Personal Growth in Chronic Illness – a Biographical Case Study of Living with Fibromyalgia

Vera Kalitzkus\textsuperscript{a}  Peter F. Matthiessen\textsuperscript{b}

\textsuperscript{a} Institute of General Practice and Family Medicine, \textsuperscript{b} Center of Integrative Medicine, University of Witten/Herdecke, Germany

**Keywords**

Chronic pain · Coping · Fibromyalgia · Qualitative study · Biography · Illness and disease, experiences · Life-changing event · Personal growth

**Abstract**

**Background/Aim:** Chronic illness can be distressing for patients. It confronts them with the challenge of having to cope with their life and of having to adjust their self-image. Nevertheless, patients often experience that they go through a process of personal growth. Although there is empirical proof of the potential that coping with severe illness has with regard to personal growth, fairly little is known about the conditions that bring about such a development. Based on a single-case study of fibromyalgia (FM) from Germany, the paper reveals the potential of a biographical approach for understanding the process of personal growth in chronic illness.

**Methods:** The case is part of a qualitative study on the occurrence of biographical transformation in severe illnesses. A narrative, biographical interview was conducted with the patient. The analysis takes objective biographical data as well as the subjective experience of the patient into account.

**Results:** Our analysis is confirmed by qualitative studies on the subjective experience of FM. Although these studies report a favorable development with some FM sufferers, they neither investigate its significance for the life of the patient nor the factors that make personal growth possible. We tried to identify biographical resources and personal strategies of the patient that facilitated her inner growth.

**Conclusion:** A biographical approach is a way towards understanding individual growth in the face of severe suffering. By including the patients’ objective life data as well as their subjective experiences, deeper insights into the process of personal growth can be gained.
Introduction

There is evidence for the fact that a crisis – in the form of illness or other critical life events – is a challenge for a person that can eventually lead beyond coping to personal growth [1–5]. Our study aims for insights into the human capacity for personal growth under conditions of severe illness. To gain a deeper understanding of that phenomenon, we focused on the lived experience of patients claiming such a development for themselves. In this article, we present a single case of our study: a patient living with fibromyalgia (FM).

The aim of this article is:
– To present a single-case study of personal growth under the conditions of FM contributing to the phenomenological evidence about the subjective illness experience of FM. It shows the value of merging the results of qualitative studies in metasynthesis [6].
– Qualitative studies on illness experience predominantly concentrate on the coping process itself, whereas only a few include the possibility of a transforming experience of personal growth. Little is known about the conditions that bring about such a development. We propose a biographical approach that takes into account a patient’s life trajectory. The inclusion of the sociocultural matrix of a patient’s life allows for deeper insights into such a development as well. Both shape the specific development options of that person and influence their subjective experience.

Methods

The case presented is part of an explorative study on patients claiming a positive development for themselves – despite of their suffering. The patient, a physician herself, learned about the study via an announcement being circulated by the Academy of Integrative Medicine, Germany. Written and oral information about the project was given and anonymity and confidentiality were guaranteed before written consent was obtained.

A narrative biographical interview in the style of Schütze [7] was conducted by one of the authors. The first phase began with a narrative question to invite the patient to talk about her experience. The interviewee was not interrupted until she came to an end with her first narrative flow. In the second phase, the interviewer asked narrative questions about further aspects relevant for the research question. In the last part of the interview, information was gathered about relevant topics that had not been touched so far. The interview took place at the patient’s home, lasted for 3 h, and was not interrupted by any disturbances. Quotes from the transcripts in this article are given in English translation. The verbatim transcript of the audio-taped interview has been analyzed by a combination of methods: an analysis of the objective biographical data [8, 9], validated by an analysis of the patient’s lived experience with content analysis and a sequential approach [10]. Each of these methods allows for deeper insights into a specific aspect of the data. Simons et al. [11] state that ‘iterative, sequential methods of analysis revealed greater complexity and depth of understanding of the phenomena than would have been achieved with one method alone’. Three categories are distinguished in analyzing the empirical data [10]:
– the lived life (objective biographical data),
– the life as narrated by the informant (self-presentation in the interview),
– the lived experience (level of emotions and meaning).

The analysis of the objective biographical data about the ‘lived life’ (e.g. parents, time of birth, schooling) is done iteratively. Going from one biographical event to the next one asks: ‘What course of action would be reasonable to assume given the sociohistorical context and the personal and family resources? What other courses of action could be imagined?’ This is done with an attitude of artificial naivety as to not restrict the imagination to the known course of events. In the light of these options, the actual choice of the person can be interpreted and a specific style of action identified (e.g. traditional vs. innovative). In the second part, the lived experience and self-presentation of the interviewee is analyzed: ‘What kind of emotions, rationales, and motivations does she talk about? Which biographical areas and possible choices are neglected?’ The respective findings are then validated in comparison with each other.

We discuss this single-case study in the light of other qualitative studies on the subjective experience of living with FM, which is made possible by a metasynthesis of these studies by Sim and Madden [6]. Due to this, we are able to validate our findings on the grounds of twenty-three studies encompassing 383 participants (360 women). Despite the constraints concerning methodological aspects of synthesizing the findings of qualitative research [6], it gives rich insight into that particular area and a means to validate our findings.

Results

Living under the Conditions of Fibromyalgia

FM, one of the ‘least well understood phenomena in medicine’ [12], describes a condition of diffuse, generalized musculoskeletal pain and aches without joint inflammation or tissue damage. It is mainly characterized by the symptoms of various pains and aches, stiffness, weakness of muscles, exhaustion, and others that can lead to devastating effects in the patient’s life. Nevertheless, FM patients can experience illness gains and a transformation of their identity resulting in increased self-respect and personal integrity [13]. However, conditions that foster such a development are unfortunately not in the focus of most of the research undertaken [13, 14]. Qualitative studies on patients’ experience with FM give concurrent evidence about the phenomenology of living under its conditions [6, 12, 15–22]. As main characteristics are identified:
– Living in almost constant pain and tiredness leading to social isolation and strain on the family life;
– suffering caused by the uncertainty of the symptoms until the time of the final diagnosis;
– uncertainty about the symptoms experienced that can lead to an estrangement from the body;
– uncertainty about therapeutic options due to the lack of medical knowledge.

Beside the impact of FM on the patients’ lives that is similar to other chronic illnesses, e.g. disruption of life, contested self and social identity, socioeconomic difficulties, uncertain future, or loss of faith in the body [23], a specific feature of FM is being a contested illness with unclear etiology and invisible symptoms exposing the patients to the danger of discredit and stigmatization [15].
The Biography of Mrs. D. – a Single-Case Study of Fibromyalgia

Mrs. D., a medical doctor and mother of three children in her 60s, has been living with FM for about 20 years. She participated in our study in order to give hope to other patients due to the course she was able to give to her life. We begin with an analysis of the objective life data (especially of Mrs. D.’s family of origin) to identify patterns of actions and behavior salient in her life before the onset of the illness. We then look at Mrs. D.’s lived experience to contrast that with the first analysis. Thus, a deeper insight into how she made sense of major events and decisions in her life is gained. Finally, we analyze the coping process with FM and the further development that her life took from there. Due to the limited space of this article, the analytical process, especially the iterative process of the analysis of the objective life data, cannot be given in detail.

Family of Origin – Objective Life Data and Their Interpretation

In the last days of World War II in May 1945, Mrs. D. was born in a small town in industrial middle Germany as a second daughter, her sister being 2 years older than her. Her mother (born 1908) stemmed from a large farmer’s family. Education, especially higher education of girls, was probably neither seen as a value nor pursued by the family. If the family is firmly rooted in a traditional pattern, it could be assumed that she has been educated to become a good housekeeper and mother. She will probably choose a husband with a farmer’s background to continue her family pattern.

The father of Mrs. D. was born into a craftsman’s family in a larger city in the same area in 1909. Either a traditional pattern or a pattern of social advancement seems to be possible. He chose to break with the traditional pattern of his family, opted for social advancement, and became a dentist. With Mrs. D.’s mother he married a woman who showed her orientation toward social advancement, but – given her farmer’s background – provided a stable basis in times of socioeconomic crisis. Most of her mother’s siblings stayed in the area and formed an extended family network, supporting each other in times of severe economic and social hardship.

Two scenarios for the family mandate of the couple’s daughters seem to be plausible:

– to keep up the traditional pattern of their mother’s family (especially in times of sociopolitical tensions) and marry back into a farmer’s family;

– to continue their father’s strive for social advancement (especially as there is no son to fulfill that role) and choose education and training in a field of socially accepted professions for women at that time (e.g. teaching, nursing, physiotherapy).

Mrs. D.’s father died in April 1945 during the last days of the war and shortly before Mrs. D.’s birth. Thus, Mrs. D.’s mother had to raise both children on her own. She did so with the help of her sisters and mother, jointly starting a small business with home knitting. Mrs. D. and her sister grew up without a father or another male significant other. In 1956, Mrs. D.’s mother became seriously ill, suffering from cirrhoses due to hepatitis B and being treated as an inpatient for a long time. During that time, the sisters were looked after by their aunt and grandmother. At the age of 13, Mrs. D. went to a convent boarding school as this enabled her to attend a school for higher education in the next largest city. The life with the nuns in the convent was very constrained and offered hardly any freedom. At the age of 18, she managed to rent a room in the house of a family and lived there during her last year before graduation in 1966.

Early Childhood and Youth

The narrative Mrs. D. recounts of her early years shows that she felt isolated and like an outsider. She realized that she did not know the feelings of deep joy and joyfulness she saw in other children, but felt that this was just normal for her:

Well, the fact that I could not feel things that other people could feel. (...) Somehow a dimension is missing, and I felt that, I did feel it physically (...) that only very rarely I could get out of this tightness.

The relationship with her mother was very strained, which she traces back to the fact that her mother tried – unsuccessfully though – to induce an abortion while she was pregnant with her. The mother was overstrained with caring alone for her daughters and securing their economic survival. Mrs. D. suffered from frequent beatings by her mother and grandmother and probably also from molestation by male family members from her mother’s side. She tried to get away from home as early as possible. Even in her school holidays she chose to stay with the nuns in the convent instead of going back home. Her aim to study medicine developed very early and was the reason for her to concentrate on higher education. She believes that her goal arose due to the severe illness of her mother. However, the analysis of the objective life data, as given above, points to the important influence of her absent father (continuing his striving for social advancement in the medical profession). Furthermore, as Mrs. D. talked about resources that enabled her to endure her illness, she recounts the story of her father expressing his joy of expecting a second child in a letter from the front to her mother:

Well, one of my roots that made it possible for me to get through all this, is – I think – that my father believed in me. That’s what he writes in his letters. He was looking forward to me.

The analysis of the self-presentation in the interview revealed the prominent role of her father as well. For this, the analysis of the first sentence of an interview is pertinent [24]. She begins the narrative of her life as follows:

Yes, I want to begin very early with my story. I was born in ’45, 2nd of May, just during the last days of the war. My father stayed in the war. He
was home last in November, December ’44. So he never got to know me. Killed in the war on 20th of April ’45. I’m the second daughter. My mother must have been totally overburdened with her second pregnancy ... I know all that from letters from my father [to my mother] ...

We can conclude from the above that there is a breach in the family’s orientation toward social advancement due to socio-historic circumstances of war. Because of the father’s death, her mother has to secure the economic survival. Yet, Mrs. D. shows the willpower to pursue the mandate inherited by her father by following him into the profession of medicine. She fought for her higher education against the traditional milieu of her mother’s family and restricted economic resources and eventually applied to university to study medicine. The way in which she coped with the adversities in her youth can be interpreted as a successful strategy of survival. It shows her strength of character and willpower as well as her autonomy from the judgment of her social surroundings (family, peer group). However, the weak areas in her life also become apparent: a feeling of emotional deprivation and social isolation, difficulties in building trustful and meaningful relationships, and an inability to experience deep joy.

Her Adult Life
In 1966/67, Mrs. D. began to study medicine. This is the first time of her life with a significant range of personal freedom she could have used to create a social life for herself. Instead, as we learn from her narrative, she solely concentrated on her studies and on pursuing a professional career. Nevertheless, she became acquainted with her future husband during the wedding of an old school friend. They got married in 1971 – due to ‘pragmatic reasons’ (housing), as she states. Mrs. D. postponed pregnancy until the time of her first permanent employment as a medical doctor. Her field of professional interest changed from internal medicine to general/family medicine until she finally settled for pediatrics. During all these years she took part in a large number of trainings in the field of psychosomatic medicine and bodywork therapies. She also specialized in the field of infant development.

Being a Mother and a Doctor
Mrs. D’s first daughter was born in 1976. She returned to work full-time 2 months after giving birth and worked a split shift that gave her time to care for the baby during the extended lunch break. As her husband worked as a teacher he could take care of the child in the afternoon, at times bringing the baby for breast-feeding into the clinic where she worked. In 1978, her second child, a son, was born. Again, she returned to work after 2 months’ maternity leave.

Despite of her professional training in the fields of child development, psychosomatic medicine, and related subjects, she recounts her feelings as a young mother of being very ‘functional’, believing that children do not need so much a mother than just a person to take care of life’s necessities (e.g. feeding, clothing). She also described her difficulties of giving tenderness and physical affection to them. Only with the years of her further professional training and experience in pediatrics did she realize that children also need ‘a mother’.

She recalls the feeling of leading two separate, non-related lives during this period, one at home, the other at work. Her husband took no interest in her work as a physician, the relationship was strained, and he showed signs of having a problem with alcohol (although he did not show any form of obtrusive or aggressive behavior). She decided that if she wanted to pursue her work as a physician while having small children, she has to renounce from any form of social life or private time for herself. Her life would consist solely of being a mother and being a doctor.

The Onset of Fibromyalgia
FM showed its devastating effects in the life of Mrs. D. as it is also accounted for in other studies [6]. The problematic development began with a diagnosis of viral meningitis during her third pregnancy. (To date, it is medically discussed whether that could be a cause for FM.) After the 2-month maternity leave she returned to work, but only part-time. At the age of 40 she experienced the onset of the first symptoms. She recounts feeling exhausted, tired, and always being cold, while medical examinations revealed no causes for her condition. She describes:

Yes, I kept noticing that I was more and more exhausted. That I always had to lie down and sleep in between, that I couldn’t drive anymore. That I was often so tired that I literally couldn’t keep my eyes open. And that I found it harder and harder to recover after working night shifts. (...) I just felt exhausted all the time, totally exhausted. And then my mood also hit rock bottom.

Mrs. D. also struggled with unexplainable symptoms, and despite of being a medical professional herself, it took 8 years after the onset of the illness to make a diagnosis. She experienced that as great relief as it made sense to her what she learned about FM, especially that the pains could be psychosomatic. Treatment options for her symptoms were scarce and did not help her much. Her condition decreased substantially during a period of 15 years, resulting in depression and phases of suicidal risk. She talks about living in an ‘existential vacuum’. She was treated several times as an inpatient for 2–3 months. Back home, she continued with psychotherapy, especially integrative psychotherapy according to Hilarios Petzold [25], and a regiment of physiotherapy. She managed to keep up her responsibilities as a doctor and her social role as a mother, concealing her illness both from the wider family and the social field. Although she managed to accomplish her tasks, it took her twice as long than before. Despite of a further decline of her condition, she worked as a physician until the end of 2001. Her illness also caused stress for her family and problems in her relationship with her husband which eventually led to separation.
From Coping to Personal Growth

As has been shown, her illness led to a restriction of life-related possibilities. Only with great effort did she manage to keep up her role as a mother and her duties at work. On the other hand, as will be shown, the illness allowed her to re-evaluate her priorities in life, eventually leading to further development of aspects of her personality that – in her perspective – were necessary and neglected in her life before the onset of the illness.

Starting a New Life

When her youngest daughter finally moved out, Mrs. D. decided to start a new life in a larger city nearby. She rented a small apartment near the city center and decorated it with bright colors. She kept up her regime of sport and body-oriented psychotherapy and still felt strong enough to take courses at the local university. In this phase of her life she worked on improving the relationship to her children that had suffered badly due to her illness. She aimed at improving her relationship to other people as well and looked for meaningful ways of engaging with others without overstepping her boundaries. To date, she has created for herself a stable social environment, providing enough personal freedom and options to retreat while also keeping her intellectually engaged and providing ample social contact.

What Allowed such a Development?

The biographical analysis showed that Mrs. D. could draw on resources to cope with her illness from her past (her family of origin’s will to socially advance, supportive significant others in times of great restriction, successful achievement of personal goals) as well as traits of her character (strong will, intelligence). However, this was not sufficient: FM forced her to look at the hereto underdeveloped areas in her personal life – self-care, self-appraisal, reappraisal of life outside the professional world, discovery of the world of emotions, bodily awareness. It is striking how she seemingly anticipated that need by her (concerning the underlying motives) unconscious choice of professional specification in social pediatrics, infant development, and psychosomatic medicine. In the course of her illness and fostered by body-oriented therapeutic approaches, she became more sensitive to her feelings and the symptom language of her body.

Nevertheless, she underwent long phases of great despair and suffering leading to suicidal thoughts. Only with the support of her respective therapists has she been able to cope during these dark phases, she says. She points out that it was the therapeutic relationship rather than the specific therapeutic methods that helped her through. She emphasizes how important it is for patients in severe distress to be given some kind of hope and, without diminishing their suffering, to point out positive areas in life and possibilities for development. This instilled hope in her not to give up. Through the body-oriented therapeutic approaches, especially the Feldenkrais method, she also became more sensitive to her feelings and the symptom language of her body. A body-mind-oriented approach is also validated by other studies as a tool to manage chronic pain conditions. Shariff et al. [26] found that a sense of well-being is achieved not through pain control alone, but also through various mind/body techniques for managing pain, accepting new limits, and adjusting the way people relate to themselves.

In retrospect, she came to the conviction that her body is providing the symptoms for her that she needs to (re-)evaluate her actions and her way of living. It shows a re-evaluation of living with FM and a reconcilement with her body. She states:

Well, I look at it that way that I have to have such strong physical symptoms because I pay so little attention to these things. For 17 years I was never ill. I was sick for half a day during all of my three pregnancies, that was all. And then it really hit me. And I just need pretty tough physical symptoms when I'm on the wrong track. It's still like that. Then I'm just exhausted, I fall asleep, I can no longer concentrate and so on …

Mrs. D. shared her story for use in our study to contribute a ‘growth story of fellow survivors’ [27] to other patients as she had experienced the benefit of these kinds of stories in her own life. She points out the necessity for patients with FM to take initiative in creating their therapeutic scheme, to motivate themselves for regular physical exercise, to observe a conscious and healthy diet, and to work on cognitive restructuring and a positive outlook on life. Mrs. D.’s evaluation of her growth process resonates with the most salient themes of posttraumatic growth identified by Chun and Lee [28] in their study on posttraumatic growth in people with spinal cord injury: ‘experience of meaningful family relationships, experience of meaningful engagement, and appreciation of life’.

Discussion

Qualitative studies on the patients’ perspective give valuable insights into the phenomenology of living with a specific disease. Nevertheless, the challenges posed by the specific symptomatology of a disease fall on the matrix of an individual person’s life with their own specific biographical context (e.g. lived experiences, personal resources, sociocultural conditions). For this we propose a biographical approach. The generalizable findings about the phenomenology of living with the symptoms of a specific disease have to be seen in the context of the individual experience of the illness as it unfolds itself in this person at that point of their life with their specific composition of biographical challenges and resources. Especially in chronic illness, medical and therapeutic practitioners are asked to support patients in their endeavor to lead a meaningful life despite of their disease. In order to achieve this, medical knowledge about the patient has to be comple-
mented by the knowledge about the unique and irreproducible situation of that individual person in that specific time and place [29].

Despite of the well-documented challenges of living with FM, patients can go beyond successful adaptation as is mentioned in various studies, although not analyzed in depth [6, 12, 15, 20]. The case study presented here gives insight into the areas of life in which personal growth can be experienced by the patients. According to Arthur Kleinman, a stance of ‘empathetic witnessing’ [30] is called for that acknowledges not only the illness experience, but also broadens its view to encompass biographical aspects of the patient, too. It is important to bear in mind that a reappraisal of life is possible even then, but patients might need therapeutic and social support to undertake such a development.

**Disclosure Statement**

The authors have no conflicts of interest to disclose.

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