

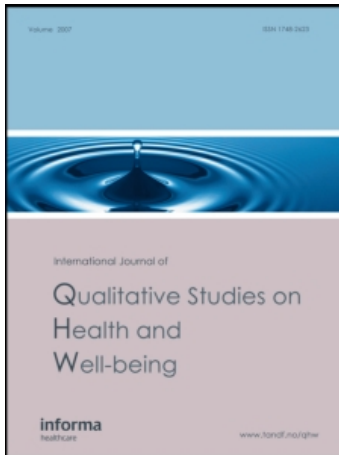
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ORIGINAL ARTICLE

Temporal experiences of persistent pain. Patients' narratives from meetings with health care providers

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Abstract

This article is based on a study of 20 adults with persistent non-malignant pain histories lasting from three to more than 30 years. A narrative approach was used to investigate how the participants experienced their daily life with persistent pain. Data were collected by in-depth interviews, transcribed verbatim and analysed using a hermeneutic phenomenological approach. The study revealed disjunctions in the participants' lives between the temporal structure of pain experience, and the common, social time. The results were, first, the temporal unpredictability of the informants' pain experience, which constituted an obstacle to communicating the pain; second, the importance in health care provision of the patients' pain history. Pain invaded the participants' lives insidiously, and forced their consciousness episodically away from the common world. This temporal "confinement" caused problems of relating their pain experiences in objective time. The participants used narratives, metaphors, and emphatic expressions. When health care providers focussed on the here-and-now situation, the unpredictable though long-term character of the pain was disregarded. Several participants told of disappointing meetings with professionals, and of ineffective treatments. The importance of telling the whole pain history was emphasized. Through exploring and explicating their experiences in narratives, some participants expressed that their temporal perspective was being extending to future possibilities. The article concludes that professionals should give attention to the temporal development of pain, by listening with empathy and imagination to gain an understanding of how their patients' lives have evolved. When patients are given time to "tell the whole story", the professionals and the patients may develop and share a temporally continuous perspective that spans past, present and future.

Key words: *Persistent pain, temporality, narrative methods, subjective time, objective time, meetings between health care providers and pain patients*

Introduction

A large number of persons in Western countries suffer from chronic non-malignant pain, which seriously affects their daily activities and social and working lives. A survey of 15 European countries documented that moderate to severe chronic pain occurs in 19% of the adult population, of whom 40% experienced inadequate management of their pain (Breivik, Collett, Ventafridda, Cohen & Gallacher, 2006). The International Association of Study of Pain (IASP) distinguishes between acute and chronic pain. The criteria for chronic pain are a duration exceeding 3 months, the expected normal time for recovery, and the failure of standard biomedical interventions (Niv & Devor, 2004; IASP, 2007). To

avoid expressing a resigned view of the prognosis, the term "persistent pain" is recommended instead of "chronic pain" (The Swedish Council on Technology Assessment in Health Care, SBU, 2006). In this article, we use the term persistent pain.

Temporality appears as a central issue in many studies of persons with persistent pain (Brough, 2001; Honkasalo, 1998; Thomas, 2000). The development of persistent pain is described as a life phase during which pain development constitutes its own time within time, and where the common time is sometimes threatened by collapse. The routines of everyday life and plans for the future are slowed down and made uncertain, and the options and possibilities of the person are gradually reduced (Breivik

et al., 2006; Leder, 1990; Toombs, 2001). Leder (1990) maintains that pain asserts itself not only by its sensory intensification but also through its characteristic temporality, which he terms its “episodic structure”. Pain of a persistent nature manifests episodic temporality, a continual reassertion of its presence, “as if the pain were ever born anew, although nothing whatsoever has changed” (Leder, 1990, pp. 73). Since pain is the consolidation of the unpleasant, it places upon the sufferer what Leder terms an “affective call” (Leder, 1990, pp. 73). The person’s attention is occupied by the negative quality of pain. Persistent pain continues to hold the attention in periods where pain increases in intensity.

Several studies of patients living with persistent pain have shown how physicians and patients may find themselves separated by a decisive gap in understanding (Breivik et al., 2006; Sundstrøm, 2001; Thomas, 2000). The phenomenologist Toombs (1990) has related this gap to the temporalities of illness and pain. These perspectives will be presented next and included in the discussion of the results.

Temporality and the concept of illness

Various concepts of illness and disease may comprise different temporal perspectives. In the Hippocratic medicine of antiquity, illness was seen as an ongoing flowing process, a life phase: the illness phase (Benner, 2001; Foucault, 2003; Clark & Mishler, 1997). This temporal perspective required that the physician paid close attention to the progression of the illness through its entire trajectory. The disease was understood as an individual course, spanning anamnesis, present condition and future prognosis.

In modern medicine, the patient’s illness is usually defined as disease, in terms of recent objective, quantifiable data (Benner, 2001; Foucault, 2003; Young, 2002). In this paradigm, the characteristic temporal view of illness is the discrete snapshot of the moment, which focuses the here-and-now situation and is limited in time and context. Accordingly, the presence and nature of illnesses are detected through examinations and testing of samples. Diagnosis defines the illness as a distinct entity and directs further treatment (Benner, 2001; Clark & Mishler, 1997; Toombs, 1990). The diagnosis partly constitutes the general concept of pain and illness of modern society, and hence is important to the self-understanding by those designated as ill (Bury, 1982).

In a temporally contracted diagnostic model, the patient’s subjective experience of pain developing over time may however be relegated to the periphery of interest. There is a risk of the patient’s experience

being overlooked or not taken seriously (Honkasalo, 1998; Toombs, 1990). Both these temporal perspectives on illness, as a process in life and a present situation, are operant in society and in health services today, and may create a tension of temporalities when health care providers and patients with persistent pain meet.

Temporality of pain: Philosophical perspectives

Patients often report that their awareness of time alters radically when they are in pain (Brough, 2001; Honkasalo, 1998; Young, 2002). Brough (2001) and Toombs (1990, 2001) analyse the temporality of illness from a philosophical perspective of the consciousness of time. They discuss explicitly the temporality of pain experience, using Husserl’s philosophy, understood as reflection on conditions for conscious awareness, which aims at revealing the essential structures always present in our experience but overlooked or only obscurely glimpsed. Husserl examined the nature of consciousness in its character of always being consciousness of something. He maintained that, because we are conscious of the here and now, consciousness and time consciousness are one and the same.

Husserl distinguished between objective time, which can be measured by clocks and calendars, and subjective time. He claimed that the constitution of time must be explained by the constitution of temporal objects in consciousness (Toombs, 1990). According to Toombs and Brough, immediate pain is a temporal object for consciousness. The object is temporally extended and experienced as a whole, and appears as a continuum because it’s immediate past and future provide horizons for the present (Brough, 2001; Toombs, 1990). Husserl termed the consciousness of the immediate past “retention”, and the awareness of immediate future “protention”. The ongoing, immediate experience of the temporal phases of an object (such as pain) is evoked through the interplay of retentions and “protentions” in the stream of consciousness (Brough, 2001; Leder, 1990). Toombs (1990), following Husserl, compared this to listening to a melody: I hear not only the present note that is now sounding but also retain in my present consciousness the previous note and anticipate a future note as the melody unfolds temporally.

In the analysis of Toombs (1990), inspired by Husserl, pain as a temporal object is experienced as a whole. Pain extends across past, present, and future. “Living through” the pain means that the pain sensation is experienced as extended in duration: the “now” of lived time is an elastic form that can expand or contract; it is not fixed in distinct “now”

points along a given time line. The temporality of immediate experience differs from the formal structures of clock and calendar time. This may constitute incommensurability between objective time and the immediate time in pain (Brough, 2001; Toombs, 1990). The phenomenological perspective on temporality gives insight into pain as lived experience in subjective time. It is a part of patients' understanding of their situation and is often implicit in their meetings with health care personnel.

This article is based on a study where patients of a pain clinic were invited to talk about their lives with prolonged pain. Temporality of pain experience appeared as one of three main themes in the data material, and it is the central topic for this article. The aims of this article are to explore how the informants experienced temporality of pain in their lives; and the significance of this temporality of pain experience in their meetings with health care providers. The research questions are:

- How do participants experience the temporal aspects of persistent pain?
- How does the participants' experience of the temporality of persistent pain affect their meetings with health care providers?

Methods

The methods of data gathering and analysis described in the following were used in the project as a whole, on the total data material. *Three* main themes were identified. In this article, we discuss one of them, the temporality of pain experience. The other two main themes are discussed in separate articles (Nilsen & Elstad, 2006, 2008).

Research design

To explore how participants experienced life with persistent pain, and how pain influenced their daily life, a narrative approach seemed appropriate. Narrative theory holds that the basic way to explore and explicate the meaning of human experiences is to narrate the experiences and to listen to the narrations of others (Ricoeur, 1999; Riessman, 2001; Skott, 2004). This is especially relevant when life events involve a disruption between the self and society, or between the ideal and reality, which is shown to be the case when living with persistent pain and its consequences (Bury, 1982; Honkasalo, 1998; Leder, 1990; Thomas, 2000). The participants' pain histories are of long duration and are an integral part of their life histories. It is also a distinct period within their lives. As time structure is an explicit aspect of the narrative, this approach is well suited to

exploring the temporal dimensions of the informants' experiences.

The focus of the study was on the development of the participants' lives with persistent pain, not on the persistent pain as such. Accordingly, the participants were asked to relate how their lives had evolved after the pain developed. Ricoeur's interpretation theory (1999; 2005) holds that the gaining of knowledge and understanding about lived experiences cannot pass directly from one person to another but must be constructed through the hierarchical interpretation of text. We found his hermeneutic phenomenological approach relevant to analysing how the experience of living with persistent pain was presented in the personal narratives of the participants. Such an interpretation integrates explanation and understanding in a dialectic movement, starting from the properties of the text (Ricoeur, 1999, 2005).

Participants

The study sample comprised 10 men and 10 women who were recruited from outpatients attending a pain clinic run by a hospital in the northern part of Norway. The inclusion criteria were that the participants should be adult persons, with persistent non-malignant pain and with no clear diagnosis for at least parts of their pain history, because this is a special challenge in living with persistent pain. An equal number of men and women were included, to enhance the possibility of variation of experience in the data. Gender was however not a special focus and gender differences are not explored in the study. The participants were aged between 26 and 63 years (mean 42.7 years), the duration of pain experience ranged from three to more than 30 years, and participants' physical conditions differed. Patients were referred to the pain clinic by their doctors, who considered its specialist facilities useful. As patients at a pain clinic, the participants constitute a selection from a larger population of patients with persistent pain.

Data collection

All interviews were performed individually and were conducted by the first author. The interviews started with the participants being asked to tell their "personal story", from the first occurrence of their symptoms and pain up to the present. The participants were asked to talk freely about this period in their lives, and given ample scope for their own reflections, with the interviewer consistently taking the role of listener (Kvale, 2000; Riessman, 1993, 2001). The interviews took place in the participants' homes or in a chosen meeting room. They lasted

from two to three hours and were audiotaped and transcribed verbatim by the first author.

Data analysis

The first readings of the material revealed its explicit temporal structure, where the pain experience appeared as embedded in the life narrative of the participants. By means of their narratives, the informants explored their pain problems by looking back to earlier events, and forward towards future expectations. In the analysis, we tried to preserve this structure, by doing first a *narrative analysis* of each interview, and then a *thematic analysis* of the narratives across the material. The narrative analyses were performed according to the phenomenological–hermeneutical method developed by Lindseth and Nordberg (2004), inspired by Ricoeur’s philosophy. The method consists of three steps—first naïve reading; second structural analysis; and third comprehensive understanding.

At the second step, the structural analysis, we chose Labov and Waletzky’s (1997) definition of a personal narrative to guide the identification of units of meaning from the interview of each participant. The narrative analysis was thus performed by combining the methods of Lindseth and Nordberg, and of Labov and Waletzky. Our reason for this approach was that Labov and Waletzky (1997) present an explicit method of identifying principal units of meaning in a narrative. Their method aims to ensure that the narrative structure of the units is preserved through the analysis. According to Labov and Waletzky, a personal narrative consists of six parts: (1) abstract (core narrative); (2) orientation (who, where, when); (3) complicating action (what happened); (4) evaluation (the effect on the narrator); (5) resolution (what impact did it have); and (6) coda (bringing the story back to here and now). At this second step, the narrative content of each interview was identified, and stories within the stories were selected. The selected stories, named core narratives, were reflected on against the understanding derived from the first, naïve reading, and then related to each other and sorted into sub-themes according to their content. The first author did this. Assisted by the co-author and colleagues in a research group, the sub-themes were examined and interpreted into higher-level content of meaning, by going back and forth between the naïve understandings, the core narratives and the sub-themes until all were condensed as different themes (Frank, 2000; Riessman, 1993, 2001; Skott, 2004). The purpose of this comprehensive interpretation was to bring forth significant units as basis for developing themes central for the narrative of each interview

(Bailey, White, & Pain, 1999; Larsson, 1993; Riessman, 2001).

The next step, the thematic analysis of narratives, aimed to interpret the text as a whole, by producing themes across the material (Lindseth & Nordberg 2004). This meant recontextualizing the text through reflecting on themes and sub-themes against the research questions, theory and previous research. Sub-themes that related to temporality and pain were synthesized into themes. The sub-themes “insidious and episodic pain as a temporal trait”, “to narrate pain experiences in objective time order”, “challenges of conveying pain experiences to others” were identified and condensed into the theme “the unpredictability of pain, and its affect on communication”. The sub-themes “the impact of temporality on pain assessment” and “telling the whole story” were condensed into the theme “the importance of the pain history in health care provision”. Through this process, one of the three *main themes* of the project was identified as “the temporal experience of persistent pain”.

Ethical considerations

Ethical matters were considered throughout the project. The patients that attended the pain clinic were given written information about the project. Those who wished to participate contacted the project leader. They were then informed about the aim, method of the study, that participation was voluntary, and they were free to withdraw at any time without offering an explanation. Informed consent was obtained from the participants after they had received written and oral information. The study was approved by the Regional Committee for Medical Research Ethics and the Data Inspectorate at the Privacy Ombudsman for Research, in conformity with current Norwegian regulations for ethical research practice (Reuter, 2003).

Looking back on a painful period in one’s life may be emotionally stressful (Reuter, 2003). The participants indeed became upset when talking about some of their meetings with clinicians. The interviewer was therefore prepared to be cautious and to take care of the participants in case stressful reactions were brought on by the conversation. The participants had the option to contact the pain clinic if they felt the need afterwards, which none of them did.

The participants were used to speaking about their pain experiences. Even so, several claimed that this was the first time they had related their stories in a connected way. Usually they only discussed fragments of their experiences in their meetings with health care personnel. Some participants expressed

their satisfaction at having the opportunity to relate their “whole story”.

Results

Through the focus on how the participants' lives developed, the data presented a temporal structure. The informants explored in the narratives their pain problems by looking back to earlier events, and forward towards future expectations. The participants emphasised their meetings with health care providers as important events, in particular when a lack of common understanding was evident. The two themes, derived from sub-themes in the narratives are in the following presented as “the unpredictability of pain, and its affect on communication” and “the importance of the pain history in health care provision”. The analyses are based on data from all the interviews. The participants are presented under fictitious names.

The unpredictability of pain, and its affect on communication

Insidious and episodic pain as a temporal trait

Many of the participants described their pain problems as beginning with an event that caused acute pain, which they then expected would last only a short time. It took some time before the pain became so intrusive that they started worrying and sought a doctor's advice. They confirmed that pain might develop in an insidious manner, as Mathis did in his narrative.

It started in a car accident in 1990, 9 June actually, in 1990. I didn't really feel any pain, just got numb in my head and body. Time passed, it was really a month, half a year or two years after, and then the pains in the neck appeared. Then they were gone. I didn't think about them any more. It started at its worst in 91, 92 really. I think it was 92; it was so devilishly painful that I went to the doctor and was referred to a physiotherapist. However, it only got worse and worse, I don't know how to explain it, they came and went those pains. In the end, I got used to it, clenched my teeth and just worked. The time passed, and it got worse and worse. In 96, or I think it was in 97, it started to get so bad that I was unable to concentrate when talking to customers, and sometimes I could not remember what we had talked about. In the end, I couldn't take it anymore; I just had to give up. It has really become a new era for me, before and after 1990.

Mathis gradually became aware of the need to seek help, as his pains increasingly affected his

performance. He recounted that in consequence, he had to reorganize his everyday life; he was sick listed and then had to live on a disability benefit. He was compelled to change his plans for the future, and at the time of the interview, the consequences of the pain limited his options in life severely.

The episodic character of the pain is evident in many of the stories. The pain came, went and varied in intensity and duration. Some participants linked the variation to physical activities that they chose to perform, even though they knew that their pain would increase. One man explained that he chopped wood from time to time, and then experienced “days of hell” afterwards. Arne described his situation like this:

Of course they may often think that it is something you imagine. I went to the doctor, and suddenly the pains were gone. Immediately afterwards they were back again. It is not easy to understand.

Many described these changes as completely unpredictable, that they dominated the participants' everyday life, and made it difficult to plan beyond the present day. Randi explained:

“It is a pain pattern that goes up and down; you have some bad days and some better ones. This makes it difficult to plan anything, because things change quickly and go wrong.”

The unpredictability of the pain also made her worry that others might regard her as unreliable both at work and in her leisure time, because the pain often prevented her from meeting commitments.

To narrate pain experiences in objective time order

After many years, most of the participants were still in search of a plausible cause of their pain problems. This involved many meetings with health care providers. The participants related how, when seeking assistance from health care providers, they attempted to describe their pain by narrating a story. In their interview narratives, the participants were also obliged to construct a presentation of remembered past events and pain sensations, partly by using medical language. They presented a sequence of events in the social and objective time of calendars and clocks, reflected on their pain as a symptom of some imaginable disease, and remembered the time of some events precisely, in the way Mathis did. However, most of the participants talked about how the pain demanded their attention and caused concentration problems in their daily life. As the story of Mathis also shows, it was difficult to

identify the time, sequence and duration of the pain experiences. When they did not remember events according to the objective time scale, they complained of their memory. Kathinka put it like this:

“I’m trying to tell the story as well as I can, but, I’m so bad at remembering precisely, when I have pains and such things, because you don’t walk around thinking about it, how it’s been.”

Challenges of conveying pain experiences to others

According to the participants, it was a challenge to communicate their pain problems to others. Several quoted the proverb “The one who wears the shoe is the one who knows where it pinches”. They complained of difficulties in finding adequate words to describe their experience of pain. These problems were probably increased by their experiences of unpredictable pain into processes of social communication. Gro expressed it this way:

I told my doctor: ‘Try to understand, I’m in so much pain, I know my body better than you. You don’t know my body; you don’t know how I feel; you don’t know how hard and painful my muscles feel. Even if you press and feel my body, you won’t find my pains’.

Some of the participants tried to disclose their pain experiences by using metaphors, as “it is like an iron bolt in my neck”. Arne painted this word picture:

Imagine a shiny, round ball; it is red, inside my head somewhere. It is there all the time, and you are noticing it. Then it goes bang, shoots out spikes, and sparks. That pain is very intense, and comes so suddenly that I am totally knocked out. However, the worst is when the pain increases and goes on over time. I cope very badly with that. Then I feel that I am sitting in a straitjacket and cannot manage to break out. That is a real strain.

They sometimes used intensifying expressions, such as “devilishly painful”, in an attempt to make the pain experiences communicable to others. Nevertheless, many of the participants had the same experience as Randi:

I have tried to explain to my doctor, and tried to explain, but I have felt that there has been a lack of response. He has not understood what I’ve said; he has not really understood what it’s all about.

The participants told how meetings with health personnel sometimes left them exasperated, and they

described feelings such as rage, low spirits, sadness, worry, stress and discouragement. Several of the participants stated that they were left with the feeling that they had not been heard or taken seriously, nor even believed. All the participants touched upon their apprehension about being regarded as hypochondriacs. May explained as follows:

You don’t dare to say so if you’re hurting in two places. You’re worried they’ll think: “Oh my God, she must be a hypochondriac.” That’s the fear you must bear in addition, right. It’s been an additional burden over the years.

The importance of the pain history in health care provision

The impact of temporality on pain assessment

Many of the participants had a pain history that started acutely, with injury or illness, and unexpectedly developed into prolonged pain. They spoke repeatedly of the time and energy they had spent in trying to find an explanation they could accept. Although none of them believed they could ever be free from the pain, they expressed their determination to explore all avenues to moderate their pain, and they were convinced that an acceptable explanation would enable them to start thinking ahead. Many participants considered that events from their past might provide meaningful explanations for their pain. One of them was Charlotte, who had become more and more disabled by increasingly frequent bouts of severe stomach pain:

I had an operation when I was a little girl. It gave me peritonitis too. I have often wondered if that’s where it comes from. During the last two years, I have often asked my doctor, and at the hospital here, if they could check that, but no. When they don’t have anything else to test for, they could do this just to see at least. But they didn’t think it had anything to do with my pain problem today, and they know better than me.

Charlotte’s explanation did not elicit much of a response from her doctors. She was not satisfied, because she was concerned of the future: “That treatment, it does not work. The pains, they pass, I guess they do, but they *always return*, with increasing frequency.”

The participants gave several examples of experiences when health care providers paid little attention to the progression of pain over the years, or did not consider previous treatments and their results. The participants expressed the opinion that treatment

was too often prescribed from the here-and-now situation, which might differ from the total development of the pain. Sometimes they expressed frustration at this temporal difference in outlook, which they considered resulted in treatments or examinations that were inaccurate or of little help. In some cases, participants stated that the treatment at best had no purpose and at worst caused more injuries or worsened the pain situation. Several expressed the same feelings as Gro, who gained the impression that the doctor instead of listening to her story, prescribed treatment from his own interpretations of the situation:

My doctor gave me antidepressants without me being aware of it. He told me later. He wanted to get rid of a problem, so he gave me 'happy pills' that made me so weird. You know, I got so pissed off that I threw the drugs in the toilet. I won't accept this, I'm not mentally ill. I want help to get by.

Other participants stated that they were met with a passive attitude towards their pain, which they found the most wearing. Years had passed and little had been done, as in the story of Randi:

In one way, I feel that my doctor let me down. It took many years before he started looking into this. When I look back . . . I feel that it's gone to rack and ruin; yes to rack and ruin, without me really understanding what's happened.

Telling the whole story

In other cases, participants told about health care providers who they believed took their concerns seriously. These providers gave the participants time to tell their whole story. They also often made examinations that were more complete, and the participants expressed increasing optimism as they felt that something was being done. It gave them the prospect of "moving on". Staff at the pain clinic, for instance, took seriously and investigated patients' descriptions of their entire pain history, including reflections on previous events of possible relevance for the current pain. The participants also considered that these health care providers gave more emphasis to the participants' own perspective on the future. Charlotte made these evaluations:

In that way, it was good coming to the pain clinic; they managed to understand what I have been through, managed to understand what the right treatment was, and they referred me to gastro[enterology] for further investigations. That was

amusing, because that's what I've been asking for, for the last two years.

Some of the participants after visiting the pain clinic spoke about the "light in the tunnel". Gro told how for the first time she had seen a doctor who understood her situation: "I have a new doctor now. To put it plainly, she's really nice and understanding. She listens and understands. She just gets how the patients feel. That indicates that she's an uncommonly good doctor." Although the participants were not promised a life free from pain, meetings with health care providers such as these had a positive effect on their life situation. To share the narrative of pain with a listener appeared in any case as important for the participants.

Summary of findings

The theme "the unpredictability of pain, and its affect on communication" appeared from sub-themes that indicated how, in an insidious way, episodic and unpredictable pain had become persistent, and increasingly limited the scope of their lives. As the pain occupied their attention, the participants experienced problems of identifying and describing times, sequences and duration of pain experiences in accordance with objective time. It was also a challenge to find words to describe the pain and communicate their problems. The participants tried to overcome these difficulties by using metaphors and emphatic expressions. The second theme "the importance of the pain history in health care provision" appeared from sub-themes that indicated how challenges with health care providers arose from problems of relating and communicating pain experiences in accordance with objective time. The participants often experienced that health care providers seemed to focus on the pain problems at the time of the consultation, and did not take into account its episodic character or the possible relevance of earlier events. They experienced that the prescribed treatment from this restricted perspective often failed. The informants emphasised the importance of being able to tell their whole pain history to health care providers.

Discussion

The theme of the study as a whole is life with persistent pain, rather than the pain of itself. When the participants related about temporality of pain experiences, as explored in this article, the focus of their stories however narrowed from the context of everyday life, and came closer to the isolating experience of pain itself.

The temporal unpredictability of persistent pain

Its insidious onset

In the participants' narratives, pain produced increasing problems with concentration and attention. Leder (1990) claims that while the body is functioning without problems, it tends to disappear or be transparent for our consciousness. In Mathis' story, it is evident that the increasing pain problems hindered him to concentrate on his work, because his attention was forced inwards into his painful body. This "affective call" is compulsive, and because of its typically involuntary character, it produces a reorientation of the person's whole being (Leder, 1990). This compulsive transfer of attention produced increasing challenges for the participants when the pain became persistent. This is significant for the finding that pain was experienced as developing insidiously from acute onset to persistent condition. The participants, while dominated by the pain, had systematic difficulties in grasping it.

Owing to the insidiousness of experience, it was also problematic for the participants to know when to seek help, and from whom. Many were uncertain and waited long before they contacted a doctor. This agrees with Bury (1982), who points out as one important feature of chronic illness its gradually transition from trivial symptoms to a developing and persisting disability, in particular when symptoms match those that is common in a population. This is the case with pain. We also found that participants were unsure about whether and how to disclose the illness to significant others.

Participants related how they were often met with a passive attitude when they did seek professional help. It took long time before health care providers began to look more deeply into the situation. Most of the participants had lived with persistent pain for many years before they were referred to a pain clinic for examination of the total situation. This indicates that health care providers should be more attentive to the systematic insidiousness and uncertainty of pain experiences, especially regarding the period when the pain develops from acute to persistent. By focussing on pain as a temporal experience, the possibility for intervening at an earlier stage may increase.

Its episodic structure

The majority of the participants described the pain as episodic and varying in intensity. The unpredictable though persistent temporal structure of pain was difficult to explain, both to relatives and neighbours, and in meetings with health care providers. Clinical

pain assessments, when based exclusively on the condition at the encounter, risked being random, as when Arne found that his pain was gone when he reached the doctor. Consequent worries about being regarded as unreliable hypochondriacs placed the participants in a position where they had to defend themselves constantly, and jeopardised their self-respect in a situation that in itself was confused. Similar findings have been reported (Honkasalo, 1998; Råheim, 2002).

When patients and health care providers interact with markedly different temporal perspectives, care providers may lose or ignore vital information about the patient's actual condition, and are consequently in danger of making shallow or unfounded judgments of the patient's situation. The patient's needs for further clarification and other types of treatment may be ignored (Sundström, 2001). In the present study, the majority of the participants related of prescribed examinations and treatment that were imprecise and not very helpful, and in some cases worsened the situation. This indicates that it is a challenge for professionals to consider the episodic, variable and unpredictable structure of persistent pain in their, often short, encounters with patients.

Difficulties in communication: The confinement of persistent pain

The participants interpreted their problems of remembering exact times as failure of memory. Leder (1990) claims that our awareness of time changes as pain forces the attention away from the world and the clock time. Toombs (1990) also maintains that extraordinary experiences, such as pain peaks, create the feeling that time seems to stand still, with past and present coalescing "into a stagnating present" (1990, pp. 237). Her phenomenological analysis of inner time consciousness reveals how the recalling of past pain is distinct from immediate pain experience (Toombs, 1990). When the participants in this study had difficulties in remembering times and sequences, part of the explanation may be that the pain was lived through in an immediate, subjective time and that it forced their attention away from objective time. In this aspect, there seems to be no difference between acute and persistent pain. In other studies, patients with persistent pain reported that time seemed to stop, the future was uncertain and unpredictable, and their lifeworld had shrunk (Honkasalo, 1998; Råheim, 2002; Thomas, 2000). Leder (1990) also states that a person in persistent pain may experience a temporal constriction, where a painless past is all but forgotten, and a painless future may be unimaginable. Arne described this as being confined and bound in a straitjacket.

The participants also discussed their difficulties in finding words that adequately described their pain experience. It is well known that physical pain seems to defy description. Definitions of pain have attempted to take the problem of communicating pain into consideration, such as the IASP's consensus definition (www.iasp-pain.org), which states that pain is a subjective experience and therefore difficult for others to understand or share. This must be related to one of the most striking characteristics of persistent pain, namely its invisibility to others, even to professionals (Brough, 2001; Honkasalo, 1998; Madjar, 2001). Thus, it becomes a necessity for persons with persistent pain to face the challenge of explaining their situation in words. Many of the participants described, as Gro and Randi did, situations where they experienced a radical lack of dialogue and mutual understanding. Toombs (1990) considers that these problems may result from the participants' attempts to communicate their pain in temporal terms that did not fit their actual experiences of the pain. Although it was necessary for them to interpret their pain experiences to others, problems arose when they tried to describe their pain with reference to an objective timescale.

The narratives indicate, however, that it is not impossible to communicate aspects of persistent pain experience. The participants attempted to describe it by telling their whole story, focusing on the continuity of pain experiences over time, using metaphors, word pictures, and emphatic expressions. In an imaginative way, they tried to open up a tentative understanding of their experiences of pain. This finding agrees with Brough (2001), who claims that metaphoric language and the use of imagination may contribute to a shared understanding of illness. This indicates that health care provision cannot be dependent on precise descriptions of the pain. A condition for understanding is often to take the time needed to listen to the stories, and to listen with imagination and empathy.

The importance of telling the whole story

When Charlotte described her pain from a lifetime perspective, she sought explanations from past incidents as a means to looking ahead. Many studies have found that adequate explanations of causes are essential for persons in chronically illness; for acceptance of the situation, and for planning the future (Thorne, Paterson & Russell 2003; Persson & Ryden, 2006; Taylor, 2001). Charlotte was concerned about the possibility of receiving a causal chain behind the pain, because it would fix important points in objective time; while the lack of explanation made everything temporally uncertain. However, she was

offered treatment based on the present state, though her pain problems had persisted over several years. Her past was not taken into consideration, and her speculation about how previous disease might contribute to the actual pain was not deemed relevant. Toombs (1990) maintains that in such situations, the voice of the patient may become something that doctors try to pass by, to get to the point, which is today's issue.

Most of the participants had not received an adequate explanation for their pain. The health care providers were thus confronted with patients who presented with illnesses but not with defined diseases. With pain that partly defy verbalization, professionals may feel insecure, become uncertain of what to do, and may be led to suspect that the patients' subjective report is unreliable (Sundström, 2001; Toombs, 1990). It may be easy to avoid listening at length to the patient's story. Many of the participants related how they were disappointed by experiences like this, which influenced their self-image negatively. The professional meeting became in consequence a situation of the kind described by Sundström (2001), p. 124) as "poor or disastrous—at least for the patient".

However, the participants also described how they had met with health care providers who considered their pain problems from the wider temporal perspective of their patient's life. By telling the whole story and exploring continuity between past, present and future, the possibility of finding a meaningful explanation and treatments that are more accurate, may increase. The importance of the whole story goes however deeper. It is previously mentioned how narrative theory holds that human experiences basically are explored and explicated through being narrated to others, and that this is of special relevance when life events have created a disruption between self and society. As we have seen, the participants of this study are in that situation. When some of the participants mentioned that they now could "see the light in the tunnel", one may ask if this is a sign that they now were able to widen their temporal perspective to include a future life. Though the participants were not promised a life free from pain, there were indications that being met with a temporal perspective that included their past, present and future might help to point towards a future.

Conclusions

The study has revealed disjunctions in the participants' lives between the temporality of pain and common, social time. Owing to its temporal unpredictability it is an obstacle for patients to

communicate their pain experience, it seems important that professionals do not expect sequentially precise narratives from patients with prolonged pain. Professionals should give attention to pain's temporal dimensions, by listening with empathy and imagination to try and gain an understanding of how their patients' lives are evolving over time. When patients are given time to "tell the whole story", the professionals and the patients may develop and share a temporally continuous perspective that transcends the temporal confinement of the pain. When patients extend their perspective into the future, possibilities of more accurate treatment, meaningful explanation, or acceptance, may become apparent.

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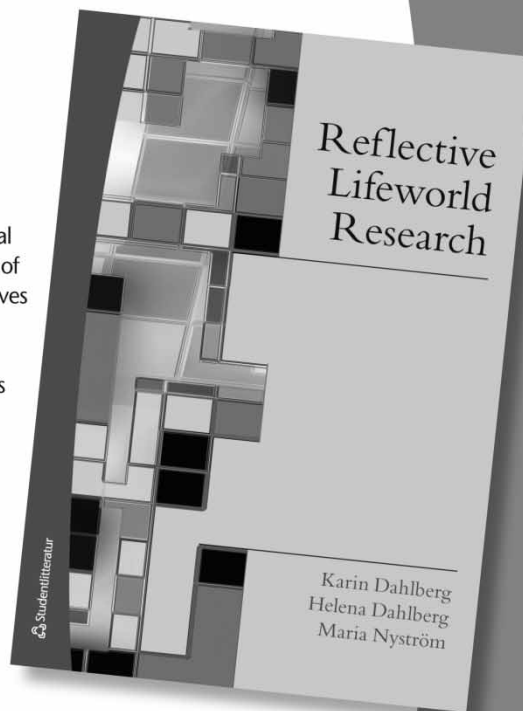
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