

A suffering body, hidden away from others: The experience of being long-term bedridden with severe myalgic encephalomyelitis/chronic fatigue syndrome in childhood and adolescence

Silje Helen Krabbe^{1,2}  | Wenche Schrøder Bjorbækmo¹ | Anne Marit Mengshoel³ | Unni Sveen^{4,5} | Karen Synne Groven^{1,6}

¹Department of Physiotherapy, Faculty of Health Sciences, Oslo Metropolitan University, Oslo, Norway

²Children's Surgical Department, Division of Head, Neck and Reconstructive Surgery, Oslo University Hospital, Oslo, Norway

³Department for Interdisciplinary Health Sciences, Faculty of Medicine, University of Oslo, Oslo, Norway

⁴Department of Occupational Therapy, Prosthetics and Orthotics, Faculty of Health Sciences, Oslo Metropolitan University, Oslo, Norway

⁵Department of Physical Medicine & Rehabilitation, Oslo University Hospital, Oslo, Norway

⁶Faculty of Health Studies, VID Specialized University, Sandes, Norway

Correspondence

Silje Helen Krabbe, Department of Physiotherapy, Faculty of Health Sciences, Oslo Metropolitan University, Pilestredet 50, Oslo 0167, Norway.

Email: siljehel@oslomet.no

Funding information

Norwegian extrafoundation for Health and Rehabilitation

Abstract

In this article, we present findings from a qualitative study examining how young women experience being long-term bedridden with myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), during childhood and adolescence. The aim is to explore how young women who fell ill with ME/CFS during childhood and adolescence look back on their lived experience of being long-term bedridden from the vantage point of being fully or partially recovered. Informed by a phenomenological theoretical perspective, the researchers applied a narrative methodological approach involving the analysis of interviews with 13 women, aged 16–29 years at the time of the interview. Attention was particularly paid to how participants structured their narratives and to the events (telling moments) they identified as important. Four major storylines were developed: *Ambivalent responses to the presence of others*; *A body on the edge of life*; *An eternity in the dark*; and *Recasting painful memories of being bedridden and alone*. Based on our findings, we argue that the experience of being long-term bedridden with ME/CFS during childhood and adolescence can be understood and communicated as a plot in which individuals find themselves pushed to the extreme limit of suffering and loneliness.

KEYWORDS

adolescence, children, chronic fatigue syndrome, myalgic encephalomyelitis, narrative, phenomenology, severe illness, women

1 | INTRODUCTION

In this article, we present findings from a qualitative study examining how young women experience being long-term bedridden with severe myalgic encephalomyelitis (ME), also known as chronic fatigue

syndrome (CFS), during childhood and adolescence. The study is part of a larger qualitative research project exploring 13 young girls' and female adolescents' experiences of falling ill with (Krabbe et al., 2022) and being in recovery from severe ME/CFS (Krabbe et al., 2023). Participants shared their unique personal experiences of this

This is an open access article under the terms of the [Creative Commons Attribution](https://creativecommons.org/licenses/by/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2024 The Authors. *Nursing Inquiry* published by John Wiley & Sons Ltd.

disabling and complex illness characterized by profound fatigue, malaise, unrefreshing sleep, sensory sensitivities, gastrointestinal symptoms, orthostatic intolerance, and cognitive impairment (Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue, Syndrome, Board on the Health of Select Populations, & Institute of Medicine, 2015). As previous research has revealed, some individuals with ME/CFS eventually become so ill that they remain bedridden for long periods of time, housebound, and unable to carry out most activities (Rowe et al., 2017). Paradoxically, during this critical life situation, patients in desperate need of medical care often struggle to find and receive appropriate help (Baxter et al., 2021; Webb et al., 2011).

While the prevalence of ME/CFS among children and adolescents has been estimated at 0.1%–0.89% (Estévez-López et al., 2020; Lim et al., 2020), there is less clarity regarding the number of children and adolescents who become severely ill. However, clinicians have suggested that between 2% and 5% of children and adolescents living with CFS/ME eventually become so ill that they remain bedridden for months or years (Rowe et al., 2017). In the medical literature, these young people are described as a group of patients with the most critical degree of ME/CFS: a level of illness whose course is uncertain and which may last for years, despite the fact that children and adolescents generally are considered to have a better prognosis for recovery than adults (Moore et al., 2021; Rowe et al., 2017).

The process of falling severely ill with ME/CFS during childhood and adolescence has been described as a traumatic struggle to manage inexplicable bodily changes. Patients experience a sense of being separated from their body, the disruption of social relationships, and, in some cases, long periods of being confined to bed (Krabbe et al., 2022). Adolescent patients have described their sense of vulnerability and acute disconnection, whether from their own body or from their wider social world. They have spoken of the torment of not being able to make choices and of what it is like to be totally dependent on their families (Njølstad et al., 2018; Parslow et al., 2017; Williams-Wilson, 2009). To the best of our knowledge, however, no empirical research has as yet explored the experiences of young individuals forced to spend months or years in bed as a result of ME/CFS.

Insights into the existential dimensions of barely being alive and losing one's sense of self in the illness (Dafoe, 2021) have come from first-hand accounts, some of them shared on social media and in most cases involving adult patients. When the stories of young people suffering from severe forms of ME/CFS enter the public sphere, they tend to be related by parents or caregivers and sometimes by the patients themselves (Brea, 2017; Prior & Castillo, 2015; Schaathun, 2020).

In this study, we seek to address this gap in the scientific literature by exploring the lived experiences of young women patients with ME/CFS who were bedridden for extensive periods during their childhood and adolescence but are now in significant recovery or fully recovered. More precisely, we explore the lived, embodied experience of being bedridden for months or years in a darkened room and how this state relates to lived time, lived space, lived relations, and the lived body. Our use of the phrase “being

bedridden with ME/CFS” therefore carries the connotation of a long-term state of being housebound and confined to bed. We address the following question: *What and how do young women tell about being bedridden with ME/CFS during childhood and adolescence?*

2 | THEORETICAL FRAMEWORK

This qualitative study is informed by the phenomenological theoretical perspective of the French phenomenologist Merleau-Ponty (1962) and his understanding the body as our basic source of all our experiences and understanding of the world. Building on Merleau-Ponty's (1962) insights, van Manen (2016) suggests that the fundamental structure of the lifeworld comprises four universal themes or existentials: *lived body, lived relations, lived space, and lived time* (van Manen, 2016). These four elements form a unity, always interacting and co-existing with each other, and we consider them relevant for a qualitative investigation of the experience of being bedridden.

Merleau-Ponty argues that the *body* is our basic source of experience and perception: “The body is the vehicle of being in the world, and having a body is, for a living creature, to be involved in a definite environment, to identify oneself with certain projects and be continually committed to them” (Merleau-Ponty, 1962, p. 82). We exist as bodily situated beings, embedded in the world and conscious of it through the medium of our body. The lived body is not the body as it appears to others; rather, it is the body as it is lived: inseparable from us, endlessly interpretative and sensitive.

We experience ourselves in relation to others and through others; we are social and relational beings. Merleau-Ponty described the body's double positioning in the following way:

There are two views of me and my body: the body for me and the body for others (...). It is indeed not enough to say that the objective body belongs to the realm of “for others,” and that my phenomenological body to that of “for me,” and we cannot refuse to pose the problem of their relations, since the “for me” and the “for others” co-exist in one and the same world, as proven by my perception of an other who immediately brings me back to the condition of an object for him. (Merleau-Ponty, 1962, p. 106)

According to this notion, we are in a double position of both seeing and being seen, touching and being touched; we are both subjects and objects to ourselves. While individuals who are bedridden with severe ME/CFS are the only ones to experience their illness from within, others can observe their objective bodies and respond by, for example, taking a blood sample or checking that a nasogastric tube is in the right position.

In the absence of illness, our lived body is not usually the focus of our attention as we engage with everyday life (Leder, 1990). But

when something happens to the body, our attention shifts in its direction (Leder, 1990).

The term *lived relations*, or relationality, refers to the relations we maintain with others. From a phenomenological perspective, our experience of our body is a social as well as an individual phenomenon. We are social and relational beings, situated in a specific time, place, and cultural context and always intersubjectively engaged in the world we inhabit (Heidegger, 1953/2010). In illness, our lived relations can change profoundly; for example, we may become dependent on the support of others or may find ourselves unable to maintain our customary social relationships.

Lived space refers to the spatiality of the situation, to felt space rather than a physical place: "To be a body, is to be tied to a certain world, as we have seen; our body is not primarily in space, it is of it" (Merleau-Ponty, 1962, p. 148). This space is preverbal and prereflexive and as such is not something we reflect upon. The experience of lived space can change profoundly in illness, which may curtail our ability to act upon the world and force us to make changes in the way we live: for example, having to stay in bed for weeks or months.

Lived time is the subjective experience of time as opposed to clock time. For Merleau-Ponty, time exists for us only because we are situated in it and become aware of ourselves as already committed to it: "I am not in space and time, nor do I conceive space and time; I belong to them, my body combines with them and includes them" (Merleau-Ponty, 1962, p. 140). During illness, we may experience lived time differently: as moving slowly, for instance, when we struggle with something and passing quickly when we enjoy time with friends.

Another core concept for an understanding of illness is *bodily intentionality* (Merleau-Ponty, 1962). When we see, think, hear, or act during our everyday lives, these actions are always directed toward something; they are intentional. Merleau-Ponty (1962) observes how our body and our bodily movements are always directed toward something in our environment and have specific goals. Bodily intentionality makes us become aware of different bodily movements and enables us to make sense of them, thereby unifying them into meaningful action (Merleau-Ponty, 1962). In everyday life, then, the body is all about spontaneity, possibilities, and freedom of action. But if our situation radically changes (e.g., if we find ourselves experiencing extreme fatigue), our spontaneity for action changes.

To explore young women's lived experiences of being long-term bedridden with ME/CFS, we opted for a narrative methodological approach. According to narrative theory, storytelling is our fundamental way of making meaning out of our experiences (Mattingly, 1998; Polkinghorne, 1988). Narrating a story is a meaning-making process where events are linked together in a temporal way to create a coherent whole, as well as create meaning by connecting experiences from the past with current events and with expectations for the future (Mattingly & Garro, 1994). Moreover, it helps to structure our experiences in the form of stories (Mattingly, 1998).

In our research, our analytical focus was on the way in which participants, speaking from the vantage point of the present, look back at the time when they had been bedridden. How did they narrate and make sense of what had happened to them? More

specifically, what events or moments did they find particularly relevant to their experience of being bedridden? We understand such events as significant moments (or telling moments), ones which participants highlighted as they sought to make sense of what had happened to them in the past (Mattingly, 1998). We were interested in how participants perceived interconnections between these events and the role they played in meaning making.

Phenomenology allows for an in-depth understanding of the meaning of being long-term bedridden with severe ME/CFS. By combining phenomenology with narrative analysis, we can access not only the content of the experiences but also the ways in which we can interpret and give meaning to those experiences through storytelling.

3 | METHODS

3.1 | Recruitment and participants

To be included in this study, participants had to meet the following criteria: to be women, aged 16–30 years, and who had been ill with ME/CFS for more than a year but now considered themselves to be in recovery or fully recovered. Women were chosen because of the higher incidence of ME/CFS among females. Participants had to verify that they had received their diagnosis of ME/CFS from a physician, as we did not have any access to their medical records. There were no limitations in maximum years since the participants had been bedridden. Given the narrative approach of this study, participants were required to be able to speak Norwegian fluently.

Recruitment was conducted by the first author, who placed advertisements on two websites concerned with health care for women and women's social rights. Potential participants were asked to contact the first author directly by e-mail or phone. Candidates who met the criteria received a detailed information letter about the study and a consent form.

Altogether, 17 women made contact, of whom 13 were selected as participants (two candidates had not been diagnosed by a physician, one was too old to participate, and one dropped out). Participants were aged between 16 and 29 years and had been bedridden from ME/CFS from 2 to 10 years. They lived in different parts of Norway, in both rural and urban settings. At the time of being interviewed, all were in full-time or part-time education or employment. Six of the women were married or lived with a partner, and one participant had a child. The participants were informed that they would be interviewed by the first author, a female pediatric nurse with long experience of working with children and adolescents. The first author was not known to any of the participants before the interviews.

3.2 | Narrative interviews

The first author conducted individual narrative interviews between May and September 2019. Interviews took place at participants' homes or in a room reserved for private conversations at a university/local library

near the participant's home. Each interview lasted from 60 to 150 min and was digitally audiorecorded. Recordings were transcribed verbatim by the first author shortly after each interview.

The aim of the interview process was to generate data by helping participants tell their story as freely as possible (Riessman, 2008). In narrative interviewing, the goal is to generate detailed accounts rather than short answers or statements (Riessman, 2008), making it important for the interviewer to create an atmosphere that encourages storytelling. Participants in our research were invited to freely tell their stories in their own words, with little interruption from the interviewer. To start things off, the first author asked overarching questions such as "Can you tell me about the time before and when you became bedridden?" and "What was it like to be bedridden?" The participants often jumped back and forth in time, and their stories could undergo a sudden shift as they remembered events or episodes that now struck them as significant.

3.3 | Analysis

Analysis of the interview data was done by the first author in close collaboration with her four co-authors. Our narrative analysis was inspired by Riessman's (2008) thematic analysis and also her structural analysis, which draws on the work of Labov and Waletzky (1966/2003). We viewed this combined analysis as particularly suited to our efforts to capture key events and moments, as narrated by participants, and also to analyze first how each individual's storytelling was organized and sequenced to understand the range of meanings associated with being long-term bedridden and, thereafter, to examine the meanings across the individuals' stories.

All the audio recordings were listened to several times and transcripts were read repeatedly so that we could gain an overall impression of their content. On this basis, it became clear to us that the stories' contents revealed a strong focus on the bodily experience of being bedridden.

For our narrative thematic analysis, we focused on one interview at a time and posed the following question: What kind of events or telling moments appear central to the experience of being bedridden? On this basis, we identified and analyzed sequences of events in participants' stories which appeared of particular relevance within each individual's story to the experience/phenomenon of being bedridden.

The excerpts were coded, analyzed for temporal coherence, and sorted into analytic themes, that is, narrative storylines. During this process, attention was directed toward what was said in the individual interviews and which events were interrelated and thereby formed a storyline. Then, an analysis across interviews was performed to look for similarities in storylines and identify any possible counter-narratives (Riessman, 2008). In line with Riessman's (2008) structural analysis, we directed our attention to how each story was structured, in particular how telling moments were put together to make a connected and coherent whole. For Riessman, a fully formed narrative contains six elements: an abstract, an

orientation, a complicating action (the event sequence, plot, or turning point), a resolution (outcome of plot), an evaluation, and a coda (ending the story and bringing action back to the present) (Riessman, 2008). In addition, we looked for similarities and contrasts in participants' stories, all of which included information about their experience of body, time, space, and lived relations.

During this process, codes and potential themes were collectively discussed several times by the co-researchers. We gradually came to the realization that our findings could be understood with the help of the four existentials presented by van Manen (2016). We made use of these to understand what the storylines, events, and moments narrated by participants were about.

3.4 | Ethical considerations

The study was approved by the Norwegian Regional Committee for Medical and Health Research Ethics (2017/2451), Social Science Data Service (477809), and was conducted in accordance with the Helsinki Declaration Act and Health Research Act of Norway. The Service for Sensitive Data was used as required for collecting and storing sensitive data. Only the first and the last author (K. S. G.) had access to the interviews and the transcribed material; the three other authors had access only to the anonymized transcriptions.

Participants were informed they could withdraw from the study at any time. All signed written informed consent forms before each interview. To maintain anonymity, all names, locations, and disclosing events have been changed or omitted in the text.

Sharing stories about prior experiences of illness was not easy for the participants. It could be traumatic to go back and recall what it was like to be long-term bedridden. For some participants, their memories of that period had become blurred. During interviews, participants were encouraged to take breaks or change the subject if they experienced discomfort and/or anxiety. The first author paid careful attention to how participants responded emotionally while being interviewed, watching out to see whether the process was becoming overly burdensome and/or emotionally taxing for them. Participants received follow-up telephone calls from the first author after being interviewed and were also encouraged to contact her should the need arise. Overall, however, participants seemed to regard telling their stories as a positive experience. Some had never before shared their stories, except with family and very close friends.

4 | FINDINGS

In line with the narrative tradition (Riessman, 2008), we present our results in the form of four storylines, which we regard as illustrating some key features of the accounts given by the 13 women in this study. In our presentation, we focus on the narratives of four particular women—Amalie, Sara, Cecilia, and Fiona (all pseudonyms)—so as to highlight details of their experiences and shed light on what they said and how they structured their stories.

Three of our 13 participants had fallen ill during late childhood (10–12 years), nine in early adolescence (12–16 years), and one in late adolescence (19 years). Participants described experiencing only moderate symptoms when they first became ill during childhood or adolescence. Gradually, however, their symptoms became worse (Krabbe et al., 2022). The length of time participants were bedridden ranged from 1 to 9 years. While some spent much of the day in bed, housebound, and unable to carry out most activities, others alternated between periods of being bedridden and times when they could briefly engage in activities—for example, watching a movie or spending time with friends.

Participants who were completely bedbound had to depend on help from family or home-based carers to fulfill their most basic needs. Most participants struggled to eat sufficiently because of nausea, lack of appetite, and profound fatigue. Two women (Amalie and Sara) had received a nasogastric tube for nutrition, while others lost a lot of weight during their illness. A few participants told of being admitted to hospital because of their eating problems and critical fatigue; unfortunately, their condition seemed to worsen as a result of their hospital stay. All participants told of how profoundly disabling it was to be long-term bedridden. As all of them were sensitive to light and sound, being bedridden meant always being in the dark, with minimal noise.

For most of the participants, it was emotionally difficult to go back in time, recount past experiences, and reflect upon their lives as bedridden individuals. It was often difficult for them to find the right word to describe what they had been through.

We include excerpts from interview transcripts in which participants provided particularly rich and illuminating descriptions of their experience of being bedridden and/or shared key events and telling moments. In the excerpts (set in italics), the symbol [...] signifies that two identified sequences were found to be related, while three dots ... indicate a pause in the narrative.

4.1 | Storyline 1: Ambivalent responses to the presence of others

Bedridden and unable to perform basic tasks, participants had to be taken care of by others. But because of their sensitivity to light and sound, the presence of others could create difficulties and provoke ambivalent reactions.

Amalie fell ill with ME/CFS during adolescence. After a few years' struggling with exhaustion and pain, she became bedridden and did not leave her bed for nearly 3 years. Here, she describes how difficult this situation was for her:

My mum took care of me during those years and after some time nurses from home-based care helped us, they were the only ones entering the room. They changed my diaper and connected my nutrition to the nasogastric tube. We communicated by nodding and whispering, it was the only thing I was capable of [...] I

felt isolated and even if I wanted to, I couldn't manage contact. I saw my brother only once or twice during those years... I did not actually see anything, it was dark, but I knew he was there at the end of the bed. I remember the suffering I felt in his presence, the sound of him in my room.

In her retrospective account of her experience of being taken care of by others, Amalie highlights the restricted nature of this social contact, much of which was directed toward helping her fulfill her primary needs. Amalie recalls how this limited contact was all she was capable of. A conversation demanding long answers or explanations was beyond her capabilities; she could handle only simple communication requiring a yes or no answer. Those entering Amalie's darkened room were restricted to her mother and a few professionals.

The complicating event in her storyline is the arrival of her brother on a visit. The consequence is that Amalie experiences the presence of her brother, even the sound of her brother, as immensely painful. Because she is already suffering, she has to be protected from such contact. To prevent her from suffering more than she already does, her brother is barely let into her room.

Looking back on this event, Amalie recalls that she wanted to have contact with others but was unable to do so, beyond matters relating to her day-to-day existence. The only contact she could manage was the type which did not demand a personal or emotional response from her. The encounter with her brother, however, was something completely different. It turned out to be a kind of contact she found very hard. The presence of her brother and the relationship between them demanded something different from her: an emotional and relational response.

The arrival of her brother sends Amalie into emotional turmoil. His presence seems to remind her of all the things she can no longer do, the life she can no longer participate in. She realizes she is no longer able to be the sister she once was. It is the kind of feeling one cannot distance oneself from and it tears her up inside: a kind of existential suffering. She is isolated, separated from those she wants to be with, and unable to live the life she used to live. She experiences loss in so many ways that her emotional state becomes existentially unbearable. Amalie's only way to survive this suffering is to avoid it by distancing herself from her brother.

4.2 | Storyline 2: A body on the edge of life

Despite the severity of their illness, participants could experience changes while being bedridden; their discomfort could change in intensity, or a new form of bodily discomfort could emerge.

Sara provides a flavor of this in her story of an event that occurred while she was ill for an extended period of time. Sara fell ill during adolescence, and in her account, she describes how she spent years in darkness, without any sign of getting better. She is fed through a nasogastric tube, is at all times very sensitive to sounds and

light, and never leaves her bed. Then a change occurs—a dramatic turning point. This is when, already severely ill, Sara experiences a turn for the worse:

I had been ill for nearly two years when it happened. It was New Year's Eve and there were fireworks, the sound of them... it was just such terrible suffering. We had to move me from my dark room to another room with soundproof windows. Just being carried into another room... during the fireworks was a tremendous burden for me. I felt seasick and it just got worse [...] I had my nasogastric tube for feeding, and entered a long period of extreme nausea... I could not tolerate the nutrition. I was barely alive [...] I really don't understand how I survived it.

Sara begins by giving an overall picture of the situation and the sudden change she experiences. The complicating action in her narrative is that this sudden explosion of sound triggers a very strong, indeed painful reaction on her part, prompting those caring for her to move her to another room. Although this transfer is meant to ease her suffering, the opposite occurs: her suffering intensifies, she cannot tolerate any intake of food (even via her nasogastric tube), and she enters a state of being (in her own words) “barely alive.” From the perspective of the present (the coda of her narrative), Sara questions how she survived being this ill.

For Sara, the shift from one room to another—done with the best of intentions—intensifies her suffering. Despite her best efforts to cope, she finds her experience of her lived body and lived space profoundly affected by the move. Her lived space turns into something she cannot control or orientate herself in; she now feels herself to be on “shaky ground.” As if protesting, her vulnerable body reacts strongly to this unstable ground and increasing level of suffering by refusing to take in food. The body has changed so dramatically that Sara feels herself on the edge and close to dying. Her state of being is one of existing between something, a sort of liminality between life and death.

As Sara describes this experience, it is hard for her to find words that are not associated with death. She emphasizes how she felt barely being alive and how, in retrospect, she cannot understand how she survived this suffering. Thoughts of death seem impossible to avoid.

4.3 | Storyline 3: An eternity in the dark

When bedridden, participants were very sensitive to both light and sound and as a result had to spend most of their time in a darkened room, alone. Cecilia provided a particularly vivid account of this experience. Cecilia fell ill with mononucleosis during adolescence, and her condition had worsened. While there were times when she could move about, there were also periods

when she was completely bedridden. While bedridden, Cecilia found that her bodily discomfort could vary in intensity:

It was not the same all the time. I had periods that were very hard on me, and I was barely hanging on. I was sensitive to light... yeah, you probably heard the same thing from others, but the pain was the worst thing about it: my body got so tense, it was just too much. Even my jaw hurt intensely, and my shoulders were like this [demonstrates by tensing and raising her shoulders]. I couldn't sleep with all the pain. I just lay there, you know, and I could not do anything, I did not think much. For ages I just lay there in a darkened room and existed [...] It just made me, I don't know, like really weak. If I needed to drink, they would help me and lift my head.

As she retrospectively elaborates on how she experienced living with intense suffering, Cecilia recalls that this was not an unchanging experience but one with some dynamic element to it. The complicating action in her narrative is when her lived situation becomes unbearable. Experiencing intense pain, she is unable to sleep. Her pain-ridden body not only occupies the forefront of her attention, it seems to be all consuming and the only thing she is able to notice. The pain takes all her attention; there is no escape from it, no possibility of distraction. She must simply remain bedridden in her darkened room, avoid thinking too much and simply survive, without knowing when or whether she will get better. Perhaps that day will never come.

Looking back at this experience from the vantage point of the present, Cecilia describes how lying there in the dark for such a long term was exhausting and made her feel “really weak.” She needed the support of others even to drink—and to survive.

Living this painful and helpless existence in a darkened room for extended periods of time can be understood as an existential experience: that of living a nightmare. The nightmare is one of bodily suffering, helplessness, powerlessness, and leading an almost hidden existence in the dark. In Cecilia's narrative, darkness not only shields her from light; it is also an existential darkness where body, time, space, and life are more or less out of play. Cecilia herself is out of play, hidden away in the darkness. Time passes by very slowly, almost as if it were eternal time. Cecilia's experience of lived space, too, resembles an eternal darkness.

4.4 | Storyline 4: Recasting painful memories of being bedridden and alone

Participants also had to contend with emotional difficulties. Loneliness was a particular problem, given their inability to cope with the presence of others.

Fiona fell ill during late childhood and was ill for more than 7 years. The first 3 years she was able to move around and talk to others, but then, she became bedridden and almost totally isolated.

In her account, Fiona told of how her memories of being isolated and lonely still had the capacity to scare her and described how she dealt with these very vivid recollections in the present day:

I do get scared from time to time because I remember being ill so clearly. You know, all those years in a darkened room, I find it very strange it was me. But if I close my eyes, I can remember it as if I were still there. If I imagine myself lying there, I can touch something, like a physical thing, to bring myself back where I am. Sometimes I visualize myself going over to the bed where I'm lying. I comfort that other "me" so that neither of us are alone; we can kind of mourn together. You see, I was dealing with all these thoughts alone and I was not able to talk to anyone. It was very lonely indeed.

Fiona begins by emphasizing her clear memory of being ill and long-term bedridden. She now finds it strange that it was her lying in that bed. The complicating action is the way this memory still deeply affects Fiona even today: it retains the power to scare her.

Fiona tells of how, when she was ill, she had to struggle with her heavy thoughts all by herself, despite longing to be near those she loved. This absence of others deeply affected her experience of being ill. From Fiona's perspective, others did not understand or even notice how alone she felt. The consequence in this storyline is that Fiona tries to help herself by picturing the young, lonely Fiona lying in bed. She then imagines the present-day Fiona—older and fully recovered—going over to the bed to offer the girl comfort and company. The coda revolves around creating a new memory where Fiona does not mourn alone.

The experience of illness—a strange and frightening time—continues to exert a strong influence on Fiona's life. She finds it difficult to relate to this strange past and make meaning out of it. It is as if it were someone else lying on that bed. The most difficult memory, for Fiona, is the loneliness she suffered and the inability of others to grasp this. The act of visiting oneself in the past can be understood as Fiona's way of helping herself heal today—her present self—by providing herself with what she needed when she was ill. By visiting herself in the past, she creates a memory of being bedridden. In this newly constructed memory, Fiona is not alone: she receives emotional support and can share her thoughts with another. Through this joint mourning, she creates a form of belongingness.

It is human to want to share. We need to share what happens to us. Sharing our emotions and experiences with others can help us to make meaning out of what we have been through.

5 | DISCUSSION

On the basis of our findings, we argue that the experience of being long-term bedridden with ME/CFS can be understood and communicated as a plot, to which we have given the title "A suffering body, hidden away from others." This narrative draws on and incorporates four storylines: *Ambivalent reactions to the presence of others; a body on the edge of life; an eternity in the dark; and recasting painful memories of being bedridden and alone.*

In this discussion, we elaborate on our understanding of this shared narrative plot and the four storylines. In line with our narrative framework, the basis of each storyline is a telling moment experienced by a participant. The storyline is then structured according to *how* and *what* the participant told about the experience (Labov & Waletzky, 1966/2003; Mattingly, 1998; Riessman, 2008). While the storylines are shared by the women, the events and moments varied.

Based on our findings, we argue that the storylines incorporate key insights into van Manen's (2016) "four existentials": lived body, lived time, lived space, and lived relations. The narratives reveal the complex ways in which the four existentials intertwine and impact one another during a time of suffering in a dark room. For example, in the first and second storylines, the focus is on the interconnection of lived body, lived space, and lived relations; the third storyline illuminates the linkages between lived body, lived time, and space; and the final narrative sheds light on the interplay between lived body, lived time, and lived relations.

The first storyline, based on Amalie's recollected experiences, highlights the ambivalence that surrounds social contact while being long-term bedridden. While Amalie yearned for such contact, an emotional encounter with her brother actually increased her burden of suffering. As social and relational beings, we live in the double position of both seeing and being seen and touching and being touched; we are both subjects and objects to ourselves (Merleau-Ponty, 1962). This insight helps us understand the ambivalence Amalie experienced. When others entered her room to carry out routine body-related actions (such as replacing the bottle attached to her nasogastric tube), for Amalie, this contact was purely practical and related to her physical body (vital relationship). In this situation, her reaction was possibly one of objectifying her body and distancing herself from what was being done to it. In contrast, the presence of her brother evoked a relational focus and a strong personal connection (emotional relationship). In this emotionally charged situation, it was impossible for Amalie to objectify her body or distance herself.

When involved in relations that are purely practical, individuals manage to change perspective and objectify the body; this can be understood as "the body for others." However, in emotional relationships, the body is experienced as subjective; it can be understood as "the body for me." It is as if the emotional connection becomes too intense to handle and impossible to distance oneself from. The upshot is that suffering increases. The only way to endure these emotional relations while bedridden seems to be to avoid them,

even if this means feeling lonely. For Amalie, this continual distancing from loved ones seems to have been a very lonely process and one which left lasting scars.

The second storyline, *A body on the edge of life*, illustrates the way in which the fragile suffering body can respond to changes in the surroundings. In Sara's narrative, the body in pain is very much at the forefront of attention, in contrast to a healthy silent body keeping itself in the background and almost disappearing from our self-awareness (Leder, 1990). In this situation, attempting to escape by focusing outward or otherwise distracting oneself is futile; the degree of suffering being experienced is so overwhelming it cannot be ignored. This suffering is a constant reminder of the "here and now" body, in which "present pain is everything, it has swallowed up the world" (Leder, 2016, p. 449).

A suffering body is sensitive to changes in the surroundings. When Sara's lived space is turned into something in which she cannot orientate herself, she ends up losing control. She feels "seasick"—a combination of nausea and dizziness which continues long after the shift to another room.

No matter how hard participants sought to reconstruct their spatiality, their efforts were accompanied by a sense of "free falling" or losing control of their being, almost as if someone else had taken that over. Reflecting on chronic pain, Leder (2016), p. 453 comments: "This body will not just torture me, it will kill me." This suggests a kind of duality between "me" and "my body," reflecting how severe illness involves not merely symptoms but also the lurking presence of death, with its capacity to disrupt the experience of the future (Leder, 2016). Individuals caught up in extreme suffering may experience changes in their perception of lived time so that the present and the future become difficult to imagine.

According to Heidegger (1953/2010), we live our lives in relation to the future; our activity is directed to our desired goals. But when we find ourselves long-term bedridden, struggling with suffering that has no end in sight, the uncertainty of our lives becomes existentially difficult to live with. To be bedridden is to live on the cliff edge of suffering, to exist in the liminality between life and death. Even so, the body is still active, still doing something. In Sara's case, her body's protest against taking in food may signify that change is on its way. Perhaps there is still hope that things can improve, as the protest indicates that the body has not yet given up.

The storyline, *An eternity in the dark*, describes what happens in the wake of an act of care intended to protect the bedbound patient. After removing all stimuli and making the surroundings safe in every possible way, what happens then? Spending an eternity in the darkness, hidden away from life, in no way seems to heal the body. Although the bedridden body seems to be on a mission to rest and sleep, endless isolation in the dark only seems to make it weaker as time passes. A change in the situation—a sudden intensification of pain—results in a comprehensive change in embodied experience and existence. Lived time and space is perceived in a different way than before. Time and space only exist for us because we are situated in them (Merleau-Ponty, 1962); they exist for us only as lived. When we live in an eternity of darkness, shielded from all stimuli, our world is

somehow pressed inward. Our space becomes narrowed down; it is emptied of the possibilities that used to be there. While life outside the darkness continues, we are barely part of it. Time seems to move slowly. Life becomes a matter of just lying there in the dark, waiting and not knowing what will happen next.

For humans, darkness is normally associated with going to sleep in the evening. Perhaps it is the sense of sameness being experienced—same being, same darkness, same time, and same suffering—that invites the term "eternity." Whatever the case, the narrative reveals how body, time, and space intermingle, affecting lifeworld in an existentially difficult way.

Finally, the storyline "Recasting painful memories of being bedridden and alone" sheds light on the phenomenon of visiting oneself in the past in an effort to help oneself in the present. It also has a bearing on making meaning of past experiences, of making a coherent self. As the narrative reveals, it can be difficult to understand and make meaning out of an experience that cannot be shared with others. Viewed from the perspective of the present, past experience may even seem unreal.

Merleau-Ponty notes that while living in the present, we carry our past with us, along with expectations for the future: "My present outruns itself in the direction of an immediate future and an immediate past and impinges upon them where they actually are, namely in the past and in the future themselves" (Merleau-Ponty, 1962, p. 418).

As part of an effort to visualize a different past experience—one better than what actually occurred—a new memory may emerge. In the last storyline, creating a memory where two participants (two versions of herself) are provided with the comfort needed and one does not grieve alone. This memory seems to help gain a better understanding of what happened to her; it helps her make meaning out of her past.

Taken together, the four storylines reveal how participants' awareness of their body is indeed a social phenomenon, dependent on the presence of others (Leder, 1990). As they lay bedridden in the dark, struggling with pain and isolated from others, participants sensed that those around them had little understanding of their unending battle with suffering and loneliness. This sense of loneliness seems to be an essential and profoundly difficult aspect of being severely ill and bedridden with ME/CFS in childhood and adolescence. For Ratchliffe (2022), p. 16, loneliness "is not a singular emotion in its own rights. Instead, it consists in a distinctive sense of exclusion, detachment or not belonging that is integral to a wider-ranging experience of relating to the social world." In other words, loneliness is about the absence of something else, the absence of feeling part of something (Ratchliffe, 2022). Experiences of loneliness and feeling disconnected from former life have been underlined in previous research involving young persons with ME/CFS (Jelbert et al., 2010; Njølstad et al., 2018). Polakovská and Řiháček (2022) present a meta-summary of qualitative studies on the experiences of persons suffering with medically unexplained physical symptoms. Like our participants, these persons emphasize the profound impact of the isolation and loneliness that result from their illness. They

describe a strong desire to share their experiences and to be understood by others as they search for explanations as to why they are ill and confront the unpredictable nature of the illness (Polakovská & Řiháček, 2022). These studies also indicate how existentially difficult it can be to live with medically unexplained conditions.

Children and adolescents who become bedridden enter an existence far removed from the life normally led by young persons, especially those in Western societies. Childhood and adolescence are times in life when friends are especially important and when relationships are essential to one's identity and sense of belonging (Bakken, 2022; Helseth & Misvær, 2010). Young people often plan and perform their own activities in their world; they have body agency, control their bodily movements, and impact events in their environment (Gallagher, 2000). Our findings highlight the extent to which such possibilities are denied to young people who become long-term bedridden as a result of ME/CFS. These children and adolescents find themselves deprived of opportunities to acquire a sense of belonging, cultivate friendships, become active in peer groups, and in general lead a normal young person's life. In addition, their sense of bodily agency may be disturbed or disrupted; they may experience a shift in their bodily intentionality (Merleau-Ponty, 1962) as they lose their ordinary way of acting. With their access to others restricted, these young people experience an intense degree of loneliness, one that disrupts their sense of belonging to the world and pushes them closer to the edge of life. This is arguably what makes it so existentially difficult to be bedridden with ME/CFS in childhood and adolescence.

The four storylines also illustrate how the lived body, lived space, lived time, and lived relation are woven into the existential suffering of being bedridden. Coexistent and inseparable, the four essentials infuse the lifeworld of each of our participants.

6 | METHODOLOGICAL CONSIDERATIONS

To gain insight into young women's retrospective experiences of being bedridden during childhood and adolescence, we sought participants who were in recovery or fully recovered from ME/CFS. We considered it unethical, as well as difficult in practical terms, to attempt to interview those who were bedridden with ME/CFS. The lack of research involving such participants suggests that other researchers have been aware of this ethical consideration.

Our participants formed a heterogeneous group of women, drawn from different parts of Norway and with different social backgrounds and educational levels. We consider that this heterogeneity contributes to the richness of the data material and transferability of the findings. Additionally, the length of time from illness to recovery varied between participants, adding further diversity and depth to the data.

Our exclusivity on women has implications for the relevance of the results for men with ME/CFS. The illness can manifest differently in men, and gender-related experiences may vary. However, the

experience of being long-term bedridden and isolated with ME/CFS, along with the existential suffering, could be pertinent for both men and women, involving as it does human aspects that transcend sex-based distinctions (Bakken et al., 2023). That said, there is a need for further research into the specific ways in which boys and men experience being long-term bedridden with ME/CFS.

In line with the narrative research approach, we do not claim that our study offers more than a selection of narratives about the phenomenon of interest. Throughout, we have sought to capture potentially essential aspects of the experience of being long-term bedridden and to construct possible interpretations of this experience. We contend that the patterns and themes that we developed from our phenomenologically informed narrative study contribute to the body of knowledge regarding young women's experience of being long-term bedridden with ME/CFS during childhood and adolescence. In particular, our themes emphasize the gravity of this experience and its ability to threaten a young person's whole existence.

The five authors, all of whom have experience with various qualitative research methods, come from a range of professional backgrounds, from nursing to occupational therapy and physiotherapy. Our different backgrounds have reinforced our ability to collaborate, challenge and ask critical questions regarding our different preunderstandings and interpretations of the material. All of us sought to maintain a reflexive, open, and curious attitude throughout the research process. During the process of analyzing the data, we benefited considerably from group discussions: it was not always easy to understand what the informants told about the process of being severely ill. For example, while working on events relating to the presence of others while bedridden, as in storyline 1, "ambivalent reactions to the presence of others," it was not easy to grasp what this phenomenon was about or judge whether different participants were describing the same phenomenon. Group discussion, together with the use of the phenomenology, enabled us to get a better grasp of the meaning of this phenomenon and to realize that participants were using different words, and drawing on a range of situations, to describe what were in fact similar experiences.

7 | CLINICAL IMPLICATIONS

Our findings underline the importance of health professionals listening to, and learning from, the stories of young individuals who have experienced being long-term bedridden with ME/CFS. We believe the stories that emerged from our research contribute to a broader and more nuanced understanding of what is at stake for young people who find themselves in this situation. Such children and adolescents are totally dependent on their carers and on the help they receive from healthcare professionals.

Healthcare professionals working with these patients, nurses in particular, need to regard such patients as unique individuals who are in existential crisis and desperately in need of support. They need to understand how deeply the experience of severe illness permeates

the young person's whole existence. Nurses can play an important role in developing individualized care plans which address the formidable challenges associated with severe ME/CFS. This might involve collaborating with a multidisciplinary team to address medical treatment, rehabilitation, mental health, and social support. For instance, patients are likely to need help to relieve symptoms such as pain and nausea and to maintain their nutritional intake. Additionally, they need an environment adjusted to their specific needs (Montoya et al., 2021). Here, nurses and other health professionals could help patients devise low-energy strategies to better communicate their situation and needs.

Given the vulnerability of these young people, it is essential that their personal autonomy is respected and that treatment options are discussed and agreed upon with their full involvement, alongside that of their carers. Nurses have a crucial role to play in maintaining and advocating for this autonomy, given that they often serve as a bridge between patients and the broader healthcare system. This underlines the importance, especially for nurses working in specialist, community, and home-based care, of developing greater awareness of what it is like to be a young person struggling with severe ME/CFS.

In this study, we liken the experience of being long-term bedridden to being pushed to the edge, to an extreme of suffering that verges on death. Dafoe (2021) similarly argues that being bedridden with ME/CFS can be like being dead in the sense that the person loses much of herself/himself in the illness (Dafoe, 2021). This has important implications for clinical care, both when patients are ill and when they are in recovery. Our findings suggest that young patients require help and support not only throughout their period of illness but also later, as they seek to cope with recollections and memories in subsequent years. Their experiences are difficult to communicate and hard for others to understand.

Recent research involving child and adolescent patients with ME/CFS reveals how profoundly the pain they endure affects their mental health and limits their ability to participate in everyday life (Serafimova et al., 2022). Loneliness and isolation permeate their experience while severely ill, echoing the findings of earlier research involving adolescents severely affected by ME/CFS (Williams-Wilson, 2009). With their mental well-being tested to the limits, young patients require clear information that, while not minimizing the seriousness of their situation or disguising the likelihood that recovery will be a slow process, gives them hope for the future.

ACKNOWLEDGMENTS

The authors would like to thank the young women for sharing their experiences and reflections about being long-term bedridden with CFS/ME. We would also like to thank Ingrid Bergliot Helland and Berit Widerøe Njølstad for their contribution as health professionals in the field who acted as a resource group for the project. Additionally, we would like to thank Madhi Bereksten for her contribution to user involvement in the study. Last and very importantly, we would like to thank Norwegian Women's Public Health Association for contributing to user involvement in this

study. This work was supported by the Norwegian Extrafoundation for Health and Rehabilitation (2019/FO244604).

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data supporting the findings of this study can be obtained by contacting the corresponding author. However, the data cannot be publicly disclosed due to privacy and ethical constraints.

ORCID

Silje Helen Krabbe  <http://orcid.org/0000-0001-6517-1044>

REFERENCES

- Bakken, A. (2022). *Ungdata 2022: Nasjonale resultater (NOVA Rapport 5/22) [Youth data 2022: National results]*. NOVA, OsloMet. <https://hdl.handle.net/11250/3011548>
- Bakken, A. K., Mengshoel, A. M., Synnes, O., & Strand, E. B. (2023). Acquiring a new understanding of illness and agency: A narrative study of recovering from chronic fatigue syndrome. *International Journal of Qualitative Studies on Health and Well-Being*, 18(1), 2223420. <https://doi.org/10.1080/17482631.2023.2223420>
- Baxter, H., Speight, N., & Weir, W. (2021). Life-threatening malnutrition in very severe ME/CFS. *Healthcare*, 9(4), 459. <https://doi.org/10.3390/healthcare9040459>
- Brea, J. (2017). *Unrest* [Film]. Brea Jennifer.
- Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue, Syndrome, Board on the Health of Select Populations, & Institute of Medicine. (2015). The national academies collection: Reports funded by national institutes of health, *Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness* (pp. 71-139). National Academies Press. <https://doi.org/10.17226/19012>
- Dafoe, W. (2021). Extremely severe ME/CFS: A personal account. *Healthcare*, 9(5), 504. <https://doi.org/10.3390/healthcare9050504>
- Estévez-López, F., Mudie, K., Wang-Steverding, X., Bakken, I. J., Ivanovs, A., Castro-Marrero, J., Nacul, L., Alegre, J., Zalewski, P., Słomko, J., Strand, E. B., Pheby, D., Shikova, E., Lorusso, L., Capelli, E., Sekulic, S., Scheibenbogen, C., Sepúlveda, N., Murovska, M., & Lacerda, E. (2020). Systematic review of the epidemiological burden of myalgic encephalomyelitis/chronic fatigue syndrome across Europe: Current evidence and EUROMENE research recommendations for epidemiology. *Journal of Clinical Medicine*, 9(5), 1557. <https://doi.org/10.3390/jcm9051557>
- Gallagher, S. (2000). Philosophical conceptions of the self: Implications for cognitive science. *Trends in Cognitive Sciences*, 4(1), 14–21. [https://doi.org/10.1016/S1364-6613\(99\)01417-5](https://doi.org/10.1016/S1364-6613(99)01417-5)
- Heidegger, M. (1953/2010). *Being and time*. (J Stambaugh, trans). State University of New York Press.
- Helseth, S., & Misvær, N. (2010). Adolescents' perceptions of quality of life: What it is and what matters. *Journal of Clinical Nursing*, 19, 1454–1461. <https://doi.org/10.1111/j.1365-2702.2009.03069.x>
- Jelbert, R., Stedmon, J., & Stephens, A. (2010). A qualitative exploration of adolescents' experiences of chronic fatigue syndrome. *Clinical Child Psychology and Psychiatry*, 15(2), 267–283. <https://doi.org/10.1177/1359104509340940>
- Krabbe, S. H., Groven, K. S., Schröder Bjorbækmo, W., Sveen, U., & Mengshoel, A. M. (2023). The fragile process of homecoming: Young women in recovery from severe ME/CFS. *International Journal of Qualitative Studies on Health and Well-Being*, 18(1), 2146244. <https://doi.org/10.1080/17482631.2022.2146244>

- Krabbe, S. H., Mengshoel, A. M., Schrøder Bjorbækmo, W., Sveen, U., & Groven, K. S. (2022). Bodies in lockdown: Young women's narratives of falling severely ill with ME/CFS during childhood and adolescence. *Health Care for Women International*, 44(9), 1155–1177. <https://doi.org/10.1080/07399332.2022.2043862>
- Labov, W., & Waletzky, J. (1966/2003). *Narrative analysis: Oral versions of personal experience*. University of Washington Press.
- Leder, D. (1990). *The absent body*. University of Chicago Press.
- Leder, D. (2016). The experiential paradoxes of pain. *Journal of Medicine and Philosophy*, 41(5), 444–460. <https://doi.org/10.1093/jmp/jhw020>
- Lim, E.-J., Ahn, Y.-C., Jang, E.-S., Lee, S.-W., Lee, S.-H., & Son, C.-G. (2020). Systematic review and meta-analysis of the prevalence of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). *Journal of Translational Medicine*, 18(1), 200. <https://doi.org/10.1186/s12967-020-02269-0>
- van Manen, M. (2016). *Researching lived experience: Human science for an action sensitive pedagogy*. Routledge.
- Mattingly, C. (1998). *Healing dramas and clinical plots: The narrative structure of experience*. Cambridge University Press.
- Mattingly, C., & Garro, L. C. (1994). Narrative representations of illness and healing. *Social Science & Medicine* (1982), 38(6), 771–774.
- Merleau-Ponty, M. (1962). *The phenomenology of perception*. (C. Smith, trans). Routledge.
- Montoya, J. G., Dowell, T. G., Mooney, A. E., Dimmock, M. E., & Chu, L. (2021). Caring for the patient with severe or very severe myalgic encephalomyelitis/chronic fatigue syndrome. *Healthcare*, 9(10), 1331. <https://doi.org/10.3390/healthcare9101331>
- Moore, Y., Serafimova, T., Anderson, N., King, H., Richards, A., Brigden, A., Sinai, P., Higgins, J., Ascough, C., Clery, P., & Crawley, E. M. (2021). Recovery from chronic fatigue syndrome: A systematic review—Heterogeneity of definition limits study comparison. *Archives of Disease in Childhood*, 106(11), 1087–1094. <https://doi.org/10.1136/archdischild-2020-320196>
- Njølstad, B. W., Mengshoel, A. M., & Sveen, U. (2018). 'It's like being a slave to your own body in a way': A qualitative study of adolescents with chronic fatigue syndrome. *Scandinavian Journal of Occupational Therapy*, 26(7), 505–514. <https://doi.org/10.1080/11038128.2018.1455895>
- Parslow, R. M., Harris, S., Broughton, J., Alattas, A., Crawley, E., Haywood, K., & Shaw, A. (2017). Children's experiences of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): A systematic review and meta-ethnography of qualitative studies. *BMJ Open*, 7(1), e012633. <https://doi.org/10.1136/bmjopen-2016-012633>
- Polakovská, L., & Řiháček, T. (2022). What is it like to live with medically unexplained physical symptoms? A qualitative meta-summary. *Psychology & Health*, 37(5), 580–596. <https://doi.org/10.1080/08870446.2021.1901900>
- Polkinghorne, D. E. (1988). *Narrative knowing and the human sciences*. SUNY Press.
- Prior, R., & Castillo, N. (2015). *Forgotten plague* [Film]. Electric Puzzle Production.
- Ratchliffe, M. (2022). Loneliness, grief, and the lack of belonging. In L. Dolezal & D. Petherbridge (Eds.), *Phenomenology of belonging*. SUNY Press.
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. Sage.
- Rowe, P. C., Underhill, R. A., Friedman, K. J., Gurwitt, A., Medow, M. S., Schwartz, M. S., Speight, N., Stewart, J. M., Vallings, R., & Rowe, K. S. (2017). Myalgic encephalomyelitis/chronic fatigue syndrome diagnosis and management in young people: A primer. *Frontiers in Pediatrics*, 5:121. <https://doi.org/10.3389/fped.2017.00121>
- Schaathun, P. (2020). *Left out* [Film]. UpNorth Film.
- Serafimova, T., Ascough, C., Parslow, R. M., & Crawley, E. (2022). Experiences of pain in paediatric chronic fatigue syndrome/myalgic encephalomyelitis: A single-centre qualitative study. *BMJ Paediatrics Open*, 6(1), e001201. <https://doi.org/10.1136/bmjpo-2021-001201>
- Webb, C. M., Collin, S. M., Deave, T., Haig-Ferguson, A., Spatz, A., & Crawley, E. (2011). What stops children with a chronic illness accessing health care: A mixed methods study in children with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). *BMC Health Services Research*, 11(1), 308. <https://doi.org/10.1186/1472-6963-11-308>
- Williams-Wilson, M. (2009). "I had to give up so, so much": A narrative study to investigate the impact of Chronic Fatigue Syndrome (CFS) on the lives of young people [Unpublished dissertation]. Bournemouth University. <https://core.ac.uk/reader/4900510>

How to cite this article: Krabbe, S. H., Bjorbækmo, W. S., Mengshoel, A. M., Sveen, U., & Groven, K. S. (2024). A suffering body, hidden away from others: The experience of being long-term bedridden with severe myalgic encephalomyelitis/chronic fatigue syndrome in childhood and adolescence. *Nursing Inquiry*, e12625. <https://doi.org/10.1111/nin.12625>