Chapter 18

Meanings of Chronic Pain in Patient Interactions with Health Services

Karin Säll Hansson, Carina Elmqvist, Gunilla Lindqvist and Kent Stening

Abstract Chronic pain causes suffering for patients and managing chronic pain is one of the most common assignments in the health service. Health care professionals can profoundly influence the meaning patients and their families attribute to pain experience. Patients with chronic pain may feel discredited and called into question by skeptical medical professionals. Patients may have to fight to receive entitled care and to suggest suitable treatments. To contribute to medical decision-making and improved patient outcomes, health care professionals should integrate phenomenological narratives and stories about pain into health care in parallel with consulting the medical evidence. Professional care structures should not make health care professionals feel torn between meeting patient needs for existential support and the demand of meeting high clinical work-loads. Narratives and stories can provide shared structures that allow patients and medical professionals to make decisions that feel meaningful, accurate, and clear. Many patients use psychological strategies in their everyday lives in order to live meaningfully with persistent pain; but, this is not enough. Healthcare professionals need "dare to open up and accept personal and deep conversations with patients" about their pain experiences and the lived consequences of persistent pain.

1 Introduction

Let's start with a patient's true story about an encounter at an Emergency department (ED). This narrative highlights some of the issues that will be discussed further in the chapter.

> A young woman arrived to the ED by ambulance one Wednesday afternoon. She has had a terrible pain for a week and had barely slept at all because of the pain. Several of her joints were subluxated after an examination a week earlier. She could barely walk to the bath-

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K.S. Hansson (✉) · C. Elmqvist · G. Lindqvist · K. Stening
Department of Health and Caring Sciences, Linnaeus University,
391 82 Kalmar, 351 95 Växjö, Sweden
e-mail: karin.sall_hansson@lnu.se

S. van Rysewyk (ed.), *Meanings of Pain*,
DOI 10.1007/978-3-319-49022-9_18

> room, she felt sick and she vomited. It was very hard for her to drink and eat. Her lips were swollen and ulcerated and she was very, very tired. The young women had not dared to go to the emergency department. She was afraid of how she would be treated and she was afraid of being disbelieved. It was possible to read her three diagnoses in her journal; Ehler-Danlos syndrome (hypermobility), narcolepsy (sleeping disorder) and Mb Chron (an inflammatory bowel disease).
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> The ambulance nurses told the registered nurse (RN) and the assistant nurse at the ED that the young women was so sick and pained that she was needed a real bed instead of a stretcher. The RN and the assistant nurse took good care of the young woman. She got a bed and a small plastic mug with water. The RN and the assistant nurse put her into a room and closed the door. One and a half hours later another RN arrived into the room. She said hello to the young women, her husband and her mother. However, the RN did not ask the young women about her pain or if she needed anything. She only said that the physician will arrive soon. The young women and her relatives stayed in the room for another two hours before the physician arrived. He tried to examine her. The young women screamed in pain. The physician said:
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> "You are too sick to be here at the ED. It's better for you to go home! We can't do anything for you."
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> The young women's mother objected and told the physician that they had done all they could at home! The physician said he would talk to his colleagues. He came back after 20 min and said, "There are no beds at all available for you at the hospital! It's better you go home!"
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> The young women began to cry. Her mother refused to accept that there were no beds for her very sick daughter. The physician promised again to consult other colleague, this time an anaesthetist. The physician came back after some minutes and said, "We do not deal with such pain during this time of day!"
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> The young women's mother did not accept this argument either. One hour later the anaesthetist came to see the young women at the ED. Having met and conversed with the young women he decided to put her in the intensive care unit. The young woman was then admitted to intensive care unit for a week and then she was three weeks at a medical unit.

As this story shows, healthcare professionals (HCPs) can negatively affect patients with pain and their relatives and contribute to their suffering. The young woman in ED suffered through the unreflective thoughts, actions, and lack of knowledge of the HCPs (Rehnsfeldt and Eriksson 2004). However, if a patient with chronic pain arrives at the ED, HCPs might feel unprepared and disempowered. There are several reasons for this. First, patients with chronic pain are not typically received at ED. Second, HCPs may think ED is an acute environment only and may feel unprepared to treat patients with chronic pain. Third, they are also concerned whether a patient with chronic pain may block patient beds. Fourth, HCPs describe some patients with chronic pain as "dramatic" or causing a "sinking heart" because they are unsure how they should treat them. Sometimes, HCPs avoid patients with chronic pain or take a deep breath outside the patients' room before entering to administer care (Gauntlett-Gilbert et al. 2012). Finally, while pain is central for the patient with pain, HCPs prioritize other symptoms such as signs of heart disease and other critical illnesses before patients with chronic pain (Bergman 2012).

Within emergency care, when there is no need for life-saving actions, patients and relatives often experience what we prefer to call an *interspace* in encounters with HCPs. An interspace includes a meaning of distance between patients and HCPs where patients paradoxically feel being in focus and at the same time not being in focus—a paradox of care. Professionals take serious responsibility for the medical aspects of medical care, but often forget to talk to the patient about how he or she feels and why, which can create an interspace, or worsen one that already exists. At the same time a HCP may feel torn between meeting patient needs for existential support and meeting the high demands of work. In this way an interspace reduces the optimal handover of information between both parties (Elmqvist 2016). A patient may feel he must fight to be a credible patient. Further, the environment in the ED may also be an important contributor to creating an interspace for the patient when for example the examination rooms are perceived to have a meaning of sterility and flatness (Elmqvist et al. 2011).

Patients with pain, especially those with chronic pain, are more at risk to be discredited by health care professionals than patients with other chronic diseases. A reason for this lies in the significant clinical challenge of accurately recognizing pain (Breivik et al. 2006; Craig 2009). Pain is far more difficult to measure and therefore manage than chronic diseases such as diabetes or heart failure (Garbez and Puntillo 2005). When patients with chronic pain arrive at the hospital they often feel disappointed (Gauntlett-Gilbert et al. 2012). When pain is not recognized by HCPs, it can increase patient suffering (Banz et al. 2011).

Due to personal experience, each living person has an intuitive understanding of what acute pain is like. Intuitively, we expect that it will eventually end. This isn't the case in chronic pain. Chronic pain constitutes a never-ending story for the one who suffers it. Chronic pain is now seen as a global public health problem which causes great suffering for those affected (Giordano and Schatman 2008). It constitutes a major health care issue in Europe, and is poorly understood and managed (Breivik et al. 2006; Craig 2009). Chronic pain is becoming more prevalent in the general population compared with different diseases or health conditions and mainly affects older female adults, contributing substantial comorbidities to this group (Freburger et al. 2009; Goldberg and McGee 2011). The European Federation of the IASP (The international Association for the Study of Pain) (EFIC) declaration from 2001 expressed that, "*very few people die of pain, many die in pain and even more live in pain*". So, "to live with pain", affects the patient's life as well as the relatives at every turn. To face doubt from HCPs can turn the life of the patient and family into a bitter struggle for recognition of lived reality. The reality of hospital functioning can provide challenging experiences for patients, which can include long waiting times and failure on the part of some HCPs to reschedule appointments (Cooper et al. 2008). Patients find it irksome when some HCPs arrive late to or cancel an appointment, especially when such changes are not communicated to the patient beforehand (Osterhof et al. 2014).

There is a need to accurately describe chronic pain patient experiences within health service settings, their expectations of such experiences, and what they mean to patients and clinicians. Although the specific experiences and what they mean will vary considerably across patients with chronic pain, it is probable that patients experience at least a partial commonality of meanings. These shared meanings may be generalizable to patient groups or sub-groups, and could highlight areas for improvement in patient care, as well describe important success stories. Patient and HCP quotations presented below are taken from a qualitative phenomenological study conducted in Sweden, which included interviews with eight patients with chronic pain about their experiences in the health service (Hansson et al. 2011).

2 Patient and Health Care Professional Expectations About Clinical Encounters

HCPs and persons with chronic pain have different expectations of each other, of clinical care, and what it means to live with pain. Patients with chronic pain want to be seen as *persons*, not as a hospital number or a patient with no name (Hansson et al. 2011). Patients expect to be treated by HCPs as human beings with self-worth. They want to be seen, heard and taken seriously (Jakobsson 2008), and to actively participate in their own healthcare (Hansson et al. 2011).

HCPs are expected to be professional, to understand how pain works, as well as being knowledgeable about what it is like to live with chronic pain. Patients expect to be asked to describe their pain in their own words: "*If you don't get the chance to say something yourself, then they can't know how you feel and how much pain you've got*" (Hansson et al. 2011).

Patients view medical evidence alone as insufficient for HCPs to understand what it is like to live through chronic pain from a personal point of view. Persons with chronic pain expect that HCPs should believe what is reported to them and to integrate these personal accounts with the medical evidence (Reynolds 2004). However, there is a patient expectation for a 'quick fix' that involves pain being quickly recognized, treated and relieved by HCPs, and that revolutionary discoveries will emerge to relieve pain in the same way. This expectation includes a desire to eliminate pain, to do the everyday activities others can effortlessly do, and that HCPs will say, "*that's what's wrong, now, we know what to do*" (Hansson et al. 2011).

It is important to patients that HCPs are supportive and are willing to communicate about pain; unfortunately, desired support and open-mindedness is often lacking in health service settings. Patients experience a lack of engagement with HCPs (Juuso et al. 2014) as well as a lack of meaningful communication with them (Grace 1995). Patients with chronic pain want to consult with a medical professional who is willing to really listen to them narrate pain experiences. As a result of these experiences, patients are forced to find support primarily within family and peer groups, both of whom in turn expect dedicated care from the HCPs (Ojala et al. 2015). Patients with chronic pain think HCPs need to have more knowledge about pain, and they expect HCPs to consult with more knowledgeable colleagues for alternative views. One patient stated: "*It's not good to have pain; you heal a lot slower if you have pain, it's been proved, and all nurses should know that*" (Hansson et al. 2011). Furthermore, patients view it as positive if HCPs admit to patients that they do not have sufficient knowledge about pain, and instead ask the patient to talk about his/her lived experiences of their pain and the meanings of such experiences (Hansson et al. 2011).

Patients may find it difficult to access HCPs for support when they need it. They have expectations of using email, voice messaging and landlines to directly communicate with HCPs (Upshur et al. 2010). Demands for medical care are increasing; yet, the resources available to meet these demands are shrinking. This problem has resulted in finding new ways to support patients. The use of Information and Communications Technology (ICT) in health service settings—*technology-based healthcare* (Fagerström et al. 2016)—can allow patients to communicate with their care manager when face-to-face contact with HCPs is not possible. ICT may be a convenient tool to supplement face-to-face communication with patients. However, patients prefer face-to-face contact as the first communicative option (Skuladottir and Halldorsdottir 2011).

From the point of view of HCPs, care of patients with chronic pain is difficult and frustrating. They think it is extremely challenging to provide pain management and to trust the patient's self-assessment of pain. HCPs think patients who do not complain about their pain are perceived easier to care for (Blondal and Halldorsdottir 2009). Some patients who do not look or act like they should be in pain, despite personal reports to the contrary, are difficult to believe (Reynolds 2004; Larsen et al. 2012).

HCPs consider patient education about pain a very important part of the treatment of pain to correct maladaptive beliefs about pain that patients may have developed. Furthermore, HCPs think it is important to assist chronic pain patients to widen their perspective about pain and help them to look away from only negative aspects of living with pain. Patients should learn to actively live with pain, rather than passively through its aversive and functionally disabling nature (Ojala et al. 2015).

3 Experiences and Meanings of Clinical Encounters

Persons with chronic pain describe clinical encounters with HCPs as mostly negative (Hansson et al. 2011). They describe not being accurately or sufficiently examined, inappropriate investigations and referrals, missing test results, and HCPs who lack knowledge of chronic pain. Furthermore, they often describe meeting with HCPs as upsetting, disempowering and a battle to be understood (Robinson et al. 2013). "*There's been many occasions when I've just sat down and just collapsed because I don't know what to do, I've just felt like a nobody suddenly*" (Hansson et al. 2011). On some occasions, patients observe that they are met with arrogance; they are questioned and seen as idiots. "*When the doctor took a test and couldn't* *get confirmation that the test was wrong then they became sort of frustrated and they looked at me as though I was nutty, that's how I felt*" (Hansson et al. 2011).

It happens the patients receive a pat on the back and the answer that there is nothing that can be done about the pain. Patients have also been told that pain is natural and that there are others who are worse off than themselves. "*I gritted my teeth and felt no you bloody swine. That's what I thought ... I couldn't manage to say anything.... I was in such pain and was so disappointed. I felt he didn't believe me. He hadn't a clue as to how much pain I had*" (Hansson et al. 2011). Sometimes, patients wonder if they would be in this situation if they had been correctly treated when they began therapy against pain (Larsen et al. 2012).

Some clinical encounters between patients and HCPs were experienced by patients as positive (Hansson et al. 2011). To be approached in a positive manner is seen as self-evident and as a natural human action. To be able to explain one's situation, to be asked how one feels, how the treatment is working, and what help is needed, are positive experiences. Receiving a diagnosis feels like self-confirmation and gains meanings of hope for the future. "*It was wonderful, I felt that I got my human dignity back, it was like coming to heaven, it was like coming back to life again*" (Hansson et al. 2011). A diagnosis is a huge relief (Larsen et al. 2012).

Patients desire accurate information about their diagnosis and consequences in terms they can readily understand (Cooper et al. 2008). If HCPs give good evidence-based explanations of their decisions, then it is easier for patients to understand and accept what the HCP decides. The key factors in patient-centered decision-making are to involve the patient and listen to their wishes and tailor information to the individual patient. Patients also trust HCPs who are perceived to have adequate knowledge about their pain and how to treat the pain (Eriksson et al. 2016). Unless a patient is perceived as a unique person requiring dedicated attention, patients find it very difficult to open up to nurses to tell her/his life story in the form of intimate thoughts, feelings and experiences (Gudmannsdottir and Halldorsdottir 2009).

Patients who meet the same HCPs every time feel it is easier for them to describe pain and how it changes over time (Matthias et al. 2010; Eriksson et al. 2016). Meeting new HCPs makes patient participation more difficult and can result in emotions of anxiety and frustration, and meanings of concern for the future (Hansson et al. 2011; Gonzales et al. 2015). Patients who feel disbelieved in reporting personal pain have a negative meaning of being passed over. This feeling and meaning is strong if HCPs do not regularly ask patients about their pain or follow-up on pain treatments. The patient may come to feel that they are not allowed to mention pain or pain-related topics (Grace 1995).

Eriksson et al. (2016) describes how professional disbelief may first appear in the acute phase, which transfers to chronic pain. In these situations, patients do not dare ask for pain management because HCPs look busy, walk quickly, and apparently have no time to talk. So, patients do not want to disturb HCPs; they think they have more important things to do (Faulkner 1995; Jakobsson 2008; Eriksson et al. 2016). A consequence of this is that the patient hesitates to ask for advice on pain treatment, and feels isolated from other people (Eriksson et al. 2016). For example, patients perceive that it is easier to approach nurses concerning prescribed analgesics than physicians, but they don't have all the answers patients need. The nurse assistant talks to the senior nurse who then talks to the physician. HCPs often tell patients to wait for analgesics. In such situations, patients have to wait and "bite the bullet", sometimes for several hours. If patients press further for more analgesics they risk denial. A case arose when a patient requested more analgesics, but HCPs hesitated and claimed that the patient asked for more analgesics too often (Eriksson et al. 2016). However, some HCPs are mindful of patient needs, and do counsel patients to take prescribed analgesics. This makes the patient feel understood. Patients feel safer and less frustrated if they are asked about their pain experiences.

When it comes to the treatment of pain, trust between both parties is of great importance (Jakobsson 2008; Matthias et al. 2010; Wuytack and Miller 2011; Eriksson et al. 2016). If the opposite occurs, patients may come to feel abandoned or neglected (Eriksson et al. 2016). More philosophically, the patient perceives the HCP, but the HCP doesn't perceive the patient. I am close to the HCP, but he is not close to me. Such clinical encounters have the feature of impersonality, and this feature can originate a meaning of desolation in the patient. Desolation is the personal experience of the inevitable failure of the search for reciprocal love. Initially directed towards HCPs, desolation may develop into a felt emptiness towards the health service as a whole. Such patients reach out hopelessly into perceived oblivion for HCP contact, all the time perceiving that there is nobody to notice or care for them. However, there is hope. Reciprocity in a care relationship can partly be achieved when HCP and patient co-operatively understand what each other's needs and strengths are (Snellman 2009).

All persons suffer in life depending on conflict or disruption to relationships or through personal illness, disease or pain. Patients with pain suffer when pain is perceived to interrupt, burden or permanently harm functional abilities and sense of well-being (Price and Barrell 2012). Pain-related suffering may differ based on whether pain is acute or chronic and on the meaning of pain as a personal burden that persists without meaningful relief (Price and Barrell 2012; Arman 2015). Persistent stress and anxiety can worsen pain and, over time, negatively affect personal well-being; that is, the person as a whole (Price and Barrell 2012). Pain-related suffering is also associated with depression, anxiety, hopelessness, frustration and anger (Breen 2002). Impaired relationships which disrupt or harm one's sense of personal meaning, as described in this chapter, also contribute to patient suffering. Patients may struggle to cope with symptoms and to achieve balance in a life dominated by unrelenting pain (Berglund 2014). Some patients with chronic pain may suffer less than others due to a stoical attitude (Robinson et al. 2013).

4 Patient Strategies for Living with Pain

Patients need personal strength to manage challenging encounters within the health care system. Stubbornness is a necessary personal trait in order to get care, "*If it had been a person who wasn't as strong as I am, then it wouldn't have been easy. It's* *terrible!*" (Hansson et al. 2011). Patients felt forced to use their own initiative and make suggestions to HCPs for alternative treatments (Hansson et al. 2011). At times they felt that HCPs do not make sufficient effort to help. "*You have to be a doctor yourself to know what treatment you should have. If I hadn't looked for help then I wouldn't even have got there*" (Hansson et al. 2011). The general perceived opinion is that "*you were lucky if you met a person who would listen*" (Hansson et al. 2011). According to patients, pain is a private experience; but there are obvious signs when someone is in pain. They expressed surprise that HCPs did not perceive these behavioral manifestations. "*That you're actually crying, that you are so tense // you're sending clear signals about having such pain and if you were to stop and look ... you can't fake things like that*" (Hansson et al. 2011). If patients present in the clinic looking "*too healthy*", they are met with skepticism by HCPs (Hansson et al. 2011). Some patients feel forced to appear and behave in certain ways in order to be trusted by HCPs. For example, they do not appear sunburned, use make-up or look happy (Werner and Malterud 2003).

Patients think that they are entitled to receive treatment and medical information based on evidence, but such information may not be forthcoming because HCPs consider it inappropriate. However, with greater knowledge about pain, patients themselves could participate more in clinical consultations, and share clinical decision-making and planning. Participation entails being active oneself and calling attention to one's needs and openly expressing wishes about treatments. On the other hand, greater knowledge could have a negative meaning, because some HCPs might perceive patients with knowledge about pain as a threat to their professional expertise. In these situations, patients perceive they are nagging, whining, troublesome or selfish persons (Hansson et al. 2011). When patients try to draw clinical attention to their pain, they are afraid of being seen as a troublesome inconvenience. They are afraid of being perceived as argumentative and creating conflict within the health service (Eriksson et al. 2016).

Intimate and supportive communication between patients and HCPs is extremely important for patients. Sensitive clinical communication conducted in an informal, conversational manner fosters a sense of vested participation in patients (Cooper et al. 2008). HCPs can ask patients about pain in different ways. For example, patients may be asked to assess pain intensity with a numeric rating scale without adequate explanation of why. '*He doesn't seem interested... I haven't had any success when... saying how I feel about it or what it's like*' (Hansson et al. 2011). Pain assessment can create a strategic dilemma: "*if I register a five... I may then not receive enough pain relief and then I have to register a higher figure in order to get more*" (Hansson et al. 2011). Nurses in particular are perceived to have a key therapeutic role in the health system (Hansson et al. 2011). They are well-placed to clearly explain to patients what pain assessment scales are and their intended medical use (Eriksson et al. 2016).

Some patients may imagine the future as scary and dark and they feel reluctant to ask about HCPs or significant others the future because they are afraid. They want to continue living as they always have. It is important for HCPs to guide patients to narrate their concerns about the future and enduring pain and help them to accept this new life and the prospects of pain control. HCPs should encourage such patients to reflect on their life with pain and help them to make evidence-based decisions to achieve personal goals. HCPs must adopt a more empathic and caring approach to patients with pain (Bergman 2014)..

5 Towards a More Caring Approach to Pain Management

According to the world-view of natural science, human beings are neurobiological organisms, compelled by an ancient causality and relating to each other through mechanisms and laws that control us and every other thing. By contrast, in the shared world of personal experience, we are persons, acting in the world and relating to other humans through beliefs, intentions, feelings, and experiences. The second world describes concepts that refer to human ‘intentionality’, to use a term from the philosophical discipline of phenomenology. The term ‘intentionality’ means the quality of referring to, or describing, an object of personal experience. I myself am the object of my own painful experience; in my perception of pain in another person, the object of pain is someone else in the world neighboring my experience (The *Lebenswelt* or, ‘lifeworld’). An ‘intentional understanding’ describes the lifeworld in terms of the personal meanings implicit in our everyday lives and actions. Thus, an intentional understanding of pain is concerned not to explain pain in terms of neurobiology so much as to be ‘at home’ in it; describing common or idiosyncratic personal meanings about pain, showing why meanings of pain change over time and how they interact with the body and the lifeworld.

In good health, we take our lifeworld for granted and we seldom reflect on its meaning for us (Dahlberg and Segesten 2010; Ekebergh 2015). Within our lifeworld, our body is a lived body. This means that we not only have a body, we live our body and we experience the world around us through our body. Therefore, any change in our body, as for example pain, also means a change in our perception of our lifeworld as well as a change of our access to it (Merleau-Ponty 1945/2006; Dahlberg and Segesten 2010). To live with pain is not only to live with the pain itself; it is about relating a body with pain to the world. A body is more than its physical organs; a body is a lived body, as described above, and it needs to be understood in health service settings in terms of this wholeness. For a person with pain this wholeness appears if the encounter with HCPs intertwines the stories of the body with the soul and the world in order to create meaning for the patient (Merleau-Ponty 1945/2006).

Being viewed as a person and not just as a patient with pain involves more than consulting a patient’s medical record. It also entails showing sensitivity towards a patient’s lifeworld in which his or her lived pain is immersed (Dahlberg and Segesten 2010; Ekebergh 2015). “*It’s not just about how you cope with the day; you have to cope with the night as well*”. Patients felt that HCPs were self-focused on concerns within the world of their respective medical fields and disinclined to consider other physical problems that could challenge their expertise (Hansson et al.

2011). Again, patients wish to be regarded as persons; HCPs need to see the person behind the pain (Ojala et al. 2015).

Patients prefer open person-centered communication with an empathically supportive style that enables co-engagement (Ullrich et al. 2014). To communicate in this intimate and supportive way with HCPs is extremely important for the patient with chronic pain (Hansson et al. 2011). Good clinical communication includes developing a feeling of participation, appropriate language-use (e.g., for diagnostic information), and time for mutual listening and talking. It also includes getting to know the patient as a unique person and inspiring the patient to take part in this reciprocal process (Cooper et al. 2008). Patients prefer clinical encounters to have a conversational rather than exclusively biomedical tone. The meaning of biomedical information is rarely self-evident to patients. Patients and HCPs must decide together which information to consider and which to reject, and how to make shared decisions accordingly. Patient narratives can help structure conversations in the clinic, and provide meaningful pathways to decision-making.

HCPs that show empathy and understanding in this way are more effective in helping patients feel they are being taken seriously and not being called into question, either mentally or physically (Hansson et al. 2011). Treatments are not only prescribed medications; they could also include a management plan with individualized goals (Upshur et al. 2010). Ojala et al. (2015) suggests that chronic pain management must be personalized. Patients need to be taught to sensitively reflect on the total lived experience of pain instead of just the aversive sensation. It is important to include family members in this task. Such reflection can aid HCPs to build a management plan for treatment.

Fredriksson (1999) describes two different attitudes about dyadic interactions involving patient and clinician. First, “being there” is characterized by attentiveness to the other, where the patient fulfils a passive role solely attending to the clinician, whereas the clinician adopts an active role, treating the patient’s report of pain only as a means to the end of giving it a biomedical interpretation. Within the context of this chapter, we endorse a relation of “being with” the patient. This is characterized by a meaning of mutual receiving, in which HCPs are present in the encounter as medical professionals and human beings. Conversely, patients are encouraged to learn more about the science of pain without fear of professional push-back from HCPs. A version of this model of care is developed in more detail in Chap. 17 by John Quintner and Milton Cohen.

6 Conclusion

Clinical encounters between patients and HCPs reveal mutual expectations and strategies in play which can deeply affect the patient-clinician relationship, and patient outcomes. Our phenomenological exploration of these interactions has revealed a significant gap between patient expectations about medical treatment for pain and HCPs knowledge about pain control. Patients may have to fight for care and may struggle to navigate a perceived complex health service system. Patients with chronic pain suffer due to meaningful negative changes to their lifeworld. They are concerned about the future and enduring pain as a burden over time without meaningful relief.

Most importantly, patients ask for empathy and to be believed. They want to be seen as human beings *with pain* and not as *pain patients*. They expect HCPs to be professional, inclusive, to understand what pain is, and know how best to assess and manage it. HCPs should show sensitivity to psychosocial dimensions of pain, not merely the aversive sensation assessed with simple rating scales. From the HPC point of view, patients with chronic pain are often seen as 'heart sinkers.' If HCPs think the opposite way, such patients can have a very hard and 'heart sinking' life. However, if the HCP takes the patients point of view and learns from the patient in terms of his or her personal lifeworld and reflects on the information they receive from patients in this way, the encounter them would likely be more positive. HCPs can *be with* patients in a caring capacity by encouraging a shared conversation about pain and how to manage it. In clinical encounters, HCPs can encourage sharing of personal narratives and stories about pain in parallel with consulting the medical evidence. Narratives and stories may allow patients and HCPs to make shared decisions that feel meaningful and accurate to both parties. In turn, HCPs need support to manage feelings of being torn between meeting patient needs and the high work-loads.

Many studies reporting clinical encounters involving patients with pain are designed from a HCP point of view (Bergman 2012; Blondal and Halldorsdottir 2009; Clark and Iphofen 2005; Gauntlett-Gilbert et al. 2015). The present chapter contributes accounts of the lived experiences of patients in health service settings, but similar qualitative or mixed method studies are needed to corroborate these experiences and meanings, and to generate new research questions with a clinical focus. Phenomenological studies on this topic are disappointingly few, but the in-depth information they uniquely provide is not available to quantitative research methods.

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