

# Chronic Illness

<http://chi.sagepub.com/>

---

## **Chronic pain as a narratological distress: a phenomenological study**

Maya Lavie-Ajayi, Nitsan Almog and Michal Krumer-Nevo

*Chronic Illness* published online 31 May 2012

DOI: 10.1177/1742395312449665

The online version of this article can be found at:

<http://chi.sagepub.com/content/early/2012/05/31/1742395312449665>

A more recent version of this article was published on - Aug 7, 2012

---

Published by:



<http://www.sagepublications.com>

**Additional services and information for *Chronic Illness* can be found at:**

**Email Alerts:** <http://chi.sagepub.com/cgi/alerts>

**Subscriptions:** <http://chi.sagepub.com/subscriptions>

**Reprints:** <http://www.sagepub.com/journalsReprints.nav>

**Permissions:** <http://www.sagepub.com/journalsPermissions.nav>

Version of Record - Aug 7, 2012

>> [OnlineFirst Version of Record](#) - May 31, 2012

[What is This?](#)

# Chronic pain as a narratological distress: a phenomenological study

Maya Lavie-Ajayi, Nitsan Almog and Michal Krumer-Nevo

## Abstract

**Objectives:** This paper reports finding from a study that focused on people living with chronic pain, chronicling their experiences of pain and emotional distress, and their social and personal narratives.

**Methods:** The paper presents an interpretative phenomenological analysis (IPA) of six interviews conducted with men and women aged between 27 and 61. The interviews were taken from a larger study of the experience of chronic pain.

**Findings:** Chronic pain is a double faced phenomenon: a vivid and total experience on one hand, an elusive and deceptive phenomenon on the other. The nature of this phenomenon – together with the medical and public discourse that ignores and delegitimizes chronic pain this condition – prompts people to question their own experiences and to face what we define as a *narratological distress*.

**Discussion:** Narratological distress is the internal battle between two unwanted narratives: The elusive delegitimizing narrative of denial, which seeks to ignore the experience of pain; and the narrative that acknowledges the pain, but with the price of accepting oneself as “ill” or “disabled.”

## Keywords

Chronic pain, interpretative phenomenological analysis, narratological distress, emotional distress, biographical disruption

Received 8 April 2012; accepted 19 April 2012

## Introduction

The human experience of chronic pain is multidimensional combining of sensory and affective experiences.<sup>1</sup> It comprises a variety of disturbing emotions, beyond the sensation of pain, such as depression,<sup>2,3</sup> anxiety,<sup>4</sup>

---

Spitzer Department of Social Work, The Israeli Center for Qualitative Research of People and Societies (ICQM), Ben-Gurion University of the Negev, Beer-Sheva, Israel

### Corresponding author:

Maya Lavie-Ajayi, Department of Social Work, Ben-Gurion University of the Negev, PO Box 653, Beer-Sheva 84105, Israel

Email: laviema@bgu.ac.il

frustration and anger.<sup>5</sup> To understand the source and experience of these negative emotions, Price<sup>6</sup> suggests a model in which negative emotions are the result of the cognitive processing of the meaning and the future implications of pain. The intensive sensation of pain often interferes with daily functioning: the performance of important relationships, social roles and activities.<sup>7-9</sup> This can have a debilitating effect on patients' sense of self<sup>10</sup> and identity. It is this "assault on the self"<sup>10</sup> that is often considered to be the basis of suffering for people living with chronic pain.<sup>11</sup> This paper aims to deepen our understanding of the immense burden of chronic pain in people's lives by throwing light on the unique difficulties that patients deal with as they struggle to integrate the narrative of chronic pain into their life stories. Based on a phenomenological study, we explore the meaning of chronic pain.

## Chronic pain

In 2001, the European Parliament declared chronic pain a major health problem, recognizing it as a disease in its own right.<sup>3</sup> A large European survey suggests that one in five adults suffer from chronic pain, defined as pain lasting more than 6 months.<sup>3</sup> Chronic pain is often a medically unexplainable condition and lacks diagnosable organic findings.<sup>12,13</sup> As such, chronic pain presents a challenge to standard biomedical models; many now accept the biopsychosocial model as a framework for the interpretation and treatment of chronic pain.<sup>13</sup> This model refers to chronic pain as a subjective experience, influenced by the complex interaction of biological, psychological and social factors.

There is a growing body of qualitative research on the experience of chronic pain stemming from this position.<sup>14-17</sup> A recurring theme in these studies is the patients' struggle for legitimization of their

experience. This is often questioned because of the invisibility of this condition, the difficulty to diagnose and treat it, and its subjective nature. Thus, some people described their struggle with stigma,<sup>18,19</sup> scepticism and distrust, trying to be seen and to be believed,<sup>20</sup> wishing to gain "credibility for their pain as real and somatic rather than imagined or psychological" (p.1035).<sup>15</sup> These qualitative studies are corroborated in the European survey, which found that negative attitudes and distrust from health care providers, friends and family experienced by some patients add to patients 'immense burden' (p.301) and impact their self esteem.<sup>3</sup>

## Chronic pain and the struggle for meaning

In a seminal paper, Bury<sup>21</sup> defined chronic illness as *biographical disruption*. He argued that the occurrence of chronic illness disrupts the structures of everyday life and future plans, and as such represents an assault on the individual's sense of identity, leading to the re-examination of personal, familial and work-related biography and self-narrative. The experience of biographical disruption is influenced by the social context, the nature of the symptoms and perceptions about their illness.

Another major contribution to this research field was made by Frank,<sup>22</sup> who brings to attention the role of the body as a storyteller. Experiencing chronic illness involves the need to change the story of the body. The story of a healthy body is no longer relevant; the new story the body tells demands a new meaning and interpretation. However, the stories and information that the body carries are neither heard nor understood easily, since 'the modern experience of illness' is characterized by the dominance of medical language. In these arenas of medical language, 'physical regimes', the stories of the body are often unrecognized,

and invalidated, posing a challenge to patients who seek to communicate their body experiences to medical professionals. This may lead to the patients giving up on their stories, adopting the biomedical language which, although alienated from their own experience, carries the potential of recognition. Frank termed this situation *narrative surrender* (p.6).<sup>22</sup>

Bury and Frank have inspired much work about the influence of chronic illness on personal narratives, focusing on different possible narratives that people adopt following the onset of the illness. Yet, chronic pain introduces a unique challenge to patients' narratives due to its invisibility (even through medical investigations) and because it is often medically inexplicable. Hence, people living with chronic pain must cope with the personal experience of biographical disruption, in a unique context of social delegitimization. The current literature highlights the emotional distress that arises from this social and medical discourse. In this paper, we add to this by providing an analytic focus on the source and experience of patients' emotional suffering in relation to the unique nature of chronic pain. We coin the term *narratological distress* to define their interpersonal struggle for meaning and how it affects their emotional distress.

## Research design and methodology

This paper is based on an analysis of six narrative interviews with women and men experiencing chronic pain, taken from a larger dataset collected as a part of a study on psychosocial experiences of chronic pain. The study followed the methodology developed by The Health Experiences Research Group at the University of Oxford (UK), which has been used over the last decade in a number of studies examining experiences of health and illness.<sup>23</sup> Ethics approval for the

study was granted by the Ethics Committee at Ben-Gurion University, Israel. The interviews were conducted by the second author at the interviewees' homes during the summer of 2011. Each interview lasted about two hours and was conducted in two parts. In the first part, interviewees were asked to tell their stories of chronic pain through an open question. In the second part, interviewees were asked direct questions regarding the diagnosis process, treatment and the influence of pain on their relationships, work and other aspects of life. With the interviewees' written consent, the interviews were all audio-recorded for transcription. All the interviews have been analyzed using grounded theory. This analysis will be published on-line in a format designed for patients and their families, according to the model of [healthtalkonline.org](http://healthtalkonline.org)

For this paper, we have chosen to focus specifically on the experience of pain, emotional distress and social and personal narratives. A further analysis using interpretative phenomenological analysis (IPA) was carried out on six interviews. IPA is an idiographic approach to analysis, with the aim of achieving an elaborated and nuanced analysis of specific instances of lived experience.<sup>24</sup> It is considered very useful in exploring the meaning and significance attached to bodily states.<sup>24</sup> In line with the IPA focus on a thorough analysis of a small number of interviews, our selection was based on the narratological depth and richness of the interviews. Furthermore, we looked for variation in terms of age, gender and cause of chronic pain.

## Participants

Aged between 27 and 61, the participants varied in terms of gender, family status and source of chronic pain. Two men and four women, five of them with children, four are married, one is single and one is divorced.

They were recruited through the snowball methods and via internet forums. Three of the interviewees were diagnosed with fibromyalgia, two with arthritis, one with CRPS and one with spinal cord injury.

## Findings

What we call ‘narratological distress’ is the result of the unique emotional tension created by chronic pain. This is a tension between two, often contradictory, faces of the phenomenon. On the one hand, it is keenly—sometimes excruciatingly—and acutely felt, with the consequences radiating to all aspects of life; on the other hand, chronic pain is an elusive and deceptive phenomenon, sometimes ignored, denied or delegitimized by family members, health professionals and the medical establishment and by public discourse. This doubled tension is not merely at the surface but goes to the very core of the personal experience of the condition, leading to narratological distress.

## Chronic pain as a vivid experience

Chronic pain is described by the interviewees as a vivid and total experience which affects both the individual and their surroundings.

The bodily experience of chronic pain is overbearing, dominant and domineering. It is always there, in the body and mind, hurting, distressing and distracting.

The pain is there 24 hours a day to varying degrees... I don't have a day or an hour without pain. It means always... in some way, it turns out to be a very clear part of you, it exists, it is always there". (Gal)

The interviewees use different metaphors, such as labor pains and torture, to describe how unbearable the experience of pain is for them, emphasising the profound nature of the experience on a daily basis.

The totality of chronic pain does not only manifest itself in physical experiences, it forces major changes in all aspects of life. These changes are so severe that one interviewee describes people who live with chronic pain as “*people whose lives were taken away*” (Neta). Neta describes herself as being a healthy and competent person with a great interest and investment in life, one who “*runs and jumps all day*”. But after the onset of her condition, she changed to being housebound, hidden from others, only interested in treatment for her condition: “*This is despairing and it's very frustrating, as if you were person X, and now you are X minus*”.

The other interviewees describe similar experiences. The pain affects their daily function on every level, in their relationships and at work.

It is not only to suffer the pain, it is also, the people around you also have to suffer. Because you don't smile, in a way you show it outside, and they feel uncomfortable to be with you. And it could be that because of it I don't sit with friends any more. I used to have lots of friends. (Gideon)

And you can see it with other things as well. Exhaustion, before I was in this current situation... I was workaholic I used to work around the clock, full of vigor, I was a very punctual person. And suddenly a state of confusion, a situation that I cannot fill any form. (Daniel)

The interviewees give many examples of interactions with friends and at work where the experience of chronic pain affects their functioning. But their behavior has not changed just in the public sphere; their behavior, functioning and experiences in the private, intimate sphere has also changed. They often use the same descriptive term: “*I have become a burden to others*”. Of the six interviewees, five are (or were) married, and they speak about the difficulties that chronic pain brought to their marriage

so much so that one of them sees these difficulties as the reason for his divorce. In addition, they describe the effect of chronic pain on their parenthood, especially,—but not only—with young children:

It is the children who need their time, their quality time with the father, that I couldn't pick them up, I couldn't do activities that were important for them. And family celebrations I have stopped, I have become a shadow of my former self. (Daniel)

It means that suddenly I cannot function at home . . . the kids want to sit beside me, they lean on me, and I can't stand it that they lean on me. It is like the dream of every mother that the children will come and snuggle indulge a bit, and how can I tell them that it hurts me? (Inbal)

The lasting physical pain—and its impact on personal functioning and behavior—caused our interviewees great emotional pain and distress. They speak about nervousness, frustration, disappointment and despair.

I think it affects the, the depression. I mean as the situation is more serious and more difficult so also emotionally it is harder to deal with it. (Limor)

I lost the will to live, I lost the will, I wanted serenity, I wanted few hours without the pain for this I was willing to do everything for it. (Daniel)

### Chronic pain as an elusive experience

Although chronic pain is such a vivid, permanent and total experience, the interviewees describe it also as an *elusive and deceptive phenomenon*, since the pain is invisible and changes in severity, often without warning.

The interviewees relate to the tension between the strong and personal experience of chronic pain, and its invisibility in the

context of interpersonal relationships with professionals, family members and friends. In addition, they describe their experience of pain as changing dramatically in nature during the course of a day, a week or across different seasons of the year. The dynamic nature of chronic pain leads also to a changing and varied impact on their functioning and physical behaviour, as well as on their interpersonal behaviour. This elusiveness makes it especially difficult for the patients to adapt to the experience of chronic pain, since they themselves cannot anticipate when, where and to what degree they will experience it:

It is really disturbing, at the worst unpredictable moments. It can be in the middle of an opera in which I feel I had to stand up and scream, but I don't. (Gal)

I am at work and suddenly find myself unable to descend the stairs. I want to go down the stairs but I cannot, my knees will not bend, they won't support my legs. The first time, you ask yourself "what is going on?" Then it passes, OK. Then the second time [it happens], you say, "It's impossible, it can't be happening to me again . . . what's wrong with me? What's happening to my knees? And suddenly, you look around to see who has noticed you, who has noticed you trapped on the staircase. (Inbal)

Both Gal and Inbal describe powerful situations of being suddenly in pain demonstrating both the invisibility and the dynamics of their pain. The dynamic and elusive nature of chronic pain makes it difficult for patients to convince other people, —including doctors—about their condition, and makes finding a proper remedy harder:

You cannot come to the doctor and tell him 'look it hurts me here'. You say 'look, today it hurts me here but two hours ago it hurt me there'. It is impossible [because] you cannot define it.' (Gideon)

The invisibility and the elusive and dynamic nature of chronic pain make it

harder for family members, friends and even health professionals to understand the experiences of the patients. Interviewees describe situations in which people around them—the people who are supposed to be their circles of support—deny, conceal or delegitimize their experiences, suggesting that they are either pretending or exaggerating their condition.

People close to me don't accept it. They are angry like, 'what? With all the medications and you are still like that?' (Einat)

The doctors don't believe you and the family don't believe you and no one believes you. (Gideon)

I can tell you what not to believe means. I was in the hospital, in the neurological department with a very difficult pain that I even couldn't breathe. And the head of the department decided that I am in this condition because my partner was working far from home and did not come home, so to demand his attention I hospitalized myself when I had two small children at home. Such absurdness. (Gal)

A few of the interviewees compared their situation to cancer, as an example of a well-known illness that people can accept and show sympathy for, as opposed to the experience of chronic pain, which is unrecognized and as such difficult to be accepted.

The fact that health professional show a similar disbelief and lack of awareness causes much anger, frustration and emotional pain. In the interviews, the doctors were positioned as suspicious, contemptuous and even aggressive in accusing people with pain of making false complaints, malingering and oversensitivity. This lack of acknowledgment by the medical community was echoed by the absence of acceptance, awareness and sympathy that they were obliged to face from their surroundings. Formal medical committees, which serve as the forum for defining the rights of patients to claim benefits and assistance on the basis of said conditions, are described as a major

battle ground in connection with the legitimization of chronic pain. The interviewees describe their experiences with medical committees as unpleasant, provoking feelings of guilt, shame, anger and frustration.

They (treat) you as a liar in advance, and you have to prove them the other way around. (Gal)

I came in and the doctor started touching my foot and I started crying and shouting, and he said 'come on, you are exaggerating!'... I am so furious with this, he really degraded me. (Neta)

Even in cases where our interviewees had a supportive family or partner, they still had to face in one way or other judgmental and negative social reactions. This aspect of their experiences was so severe that some remarked that they were not sure "*what is worst the chronic pain or the social position*" (Limor).

### Chronic pain as narratological distress

As described earlier, chronic pain is by nature a double-faced experience, constituted by the tension between the vividness of the experience and concurrently its dynamic and illusive nature. Similarly, the implications of chronic pain are manifested in every sphere of life, yet often not understood or accepted by family, friends and medical professionals. Our interviewees describe their emotional distress caused by both the physical pain itself and by its social delegitimization. The friction between these different faces of chronic pain causes a narratological distress, a distress which is the result of the interviewees' doubts regarding their own experiences and the difficulty in shaping a coherent narrative.

I was in excruciating pain, my muscles were locked and all the time like excruciating pain and the pain moves from place

to place. And the doctors started to say to me ‘maybe you should see a psychiatrist, maybe you take it too hard, you believe in a pain that does not exist anymore’ and all kinds of stuff like that. To be honest I did start to think seriously about it. I started to think that something in my head was wrong and maybe I create the pain myself. (Daniel)

Though they all want to change social perceptions and the lack of awareness about chronic pain, at times these perceptions are so forceful and dominant that the patients themselves begin to doubt their own narratives. Daniel describes internalising the social dispute and consequently experiencing two internal narratives: one of excruciating pain and the other of imaginary pain. Other interviewees also describe extreme situations of surrender to the medical discourse that denies their pain, even against their own bodily knowledge:

A lot of people say ‘well the doctor said that it is ok, so why are you playing that game?’ And I can tell you that it happened to me once when I came back from the doctor and just tried to move my foot, because I said [to myself], ‘well maybe it is just in my head’, and I tried to move my leg and then I said [to myself], ‘well ok, it is not just in my head’. But it really gets into you. (Neta)

Neta describes how social apprehension together with medical disbelief gives rise to such an absurdity of not trusting one’s own bodily sensations. The moment Neta describes is but an extreme version of the daily experience of narratological distress. This self doubt, the internalization of external doubt, was not only a specific reaction to a difficult medical encounter but also part of an on-going experience of questioning one’s own experiences:

I mean, again, I have already filed a claim to the National Insurance Institute. But

yes, there are mornings in which I wake up and tell myself ‘will you please snap out of it already?’ Like ‘what is your story?’ (Limor)

An understanding of Limor’s story can shed more light on the context of narratological distress. As she explains, filling the claim to the National Insurance Institute was not merely an administrative task but in fact the culmination of an internal process:

A month and a half ago I applied to the National Insurance Institute after a lot of years that I didn’t want to do it. Just because I really reached an internal understanding that it is really disability, it is not some imaginary thing, not trivial or something you can make arrangements for, it is really a kind of disability. (Limor)

The difficulty in believing one’s own pain, as Limor describes, stems not only from the social delegitimization of chronic pain but also from the difficulty to accept the term ‘disability’, which is related to social political and cultural discourse,<sup>25</sup> into her life. Facing this duality makes the self the arena for an interpretational battle, where different narratives compete against one another for dominance, recognition and acknowledgment. If the elusive, denying and delegitimizing narrative wins, they will have to ignore the pain; but if the narrative of pain wins, the patient will have to accept their illness as a disability. Both alternatives are problematic, since they conceal a significant part of their experiential knowledge and sensations.

We have coined the term narratological distress in order to describe this battle, in which people with chronic pain do not trust their feelings and bodily experiences. They struggle—and sometimes fail—to communicate their bodily experiences with themselves; they struggle to develop a narrative which gives meaning to the experience of the

self, one that will be recognized as valid by the outer world.

## Discussion

Widdershoven<sup>26</sup> argues that narratives are interpretations of the human experience which makes meaning explicit, as he claims “Life and story are internally related. They underline that the meaning of life cannot be determined outside of the stories told about it.” (p.9). Nevertheless, the connection between story and life is not always simple or straightforward. Based on a phenomenological analysis of six interviews, we describe chronic pain as creating narratological distress, similar to Bury’s disruption.<sup>21</sup> Chronic pain is described our interviewees as a life-changing illness. They describe a re-examination of personal, familial, and work-related issues, and the struggle to readjust their lives and identity to their new situation. On the other hand, they describe at times what Frank calls a narrative surrender.<sup>22</sup> They relate moments in which they surrender to the narrative of the absence of illness. Facing skepticism from family, friends and health professionals, they ask themselves to submit to the external narrative, which positions their pain as imaginary or as an exaggeration, paying the price of alienation from their own experiences and pain.

Narratological distress is the internal battle between bodily knowledge and social denial, between two unwanted narratives. Narratological distress in chronic pain is affected by the elusive, deceptive and subjective nature of chronic pain. The fluidity and inconsistency of the condition puzzles our interviewees, a puzzlement strengthened by scepticism and delegitimization in the medical and public discourse. Yet, this is not the whole story. Coming from the narrative perspective we are aware of patients’ difficulty in accepting the identity of “disabled”<sup>25</sup> or “ill” when facing different health conditions. With chronic pain, the

assault on the self is doubled; the patient struggles with the new identity of ill-health and disability, whilst seeking to defend this new unwanted identity from their surroundings, which delegitimizes their pain. Wendell<sup>27</sup> describes similar situations when referring to what she terms “unhealthy disabled,” i.e. people who live with chronic illness that affect their functioning, and thus struggle to give meaning to their experiences as healthy, sick and disabled at the same time.

## Strengths and limitations

Although this paper focuses on six interviews in Israel, the findings corroborate existing quantitative and qualitative literature on chronic pain in Europe and USA demonstrating that patients with chronic pain are marginalized and stigmatized by the prevailing public discourse.<sup>15,16,18,21,28</sup> Furthermore, the term narratological distress—as defined in our study—echoes the findings of other studies that demonstrate the need of the self to protect itself,<sup>10,29</sup> against the power of healthcare professionals who determine patients’ beliefs about their own experiences.<sup>22,25</sup> Our term emphasizes the inter-subjective nature of this battle.

## Funding

The project described was supported by funds from the Gertner Institute and Ben Gurion University of the Negev. The content is solely the responsibility of the authors and does not necessarily represent the official views of Gertner Institute or Ben Gurion University.

## References

1. Rainville P, Huynh Bao QV and Chrétien P. Pain-related emotions modulate experimental pain perception and autonomic responses. *Pain* 2005; 118: 306–318.

2. Blackburn-Munro G and Blackburn-Munro RE. Chronic pain, chronic stress and depression: coincidence or consequence? *J Neuroendocrinol* 2001; 13: 1009–1023.
3. Breivik H, Collet B, Ventafridda V, et al. Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. *Eur J Pain* 2006; 10: 287–333.
4. Dersh J, Polatin PB and Gatchel RJ. Chronic pain and psychopathology: research findings and theoretical considerations. *Psychosom Med* 2002; 64: 773–786.
5. Wade JB, Price DD, Hamer RM, et al. An emotional component analysis of chronic pain. *Pain* 1990; 40: 303–310.
6. Price DD. *Psychological mechanisms of pain and analgesia*. Seattle, WA: IASP Press, 1999.
7. Walker J, Holloway I and Sofaer B. In the system: the lived experience of chronic pain from the perspectives of those seeking help from pain clinics. *Pain* 1999; 80: 621–628.
8. Cunningham MM and Jillings C. Individuals' descriptions of living with fibromyalgia. *Clin Nurs Res* 2006; 15: 258–273.
9. Miles A, Curran HV, Pearce S, et al. Managing constraint: the experience of people with chronic pain. *Soc Sci Med* 2005; 61: 431–441.
10. Smith JA and Osborn M. Pain as an assault on the self: an interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychol Health* 2007; 22: 517–534.
11. Morris DB. *The culture of pain*. Berkeley, CA: University of California press, 1991.
12. Harris S, Morley S and Barton SB. Role loss and emotional adjustment in chronic pain. *Pain* 2003; 105: 363–370.
13. Gatchel RJ, Peng YB, Peters ML, et al. The biopsychosocial approach to chronic pain: scientific advances and future directions. *Psychol Bull* 2007; 133: 581–624.
14. Moore AP, Holloway I, Lamberty JM, et al. Chronic pain as perceived by older people: a qualitative study. *Age Ageing* 2005; 34: 462–466.
15. Werner A, Widding Isaksen L and Malterud K. I am not the kind of woman who complains of everything: Illness stories on self and shame in women with chronic pain. *Soc Sci Med* 2004; 59: 1035–1045.
16. Werner A and Malterud K. It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors. *Soc Sci Med* 2003; 57: 1409–1419.
17. Baker TA and Wang CC. Photovoice: use of a participatory action research method to explore the chronic pain experience in older adults. *Qual Health Res* 2006; 16: 1405–1415.
18. Holloway I, Sofaer-Bennett B and Walker J. The stigmatization of people with chronic back pain. *Disabil Rehabil* 2007; 29: 1464–1466.
19. Glenton C. Chronic back pain sufferers – striving for the sick role. *Soc Sci Med* 2003; 57: 2243–2252.
20. Haugli L, Strand E and Finset A. How do patients with rheumatic disease experience their relationship with their doctors? A qualitative study of experiences of stress and support in the doctor–patient relationship. *Patient Educ Counsel* 2004; 52: 169–174.
21. Bury M. Chronic illness as biographical disruption. *Sociol Health Illness* 1982; 4: 167–182.
22. Frank AW. *The wounded storyteller: body, illness, and ethics*. Chicago, IL: University of Chicago Press, 1995.
23. Herxheimer A, McPherson A, Miller R, et al. A database of patients experience (DIPEX): new ways of sharing experiences and information using a multi-media approach. *Lancet* 2000; 355: 1540–1543.
24. Smith JA, Flowers P and Larkin M. *Interpretative phenomenological analysis: theory, method and research*. London: Sage, 2009.
25. Corker M and Shakespeare T. Mapping the terrain. In: Corker M, Shakespeare T (eds) *Disability/postmodernity: embodying disability theory*. New York, NY: Continuum, 2002, pp.1–17.
26. Widdershoven GAM. The story of life: hermeneutic perspectives on the relationships between narrative and life history. In: Josselson R, Lieblich A (eds) *The narrative study of lives*. Vol. 1, Newbury Park, CA: Sage, 1993, pp.1–20.
27. Wendell S. *The rejected body: feminist philosophical reflections on disability*. New York, NY: Routledge, 1996.
28. Lillrank A. Back pain and the resolution of diagnostic uncertainty in illness narratives. *Soc Sci Med* 2003; 57: 1045–1054.
29. Eccleston C, Williams A and Stainton-Rogers W. Patients' and professionals' understandings of the causes of chronic pain: blame, responsibility and identity protection. *Soc Sci Med* 1997; 45: 699–709.