

CASE REPORT

Living a meaningful life with chronic pain – further follow-up

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Introduction

Case studies arise out of the desire to understand complex social phenomena such as chronic pain, from a holistic and real-world perspective [1]. As such, the case presented here is of a woman called Ann, in her late forties. She received a diagnosis of cancer as a child and has since then gone through multiple surgeries, chemotherapy, and radiation therapy, followed by several exacerbations and rehabilitation stays. We first met Ann when she wanted to join our cognitive therapy group for chronic pain [2]. We later contacted her again as we believed that her story would have wider relevance for all pain sufferers who strive to gain a meaningful life and need help to grasp what are the driving forces in this process. Her story is also important to healthcare workers to ensure that they can provide adequate help when chronic pain becomes a major challenge in life. We have followed Ann's journey, with its ups and downs from early childhood until now, and as an independent part-time working woman with a family, is still fighting for a meaningful life.

Chronic pain is a severe and frequent cross-cultural healthcare problem. Functioning in most domains of life can be affected, such as everyday life, working life, physical, emotional and social well-being, and quality of life

Key Clinical Message

Living a meaningful life with chronic pain seems to depend on the patient having the leading role in their own life. Adequate assistance from healthcare professionals should be balanced during changing circumstances. Successful follow-up demands an independent biopsychosocial–spiritual–existential perspective, where patient-centered care and a focus on resilience go together.

Keywords

Biopsychosocial–spiritual–existential, chronic pain, patient-centered care, resilience

[3]. As there is no cure or medical intervention that can fully resolve their problems, individuals with chronic pain must often deal with a future having an unforeseen course [4]. Patients often experience a vicious circle and search for meaning, which involves understanding of the situation and its implications [5]. As a result, pain is only one of many issues that should be addressed in rehabilitation. Clearly, physical as well as emotional support is required according to the patient's continuously changing needs. In addition, the available personal resources and goals must be revealed [2]. There is growing awareness that the successful treatment of chronic pain must be multifaceted and individualized, as psychosocial factors can affect the total life situation of the sufferer. This implies that the biomedical perspective, which is primarily concerned with curing disease and controlling symptoms, should be supplemented with a biopsychosocial focus [6] and is later extended to include spiritual [7] as well as existential dimensions [8]. Hutchinson emphasizes that whole patient care must address the totality of the patient's relational existence [9]. In this context, an important challenge is that patients often have a biomedical understanding of pain, while those who offer treatment have a broader understanding and approach to the problem [10], which must also be detached.

The patient as professional acknowledges their expertise and participation in own rehabilitation [11]. In recent years, a patient-centered care framework has been developed to improve such care and has been incorporated in several healthcare reforms. To be patient-centered, the provision of health care needs to be more flexible to meet the person's needs [12]. To succeed, there is a need for competent practitioners who are able to manage all the factors and challenges that exist within care environments, and who can engage in processes that place the affected person at the center of caring [12].

While most articles focus on the negative aspects of pain, there are individuals – such as Ann – suffering from chronic pain who still manage to live a good life. She can be described as having pain resilience health resources [13–15]. Among potential important resilience factors, Gatchel et al. [15] mention optimism, hope, and the ability to find benefits. As previous research has indicated [13–15], chronic pain-related resilience mechanisms include both a high level of well-being and positive interactions. These mechanisms should therefore be highlighted during rehabilitation. However, there is little research about the usefulness or meaning of resilience in those with chronic pain [4, 13]. Moreover, a link between meaning and pain in clinical practice is still missing [16]. Longer follow-up studies also seem to be missing. As such, we wish to address these gaps in the literature in this case report.

When we contacted Ann again 10 years later, we used an open approach which focuses on story as the object of inquiry [17], and posed one follow-up question to search for driving forces in her life: “Would you please tell us about your experiences and life situation from the last time we had contact?” Written informed consent was obtained from her beforehand.

Case Presentation

She started presenting her story by incorporating biomedical as well as psychosocial aspects in this chronological way to make sense of events in her life:

In 2010, I ended up with being unwillingly disabled, but I was not content with this decision. At that time, I worked in half position. However, when I look back, at that time it was correct as I could not walk. Neither training nor help from the physiotherapist alleviated my pain. The year after, I had several rehabilitation stays, and I was told to do less training and use more time for my own restitution. Several hospitalizations followed, where they told me that an earlier operation was not successful. Three doctors gave me different explanations for the worsened situation in which I found myself. I ended up by finding out that one is

strongest alone. During that period, I clung to the task I still had as a conflict counsellor in the community.

When looking back at my diary entries for 2011, I think I was suffering from depression. Perhaps I should have asked for more help. But it seems like continuing my studies was of great help to me. I see I have also written something about my pain. It is important to be engaged in something.

In 2013, she started again studying as a decentralized master's student. She marked a half-time point in her studies: “Now I have only one year left!” In 2016, she had finished her studies and expressed the following:

A new goal is reached! This was a victory, which was celebrated!

She ended her report by referring to a poem in which the spring and willpower win, life wins, and emphasizing that we all have a task to perform on earth.

In 2017, she was back to work as a teacher with a load of 30%. She expressed: “It gives me so much in so many different ways!” Her comeback she described was possible as she then used new depot medicines and had started yoga training. She deepened her situation by explaining:

When we do not see that our physical and mental health go hand in hand, we are not able to do what is needed. After several rehabilitation stays, I realize that not everybody is ready for their own efforts or can listen to those who manage life in spite of its challenges, they want treatment or easy solutions that solve their problems.

A positive focus was deepened through her log where writing was emphasized as a valuable daily tool and described as cognitive self-help therapy.

I admit that I become very exhausted easily, and that is most frustrating. When I can plan and control my own day, I function much better. So altogether, I feel well, although my husband does not always agree with me. Now, I can go mountain climbing again.

When we asked about her present medication and organized treatment, she gave the following information: “Nobligan retard 100 mg morning and evening. Eventually Voltarol Forte 23.2 mg/gel; physiotherapy together with strength training 2–3 times per week for 25 years has now stopped; yoga training in a group once a week and joining organized tours in the mountains.”

Methods

A phenomenological–hermeneutic approach was used to provide structure, elicit meaning, and interpret the

phenomenon under study [17], while searching for individual driving forces in life. The empirical material consisted of nuanced and detailed descriptions, as the participant was contacted twice with additional questions to ensure that the data set was as complete as possible.

Analysis and validation

Thematic analysis was used here as it refers to a method for identifying, analyzing, and reporting patterns (categories) that emerge within the narrative content [18]. The two main steps were reading through Ann's descriptions independently and then trying to make sense of the data. A coding scheme was used as simple indexing to evoke ways of capturing various types of actions or events. Then, collectively the two researchers examined the descriptions to make sense of what was being said. Finally, a thematic map of the analysis was made to connect different codes into categories and theme development [17]. To validate the findings, our own style of rigorous empirical thinking was considered carefully along with alternative interpretations. In addition, sufficient presentation of evidence was secured through a dialogue.

Findings

The researchers were surprised how well the data were formulated and structured, reflecting that writing had been used as a daily tool through many years. Through her reports, Ann's perspective as well as abstraction changed as she reflected on her life situation. The coding process identified several categories; some are similar to her previous life story and illuminate individual and important therapeutic factors that might help reduce pain:

- taking a leading role during ups and downs, and never giving in;
- being aware of the need for balance between activity and rest;
- being aware of the body–mind connection;
- considering education as a possibility when life “stops”;
- being optimistic and self-rewarding by setting subgoals;
- actively promoting positive aspects of the experience through writing a log;
- stabilizing the pain situation using medication and complementary approaches;
- mountain climbing as a goal when “down” and as a reality when she felt she had enough energy; and
- writing as cognitive self-help tool.

The categories listed above were abstracted in one main theme: “Striving for a meaningful life.”

Discussion

We report a case where various actions or events are fundamental driving forces to gain a meaningful life. To find out what her life situation was like and how she made meaning of several adverse events, we had to pay close attention to all the data we had received from her initially and during the follow-up, looking for connections and reinforcements. As seen in Ann's story, the negative effects of chronic pain often increase gradually over time and have impacts on most aspects of life. According to West et al. [4], learning to live with pain through life involves exploring causes, looking for possibilities and relief as the situation changes. As described by Ann, new perspectives on thoughts, emotions, and behavior related to living with pain can arise through writing as a therapeutic tool [19].

Despite her limitations, she was capable of taking the necessary steps to confront and adapt to her adverse health conditions. Ann was able to present a positive identity as an expert in managing her own condition. It seems clear that her unique and varied approaches to the situation, which made her a winner, were important in her efforts to preserve her sense of self and find meaning in life described as a rebuilding process [5]. According to van Rysewyk [16], experiencing meaning is considered an important factor in reducing suffering and adjusting to illness. Obviously, Ann was able to identify positive aspects of several adverse events, considered an important aspect of resilience [13]. In addition, we have added goal orientation, hope, and writing as important driving forces. These resilient factors are considered important by shifting her life goals to be more realistic as illustrated by her reduction in disability pension and starting part-time working.

As can be seen from this case report, individuals such as Ann suffering from chronic pain seem to possess several pain resilience health resources. This means that she has been able to use adaptive strategies in coping with pain, possesses a belief that pain is controllable, and has shown great emotional knowledge and skills. Moreover, people like her demonstrate an optimistic outlook on life and express the belief that life has a meaning [4, 5]. Ann admitted that health carers could still be of help, but it is yourself that have to do the job by investing in training, rest, and searching for adjusted job and education. Clearly, the extended biopsychosocial models of pain can be adopted [7, 8] and help in balancing daily life. This overall understanding of pain, focusing on both disease and illness and the complex interactions between biopsychosocial, spiritual, and existential components [6–8], should lay a common ground for patients as well as healthcare workers when searching for protective factors

within a whole person care model [9]. Ann has demonstrated a continuously positive attitude to life and her own situation throughout her narrative. As described by Finan and Garland [14], *positive affect* is associated with an array of health benefits. Among these, central aspects are being a buffer for maladaptive cognitive and affective responses to pain, leading to goal orientation that enhances self-management.

Guides for the promotion of patient-centered health care exist and are consistent with directions internationally as a global movement [12]. Ann has received sporadic help locally as well as centrally, which represents a challenge when coordinating and offering patient-centered healthcare services. Obviously, there is still much to be done in developing healthcare cultures to match this new trend, especially when it comes to persons such as Ann living in decentralized districts. However, when such holistic care succeeds [9, 12], the outcome is said to enhance the care experience for both patients and healthcare workers [12]. To be aware of this might help in reducing the feeling of pain and lessen the burden for the sufferer. Our main message is that a resilience model as part of patient-centered care – focusing on strengths and resources – must be naturally incorporated in all healthcare reforms. Moreover, this could encourage healthcare workers to pay more attention to what is working in individuals' lives [12] and to maximize physical well-being, psychosocial well-being, and autonomy. In this way, living a meaningful life with chronic pain seems possible.

Each person experiences pain individually. Although this story has been a personal one, its subjective truth is of wider relevance as it can tell us something about how the *self* is constructed and maintained in the long run during changing circumstances caused by chronic pain. The lived world around the person seems to have a strong influence on their responses to pain and suffering. As we see it, the extent to which living a meaningful life with chronic pain is possible depends on many complex factors, such as a person's belief system and attitudes, a supportive system that can assist in strengthening the health and resources of the patients, and the extent to which the healthcare worker understands the overall situation.

Conclusion

Insights raised from the case report, considered from a holistic real-world perspective, can be seen as sensitive and valuable clinical tools to help improve care for a vulnerable group of people suffering from chronic pain, where there seems little hope for the future. We argue that better biopsychosocial–spiritual–existential understanding, incorporated in a resilience model and patient-centered care, could encourage clinicians to pay more

attention to what is actually working in an individual's life.

Conflict of Interest

None declared.

Authorship

ED: designed the study, collected and analyzed the data, and prepared the manuscript. BF: designed the study, collected and analyzed the data, and prepared the manuscript.

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