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Exercising an individualized process of agency in restoring a self and repairing a daily life disrupted by fibromyalgia: A narrative analysis

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ABSTRACT

Objective: Fibromyalgia is a chronic condition that has major impact on people's lives. This study examines individuals' illness trajectories, with a particular focus on daily life experiences and self-managing.

Methods: Narrative interviews were conducted, asking participants to story their daily life experiences from illness onset to the present, and to reflect on the future. Embedded in their storying were experiences of recently being diagnosed, navigating daily life in the face of illness, and participating in a self-management intervention. The data underwent a narrative analysis.

Results: In keeping with the idiographic focus of narrative research, two individuals' stories were chosen to portray an individualized process of self-managing illness in daily life. The storylines 'Resuming prior self and life' and 'Taking life and self in new direction' illuminate how individuals with differing illness trajectories and life situations autonomously apply resources available to them in their lives. They make sense of illness by bringing together their own lifeworld experiences of stress and factual knowledge and, through a process of individual agency, discover and try out what is right to do in their own life in the face of chronic illness.

Conclusions: These two storylines illustrate that a self-managing process is an individual process nested in the person's social context. Self-management encompasses an individualized process of agency in remaking daily life and reconstructing a sense of self.

1. Introduction

Fibromyalgia is a prevalent, chronic, fluctuating, musculoskeletal pain condition, characterized by widespread pain (Mengshoel, 2022; Queiroz, 2013). It is accompanied by multiple other symptoms, such as excessive fatigue, non-restorative sleep, headache, irritable bowel, cognitive problems, and depression (Wolfe et al., 2016). The aetiology of FM is still unknown, but patients consider physical, mental and/or social stressors to play causal roles (Furness et al., 2018), and a long stressful trajectory of recurrent episodes of localized pain can be experienced before culminating in widespread, persistent pain (Mengshoel, 2022). The pathogenesis is assumed to involve various interacting systems, such as upregulation of nerve impulses within the central nervous system, changes in the neuroendocrine and autonomous nervous systems, genetic vulnerability, and depression (Chinn et al., 2016; Clauw & Crofford, 2003). However, which mechanisms are primary or secondary is an unsolved puzzle.

The diagnosis of fibromyalgia cannot be verified by any biochemical or radiographic measures, and a diagnosis relying on patient-reported symptoms raises scepticism as to its 'realness' (Madden & Sim, 2016; Roitenberg & Shoshana, 2021). Thus, patients experience their suffering being ignored, trivialized, or psychologized by health professionals (HPs), and patients find the diagnosis to lack social legitimacy (Madden & Sim, 2016; Mengshoel et al., 2018). This may cause fibromyalgia to be experienced as an 'empty' diagnosis, conveying information but little understanding (Madden & Sim, 2006). Multimodal non-pharmacological modalities and drugs are recommended as treatment (Eich et al., 2012; Macfarlane et al., 2017). However, patients may find such approaches inappropriate, as, for example, they may fear addiction or adverse effects from drugs and may feel worse following

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exercise (Climent-Sanz et al., 2024). Hence, patients may not adhere well to prescribed treatments, and clinicians may consider them to be demanding and unmotivated (Roitenberg & Shoshana, 2021). Thus, uncertainty remains about what HPs and patients should do, and knowledge about what patients find helpful to recover is needed.

The dominant understanding of recovery in medicine relates to effectiveness of therapies targeted at normalizing signs of biological disease, relieving symptoms, and improving functioning, while from a patient perspective, recovery may also include a patient's existential and social suffering and own healing work (Mengshoel & Feiring, 2020). Mishler (2005) applies the terms 'voice of medicine' and 'voice of life-world' to differentiate between HPs' factual knowledge and patients' own experiences. Within the 'voice of medicine', fibromyalgia relates to uncertainty about the realness of diagnosis, prognosis, and effective treatments (Doebl et al., 2020). To address the complexity of the illness, multidisciplinary self-management interventions are offered to patients with fibromyalgia. A recent systematic review demonstrated that such interventions have varying pain-relieving effects, but these are not long-lasting (Geraghty et al., 2021). A systematic synthesis of qualitative studies showed that participants appreciated such interventions, but it was challenging to practise the self-management skills after completing the interventions (Hu et al., 2024). According to Lorig et al. (2020), self-management interventions follow a principle of improving health by adopting a healthy lifestyle and applying self-management skills to overcome disease-related physical and psychological problems. Thus, self-management interventions are mainly oriented to overcoming typical problems associated with disease, and patients' individual experiences and needs may receive less attention (Black et al., 2024).

Qualitative interviews with patients have demonstrated the immense disruption fibromyalgia imposes upon their lives, challenges in accessing treatments, and inadequacy of many such treatments. At times, pain and fatigue flare up and dominate daily life, relegating other concerns (Ashe et al., 2017). Individuals' illness is also described as a journey with shifting concerns over time: including occurrence of inexplicable symptoms, stress in seeking a diagnosis, fighting against the social illegitimacy of a fibromyalgia diagnosis once it is obtained, striving to attain validation of illness, grief over lost capabilities and self, uncertainty about the future, and lack of support (Raymond & Brown, 2000). Patients may also have to resist a cultural image created by the media linking patients with fibromyalgia to 'patienthood' and an unwillingness to engage in processes to overcome disability (Oldfield et al., 2018). Hence, Cassel (2004, 2013) suggests that HPs need to understand patients with chronic illnesses and long-lasting suffering from the voices of both medicine and the lifeworld. While much is known about the clinical complexity of fibromyalgia, there has been less focus on exploring patients' efforts to craft a meaningful life in the face of fibromyalgia.

Few people recover from fibromyalgia, but those who do related their recovery to personal healing work guided by their interpretation of increased pain as a 'warning signal' of too much 'life stress', and modifications of daily life accordingly (Eik et al., 2022; Grape et al., 2015; Mengshoel & Heggen, 2004; Sallinen et al., 2012; Wentz et al., 2012). The individuals interviewed in this study participated in a self-management intervention, including lectures on medical knowledge concerning fibromyalgia and evidence of patients' recovery trajectories. The voice of the individual's lifeworld was addressed by exercises where peers and health professionals shared, explored, and discussed possible ways to manage illness and stress in an individual's daily life situations (Mengshoel et al., 2021).

Recently, fibromyalgia has been described as an illness highly variable between and within patients, and a more in-depth understanding of this phenomenon was called for (Black et al., 2024; McMahon, Murray, & Simpson, 2012). Our aim was, accordingly, to explore individuals' stories about daily life experiences and self-managing processes as these develop and change over time.

1.1. *Recovery, daily life, and self*

The concepts disease and illness are used to clarify the medical and personal perspectives, respectively, on people's maladies (Lupton, 2012). These perspectives may link to different understandings of health – for example less disease, or more wellness in daily life despite disease – suggesting that recovery may take various routes and end up at different destinations (Mengshoel & Feiring, 2020). Disease is a medical term referring to biological abnormalities, and consequently, health here means fewer or no such abnormalities (Hofmann, 2001). This theoretical understanding is successfully applied to therapies for acute injuries and diseases but seems a less relevant health outcome in chronic conditions (Cassell, 2013). Illness connotes a person's experiences of suffering through living with a disease in an otherwise healthy world (Kleinman, 1988). The body is not taken for granted any longer (Bury, 2005), whereas prior to the disruption occasioned by illness, people 'move though their everyday routines without attention to their bodies as bodies' (Becker, 1997 p. 81). Accordingly, recovery connects to a process of understanding the meaning of illness (Kleinman, 1988) and actions to position health in terms of wellness in the foreground and illness in the background (Paterson, 2003). In this way, health becomes attainable in the presence of chronic illnesses.

Illness and wellness are experiential, lived phenomena that are both personally and socially shaped (Bury, 2005). Charmaz (1991) relates chronic illness to various impacts on daily life: interrupted normal life, intrusion on daily activities, and immersion in illness. Thus, more wellness implies considering the biological body, existential body, and the body in a sociocultural context, and taking action to reverse the impacts of illness (Lupton, 2012). Within the symbolic interactionist tradition, Mead (1934) developed a notion of the self as a form of self-consciousness that constructs a person's identity and is developed through social interaction and the adoption of social roles. Hence, living a restricted life often has consequences for a person's self, as the self is situated in daily life and actively constructed and construed during the life course (Holstein & Gubrium, 2000). The term 'biographical disruption', therefore, may mark a disjuncture between enacting a self in daily life before versus after the onset of illness (Bury, 1982), alongside the bodily disruption that illness may bring about (Becker, 1997).

However, the concept of biographical disruption has been criticized for considering those with chronic illness to inhabit a passive sick role, thereby ignoring that they may actively engage in redefining a relationship between illness, daily life, and self. For example, people with osteoarthritis 'normalized' joint pain as being an inevitable part of ageing despite disturbing daily life (Sanders et al., 2002), and people with low back pain downplayed the role of life disruption to maintain or reconstruct a former self (Sanders et al., 2015). Kelly and Field (1996) point out that as bodily functioning alters, social conceptions and identity may also change. Another concept, 'biographical suspension', describes a person who rejects the idea that illness is a lasting condition (Bunzli et al., 2013). Therefore, a former self and daily life are put 'on hold' until recovery occurs, and in the meantime, a person is positioned in a liminal state between 'usual me' and 'sick me'. In contrast, the term 'redemptive self' signifies a person transforming negative life experiences to a move in a positive direction (McAdams, 2012).

2. Methods

2.1. *Narrative design*

Narrative interviews were conducted to facilitate patients in freely telling stories about their illness and recovery trajectories. People tell stories to make sense of their own experiences by weaving together past, present, and expectations for the future into a coherent whole (Riessman, 2008). Frank (2012, p. 33) claims that stories are 'artful representations of lives; stories reshape the past and imaginatively project the future. Stories can revise people's sense of self'. In storytelling, people select events that are important and make a difference to them, marking a turning point (Mattingly, 1998). Thus, storytelling is not simply a reproduction of what has happened in a person's life; rather, it is a reconstruction of what a person finds significant in the past for a present understanding. 'The truth of stories is not only what *was* experienced, but equally what *becomes* experience in the telling and its reception' (Frank, 1995, p. 22). Narrativizing means to situate experiences in the lifeworld, and a narrative analysis investigates both the content and the context of a person's life and how it is textually presented in an individual's storytelling. Elliott (2005) states that a narrative is produced for a specific listener or audience. Hence, both the context and the creation of a narrative are essentially social.

Narrative analysis is characterized by the notion of a trajectory over time (Roberts, 2002), and Murray (2015, p. 87) similarly defines a narrative as 'an organized interpretation of a sequence of events.' Accordingly, whilst approaches such as content analysis (Drisko & Maschi, 2015), thematic analysis (Braun & Clarke, 2022) or grounded theory (Sim, 2018) predominantly develop insights *across* individuals' accounts, looking for forms of conceptual commonality or variation in the data, in what Riessman (2008) calls a 'category-centred' approach, narrative analysis takes a more idiographic, 'case-centred' approach (Riessman, 2008). This is one that focuses *within* people's stories in order to capture their individuality and the meaning of their telling. Hence, 'narrative scholars keep a story 'intact' by theorizing from the case rather than from component themes (categories) across cases' (Riessman, 2008, p. 53). In the process, 'particular narratives can be put under close scrutiny for analytical purposes' (Esin, 2011, p. 104).

2.2. Recruitment

The present study focuses on the participants' stories 12–18 months after completing a self-management intervention at a rheumatism hospital. The participants were recruited to the program consecutively among those referred by family physicians (GPs). Forty patients completed the program during the project period, and ten patients were interviewed at this follow-up. Three participants, including one on whom we are focusing in this paper, had also been interviewed at their entry to the program and were interviewed a second time, while the rest were interviewed for the first time.

2.3. Ethics

The Norwegian Social Science Data Services approved the research project (no. 2018/57956/3/EPA). Before the interviews, the participants received written and oral information about the project and their right to withdraw from the study without risking any negative consequences for further services at the hospital. The participants were assured of anonymity, and data were stored on the University's secure research server. All participants provided consent.

2.4. Narrative interviews

The first author performed the interviews by telephone and audio-recorded them. She had met three women previously, but the others were unknown to her. She presented herself as a university academic involved in research on patients' illness and recovery experiences. In the interviews, the participants were invited to tell stories about overarching themes: 'Please, tell me about your illness from its beginning, the help and support you have received during the illness course, and about your daily life in the last year'. Care was taken not to direct, truncate, or impose the researcher's perspective on, the participants' stories (Elliott, 2005), nor to suppress the narrative through seeking 'relevant answers to narrowly specified questions' (Mishler, 1986, p. 68).

At the end of the interview, the participants were asked to reflect on their expectations for the future, if these had not already emerged. The interviewer followed their storytelling, facilitated further telling by uttering 'yes?'/'no?', repeated what the participants had just said in a questioning tone, or asked them to concretize experiences by providing examples (Riessman, 2008). The interviews lasted from about 60 to 140 min.

2.5. Narrative analysis

The interviews were transcribed verbatim. First, they were listened to and read several times to familiarize with the text. The participants told a coherent story of a past leading up to fibromyalgia and disruption of daily life, changes in daily life during the last months, and experiences of more good days than before. To examine these issues further, the following analytical questions were posed: what creates coherence between the past and the present, and what significant events are storied? Each story was ordered chronologically, and thereafter, a close reading and analysis of each interview were carried out to elaborate on what was told and how it was textually linked together (Riessman, 2008). The stories differed in detail and richness, and the nature of participants' suffering varied. Nevertheless, a shared pattern (meta-narrative) was found of making sense of, and exercising agency within, one's own life-world and making sense of past and present experiences by linking knowledge of fibromyalgia with experiences of one's life story, whereby participants enacted this understanding in their daily life. In keeping with the idiographic nature of narrative research, we have focused our analysis here on just two cases. Quotations from the participants in the text are marked by " …" .

3. Findings

3.1. Participants and contexts

Eight women and two men between 29 and 54 years old participated in the interviews. They had been diagnosed with fibromyalgia within the last years. One had acute onset of pain, while the others were storying a past with pain that has been "coming and going" over years, and gradually progressing to persistent pains "all over the body". Illness disrupted their daily life in various ways and prompted medical examinations without providing any resolution, and uncertainty and worries welled up. As previously noted, our analysis centres on the narratives of two participants whose stories yielded differing illness trajectories under a broader meta-narrative of exerting a sense of agency with regard to their lives and the management of their illness.

3.2. Christian – a storyline about resuming a prior life and a former self

Christian is in his 40s and lives in a town together with his spouse and three children, one of whom has a congenital brain impairment and needs assistance in daily living. Christian is a manager of a workshop. At the time of the self-management intervention, he was on sick leave, but now, one year later, he has returned to his former full-time office job. Earlier, Christian was a competitive athlete. During these years, he experienced frequent episodes of pain without paying much attention to it, as "it is normal to have some pain among athletes". After he quit elite sports, pain continued, but he found it understandable as he still exercised a lot, including weekly road cycling together with his mates. At a certain point, however, the "body became different" and disturbed his life to a degree that was impossible for him to ignore. Christian's storytelling starts with the time when diagnosed with fibromyalgia:

> After about six months with a lot of medical exams and stuff like that, my GP sent me to a rheumatologist who arrived at the diagnosis [fibromyalgia]. He sent me on to the rheumatism hospital, some new tests were performed, and the physician there came up with the same diagnosis. So really that's how it started for me. But when I joined that group [in the self-management intervention], it was only then

> that I started to understand a little bit about the different pains you've had over years. When you're in pain somewhere, then, I didn't think it had anything to do with a medical diagnosis or anything like that. I've felt these pains longer than the six months before I was diagnosed, but without thinking that I have some kind of illness. So, I sort of haven't seen myself as sick.

This quotation displays a turning point when pain disturbed Christian' daily life to such a degree that it became unmanageable and no longer ignorable. He had not seen himself as sick before, but now he consulted his GP. He was put on sick leave, and several medical examinations were performed without any definite results. After six months, there is another turning point when he received a diagnosis and attended the self-management intervention. By applying the pronoun 'you' instead of 'I' in the quotation, Christian presents himself as an observer of his past experiences and, thereby, objectifies his own subjective experience. Now, from this standpoint, he has started to reflect on the connections between past pain episodes and his present diagnosis. Christian became aware that in the past he was more frequently injured than his sport mates. Today, he relates impaired exercise tolerance to a genetic disposition, referring to his brother who has ankylosing spondylitis. He wonders if the change from previous episodic to current permanent pain was triggered by stress related to the birth of his disabled child, and that further development was accentuated by a stressful job where "I used to give 200% all the time, and even if in pain, I just fired up". Christian tells how before the self-management intervention he was "full of why's", but today, he relates his illness to a genetic disposition in combination with a stressful lifestyle.

Christian continues his storytelling by portraying how today he accommodates to illness. In contrast to the past, he does not ignore bodily signals anymore. He "listens to the body", takes care and adjusts within daily situations:

> Then, it became important to listen to your body. I wasn't good at it before, but I got onto that course and became a lot better at it. You have hardly time to listen to your body: you're going to school meetings, you're going to other meetings – I feel like I'm running all day, and that I'm always in arrears. But I must take care. Now, I feel like I can be at work as I'm much more aware of things now. I have days that can be painful and heavy, but I'm more conscious and pay attention to it and plan my day a little bit accordingly.

Again, Christian varies between terming himself as 'you' and 'I', which thereby underscores his ability to consider his situation either from a strongly first-person standpoint or as a distanced observer. Christian says that he has a lot of things that he cannot "run away from", but now, he takes short breaks during a day to restore his energy and "slows down the tempo" on bad days. He does not take any medicine, but instead, he has a glass of cognac every evening that calms him and makes him sleep well. He does not consider this "more harmful than taking pills". Christian has taken up his former life, and people accept that he cannot always take on as much as before:

> The group [cyclists] has been really good at accepting my limitations – if I fall far behind, they stop and wait. Then, we move on. They know why, so it's no big deal. They're a nice bunch, so they pay attention. It means a lot to me that even though I've been diagnosed, I don't have to put things on the shelf – I can still go hiking and fishing. I do everything as before, it's just that some days it goes a little slower.

Christian sums up his storytelling with the following statements: "most of my life is positive", and "I live as normal as far as possible". During the period of sick leave, he had put his life on hold while waiting to find out what his illness meant, and what could be done about it. But after being diagnosed and making sense of his illness, he reasserts agency over his life and resumes a former non-sick self, resuming his ordinary life. A difference is that he now takes care of himself, and even though he recognizes his susceptibility to illness, it plays a minor role as he knows what to do about it within the frame of his everyday life.

3.3. Sarah – a storyline about taking life and the self in new direction

Sarah is a woman in her early 30s who is living in a town together with her partner and two children. She has "basically no education" and has worked hard since adolescence. Nevertheless, she has become a shop manager and her family's main breadwinner. In the first interview, Sarah had been on sick leave for almost a year, in the last months mostly bedridden. Her life was immersed in illness, and she did not know what to do to bring her life on track again. She was stressed by not being able to return to work, the financial consequences of this for her family, and her inability to take part in daily care of her children. At the time of the second interview, she is working 30% in a vocational rehabilitation program and shares the care of the household with her partner. She says that she has realized that she cannot continue to live like before and is now trying out new routes in life with support from her coach in the vocational program and her GP.

In recounting the past, Sarah starts by turning to her adolescence and describes a turning point when her father died. She then had to take over the care of her three younger siblings and her mother. To support the family's finances, she started working as a cleaner after school. It became too much for her; she explains this by describing a visible change of how her body reacted with a flare of atopic eczema and swollen fingers. Sarah quit high school and started working full-time. Today, she thinks this traumatic event was a forerunner to her illness. Later, another traumatic event occurred when she gave birth to a premature child with a serious heart defect, leading to frequent hospital stays during the child's first years. She continued to work hard and took over others' work when they were sick. She had frequent episodes of pain, and finally she was in constant pain all over her body. She felt "never refreshed, and the body had no tempo". Looking back today, she thinks "I should just have listened to my body", but she continued to work until her daily life broke down. Sarah describes years of prioritizing work. This priority, she says, accords with the value her family attaches to being "hard working people". Today, she doubts this is right for anyone in her family. Her mother has fibromyalgia, and Sarah is noticing that several of her family members may suffer from it. After being diagnosed with hypermobility syndrome herself, she has also noticed that hyperflexible joints run in the family:

> I think there are more people on my mum's side who have that diagnosis [fibromyalgia] without having received it from a doctor. You notice how your body is, and how the others feel. Always tired and overworked. That's how we're brought up – to work! Then, I am told at the age of 32 that I have hypermobile joints. It's strange that no one has noticed it before. My joints are so stretchy, listen [makes the fingers cracking]. My whole family is like that. We are double-jointed!

In addition to presenting a first-person perspective, by referring to herself as 'you' she also takes a stance as a distanced, credible observer of her own and her family's experiences.

Today, Sarah cannot identify a particular time or event when her illness started. In her account, she connects heredity, bodily defects, trauma, hard work, and ignorance of the body together as causes of fibromyalgia. This insight makes her realize that she does not have a body that tolerates heavy work, and by outrunning her body's capacity for such a long time, it is understandable to her that she cannot tolerate much now and that "it will take time to rewind this". She has determined to take her life in a new direction and find out what is possible for her now, and take it from there. In recounting the last year, Sarah's storying incorporates several examples of concrete changes in her everyday activities and routines that she finds helpful. She does not stay in bed for most of the day anymore, but she has implemented a strict plan for balancing activities and resting during the day:

> I can't do many things. I have good days, and I usually get good days when I stick to my plan. So, for example, I'm at work training on Monday and Wednesday. Afterwards, I sleep. On Tuesday, I go to the grocery store in the morning, to protect myself from all the noise there in the afternoons, and then I do all the shopping we need for a week. Then, I can't take much more that day. On Thursday, I am together with the children in the scout club. When I'm out of energy, I go for a walk in the woods and shut everything else out. Listen to the birds – relaxing! I've started nature photography. Also, I have started to prepare food from scratch. Before we were very good at eating fast food. So easy! Now, we eat proper food. I've started to take pleasure in cooking. I notice that healthy food gives us [family] more energy.

Sarah's account echoes the 'voice of medicine' of restoring energy during a day by setting priorities in what must be done, discovering what gives her energy to do things, and eating energizing food. Moreover, Sarah talks much about work. In the first interview, she wanted to go back to her job as a shop manager for financial reasons. Now, part of her plan is to take her life in a new direction and look for a job where she can use her talents:

> A coach at a rehabilitation centre in the town concluded that I should apply for disability benefits. I've said all along, I don't want to go on like that for 20 or 30 years! I want to be out among people, work, and have a social life! All my friends work during the daytime. My plan is to find a job that I can stay in over time. Now, I'm knitting, trying out patterns and teaching others how to do it. I love teaching and to learn myself. It's kind of like that – what will work for me and what will not? I'm kind of an investigator.

In this account, Sarah strongly resists an identity of patienthood and unwillingness to overcome her disability. She continues by underscoring her resistance, saying "I've become tougher at speaking up for myself", creating a greater sense of autonomy in her life. In the former interview, Sarah worried about what illness meant for the future. Today, she is confident that she recovers from bad days if she "takes it easy for a few days" and that she can live well with fibromyalgia. Experiencing more good days is proof to her that she is right. To avoid overdoing things is challenging, though. One reason is that it is hard to know how much activity and exertion she can tolerate in a day, as it varies. Another reason is that on good days she easily forgets her illness and sees herself as "healthy again". Sarah says it is unlikely that her recovery has yet reached an end, but she doubts that she can ultimately rid herself of fibromyalgia. Sarah sums up by expressing a vision for her future:

> My future is probably not working in a store. I haven't finished high school, so I may have to undertake some education when my head is tuned in correctly. I haven't decided what I want to become when I grow up. Yes, I have sub-goals. You must learn to be patient. Yes, I have understood in the last year: you must prioritize a little more what gives energy and joy in everyday life – apart from working. I enjoyed working, but there was too much of it.

By saying "you must learn to be patient", and "you must prioritize", from an outsider position, she underscores her view that she has a long way to go. Today, Sarah thinks that her body is not equipped to do heavy physical work, and consequently, that her previous self as a hard-working woman brought illness upon her. Sarah's ascending story evolves from a resigned, bedridden woman, a collapsed daily life and broken self, into taking agency as an explorer creating new life purpose and a new direction for life. Thereby, she has turned her prior negative life experiences into a redemptive sense of self.

4. Discussion

The participants' storylines 'Resuming a prior life and a former self' and 'Taking life and the self in new direction' share a pattern of making sense of why they became ill and how their illness relates to daily life stress, by weaving perspectives of medicine and past and present life experiences together, enabling the participants to adjust or perform changes in daily life and create more well days. The first storyline illustrates that minor adjustments in daily life can be enough to make a substantial change, and the second storyline shows that several changes may need to be implemented over a long time. The meta-narrative in this study – making sense of past and present experiences by linking knowledge of fibromyalgia with experiences of one's life story to repair a disrupted daily life and restore a self – shows how participants exercise agency in adopting their own individualized strategies to manage their illness.

In light of Charmaz's (1991) theory of illness, the narratives presented portray a descending illness trajectory, starting with a disturbance of normal life that gradually disrupts daily activities in a way that cannot be ignored, as displayed in Christian's narrative, and for Sarah, it ends up with a life immersed in illness or 'governed by pain', as earlier demonstrated among others with fibromyalgia by McMahon, Murray, Sanderson, and Daiches (2012). A turning point for Christian occurred when illness was named, recognized and legitimized by physicians, as has previously found to be important (Arfuch et al., 2022; Sallinen et al., 2011). The role of legitimacy could also be less distinct, as exemplified by Sarah's narrative. Her storytelling dwelt mainly on the meaning of illness for her and how she created turning points related to new habits and routines in daily life. Cassell (2013) claims that beyond legitimizing the individual, it is also important for a person's illness management to provide an understanding of why he or she became ill, of what can be done about it, and of prospects for the future. Christian's and Sarah's narratives indicate that understanding the meaning of illness is urgent in at least two ways: to stop worrying, and to enable healing of a disrupted life and restoring a self to live well by.

Several self-management interventions seem to favour delivering a factual, generalized knowledge of disease mechanisms and the practise of symptom management techniques, on which HPs are the experts (Geraghty et al., 2021). How to translate this knowledge into an understanding that enables managing one's own lifeworld experiences is not obvious. Christian's and Sarah's meta-narrative suggests that for them it was important to create their own meaning of why they became ill and connect this meaning to the role of stress and illness in disrupting daily activities in their own life. This personal understanding enabled them to exercise agency in remaking a daily life that was possible for them. They frame their problems in a daily life context and find individual ways of managing their illness. In this way, one may say that Sarah and Christian are making their invisible illness more 'visible' and manageable for themselves and for their helpers. This finding raises the question as to whether the voice of medicine sometimes may reduce a patient to someone who should simply adhere to the regimens proposed by HPs. As illustrated by Christian and Sarah, self-managing may include taking care of oneself and life by realigning an individual's ruptures between body, present and past self with their social environment (Mishler, 2005). Becker (1997) argues that the disruption through illness of everyday routines severs the person's connection with his or her personal meanings and thereby leaves a void. Christian and Sarah's narratives illustrate how, in order to fill this void, 'people must redraw relationships between self, body, environment, and daily life' (Becker, 1997, p. 82).

Holstein and Gubrium (2000) claim that people need a narrative resource, i.e. meta-narrative, to individually design their personal self-managing. In a similar way, Murray (2015, p. 87) describes narrative as 'an everyday means of making sense of the disruption of illness'. The meta-narrative exemplified by Christian and Sarah implies more individual autonomy than is exemplified in adhering to self-management interventions tailored to healthy lifestyle and techniques for modifying typical diseases-related problems advocated by HPs. According to McAdams (2012), healthy lifestyle regimens are usually based on biomedical assumptions. In contrast, the strict plans followed by Sarah, and by other participants in our study, in an attempt to avoid overdoing things and manage their energy, are not imposed by HPs but result from the participants' own autonomous decisions regarding what they experience as being good or bad for them. By paying attention to daily routines and habits in terms of their own priorities, they discover what they want and can possibly do, try it out, and evaluate the outcome of their actions in a process of rebuilding a life they can inhabit. Christian's and Sarah's approaches reflect a meta-narrative pattern represented in the accounts of others who have recovered from fibromyalgia (Eik et al., 2022).

The self is formed and shaped by taking part in daily life, and the self can therefore be manifested in what people find important to tell, and the meaning an individual attaches to daily activities (Holstein & Gubrium, 2000). Our data show that when routines of daily life are disturbed or fractured, a prior self can be put on hold, or the process of creating a new self can be set in motion. In the case of Christian, the self is restored. He portrays an initial period of living with a suspended self. However, after finding out what his illness means and accommodating to it, he revives his previous life and his former self. In contrast, Sarah was bedbound by fibromyalgia, which fractured her sense of self as a hard-working woman. She is healing through self-discovery, whereby she changes her self-identity as a hard-working woman to that of a creative, talented explorer creating a better life and a new version of herself. Sarah adopts a redemptive process of renewing her sense of self. Although there were different ways in which the self underwent change among our participants, they had to varying extents turned from 'I cannot do' to 'I can, or can possibly, do', reflecting a regained agency in their life. This is in accord with a recent paper reporting that, among patients with medically unexplained illnesses, when GPs emphasized patients' telling life-stories, instead of conducting usual medical history-taking, this helped patients to make sense of symptoms and enabled them to reframe their problems, opening new possibilities of managing their illness and engaging in a process of biographical repair (Sanders et al., 2024). In addition, for Christian and Sarah the role of stress seemed to be a key to find solutions for adjusting or changing daily life situations.

A social life is of central importance for people, as was stated by both Christian and Sarah in this study. Sarah, for example, emphasized that, by staying out of work, she would lose a sense of social belonging. The strong emphasis on working life can also be considered a way to resist social stereotyping of people with fibromyalgia as lazy or workshy (Werner et al., 2004) or a stigmatizing cultural understanding of unwillingness among those who are ill to do what it takes to return to work (Oldfield et al., 2018). Thus, the participants' efforts to maintain or resume their working life may have a double meaning: both to fulfil their own desires to preserve a preferred self and to protect them from being devalued by others.

A core element within Christian's and Sarah's meta-narrative is the (re-)assertion of autonomy and the exercise of agency within the temporality of their life. This resonates with Emirbayer and Mische's (1998, p. 963) conceptualization of agency as a 'temporally embedded process of social engagement, informed by the past (in its habitual aspect), but also oriented toward the future (as a capacity to imagine alternative possibilities) and toward the present (as a capacity to contextualize past habits and future projects within the contingencies of the moment).' In the stories, the participants presented themselves as the main characters, with their own agency and resources. However, narratives are not created solely by the individual but draw on other resources within that person's life (Esin, 2011). Thus, the stories also included people with supporting roles, exemplified by Christian's sport mates and Sarah's scout club members, GP, and a coach in a vocational rehabilitation program. Nevertheless, Christian and Sarah seem empowered to decide their own way forward and to communicate and collaborate fruitfully with those supporting them. Christian tells how he has found a form of resolution. His narrative resembles what Frank (1995) calls a restitution narrative; he was sick, a resolution was successful, and he resumed his usual life, although at a slower tempo than before and by adapting his plans for daily life according to his varying health situation. Like Sarah's, most stories among our participants exemplify a quest narrative (Frank, 1995), where the main actor engages in trying out new routes and possible destinations in an unfamiliar terrain disrupted by fibromyalgia.

In our study, the future mostly concerns flares interwoven with hope that the illness will become better. All stories include setbacks in the attempt to 'organize the disorganized and give it meaning' (Murray, 2015, p. 88), although participants do not always detail them. Instead, like Christian and Sarah, they tell of the importance of having more good days than before and trying to learn from bad days what is their "maximum tolerance limit" of daily exertion. According to Charmaz (1991), good days mean minimal intrusion from illness, and the former life is in the foreground, as illustrated by Christian and partly by Sarah. In contrast, Charmaz describes bad days as being immersed in illness, where it cannot be ignored, and usual life shrinks or fades into the background, pushing patients to direct their attention to getting better. The shifts between good and bad days may make the individual oscillate between a sick self or suspended self on bad days and a preferred or former self on good days. Hence, illness fluctuations produce an uncertain self-identity, as illuminated also by men with fibromyalgia, suggesting that it can be unclear what kind of man it is possible to be (Sallinen et al., 2019).

Mattingly (2010) argues that hope is not something that is just there, like a feeling; rather, hope is lived and enacted. An increased number of good days nurtures hope for further improvement and is thereby an important driver of continuing personal recovery work and projecting oneself into a meaningful future. But if there are too many setbacks, there is a risk that hope fades and the envisioned future shrinks to a lost dream. Christian and Sarah, however, seem confident that they are on the right track. They are realistic in anticipating that upheavals in their illness will occur, but they also anticipate that their tolerance level will become clearer to them during their further move forwards.

In narrative methodology, the value of people's stories does not depend on whether a story is a true retelling of what has happened. Frank (2012) argues that people's stories report their reality as they need to tell it and in terms of what listeners are willing to listen to: in this case, to an academic interested in illness and recovery stories. Trustworthiness would be threatened if the participants were to tell stories they assumed the interviewer wanted to hear; for example, in centring their storytelling around the self-management intervention. The interviewer attempted to avoid this by asking the participants to tell a story about the illness trajectory from its onset until today. The participants did not talk much about their participation in the intervention but responded by storying how they had created meaning in illness by connecting the voice of medicine with their life-stories, and they described concrete, temporally connected actions to reorganize daily life. Another problematic issue would be if the researchers produced and interpreted data material based on the conclusions they desired. Accordingly, the data were scrutinized for counter-narratives, and the analysis is critically reviewed with help of various theories and perspectives among the authors. We argue that our participants' narratives provide novel insights into the phenomenon of self-managing as an individualized, autonomous process of adjusting or changing daily life, and that these insights may be transferable beyond this specific context and to other chronic illnesses than fibromyalgia.

5. Conclusion

This study shows a meta-narrative of self-managing as an individualized, autonomous process nested in a person's everyday social context and life-story. Such a self-management process encompasses an individual's engagement, agency, and autonomy in developing a coherence between past, present and future lifeworld experiences and remaking daily life and reconstructing a sense of self. The participants' actions created more good days, and their success in doing so creates hope for further progression. But the road ahead is challenged by illness fluctuations and unclear tolerance limits for the demands and burdens of daily life. Thus, the recovery work is not finalized, but continues in terms of preventing illness fluctuations, optimizing daily life, and maintaining a self.

CRediT authorship contribution statement

Anne Marit Mengshoel: Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Merja Sallinen:** Writing – review & editing, Validation, Supervision, Methodology, Formal analysis, Data curation, Conceptualization. **Julius Sim:** Writing – review & editing, Validation, Supervision, Methodology, Formal analysis, Data curation. **Birgitte Ahlsen:** Writing – review & editing, Validation, Supervision, Methodology, Formal analysis.

Research data deposit

The data cannot be shared in public because protection of the informants' anonymity and confidentiality of personal data.

Ethical statement

The Norwegian Social Science Data Services approved the research project (no. 2018/57956/3/EPA). Before the interviews, the participants received written and oral information about the project and their right to withdraw from the study without risking any negative consequences for further services at the hospital. The participants were assured of anonymity, and data were stored on the University's secure research server. The study applies to the Helsinki Declaration Ethical Acts of Medical Research.

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Declaration of competing interest

The authors have no relevant financial or non-financial interests to disclose.

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