme, ‘‘Psychological distress’’, is on top and is the perspective from which the figure opens and should be read. The size of the subtheme represents its value from the participants’ perspective. Determining the value of the subthemes was possible using the subjective network and the synthesis of all 34 participants’ networks.

The results indicate that chronic pain affected the physical body of the participant, his/her psychological well-being, his/her relationships with others, and future life. The participants claimed that in the acute phase, pain affected only the physical body. When the pain became chronic, it caused more harm, fear, and distress than the impairments of bodily pain. Eventually, life with chronic pain was filled with depression, melancholy, hopelessness, and a withdrawal from other people.

Figure 5. The eidetic structure of ‘‘chronic pain affects the whole person’’. This figure illustrates how the subthemes are related to each other and how they function in a chain. In reality, the related subthemes partly overlap, but they are presented separate for clarity.

The body which once was silent, reliable, and functioning became achy, unpredictable and unreliable. These changes affected negatively the participants’ role, e.g. as a father or a spouse. Every participant had lost something, such as work, spouse, children or friends. However, despite their losses, many of the participants had also found something new that was more enjoyable than they could have predicted.

All of the participants had to confront the reality that their life before pain was gone, and the loss of their past life was met with grief and was hard to accept. The participants had to build a new identity and redefine their normal life with chronic pain. The eight subthemes are presented in the following section.

Psychological distress (see all subthemes in Figure 5)

The participants consistently described experiencing sorrow, inadequacy, and a worsening self-worth because of chronic pain. Some of the participants projected the distress on themselves to punish themselves and to increase the negativity of pain to feel worse. In practice, this meant drug and alcohol abuse and suicide

attempts. Those who did not seriously consider suicide wished for a fatal accident. The relationship with pain was described as dark, hated, and coloured with black. At the other extreme, moments when pain was tolerable or disappeared were described with hope, joy or empowerment. For many of them, the distress was severe and was more difficult to understand than the physical pain.

P8 (Participant 8 in Table 1): In the beginning, I did not think that my life was going to change completely. The pain was so intense that I was afraid of it, but I thought that I would be cured soon. Now, I think I was more afraid of the psychological consequences of the physical pain, the mental pain.

Sorrow and loneliness

Without exception, the participants argued that pain and mind inseparably affected each other. In sorrow the pain intensified, which again increased the sorrow. The participants described their life with pain as being absent of joy or hope for the better. They were hardly interested in anything and the formerly happy and active participant became melancholic and passive. The participants' lives were lonely, desperate, and filled with sorrow, which manifested as crying. The participants felt lonely because pain had separated them from other people. On the other hand, some of them wanted to be alone and said that they could not stand the laughter and happiness of others because it made them feel more miserable. This made some of the participants reluctant to form new relationships.

– P28: My wife left due to my pain to live with our two seriously ill children. The boys cannot communicate and I also have this terrible unrelenting pain. I felt that my pain worsened after the divorce. I am so alone and missing a company to share this whole mess. This is not human life at all.

Extreme emotions

The participants said that the pain-related emotions covered the whole spectrum of emotions, including distress, fear of pain, and insufficiency, which increased the negativity of the pain experience. In victimised pain, the emotions of sorrow, despair, depression and hopelessness were experienced as more disabling. One participant (P34, Table 1) described the emotions in chronic pain as "Like in a rollercoaster, from one extreme to another", meaning that emotions changed in a blink of an eye according to the experience of pain. The participants described being exhausted due to their unremitting pain. The exhaustion was partly due to a failure to receive understanding, support, and consolation from family and spouse. A spouse, man or woman, understated the participant's chronic pain and dominated their marriage. Some of the participants experienced the relationship as so unsettling that the only alternative was to obtain help from a health care professional.

– P16: I just felt that I needed to talk to somebody. My husband had retired, and he used alcohol every day. Even when he was sober, he was mean, and when drunk, he was so awful that I could not stand him. All I could hear was how miserable I was.

Physical deterioration

The most common change in the participants' bodies was the deterioration of its function, which the participants described as the "inability to do the tasks they used to do". With the word "inability", they did not signify a complete inability, but they had become slower and more careful, particularly in ambulation.

Their body was no longer workable but had become insecure and unpredictable. This unpredictability made their lives restricted and necessitated advanced planning.

– P29: I used to drink a cup of coffee in the morning and go to work, just like that. Now, in the morning, I have to think of what kind of day this will become. I have to plan my day according to my pain.

The participants stated that before pain, they used to have bodies that were silent and did not feel anything. Chronic pain led their bodies to feel decayed, powerless and older, which manifested in impaired movement. The worst scenario and the biggest future fear were becoming restricted to a wheel chair and as handicapped being assisted by others.

– P18: I remember when I could not go to the toilet and my husband had to bring the potty for me. I felt myself a handicapped woman who had to be assisted by others.

Losses in life

Many of the participants were obliged to retire due to their chronic pain and had to leave their relationships with colleagues and work that had made them feel important and needed. Many of the participants' friends had also left them, but those friends who had stayed did not demand any explanations and believed the reality of pain. Those friends had accepted the new identity of the participants and were supportive and ready to help. Losses in relationships were difficult to handle and accept, especially when the loss concerned a spouse or an own child. According to the participants, losses contributed additional distress and were experienced as unfair.

– P14: My pain was so intensive that my husband divorced me and took the children with him. I felt it was terrible, but I thought that I could not take care of them.

The participants' hobbies or exercise became less intense with chronic pain. The participants felt that the requirements for these activities were less, which they found very positive, as there was no need to try harder; lesser was now sufficient.

– P18: I cannot exercise as much as I used to do. As to my housework, I have very low requirements, and I do them when I can.

I am not enough

In the interviews, the participants reflected on their role as a man, woman, wife, or husband, and discussed how different losses had affected their role. Particularly to those who had been active and effective, the impairments were interpreted as difficult and as a permanent loss of identity. The physical disability was experienced as an insufficiency in relation to oneself or to the spouse, which affected the participant's psychological capacity to handle the deficits.

– P17: Chronic pain has ruined our sex life, which has affected my role as a wife and a woman and led me to question if I am whole anymore.

I want to be like others

The participants dreamed of being pain-free, but they explained that being pain-free did not mean being healthy. Their comments

were as following “I have pain but I am healthy and I want to be like the others”. The participants described how they covered their impairments and avoided situations where their pain might increase. Some of them did almost anything to hide their pain and to be like others. Most of the participants alleviated their pain by moving. Doing that they felt restless, but moving was the easiest way to relieve their pain. At night, moving was difficult, which caused sleeping problems and decreased the quality of sleep.

- P32: At night, I walk, I stretch, and I take pills and do anything to alleviate my pain. My head is in chaos, full of desperation. I cannot stand this kind of life.

Redefining normal life

The participants reported how they had to redefine normal life. The criteria of the life before pain were no longer applicable. Their redefined normal life was different but not worse, and the participants said that they had to confront the reality and accept that their life in the future will be like this.

- P19: I do not have a personality anymore and my physical appearance has changed. I do not look like I used to look; I was slimmer before and dressed with fashion. Everything has changed because my hand does not function properly anymore. This is my life now and forever.

Discussion

The main finding of this study was that physical pain or impairment was not the biggest complaint, but those were the psychological distress, worry, solitude, and despair (Figure 5). If one of these stressors accumulated, the stressor exacerbated the pain experience, deteriorated the quality of life and maintained the vicious circle. Chronic pain leaded to a complete stop of the previous life, with losses ranging from work to friends. Pain also contributed to the formation of a new identity and a new definition of what normal life is with pain. The complete change of life was hard to understand and accept.

The Cartesian legacy was strong in the participants’ descriptions of pain. For them, pain was a physical aversive sensation and none of the participant used the word “experience” to describe the pain. However, when asked, the participants described how the physical pain affected on their emotions, identity, and everyday life. According to the participants, the emotional reactions were the most significant consequences of physical pain, which agrees with other findings [7]. The participants claimed that it was easier to understand the physical pain than the psychological responses to it. The participants usually described their pain in physiological words such as “broken, torn” or “compressed”, as in a study by Snelgrove and Liossi [18]. Each of the participants agreed that physical pain and psyche were related but their relationship and the reason one reacted in a certain way remained elusive. The explanation may be to conceptualise the body only as an object (that we possess) consisting of bones, nerves, cells, and liquids instead of an object and a subject (that we are) and together conceptualise the body as corporeal and mental as the “lived body”. The “lived body” is the body that experiences, the body that an individual recognises as self. The objective body is a part of the “lived body” that is typically used in medicine and physiotherapy for interventions whereas the “lived body” can be only experienced.

Another interpretation may be found in the subjective attitude towards chronic pain, in phenomenological words; in the subjective meanings for pain. The more negative meaning for

pain, the worse the pain feels, the more distress the pain arouses, and the lower one’s self-esteem and quality of life. Suffering from pain is a general expression, but the expression is obscure and refers only to the sensation of pain which is always negative and aversive. Suffering is the meaning one attributes to chronic pain; suffering is how the pain is experienced [19]. This implies that pain education should make a clear distinction between the aversive sensation of pain and the experience of pain, i.e. sensation versus how the pain affects the patient’s life [8,20]. Therefore, Sessle’s [10] argument of pain education for health care professionals and general population is well justified.

The participants argued that emotional responses to pain and behaviour were harder to understand and explain as compared to physical dysfunctions (Figure 5), because chronic pain affected their sleep, ability to exercise, and social activities as in another study [4]. The Cartesian legacy necessitates that pain must have a trauma, visible evidence that is true and describes the dysfunctional body as a malfunctioning machine. The participants described how their painful body was felt as alien and useless; the body that once had enabled them to do something was now decayed, disabled physical activities and was a constraint. Similar results have been reported in the other studies [4,21–24]. However, also controversial results have been reported [25] wherein chronic pain does not decrease daily physical activities. Therefore, the constrictions of chronic pain are relative. In our study, the participants had identified softer forms of physical activities that were more suitable for their present physical condition. In fact, many of the participants said they preferred the recently found activities and said that they were happy and enjoyed exercising for fun, instead of sweating and pushing harder. In chronic pain, black and white thinking, over-generalisations, and fixed beliefs are common. Restriction of a familiar function or activity is interpreted as a complete loss; a notion that must be revised in rehabilitation.

The participants were a heterogeneous group of chronic pain patients (Table 1) who considered before the onset of pain that it was self-evident that their body is always functioning properly. With chronic pain, most fears were related to the worry that the symptoms would become permanent and worsen. Body changes were interpreted as dysfunctional, and the worst fear was to be confined to a wheel chair. Thus, in rehabilitation both psychological rehabilitation and a graded exposure to pain are necessary [8] but most of all, access to early pain treatment to prevent chronification [10].

According to the participants, the origin, type, and impacts of pain varied (Table 1), but the psychological responses such as distress, anxiety, fear, sorrow, and despair about pain were more convergent and disabling (Figure 5). The participants stated that they had very few emotionally stable periods. Their lives were more labile including exhaustion and depression following the course of pain and uncertainty over the future. Drench et al. [6] state that the mind and body are nowhere in medicine more closely linked with each other than in chronic pain. Consequently, psychological responses and acting strategies are dependent on what we think of pain, in which fear of pain is the essence. In clinical terms, pain beliefs and self-efficacy predict disability and depression, but high education inhibits pain beliefs and enhances recovery [26].

The participants described that most of their losses with chronic pain were related to their identity as a woman/man and spouse or to difficulties in relationships with friends or work. These relationships reflect the participants’ cognitive ability to handle their altered identity, lifestyle, and the misinterpretations of pain by their friends or colleagues. This supports the idea that it is crucial to educate the patient and the family to cognitively

handle the impacts of chronic pain. The participants often described themselves and their physical qualities as “invalid, cripple” or “handicapped” by impaired functioning and appearance. The stigmatised impairments negatively affected their self-esteem and identity, which is in agreement with another study [18]. More precisely, chronic pain patients judge themselves through the others’ eyes, i.e. in a way that the chronic pain patients think the others see them.

The participants argued that chronic pain had deteriorated their independence and ability to live the life they desired, and these expressions are in line with other studies [23,27,28]. On the other hand, as the participants claimed, the attitude of others was to avoid the participants because they were not “normal, like them”, which was the reason that the participants felt abandoned. However, neither past studies nor any of the participants defined a normal life. The participants referred to their life without pain as normal or stated that they were “unable to do their desired activities”. Both of these ideas are obstacles in acceptance of pain, the former representing living in the past and the latter exhibiting a negative content. There is not merely only one normality but a variety of normalities. Normality will vary between individuals and within individuals depending on their age, unemployment status, and presence of children. In general, normal life depends on the course of life and contextual factors.

The vast majority of the participants admitted that they had adapted to life with chronic pain and encouraged themselves in the process in order to be like he/she really was, not shaming, understating or underestimating oneself but gathering the pieces of the individual to build a whole human being with a new identity. They had redefined normal life and confronted the reality that chronic pain will persist. Hardly any of the participants wanted to use the word “acceptance”. The word was interpreted as strange because pain was an unwanted and involuntary illness that disabled and distressed. The participants needed help from health care professionals and support groups, but the family remained the best supporter. The most needed help was to talk to someone and not being left alone, as in the study by Lundberg et al. [20].

Taken together, for a chronic pain patient, most of the difficulties are related to pain management, coping with unwanted physical impairments and psychological suffering during the course of life and accepting oneself in one’s own right. Therefore, it is misleading to talk about physical or psychological pain. Pain does not affect either/or but holistically the whole human being which is supposed to be recognised and acknowledged in health care.

Strengths and limitations

The first strength of this study is that we provided a holistic understanding of the effects of chronic pain. The second strength is the adequate number of heterogeneous chronic pain participants, as no new meaning units were found in the 34th participant’s interview indicating a saturated data. A third strength is the multidisciplinary team that formed the meaning structures and performed the final synthesis.

Regarding the limitations, we do not claim that this is the only eidetic structure of “Chronic pain affects the whole person” (Figure 5), but the team’s systematic analysis provides credibility to the results. Many of the participants were interviewed and listened to for the first time, which might have influenced some meaning units to be exaggerated in their significance. Although the results agree with other studies, they should not be generalised to all chronic pain patients or extrapolated to other cultures.

Trustworthiness of the study

A descriptive phenomenological method is a valid method to find the meaning of the experience and it can be regarded as an extension in the spirit of science [29]. In the meaning analysis, the team bracketed their previous knowledge of pain aside, and described the experience of chronic pain as it presented itself to the participants. As Giorgi [14,15] states, bracketing is a part of reduction, “means that we should not let our past knowledge be engaged while we are determining the mode and content of the present experience”. Merlau-Ponty [12] has argued that reduction can never be complete, and that the past history and knowledge cannot be abolished. Giorgi [14,15] also explains that a present experience is always compared to a past and is often interpreted as being identical which is important to be aware of but stating them as completely identical leads to false conclusions. In the beginning of this study each researcher acknowledged that this is going to be different from the previous studies and this required a different perspective and a different method. The research group discussed about the meaning units and meaning perspective, and made the critical question according to the meaning analysis. Therefore, it might have been easier for us to bracket our previous knowledge of pain and rather to be excited about the results this holistic approach does give to us.

Conclusions

The results indicate that the effects of chronic pain are mostly psychosocial, indicating a need for a multidisciplinary rehabilitation. Rehabilitation has two aims: The first is to disclose the subjective meanings of pain and the second is to counsel the patient to understand and to manage the effects of chronic pain. But the most cost-effective treatment is prevention, so in health care every pain patient must be taken seriously.

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Declaration of interest

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