The long, arduous road to recovery: an exploration of the experiences of young Norwegian women falling ill with ME/CFS during childhood and adolescence

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In one of the first interviews, I got this question from one of the young women “You are not personally involved in ME/CFS, and this is not your field of work from the beginning -why did you decide to do this study?” She continued, “people who are not involved in ME/CFS, they do not care about those suffering”. First, I was taken a bit of guard, as if we just switched roles and the young women doing the interview. However, I understood she was sincerely interested, and I answered that it made an impression on me that she asked me that question. I answered that I want to bring ME/CFS into awareness and contribute to knowledge about recovery in ME/CFS. But most of all, I said because I care, and I feel privileged to get this chance. Today, I feel grateful for this question and at the time, it made me reflect and find the most important reason for me to do this study. I just took for granted and that it was natural for me to do this because I got the chance. My main reason and my motivation all along, has been because I care.

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Silje Helen Krabbe
30th of August 2023

…Once the storm is over, you won't remember how you made it through, how you managed to survive. You won't even be sure, whether the storm is really over. But one thing is certain. When you come out of the storm, you won't be the same person who walked in. That's what this storm's all about.
Haruki Murakami, *Kafka on the shore*

SUMMARY

Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), is a complex, often long-term illness characterized by debilitating fatigue, Post-Exertional Malaise (PEM), and loss of physical and cognitive functioning. To date, the etiology and pathogenesis of ME/CFS are unclear, no objective clinical test can verify the condition, and no curative treatment is available. ME/CFS can strike severely, leaving some children and adolescents bedridden for years. Children's and adolescents' experiences of falling ill, being severely ill, and recovering from this debilitating illness have yet to receive detailed investigation. Thus, this thesis explores the experiences, derived from first-person testimonies, of young women who are now in recovery or fully recovered from severe ME/CFS after falling ill during childhood and adolescence.

The empirical material in this thesis consists of narrative interviews with thirteen young women (aged 16-29 years) who fell ill with ME/CFS during childhood or adolescence but now consider themselves to be considerably better or fully recovered. A qualitative narrative methodological approach, inspired by Riessman's (2008) thematic and structural analysis, was applied, within the framework of a phenomenological theoretical perspective informed by the insights of the French phenomenologist Maurice Merleau-Ponty (1962) and his understanding of lifeworld and the lived body as the basic source of all our experiences and knowledge.

The results are presented in the form of three articles. The first focuses on what the young women told about their experience of falling severely ill with ME/CFS during childhood and adolescence. Here, the identification of common themes encouraged the emergence of a shared narrative, '*Bodies in lockdown'*. This comprises three storylines: *The active and meaningful life I used to live* (where participants describe their active, taken-for-granted life prior to illness); *Gradually developing unhomeliness and being pushed toward the edge (*participants' accounts of the onset of illness, and of struggling to stay active despite constant bodily deterioration and feeling alienated from their habitual way of being); and *Left abandoned on the sidelines (*participants' accounts of ending up severely ill, completely incapacitated and dependent on others, with a body essentially in lockdown and no prospect of recovery).

The second article presents findings related to participants' experiences of being severely and long-time bedridden from ME/CFS during childhood and adolescence. The results are presented in the form of four storylines: *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.* These storylines share a common plot: *A suffering body hidden away from others*. Together, the storylines build a picture of participants' overwhelming bodily discomfort and long-term, seemingly endless isolation. The women's limited access to others brings with it profound loneliness and suffering; it disrupts their sense of

belonging to the world and pushes them closer to the edge of life. These results underline the existentially challenging nature of being long-term bedridden and severely ill with ME/CFS.

The third paper focuses on what participants told about their experience of recovering from severe ME/CFS. The findings are presented through two storylines. The first, *Exploring and building an understanding of own bodily limits and capacities*, reveals how participants were able to test their bodily capabilities in a safe place, slowly creating a more confident self and regaining a sense of belongingness in a world shared with others. The second storyline, *Bodily awakening of self: From a dark place to a fragile and unfinished process of reuniting with one's own body and world*, captures women's accounts of their complex and demanding process of recovery after being severely ill. Here, participants describe how they explored possibilities for action, simultaneously worrying about and making sense of setbacks. Altogether, recovery emerges as an inter-personal, contextual, fragile and non-linear process of homecoming, based on gradually rising bodily-based self-knowledge. The findings indicate that recovery from ME/CFS in childhood and adolescence is indeed possible, although the process can take years, with remissions and relapses likely to be part of the process.

Taken together, the findings of this thesis suggest that falling ill, being ill, and recovering from severe ME/CFS is a complex, long-lasting and dynamic process permeated by suffering that is often intense and existentially challenging. However, if given the possibility, young patients can throughout the process learn to adapt, discover new ways of using their body, and devise fresh ways of living with illness. The process of recovery from ME/CFS involves recreating one's lifeworld and developing new habitual ways of action. On this basis, suffering can become endurable and existentially easier to live with; over time the young person moves towards living a meaningful life and being healthy in a new way. Overall, this thesis enriches the debate and adds to the knowledge base regarding severe illness and recovery among young people with ME/CFS.

SAMMENDRAG

Myalgisk encefalopati (ME), også kjent som Kronisk utmattelsessyndrom (CFS), er en kompleks, ofte langvarig sykdom, preget av betydelig og tidvis invalidiserende fatigue, anstrengelsesutløst sykdomsfølelse (PEM), og tap av fysisk og kognitiv funksjon. Fortsatt er etiologien og patogenesen ved ME/CFS uklar. Ingen objektiv klinisk test kan påvise sykdommen, og ingen kurativ behandling er tilgjengelig. ME/CFS kan medføre alvorlige konsekvenser, og noen barn og ungdommer blir sengeliggende i årevis. Barn og ungdommers opplevelse av innsykning, alvorlig sykdom og tilfriskning fra denne belastende sykdommen, har til dags dato ikke blitt detaljert og grundig forsket på. Hensikten med denne avhandlingen var derfor å utforske hva unge kvinner i tilfriskning eller friske, som ble syke i barne- og ungdomsårene, forteller om opplevelsen med innsykning, sykdom og tilfriskning ved alvorlig ME/CFS.

Det empiriske materialet i denne avhandlingen består av narrative intervjuer med tretten unge kvinner (i alderen 16-29 år), som ble syke av ME/CFS i barne- eller ungdomsårene, men som nå anser seg selv som betydelig bedre eller fullt friske. En kvalitativ narrative metodisk tilnærming, inspirert av Riessmans (2008) tematiske og strukturelle analyse, ble brukt, innenfor rammen av et fenomenologisk teoretisk perspektiv informert av innsikten til den franske fenomenologen Maurice Merleau-Ponty og hans forståelse av livsverden og den levde kroppen som grunnleggende kilde til all vår opplevelse og kunnskap.

Resultatene presenteres i form av tre artikler. Den første fokuserer på hva de unge kvinnene fortalte om deres opplevelser av å bli alvorlig syk med ME/CFS i barne- og ungdomsårene. Identifiseringen av felles tema resulterte i at funn ble presentert i form av et felles narrativ: *Nedstenging av kroppen*. Narrativet baserer seg på tre storylines: *Det aktive og meningsfulle livet jeg levde* (deltakerne beskriver sitt aktive, gitte liv før sykdom); *Gradvis utvikling av hjemløshet og bli presset mot kanten/stupet* (deltakernes beretninger om sykdomsutbrudd, kamp om å holde seg aktive til tross for konstant kroppslig forverring og følelsen av fremmedgjorthet fra sin habituelle væren); og *Etterlatt på sidelinjen* (beretninger om å ende opp alvorlig syk, avhengig av andre, når kroppen har stengt seg ned og det ikke er utsikter til bedring).

Den andre artikkelen presenterer funn knyttet til deltakernes erfaringer med å være alvorlig syk og langvarig-sengeliggende med ME/CFS i barne- og ungdomsårene. Resultatene presenteres i form av fire storylines: *Ambivalente responser på andres tilstedeværelse; En kropp på kanten av livet; En evighet i mørket;* og *Gjenskaping av smertefulle minner om å være sengeliggende og alene*. Disse storylines deler et felles plot: En lidende kropp gjemt borte fra andre. Sammen bygger historiene et bilde av deltakernes overveldende kroppslige ubehag, samt langvarige og tilsynelatende endeløs isolasjon. Kvinnenes begrensende tilgang til andre fører med seg dyp ensomhet og lidelse; det forstyrrer følelsen av å tilhøre verden og skyver de nærmere kanten av livet. Disse funnene understreker det eksistensielt utfordrende ved det å være langvarig sengeliggende og alvorlig syk med ME/CFS som ung.

Den tredje artikkelen fokuserer på hva deltakerne fortalte om deres opplevelse av å være i tilfriskning fra alvorlig ME/CFS. Funnene presenteres gjennom to storylines. Den første, *Utforske og bygge en forståelse av egne kroppslige grenser og kapasitet,* beskriver hvordan deltakerne var i stand til å teste sin kroppslige toleranse på et trygt sted og sakte skape et mer selvsikkert selv og gjenvinne en følelse av tilhørighet med andre. Den andre storyline, *Kroppslig overvåkning av selvet: Fra et mørkt sted til en skjør og uferdig prosess med å gjenforenes med egen kropp og verden*, fanger unge kvinners beretninger om deres komplekse og krevende tilfriskningsprosesser etter å ha vært alvorlig syk. Her beskriver deltakerne hvordan de utforsker muligheter for handling, samtidig som de bekymrer seg for og prøver å forstå sine tilbakefall. Samlet fremstår tilfriskning som en mellommenneskelig, kontekstuell, skjør og ikke-lineær prosess av å føle seg hjemme i egen væren basert på gradvis økende kroppsbasert selverkjennelse. Funnene indikerer at tilfriskning fra ME/CFS i barne- og ungdomsårene faktisk er mulig, men prosessen kan ta år og bedring og tilbakefall vil sannsynligvis være en del av prosessen.

Samlet sett, tyder funnene i denne avhandlingen på at det å bli syk, være syk og det å bli bedre av alvorlig ME/CFS, er en kompleks, langvarig og dynamisk prosess. Lidelse gjennomsyrer hele prosessen, og kan være intenst og eksistensielt utfordrende, men hvis gitt muligheten, kan unge gjennom prosessen lære seg å tilpasse seg og oppdage nye måter å bruke kroppen på. Sammen med nye måter å leve med sykdommen på. Prosessen med tilfriskning, innebærer å gjenskape ens livsverden og utvikle nye habituelle måter å handle på. På dette grunnlaget kan lidelse bli utholdelig og eksistensielt lettere å leve med; over tid beveger den unge seg mot å leve et meningsfylt liv og kan oppleve å være frisk på en ny måte. Samlet sett beriker denne avhandlingen debatten og legger til kunnskapsgrunnlaget om alvorlig sykdom og tilfriskning blant unge mennesker med ME/CFS.

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LIST OF ARTICLES

I. 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*, 1-23. https://doi.org/10.1080/07399332.2022.2043862

II. S. H. Krabbe, W. Schrøder Bjorbækmo, A. M. Mengshoel, U. Sveen and K. S. Groven. A suffering body, hidden away from others: the experience of being long-term bedridden with severe ME/CFS in childhood and adolescences (Submitted *Nursing Inquiry*)

III. Krabbe, S. H., Groven, K. S., Schrøder 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

1 INTRODUCTION

The focus of this thesis is young women's experience of illness and recovery from severe Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), during childhood and adolescence. The basis of the thesis is a qualitative study where young women (aged 16-29) who were in recovery or fully recovered from ME/CFS were invited to narrate their own experiences of illness and recovery. The aims of the study were to contribute new insights and understandings about processes of illness and recovery from ME/CFS, from a personal point of view, and to add to the literature on children's and adolescent's experience of ME/CFS via a focus on narrative accounts.

The severity of the illness suffered by the young women in this study was startling. The following extract from the account given by "Ines", one of the participants, illustrates the devastating impact of ME/CFS on her life (from paper 1):

> *I had this intense pain in my stomach and problems eating, I remember feeling so tired, I felt a little down… I never returned to school after Christmas, and I was diagnosed with Mononucleosis (Trembling voice). But my body just continued* […] *After a year, I got the diagnosis ME (CFS)… feeling exhausted, I had good days and bad days. During the first 3 years I had a teacher who gave me lessons at home, because everyone said I had to … But we should not have done it… it only made me worse. My experience would have been better if I had let go… I was so tired. I was able to spend short periods of time with my friends, but then… Others told me I would soon get better, but I just got worse… mm... I became very ill.* […] *Everything about me became so fragile, could not tolerate light or sound…I could not be among my friends… Then I stopped walking because… I did not have a chance. Maybe I should have stopped earlier… My parents lifted me off my bed and back again… later I lay on a mattress on the floor in the dark: it was the only way... My legs were so heavy, as if they were being pushed to the ground... and someone had laid rocks upon them (swallows)…*

> *Then I was not able to chew so mum tried to feed me with soup… I just could not do it… Could not move my tongue…as if it were too thin, you see... could not talk...so hard... It just got worse, and I ended up in hospital, I received a nasogastric tube for nutrition, wore diapers because… (swallows)… I left the hospital… home to my mattress in a dark, quiet room by myself. [……] Not much left of the life I used to live. Looking back, all those years and all I missed… I kind of wished I had not lost my childhood and adolescence to ME/CFS.*

The description "Ines" provided of her ordeal was unfortunately not unique. The majority of the young women in this study shared similarly horrifying experiences.

1.1 Overview of this thesis

This thesis is structured as following:

In chapter 1, a description of the historical and cultural context of ME/CFS is provided, and the aims of the study are presented, followed by a list of original papers. Chapter 2 sets out the background for the thesis and provides an overview of quantitative and qualitative studies relevant to this thesis. In chapter 3, the theoretical framework for the thesis is presented. Chapter 4 provides a detailed picture of the method applied in the papers. An overview of the findings from the three studies that constitute the thesis is offered in chapter 5. Chapter 6 focuses on a discussion of the findings, together with various theoretical and methodological considerations. Finally, chapter 7 explores the implications of the study for research and clinical practice and contributes some concluding remarks.

1.2 Historical and cultural context of ME/CFS

ME/CFS is often classified as a condition with medically unexplained symptoms (MUS). The existence of this illness has been long recognized; there are indications that conditions with similar symptoms as ME/CFS were described as far back as 1750 (Demitrack, 1998; Straus, 1991). At that time, this type of malady was known by various different names, including Febricula or “little fever”, and, during the late 19th century, Da Costa’s syndrome or “soldier’s heart” (Demitrack, 1998; Straus, 1991). In 1869, the neurologist Georg Beard described a similar condition involving fatigue, headache, anxiety and depression and also focused on the mismatch between the patient’s experience of symptoms and objective signs. At the time this condition was called Neurasthenia (or Nervous exhaustion) (Beard, 1869). In 1934 an epidemic of ME/CFS-like symptoms occurred among employees at a hospital in Los Angeles and 198 people fell ill with acute symptoms. Later, in 1955, there was a similar “epidemic” outbreak at the Royal, Free Hospital in London; this came to be known as the “Royal Free Disease”. In these and several other outbreaks, patients reported the same symptoms: headache; myalgia; paresis; symptoms or signs other than paresis suggestive of damage to the brain, spinal cord or peripheral nerves; mental symptoms; the absence or near absence of fever; and no mortality (Acheson, 1959). Women were overrepresented in all these outbreaks (Acheson, 1959).

It was during the outbreak at the Royal Free in London in 1955 that a new name - “benign Myalgic encephalomyelitis” - made its first appearance. Today, Myalgic encephalomyelitis remains the preferred term for the condition. While the label “Chronic Fatigue Syndrome” is also used widely, it has been criticized for trivializing the condition by simply focusing on the fatigue and not acknowledging other debilitating symptoms.

Irrespective of its nomenclature, ME/CFS has received a variety of medical constructions and understandings (Berrios, 1990; Lian & Bondevik, 2015; Straus, 1991; Wessely, 1990). In the 19th century, it was considered a somatic disease suffered by men and was assumed to have neurological causes. Later in the century it was constructed as “Long term exhaustion” (Lian & Bondevik, 2015). Around 1920 a shift occurred: ME/CFS was now judged to be a “women’s disease” in which psychological aspects were prominent (Lian & Bondevik, 2015). As with other conditions, such changing medical constructions need to be seen in the context of shifting societal, historical, and cultural factors (Berrios, 1990; Lian & Bondevik, 2015; Straus, 1991; Wessely, 1990). What remains constant is the controversy surrounding the condition.

The etiology and pathology of ME/CFS seem to lie at the core of this ongoing debate. During the last three decades, a number of quantitative studies have focused on biomedical aspects and possible psychological mechanisms in an effort to come up with answers about the roots of ME/CFS: does the condition have primarily biological or psychological origins? This dichotomy has given rise to disagreements and controversies among researchers, health professionals and patients, and no consensus has emerged regarding a theory of the etiology and pathological mechanisms of ME/CFS. The notion that there is just one single cause of ME/CFS is also questionable; the onset of the condition and its course of evolution may be influenced by multiple factors. Applying principles of Cartesian dualism (Bondevik & Bostad, 2003), to ME/CFS by differentiating between symptoms or causes that are “just” physical or “mental” may not be the best way forward.

In modern Western societies, where there is still a strong focus on pathology and etiology, medical technologies are seen as the most reliable methods for examining and treating patients. In line with this, Western medicine has become highly specialized and (it needs to be emphasized) often very effective. Since its understanding of disease rests on concepts and theories drawn from biology, physiology, and chemistry, this system of medicine prioritizes the observation and recording of clear biological symptoms. These in turn operate as a kind of justification of the “truth” and reality of a disease, thereby legitimizing a patient as “truly sick”. Thus, interestingly, the experiences of individuals who have recovered from ME/CFS are not necessarily legitimized, since both health professionals and patients may doubt that they were sick in the first place.

When a disease lacks a defined medical explanation and treatment, as is the case with ME/CFS, there seems to be more space for cultural understandings and influences, along with historical perspectives (Lian & Bondevik, 2015; Lian et al., 2019; Straus, 1991; Wessely, 1990), given the different ways in which ME/CFS, has been understood in the past. The lack of medical knowledge surrounding ME/CFS also creates medical uncertainty, leaving room for various treatment options, whether those offered by a country’s health care system or by private health providers. Additionally, when there is no medical evidence, or the evidence is poor, professionals appear less likely to recognize and engage with an individual’s experiences and bodily knowledge (Dumit, 2006; Hydén & Sachs, 1998; Nettleton, 2006).

While the controversy surrounding ME/CFS seems set to continue, with no end in sight, the voices of those suffering from ME/CFS need to be listened to, so that these patients’ experiences become a resource for a better understanding of what it is like to be ill with ME/CFS – and to edge slowly towards recovery.

1.3 Aim of the thesis

The overall aim of this PhD project is to explore the following overarching question: *What do young women who are now in recovery or fully recovered from severe ME/CFS after falling ill during childhood and adolescence tell about their illness and recovery experiences of ME/CFS?*

The following questions are addressed in the papers:

In the first paper:

What do young women who are in recovery from ME/CFS have to tell about their experience of falling severely ill during childhood and adolescence?

In the second paper:

What do young women tell about being bedridden with ME/CFS during childhood and adolescence?

In the third paper:

What do young women who suffered ME/CFS during childhood and adolescence tell about their bodily experiences of becoming better, from their present position of being in recovery or fully recovered?

2 BACKGROUND

Until recently, research regarding ME/CFS was dominated by quantitative studies focusing on the biomedical aspects of the condition. However, the past two decades have seen the publication of a growing number of qualitative studies. These have sought to explore the experience of ME/CFS from the perspective of different sufferers: adults, children and adolescents. In the following, the focus will be on children's and adolescents' perspectives on ME/CFS; where the literature on children and adolescents is scanty, reference will also be made to research focusing on adults. The literature cited below represents a selection drawn from what has become a substantial body of work. I consider all of the examples I have selected, which include both quantitative and qualitative studies, relevant to this thesis and to an understanding of ME/CFS in children and adolescents. This chapter is organized under two main headings: 2.1 Quantitative studies related to ME/CFS in children and adolescents; and 2.2 Qualitative studies of ME/CFS – children's and adolescents' experiences of illness and recovery. The aim of the first section is to provide a general overview of scientific knowledge as viewed from a disease perspective, while that of the second section is to take a broad look at research exploring patients' lived experiences (the illness perspective adopted by this thesis). This structure is intended to underline how quantitative and qualitative research studies contribute different kinds of knowledge and that both forms of research are important for our understanding of ME/CFS.

2.1 Quantitative studies related to ME/CFS in children and adolescents: the condition viewed from a medical perspective

This section is structured in the following way: 2.1.1 Defining and diagnosing ME/CFS; 2.1.2 Etiology; 2.1.3 Treatment; 2.1.4 Quality of life in children and adolescents; 2.1.5 Recovery from ME/CFS in children and adolescents; 2.1.6 Summing up quantitative studies related to children and adolescents.

2.1.1 Defining and diagnostic criteria ME/CFS

ME/CFS is a complex, often long-lasting illness characterized by prolonged debilitating fatigue, Post-Exertional Malaise (PEM) and loss of physical and cognitive functioning (Rowe et al., 2017). The illness is characterized by a broad spectrum of severity, ranging from mild to moderate, severe and very severe (Montoya et al., 2021; Rowe et al., 2017). Although ME/CFS affects both sexes, women are overrepresented (Jason et al., 2020; Knight et al., 2019; Lim et al., 2020). While ME/CFS can strike at any age, children under the age of 10 fall rarely ill with it (Knight et al., 2019) There seem to be two age peaks of debut incidences in ME/CFS: one (for younger people) between 11 and 19 years old, and the second (for adults) in the age range 30-39 (Bakken et al., 2014). ME/CFS afflicts individuals from different ethnic groups and cultures and strikes all socio-economic groups (Jason et al., 2020).

The global prevalence of ME/CFS is difficult to determine in the absence of any objective diagnostic tool or agreed classification criteria. As a result, estimates vary considerably (Lim et al., 2020). In the USA, a recent community-based survey of 10,119 young people aged 5-17 years revealed an incidence of 0.75% (Jason et al., 2020). In Australia, research indicates some degree of regional variation for the pediatric incidence of ME/CFS: from 1.31-17.48 per 100 000 for adolescents between 10 and 17 years old, and 0.25 per 100 000 for children aged 4-9 (Knight et al., 2019).

A systematic review and meta-analysis of research findings on the prevalence of ME/CFS (all ages), which included 7 studies involving children and adolescents, estimated the prevalence among children and adolescents to be 0.89 % in the systematic review and 0.55 % in the meta-analysis (Lim et al., 2020). Another recent systematic review (which included only one study with children and adolescents, which dated from 2007) reported the prevalence of ME/CFS (all ages) to be 0.1 % (Estévez-López et al., 2020). The study involving children and adolescents had a sample of 842 participants and found a prevalence of 0.1 % for those aged 11-15 (Rimes et al., 2007).

To sum this up, the prevalence of ME/CFS among children and adolescents is estimated to be between 0.1 % and 0.89 %. However, results from the systematic review of recent studies in Australia indicate that the prevalence of ME/CFS in children and adolescents may have been underestimated.

There are different diagnostic criteria for ME/CFS, with the Fukuda criteria, the Canadian Consensus Criteria (CCC), the International Consensus Criteria (ICC), and the Oxford criteria all in common use (Strand et al., 2019). These diagnostic criteria comprise clusters of self-reported symptoms, but the type of symptoms included differ, as does the weightage accorded to them. In Norway, recommendations (Helsedirektoratet, 2015) set out diagnostic criteria for children (Jason et al., 2006), but different diagnostic criteria may be used in the case of adolescents.

Table 1 sets out the diagnostic criteria for ME/CFS in children and adolescents as recommended by Jason et al. (2006):

Table 1 Pediatric diagnosis in ME/CFS (Jason et al., 2006)

A diagnosis is based on the persistent symptoms as below:
1. Clinically evaluated, unexplained, persistent or relapsing chronic fatigue over the past 3 months that: A. Is not the result of ongoing exertion B. Is not substantially alleviated by rest C. Results in substantial reduction in previous levels of educational, social and personal activities D. Must persist or reoccur for at least three months
2. The concurrent occurrence of the following classic ME/CFS symptoms, which must have persisted or recurred during the past three months of illness (symptoms may predate the reported onset of fatigue). A. Post-exertional malaise (PEM) and/or post-exertional fatigue. B. Unrefreshing sleep or disturbance of sleep quantity or rhythm disturbance. C Pain (or discomfort) that is often widespread and migratory in nature. At least one symptom from any of the following: Myofascial and/or joint pain Abdominal and/or head pain D. Two or more neurocognitive manifestations: Impaired memory (self-reported or observable disturbance in ability to recall information or events on a short-term basis) Difficulty focusing Difficulty finding the right word Frequently forget what wanted to say Absent mindedness Slowness of thought Difficulty recalling information Need to focus on one thing at a time Trouble expressing thought Difficulty comprehending information Frequently lose train of thought New trouble with math or other educational subjects

E. At least one symptom from two of the following three categories: (1) Autonomic manifestations: Neurally mediated hypotension, postural orthostatic tachycardia, delayed postural hypotension, palpitations with or without cardiac arrhythmias, dizziness, feeling unsteady on the feet–disturbed balance, shortness of breath. (2) Neuroendocrine manifestations: Recurrent feelings of feverishness and cold extremities, subnormal body temperature and marked diurnal fluctuations, sweating episodes, intolerance of extremes of heat and cold, marked weight change-loss of appetite or abnormal appetite, worsening of symptoms with stress.
3. Immune manifestations: Recurrent flu-like symptoms, non-exudative sore or scratchy throat, repeated fevers and sweats, lymph nodes tender to palpitation– generally minimal swelling noted, new sensitivities to food, odors, or chemicals.
Exclusionary conditions: Any active medical condition that may explain the presence of chronic fatigue Some active psychiatric conditions that may explain the presence of chronic fatigue
May have presence of concomitant disorders that do not adequately explain fatigue, and are, therefore, not necessarily exclusionary.

The diagnosis of ME/CFS is based on the person's self-reported symptoms, or symptoms as reported by parents, together with the exclusion of other diseases or causes of fatigue (Fukuda et al., 1994). According to one recent longitudinal study, in the case of children and adolescents it may take years to receive a diagnosis (Rowe, 2019). Different diagnostic criteria, different clinical practices and the lack of an objective clinical test can contribute to this delay in receiving the diagnosis (Clayton, 2015; Rowe et al., 2017). However, ME/CFS remains a contested illness among physicians and health professionals, who often have little knowledge about the illness. The delay in diagnosis can increase the risk of children and adolescents ending up with the wrong diagnosis while preventing them from receiving the medical care and support they urgently need (Knight et al., 2019; Knight et al., 2013; Webb et al., 2011).

The fact that ME/CFS can fluctuate in intensity and develop over a period of years means that a child or an adolescent can end up being severely affected and even bedridden, sometimes for long stretches of time (Montoya et al., 2021; Rowe et al., 2017). Being bedridden with ME/CFS is often a long-term experience in which the housebound patient spends much of the day in bed, unable to carry out most activities (Montoya et al., 2021). Since the level of fatigue can vary, both during the day and from one day to the next, life becomes highly unpredictable for the suffering person (Rowe et al., 2017). Children and adolescents who become severely affected can end up being bedridden and dependent on care to fulfill their primary needs, including nutrition and hygiene (Montoya et al., 2021; Rowe et al., 2017). Clinicians have estimated that 5-10 % of children and adolescents suffering from ME/CFS become severely affected, with somewhere between 2-5 % of patients becoming *very* severely affected (Rowe et al., 2017).

Recent research conducted in the UK tracked the incidence of severe ME/CFS among children aged 5-16 over a 13-month period (Royston et al., 2022). Of a total of 175 cases of ME/CFS, 33 children were reported to be severely ill (4 more were reported as *probably* severely ill, while a further 55 were categorized as *possibly* severely ill). Being severely ill was described in this study as being very disabled, with high levels of absence from school and receiving little or no education.

A scoping review conducted by Strassheim and colleagues (Strassheim et al., 2017) examined findings from 21 separate studies involving participants who were very severely affected (housebound/bedridden) by ME/CFS. Three of these studies included children and adolescents. However, variations in the outcome measures that were used to characterize patients as having severe or very severe ME/CFS made comparison difficult. The authors of the survey highlighted the paucity of research regarding patients severely or very severely affected by ME/CFS (Strassheim et al., 2017).

More recently, research by Conroy and colleagues (Conroy et al., 2021) has drawn on the experiences of 2,138 adult participants from the USA, the UK and Norway. Of this total, 549 participants reported being severely affected (housebound), while a further 89 reported being very severely affected (housebound and bedridden).

Thus far, no research has been published regarding the incidence of severe and very severe ME/CFS among children and adolescents in Norway. In general, however, the number of children and adolescent who become severely or very severely ill with ME/CFS is thought to be small. Rowe et al.’s estimate (5-10% of those suffering from ME/CFS becoming severely affected, with 2-5 % becoming very severely affected) remains a useful indicator (Rowe et al., 2017).

2.1.2 Etiology

To date, no etiology for ME/CFS has been established, no objective clinical test to verify the condition exists, and no curative treatment is available (Cortes Rivera et al., 2019; Sharpe & Greco, 2019). In a recent systematic scoping review of literature dating back to 1979, Muller et al. (2020) found that the most common factors judged likely to cause or trigger ME/CFS came from the following four categories: immunological, psychological, infection-related, and neuroendocrinal (Muller et al., 2020). These findings may also reflect the different understandings of ME/CFS that have emerged over this period. As has been noted above, trans-national research by Jason et al. (2022) found that 60.3% of respondents reported being ill with an extensive variety of infections prior to the onset of ME/CFS. Mononucleosis constituted 30% of these infections (Jason et al., 2022). The findings of this research suggest that many infections can be associated with the onset of ME/CFS (Jason et al., 2022).

Quantitative research by Knight et al. (2013; 2019) involving children and adolescents has suggested that several factors may play a role in triggering ME/CFS, including infection, immunization, toxins, severe psychological stress and trauma (Knight et al., 2019; Knight et al., 2013). In a long-term follow-up study of young persons diagnosed with ME/CFS, Rowe (2019) found that 80% of participants reported falling ill with ME/CFS after having an infection (Roma et al., 2019). As many as 40% of participants reported being infected with Epstein Barr Virus (EBV) prior to the onset of ME/CFS. Other reported infections included Mycoplasma, Toxoplasmosis, Varicella, Rubella, Parco virus, Ross River virus, gastroenteritis and different respiratory infections (Roma et al., 2019). To sum up: infections of various types emerge as the most commonly reported trigger for ME/CFS among children and adolescents (Knight et al., 2019; Knight et al., 2013; Roma et al., 2019).

The fact that quantitative studies also indicate that a gradual onset of ME/CFS is commonly seen in children and adolescents may be linked to the large numbers of young people who suffer from an infection prior to ME/CFS (Knight et al., 2019; Nijhof et al., 2011). However, children and adolescents can also experience a sudden onset of ME/CS (Knight et al., 2019). Regarding the symptoms experienced by children and adolescents, the most frequently reported (90-100 %) appear to be prolonged fatigue, persistent headache, need for sleep, poor concentration, disturbed sleep and muscle pain and fatigue after activity (Knight et al., 2019; Roma et al., 2019). Quantitative findings also emphasize how symptoms, fatigue in particular, can fluctuate and change in intensity and severity from day to day (Knight et al., 2019; Nijhof et al., 2011; Rowe et al., 2017).

2.1.3 Treatment

In the absence of agreement on the pathological mechanisms and etiology of ME/CFS, treatment remains a major challenge. A number of studies have attempted to evaluate the effectiveness of different kinds of interventions (Kim et al., 2020).

A recent systematic review included 55 randomized controlled trials (RCTs) for ME/CFS. Of these, 25 RCTs had 22 forms of pharmacological intervention and 28 RCTs had non-pharmacological interventions (Kim et al., 2020). The 22 different types of pharmacological interventions included psychiatric drugs, immuno-modulators and mitochondrial modulators. The 28 RCTs involving non-pharmacological interventions included treatments such as cognitive behavior therapy, graded exercise therapy, rehabilitation, acupuncture and abdominal tuina (abdominal massage) (Kim et al., 2020). A total of 6,316 participants took part in these studies, of whom 457 were adolescents. Three of the 22 pharmacological interventions showed positive, statistically significant effects in the case of two immuno-modulators (Staphypan Berna and Poly(I):poly(C(12)U) and two mitochondrial modulators (CoQ(10) + NADH) (Kim et al., 2020).

Regarding non-pharmacological therapies, six RCT studies found the results of 12 categories of CBT to reveal statistical effectiveness compared to control groups. Four RCTs found graded exercise-related therapy to yield statistically significant effects, while three further RCTs found integrative consumer-driven rehabilitation, acupuncture and abdominal tuina yielding statistically significant outcomes compared with controls (Kim et al., 2020). The review concluded that, after taking coherence and reproducibility into account, no definitively effective treatment had emerged from this systematic survey (Kim et al., 2020). The findings of one study included in the review – that of White et al. (2011) - have been criticized for poor methodology and for recommending, on the basis of insufficiently substantiated data, the use of graded exercise therapy and cognitive behavior therapy (Wilshire & Kindlon, 2019).

In a further systematic review, Parker et al. (2021) evaluated the methodological quality of 14 studies focused on the mind-body training program known as Lightning Process (LP) (Parker et al., 2021). Lightning Process (LP) is a three-day personal training program developed and trademarked by the British osteopath Phil Parker. The studies, which included both quantitative and qualitative ones, were found to be of varying methodological quality. While the review identified evidence for the plausible efficacy of LP in relation to fatigue, pain, anxiety and depression, the authors called for further randomized controlled trials (Parker et al., 2021).

Overall, no specific treatment has emerged with curing nor strong evidence for illness modifying effects for ME/CFS. To date, the focus of treatment has been on relieving symptoms so as to improve patients' daily lives and quality of life (Rowe, 2023); this remains the current advice in Norway (Helsedirektoratet, 2015). However, non-pharmacological therapies may have limited symptom-relieving effects, as demonstrated among adult patients with ME/CFS (Mengshoel et al., 2020).

2.1.4 Quality of life in children and adolescents with ME/CFS

In their USA-based cross-sectional study, Roma et al. (2019) explored the quality of life reported by 55 participants, 46 of them female, with ME/CFS aged 10-30, and drew comparisons with the quality of life reported by 55 healthy participants of similar age and sex distribution. The participants with ME/CFS reported a substantially lower quality of life compared with the healthy control; indeed, their quality of life was even lower than that reported in earlier research involving other chronic conditions (Roma et al., 2019). Poor quality of life was particularly associated with participants reporting frequent post-exertional malaise (PEM).

Similä et al. (2020) set out to measure the health-related quality of life (HRQoL) of 63 Norwegian adolescents diagnosed with ME/CFS. The mean age of participants was 15 years, and the sample included 12 boys. Overall, boys scored better than girls did on the main outcome measure, and there was a positive association between HRQoL and the support the adolescents perceived from teachers and their attendance at school. Those who reported negative HRQoL had experienced ruptures in their progress through school, had participated in rehabilitation programs and reported depressive symptoms (Similä et al., 2020). Overall, the HRQoL reported in adolescents with ME/CFS was low. Such findings concur with those of earlier studies involving adolescents with ME/CFS (set against the experiences of healthy control groups) in Norway and Australia (Knight et al., 2015; Winger et al., 2015).

2.1.5 Recovery from ME/CFS

There is no international consensus on how to measure and define recovery from ME/CFS in children and adolescents, making it difficult to compare results across studies (Moore et al., 2021). Previous quantitative research points to considerable variation in recovery times. Recovery from ME/CFS can take years, with recurrent oscillations between periods of improvement and unpredictable relapse, and not every young person seems to recover (Moore et al., 2021; Roma et al., 2019; Rowe et al., 2017). A systematic review carried out by Moore et al. (2021) found that recovery rates for children and adolescents with ME/CFS at follow-up could vary from 5 % to as high as 83 %. Participants in the 10 studies covered were aged 10-19; follow-up periods ranged from 6 to 56 months; and definitions of recovery varied across studies. In most instances, recovery was evaluated in terms of higher school attendance, reduced fatigue and better physical functioning (Moore et al., 2021).

In Australia, Rowe (2019) conducted an observational cohort study in which 418 children and adolescents with ME/CFS (mean age 14.6 years) were followed for a mean of 8 years following the onset of illness (Roma et al., 2019). After 5 years, 38 % of the children reported recovery from ME/CFS; this percentage rose to 68 after 10 years (Roma et al., 2019). Research in Australia conducted by Josev et al. (2021) involved a case-control follow-up study involving 25 adolescents (aged 13-18) with ME/CFS, set against a control group of 23 individuals in the same age range. The researchers found that after a mean of 2 years after diagnosis, 82 % of adolescents with ME/CFS reported that they were still ill; 79 % of these patients still met the diagnostic criteria (Josev et al., 2021).

2.1.6 Summing up quantitative studies related to children and adolescents

There is a growing body of quantitative research focused on investigating the causes, disease mechanisms and prevalence of ME/CFS among children and adolescents. However, no definitive cause or trigger for ME/CFS within this age group has as yet been identified, and the pathogenesis of the illness is still unclear. Although estimates of the prevalence of the condition among children and adolescents vary considerably, results from recent systematic reviews point to a prevalence between 0.1 % and 0.89 %. As for causative factors, quantitative studies related to ME/CFS in children and adolescents indicate that several factors and mechanisms may be involved, including infection, immunization, toxins, severe psychological stress or trauma.

Regarding the effectiveness of treatment options, the systematic review conducted by Kim et al. (2020) of RCTs of various pharmacological and non-pharmacological interventions was unable to identify any effective intervention, once coherence and reproducibility were taken into account. Some of the interventions referred to in the systematic review have been criticized by health professionals and patients’ organizations. There is no specific treatment proven effective to cure ME/CFS, and treatment continues to focus on relieving symptoms and improving the quality of daily life. Quantitative studies have also highlighted the poor health-related quality of life experienced by children and adolescents with ME/CFS when compared with that of healthy controls. Indeed, this has been found to be worse than that associated with other chronic conditions.

Some children and adolescents end up with severe or very severe ME/CFS, becoming long-term bedridden, spending most of the day in bed, housebound and unable to carry out most activities. The prevalence of those becoming severely and very severely affected is still uncertain but seems to be low.

Finally, quantitative research has revealed important variations in illness severity and recovery rates for children and adolescents with ME/CFS. Recovery can take years; young patients experience an oscillation between periods of improvement and unpredictable relapse; and not all children and adolescents seem to recover. There is a growing body of qualitative research exploring the experiences of ME/CFS from the sufferer's perspective, and this is of major relevance and contributes to important insight about the understanding of ME/CFS from a first-person perspective. It is of importance to listen to what patients have to say and strive to make sense of their specific experiences.

2.2 Qualitative research involving children and adolescents with ME/CFS: illness experiences as told by patients

A number of studies have used structured questionnaires as a means to explore patients' illness experiences, and this has shed light on the high levels of fatigue, pain, depression and anxiety suffered by those afflicted by ME/CFS (Ali et al., 2019; Knight et al., 2019; Loades et al., 2021; Roma et al., 2019; Similä et al., 2020). Over the past two decades, the experience of being ill with ME/CFS during childhood and adolescence has also begun to be examined through qualitative interviews (Clery et al., 2022; Harris et al., 2017; Njølstad et al., 2018; Parslow et al., 2015; Parslow et al., 2018; Serafimova et al., 2022; Similä et al., 2021; Solomons, 2017; Taylor et al., 2017). While the body of qualitative research in this area remains limited, a number of systematic literature reviews have been conducted.

An example is the systematic review and meta-ethnography research conducted by Parslow et al. (2017). This surveyed 10 qualitative studies from the period 1994-2014, all of them involving children and adolescents (aged 8-18) who were invited to describe their experience of ME/CFS and its impact on their lives. Several important aspects of participants' illness experience emerged and were presented in the systematic review as four analytical themes: (a) disruption and loss; (b) barriers to coping, (c) facilitators to coping and (d) hope, personal growth and recovery (Parslow et al., 2017). This research review provided a useful overview of how ME/CFS is experienced by children and adolescents at the time I started my research.

In the following discussion, qualitative literature of relevance to my research is explored under the following headings: 2.2.1 The experience of the body in illness; 2.2.2 Relationship with peers and impact on everyday life; 2.2.3 Disbelief and lack of understanding; 2.2.4 Children's and adolescent's understanding of ME/CFS; 2.2.5 Experience of recovery; and 2.2.6 Summing up qualitative studies related to children and adolescents. Given the paucity of studies on children and adolescents in recovery from ME/CFS, section 2.2.5 draws on qualitative research involving adults.

2.2.1 The experience of the body in illness

Children's and adolescents' experience of living with a changed and restricted body over which they have lost control has been explored by a number of qualitative studies (Njølstad et al., 2018; Parslow et al., 2017; Solomons, 2017). Njølstad et al. (2018) interviewed 7 adolescents aged 12-18 who were ill with ME/CFS and conducted a thematic analysis of the interview data. Participants described how they experienced their bodies in a different way than before, highlighting that their previously familiar body now seemed alien to them. For these adolescents, body and mind now appeared as two separated phenomena; the body had become an unfamiliar object that overruled what they themselves wanted to do (Njølstad et al., 2018). Similar results were recorded by Solomons (2017) in a narrative study involving 10 adolescents aged 13-18. Analysis of their narratives revealed how the adolescents felt trapped in their own body during periods of severe illness when they were not able to move at all. This was understood as 'resigning' and as becoming a kind of passive victim of the illness (Solomons, 2017).

In Parslow et al.'s study (2015), 24 children and adolescents (11 of them boys) described their experience of illness as a range of different bodily discomforts (symptoms). The illness affected them in different ways. Some described how "everything hurts", including their legs, throat, ears, head and stomach. Some told of how the illness affected their memory and concentration, describing it as a kind of "brain fog" (Parslow et al., 2015). The bodily discomforts (symptoms) could fluctuate from day to day, with participants experiencing a sort of "boom and bust circle" of perceived energy. The fluctuations made their lives unpredictable, with both the children and the adolescents perceiving themselves as lacking control of the situation (Parslow et al., 2015). In many respects ME/CFS controlled the lives of participants and their close family members.

Parslow et al. (2017) have described how the children and adolescents in their study found that their alienated bodies prevented them from being spontaneous and doing what they wanted to do. Forced to adjust to, and learn to live, with their "new" body, these young patients became anxious - and more conscious of what they could and could not do. Although they experienced a variety of debilitating symptoms (tiredness, low energy, pain, loss of memory and sleep), the dominant symptom was fatigue. Participants also described a changed experience of self, and this made them feel emotional, vulnerable and uncertain (Parslow et al., 2017).

At the time I started my research (2019), previous studies had underlined how participants perceived their body in a different way than before, experienced losing control of their body, had a variety of symptoms that could fluctuate from day to day, and found that they had to adjust to, and learn to live with, a new and restricted body. However, there were no studies exploring how the bodily experiences of those with ME/CFS might change during the trajectory of the illness: from becoming ill to being severely ill and then recovering again. One of the goals of my research was to address this gap in the literature.

2.2.2 Relationship with peers and impact on everyday life

The impact that ME/CFS can have on children's and adolescents' relationships with peers and on their overall everyday life has been explored by several previous studies (Clery et al., 2022; Njølstad et al., 2018; Parslow et al., 2015; Parslow et al., 2018; Solomons, 2017; Taylor et al., 2017). For these young people, maintaining social relationships and connections with peers while ill with ME/CFS emerges as a major challenge. In their study, Similä et al. (2021) conducted semi-structured interviews with 18 adolescents (5 of them boys). Unable to spend time with peers because of fatigue and not being able to attend school, participants spoke of how they missed spending time with their peers (Similä et al., 2021). While they told of the difficulty other people had in understanding the illness, they also found that friends did their best to support them. However, the lack of improvement in their condition made their friends feel powerless to help (Similä et al., 2021).

The difficulty of maintaining relationships with peers was also highlighted by Njølstad et al. (2018). Participants in their study described how they went from living very active lives together with their friends to being left “on the sideline of life with peers” (Njølstad et al., 2018, p. 4). Previous activities, which used to be taken for granted, had to be carefully assessed and planned. And participants had to cope with being constantly reminded of their bodily restrictions (Njølstad et al., 2018). Solomons (2017) has described such adolescents as “being out of the loop” (Solomons, 2017, p. 188-189). Social relationships with peers become disrupted because of the severity of the illness, and young patients must watch from the sidelines as their contemporaries continue with their lives (Solomons, 2017).

Research by Taylor et al. (2017), involving semi-structured interviews with 9 adolescents aged 13-17, sheds light on the sadness and depression suffered by young ME/CFS patients. The illness results in several different forms of loss: isolation, loss of enjoyable activities, loss of social relationships, and loss of participation in education. Even when spending time with friends, participants in this study described feeling constantly anxious and worried:

> *“Constantly thinking about how, um, how much time you’ve got left and whether you should be doing this activity or not. So, um… just inevitably less enjoyable”.* (Taylor et al, 2017, p.332)

Even when they should be enjoying the company of others, the experience turns sour, and they cannot take pleasure in the activity. Parslow et al. (2015) also highlight several of the same themes, including the negative cycle imposed by limitations and how young patients end up experiencing close to total isolation. In sum, these studies describe how children and adolescents with ME/CFS are caught in a vicious circle from which it can be hard to break out. In their research with 11 adolescents aged 11-17, Clery et al. (2022) explored adolescents’ experience of school and how this contributed to their experience of ME/CFS. The study, which used semi-structured interviews and focus groups, also sought to probe the experiences of carers and health professionals. The adolescents highlighted how the illness resulted in a loss of social relationships. Not only was it difficult to maintain pre-existing friendships; absence from school made it very difficult to make new friends. Participants understood that much of the low mood, sadness and anxiety they experienced derived from their grief at missing school and losing friends (Clery et al., 2022).

The systematic review conducted by Parslow et al. (2017) revealed how participants experienced loss of normal adolescent life and loss of friendship due to the long-time isolation imposed by the illness. Being ill with ME/CFS resulted in long periods of being bedridden and housebound, depriving them of the possibility of being among peers and having social experiences normal for their age. Participants described how their exclusion from social settings left them feeling lonely and rejected, and also made them conscious that others did not understand what it was like to be ill. Additionally, they had to depend on their family much more than before. The review also highlighted how supportive relationships with peers, family and teachers helped participants to feel better understood (Parslow et al., 2017).

Previous studies have drawn attention to the major impact that ME/CFS can have on children's and adolescents' relationships with peers, their social life and their everyday activities. There is abundant evidence that ME/CFS prevents children and adolescents from participating fully in a crucial stage of their lives: one of the utmost importance for their maturation and ability to progress to adult life.

2.2.3 Disbelief and lack of understanding

Previous research has also documented how children and adolescents with ME/CFS find themselves disbelieved by health professionals (and others) and experience a widespread lack of understanding about ME/CFS (Clery et al., 2022; Njølstad et al., 2018; Parslow et al., 2017; Solomons, 2017; Taylor et al., 2017).

Njølstad et al. (2018) found that adolescent patients who tried to explain their situation to others often faced disbelief that they were actually ill, both from health professionals and from those close to them. In some cases, they were accused of being lazy and told they needed to "pull themselves together". In meetings with health professionals, they could be told their experiences were all the result of anxiety, which they did not recognize to be the case (Njølstad et al., 2018). Clery et al. (2022) reported similar findings regarding adolescents who tried to explain and justify to their peers why they were not in school. After finding themselves misunderstood or dismissed as "just being lazy", these adolescents realized that others did not understand the nature of their illness at all (Clery et al., 2022). The experience of not being believed to be ill, especially by one's peers, is also described by participants in Solomons' (2017) research. These young people felt accused by their peers of "faking it", even after receiving a medical diagnosis. Their absence from school was questioned and they were asked why they were in a wheelchair or using crutches. In some cases, friends seemed to withdraw without explanation; later on, it became clear that this was because others thought that the sick adolescents were "faking it". When talking about their illness, these adolescents found their experiences of not being believed and of feeling rejected by their peers particularly painful to talk about (Solomons, 2017).

When describing being disbelieved by peers, adolescents have connected such negative attitudes to the invisibility of ME/CFS and to its fluctuating character, resulting in day-to-day variations in their capabilities and degree of sickness (Taylor et al., 2017). In addition, peers might also be aware that in wider society ME/CFS is often not acknowledged as a real illness. Like those in Solomons' (2017) research, the adolescents studied by Taylor et al. (2017) described how they feared social judgment by others, experienced not fitting in and in general felt lonely, frustrated, anxious and at an emotionally low ebb.

Similä et al. (2021) have also explored adolescents' experiences of everyday life, including school. Adolescent participants drew attention to the lack of knowledge about ME/CFS among teachers and the educational system more generally, noting that this was impacting both their learning and their socialization (Similä et al., 2021). Adolescents also described being overlooked and not listened to, making it a real struggle for them to get the adjustments they needed in their educational plan (Similä et al., 2021). Such negative attitudes within the school system were also described by participants in the research conducted by Taylor et al. (2017), where school was seen as being inflexible, unhelpful, un-empathic and invalidating. As one participant put it, "They stopped paying attention to me and kind of made me feel like a statistic" (Taylor et al, 2017, p.333).

In their systematic review, Parslow et al. (2017) described how children and adolescents with ME/CFS also encountered unhelpful attitudes from health professionals during consultations. Sensing that their condition was being questioned, participants told of feeling unsupported and afraid of ending up with the wrong diagnosis or experiencing a delay in diagnosis. A physician might begin by asking a sick child or adolescent not about their physical symptoms but about their psychological state: whether they felt sad, or had experienced suicidal thoughts, or had even attempted suicide. Or could they simply be accused of being lazy?

This lack of medical support might cause a child or adolescent to miss out on important medical advice, perhaps try to keep active, and end up becoming even more exhausted (Parslow et al., 2017). The review conducted by Parslow et al. (2017) also sheds light on young patients' experience of stigma, resulting from the invisibility of ME/CFS and the uncertainty and skepticism surrounding it. Participants found it difficult to have an illness that was invisible to others and without a medical explanation or agreed symptoms. Facing constant questions from friends, family members and others about their condition, participants found it difficult to maintain or develop relationships with others (Parslow et al., 2017).

Children's and adolescents' own understanding of ME/CFS – in contrast to how others understand it - has been given some attention in previous qualitative research. Parslow et al.

(2017) found that participants tended to view their illness as having a physical cause (for example, an infection) or as having been triggered or accentuated by a traumatic or stressful event. Those who had suffered an infection prior to the onset of ME/CFS spoke of how long this had lasted; they understood the infection to be the cause of the main symptom: fatigue. It would often take a long time to obtain a diagnosis; in the meantime, they would maintain a high level of activity, without paying attention to their body or taking the illness into account. Some understood this combination of having an infection and maintaining normal activity to be the reason for their present condition. Others described how they had experienced traumatic and stressful events in their lives and perceived these to be the cause of their illness (Parslow et al., 2017). While those around them often seemed to question their illness, they themselves had clear views on why they had fallen ill and on what might have triggered the illness. This mismatch between their own understanding and that of others placed an additional burden on them.

2.2.5 Experience of very severe ME/CFS

To the best of my knowledge, no qualitative, no interview-based studies (excepting for the present study) have sought to explore how children/adolescents with ME/CFS experience being severely ill, housebound and long-term bedridden. In a recent personal account, however, Whitney Dafoe (2021) has described his experience of being severely ill with ME/CFS from a first-person perspective. Dafoe, who fell ill in 2004 at the age of 21, found his entire life affected in the most profound way. Characterizing his illness as extremely severe ME/CFS, Dafoe describes how the illness has developed over the years and the ways in which he has been physically and mentally affected by it. Bedridden most of the time, he suffers from severe exhaustion and post-exertional malaise PEM, is extremely sensitive to all kinds of stimulation and must isolate himself. He is too weak to speak, drink or eat, receives food through a tube or intravenous catheter and has difficulty digesting food. He communicates by signs or pre-filled notes. Dafoe describes the way in which stimuli, by connecting his mind to something, push his mind beyond its limits. Even hearing familiar voices implies too much human contact, stirs memories, and forces him to think. For Defoe, the isolation and the disruption to his life as a young adult life have moved him closer to death than to being alive; it is almost as if he does not exist anymore (Dafoe, 2021). “Having severe ME/CFS is so close to being dead. There’s really no other way to describe the experience I have had” (Dafoe, 2021, p. 13).

In this first-hand account of the experience of very severe illness, Dafoe highlights experiences similar to those described in the studies already cited. In his case, however, the extreme degree of suffering he experiences brings him to a liminal state where he is hardly alive anymore. His account has been an inspiration for my own analysis of interview data gathered from those who have been very severely affected by ME/CFS over a long period of time. His narrative has helped me grasp the extent to which very severe ME/CFS may actually threaten human existence.

2.2.6 Experience of recovery from ME/CFS

My literature search has identified only one study that describes young patients' experiences of recovery from ME/CFS (Jelbert et al., 2010). While on the face of it this seems strange, three factors need to be acknowledged: firstly, recovery from this illness often takes a long time; secondly, there are controversies about recommended treatments; and thirdly, those who become healthy again are not often seen by health professionals. In addition, some may argue that it is impossible to recover from ME/CFS, thereby delegitimizing the illness experiences of those who have indeed recovered. Nevertheless, a few long-term quantitative studies have demonstrated that over time improvement and recovery can occur among children and adolescents (Josev et al., 2021; Roma et al., 2019).

Research by Jelbert et al. (2010), which formed part of the systematic review by Parslow et al. (2017), explored the experiences of 5 adolescents (4 girls and one boy) aged 13-18 who considered themselves to be in recovery of ME/CFS. When describing their experiences of being ill and then recovering, participants underlined how recovery was entwined with returning to the things they enjoyed doing, spending time with peers, and feeling positive about the future (Jelbert et al., 2010). However, they also emphasized that the transition from being ill to becoming better and returning to everyday life was difficult and frightening. In more positive terms, they valued the stronger relationship they had developed with their family and felt that they had experienced personal growth and had got to know themselves better as a result of the illness. While some participants still experienced some minor symptoms, in general they felt themselves to have recovered and able to cope with any remaining issues (Jelbert et al., 2010). Participants' current situation of recovery forms the endpoint of the study.

2.2.6 Summing up qualitative studies related to children and adolescents

The qualitative literature on children's and adolescents' experiences of being ill with ME/CFS relies mainly on individual interviews, which are then analyzed through a variety of methodological approaches. Qualitative research illuminates how children and adolescents experience their body in a different way than before; feeling alienated from a body now out of their control, they must adjust to a new and different body. Such research also highlights the impact the illness has on social relationships with peers – at a time in life when peers play an especially important role. Through interviews, children and adolescents convey the degree to which being ill with ME/CFS deprives them of their sense of personal autonomy and freedom; they can no longer do the things they want to do or be with friends or participate in activities they enjoy. As a result, they end up feeling disconnected and excluded from their social world, and often become highly dependent on their family. Children and adolescents tell of how they are disbelieved by health professionals, teachers, and peers, all of whom doubt whether they are suffering from a 'real' illness. This consciousness of being doubted and disbelieved is a further burden they must bear.

Dafoe's first-hand account underlines the long-lasting and profoundly damaging character of being very severely ill with ME/CFS (Dafoe, 2021). The illness profoundly affects all aspects of life, is profoundly isolating and leads to the total disruption of a young adult's life. However, the experience of very severe illness from the perspective of children and adolescents has yet to receive detailed investigation.

Children and adolescents have identified both infections and traumatic events as likely triggers for ME/CFS. They have highlighted the importance for recovery of returning to everyday enjoyable activities and spending time with peers.

Two aspects of the growing body of qualitative research on children's and adolescents' experience of ME/CFS are of particular relevance to this thesis: firstly, the reality of very severe ME/CFS, and secondly, the process of recovery from severe ME/CFS. While one qualitative study has focused on the experience of recovery in adolescents (Jelbert et al., 2010), and research by Solomons (2017) has used a narrative methodological approach to explore adolescents' experiences of living with ME/CFS, to date there has been little qualitative investigation of children's and adolescent's experience of very severe ME/CFS, or of how they recover from this supremely debilitating illness, told from the perspective of being partly or fully recovered. Presently it is assumed that in hindsight, individuals put new meaning to their illness and recovery experiences.

3 THEORETICAL FRAMEWORKS

I begin this chapter by setting out the assumptions regarding reality and knowledge on which this study is based, along with the phenomenological perspective applied (3.1). I then present some general concepts within health science that are relevant to this study (3.2.1), before exploring relevant phenomenological concepts used in this study (3.2.2).

3.1 Phenomenological theoretical perspective

In terms of epistemology (theory of knowledge) and ontology (the classification and explanation of objects of inquiry or fundamental features of reality), this study is rooted in phenomenology, a philosophy which challenges the traditional separation between epistemology and ontology. In addition to understanding ontology and the view of knowledge as mutually dependent, from a phenomenological perspective, the world and subjectivity are seen as interrelated rather than separate; "Subjectivity is necessarily embedded and embodied in a social, historical and natural context" (Zahavi, 2019, p. 67).

Phenomenology is a philosophy that aims to understand *lived experiences:* that is, our subjective experiences in our own specific *lifeworld*. *Lived experience*, a concept developed from the German word *Erlebnis,* or “living through something”, refers to the pre-reflective dimension of human existence (Van Manen, 2017). For the German philosopher Martin Heidegger, the manner and meaning of lived experiences formed the primary question in phenomenology (Heidegger, 1953/2010). The term *lifeworld* signifies the world we live in: the world of lived experiences (van Manen, 2016). It is the world we know, the taken-for-granted world we do not normally question; it is the pre-theoretical world of experience (Zahavi, 2019).

From the perspective of phenomenology, what we know about the world is acquired through our being the bodies we are at any time in life. We gain our knowledge from our embodied lived experiences in various situations that take place in the specific time and space we inhabit (Merleau-Ponty, 1962). For Merleau-Ponty, all our knowledge of the world, including our scientific knowledge, arises from our embodied first-person perspective. In my own case, my understanding of the world and of myself needs to be seen in relation to others. My recognition of the intimate relationship between ontology and epistemology contributes to how I understand the world, how I position myself – and how I choose a certain design for this specific study. From my phenomenological perspective, the starting point for my study involves asking some basic questions: What kind of knowledge do we need to understand the experience of falling ill, being ill and being in recovery from ME/CFS? What is the experience of falling ill with

ME/CFS like? What is it like to be ill with ME/CFS? And what is it like to be in recovery from ME/CFS?'

A phenomenological perspective encourages me, as researcher, to pay close attention to my participants' lived experiences while at the same time seeking to make sense of what they are saying. Phenomenology offers a way to illuminate the lived experiential meanings embedded in an individual's story. Such lived experiences are, for the participants in this research, pre-reflective and pre-conscious; theorization and conceptualization follow later (van Manen, 2016). The assumption here is that the understanding of a particular illness will benefit from that illness being studied as a lived experience (Carel, 2016), before it is theorized, conceptualized and categorized (Merleau-Ponty, 1962).

Phenomenology, with its focus on the body and its understanding that we are at all times bodily situated in the world and interwoven with it, seems especially suited for exploring what it is like to live with ME/CFS. In contrast to the dualistic way of separating the body from the mind, which has long influenced Western thinking, the phenomenological position argues that, since we experience the world through our bodies, it is by being our bodies that we have the possibility to act and respond to the world, with which we are in constant reciprocal interaction. Phenomenology has contributed to a movement away from the dualistic understanding towards an understanding of mind and body as a synthesis, a unit that is our way of existing as bodily beings in the world (Dahl et al., 2019).

3.2 Key concepts used in this study

In this study I have used several concepts drawn from health science. Given the phenomenological theoretical perspective of the research, these concepts are considered in relation to lived experiences. However, I also consider how the concepts are more generally used within the health science field. I begin by briefly introducing some general health science concepts relevant to this study: those of *health, illness* and *recovery* (3.2.1*)*. I then move on to describe and explain the following concepts related to the phenomenological theoretical perspective applied in this study: *lifeworld*, *lived body*, *health, illness, suffering* and *recovery* (3.2.2).

3.2.1 General concepts

The concepts of *health, illness* and *recovery* are central for this study as it sets out to explore the experienced trajectory from health to illness and recovering health. I will now look at each of these concepts and consider their relevance for this study.

The concept of *health,* a basic feature of the modern world, is difficult to define in an absolute and concrete way. The World Health Organization (WHO) has defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1948). However, this has been criticized for being an unachievable goal for most people and lacking important aspects of reality.

During this research it became apparent that, for individuals in recovery from ME/CFS, judging whether one is healthy or not is far from simple or straightforward. Bury (2005) describes health as a taken-for-granted form of wellness of which we are made aware through its absence. For Blaxter (2010), health is a way of focusing on well-being and a person’s ability to live a meaningful life. Such approaches may be more relevant to an understanding of the subjective experience of being healthy (Blaxter, 2010; Bury, 2005).

The concept of *Illness,* too, has been defined in different ways. The American psychiatrist and social anthropologist Arthur Kleinman refers to illness as “the innately humanly experiences of symptoms and suffering” (Kleinman, 1988, p. 3). As he sees it, illness embraces not simply how individuals perceive their own symptoms and/or disability but also the perceptions of family members and of wider society (Kleinman, 1988). From this perspective, the term ‘illness’, with its focus on personal experience of human malady or suffering, can be distinguished from the term ‘disease’, with its medical focus on structural abnormalities, bodily functions and organ systems (Hofmann, 2008), and its attention to what can be observed, examined, and objectively measured.

Similarly, the concept of *recovery* can be understood in ways which vary according to the context and to the specific interpretation of the meaning of disease, illness, and health. From the medical perspective of disease, recovery involves a focus on treatments, curative effects and (functional) outcomes (Mengshoel & Feiring, 2020). While this is an important perspective, it does not contribute to an understanding of how an individual overcomes illness and achieves wellbeing (in other words, it tells us little about recovery from a first-person perspective). Recovery can also be understood as a personal experience, to be explored through a focus on a person’s illness perspective, and how recovery develops as a personal, self-directed process of healing and transformation.

A person in recovery needs to overcome illness in real, everyday situations. This can be aided by transformation narratives which emphasize the agency of the self in the healing process, as opposed to health professionals' contributions to recovery and curative treatment (Deegan, 2002). In this study, the individual's ability to achieve a state in which well-being prevails over illness is understood as crucial for the experience of being in recovery.

3.2.2 Phenomenology: core concepts used in this study

The following phenomenological concepts play a key role in this study: *lifeworld, lived body, health, illness, suffering* and *recovery*. In the discussion that follows, I make particular reference to the insights of the French phenomenologist Maurice Merleau-Ponty (1962), in particular his understanding of *lifeworld* and the *lived body* as the basic source of all our experience and knowledge. As he once wrote:

> I cannot conceive myself as nothing but a bit of the world, a mere object of biological, psychological or sociological investigation. (…) All my knowledge of the world, even my scientific knowledge, is gained from my own particular point of view, or from some experience of the world without which the symbols of science would be meaningless (Merleau-Ponty, 1962, p. viii).

For Merleau-Ponty (1962), the lived body is our basic source of experience and perceptions. We exist as bodily situated beings embedded in the world:

> 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).

Our individual body, then, is not an object among other things in the world, nor is it a passive object of our consciousness. Instead, it is inseparable, interpersonal, sensitive, interpretive and significant in itself (Merleau-Ponty, 1962). We both *are* and *have* a body; we are always subject and object to ourselves. It is through the body that we experience ourselves and our surroundings, that we express ourselves and communicate with others.

Phenomenological philosophers have understood *health, illness* and *recovery* in a variety of ways. Merleau-Ponty (1962) used the notion of the 'habitual body' to describe our normal everyday body, through which we perform mundane activities in a pre-reflective and routine manner, without consciously paying attention to what have become habits:

> Habit is merely a form of this fundamental power. We say that the body has understood, and habit has been cultivated when it has absorbed a new meaning and assimilated a fresh core of significance (Merleau-Ponty, 1962, p. 146).

The habitual body, then, can be understood as the healthy body: the body we trust, the body which can carry out our actions without our awareness. In similar vein, the American philosopher Drew Leder (1990) describes the transparent, taken-for-granted nature of the healthy body, which normally occupies the background of our attention. For the British phenomenologist Havel Carel (2016), health is characterized by the presence of a predictable and obedient body, one which enables an individual to feel comfortable and in control of their body (Carel, 2012). When the body is predictable and we experience control, feel confident and able to trust our body, we achieve what Carel (2016) calls ‘bodily certainty’. In normal everyday life, this bodily certainty is tacit and pre-reflective; it is not something we are conscious of (Carel, 2016).

From a phenomenological perspective, *illness* relates to the lived body and how it is perceived by that specific individual, rather than what it appears to be from the outside. For Carel (2016), illness is all about the question “What is it like?” How is illness experienced and made meaningful by the ill person him/herself? (Carel, 2016, p. 17). In this study, the concept of illness is used in relation to a serious, long-lasting condition which has grave consequences for individuals’ experience of health. Merleau-Ponty (1962) describes how severe illness can be understood as a “complete form of existence” (Merleau-Ponty, 1962, p. 107), gradually embedding itself in one’s being and changing one’s bodily being in the world. Since illness can be understood as a variation of bodily being, we chose to focus on how severe ME/CFS was experienced by the participants, in their specific context.

Leder (1990) describes how falling ill makes us pay attention to our bodies in a different way than we did before. When we experience bodily discomfort, our attention is drawn to our body, which no longer occupies the background of our attention. This may result in a process by which the self increasingly disassociates itself from the body: “Insofar as the body seizes our awareness particularly at times of disturbance, it can come to appear ‘Other’ and opposed to the self” (Leder, p.14). Leder describes this as the *dys-appearing* of the body; the body can no longer be taken for granted (Leder, 1990).

The Swedish philosopher Fredrik Svenaeus adopts a hermeneutic phenomenological approach to explore aspects of health and illness. He uses Heidegger's term "being-in-the-world" to describe the intersubjective nature of our relationship with the world. Rather than being understood as an external thing, the world and the self are seen as intertwined and forming a unity. Our existence and understanding therefore always constitute a "being-in-the-world" (Heidegger, 1953/2010). On this basis, Svenaeus (2022) argues that when our body is healthy and performing as usual, outside of our awareness, we enjoy a "homelike" being-in-the-world. But when the body undergoes change, as during illness, our being in the world becomes "unhomelike". When we fall ill, our embodied way of being becomes one in which we experience ourselves as alienated from self and the world (Svenaeus, 2022). The way the body presents itself in illness, as a kind of otherness, can be experienced in uncanny and merciless ways; it can permeate every aspect of ones being (Svenaeus, 2000, 2019).

Suffering, a concept which plays a key role in this thesis, is of particular relevance when it comes to the experience of illness. While the meanings associated with this concept vary, several authors have argued that suffering is not synonymous with pain, and that pain and suffering can exist independently of one another (Cassell, 1998; Eriksson, 1995).
From the perspective of phenomenology, suffering can be understood as the main way in which brokenness of the body shows itself (Dahl et al., 2019). While suffering can involve different dimensions, it is essentially involuntary and imposed; without this, it would not be understood as something an individual endures. The Swedish theologian and philosopher Ola Sigurdson (2019) describes suffering as an embodied experience or mode of being in the world. Humans' capacity for suffering is essential for an understanding of humans as vulnerable creatures (Sigurdson, 2019).

Svenaeus (2014) describes how suffering, as a mode of being, has the capacity to impact and permeate the entirety of an individual's life. Experienced at different levels, it has implications for our embodiment, our engagement with the world of others, and our core life values (Svenaeus, 2014). Through its ability to overwhelm, suffering undermines a person's struggles to remain at "home" while experiencing a sense of loss of meaning and purpose in life (Svenaeus, 2014).

Exploring the connections between suffering and human agency, Sigurdson (2019) argues that suffering can be seen as a kind of active passivity, in the sense that suffering is not a static mode of being. Suffering is rather a dynamic process of being in the world, one where health can be achieved through learning how to suffer, actively cultivating a particular perspective on the experience and working towards the goal of existential health (Sigurdson, 2019).

In the case of *recovery* from illness, injury and impairment, Leder (2019) has explored "how one can re-possibilize one's life in the face of newfound impossibilities", and how impossibilities can be both limitations and challenges in one's being (Leder, 2019, p. 174). In his article, Leder (2019) identifies three distinct embodied "movements" or progressions in illness and recovery: 1) Bodily "impossibility", which is about the loss of previous capabilities and identities as a result of illness; 2) "I'm-possibility": the discovery, through creative response, of embodied ways of accomplishing or adapting one's goals and reclaiming a degree of liberty; and 3) "I am' possibility": the discovery that there is a level of being – the "I am" - that transcends the bodily and social limitations that illness/injury has made so apparent (Leder, 2019, p. 175).

The "impossibilities" of the body in illness can make it difficult or impossible to do things in the same way as before or be in the same way as one used to be. These impossibilities, while specific and personal for each person, can also become influenced by the responses and reactions of others. Here, an "impossibility" that is invisible can be experienced differently from one that is highly visible to others (Leder, 2019).

While the "I'm-possibility" is presented as the second movement in the process, Leder (2019) cautions that the movements may not necessarily unfold in sequence. This phase is one of reclaiming an existential stance of possibilities. It is a process of re-habituating the body and finding new ways of being in illness. To be able to accomplish actions, one has to learn to use the body in new ways, adjust to new ways of being, and keep one's wellbeing at the forefront of attention. Of particular relevance to this study is the fact that all this unfolds in the context of a body that remains unpredictable, that varies from one day to another. The third movement, "I am' possibility", involves an exploration of transcendence, whether embodied, disembodied or both (Leder, 2019). In illness, the individual can feel alienated from their embodied being and lose their sense of being in control of their body. Leder (2019) argues that, by limiting bodily agency, this can threaten an individual's existence. Through an exploration of transcendence, however, one can challenge oneself to push beyond bodily limitations, to outrun the broken body. The experience of the "I am" re-possibilizes the world.

Cheryl Mattingly, an American social anthropologist whose work is of great relevance to this study, applies a phenomenological theoretical lens in her ethnographical research on occupational therapists' clinical practice. She contributes to the complex field of understanding of recovery from illness by examining how practices can make a difference for personal experiential recovery. Mattingly (1998, 2001) uses the terms "healing drama" and "eventful moments" to describe personal recovery narratives. "Healing dramas" occur when a sick individual experiences or identifies an "eventful moment" which stands out as significant and concretizes what has made a difference for that person (Mattingly & Lawlor, 2001). The individual may not be aware of these moments and their significance at the time they occur, since such moments are temporally embedded in trajectories of illness and recovery. Moreover, a recovery process does not necessarily entail a return to the healthy former body; rather, it means coming to terms with the dys-appearance of the body (Leder, 1990) and noticing available possibilities and hopes for the future (Mattingly & Lawlor, 2001). Mattingly's particular contribution is her emphasis on the importance of narratives. In order to understand how a person makes sense of processes of illness and recovery, she argues, it is crucial to investigate how that person tells a story: how they weave together experiences of the past, the present and expectations for the future to form a coherent story (Mattingly, 1998).

4 METHOD

In this chapter, I provide an overview of the method used in this study. I begin (section 4.1) by describing the qualitative study design chosen before moving on in section 4.2 to outline the study's narrative approach. In the method section (4.3), I describe the recruitment of participants, the characteristics of the women who formed the final sample, and the interview process (4.4). Further, the transcription and work with the interviews (4.5). Data analysis is explained in section 4.6, with specific reference to the thesis' three papers. I discuss ethical considerations in section 4.7 and user involvement in the research in section 4.8. In the final section (4.9), I engage researcher reflexivity to reflect on various aspects of the method and data-gathering process.

4.1 Qualitative study design

Qualitative research is a methodology which seeks to explore and understand human beliefs, behaviour, values and perceptions. It is situated in an interpretative paradigm which seeks to deepen understanding of human relationships and experiences, both culturally and historically. Supported by different theories and philosophies, qualitative research contributes to a richer understanding of our social life-world (Malterud, 2016). I understand paradigm as a concept used to describe worldview and knowledge, a way of breaking down the complexity of the world. As such, it can be understood as a distillation of what we think about the world, (Lincoln & Guba, 1985).

For this research, with its phenomenological theoretical underpinnings, a phenomenological qualitative methodology was utilized. This qualitative research approach seeks to understand and describe the universal essence of a phenomenon by investigating the everyday experiences of human beings, while striving to suspend the researcher's preconceived assumptions about the phenomenon.

Phenomenological qualitative methodology encompasses a range of different approaches, each of them with its specific focus. Since the experience of illness and recovery can be understood as a process that evolves over time, for the purposes of this research I required a methodology capable of tracking and exploring changes over time. For this reason, I opted for a narrative research design, one geared to helping the young women participating in this study to tell their stories and enabling me to undertake a narrative analysis of the content of their stories and the ways in which stories were told.

4.2 Narrative approach

In qualitative research, narrative-based approaches seek to explore stories of particular experiences, along with life histories, documents, and dialogues between people. In the case of this study, a narrative research design, focused on gathering data through semi-structured individual interviews, seemed particularly apt for an exploration of personal stories of lived experiences of illness and recovery, towards the goal of achieving a richer understanding of the meaning of becoming ill and being in recovery. In other words, a narrative research design was chosen because it seemed to offer the best way of exploring the process of falling ill, being ill and being in recovery from ME/CFS. By linking together events in the past and the present, this approach held out the possibility of creating a coherent whole while identifying specific events of particular significance.

Narrative analysis is a method that relies on extended accounts that are preserved and treated analytically as a unit. This contrasts with other forms of qualitative analysis, where often fragments of the text are coded and put into thematic categories (Braun & Clarke, 2006). By focusing on one story at a time, and sequences of action or events within the story, narrative analysis pays attention to narrative meaning, by connecting the past with the present and prospects for the future. The analyst asks *how* and *why* events are made into stories. Attention is paid to particular sequences of action or events that are embedded in the story, and to how the story is structured into an opening, a middle and an ending. The analyst strives to see how sequences are interconnected, how storylines and plots are created which capture meaning. This emphasis on temporality and meaning distinguishes narrative analysis from other kinds of qualitative analysis.

In line with the research question and the aim of the study, I sought a research design and method suited to exploring lived experiences of falling ill, being ill and bedridden for long periods, and being in recovery from ME/CFS. I discovered that narrative analysis offered a way of investigating processes that change over time and of exploring the relationship between the past and the present. I was already aware of how fundamental storytelling is in giving meaning to our experiences and giving them greater coherence. I began to research the field of illness-related narrative analysis, looking for a recipe and a concrete set of steps to guide my exploration. However, it soon became clear that narrative analysis could proceed in different ways, according to the analyst’s research question and theoretical framework – and to their definition of what constitutes a narrative (Riessman, 2008).

I decided to use Riessman’s (2008) narrative analytic approach, with its focus on *thematic* and *structural* analysis. For Riessman, thematic analysis relates to the content of the story; it seeks to respond to the question '*What* does the person tell?' Structural analysis relates to the temporal structure of the story; it seeks to answer the question '*How* is the story told?' (Riessman, 2008).

In this thesis I make a distinction between "*storytelling*" (understood as what people actually tell) and "*narrative*" (that which I, as the researcher, analyse). Although narrative and story(telling) are often used synonymously, I make this distinction so as to make it clear what I am referring to.

Storytelling is an everyday social practice, arising from people's need to tell and share what is happening to them, or has happened in the past. The practice also helps make the world understandable, both to oneself and others. While storytelling can be understood as fundamental way of making sense of experiences (Polkinghorne, 1988), it can serve different purposes for different persons (Riessman, 2008). And while it can engage us in the narrator's experiences and invite us to share their perspective, it can affect the listener in different ways (Riessman, 2008). Storytelling is essential to individuals developing a sense of self; it is important for a storyteller because it offers a way of presenting who we are, exploring who we could possibly be in the future, and shaping how we want to be understood and perceived by others.

Storytelling is nurtured by, and told within, a specific cultural and historical context. The storyteller will often call attention to different aspects, resulting in a story that varies according to time, place and audience (Riessman, 2008). When people tell their story of falling ill with ME/CFS during childhood or adolescence, the content may differ according to whether the story is being told to close friends or a researcher (like myself). The story being told will also change and develop, because our understanding of ourselves evolves over time.

There are several ways of defining '*narrative*'. Jerome Bruner (1986), for instance argues that narrative can give us a way of "ordering experiences" and constructing reality (Mattingly & Garro, 2000). By and large a narrative is sequences of events that are temporally structured, with a beginning, a middle, and an end.

Regarding the use of the term *narrative* in this study, I draw on the ideas of Riessman (2008), who argues that a story, if it is to be used for research purposes, requires interpretation and a narrative analysis to develop a *narrative* that has a meaning and a robust life beyond the individual's story.

Narrating a story is a meaning-making process, in which events are linked together to create a meaningful and coherent whole. Hence, temporality and temporal order are important in narrative analysis to create an understanding of a story's wholeness. The meaning ascribed to each event emerges in the light of the structure of the story as a whole, while the meaning and action of the story is based on the overall perception of all events (Riessman, 2008). Narrative studies rely on extended accounts that are preserved and treated analytically as interconnected units within a story. Such an approach is distinct from other types of qualitative analysis, where (for instance) fragments of the text might be coded and put into thematic categories (Riessman, 2008). By analysing how the story is structured and paying attention to particular sequences of action or events, and how such sequences are interconnected within and across the stories, one can see how phenomena become imbued with importance and meaning.

A narrative traditionally consists, firstly, of a *plot,* which determines the ordering of incidents and forms the core of the narrative. Secondly, it includes *characters* who act out the plot (Riessman, 2008). In line with Bruner (1986), a story consists of landscapes of both action and consciousness, meaning that those involved in an action will feel, think and know (Mattingly & Garro, 2000, p. 2). Understanding a story's plot involves paying attention to the narrator's inner thoughts as well as to the external events being recounted (Mattingly & Garro, 2000).

As Riessman (2008) explains, a person tells a story by weaving together past and present experiences as well as prospects for the future. Recounting past experiences from the perspective of being in recovery, as in the case of the young women in this study, can offer new insights into past experiences, including moments of particular significance from what they ascribe importance today from the perspective of being in recovery or recovered (Riessman, 2008).

4.3 Recruitment of participants

At the start of the recruitment process, my aim was to recruit between 20 and 30 young women aged 16-21 as participants in this research. Women were chosen primarily because of the higher incidence of ME/CFS among females. An additional factor was the funding of the study by the Norwegian Women's Public Health Association, which has a particular interest in women's health. Regarding the chosen age range: there is a reported higher incidence of ME/CFS in those aged between 11 and 19 years (Bakken et al., 2014), and I had hoped to recruit a sufficient number of participants from this age group. In the event I was only able to recruit five such participants by the end of two months. I therefore took the decision to extend the age limit to 30 years.

The final inclusion criteria were as follows:

- Participants were to be young women, aged 16-30, who had been ill with ME/CFS for more than a year but now considered themselves to be in recovery or fully recovered.

- Participants were to have received their diagnosis from a physician.
- Participants were not to suffer from any other severe illnesses.
- Participants had to speak, read and write Norwegian fluently.

It was not necessary for the participants to know/document the criteria used for their diagnosis of ME/CFS.

Table 2 Inclusion and exclusion criteria in the study

Inclusion criteria:
Women 16 – 30 years old Ill with ME/CFS for > 1 year Diagnosed by a physician In recovery or recovered from ME/CFS Able to speak, write and understand Norwegian fluently
Exclusion criteria:
Other severe illness

The choice to include only young women in recovery or fully recovered was based on the assumption that women able to tell their story from the position of being in recovery would provide more in-depth descriptions and contribute accounts of greater coherence than women who were still in the grip of the illness.

An advertisement was placed on the Facebook page of the Norwegian Women's Public Health Associations and on the Facebook sites of groups for young persons with ME/CFS (Appendix I).

The recruitment process took time. Eventually a total of 17 young women made contact and expressed an interest in participating in the study. This total was significantly lower than my earlier goal of 20-30 participants. One reason could be that there were insufficient numbers of women recovering from ME/CFS. Alternatively, those who had recovered might not have wanted to participate in this kind of research. Or perhaps I had not chosen the most appropriate places in which to advertise. At the end of six months, I decided (in close collaboration with my supervisors) to stop recruiting. Additionally, I also understood that in narrative studies, it is not common with a high number of participants.

Of the 17 women who made contact, 13 ended up participating in this study (Table 3). Regarding the four young women who did not participate: One had never received a medical diagnosis of ME/CFS, despite seeking medical help and being ill for more than four years. Another had received her diagnosis from a physician while she was still a child; however, her mother had not wanted this to be included in her daughter's medical record, so it was never documented that she had suffered from ME/CFS. The third young woman made contact but subsequently decided not to participate, while the fourth candidate was aged 32, and was therefore outside of the inclusion criteria.

Women who expressed an interest in participating in this study contacted me directly by email or phone. Those who met the inclusion criteria received a consent letter by e-mail (Appendix II) and were informed that I was a paediatric nurse with long experience of clinical work with children and adolescents.

I considered all 13 participants to have broad experiences of illness and recovery: essential for data gathering (Kvale & Brinkmann, 2015). A sample of 13 participants also seemed compatible with my goal of subjecting all interviews to detailed, in-depth analysis: I would consider it unethical to gather so much data that I would not be able to analyze it in depth or make the most out of each interview. The 13 participants in this study also seemed to contribute with various, nuanced and rich descriptions and information to this study. In addition, the 13 participants formed a reasonably heterogeneous sample, with varying family backgrounds and educational levels and from urban and rural areas all over Norway. I considered having a heterogeneous sample important for gathering a variety of illness and recovery stories and gaining insights into a range of meaning-making strategies.

4.3.1 Presentation of participants

Table 3 (below) provides an overview of the participants in this study. The age is at the time of the interview; onset relates to whether symptoms came suddenly or developed gradually; the duration of illness is given in months; and 'infection' records whether participants had an infection prior to ME/CFS.

Table 3 Participants in the study

Participant	**Age at time of interview**	**Onset**	**Illness duration (months)**	**Infection**	**Status at the time of interview**
(1)	18	Sudden	24		Recovered
(2)	29	Sudden	24	**	Recovered
(3)	27	Gradual	36	*	Recovered
(4)	23	Gradual	60		In recovery
(5)	26	Gradual	24	*	In recovery
(6)	17	Gradual	36	*	In recovery
(7)	29	Gradual	120		In recovery
(8)	22	Gradual	96	**	Recovered
(9)	24	Gradual	120	*	Recovered
(10)	20	Gradual	84	*	Recovered
(11)	19	Gradual	24	***	Recovered
(12)	28	Gradual	72	*	Recovered
(13)	25	Gradual	96	****	In recovery

***** Infectious mononucleosis (IM) known when diagnosed with ME/CFS

** Infectious mononucleosis (IM) not known when diagnosed with ME/CFS

*** Borrelia

**** Unknown infection

The women in this study were aged between 16 and 29 years, with a median age of 24. Three fell ill before the age of twelve; nine fell ill during adolescence; and one fell ill in late adolescence. At the time of being interviewed, 8 of the 13 participants considered themselves to be fully recovered from ME/CFS in the sense that they no longer suffered any symptoms and felt as recovered as they could be. Even so, it was important to them to maintain daily routines, get enough sleep, and for some, make time to rest if they had a very full schedule. These 8 women were either working full-time (or planning to do so) or involved in full-time education (or planning to be so) at the time of being interviewed.

The remaining five participants considered themselves to be still in recovery from ME/CFS. While they felt in much better health, these women not only had to make adjustments in their daily life (such as getting enough sleep, resting and eating regularly); they also had to plan their physical activities and social engagement, to make sure to get enough rest between them. They had never needed to make such adjustments prior to their illness. Four of the five women were studying or working part-time; one was working full-time, despite needing much rest and sleep.

All the participants considered themselves to have been healthy prior to ME/CFS. However, eight of the 13 participants highlighted that they suffered a mononucleosis infection prior to falling ill with ME/CFS. Six out of these 8 participants were aware of having this infection and later going on to fall ill and be diagnosed with ME/CFS. The remaining two did not know whether they had had an infection involving mononucleosis before receiving a diagnosis of ME/CFS. Of the 5 participants who said that they had not suffered a mononucleosis infection prior to their ME/CFS diagnosis, one reported falling ill with a borrelia-related bacterial infection prior to ME/CFS, while another reported having an unknown infection after a stay in Asia.

Importantly, all 13 participants had been bedridden and severely ill during their illness. Some had been completely bedridden for long periods of time, while others had experienced a greater degree of fluctuation in their symptoms and had been only periodically bedridden. Some had endured several years of severe illness, during which they were totally dependent on others. In all cases, parents or other caretakers had actively investigated a range of treatments during the course of their illness.

4.4 Narrative interviews

A qualitative research interview seeks to explore and understand the participant's world in order to get in-depth information about a particular phenomenon. In the case of narrative interviews, there is an additional dimension. Here the aim is to facilitate a person's ability to narrate and choreograph their own story, towards capturing events or moments that are/were particularly important for them while shedding light on the processes involved.

Narrative interviewing invites people to tell stories set within overarching themes (in this case, illness and recovery). The goal is to generate detailed, event-rich and highly personal accounts, rather than short answers or general statements. Such storytelling requires an atmosphere that is conducive, together with an interviewer able to maintain a subtle and discreet presence (Riessman, 2008). The narrator is encouraged to speak freely in their own way and to focus on telling their story rather than respond to an interviewer's detailed questions. There should be space for associations to emerge, and shifts of topics along the way.

Prior to interviews, I developed an interview guide comprising a number of open-ended questions (Appendix III). The questions focused on participants' experiences of falling ill, being ill and being in recovery, and proceeded in chronological order: life before illness, falling ill, being ill and being in recovery. Examples included "Can you tell me about your life prior to falling ill?" "Can you tell me about what it was like to experience falling ill?" "Can you tell me about the experience of becoming bedridden?" "Can you tell me about what it was like to be bedridden?" "Can you tell me about how you first became aware there was an improvement in your condition?" "Can you tell me about the experiences of becoming better?" Lastly, "Can you tell me about your plans for the future?"

These questions were designed to get participants started. Often participants would then proceed to unfold their story, following their own order of events and according to their own tempo. They were encouraged to take their time, reflect, and include aspects they remembered along the way. Sometimes they would rephrase their words, or describe a moment or phenomenon in different ways. Some participants jumped back and forth in their storytelling as they remembered things along the way.

Participants were encouraged to speak freely and with minimal interruption from me during the interviews (Kvale & Brinkmann, 2015). I focused on being an active listener. It was important that I gave them time and allowed for silence or pauses, so they could continue when they were ready, or change the subject if they found it appropriate. This enabled participants to include and reflect upon what they themselves found relevant and meaningful (Polkinghorne, 1988). When I asked questions, the aim was to clarify things or help participants continue their story. Some of the women would pause during interviews, perhaps finding it difficult to continue or, in some cases, having forgotten what they had set out to narrate in the first place. If they had lost their train of thought, I would return to what they had been saying; they would then either continue with that aspect of the story or change the subject. If they paused to say, "This is difficult for me, how can I go on telling?", I would ask questions related to something easier to talk about or just change the subject (for instance, "I can see you have a violin, are you playing?" After a while they would return to telling their story; I understood that they had just needed a break when talking about something particularly stressful.

The interviews took place between May and September 2019. I was the sole interviewer. All interviews took place at a time and place convenient to participants: their home, the University, or the local library (in a private room). Interviews lasted from 60 to 150 minutes. They were digitally audio-recorded and transcribed verbatim by me shortly afterwards. I also wrote a short reflexive summary for each interview. The purpose of this was to capture in its immediate aftermath the non-verbal communication, facial expressions, and the overall atmosphere. These reflexive notes were used as data during analysis of the interviews.

4.5 Transcription

Transcription aids analysis by creating a structure that facilitates an overview. The structuring itself can be regarded as the beginning of the analysis (Kvale & Brinkmann, 2015). However, the process of transforming a recorded dialogue into a written text can involve some practical problems (Kvale & Brinkmann, 2015). I did the transcribing of the interviews by myself, principally because it could be considered as a beginning of the analysis and a good way to develop a thorough understanding of the material. It also helped me to ensure that I captured the details and clues (verbal and non-verbal) relevant for the analysis.

I tried to do the transcriptions shortly after each interview, while my memory was still fresh. In my reflective journal I noted where the interview had taken place and relevant aspects such as how the participant and I had been seated (facing one another or side by side). When listening to the tape and transcribing I would note down why (for example) a silence had occurred or a specific action/movement/facial expression on the part of the participant. For instance, one participant had often hesitated, looked out the window and taken deep breaths when struggling to continue her story. Another participant would stop talking when she cried and make a sign with her hand that she needed a break. In some cases, participants indicated where on their body they had suffered pain when ill.

I transcribed the interviews verbatim, seeking at all times to stay as close as possible to what had been originally said. I included everything, including repetitions and participant’s use of “mm”, eh”, “you know”, and so on. I also noted non-verbal communication: gestures, coughs, laughs and physical movements participants had made to make a point. If they had used irony, which could be difficult to infer from a simple reading of the text, I made a note of their facial expression, adding that they had used their words in an ironic way. I decided to use a specific symbol (three consecutive dots) for pauses or breaks because they occurred quite frequently. Each participant was assigned a pseudonym to ensure anonymity, and the first letter of the pseudonym served to introduce each intervention/contribution by the participant in the transcript.

4.6 Analysis

To begin the process of analysis, I listened to each recorded interview and re-read transcripts several times to gain an overall understanding of the data. I made a timeline of each interview to get an overview and visualize each individual’s process of illness and recovery. I also began adding notes to the timeline to highlight specific events participants had revisited several times during their storytelling, or had described in different ways.

In the *thematic analysis*, the focus was on the content of each interview, and the extent to which events might be grouped together to form themes. Analysis of how thematic events were interconnected in the story enabled the emergence of a specific storyline. Comparing findings across the stories made it possible to see if similar themes emerged in other stories. From this, an overall understanding was developed across the stories. This was expressed as the story's *plot*, which captured what was essential. This was often expressed in a sentence or expression that embraced the whole.

As clarified in Section 4.6.1 (below) - the first of three papers relating to the process of analysis - certain elements formed part of the stories told by all participants. One example was the experience of not being believed when they were suffering, a recurrent theme which was developed into the storyline "Gradually developing unhomeliness and being pushed towards the edge". In this storyline, participants told of how their suffering was not acknowledged and how they were advised to stay active, which in turn resulted in their becoming up more severely ill (paper 1).

In the *structural analysis*, I focused on how events were temporally presented, both within the story as a whole and in different parts of the story. I looked at how each story was structured in terms of a beginning, middle and end (Riessman, 2008). I also explored the connections made between events and how these contributed to achieving a meaningful, coherent whole (Mattingly, 1998).

During analysis, I became aware of participants' rich descriptions of the body when falling ill. Often metaphors were used to convey experiences: for example, "the head did not belong to my body anymore" and "I could not move my legs, as if someone had laid rocks upon them". Here, Svenaeus' (2009) notion of illness as an "unhomelike" being-in-the-world encouraged me to pose the analytical question: "What and how do participants tell about the embodied experience of unhomeliness when falling ill?"

In Sections 4.6.2 and 4.6.3, I explain how my phenomenological theoretical framework shaped and enriched the narrative analysis, helping me make sense of the data and enabling me to address the overall aims of the study.

4.6.1 Paper 1

In the first paper, "Bodies in lockdown -Young women's narrative of falling severely ill with ME/CFS during childhood and adolescence", I sought to explore falling ill with ME/CFS as a process which developed over time.

I started by re-reading the transcripts and listening to the material several times to gain an overall understanding of it. Inspired by Riessman (2008), I asked the following analytical thematic questions: 1. *What are the women telling us about their life prior to falling ill*? 2. *What are they telling us about falling ill and becoming severely ill?* I focused on the sequences of events and experiences prior to, and after, participants' falling ill, and I looked for connections between events to illuminate changes over time. I found that, irrespective of it having a sudden or a gradual onset, falling ill was characterized by a gradual worsening of symptoms, eventually resulting in severe illness. Recurrent events were recorded as excerpted sequences, coded and explored. I then conducted a structural analysis to see how stories were structured and how sequences were presented in a temporal, causal order to create coherence and meaning (Riessman, 2008). Here, I used the phenomenological lifeworld perspective to enrich my understanding of the process and experience of falling ill. Here, Svenaeus' phenomenology of illness, especially his notion of embodied 'unhomeliness', proved particularly relevant. Additionally, I made use of Simone de Beauvoir's concepts of immanence and transcendence to shed light on the women's way of being when falling ill in a world shared with others (de Beauvoir, 2000).

The emergent of common themes encouraged me to present the analysis in the form of a shared narrative, illustrated by excerpts from different interviews. A composite narrative about the process of falling ill was developed on this basis. This comprised three storylines: "The active and meaningful life I used to live"; "Gradually developing unhomeliness and being pushed toward the edge"; and "Left abandoned on the side lines".

4.6.2 Paper 2

In the second paper, "A suffering body, hidden away from others: the experience of being long-term bedridden with severe ME/CFS in childhood and adolescence", I looked more closely at the experience of being severely ill and long-term bedridden with ME/CFS. In this paper, my narrative analysis drew both on Riessman's (2008) thematic analysis and on her structural analysis, which draws on the work of Labov & Waletzky (1967). I found this combination particularly suited to the task of capturing key events and moments, as narrated by participants, and also to analysing how these stories were organized, so as to understand the range of meaning associated with being long-term bedridden.

I began by reading the transcripts and listening to the material several times to gain an overall understanding of it. I then I conducted a narrative thematic analysis (Riessman, 2008) of each interview. I focused on one interview at a time, attempting to identify relevant recurring events to gain a sense of order. Mattingly's (1998) understanding of *telling moments* proved relevant here. I asked the following analytical question: *What kind of events or telling moments appear central to the experience of being bedridden?* By doing this, I identified and analysed sequences of events in the stories which seemed relevant to the experience of being bedridden. In the structural analysis, each interview was analysed in detail in order to see how the stories were structured and how telling moments were put together. For Riessman (2008), following Labov & Waletzky (1967/2003), there are six key elements of a "fully formed narrative": abstract (subject summary); orientation (information about the situation); complicating action (explaining what happened); resolution (consequences or how it ended); evaluation, (what it meant to the narrator); and coda (looking at the event from the present perspective). Structural analysis revealed that while these six elements featured in participants' stories, key elements were combined in different ways. Each participant organized their story in their own specific way, highlighting different aspects of being bedridden and making different points when telling their story. When people tell their story, this is often not done in a structured way, especially if the story has not been told before or told to just a few close persons. By analysing how my participants' stories were organized - how key elements were arranged and ordered - I developed an understanding of the different meanings participants made of being bedridden.

In addition to Merleau-Ponty's phenomenological insights, I was helped by van Manen's (2016) conceptualization of the fundamental structure of the lifeworld as comprising four universal themes or existentials: lived body, lived relations, lived space and lived time.

My findings were presented in the form of four storylines: 1) *Ambivalent responses to the presence of others; 2) A body on the edge of life; 3) An eternity in the dark;* and 4) *Recasting painful memories of being bedridden and alone.* I argue that, on the basis of the findings, the experience of being long-time bedridden with ME/CFS can be understood and communicated as a plot, with the title "A suffering body, hidden away from others".

4.6.3 Paper 3

In the third paper, "The fragile process of Homecoming - Young women in recovery from severe ME/CFS", I performed a narrative analysis inspired by Riessman's (2008) thematic and structural analysis, and Mattingly's (1998) concepts of healing dramas and telling moments. The focus was on events participants found especially meaningful for their process of becoming better. In line with Mattingly (1998), such events were understood to be 'telling moments' in which participants came to understand themselves and their situation in a new way. This in turn encouraged them to perceive fresh possibilities and take new actions.

For the thematic analysis I asked the following analytical questions: 1. *What are the young women telling about the experience of being in recovery*? 2. W*hat kind of telling moments or events emerge from their accounts?* In the structural analysis I focused on the temporal structure of each story, how events were organized and drawn together to form a meaningful whole. Throughout the analysis I was especially inspired by Svenaeus' phenomenology of illness and Gadamer's understanding of health (Gadamer, 1996/2018; Svenaeus, 2009). During the process of comparing and contrasting, two distinct storylines emerged. In line with the narrative tradition (Riessman, 2008), I decided to present these storylines via an in-depth analysis of two stories which I considered particularly nuanced and suitable for illuminating the lived experience and process of recovering. Although details differed, both storylines were apparent in the stories of the other participants.

The first storyline was a well-structured, finished, and coherent storyline about a young woman who considered herself to be recovered from ME/CFS: "Exploring and building an understanding of bodily limits and capacities". In contrast, the second storyline was more unfinished and not fully developed. The participant who told it considered herself to be considerably better from ME/CFS, but her process of recovery is still ongoing. Hence the title: "Bodily awakening of self: from a dark place to a fragile and unfinished process of reuniting with one's own body and world. Despite the contrasts between the two storylines, they share a common plot: "Struggling from being "unhomelike" to gradually becoming a homelike being-in-the-world". This represents one possible way of understanding what the experience of recovery process from ME/CFS can be like.

4.7 Ethics

The study was approved by the Norwegian Regional Committee for Medical and Health Research Ethics (REK) (2017/2451) (Appendix IV) and the Social Science Data Service (REF 477809) (Appendix V) and was conducted in accordance with the Helsinki Declaration Act and Norway's Health Research Act. Gaining such approval was important to ensuring the quality of the study. The Service for Sensitive Data (TSD), was used as required for collecting, working with and storing sensitive data. The main supervisor (KSG) and I had access to the transcribed material; the three other authors involved in the study had access to the anonymized transcribed material.

The participants were not previously known to me. All were informed from the start (the beginning of the recruitment process) that I was a paediatric nurse with 22 years of clinical experience with children and adolescents in hospital wards. They also knew that I had had some experience of working with ME/CFS patients and also of conducting interviews.

Beauchamp & Childress (2013, p.13) identify four ethical/moral principles that together constitute a framework for ethical research: (1) respect for autonomy (respecting and supporting autonomous decisions); (2) non-maleficence (avoiding causing harm); (3) beneficence (a group of norms pertaining to relieving, lessening, or preventing harm and providing benefits and balancing benefit against costs and risks); and (4) justice (a group of norms for fairly distributing benefits, risks and costs). While all four principles are relevant for this study, those relating to autonomy and non-maleficence were particularly apposite.

Regarding non-maleficence (Beauchamp & Childress, 2013), the principle of 'not doing harm', it was clear that, for participants, taking part in this study could potentially become an additional emotional burden. They would be asked to think/go back to a very difficult time in their lives, and this might bring back bad memories and make them feel sad. A further problem was the fact that ME/CFS remains a medically unexplained illness whose sufferers often confront disbelief and scepticism on the part of others. Participants might well have experienced this during previous encounters with medical professionals and might therefore have negative experiences of sharing their stories with a health professional such as myself.

Regarding the principle of respect of autonomy: from the first contact with the participants, it was important to me to maintain a sensitive and careful attitude. Each participant was carefully informed about the study, encouraged to ask questions, and assured that they could withdraw from the study at any time if they changed their mind. Given the fact that interviews might be stressful for participants, I made it clear that they could decide what they would and would not talk about, and that they were the ones making decisions. During discussions on when and where to conduct interviews, I was careful to accommodate participants' needs and preferences.

Although I was previously unknown to all participants, they were aware that I was a paediatric nurse with long clinical experience of working with children and adolescents, and additionally, that I had experience of doing interviews. I think my previous interviewing experience may have contributed to a calm atmosphere where both participant and I found our "roles" quite quickly.

During interviews, I sought to be constantly aware of how difficult and even traumatic the process might be for participants. I did not push them if they changed the subject or just stopped talking. Instead, I let them pause and simply waited for them to resume their storytelling. Often, they would return to telling about severe illness later in the interview, using different words or metaphors in their description. It seemed that telling their story might be difficult for them when they lacked the vocabulary to explain the complexities.

As each interview unfolded, I strove to be sensitive, observant, and calm. By paying close attention to the participants, I was able to judge the impact I might be having on them, and this enabled me to adjust the tempo and my choice of questions/prompts. Some participants needed a bit more time when narrating, and/or needed more frequent breaks along the way. This often resulted from their becoming emotional or tearful. If this happened, I would ask if they needed a break -- or wanted to change the subject. Other participants would relate their story non-stop, and I would barely need to make any intervention, other than to offer a supportive “Yes, I understand” or “mm”.

It was especially important to pay attention if participants told of something that was potentially harmful to them. Fetterman (1983) describes the notion of “Guilty knowledge and dirty hands”: that is, the possibility of becoming privy to information that requires you to make some form of intervention (Fetterman, 1983). In a clinical setting, where responsibilities and obligations are clearly defined, there is a better possibility for such follow-up action. But during interviews one can never really predict what will happen or what kind of stories one will hear. My main supervisor and I had agreed (in advance) a plan for any situation where I became concerned about a participant. The agreement was that I would do a follow-up, stay in contact with the person and talk about their seeking medical advice if necessary.

I made an agreement with all participants that I would contact them one week after the interview to make sure they were doing well. Additionally, they were told to contact me if they wanted to talk after the interview. When I contacted the participants after a week, I found all of them to be doing well. All were appreciative, even relieved, about having had the possibility to share their stories. All emphasized that it was important for them to be part of this study and to perform the interview, despite this being tough and emotionally difficult for them. Overall, they described it as a positive experience, and a kind of relief. They knew that the research concerning personal experiences of recovery in ME/CFS is sparse, and they recognized the need for this kind of study. What made a major impression on me was that several of the participants spoke of never having disclosed their story about ME/CFS to anyone outside their family circle or closest friends. I realized that this might not have been the case if they had suffered a more recognized illness.

Throughout the research process, participants’ names, location, education level and other potentially disclosing aspects were anonymized. Each participant was assigned a pseudonym.

4.8 User involvement

User involvement has played a key role in this study, particularly in the process of developing suggestions for clinical implications. In this study, I use the term “user” to embrace two categories: persons with their own experience of illness and recovery in ME/CFS, *and* experienced researchers and health professionals engaged in clinical work with ME/CFS patients. The reason for including both was to ensure that the user involvement was broad-based, covering both personal experiences and professional understandings.

Norway’s specialist ME organization (Norges Myalgisk Encefalopati forening), was invited to participate in the development of this study. The organization commented on the project plan, especially in relation to how the project met their needs and ideas. Their comments on the aims and design of the project, and the concepts used, were constructive and contributed to several changes to the project plan. However, differences of perspective surfaced, especially around the understanding of ME/CFS as an incurable illness. Here, the organization took the position that focusing on participants who were in recovery or had fully recovered might be seen as hurtful or even provocative by people still suffering from ME/CFS.

Naturally, it was not my intention to provoke or cause any harm to those still suffering from ME/CFS. That said, there are young persons who, having been previously diagnosed with ME/CFS, *do* become better and do recover. It remains my opinion that it is important to study ME/CFS from the first-person perspective of those now in recovery or fully recovered, since this contributes to a broader understanding of the illness.

For the next stage of user involvement, I set up a user panel comprising three members. One was a young woman, Madhi Bareksten, who herself had recently recovered from ME/CFS and could therefore represent patients. The other two members were both experienced clinicians at Oslo University Hospital, working with the patient group: Ingrid Bergliot Helland (a physician specializing in paediatrics) and Berit Widerøe Njølstad (an occupational therapist). These three read and went through specific parts of the material (excerpts) and later drafts of each of the three articles and gave feedback. This was to ensure that the descriptions in the articles were written in an understandable and credible way.

It was my responsibility to inform and guide the three members of the user panel, to ensure a shared understanding of their role. The feedback from the three users was mostly positive, with just a few instances in which the panel suggested small changes, such as rephrasing portions of text. The panel’s contribution was nevertheless important; it enabled participants’ narratives to be considered from different perspectives, including the point of view of a group whose members co-operated closely. In my opinion, user involvement improved the quality and relevance of this study.

4.9 Researcher reflexivity

Reflexivity in research can be understood as the thoughtful, continuing, and self-aware analysis of the intersubjective dynamics between the researcher and what is being investigated. It requires, on the part of the researcher, a critical self-reflection of the ways in which their preunderstandings, social and cultural background, former experiences, assumptions, positioning, and behavior may impact the research process (Finlay & Ballinger, 2006). My preunderstandings of the topic of this research are intertwined with my professional life as well as who I am as a person. While preunderstandings are not to be confused with bias in research, it is important that they are made clear. By engaging reflexivity throughout the research process, preunderstandings can become a relevant and meaningful resource (Malterud, 2001). Engaging in reflexivity, is of major relevance to the trustworthiness in this study, (followed up in chapter 6.2).

In this study, reflexivity was engaged at every stage of data gathering and analysis. Prior to beginning the research, I reflected on my role as researcher, sought to identify my preunderstandings, and explored my motivation for doing the study in the first place. I reflected on what I already knew about the topic, my previous experience of doing interviews, my life as the mother of two children, and the 23 years I had spent as a paediatric nurse taking care of children and adolescents in the surgical ward and also meeting children and adolescents suffering from ME/CFS in the clinic. I also wrote down my preunderstandings about qualitative research and the chosen method.

One preconception I brought to this study was that recovery from ME/CFS in children and adolescents was rare. I started searching for stories told by those who had recovered and also for research about ME/CFS and recovery. I found several personal stories about recovery, but little published research about recovery in ME/CFS. I did not understand why this should be so at the time. Other important preunderstandings derived from my paediatric nursing work. In many respects, this work has been about communication and creating good relations, towards the goal of ensuring the best care possible for patients. I have often met parents and children in stressful, critical situations, and I have seen how difficult this can be for them, both at the time and afterwards. I felt humble when I thought about what it would be like to meet these young women who had been ill during childhood and adolescence.

When doing my Master’s degree, I had done interviews with young adults with a well-recognized illness, in contrast to these young women. I was glad to have had this experience, but at the same time I had a feeling this time the interviews might be a bit different, given that participants might have had difficult experiences with health professionals and perhaps had not received appropriate help care. When writing down my preunderstandings about ME/CFS in general, it became clear to me that, as a result of my clinical experience in children’s surgical wards, I was strongly influenced by biomedical understandings of health and the disease perspective. I tended to think in terms of disease versus healthy as having no disease. I also assumed that a condition requires an ‘objective’ cause in order to be treated. I think this strong biomedical focus has connections with the hierarchy within which I work on surgical wards, where surgeons tend to be the ones giving diagnoses and making decisions about curative treatment.

I think I was also influenced by the view of ME/CFS as a scary and mysterious illness, striking at random in the most terrible way (as reported in the media). ‘If we are going to treat the patient, we need to know the cause and treatment’ has been my starting point for many years. At the same time, this has been mitigated by a nurse’s focus on with caring, on being sensitive and aware of other people’s suffering. This was perhaps a key taken-for-granted assumption on my part: one that I needed to be aware of throughout the research.

From the very start, my preconceptions and understandings of ME/CFS were challenged. One particularly tricky arena was that of language and use of terminology. Through my work in the hospital clinic, I was used to paying attention to my vocabulary when talking to children and carers, avoiding concepts or terms that could be construed as offensive or frightening. I often used the concept ‘healthy’ with children in recovery after surgery, for instance, to check that they were feeling better (even if they had a chronic condition).

During the recruitment process, I was contacted by a possible participant, to whom I replied by mail. When writing to her, I used the Norwegian word “frisk”, meaning ‘healthy’, to describe recovery. Later I understood that this was a very sensitive word and one it was inappropriate of me to have used; the possible participant wrote back to tell me that she felt offended because I had used that word. While this young woman was feeling better, she was still struggling with symptoms of ME/CFS and clearly in no condition to be interviewed. I answered her, apologizing for my insensitivity in using that term. She made contact again and in a very friendly way wished me the best of luck with the study, and I wrote back expressing my hope that she would continue getting better. I drew an important lesson from this: be careful with the words you use when communicating with persons suffering from ME/CFS - especially when they are getting better.

A striking feature of several interviews was that participants had told few people outside their family circle about being ill. Nor had they explained that their illness was the reason for their long periods of absence from school. Most participants became quite emotional and cried a lot during the interviews. I would often ask if they needed a break, but all of them decided to carry on, explaining that it was nice to tell someone about their experience. They became emotional for several reasons. Some described finding it difficult to think back to the difficult situation they had been in. Others were reminded of the years of life they had missed through being bedridden. Others got emotional just by thinking about other people they knew who were still suffering from ME/CFS. One participant subsequently emailed me to explain why she had cried so much during her interview: she had been reminded of the intensity of her symptoms when ill and how they had made her feel far from being the person she knew herself to be. Her words made a major impression on me. I remembered how hard she had struggled in her daily life, even when in recovery, and how she had done her best to not let others know about the adjustments she had to make.

I, too, found the interviews emotionally difficult. Like most people, I found it difficult to listen to personal accounts of severe illness during childhood and adolescence. It was particularly hard to listen to participants' accounts of not being believed, and of their difficult meetings with health professionals. Additionally, it was very hard listening to the stories of those who had lain bedridden in a darkened room for years, almost totally isolated from others. I understood I had to acknowledge to myself that "it is only human to react to the stories being told, and I am not a machine". Additionally, it was challenging to conceal how emotional I myself became when participants were sharing their stories and crying. I decided to be open about this at the start of each interview, saying something like: "You'll probably see that I get affected by what you are telling me". During interviews I might say: "It's an overwhelming story you are telling": and "Please just continue when you feel ready".

I tried to maintain my role as a researcher and to strike a balance between this and the role of being a paediatric nurse who was used to providing care and support to patients and their carers. I strove to listen as attentively as possible, remain empathic and supportive, and stay focused on the participants while remaining conscious of the aims of the interview. In many ways I think I tried to do what I do in the clinic: create a good atmosphere for them in which to share stories by being alert, showing that I care, and letting them tell their stories at their own pace and in their own way.

In many cases interviews proved emotionally difficult for me; at points tears would run down my cheeks. My reactions naturally affected the participants. But while some participants may have been less open about recounting their experiences, I think most of the women were well aware that their stories were emotionally difficult for others to listen to. In a way, my reactions may have helped them feel that their suffering was being acknowledged by an empathic listener. In that sense, my tears may have helped them feel freer to narrate their stories.

Before I began this study, I think I was a bit naïve. I had assumed that if you were a child or adolescent living in Norway who became severely ill you would get help from the health care system of which I am a part. During my second interview, the participant told of a very difficult meeting she had had with health professionals. When she was describing her serious symptoms, the physician present ignored her, turned to her mother and whispered questions at her. The mother became very upset, and the two of them left the room. When she asked her mother what had happened, her mother told her that the physician had asked if the daughter could have psychiatric problems or was just making it up. After that interview, I sat wondering why this participant had not been examined. Why had they not run any tests? Further interviews revealed that this kind of attitude and lack of understanding from health professionals was far from unique. I began to understand a bit more about the complexity of suffering from a medically unexplained illness that some health professionals do not believe in, and how people's suffering may remain unaddressed where no biomarkers of disease are found.

In qualitative research, it is important to make the research process explicit so others can understand how the knowledge is produced. In other words, the transparency of the research process is crucial (Malterud, 2001), and increasing the trustworthiness of the study. I acknowledge that I, as the researcher, influenced every stage of the research process; my prior experiences, background, theoretical stance, methodology, and pre-understandings of the subject all influenced how I conducted and constructed the research (Finlay & Ballinger, 2006). During interviews, the way I acted, and my relationship with the participants undoubtedly influenced participants' responses - and therefore the findings of the study.

5 SUMMARY OF THE FINDINGS

In this chapter, the main findings of the three articles, which constitutes the basis of this PhD thesis, will be presented. The first article focuses on the process of falling ill, the second, the experience of being severely ill and long-term bedridden, while the third paper looks at the process of recovery.

5.1 Summary article I

S. H. Krabbe, A. M. Mengshoel, W. Schrøder Bjorbækmo, U. Sveen and K. S. Groven (2022). Bodies in lockdown: Young women's narratives of falling severely ill with ME/CFS during childhood and adolescence. *Health Care for Women International*, 1-23. https://www.tandfonline.com/doi/full/10.1080/07399332.2022.2043862

The aim of this study was to explore what young women now in recovery from ME/CFS have to tell about their experience of falling severely ill during childhood and adolescence. Thirteen women aged between 16 and 29 years participated in the study. Most of these participants had suffered an infection prior to falling ill with ME/CFS. Participants' stories, as revealed in semi-structured, narrative interviews, were subject to narrative analysis and informed by phenomenology. Although there were differences between the women's stories, the emergence of common themes led to a presentation of the analysis in the form of a shared narrative. This comprised different excerpts from interviews presented in temporal order. On this basis, a composite narrative about falling ill with ME/CFS was developed. This suggested that young women's experiences of falling ill with ME/CFS could be understood and communicated with reference to three themes. The first, titled *The active and meaningful life I used to live*, describes the women's healthy life prior to illness and the absence of body-related concerns. The healthy body was something taken for granted and their habitual body was mostly in background of their attention. The second theme, *Gradually developing unhomeliness and feeling pushed towards the edge*, describes a gradual or sudden onset of illness, characterized by remissions, relapses and unpredictable fluctuations. The gradual deterioration of their body was experienced as a scary and unhomelike being. The women, who were advised to stay active, pushed themselves to keep their exhausted body functioning and to live up to their own and others' expectations. However, on viewing this retrospectively, the women realized that this had made their illness even worse. The third theme, *Left abandoned on the sidelines*, describes how each woman's fragile body became increasingly unfamiliar, uncanny and unrecognizable, leaving the women no longer able to take care of themselves. They described this as being pushed on to the sidelines of their body and their life; unable to reconnect with their body, they found themselves in a kind of "lockdown". Eventually they experienced their bodies as so profoundly fragile that they seemed to be approaching an existential limit, with no prospect of recovery.

5.2 Summary article II

S. H. Krabbe, W. Schrøder Bjorbækmo, A. M. Mengshoel, U. Sveen and K. S. Groven. A suffering body, hidden away from others: the experience of being long-term bedridden with severe ME/CFS in childhood and adolescence. (Submitted)

The purpose of this study was to explore what young women who are in recovery from ME/CFS tell about their experience of being long-time bedridden from ME/CFS during childhood and adolescence. Informed by a phenomenological theoretical perspective, it applied a narrative approach involving the analysis of narrative interviews with thirteen women between 16 and 29 years old. The narrative analysis was inspired by thematic analysis as outlined by Riessman (2008), and in addition a structural analysis, which draws on the work of Labov and Waletzky (1967). The women's stories were explored with reference to Merleau-Ponty's phenomenological insights and van Manen's (2016) view that the fundamental structure of the lifeworld comprises four universal themes or existentials: *lived body, lived relations, lived space* and *lived time.* The findings suggested that the experience could be understood and communicated as a plot, titled: "A suffering body, hidden away from others". In line with the narrative tradition the results were presented in the form of four storylines, which capture the accounts given by the women participants: 1) *Ambivalent responses to the presence of others; 2) A body on the edge of life; 3) An eternity in the dark;* and 4) *Recasting painful memories of being bedridden and alone.* The four storylines illustrate how the lived body, lived space, lived time and lived relation are woven into each other in participants' storytelling about their experiences of being bedridden. These young people struggled with different kinds of bodily discomfort, pain in particular, and also suffered through being forced to isolate themselves from others in what they portray as an eternity. With limited access to others, these young people experienced an intense degree of loneliness and suffering, one that disrupted their sense of belonging to the world and pushed them closer to the edge. This is arguably what makes it so existentially difficult to be long-term bedridden with ME/CFS in childhood and adolescence.

5.3 Summary article III

S. H. Krabbe, K. S. Groven, W. Schrøder Bjorbækmo, U. Sveen and A. M. Mengshoel (2023). The fragile process of Homecoming - Young women in recovery from severe ME/CFS. International Journal of Qualitative Studies on Health and Well-being. *International Journal of Qualitative Studies on Health and Well-being*, *18*(1), 2146244. https://www.tandfonline.com/doi/full/10.1080/17482631.2022.2146244?src=recsys

The aim of this study was to explore experiences of recovery narrated by young women who had fallen ill with severe Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), during childhood and adolescence, with the focus on what they say about their past experiences from the perspective of the present. The women were between 16 and 29 years old, and 13 women participated in the study. A qualitative narrative approach informed by a phenomenological theoretical perspective was adopted to explore what the women found significant and meaningful in their recovery process. The narrative analysis was inspired by Riessman's (2008) thematic and structural way of analyzing, and by Mattingly's concepts of healing dramas and telling moments. During the process of analysis, the interviews were compared and contrasted, and differences in how the recovery process was narrated were identified. Drawing on the narratives of two participants, the findings are expressed in two storylines. The first, *Exploring and building an understanding of own body's limits and capacities*, describes how a young woman made a complete recovery by patiently testing her body's tolerance and working to create a more confident self. After years of illness and experiencing a vulnerable and strange body, she starts to explore her body in a safe world with others, supported by significant helpers. By exploring her body through movement, she gradually develops confidence in herself, along with a sense of belonging. She still has to makes various adjustments in her daily life, but the illness is slowly fading into the background, and prospects of a possible future are beginning to appear. The second storyline, *Bodily awakening of the self: From a dark place to a fragile and unfinished process of reuniting with one's own body and world*, describes a participant's complex journey from being severely ill for years to being able to explore possibilities for action. Here, the young woman is still very much on guard, worrying about and trying to make sense of setbacks. Both storylines reveal participants' need to refamiliarize themselves with the world, regain a sense of belongingness, and explore new life possibilities. Overall, recovering from ME/CFS emerges as an inter-personal, contextual, fragile and nonlinear process of homecoming, based on gradually rising, bodily-based self-knowledge.

6 DISCUSSION

In this discussion, I focus on the process of falling ill, being ill and being in recovery from ME/CFS in the light of previous research and through the lens of phenomenology. The findings in this study are narrated from the vantage point of young women who are considerably better or fully recovered from ME/CFS. The narrative plots suggest that falling ill involves a gradual bodily lockdown, that being ill involves not only suffering but also being hidden away from others, and that being in recovery from ME/CFS is a fragile process of homecoming.

On the basis of these findings, falling ill, being ill and being in recovery can be understood as a complex and dynamic process where different dimensions of suffering and attunement permeate one's being in the world. From a phenomenological perspective, suffering is an embodied experience or mode of being in the world which, rather than being simply related to illness, is also an essential dimension of the complex process of recovery. This suggests that illness/suffering and recovery should not be considered as dichotomies but rather as modes that exist side by side and impact one another. Throughout the whole process, illness, suffering and recovery cannot be separated, although what is in the foreground or background of attention shifts along the way. This is an intersubjective process of experiencing the collapse of one's being in the world and then striving to rebuild it, with or without informed or expert support.

The process of falling ill, being ill and being in recovery involves a constantly shifting lifeworld, with recovery strongly dependent on an individual's starting point and what happens along the way. The sorrow and joys of life exist side by side; in recovery the need is to focus on progress and moving forward while retaining a perspective on the past. As Leder puts it, "to heal is to reintegrate what has disintegrated, to enlarge what has shrunk" (Leder, 2016, p. 12). In recovery, the individual moves from hopelessness to discovering possibilities, from suffering to healing. But movement is rarely in one direction: at one moment the individual may sense they are reclaiming their body and are once again the agent of their own life, only to find, the next moment, that their agency is slipping away again. Recovery from ME/CFS is a fragile, dynamic complex process, and must be understood in relation to the experience of falling ill and being ill from ME/CFS.

The young women's experiences of falling ill (paper 1) and their experiences of being severely ill (paper 2) can be understood as a gradually developing brokenness of the body (Dahl et al., 2019). Here, the body ends up more or less fully incapacitated and broken down, and remains broken for an extended period. The former healthy, habitual and taken-for-granted body gradually vanishes, and is replaced by a broken body that can no longer act in the same way as before. The body's customary confident relationship with, and engagement in, the world becomes interrupted and impeded. Awareness of the body is now firmly in the foreground.

The participants described living healthy lives prior to illness, as captured by the storyline "The active and meaningful life I used to live" (Article 1). Their embodied way of being was familiar; mundane activities were pre-reflective, routinely done, and performed largely outside of awareness. This was a habitual way of being in the world, which seemed to be taken for granted. From the perspective of phenomenology, when we are in good health we exert agency over our body: we ourselves are the ones generating an action (Gallagher, 2000). On that basis, we can plan and perform our actions in the world. We might cause a chair to be moved, or we might be the one generating a specific thought in our stream of consciousness. We control our bodily movements and, through this, what happens in our environments (Gallagher, 2000, 2007). However, in order to have agency, we need to know that we are the one causing the "thing" to happen; if we do not understand that we are causing it, we are not agents.

Prior to falling ill, the young women could generate actions, control their bodily being in the world and take part in everyday social activities, just like others of their own age. However, when the body is gradually breaking down, embodied experiences become unfamiliar, and the body is perceived to actively resist a continuation of the habitual life. Attention is drawn to the body, or parts thereof, so that the body is no longer in the background of our consciousness. This 'dys-appearance' of the body interferes with what we are doing (Leder, 1990). The body take on an agency of its own; it resists or rejects its habitual way of being. Thus, illness contributes to a disruption in the women's sense of agency over their body (Gallagher, 2007), they increasingly lose their sense of being in charge of their own body and life.

The process of falling ill is captured by the phrase "Gradually developing unhomeliness and being pushed towards the edge" (Article 1). Here, the storyline reveals how participants, all of whom were just children or adolescents at the time of falling ill, gradually became aware of their illness. Whether all of a sudden or more gradually, they found themselves struggling with inexplicable bodily changes, disrupted social relationships and loss of control of their body, despite their strenuous efforts to maintain that control. The women's embodied ways of being now became unfamiliar and inexplicable; with attention now focused on the body, performing even the mundane routines of everyday life became difficult.

The process of falling ill (Article 1) involved feeling increasingly 'unhomelike' in the world (Svenaeus, 2011). Previous research has shed light on this experience of lost control over an increasingly unfamiliar body in ME/CFS in adolescence: for example, Njølstad et al. (2018). Solomons (2017) describes how such individuals feel trapped in their own body, becoming more or less passive victims of illness (Solomons, 2017). The struggles of adolescents to adjust to their changed body, the fatigue, and the degree to which life has become unpredictable have also been explored (Parslow et al., 2015; Parslow et al., 2017).

In line with previous research and our findings in Article 1, the experience of falling ill with ME/CFS seems closely connected to the suffering that stems from losing control of one's body and confronting an unfamiliar way of being in the world. The findings of this study additionally suggest that a body in the process of breaking down actively resists any continuation of 'life as normal'; such a body protests as it struggles to maintain the routines of everyday life. While the participants could in a way be understood as victims of illness, they were far from being the passive victims described by Solomons (2017); rather, they continued to struggle, they strove to endure. To that extent, they still exercised a degree of agency over their bodily being in the world.

The process of falling ill involves a body becoming more and more alienated and a life that is increasingly unpredictable. For the participants in the current study, all this took place when they were children or adolescents, with little experience of serious illness and therefore no points of comparison that might help them understand what was happening to them. Nor did they have a vocabulary with which to explain their experiences to others. In the gradually developing brokenness of the body that characterises falling ill with ME/CFS, the body seems to have an agency all of its own: it seems to be on a mission to rest and sleep. Despite this, however, the body never seems to regain energy or feel refreshed. In this context, suffering increasingly occupies the foreground of the sick individual's attention.

From a phenomenological perspective, suffering is an embodied experience or mode of being in the world (Sigurdson, 2019). On this basis, bodily suffering emerges as the main feature of "brokenness" in ME/CFS (Articles 1 and 2). The suffering mode of being takes over the sick person's entire life: their embodiment, their engagement in the world of others, their core life values (Svenaeus, 2014, 2017). Suffering does not affect simply the body: it also changes the way the suffering person perceives the world, along with their way of being in it.

The Finnish-Swedish nurse Katie Eriksson (1995) draws on humanistic science to shed further light on the phenomenon of suffering. Erikson (1995) emphasises how challenging it is to describe the nature and central features of suffering, given its complexity and the fact that each individual's experience of it is unique. According to Erikson (1995), and in line with our findings, suffering is not synonymous with pain; suffering can occur in the absence of pain, and vice versa. Further, suffering can be seen as a natural part of life and as an expression of our grief over what we have lost or are about to lose (Eriksson, 1995). To understand suffering, one must place the suffering in relation to one’s own situation and to something that could make it possible to manage suffering (Eriksson, 1995).

From the perspective of medicine and bioethics, the American physician and bioethicist Erik J. Cassell (1998) describes how suffering can be triggered not simply by disease or trauma to the body but also by a range of unwanted events: changes to one’s social roles, for example, or losing one’s sense of belonging or sense of self. Those who suffer find themselves existing within a suffering universe (Eriksson, 1995) in which suffering comes to permeate every aspect of their being (Cassell, 1998). At the same time (as mentioned at the start of this discussion) elements of recovery are also present. Suffering is also about searching, reclaiming, and discovering where possibilities may lie.

As revealed in our findings (Articles 1 and 2), participants’ suffering, although individual and unique, shared certain aspects in common. One aspect was not having their suffering believed by others (Article 1). Another was the experience of loneliness and lacking a sense of belonging (Article 2). In general, participants lacked the power to make changes or to resist what they were up against. However, they retained sufficient agency to hold fast to their own integrity, make certain choices - and stay alive.

Leder (2019) describes the newfound impossibilities of the body in illness and how one can become thwarted from doing things the same way as before. The impossibilities of the body in illness are personal and often challenge one’s sense of identity. But as Leder (2019) underlines, they are also impacted by the responses of significant others, and by the way the main features of an individual’s illness are interpreted. Leder’s arguments resonate well with the experiences of the participants in the present study. All suffered severe bodily discomfort which was invisible to others and often disregarded, downplayed or even found incomprehensible. This contributed to the women’s sense of powerlessness and loss of sense of agency. Accordingly, when the women were advised to stay active, they ignored their personal embodied experiences (Article 1) and strove to keep up their everyday activities. (In retrospect, they realised that they should have paid attention to their suffering body and stopped struggling to live as before.)

In addition, participants would have benefited from greater support from experienced professionals as well as others around them. As Erikson (1995) notes, the experience of being disbelieved or “not taken seriously by others” can contribute to a sense of not existing for others, so that the sufferer ends up in a hopeless, powerless situation. When efforts to make contact and describe the situation prove pointless, the sufferer may well feel their identity has been stripped away.

Participants narrated how, in an effort to live up to others’ expectations, they struggled to keep up their everyday life and continue their relationships with others (Article 1). As a result, they experienced being *pushed towards the edge of their bodily limits.* Similar cases of children and adolescents being disbelieved by health professionals and others have been highlighted in previous research (Njølstad et al., 2018; Parslow et al., 2017). In some cases, children were told to change their behaviour; in other cases, their condition was questioned and/or attributed purely to psychological causes (Njølstad et al., 2018; Parslow et al., 2017). Children and adolescents have described the limitations in the medical support they received and how this resulted in their missing out on important medical advice, so that their condition worsened, and their exhaustion became more profound (Parslow et al., 2017).

Negative experiences of encounters with health professionals, as presented in the current study, have also been reported by adults suffering from ME/CFS (Anderson et al., 2012; Dickson et al., 2007; McManimen et al., 2019; Tellmar et al., 2022). Their experiences offer important insights into what it is like for sick adults not to be taken seriously and how this may lead to them avoiding future contact with the health care system (Tellmar et al., 2022). Being treated in this way seems to create distance between individual patients and the health care system. Since a core task of the health care system is to alleviate suffering, one wonders where exactly patients are supposed to turn when they are in effect abandoned.

As set out in Article 1, participants gradually found themselves overwhelmed. Their body was in breakdown, they were ensnared by severe illness, and their embodied way seemed in the process of shutting down. This bodily shutting down is illustrated through the storyline "Left abandoned on the sidelines" (Article 1). When illness dramatically changes an individual's capability and habitual way of being, it closes down possibilities for the future and restricts visions of life ahead. For participants, the onset of illness brought with it the disruption of their habitual way of being; existence now became 'unhomelike' and unbearable. The women found themselves entering a kind of bodily-lockdown state of being in which the body protected itself from any external influences, even if this meant being in darkness for long stretches of time. In short, a body in lockdown ends up hidden away in the dark, no longer susceptible to any pressure from outside (Articles 1, 2).

In this situation, the women's bodily agency can be understood as an effort to protect the self by cutting all ties to the outside world. However, the women ended up experiencing disconnection not only from their own body but also from their surroundings. This disconnection has a very serious dimension to it: its ability to exacerbate suffering. No one chooses this kind of disconnection, unless it is understood as the last lifeline to stay alive. For participants, disconnection from others became essential because contact with significant others resulted in even greater suffering (Article 2).

This finding, which has not been described in previous studies, contributes to a richer understanding of the seriousness of bodily suffering associated with severe ME/CFS. For participants, entering the darkness and "being hidden in the dark" was like going deeper into a hole. But at the time it felt like the only solution, the sole possibility when one is being pushed to the edge. Once in the darkness, one has no idea how long the stay will prove, or even if there is a possibility of returning to the light. Expectations about the future and what it may hold simply melt away.

Now in the grip of severe ME/CFS, participants now found themselves dependent on caregivers, and bedridden for long or short periods of time (Article 2). The storyline "*Left abandoned on the sidelines"* illustrates how participants end up suffering out of sight and hidden away from others. In addition, the storyline "*Ambivalent reactions to the presence of others*" reveals how sick individuals who are hypersensitive to their surroundings still yearn for contact – only to find that an experience of relational focus simply adds to their suffering. In other words, when one is living in the dark, having contact with someone with whom one is emotionally close makes the task of distancing oneself and objectifying the body emotionally difficult. Hence, such contact is best avoided.

Whitney Dafoe's (2021) autobiographical account of falling ill at the age of 21, and still being ill 18 years later, exposes the profound losses he suffers and how his suffering involves isolation and being cut off from his young adult life. In his account, he describes the difficulty of being near others, mainly because he is hypersensitive to any kind of stimulation, like the participants in our study. Dafoe finds it particularly difficult to be exposed to familiar voices or the presence of loved ones. This kind of human contact stirs deep emotions and can be too much to bear (Dafoe, 2021).

For Dafoe, it is not always the stimuli themselves that create difficulties. Sometimes the problem lies with the way in which a stimulus connects the mind to something or even pushes the mind beyond its limits. This seems similar to our finding (in Article 2) that contact with others can lead to suffering because it makes sick individuals experience difficult feelings that are too traumatic to endure.

Close emotional contact, then, can lead to further suffering. At the same time, however, avoiding close emotional contact can also add to suffering. Either way, this amounts to unbearable suffering in isolation.

According to our findings (Article 2), participants' embodied experience in isolation is fragile. Seemingly small events or changes in their world threaten them with disintegration and intensify their suffering in an overwhelming way. This is illustrated in the storyline "Body on the edge of life" (Article 2). This embodied way of being seemed to push participants into a mode where living was barely possible: a state somewhere between life and death, almost an end to one's existence.

In his personal account, Dafoe (2021) provides descriptions of severe ME/CFS that could be understood in a similar way. For example, he describes how his suffering moves him closer to death than to being alive. He loses himself to the illness; it is almost as if he does not exist anymore. However, while our findings (Article 2) highlight a close to death-like mode of being, participants in our research still exerted a measure of bodily agency, despite their overwhelming weakness and exhaustion. This bodily agency persists despite being profoundly disrupted. The body is still protesting at every stimulus and every activity, whether being fed via a nasogastric tube or being moved from one room to another. It begs to be heard.

In line with Merleau-Ponty (1962), our actions and bodily movements, and the way we see, think or act, are always directed towards something and towards specific goals. Bodily intentionality makes us become aware of different bodily movements, enabling us to make sense of them and thereby unify them into meaningful action (Merleau-Ponty, 1962). To find oneself in a state of profound suffering, perhaps even on the edge of life, is to experience profound changes to one's spontaneous way of acting and one's freedom to act. From an external viewpoint, "A body on the edge of life" (Article 2) may appear to be a body on a mission to lie still and find peace. However, even here the body retains its agency. And this agency must be directed towards something: in this case, towards protesting and resisting the changes or threats the body is confronting. The body is never "just lying still"; there are too many things going on, invisible to external observers. While the storyline "Hidden in the dark" (Article 2) could be construed as involving a further step into the darkness, it could also be interpreted as the hope of taking a step towards the light. The plot "A suffering body, hidden away from others" (Article 2) can therefore be seen to encompass an act of care, an effort to protect a fragile body.

The storyline "An eternity in the dark" illustrates what happens in the wake of this act, revealing how this eternity spent without almost any human contact does not seem to heal the body. For Leder (2022, p.138), healing involves a "re-integration of various dimensions of the lifeworld that has been torn asunder by bodily breakdown." There is a sharp contrast between participants' lifeworld prior to illness and their experiences and lifeworld during their "eternity in the dark". Given the lack of integration with their former lives, it seems as if nothing heals in the dark; on the contrary, the darkness seems to make the suffering body even weaker and more vulnerable. From the outside, it might seem that changes or events in the sick individual's immediate environment are what are being perceived as threats. For the sufferer, however, the actual threat is being hidden in the dark. Removing all stimuli and protecting the person from life outside the dark room only seems to make them weaker and more fragile. Despite all the body's efforts to rest and sleep, and thereby regain strength, do not help. "An eternity in the dark" is not enough.

Lying hidden away from others, participants were deprived of nearly all human contact. In this forced isolation, they were not able to share their experiences with others (Article 2). The isolation entailed loneliness and a profound lack of belonging. Our experience of our body is inherently both intersubjective and individual; each of us is a social and relational being, situated in a specific time, place and cultural context and always inter-subjectively engaged in the world we inhabit (Heidegger, 1953/2010). The plot "A suffering body, hidden away from others" (Article 2) describes an experience taking place at a time in life when participants needed contact - and needed to share their story with others. As Arthur Frank (1995) highlights, serious illness is a "call for stories". In similar vein, Cheryl Mattingly reminds us that "The need to narrate the strange experience of illness is part of the very human need to be understood by others, to be in communication even if from the margins" (Mattingly, 1998, p.1).

This need to narrate and to share stories becomes even more important during periods of transition (for example, from childhood to adolescence and thence to adulthood), where sharing stories can provide a way of making meaning and coherence (Kleinman, 2020). As they lay hidden away from others, participants found themselves battling emotionally difficult feelings and loneliness, without being able to share this with others. Those around them saw simply a biological body, rather than the body as it was actually lived and experienced. As a result, participants were not understood to be suffering from loneliness.

The experience of loneliness can result in serious suffering; it is a distinctive sense of exclusion from something or the experience of not belonging or relating to the social world (Ratcliffe, 2022). Loneliness is when one's sense of being deprived of something, or missing something or someone, becomes unbearable. In other words, loneliness is about the absence of something else, the absence of feeling part of something (Ratcliffe, 2022).

The storyline "Recasting painful memories of being bedridden and alone" (Article 2) illustrates the effort of trying to visualize a different and better experience when one is suffering from loneliness. Making meaning of being "hidden away" is difficult when the individual is unable to share the experience with others. In this situation, a new memory – one which can be shared – offers the possibility of making better sense and meanings of what happened in the past. In the new memory, what happened in the past becomes a shared experience, one that is "seen" by someone else, who understands what the experience really involved (in this case, profound loneliness). The suffering is still there, but the sufferer is now receiving the comfort they needed; they are no longer alone.

In its deepest sense, suffering can be understood as a kind of death, an experience where something is taken away from us in a concrete or symbolic sense (Eriksson, 1995). As Erikson highlights, the fact that deep feelings of loneliness may not be seen by anyone intensifies the resulting suffering. To be profoundly lonely and not have that recognised by others is almost akin to being ‘dead’. Our findings (Article 2) suggest that experiencing extreme loneliness when hidden away in the dark can be understood as an almost existential death.

For individuals stricken with severe ME/CFS, loneliness and isolation appear to be essential parts of the experience. This has been underlined in previous research involving adolescents with ME/CFS, where young patients describe their isolation, sense of being disconnected from their former lives, and sadness at not being able to spend time with friends (Jelbert et al., 2010; Njølstad et al., 2018).

Creating a new memory of being ill, as described in the storyline, “Recasting painful memories of being bedridden and alone” (Article 2), can be understood as a way of trying to heal the broken body from the perspective of being in recovery from illness. As part of the effort to understand the brokenness of the body, particularly during the process of recovery, an individual may seek to turn the experience into something that it is possible to handle (Eriksson, 1995). Our findings suggest that this can involve transforming old memories, to the point of creating something that verges on the unreal.

For Eriksson (1995), suffering can be either endurable or unendurable. In the former, where the individual retains some degree of health, suffering and health still belong together; they are not dichotomies. Making suffering endurable, along with regaining a sense of health and wellbeing, are important features of recovery (Article 3). However, the storyline “Recasting painful memories of being bedridden and alone” (Article 2) can also be understood as a way of trying to make one’s suffering more endurable, as a strategy aimed at regaining health.

Leder (2022) describes various healing strategies individuals can employ in an effort to orient themselves towards the body in illness and their shifting lifeworld. A healing strategy could involve “freeing oneself from the body” or “embracing the body” (Leder, 2022). While it might seem challenging to employ healing strategies when suffering permeates every aspect of one’s being, our participants developed strategies that differed according to the situation (Article 2 and 3). From the perspective of being in recovery, they seemed to apply strategies geared towards healing the suffering body. The storyline “Recasting painful memories of being bedridden and alone” (Article 2), can be understood as a way of “freeing oneself from the body”, of telling oneself that the body “I have” does not need to “have me”. Here, the individual perceives the possibility of “transcending”; instead of being consumed by suffering, one can free oneself from the body by asserting dimensions of self that transcend or outrun the body

(Leder, 2022). Creating a new memory of being ill, as described in the storyline (Article 2), could be a way of “transcending” endurable suffering, of being able to return to the body “I have” without being swallowed up by the suffering. This can also be understood as a way of creating and contributing to a more “homelike” being in the world (Svenaeus, 2011).

What would it take for the broken body to leave the darkness? What would it take to make one’s unendurable suffering more endurable? Despite lying broken in the enduring darkness, the body gradually seems to change its mission. Its agency shifts towards an effort to heal; through the healing, the process of recovery can begin (Article 3). In this third paper, the process of recovery from ME/CFS is described as “The fragile process of homecoming”, with the plot: “Struggling from being unhomelike to gradually becoming a homelike being in the world”. Here, participants described how they sought to make their bodily suffering more understandable, and their unendurable suffering more endurable. They engaged in an exploratory process by which they sought to re-gain belongingness by moving from an ‘unhomelike’ being-in-the-world to one that was more ‘homelike’ (Svenaeus, 2011).

As the findings reveal (Article 3), being in recovery was an inter-personal, contextual, fragile and nonlinear process in which the participants slowly and persistently built a more homelike being in the world. Making one’s being more homelike can also be understood as an attempt to heal one’s suffering being in the world, make one’s unendurable suffering more endurable, and gradually regain a sense of wellbeing. According to our findings, the young women searched for ways to gain bodily knowledge and become able to trust their body again, as illustrated in the storyline: “Exploring and building an understanding of bodily limits and capacities” (Article 3). In this storyline, participants described how health professionals familiar with ME/CFS made important interventions throughout the process. As a result, participants experienced support and strong relationships, and gradually felt more confident when exploring their limits and capacities. Their explorations of the suffering body involved learning about, and understanding, setbacks as they gradually regained trust and reconnected with the body.

Mattingly and Lawlor’s (2001) notion of “healing dramas” contributes to the understanding of recovery from ME/CFS. For these researchers, recovery may be more about reclaiming the body and exploring new body-related possibilities than about a return to the healthy former body. In recovery, an individual may experience “healing moments”: insights or turning points that may not be noticed by others (Mattingly & Lawlor, 2001). Leder (2019) makes a similar point when discussing the “I’m-possibility” experienced during recovery from illness. After the threats severe illness has made to one’s identity and repertoire of possibilities for action, the “I’m-possibility” is about finding new ways of being in illness and reclaiming an existential stance that is open to possibilities. It is about being able to accomplish actions, even if these differ from those performed prior to falling ill. And it is an always intersubjective process, one where one learns to adapt to new ways of using the body, and to a new way of being in illness that can alter from day to day (Leder, 2019). This altering of one's bodily way of being seems particularly relevant in the case of an illness like ME/CFS, where setbacks and fluctuations are frequent and seem an integral part of both the illness and the recovery process.

In essence, then, the process of recovery from ME/CFS involves refamiliarizing oneself with one's body, modifying and reclaiming one's bodily being, and searching for new ways to act and be in the world. During recovery, our participants live with, through and 'as' the body they are; their embodiment is inescapable (Leder, 2016, p. 10). Awareness of the body alters, and the focus of attention shifts from what is happening in the surrounding environment back to the body, which once again comes to occupy the foreground. While such shifts of focus are something we all experience, in the case of those recovering from ME/CFS this shifting perspective may be related to bodily changes, discomfort, or worries about possible changes. Should a focus on the body come to preoccupy an individual's awareness, this may signify that the body is once again turning into a "problematic object" (Leder, 2016). The moment we become conscious of our body, "being our body" changes into "having our body", and the body becomes manifested as an objectified, even strange 'thing'. It is not necessary to experience bodily discomfort for this to happen; worrying about the possibility of discomfort may once again push the body to the foreground of attention, making it difficult to focus on anything else. Whether or not bodily discomfort is present, the focus is still very much on the body.

This underlines the complexity of the "I'm-possibility" process for those recovering from severe ME/CFS. This process appears to involve an understanding of embodied being in illness and in recovery. Recovery from ME/CFS is therefore strongly connected to the experience of illness. For as long as an individual retains a great fear of setbacks, recovery is both complex and fragile. But as Leder (2019) emphasizes, recovery is about being able to accomplish actions, learn new ways of using the body, and accept one's limitations so as to reduce stress and gain a sense of peace. Even if new actions are very simple and modest, they will be rich in meaning for the suffering person. It could be a case of just thinking about moving one's hand, planning how to do so, and then after a while actually performing this action (Article 3). By a process of slow, brick-by-brick effort, individuals discover the possibility of acting in new ways - and slowly learn to trust the body once again.

This process involves coming to understand the inevitability of setbacks as a way of making one's being more acceptable and predictable. Leder (2016) describes how he sought to befriend his injury and pain by asking his body "what do you want?" and entering into negotiations with it, despite this somewhat dualistic separation of the body from "me".

Our findings (Article 3) suggest that the "I'm-possibility" of the body involves the slow acquisition of a new-habitual body, and recognition that it is possible for the broken body to carry out new habitual actions. Even a body that has been badly broken can be transformed into something new.

In the storyline: "Exploring and building an understanding of bodily limits and capacities" (Article 3), the exploration of the body in illness emerges as a healing strategy where one is "embracing the body". Following Leder (2022), it can be seen as the "I am-with" experience of the body: one where, rather than trying to free oneself from the broken body, one opts to embrace it and attempts to come to an acceptance of it. Changing one's way of thinking about the body makes it possible to once again be "with the body", rather than battle against it - even if this means losing a sense of control over one's bodily being. By accepting and exploring one's bodily being, one can slowly begin to heal, to build a more homelike being in the world (Article 3).

For participants, the process of recovery took different forms (Article 3). The women's struggle to make sense of their bodily being and its response to movements and stimuli such as bright light and sound is described in the storyline: "Bodily awakening of the self: From a dark place to a fragile and unfinished process of reuniting with one's own body and world". This storyline reveals how a broken body is brought back, or reconnected, to life in a world shared with others. This bodily "awakening" was fragile and often took place in the absence of support and long-term follow-up from health professionals familiar with ME/CFS. Participants were aware that their attempts to reconnect with their body and the outside world might fail, and the uncertainty and fragility was at times overwhelming.

These experiences of awakening can be understood as "healing dramas" (Mattingly & Lawlor, 2001). Although often invisible to others, they resulted in the exploration of body-related possibilities. Despite their fleeting character and the uncertainty surrounding their outcome, these small healing offered participants hope for the future and restored a measure of trust in their suffering bodies. They seemed to signify a movement forward; participants described experiencing a sense of wellbeing, which encouraged them to expose themselves to new experiences and regain a sense of belonging. Over time, their suffering slowly became more endurable. At the same time, the women experienced doubt and setbacks which caused them to lose hope and once again feel disconnected from their bodily being. Somehow, they had to find it within them to resume the struggle.

For individuals who are severely ill with CFE/MS, there is a striking profundity to the process of recovery, as illustrated by the storyline "Bodily awakening of the self: From a dark place to a fragile and unfinished process of reuniting with one's own body and world" (Articles 2 and

3). That participants compare this bodily awakening to “rising from the grave” suggests that the experience of being severely ill and bedridden in a darkened room is somewhat akin to an experience of “being in the grave”. Leaving the grave is fragile and uncertain; it involves being constantly on guard. This kind of guard is very strenuous and the fear of ending up in the grave again is overwhelming.

This storyline points to a strong connection between recovery and bodily agency. In order for participants to once again experience agency, they had to know they were the ones causing thing to happen. Without that, they would still view themselves as passive “victims”, vulnerable to setbacks that happened without any warning or apparent cause.

Adolescents’ accounts of experiencing setbacks during the process of recovery from ME/CFS have been explored in previous research. In the study by Jelbert et al. (2010), adolescents describe how they were aware of possible relapses, accepted them as a natural part of the recovery process, and felt confident about being able to cope with them. These adolescents described how they had to pay attention to their body and adjust their level of activity, but nevertheless considered themselves to be recovered (Jelbert et al., 2010). These findings indicate that adolescents who know how to deal with setbacks, accept them and understand their body and view themselves as fully recovered from ME/CFS. This is borne out by the findings of the current study (Article 3), which underline the importance of gaining bodily knowledge and being able to make meaning out of setbacks during recovery. On this basis, individuals can re-experience a sense of bodily control and reconnection with the body while understanding their own limits and capabilities.

However, our findings (Article 3) do not reveal the same degree of acceptance of illness as that articulated by the adolescent participants in the research conducted by Jelbert et al. (2010). Our findings (Article 3) underline the gradualness of the process of reuniting with the body, gaining bodily knowledge, and regaining bodily agency. This slowness may be connected to the length of time our participants had been severely ill prior to recovery: while the participants in Jelbert et al.’s study had been ill for between one and a half and two years, most of the participants in our study had been ill for much longer periods, in some cases more than ten years. Additionally, it is not known how severely affected the adolescents in Jelbert et al.’s study had been, as compared with the participants in our study. This makes comparing the findings of two different studies complicated. However, given the general paucity of research on recovery from ME/CFS, both studies contribute valuable insights into young people’s experience of recovery from ME/CFS.

In the findings presented in Article 3, the process of recovery emerges as a self-driven process of gaining bodily knowledge, with some participants receiving strong support from health professionals familiar with ME/CFS throughout the process. In a recent study, Kalla & Simmons (2020) describe women's experiences of recovery from ME/CFS as finding one's own way of healing, despite receiving little expert support and despite being told by medical professionals that recovery was impossible. This lack of support from health professionals was also described by some of our participants (Article 3). Although these participants received some help during the "awakening" period, for the most part the absence of support greatly affected their recovery process.

In the study by Kalla & Simmons (2020), women participants described how they had engaged in a search for different routes to recovery, and had embraced the stories of those who had already recovered from ME/CFS. This process involved various strategies. Participants might give themselves permission to heal, changing from a focus on illness to a focus on possibilities, hope and moving towards wellness (Kalla & Simmons, 2020). They described being highly focused on taking charge of the situation, gaining "self-agency" and autonomy in their lives (Kalla & Simmons, 2020).

The notion of recovery as a self-driven process is also highlighted by adult participants in research by Brown et al. (2017). Here, too, participants searched for ways to recover without help from health professionals. They measured their progress in a systematic way, comparing what they could do compared with their situation prior to falling ill. They also focused on changes and what they could actually do (Brown et al., 2017). This process, together with the changes they experienced, seemed to help them to describe recovery for themselves. Over time they came to consider themselves as closer to being fully recovered than to being ill (Brown et al., 2017).

As with our findings (Article 3), these studies (Brown et al., 2017; Kalla & Simmons, 2020) underline recovery as an ongoing process of exploration which can take a long time. This previous research also highlights how recovery is a strongly self-driven process, where each individual strives to gain bodily knowledge, explore possibilities for action and make necessary adjustments in life.

Our findings (Article 3) add nuance to this overall picture by revealing that those entering the process of recovery after "awakenings" but without support from health professionals seem to experience a more troublesome and fragile journey. Our findings also indicate that, in the case of recovery from ME/CFS, much depends on where an individual is coming from. In the storyline, "Exploring and building an understanding of bodily limits and capacities" (Article 3), participants who experienced support from health professionals, caregivers and "peers" spoke of how they gradually felt more confident in their bodily being while exploring their limits and capacities. This kind of support was often experienced as a type of "teamwork"; for example, young women would use the words “we” or “team” when describing their experiences. This support seemed to give participants a sense of belonging and the possibility of healing from their previous loneliness.

It bears emphasis that participants in the current study were younger than those in the research conducted by Brown et al. (2017) and Kalla & Simmons (2020). In addition, they may have been more severely ill than the adults in those two studies. It is possible that younger persons who have been extremely ill may face greater difficulty than adults when it comes to “taking charge” of their own illness without the support of health professionals.

The findings of the current study underline how Leder’s (2019) concept of the “‘I am’ possibility” contributes to an understanding of the way in which individuals in recovery from CFS/ME challenge themselves to expand their bodily capability. The “I am’ possibility” should be understood as an exploratory process and a level of being that transcends the embodied being’s limitations in illness (Leder, 2019). By engaging in transcendence there is the possibility of exploration without rejecting the body. Here, one “exercises” the way one is thinking about the illness and one’s limitations, opening oneself up to experiences beyond bodily limitations resulting from illness. Havi Carel (2014) is referred to by Leder and she describes how our thinking is always free: whatever the state of our body, we can engage in imagination, feel emotions and develop our intellect (Leder, 2019, p. 183-184). Possibilities exist even when there are major embodied limitations. In the “I am’ possibility” lies the possibility of rekindling hope for the future and imagining what that future might be like.

If given the possibility, children and adolescents can “take charge” and exert agency, even with a broken body. However, in order to experience agency over their own lives they need to be seen as the individuals they are and that they are full of resources, instead of passive victims to the illness and that they possess possibilities -it is never without hopes and possibilities. As described in this thesis, being ill with ME/CFS and recovering from it is a complex and demanding process, with many layers of suffering. The compassionate support of others is vital at every stage, since an individual who suffers alone may well feel they have been abandoned. Each sick individual needs to experience compassion - and be seen.

Sigurdson (2019) reminds us that suffering is part of human agency and is a dynamic mode of being in the world. If being given possibilities and support, the broken body will be able to carry out new habitual actions; suffering will become endurable and existentially easier to live with over time. But for this to happen, the individual needs patience, endurance and the ability to sense small changes that seem almost invisible but may be of long-term significance. If riding one’s bicycle downhill is the only riding one is capable of for now, the fact that one is able to ride a bike at all can be a deeply meaningful experience. As the individual in recovery gradually regains agency over their own actions, life slowly begins to be more predictable, hope builds and thoughts turn to plans for the future.

6.2 Theoretical and methodological considerations

This section presents and discusses some relevant methodological and theoretical considerations in this thesis. The section begins with discussing the trustworthiness and transferability of this thesis and include a discussion of strengths and limitations.

6.2.1 Trustworthiness and transferability of findings

The concepts used to assess the quality of qualitative research (Malterud, 2001) differ from those used to evaluate quantitative research. In the following I have used the concepts of *trustworthiness and transparency* to explore key methodological issues raised by this study. In general, qualitative research needs to show evidence of being systematic, trustworthy and reflective. Trustworthiness is closely related to *transparency*: ensuring that each step of the research process is clear and understandable to others, so that they can critically assess the quality of the work. Trustworthiness is about making explicit and transparent every stage of the research process: its design, how data was collected and then analysed; the findings and how they are presented; further, there is a need for consistency between the epistemology, the research question, the methods used, and the reporting of findings (Lincoln & Guba, 1985).

It is of essence to assess and approach the validity of this study, from within its situated perspective, tradition that frames it and its epistemology and theory that inform the study (Riessman, 2008). Based on the narrative analysis informed by phenomenology, I approach the trustworthiness of this study based on the position of narrative research and informed by the theory of phenomenology. In relation to narrative approach, two levels of validity are especially important to focus on, the story told by a research participant and the validity of the analysis - or story presented by me as the researcher (Riessman, 2008).

Trustworthiness has been emphasized throughout the research process. I have tried to make explicit what was done at each stage, and to document and be transparent about the reasons for making specific choices and how theories informer the process. In all three articles, I made an effort to describe the process of recruitment, collection of data, the participants and the steps of the analysis. I was aiming for the research process to be transparent and clearly documented to its readers. In the thesis, I have sought to explore in greater detail the differences between the story from the participants' perspective (what participants tell) and the narrative (what I as the researcher analyze). This distinction rests on the assumption that, for research purposes, a story requires narrative analysis and that a narrative should reflect a robust life beyond the individual's story. Throughout the analysis I sought to capture potentially essential aspects of the experiences and construct possible interpretations of the experiences. I have also made a point of describing how we, as the authors of the three articles, collaborated and challenged one another throughout the analytic process to gain insight and discuss possible different understandings. I consider that this ability to supplement and contest each other's understandings and statements forms an important part of the reflexivity and strength in this study. While there will always be different understandings of experiences, this focus on the trustworthiness of the research has for me resulted in interesting reflections and insights. In addition to the collaboration among us authors, we invited and involved a young woman in recovery (not participating in the study) and two health professionals working with the patient group to read through the findings and interpretations in the study. This is described and elaborated on in chapter 4.9. This was an important part of the research process and a way of checking referential adequacy in the preliminary findings.

Given that the findings of this study have been interpreted and understood within the theoretical framework of phenomenology, it was important to describe this in some depth in all three articles, along with the reasons for choosing to combine a phenomenological framework with a narrative approach. To strengthen the trustworthiness of the research, when presenting the findings in the three articles I used rich, multiple and often long excerpts from the accounts, given by all the participants to illustrate variation and range in the data. This was also important as a means of showing the connection between the material and the storyline, plot and conclusion being drawn in each article.

In this study, the focus has been on describing what is involved – in all its richness and nuances -when children and adolescents fall ill with ME/CFS, suffer long periods of severe illness and then finally embark on the road to recovery. There are several reasons for this. Recovery from ME/CFS, even in the case of young persons, remains a matter of controversy. Debate continues as to whether recovery from ME/CFS is even possible. In this thesis I have chosen not to focus on the discussions taking place in the medical field, on social media and among patient organizations. This important focus could have given a contribution to this thesis and insight into the ongoing debate this thesis, limitation in this thesis. For me, the main task has been to describe how severely ill the participants in this study have been, how many of them were ill for long periods of time, and how they have spent years recovering from ME/CFS. As I see it, there is no doubt that my young women participants have been severely ill with ME/CFS, or that they are now in recovery or fully recovered. If I had decided to focus purely on the process of recovery, the question of whether these women had had ME/CFS in the first place might have been of greater relevance.

Transferability refers to the extent to which findings and insight from the study, can contribute to wider body of knowledge and apply to, or have relevance for, contexts groups or settings beyond that of the specific study (Lincoln & Guba, 1985). Malterud (2001) uses the concept of external validity when discussing this question. Transferability refers to generalizability of the findings and one can naturally not know where the findings might be "transferred to". However, for me as a researcher, by aiming for thick descriptions, in which I have focused on, it might be easier for others to evaluate transferability of this study, by recognizing similarities and differences to other situations and contexts. There are several aspects to consider here, including the research question itself, the participants selected, the theoretical framework applied and the method of analysis. In this thesis, the intention was not to describe all possible narratives about falling ill, being ill and being in recovery from severe ME/CFS. A narrative study can never capture all circulating narratives, and this thesis explores just a handful of personal accounts. However, the fact that the stories told by the young women shared several common features enhances the relevance of the study and its contribution to a wider body of knowledge. In particular, our findings relating to suffering, meaning-making, agency and the process of 're-possibilizing' in recovery appear to have wider applicability. In addition, findings from previous studies related to recovery from Fibromyalgia from a first-person perspective have taken a similar direction as the findings of our study (Eik et al., 2022; Grape et al., 2015; Grape et al., 2017; Mengshoel & Heggen, 2004).

In this study, participants formed a relatively heterogeneous group: they came from different backgrounds, had different educational levels and were drawn from various parts of Norway, both rural and urban. This heterogeneity may to some degree strengthen the transferability of the findings, especially in relation to women's experiences of suffering from other unexplained medical conditions. However, regarding heterogeneity, none of the young women had a minority ethnic background, and this could be considered a limitation in the study.

Given the current paucity of research on the impact of being severely ill and being in recovery from ME/CFS on the lives of children, adolescents and young adults, there is little with which to compare our findings. This arguably underlines the importance and relevance of our findings, along with the need for further research.

7 CONCLUDING REMARKS

7.1 Conclusion

Falling ill with severe ME/CFS can be understood as a process by which individuals gradually find themselves in the grip of an emergent suffering that can last for years. This is characterized by loss of control over one's embodied being and a strong sense of being disconnected from one's bodily being in the world. Profound uncertainty prevails; suffering permeates every aspect of one's bodily being; over time it is as if the body has locked itself down, shielding itself from all external influences by hiding away in the dark for long periods of time.

With ME/CFS, the body's mission to heal itself has an existential nature, making the memory of being severely ill existentially difficult to live with. Recovery from ME/CFS develops as a continuously demanding process, one that at every stage requires determination, bodily based self-awareness and self-knowledge. In order to recover, individuals need to experience once again being agents over their own lives, to be seen as individuals, and to be acknowledged by others. The process of recovery involves learning to adapt, discovering new ways of using the body and finding new ways of being in illness – ways which may vary from one day to another. In time, the broken body acquires the possibility of carrying out new habitual actions, and suffering becomes endurable. Recovery from ME/CFS involves recreating one's lifeworld; it is a process of rebuilding and restoring, of transforming the once broken body into something new. Through recovery and the dynamics of living, the individual moves towards living a meaningful life and being healthy in a new way.

7.2 Clinical implications

As the findings of this thesis underline, to date, there is no single way by which those suffering from severe ME/CFS can regain their health. Nor is there one specific treatment that could be recommended to all children and adolescents who fall ill with ME/CFS. In Norway, no governmental advice about curative treatments for ME/CFS has been issued (Helsedirektoratet, 2015); the only advice available is on how to relieve some of the symptoms, for example medications for pain and nausea.

The findings of this study indicate that recovery from ME/CFS in childhood and adolescence is indeed possible. However, the process can take years, with remissions and relapses likely to be part of both the illness and recovery. Our findings emphasize the importance of several aspects for the process of recovery. When children and adolescents fall ill with ME/CFS, they need to be heard by others and have their suffering recognized. They need help in understanding what is happening to their body and the meaning of what the body tells them with significance to what to do and how to manage an unfamiliar situation on daily basis.

Throughout, children and adolescents need to receive the help and support of health professionals familiar with the illness. If a young person is not heard and their suffering is not recognized, this may result in delayed diagnosis and failure to provide the medical help and support that individual needs. Falling ill with severe ME/CFS may result in a young person being unable to attend to their basic needs. In the absence of support, this could lead to malnutrition or even starvation.

This study contributes important insights into what it is like to be severely ill and bedridden with ME/CFS for years on end. The findings reveal this experience to be simultaneously dramatic, lonely and traumatic, its severity enhanced by the difficulty sufferers weakened by illness have in sharing their worries and explaining their situation to others. Given that severely ill individuals often experience nausea and/or pain, it is important that they receive help to relieve symptoms, maintain their nutritional intake and have a more endurable situation. Additionally, they need an environment adjusted to their specific needs and capable of being further adjusted as the illness evolves. Given the lack of research regarding the specific health care needs of young people who fall severely ill with ME/CFS, it is tempting to come up with specific proposals geared to easing their situation. However, this would be to deny the highly individual character of each individual’s experience, in part caused by significant variations in symptoms.

For those working with children and adolescents who have severe ME/CFS, it is important to find ways of communicating that do not demand much strength or effort: prewritten notes, for example, or having specific targets/needs written on a board which can be pointed at (“I am thirsty”; “I feel nauseous”). Being severely ill leaves individuals in a highly vulnerable state, and it is essential that the personal autonomy of the suffering person is respected and that treatment options are discussed and agreed upon with their full involvement, alongside that of their caregivers.

Our findings underline the importance of listening to the stories not only of those who are severely ill with ME/CFS but also of those in recovery. Much can be learnt from their stories, which help us towards a deeper and more nuanced understanding of this devastating illness. The findings also underline how gaining support and help from health professionals familiar with ME/CFS can ease individuals’ passage through the recovery process. Gaining bodily knowledge about the body in illness, including the fact that setbacks are a natural part of recovery, seems crucial. Sufferers also need to be aware that recovery will take time and that it is a demanding process.

During the process of recovery, clinicians need to focus on the whole of the person's suffering, not simply on that related to their physical body. There is a brokenness of the body in ME/CFS that takes time to heal. The individual needs help to process what they have gone through and regain bodily confidence. Children and adolescents who have been severely ill for long periods need to understand that recovery and resuming everyday life, including going back to school, will take time. By explaining the time dimension of ME/CFS, its fluctuating nature and the need for patience, health professionals can help young patients to keep believing, hoping and striving for recovery.

7.3 Implications for research

The phenomenological perspective adopted by this researcher adds to the theoretical understanding of illness, suffering and recovery by presenting them as a lived experience that changes over time and takes place in a world shared with others. The phenomenological framework contributes to a better understanding of illness from the perspective of the suffering individual: for example, the way in which severe illness gradually permeates the totality of a person's being, and itself becomes a way of being, despite its alienating character.

This thesis also demonstrates the relevance and value of narrative analysis as a method for exploring personal experiences of ME/CFS, including the changes that take place over time and the meaning and coherence individuals are able to construct throughout the process.

While some of our findings conform with those of earlier research (for example, studies by Njølstad et al., 2018, Parslow et al., 2017, and Solomons, 2017 on the experience of falling ill with ME/CFS and the process of losing control of one's bodily being in the world), this thesis also breaks new ground. It adds to our understanding of what it is like to be severely ill for prolonged periods, and what is put at stake for these persons - an area which has been little explored, even in relation to adult sufferers. It makes a significant contribution to our understanding of young persons' experiences of recovery. Previous attempts to gather first-person accounts of recovery have included research with a few adolescents by Jelbert et al, (2010) and a handful of studies involving adults (Brown et al., 2017; Kalla & Simmons, 2020). In this context, the understanding of recovery from ME/CFS presented in this thesis – that it is a continuously demanding process, one that requires determination, bodily based self-awareness and self-knowledge at every stage - is a significant contribution to knowledge regarding recovery from this highly debilitating illness.

Additionally, what our study also confirms regarding existing research, is the experience of being disbelieved of suffering of ME/CFS by others and in specific health professionals. Based on this, it is of great importance to study how to increase the knowledge of ME/CFS in the general population and in specific among health professionals. In addition, how to change the attitude against those suffering from illness being medically unexplained and in different occasions considered an illness low in the hierarchy (Grue et al., 2015).

Common features of falling severely ill and being long-term bedridden with ME/CFS have been highlighted by this thesis. In particular, it emerges as a very lonely and at times traumatic experience, and one that leaves lasting scars. The specific health care needs of those who fall severely ill require further research, although this study provides some indications. The hope is that this study will encourage other researchers to apply a range of different theoretical perspectives to the question of what it is like for young people to be *severely ill* and then in recovery from ME/CFS. On that basis, a deeper understanding of this immensely challenging experience can surely develop.

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Appendix I: Text -Recruitment for the study

Hei,

Dette er en forespørsel om å delta i forskningsprosjektet «Hvordan og hva forteller unge kvinner med kronisk utmattelsessyndrom ME/CFS om sine bedringserfaringer»?

Det finnes i dag lite kunnskap om bedringsprosesser og tilfriskning av ME/CFS. Vi søker deg som er jente mellom 16 og 30, som har vært syk i over ett år og nå blitt frisk eller betydelig bedre av sykdommen.

Hensikten med denne studien å utvikle ny kunnskap om hva ungdom selv anser å være betydningsfullt i bedringsprosessen. Dette er et doktorgradstudium og hvis du ønsker å delta innebærer det at du vil bli intervjuet av stipendiat Silje Helen Krabbe. Du velger selv hva og hvordan du vil fortelle om dine erfaringer om å være syk og bli bedre. Prosjektleder (hovedveileder) for studien er førsteamanuensis Karen Synne Groven, fakultet for helsefag (Institutt for Fysioterapi), OsloMet.

Appendix II: Information and consent for participants

Vil du delta i forskningsprosjektet

Hvordan og hva forteller unge kvinner med ME/CFS om sine bedringserfaringer

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å utvikle ny kunnskap om hva ungdom og unge voksne selv anser som betydningsfullt for at de er blitt bedre. Gjennom å undersøke unge kvinners sykdoms- og tilfriskningserfaringer med ME/CFS kan vi finne ut hvordan de skaper mening av sine erfaringer. Slik kan det utvikles ny kunnskap relatert til hva som fremmer og/eller hemmer bedringsprosesser og andre endringsprosesser samt betydningen av medikamentell og/eller ikke medikamentell behandling i denne prosessen.

Hvem er ansvarlig for forskningsprosjektet?

OsloMet – Storbyuniversitetet er ansvarlig for forskningsprosjektet.

For å delta i studien er det ønskelig at du tilfredsstiller følgende kriterier:
-16-30 år
-har hatt ME/CFS i mer enn 1 år
-har blitt betydelig bedre av sykdommen slik at du i dag vurderes/vurderer deg som frisk eller nesten frisk i perioder eller mer eller mindre hele tiden.

Hva innebærer det for deg å delta?

Å si ja til å delta i denne studien innebærer at du da sier ja til å delta på et intervju med PhD-student Silje Krabbe og/eller prosjektleder Karen Synne Groven. Intervjuet vil vare omtrent en time og tas opp digitalt dersom du samtykker til det. Etterpå vil intervjuet skrives ned og lagres på en sikker måte slik at ingen andre en PhD-studenten, Silje Krabbe og PhD-veiledere til Krabbe får innsyn. Resultatene vil publiseres som artikler og inngå i Silje Krabbes PhD-avhandling

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

- *Det er kun PhD-student Silje Krabbe, og hennes hovedveileder og prosjektleder Karen Synne som vil ha tilgang til navn og kontaktinformasjon om deg.*
- *Når det gjelder tilgang til intervjuene er det kun Silje Krabbe og hovedveileder Groven samt med-veiledere Wenche Bjorbækmo, Unni Sveen og Anne Marit Mengshoel som vil kunne ha tilgang til disse.*
- *Navn og kontaktopplysninger om deg vil lagres på en egen navneliste adskilt fra intervjuene. Datamaterialet vi lagres på et sikkert sted slik at ingen uvedkommende får tilgang, i tråd med OsloMet sine retningslinjer for sikker datalagring.*
- *Det er PhD-student Silje Krabbe og hovedveileder som samler inn, bearbeider og lagrer data i forbindelse med intervjuene.*

Når intervjuene transkriberes til tekst vil vi anonymisere deg ved at navn, bosted, familiemedlemmer, jobbsted, osv, slik at andre ikke har mulighet til å identifisere deg når resultatene publiseres.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?
Prosjektet skal etter planen avsluttes 01.03.2025 og da vil alle intervjuer og kontakt informasjon om deg slettes, inkludert personopplysninger. Når det gjelder anonymisert materiale som har inngått i foreløpige analyser kan dette lagres for videre forskning og publisering. Det vil da kun være deltakere i prosjektet som har tilgang til disse analysene.

Dine rettigheter
Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?
Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra *OsloMet – Storbyuniversitetet* - har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?
Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- OsloMet – Storbyuniversitet v/ Karen Synne Groven (prosjektleder og hovedveileder) e-post: karensy@oslomet.no og tlf: 93028883. Du kan også kontakte PhD-student Silje Krabbe på telefon: 40 60 72 15.
- Vårt personvernombud: Ingrid Jacobsen (ingrid.jacobsen@oslomet.no)
- NSD – Norsk senter for forskningsdata AS, på e-post (personvernombudet@nsd.no) eller telefon: 55 58 21 17.

Med vennlig hilsen

Karen Synne Groven	*Silje H. Krabbe*
Prosjektansvarlig	PhD-student
(Forsker/veileder)	

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet «Hvordan og hva forteller unge kvinner med ME/CFS om sine bedringserfaringer» og har fått anledning til å stille spørsmål. Jeg samtykker til:

☐ å delta i *intervju*

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. 01.03.25.

(Signert av prosjektdeltaker, dato)

Appendix III: Interview guide for the study

Intervjuguide

1. *Kan du fortelle litt om deg selv?*
2. *Kan du fortelle meg fra perioden du fikk ME/CFS?*
3. *Kan du fortelle meg om fra perioden da du var syk?*
4. *Du ble etter hvert bedre. Hva skjedde i denne perioden?*
5. *Hvordan har du det i dag?*
6. *Hvordan har denne samtalen vært for deg?*
7. *Har du noe annet du ønsker å tilføre?*

Appendix IV: Ethical approval -REK

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Hege Cathrine Finholt, PhD	22857547	03.12.2018	2017/2451/REK sør-øst D
			Deres dato:	**Deres referanse:**
			03.12.2018	

Vår referanse må oppgis ved alle henvendelser

Karen Synne Groven
OsloMet - storbyuniversitetet

2017/2451 Hvordan og hva forteller personer med ME/CFS om sine bedringserfaringer?

Forskningsansvarlig: OsloMet - storbyuniversitetet
Prosjektleder: Karen Synne Groven

Vi viser til søknad om prosjektendring datert 03.12.2018 for ovennevnte forskningsprosjekt. Søknaden er behandlet av sekretariatet for REK sør-øst D på fullmakt, med hjemmel i helseforskningsloven § 11.

Endringene innebærer:
- Nye prosjektmedarbeidere: Unnii Sveen, Silje Krabbe.
- Rekruttering gjennom Faggrupper og gjennom snøballs metoden (at noen som deltar i studien kjenner andre som også tilfredstiller inkluderingskriteriene og kan være med som de da ber ta kontakt med prosjektleder eller PhD-kandidat).

Vurdering
REK har vurdert søknaden og har ingen forskningsetiske innvendinger til endringene av prosjektet.

Vedtak
REK har gjort en forskningsetisk vurdering av endringene i prosjektet, og godkjenner prosjektet slik det nå foreligger, jf. helseforskningsloven § 11.
Vi gjør samtidig oppmerksom på at etter ny personopplysningslov må det også foreligge et behandlingsgrunnlag etter personvernforordningen. Det må forankres i egen institusjon.

Klageadgang
REKs vedtak kan påklages, jf. forvaltningslovens § 28 flg. Eventuell klage sendes til REK sør-øst D. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst D, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Vi ber om at alle henvendelser sendes inn på korrekt skjema via vår saksportal: http://helseforskning.etikkom.no. Dersom det ikke finnes passende skjema kan henvendelsen rettes på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen

Knut Ruyter
Avdelingsdirektør
REK sør-øst sekretariatet

Hege Cathrine Finholt, PhD
Rådgiver

Kopi til: *karen-synne.groven@hioa.no; postmottak@hioa.no*

Appendix V: Ethical approval -Norsk senter for forskningsdata NSD

Meldeskjema
Hvordan og hva forteller unge kvinner med ME/CFS om sine bedrings…
Vurdering

Vurdering av behandling av personopplysninger

Referansenummer
477809

Vurderingstype
Standard

Dato
19.02.2019

Prosjekttittel
Hvordan og hva forteller unge kvinner med ME/CFS om sine bedringserfaringer

Behandlingsansvarlig institusjon
OsloMet – storbyuniversitetet / Fakultet for helsevitenskap / Institutt for fysioterapi

Prosjektansvarlig
Karen Synne Groven

Prosjektperiode
01.03.2019 - 01.03.2024

Kategorier personopplysninger
Alminnelige
Særlige

Lovlig grunnlag
Samtykke (Personvernforordningen art. 6 nr. 1 bokstav a)
Uttrykkelig samtykke (Personvernforordningen art. 9 nr. 2 bokstav a)

Behandlingen av personopplysningene er lovlig så fremt den gjennomføres som oppgitt i meldeskjemaet. Det lovlige grunnlaget gjeldertil 01.03.2024.

Meldeskjema

Kommentar
Det er vår vurdering at behandlingen vil være i samsvar med personvernlovgivningen, så fremt den gjennomføres i tråd med det som erdokumentert i meldeskjemaet med vedlegg, samt i meldingsdialogen mellom innmelder og NSD, den 19.02.19. Behandlingen kan starte.
MELD ENDRINGERDersom behandlingen av personopplysninger endrer seg, kan det være nødvendig å melde dette til NSD ved å oppdateremeldeskjemaet. På våre nettsider informerer vi om hvilke endringer som må meldes. Vent på svar før

endringen gjennomføres.
TYPE OPPLYSNINGER OG VARIGHETProsjektet vil behandle særlige kategorier av
personopplysninger frem til 01.03.24.
LOVLIG GRUNNLAGProsjektet vil innhente samtykke fra de registrerte til
behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp
tilet samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er
en frivillig, spesifikk, informert og utvetydig bekreftelse, som
kandokumenteres, og som den registrerte kan trekke tilbake.
Lovlig grunnlag for behandlingen vil dermed være den registrertes uttrykkelige
samtykke, jf. personvernforordningen art. 6 nr. 1 a), jf.
art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2).
NSD legger til grunn at taushetsplikten ikke er til hinder for rekrutteringen
av utvalget.
PERSONVERNPRINSIPPERNSD finner at den planlagte behandlingen av
personopplysninger vil følge prinsippene i personvernforordningen:
- om lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte
får tilfredsstillende informasjon om og samtykker tilbehandlingen-
formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for
spesifikke, uttrykkelig angitte og berettigede formål, og ikkeviderebehandles
til nye uforenlige formål- dataminimering (art. 5.1 c), ved at det kun
behandles opplysninger som er adekvate, relevante og nødvendige for formålet
medprosjektet- lagringsbegrensning (art. 5.1 e), ved at personopplysningene
ikke lagres lengre enn nødvendig for å oppfylle formåletDE REGISTRERTES
RETTIGHETER

↑
De registrerte vil ha følgende rettigheter i prosjektet: åpenhet (art. 12),
informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art.
17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20).
Rettighetene etter art. 15–20 gjelder så lenge den registrerteer mulig å
identifisere i datamaterialet.
NSD vurderer at informasjonen som de registrerte vil motta oppfyller lovens
krav til form og innhold, jf. art. 12.1 og art. 13.
Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har
behandlingsansvarlig institusjon plikt til å svare innen en måned.
FØLG DIN INSTITUSJONS RETNINGSLINJERNSD legger til grunn at behandlingen
oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d),
integritet og konfidensialitet(art. 5.1. f) og sikkerhet (art. 32)
For å forsikre dere om at kravene oppfylles, må prosjektansvarlig følge interne
retningslinjer/rådføre dere med behandlingsansvarliginstitusjon.
OPPFØLGING AV PROSJEKTETNSD vil følge opp ved planlagt avslutning for å avklare
status for behandlingen av personopplysninger.
Lykke til med prosjektet!
Kontaktperson hos NSD: spesialrådgiver Kjersti HaugstvedtTlf.
Personverntjenester: 55 58 21 17 (tast 1)

↑

Article I

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*, 1-23. https://doi.org/10.1080/07399332.2022.2043862

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Routledge
Taylor & Francis Group

Bodies in lockdown: Young women's narratives of falling severely ill with ME/CFS during childhood and adolescence

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ABSTRACT
Thirteen women (16–30 years) storied their experiences about the process of falling severely ill with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome during childhood and adolescence. We performed a narrative analysis informed by phenomenology which yielded three central themes: The active and meaningful life I used to live; gradually developing unhomeliness and feeling pushed toward the edge; and left abandoned on the sidelines. Out of the incomprehensible and unpredictable emerges an understanding of the scale of their ordeal, along with advice that may have made it worse. This portrays a gradual developing uncertain, unhomely life situation with no outlooks for future recovery.

ARTICLE HISTORY
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In this article we present findings on how young women experience Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), during childhood, adolescence and early adulthood.

ME/CFS is a complex and serious long-term illness characterized by overwhelming fatigue and post-exertional malaise (PEM) (Rowe et al., 2017). The illness may cause substantial loss of physical and cognitive functions. Diagnosis is based on the person's self-reported symptoms, or symptoms as reported by parents, and by excluding other diseases or causes of fatigue (Fukuda et al., 1994). To date there is no objective clinical test to verify the illness, nor is there any international consensus regarding diagnostic criteria for ME/CFS. A variety of clinical yardsticks, including the Fukuda criteria, the Canadian Consensus Criteria (CCC), the

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This article has been corrected with minor changes. These changes do not impact the academic content of the article.

International Consensus Criteria (ICC), and the Oxford criteria are in common use (Strand et al., 2019).

Diagnosis in children and adolescents is often delayed because of the complexity of CFS and the existence of diverse diagnostic criteria and clinical practices (Clayton, 2015; Rowe et al., 2017). Individuals risk ending up with a different diagnosis, and this delay in diagnosis can prevent them from receiving appropriate health care (Gimeno Torrent, 2022; Webb et al., 2011).

According to some researchers, the prevalence of ME/CFS among children and adolescents is somewhere between 0.1% and 0.55% (Lim et al., 2020; Nijhof et al., 2011; Rimes et al., 2007). In the case of young children there appears to be no great differentiation on the basis of sex (Knight et al., 2013; Nijhof et al., 2011). However, for adolescents the risk of falling ill with ME/CFS has been put at between three and four times higher for girls than for boys (Rowe et al., 2017).

Among adults, ME/CFS is more prevalent among women across all categories, including age, ethnicity and socio-economic status (Jason et al., 2020; Ranjith, 2005).

Nevertheless, ME/CFS is still poorly understood and there are ongoing controversies about the nature, causes and treatment of the illness (Groven & Dahl-Michelsen, 2019; Sharpe & Greco, 2019).

Our decision to focus on women derives from the much higher prevalence of ME/CFS among women and the lack of legitimacy attached to women suffering from this condition.

ME/CFS can have either a gradual or a sudden onset. Gradual onset is more common in younger children, with the condition developing over months or years (Rowe et al., 2017). Symptoms can vary in severity and can fluctuate from one day to the next (Rowe et al., 2017). Both children and adolescents may suffer an acute infection prior to falling ill with ME/CFS (Katz et al., 2009; Knight et al., 2013; Nijhof et al., 2011).

Studies involving adults with ME/CFS suggest that in addition to the health issues raised by the illness there are also considerable social costs. Individuals can find themselves cut off from day-to-day life and normal social relations, and thus feel isolated. The fact that ME/CFS receives so little social recognition and legitimization can also result in individuals blaming themselves for being ill (Gimeno Torrent, 2022). Some of these social consequences have been reported by children and adolescents with ME/CFS (Parslow et al., 2017), and it seems likely that social aspects are woven into their experience of becoming ill.

ME/CFS is poorly understood by both health professionals and the general population (Anderson et al., 2012; McManimen et al., 2019; Parslow et al., 2017), a state of affairs that seems linked to the lack of recognition of ME/CFS as a serious illness (Gimeno Torrent, 2022).

In her recent editorial in *Health Care for Women International*, Covan (2022) argues that it is precisely because ME/CFS primarily affects women that it has failed to receive the recognition and focus it deserves among medical researchers and professionals. For Covan (2022), women suffering from medically unexplained illnesses have throughout history found themselves "misunderstood, misdiagnosed, and mistreated".

Unfortunately, this may also be the case for children and adolescents suffering from ME/CFS.

In the case of adolescents, scholars have documented their sense of being disbelieved and misunderstood by those around them, health professionals included (Fisher & Crawley, 2013; Jelbert et al., 2010; Njølstad et al., 2019; Winger et al., 2014). Further, living with this illness in adolescence can impede the ability of older children to maintain normal relationships with friends and family, resulting in an inescapable separation from the world of others (Njølstad et al., 2019; Parslow et al., 2015; Williams-Wilson, 2009; Winger et al., 2014).

Adolescents have described the experience of being ill with ME/CFS, including the way in which the exhausted body feels unfamiliar and incapable of "obeying" or recovering as before (Njølstad et al., 2019; Parslow et al., 2018; Winger et al., 2014). The emotional burden of living with ME/CFS puts children and adolescents at greater risk of developing anxiety and/or depression (Fisher & Crawley, 2013; Lievesley et al., 2014; Taylor et al., 2017).

In rare cases, children and adolescents fall severely ill with CFS, remaining bedridden for months or even years (Rowe et al., 2017). Thus far, however, there has been little research on the experiences of children and adolescents falling severely ill and spending years in bed isolated from society. Consequently, we have little insight into their everyday lives, psycho-social health and health needs (Loades et al., 2021; Strassheim et al., 2021). Overall, young people's narratives of falling severely ill with CFS during childhood and adolescent remains a neglected area of research.

The narratives of young people who have recovered from ME/CFS would seem to be of particular value, given that children and adolescents who are ill often find it difficult to tell their story, resulting in fragmented or broken narratives (Bülow, 2008).

To bridge this gap in the literature, we conducted a narrative exploration of the experiences of young women who fell severely ill with ME/CFS during childhood or adolescence.

We invited 13 young women who were in recovery from ME/CFS after years of severe illness to tell us how they now made sense of their past experiences of gradually falling severely ill from ME/CFS. We thought that their perspectives would be especially valuable, since they were in a position to narrate coherent stories, rather than ones that might be chaotic and fragmented (as can be the case with the narratives of people still experiencing serious illness).

In this article, we explore the themes that emerged from our study, focusing on how bodily experiences and lived life are interwoven in the women's narratives we address the following question:

What do young women who are in recovery from ME/CFS have to tell about their experience of falling severely ill during childhood and adolescence?

Theoretical framework and research approach

We framed our study in the theoretical perspectives of phenomenology, which we regard as enabling the application of a lifeworld perspective to the process and experience of falling ill. According to the phenomenological tradition, symptoms of illness (such as discomfort, tiredness, and fatigue) are understood as related to the lived body: the body as it appears to the person who is this body, not the body as it appears to others from outside (Merleau-Ponty, 1962). A person's lived body is not an object among other things in the world but rather the person's perspective on the world. An individual is conscious of the world through the medium of his or her body (Merleau-Ponty, 1962).

Heidegger (1953/2010) focuses on the everyday world of being and understanding, and the different modes of what it means to 'be'. He uses the term "Dasein" to describe the "being-there" of human existence. "Being-there" means we are situated in the world and always inter-subjectively engaged in the world we inhabit. For Heidegger, "Understanding of being is itself a determination of being of dasein [Seinverständnis ist selbst eine Seinsbestimmtheit des Daseins] (Heidegger, 1953/2010, p.11). This means that we have an existential relation to our own existence in asking what it means to be (Heidegger, 2010). According to Heidegger, our relationship to the world should be viewed as the way we are in the world: our "worldliness". Here, the world is not understood as an external thing, since our "worldliness" and "dasein" form a unity; there is no distinction between the objective (the world) and the subjective (ourselves as individuals). Human existence and understanding are therefore always a 'being there' in the sense of being-in-the-world (Heidegger, 2010). Hence, bodily experiences of falling ill cannot be separated from who the sufferers are and how they live and inhabit their situation.

In an interesting contribution to the phenomenology of falling ill, Svenaeus (2011) notes how illness obstructs the sick individual's entire being-in-the-world and makes it unhomelike. Our bodies usually function without our being explicitly conscious of bodily actions or seeking to control them (Svenaeus, 2001a). The world as we know it is ours, but at the same time we cannot entirely control it or have knowledge about every aspect of it (Heidegger, 1953). For Svenaeus (2000), the body has an alien dimension to it, even in the absence of illness. When we fall ill, our bodily being appears to us in an unfamiliar way; we sense our bodies to be different and unlike our habitual, healthy way of being-in-the-world (Svenaeus, 2009).

To fall ill is to succumb to a gradual process of bodily alienation, both in respect of the individual lived body and of its relationship with the world (Svenaeus, 2001b, 2009). Falling ill always has a temporal dimension to it. Svenaeus (2011) suggests that the temporal structure of illness can be conceptualized as an alienation of past and future, a rupturing of an individual's life in such a way that past and future appear in a new light. Falling ill imposes an unfamiliar way of being-in-the-world, one that simultaneously belongs to the person and does not (Svenaeus, 2011).

In order to explore such insights in the specific context of the lives of young women, we opted to employ a narrative methodological approach. We saw this as particularly relevant for studying human experiential processes, i.e., how people make sense of what happens to them over time. Storytelling is understood as a fundamental way for humans to make sense of their experiences (Polkinghorne, 1988). While constituting the past, narratives also offer individuals the opportunity to make meaning of past experiences and connect them to the present and the future (Riessman, 2008). Such meaning-making involves linking things together to form a coherent whole; one event follows another in a temporal way. We perceived the combination of a phenomenological theoretical perspective with a narrative approach as particularly apt for an exploration of the ways in which lived meanings evolve and change over time.

Falling ill with a severe condition can be viewed as a biographical disruption, one that disrupts the person's expectations of continuity in life. In this situation, storytelling offers a way to make sense of events and develop continuity in one's life experiences (Mattingly & Garro, 1994; Riessman, 2008). At the same time, storytelling is also nurtured by the individual's specific cultural and historical context. When narrating, storytellers will call attention to different things according to who is listening or where narration is taking place. To this extent, the researcher can be considered a co-creator of the unfolding story. But while the story can be told in different ways, it always stays connected to experiences in life and the meaning the narrator ascribes to them (Mattingly, 1998; Riessman, 2008).

Method

Recruitment and participants

We went about selecting participants on the basis of clear inclusion criteria: participants were to be women aged between 16 and 30 years who had fallen ill with ME/CFS during childhood or adolescence but who had since fully recovered or perceived themselves to have made a significant recovery. In addition, all participants were to have been diagnosed with ME/CFS by a physician, to have been ill for more than a year, and to be able to speak, read and write Norwegian.

We recruited participants by placing an advertisement on two Norwegian websites, particularly concerned with health care for women and improving women's rights in society. Those interested in participating contacted the first author by e-mail or phone. Candidates who met the inclusion criteria were then sent detailed information about the study, along with a consent letter.

A total of 17 women made contact, of whom four were excluded or dropped out. The 13 remaining participants lived in different parts of Norway, both urban and rural. At the time of being interviewed, all were engaged in full- or part-time education (at high school, college or university) or were working (full- or part-time). Six were married or living with a partner and one had children. All the women were from middle class homes, with both their parents working (the parent of one of the participants had taken sick leave at times to look after her when she had been ill). None of the participants was previously known to the first author. All participants were informed that they would be interviewed by a female pediatric nurse with long experience of clinical work with children and adolescents.

Narrative interviews

All interviews were conducted by the first author in May-September 2019. Dates and locations for interviews were decided in collaboration with participants. Interviews took place in participants' homes, university settings or local libraries, according to participants' convenience.

In order to capture the young women's experiences of falling ill with ME/CFS, narrative interviews inspired by Riessman (2008) were conducted with each participant. Participants were asked to describe in their own words their lives prior to their falling ill; during their illness; and in the present day. Assured at the outset that there were no 'right' or 'wrong' stories or answers, participants were encouraged to speak freely.

The first author began each interview by posing a few open questions to help participants get started: “Can you tell me about your life prior to falling ill?” and “Can you tell me what it was like to experience falling ill?” Follow-up questions were sometimes asked to encourage participants to elaborate or clarify meanings. Narration often involved the young women jumping back and forth in time as they remembered specific events or experiences.

Interviews lasted between 60 and 150 minutes. Each was digitally audio-recorded and then transcribed verbatim by the first author shortly after the interview concluded. In addition, the first author wrote a short reflexive summary aimed at capturing non-verbal communications, facial expressions and the overall atmosphere of each interview in its immediate aftermath. These reports also formed part of the data for analysis.

Analysis

Our narrative analysis, inspired by phenomenology and in particular Svenaeus’s phenomenology of illness, drew on Riessman’s (2008) thematic and structural analysis. In order to achieve an overall impression of participants’ stories of falling ill, each interview was listened to several times and transcripts were read repeatedly.

For our thematic narrative analysis, we posed the following questions: What are the women telling us about their lives prior to falling ill? What are they telling us about falling ill and becoming seriously ill? We focused on the sequences of events or experiences that expressed a participant’s life before they became ill. We then examined the process of falling ill, including the onset and gradual worsening of symptoms on the path to severe illness.

Excerpted sequences were then coded and explored further. We sought to probe the structure of narratives, including the ways in which the sequences were presented in a temporal, causal order to create narrative coherence and meaning (Riessman, 2008). Certain common themes gradually became apparent: for example, participants described experiencing profound changes in their bodily-being-in-the-world when falling ill.

The emergence of common themes encouraged us to present our analysis in the form of a shared narrative, illustrated by excerpts from specific interviews to illustrate what was said in a temporal order. On this basis, a composite narrative about the process of falling ill was developed.

Ethics

The study was approved by Regional Committee for Medical and Health Research Ethics, Social Science Data Service and conducted in accordance with the Helsinki Declaration Act and the Health Research Act of Norway. The Service for Sensitive Data was used as required for collecting and storing sensitive data. Only the main supervisor and the first author have had access to the interviews and the transcribed material. Informed consent was given by the participants prior to each interview.

The interviewer was aware that, given the distrust and disbelief participants may have experienced from health professionals, they might feel vulnerable when relating their illness story to someone who was also a health professional. It was important for the interviewer to pay attention to the young women's reactions and emotions when narrating their stories, so that the situation would not become unnecessarily burdensome for them.

Findings

Of the thirteen women participants, twelve told of falling ill when they were between 10 to 18 years old; the remaining participant had fallen ill at the age of 22 years. The women had experienced either a sudden or a gradual onset of illness, and the process of falling ill often comprised periods of remission and relapse. Most of the women had suffered an infection prior to falling ill. Some were aware of having an infection with mononucleosis prior to falling ill with ME/CFS, while others first got to know that they at some time point had had an Epstein-Barr virus (EBC) infection when diagnosed with ME/CFS.

Participants described their current memories of how they experienced falling ill. Looking back, they recounted the onset of illness by describing various kinds of infections they had contracted, which in retrospect they now saw as significant factors in why they became ill. All the women depicted becoming and being ill as a distressing and traumatic period in their life. For them, it was essential to try to make sense of why they had fallen ill. What had triggered their illness? What had happened before and during the process of either suddenly or gradually falling ill with ME/CFS?

Our presentation starts with participants' descriptions of living a healthy life prior to illness. This is followed by accounts of experiencing the onset of unexplained bodily discomfort, which then gradually builds toward severe illness.

Despite nuances of difference between the women's stories, their experiences of falling ill with ME/CFS can be understood and communicated as a composite narrative under the following themes: "The active and meaningful life I used to live"; "Gradually developing unhomeliness and being pushed toward the edge"; and "Left abandoned on the sidelines".

In the excerpts from transcripts presented below, all participants appear under pseudonyms. Any quotation that might disclose a particular participant's identity has been omitted. The symbol […] signifies that two identified sequences were found to be related, while three dots … indicate a pause in the narrative.

The active and meaningful life I used to live

When recalling the time before falling ill with ME/CFS, participants told of leading active lives, whether at school, in terms of leisure activities, or simply about hanging out with their friends. Bodily experiences did not feature in their narratives, aside from references to having a well-functioning body which enabled them to participate fully in whatever they enjoyed doing. Their embodied being was mostly familiar and gave them a sense of belongingness.

Here, Amalie describes her vigorous adolescence prior to suddenly falling ill:

> *I was kind of active… was part of a political organization and my friend was the leader so we sort of spent a lot of time there… I had long days in school… played an instrument so I practiced a lot, played in different bands… a lot going on… my week was kind of filled up!*

For Mia, spending time with friends and taking part in different activities were important aspects of pre-illness life:

> *Well before I fell ill… it was in high school… I focused on my sport, and I was good at it! Sport was my safe place where I could be myself, be social and not worry about a thing. I think a lot of my self-esteem and self-worthiness were connected to being an athlete. […]*
> *I did well in school (swallows) but it was difficult for me…it was a lot of… I was kind of bullied and left out in school…called things… I hated school because of that…*

Despite her young age, Mia was an accomplished athlete, and this was an important part of her perception of herself. For other participants, too, hobbies contributed to their sense of belonging, safety and self-development.

As healthy beings, the young women had experienced life as mostly predictable and familiar, even if they also faced specific challenges. For Mia, being 'good at' sport shielded her from social exclusion and bullying at school. For Elisabeth, dance offered an opportunity to relax and 'be myself':

> It was like four or five times a week… intense for a couple of hours… the best way to sort of… let your mind flow…and flow with the music…use your body…

> completely calm… Just have fun and dance…The social part of dancing was… I could be myself you know. I found it very difficult, becoming ill… I used to have so much energy… then not be a dancer. I spent years adjusting to it… accepting it.

In other women's stories, too, performing a specific sport or activity was an essential part of their life and social being-in-the-world.

In their stories of life prior to falling ill, participants described having more or less no body-related concerns. Their bodily being was mostly familiar and to be trusted, and this contributed to their sense of belonging, safety, and self-development as they made the transition from childhood to adolescence. Being healthy was something they took for granted; the habitual body was mostly in the background of their attention, enabling them to enjoy life.

Gradually developing unhomeliness and feeling pushed toward the edge

Participants then moved on to recall the process of falling ill. Two forms of onset were described: sudden and gradual. While participants with sudden onset experienced it as happening without any warning, participants with gradual onset recalled how it started with an infection from which they had expected to recover. Whether their onset was sudden or gradual, falling ill involved remissions, relapses, and unpredictable fluctuations between better and worse days as the downward spiral continued.

The unpredictability of their situation now challenged the participants 'habitual life. This is how Ines describes falling ill with Mononucleosis as a child:

> I had this intense pain in my stomach… and problems eating…I remember feeling so tired…felt a little down… I never returned to school after Christmas and I was diagnosed with mononucleosis (trembling voice). But my body just continued […]
>
> After a year, I got the diagnosis ME (CFS)… feeling exhausted, I had good days and bad days. For the first 3 years I had a teacher who gave me lessons at home, because everyone said I had to … But we should not have done it… it only made me worse. My experience would have been better if I had let go… I was so tired. I was able to spend short periods of time with my friends, but then… Others told me I would soon get better, but I just got worse… mm… I became very ill.

Ines here describes how her familiar, taken-for-granted body became more and more unfamiliar. She sank into exhaustion and pain and had difficulty functioning. Her failure to recover from Mononucleosis resulted in uncertainty, and it was a whole year before she received an explanation and a diagnosis. All the while, she was told by others to keep up her schoolwork and stay in contact with her friends. Ines's experience of falling ill can be understood to have become unnecessary demanding due to others' understanding or misunderstanding. She was told she would recover, but this did not happen.

The length of time before receiving a diagnosis emerged as a common element in the women's narratives, as was advice to keep up their normal daily routines. As Kristin put it:

> The weeks passed by and all I did was sleep… I was exhausted… tried to keep up with school… felt as if I had run a marathon when I woke up in the morning and then you are supposed to begin the day. You sort of take it for granted that when you wake up, you'll feel refreshed, right? […].
>
> I gradually lost friends because I was too exhausted to join them. In the end they would stop asking me to join them, knew I would not show up

Kristin experienced extreme exhaustion; even if she slept a lot, she never woke up feeling refreshed. Her body now became unfamiliar and intrusive. From her earlier life experiences, she expected to wake up refreshed, but this was no longer the case. Instead, Kristin felt as if she had "run a marathon". This was a new, unhomelike being-the-world.

In her narration, Kristin also expressed ambivalence: despite sleeping much of the time and thereby taking care of her body, she also did her best to keep up her former social life. But having lost her habitual body, she found herself unable to do so. Eventually her friends stopped asking her out.

This creeping isolation surfaces in the accounts of other participants, all of whom are repeatedly advised to stay active. Complying with such advice and expectations now becomes a real struggle, as Camilla testifies:

> Doctors told me I suffered from school phobia and that I was making everything up. My parents were told "the best medicine" was to push me to participate in school, so they did… But I was not a lazy child. I just… I dread going to school because I was so tired [……]
>
> I remember dad drove me to school and I was not capable of getting out of the car because I was so tired… I just got worse… We kind of did the opposite of what we should have done… this was hard on my parents, they really did all they could to help me.

Here, her doctor seems to ignore Camilla's experiences of her lived body. Applying a medical gaze, the doctor can detect no signs of disease and concludes that the patient herself is 'the problem': a lazy child. But Camilla refuses to accept this. She perceives herself as an exhausted, struggling person, one who is uncertain and scared about her body not obeying.

From the perspective of the present, Camilla knows that her parents regret having heeded what they now understand to have been wrong advice. But at the time, the fact that the doctor – the embodiment of professional authority – discounted Camilla's own observations caused her parents to doubt the reality of their daughter's exhaustion, illness and inability to behave as before.

Participants provided many examples of how they were disbelieved and distrusted by health professionals, including medical specialists with considerable authority in their field. In the absence of any biomedical evidence for their experiences, several of the participants found themselves "thrown around in the system", both when undergoing diagnostic assessment and during treatment. Lisa describes it thus:

> I was sent for a psychological evaluation and was put on antidepressants… Next thing a center for sleeping disorders and I had to fill out this questionnaire "Are you capable of normal activity?" and "Do you take pleasure in doing things like before". I answered "No" because I was not capable of doing anything. The doctor took a quick look at my answers to the questionnaire and said, "You are depressed, and you are taking too many painkillers". I was not depressed […]
>
> I did not have the vocabulary to express what had been happening to me. When I feel exhausted, I tend to cry, and I found it so difficult to explain… I remember once, on National Day, I just lay on the sofa and cried because I was in so much pain. When you try to explain but no one listens or helps. Every day was pain and struggle, but I was not depressed… it was just… that I only became worse.

As professionals failed to find any biomedical explanations for her condition, Lisa was referred for a psychological evaluation. She was asked to answer a standardized questionnaire which did not address her lived situation. The medical conclusion that she was depressed made no sense to her, nor did she appreciate being told she was taking too many painkillers. Lacking the vocabulary to defend herself, Lisa could not take issue with the medical verdict. She felt abandoned and helpless.

The women narrated how their bodies became increasingly at the forefront of their attention. "I felt as if I had run a marathon" was how one participant described her struggle to keep up. The metaphor of the marathon conveys how exhausting life has become; the women must push themselves to complete even small tasks in order to live up to their own and others' expectations. But their "new" bodily experiences were not recognized as meaningful and significant by medical professionals. Instead, they were advised to stay active, which in retrospect they recognize as wrong.

For participants, the gradual deterioration in their bodies represented a scary and unhomelike experience of being-in-the world. Pushed by others to keep their exhausted bodies functioning, they tried to comply. But this meant ignoring or suppressing what their own bodies were telling them. It was as if they had been pushed to the sidelines - of their body and of their life.

Left abandoned on the sidelines

Looking back, the young women portrayed their bodies as becoming more and more unfamiliar, uncanny, and unrecognizable. Eventually they experienced their bodies as so profoundly fragile that they seemed to be approaching an existential limit. At this point, the women were no longer able to take care of themselves. As narrated by Ines:

> Everything about me became so fragile, could not tolerate light or sound…I could not be among my friends… then I stopped walking because… I did not have a chance. Maybe I should have stopped earlier… My parents lifted me off my bed and back again… later I lay on a mattress on the floor in the dark: it was the only way… My legs were so heavy, as if they were being pushed to the ground… and someone had laid rocks upon them (swallows)…
>
> Then I was not able to chew so mum tried to feed me with soup… I just could not do it… Could not move my tongue…as if it was too thin, you see… could not talk…so hard… It just got worse and I ended up in hospital, I received a nasogastric tube for nutrition, wore diapers because… (swallows)… I left the hospital… home to my mattress in a dark, quiet room by myself. [……] Not much left of the life I used to live. Looking back, all those years and all I missed… I kind of wished I had not lost my childhood and adolescence to ME (CFS).

Like several other participants, Ines described how her fragile body stopped obeying her and how the presence of others became unbearable. She described feeling as if she were no longer in control of her body; she experienced her body forcing her to the ground and restricting her ability to move. Should she have avoided pushing her exhausted, fragile body earlier? She then told of her dependence on others in order to eat and fulfill her primary needs for staying alive. When her normal, taken-for-granted body stopped working, Ines was reduced to lying on her mattress: a cruel situation which went on for several years. Her family protected her from all stimuli, it was necessary for her to survive at the time. This was a lonely and suffering situation and nothing anyone choose for themselves. Looking back, she saw this period as the loss of her childhood and adolescence, one which deprived her of all possibilities of engagement as a youngster.

Elisabeth provided a powerful description of how her body stopped functioning:

> It took a while before my body fell apart… but I just got more exhausted… in time my body just stopped, as if "it's enough". As if I had hit a wall… I got a period of "blackout" and slept for 24 hours in a dark room. Lost my appetite, lost weight, the need to go to the bathroom… I lost it all… and could not do anything about it… just constantly exhausted. The "blackout" came without warning and that was the worst part. All of a sudden, nothing "firing" in my body – you are not thinking or dreaming… just "Boom!" … As if the body were shutting down…

Elisabeth describes how she hit the wall and experienced terrifying episodes of "blackout". Losing her appetite along with the need to go to the toilet, she seemed to enter another state of existence. In her description, she likens her body to a machine: one which falls apart, fails to fire up, or simply shuts down ("boom"). This "blackout" can be compared to a kind of bodily "lockdown".

Using different words, Kristin narrated a similar experience:

> I did not recognize myself… looked like a ghost… I did not feel that my head belonged to my body… I was kind of trapped in my own body… as if I could not enter the body… I just felt as if… this body is not mine… everything I felt, and thought was somehow wrong…and I could not help it… it just happened… I did get a bit anxious… and I could not talk… My body felt so heavy. It is difficult to explain…it was so difficult to be in the situation and I do not know what to compare it with… I really did all I could, but nothing helped… so hard… (swallows) a living hell…

Kristin narrated feeling trapped by but also separated from her body, which no longer seemed to belong to her. Describing herself as resembling "a ghost", she felt unable to reconnect with her body, which seemed in "lockdown".

Discussion

Our findings suggest that the experience of falling ill with ME/CFS can be understood and communicated as a shared narrative organized chronologically on the basis of three storylines. The first storyline, "The active and meaningful life I used to live", describes the time before participants fell ill, when they experienced their bodies in habitual, taken-for-granted ways. The second storyline, "Gradually developing unhomeliness and being pushed toward the edge", illuminates the onset of illness and the constant deterioration of the body, resulting in alienation from the body and from life as it was lived before. Finally, the storyline "Left abandoned on the sidelines" tells of participants' entrapment in severe illness and the shutting down of their lives.

Viewed through the lens of phenomenological theory, falling ill with ME/CFS emerges as a gradual process of falling victim to alienation, dys-appearance of the body, and a sense of unhomelike being-in-the-world.

The first storyline, "The active and meaningful life I used to live", underscores the familiarity and trustworthiness of participant's bodies prior to the onset of illness. Writing about the habitual body, Merleau-Ponty notes that "We say that the body has understood and habit has been cultivated when it has absorbed a new meaning and assimilated a fresh core of significance" (Merleau-Ponty, 1962, p. 146). In line with this, the women's narratives illustrate how their bodies were mostly taken for granted and in the background of their attention, as is usually the case among healthy people. Participants lived with ongoing tacit certainty about their bodily ability in a familiar, manageable world (Carel, 2016). The body we live, have, and usually know is our habitual body. But when we fall ill, all this may change.

The second narrative, “Gradually developing unhomeliness and being pushed toward the edge”, illustrates how participants became more and more aware of their illness. Although the severity of illness fluctuates, these fluctuations are unpredictable, and over time there is a downward spiral of becoming worse. Participants’ being-in-the-world gradually becomes less and less familiar. Despite this, the women, being just children or adolescents at the time, seek to maintain an ordinary life and normal activities as per the advice they receive from physicians and other people around them. At the same time, the process of falling ill is experienced as an alternation of feelings of ‘homelikeness’ and of feeling more and more ‘unhomelike’ being in the world (Svenaeus, 2011). However, this understanding is not acknowledged by others, who tend to disregard participants’ lived experiences. Instead of being helped to understand the meaning of their pain and exhaustion, participants are told to ignore their unfamiliar body. They now try to suppress what their bodies, now at the forefront of their attention, are telling them. They live in an unfamiliar world of pain and intense exhaustion: what Leder (1990) describes as a bodily dys-appearance.

During illness, the dys-appearing body directs attention to the body itself, thereby obstructing and disabling an individual’s engagement with others and the world. In its latter stages, this bodily dys-appearance becomes so severe as to compel participants to give up. Left abandoned on the sidelines, they become completely dependent on parents or other caregivers.

Becoming and being ill constitute a special form of unhomelike being. The subjective and inter-subjective meaning structure of the body-subject undergoes profound change, and the understanding of the world as always relational and interconnected becomes disrupted (Svenaeus, 2011). Unhomeliness changes the openness of the self to the world, and this change in embodiment leads to the experience of the otherness of the body. In our study, the women spoke of a sense of alienation from their bodies while at the same time recognizing that these bodies were indeed their own.

Given the difficulty of describing unfamiliar experiences, participants turned to metaphor, including that of running a marathon. This metaphor conveys not just the struggle involved in keeping up activities but also the need for time to rest: after all, it is wrong to push oneself after having run a marathon. When the body resists, one starts to pay attention to it; the body becomes an object for inspection. Such objectification of the body may lead on to alienation: the experience of the body as a thing outside oneself, as something other than oneself. In illness, the otherness of the body can present in uncanny and merciless ways (Svenaeus, 2000). In the case of ME/CFS, living with the disease has been likened to having someone else in control of one's body (Njølstad et al., 2019).

Falling ill is an embodied, inter-subjective experience, one which cannot be separated from an individual's specific world (Heidegger, 1953/2010). In a world shared with others, falling ill with a condition for which medical professionals have found no biomarker seems to be deeply problematic. Along with not being understood or listened to, the patient is likely to feel mistrusted. When medical evidence for an illness is scanty or non-existent, professionals are unlikely to recognize patients' personal experiences and bodily knowledge (Dumit, 2006; Hydén & Sachs, 1998; Nettleton, 2006). There will be a mismatch between how the patient understands herself and her situation and how professionals and others understand them. This discrepancy in understanding has been previously documented by researchers in both children/adolescents (Parslow et al., 2017) and adults (Anderson et al., 2012; Åsbring & Närvänen, 2003; Dickson et al., 2007; McManimen et al., 2019; Gimeno Torrent, 2022). The present study expands such insights by revealing how the situation seems to be made worse when young patients are told simply to ignore unexplained pain and fatigue.

Health professionals may remain blind to the patient's gradual alienation from her body, even as she seeks to suppress this strange body and keep going – not simply to comply with medical instructions but also to resist her own social dys-appearance (Slatman, 2014). Given a situation in which the individual is not even seen or recognized as being ill, the best thing to do is struggle on, ignoring what the body is asking for. Such a process may have reinforced participants' way of objectifying the body and therefore the alienation involved in falling severely ill.

Researchers have suggested that situations where the existence of illness has come under question or doubt may lead patients to doubt the reality of their illness (Winger et al., 2014).

Lack of understanding on the part of others may accelerate the process of bodily alienation, prompting patients to question their own experience. The uncertainty can make a person devalue her experiences and blame herself for becoming ill in the first place. She may turn to explanations to account for her becoming ill (Gimeno Torrent, 2022). Along with women, children and adolescents suffering from medically unexplained illnesses run the risk of being misunderstood and misdiagnosed (Covan, 2022). This can lead to an unfortunate delay in diagnosis and the provision of appropriate care (Webb et al., 2011).

When we fall severely ill, we experience a sense of alienation from our customary 'homelike' bodily being. Our being now becomes 'unhomelike' (Svenaeus, 2001b). This theoretical understanding connects with our third storyline, "Left abandoned on the sidelines", in which participants describe the disintegration of their fragile bodies toward an alien ghost-like state. They have become separated from their body and their life world, and now even the presence of others becomes unbearable.

The phrase "looked like a ghost" applied by a person in the present paper, becomes a way to explain the dramatic, alien experience of falling ill with an unexplainable illness. A ghost refers to a pale, non-existing person, one who has left our world and who, while invisible to self and others, is at the same time visible to self and others. Using the metaphor "ghost" can be understood as the self-experience of existing – but simultaneously separated from the world. The word conveys the sense that "I have left the world of others, as the person I used to be". It suggests that as a result of falling ill one has lost one's belongingness and self-perception. A kind of existential breakdown, understood as a "lockdown" of the life one used to live, has taken place. In a similar vein, the experience of ME/CFS as a kind of "lockdown" has been metaphorically described as "a social death" and a "death in life" to convey an inescapable separation from a world shared with others (Gimeno Torrent, 2022).

Taken together, the women's narratives reveal the unbearable, brutal consequences of falling severely ill. The very process of 'being' now becomes frightening and intrusive. Insecurity, worry and anxiety loom large. It becomes impossible to connect to one's permanently alienated body and 'unhomelike' being in the world. The fragile body edges toward an alien, ghost-like state, toward a lockdown of body and life.

There is a profound contrast between this overwhelming perception and the views of health professionals who discount the disease or minimize its impact. The failure to listen to what the patient has to say, including what makes them feel better or worse, intensifies the patient's sense of helplessness, of being sidelined. The patient experiences a gradual detachment from their now fragile body; there seems no possibility of reconnecting body and self.

The French philosopher and feminist, Simone de Beauvoir can contribute to our way of understanding the participants' experience of unhomeliness when falling severely ill. Humans are born free and not shaped by nature, but it is up to the person, her- or himself to realize this freedom (de Beauvoir, 2000). However, given that women's bodies are different than men's their lived experiences are likely to be experienced as different (de Beauvoir, 2000). At the same time, de Beauvoir seeks to problematize our traditional understanding of women as subordinate men. In particular, she argues that women have a responsibility to transcend themselves. Transcending oneself entails asserting oneself giving priority to one's own needs and desires. De Beauvoir also introduces the term 'immanence' to explain why some women and girls tend to focus on pleasing other's needs and desires before asserting their own. This is risky, according to de

Beauvoir, because women in immanence might end up passive, feeling alienated and lost, a victim of other individuals' recommendations and desires. This process of alienation entails embodying traditional norms of womanhood, so that she will never be free (de Beauvoir, 2000). The tendency of young girls and women to suppress their own bodies by trying to live up to the expectations of others, despite falling severely ill, might be interpreted as a kind of (bodily) immanence. In an ongoing process of suppressing their own needs and bodily signs, they get more and more alienated from themselves (and their bodies). In addition, they alienate themselves from friends and from the ordinary life of children, teenagers and young women. Their exhaustion constitutes the absolute opposite of the Western ideal of the young female: energetic, strong and socially engaged. As they become increasingly ill, the girls strive to do as they are told, suppressing their bodies and living up to the expectations of others. But finally, they have to give in. Forced by their condition to withdraw from school, all social life and normal youthful activity, they fail in every aspect of being a girl in the process of becoming woman. In such a situation, it is difficult to break away from cultural and social boundaries, and just be allowed to fall ill. Hence, understanding the immanent body's "shutting down" or going into "lockdown" during illness is to see it as a strategy by which the body protects itself, whether from itself or from external influences (or both). After all, a body that is shut down is no longer susceptible to being pressured into anything. It must be allowed to be at peace, be taken care of - and just be.

Strengths and limitations

For this study, our participants were young women who were in recovery or who had fully recovered from ME/CFS. We made this choice in order to gain insights from narratives which, we judged, would have greater coherence than accounts from those still struggling with serious illness.

Some important criteria have been identified toward enhancing the trustworthiness of narrative analysis (Riessman, 2008). In this study, the details of the interview procedure are made clear, together with the relationship between the participants and the first author. While the professional status (nursing) of the first author may have had some impact on how participants communicated their stories, to a large extent the women used non-medical terminology and were able to provide rich descriptions of their experiences.

In an effort to strengthen the transparency of the study, we made a point of relating our work to previous research on ME/CFS. We have striven to describe our theoretical framework in detail, to present our analysis and findings in a comprehensible way, and to connect with theory at every stage. As the authors of this research, we have found that our different professional backgrounds and experiences enabled us to discuss and question each other's preunderstandings and interpretations. Taken together, these factors strengthen the trustworthiness of our research and findings.

With respect to transferability, it bears emphasis that our young women participants were a relatively heterogeneous group, drawn from different parts of Norway and with varying family backgrounds and educational levels. In addition, a narrative study can never aspire to cover all circulating narratives. However, the stories that emerged from our young women participants had many common features, underlining their relevance for a wider understanding of such experiences.

Clinical implications

Our findings highlight how advice from health professionals pushed severely ill young people to continue with their everyday lives even when they were experiencing incomprehensible bodily changes. Various factors, including youth, lack of comprehension of what was happening to their bodies, and lack of vocabulary to express what was happening to them, made it difficult for young people to stand up for themselves and resist professional advice. This underlines the need for health professionals and others working with children and adolescents to listen to what young patients have to say – and strive to make sense of their specific experiences. In the absence of this, young people who fall ill with ME/CFS may be denied important aspects of their transition from childhood and adolescence to adulthood. It is also possible that medical advice to stay active may actually be contributing to the severity of illness suffered by such young people. The specific health needs of children and adolescents falling severely ill are proposed for further research.

Concluding remarks

Through the prism of three storylines, this study offers insights into the experiences of a small group of young women, all of whom fell severely ill with ME/CFS during childhood or adolescence. Told from the vantage point of total or near-complete recovery, the stories evoke the healthy lives enjoyed by the women prior to falling ill, their subsequent traumatic struggles with inexplicable bodily changes and disrupted social relationships. Out of the incomprehensible and unpredictable emerges an understanding of the scale of their ordeal, along with the factors that may have made it worse.

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Article II

S. H. Krabbe, W. Schrøder Bjorbækmo, A. M. Mengshoel, U. Sveen and K. S. Groven. A suffering body, hidden away from others: the experience of being long-term bedridden with severe ME/CFS in childhood and adolescences (Submitted *Nursing Inquiry*)

A suffering body, hidden away from others: the experience of being long-term bedridden with severe ME/CFS in childhood and adolescence.

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 semi-structured interviews with thirteen women, aged 16-29. The women's stories were explored with reference to Merleau-Ponty's phenomenological insights and van Manen's (2016) "four existentials": lived body, lived relations, lived space, and lived time. Attention was also paid to how participants structured their narratives and to the events (telling moments) they identified as particularly important. Four major storylines emerged: *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.* On the basis of 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

Myalgic Encephalomyelitis, Chronic Fatigue Syndrome, children, adolescence, women, severe illness, phenomenology, narrative

Introduction

This time, it was different. I understood I had hit the ground big time. I was knocked out. I collapsed and just lay there. I gave up on everything [….] Mum entered the room and talked to me. I knew she was there, and I knew she was talking… but I could not communicate. I was barely on the surface. My body just stopped taking it all in and nothing affected me… as if I had gone into hibernation, you know, when bears go into hibernation during the winter. You're not thirsty or hungry, not thinking, you're just constantly exhausted. Like a comatose state of being. It was as if I was nothing.

This excerpt sheds light on the experience of being long-term bedridden with Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), during childhood and adolescence. The words are told in retrospect by "Mina", a young (nationality) woman who is one of 13 participants in the study which forms the basis of this article. The study is part of a larger qualitative research project exploring young girls' and female adolescents' experiences of falling ill with (Krabbe et al., 2022), and being in recovery from, ME/CFS (Krabbe et al., 2023). Participants shared their unique personal experiences of this disabling and complex illness characterized by profound fatigue, malaise, unrefreshing sleep, sensory sensitivities, gastrointestinal symptoms, orthostatic intolerance and cognitive impairment (IOM, 2015).

Sadly, the young women in our study, all of whom had to contend with severe symptoms as a result of falling ill with ME/CFS, are far from being the exception. 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 incidence of ME/CFS among children and adolescents has been estimated at 0.1- 0.89 per cent (Estévez-López et al., 2020; Lim et al., 2020), there is less clarity regarding the number of children and adolescents who become bedridden because of the severity of their symptoms. 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 (reference xxx). 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 best 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 autobiographical 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 literature by exploring the lived experiences of young women ME/CFS patients 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?

Theoretical framework

This qualitative study is informed by the phenomenological theoretical perspective of the French phenomenologist Merleau-Ponty (1962) and his understanding the lived 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 (1962) argues that the *lived 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 (1962), 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 inter-subjectively 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 pre-verbal and pre-reflexive, 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, or temporality, is the subjective experience of time, as opposed to clock time. For Merleau-Ponty (1962), 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 when we struggle with, for instance, or 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 towards something; they are intentional. Merleau-Ponty (1962) observes how our body and our bodily movements are always directed towards objects 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 (for example, if we find ourselves experiencing extreme fatigue), we may lose our spontaneous way of acting.

In order 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 in order to create a coherent whole.

Storytelling also provides the opportunity to 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, looked back at the time when they had been bedridden. How did they narrate 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.

Method

Recruitment and participants

In order to be included in this study, participants had to meet the following criteria: to be women, aged 16-30, who had fallen ill with ME/CFS during childhood or adolescence but who now perceived themselves to be fully or significantly recovered. Participants had to have been ill for more than one year, and to have received their diagnosis of ME/CFS from a physician. All were required to have good language skills, and to be able to speak, read and write 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 two to ten 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 prior to the interviews.

Narrative interviews

The first author conducted individual narrative interviews between May and September 2019. Interviews took place at participants' homes, at the university or in a private location (for example, a local library) near a participant's home. Each interview lasted from 60 to 150 minutes and was digitally audio-recorded. 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 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.

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 (1967). 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 how these stories were organized and sequenced in order to understand the range of meanings associated with being long-term bedridden.

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. The excerpts were coded, analyzed for temporal coherence, and sorted into analytic themes. 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).

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 to the experience/phenomenon of being bedridden.

In line with Riessman's (2008) structural analysis, we then directed our attention to how stories were structured, and in particular how telling moments were put together. For Riessman, a fully formed narrative contains six elements: an abstract, an orientation, a complicating action, a resolution, an evaluation, and a coda (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.

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 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 prior to 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.

Findings

In line with the narrative tradition (Riessman, 2008), we present our results in the form of four storylines, which we regard as representative 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 how they structured their stories.

Three of our 13 participants had fallen ill during late childhood, nine in early adolescence and one in late adolescence. 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 one year to nine 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 activity -- 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 fulfil 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 words 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.

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 three 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 (holds her breath).*

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 towards helping her fulfil her primary needs. Amalie recalls how this limited of 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.

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 bodily discomfort could emerge.

Sara provides a flavour 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 […] Although I had my nasogastric tube for feeding, I entered a long period of extreme nausea, and 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. She explains that after being ill for a long time she experiences a sudden change as a result of fireworks being let off on New Year's Eve. 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. While she is being carried there, Sara experiences nausea she likens to being seasick, and this only gets worse with the passage of time. 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.

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, perhaps for ever.

Looking back at this experience from the vantage point of the present (coda), Cecilia describes how lying there in the dark for such a long time 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.

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 seven years. The first three 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 invalid 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 becomes 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 fictive 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.

Discussion

On the basis of our findings, we argue that the experience of being long-time 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 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 share the same structural elements, the order in which these appear varies.

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. 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, 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 outwards 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. Leder’s (2016), observation “This body will not just torture me, it will kill me” (Leder, 2016, p. 453). This reflects 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 temporality, 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 as not yet given up.

Cecilia’s 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 Cecilia’s situation – a sudden intensification of her pain – results in a comprehensive change in her embodied experience and existence. She perceives lived time and space 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 inwards. 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.

For humans, darkness is normally associated with going to sleep in the evening. Perhaps it is the sense of sameness that Cecilia experiences - same being, same darkness, same time, same suffering - that invites the term ‘eternity’. Whatever the case, her narrative reveals how body, time and space intermingle, affecting her 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 Fiona’s 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 Fiona’s case, she creates a memory where two participants (two versions of herself) are provided with the comfort they need and do not grieve alone. This memory seems to help Fiona 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 difficult feelings and loneliness. This sense of loneliness seems to be an essential and profoundly difficult aspect of being bedridden with ME/CFS in childhood and adolescence. For Ratcliffe (2022), loneliness: “is not a singular emotion in its own right, but a distinctive sense of exclusion or not belonging that is integral to a larger experience of relating to the social world" (Ratcliffe, 2023, p. 15). In other words, loneliness is about the absence of something else, the absence of feeling part of something (Ratcliffe, 2022).

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, 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. Such 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. 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 experience of being bedridden. Coexistent and inseparable, the four essentials infuse the lifeworld of each of our participants.

Methodical considerations

In order 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 women who were still bedridden with ME/CFS. The lack of research with this specific perspective suggests that other researchers have been aware of this ethical consideration.

Our participants formed a heterogeneous group of women, drawn from different parts of (country) and with different social backgrounds and educational levels. We consider that this heterogeneity contributes to the richness and transferability of the findings.

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 have emerged from our phenomenologically informed narrative study contribute to the body of knowledge regarding the experience of being long-term bedridden with ME/CFS.

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.

Clinical implications

Our findings underline the importance of 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 health care professionals. They 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). 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.

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 ME/CFS patients 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.

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Article III

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EMPIRICAL STUDIES

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The fragile process of Homecoming - Young women in recovery from severe ME/CFS

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ABSTRACT

Purpose: To explore the recovery narratives of 13 young women who had fallen ill with severe Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), during childhood and adolescence, with the focus on what they had to say about their past experiences from the perspective of the present.

Method: A qualitative narrative approach, informed by a phenomenological theoretical perspective, was adopted to explore what the women found significant and meaningful in their recovery process. Data analysis of in-depth narrative interviews was performed which are presented to readers through the stories of two particular participants.

Results: The first story describes how one participant made a recovery by testing her body's tolerance and working to create a more confident self. The second story describes a complex exploration of possibilities for action in recovery, along with a struggle to make sense of setbacks and hold on to what has been gained.

Conclusion: Recovering from ME/CFS emerges as an inter-personal, contextual, fragile and nonlinear process of homecoming, based on gradually rising bodily based self-knowledge. Illness slowly fades away into the background, and there is the prospect of a healthier tomorrow.

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Adolescents; children; women; chronic fatigue syndrome; myalgic encephalomyelitis; recovery; lived experiences; narratives

Introduction

In this article we present findings from research involving young women who experienced severe Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), during childhood and adolescence but who had subsequently recovered, either fully or partly.

Our study forms part of a larger Norwegian project exploring young girls' and female adolescents' experiences of falling ill, being ill and being in recovery from ME/CFS.

ME/CFS is a serious and complex illness characterized by debilitating fatigue, post-exertional malaise (PEM) and loss of physical and cognitive function (Rowe et al., 2017). It can affect persons of all ages, cultures, ethnic groups and socio-economic groups (Jason et al., 2020), although women are overrepresented (Ranjith, 2005). To date, the aetiology of ME/CFS has not been established and no curative treatment for the illness has emerged (Sharpe & Greco, 2019). There is no objective clinical test to verify the illness.

From a health care perspective, children and adolescents are generally considered to have a better prognosis for recovery from ME/CFS than adults (Moore et al., 2021; Rowe et al., 2017). However, while for adults there are multiple ways of defining and measuring recovery from ME/CFS (Adamowicz et al., 2014), recovery rates among children and adolescents vary considerably, and there is no international consensus on how to measure and define recovery (Moore et al., 2021). The most common outcome parameters for children and adolescents relate to school attendance, fatigue, and improvement in physical functioning (Moore et al., 2021).

The complexity of the illness, together with its fluctuating symptoms, and their tendency to vary over the course of an individual's lifespan, make it difficult to judge whether someone is in recovery or is simply experiencing a temporary, random improvement (Devendorf et al., 2019). Acquiring longitudinal data on those recovering from ME/CFS represents a further challenge. Persons who recover, particularly at an early

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age, may stop seeking medical help, without physicians knowing whether the condition of such patients has actually improved. The fact that a patient has recovered will not necessarily be registered and the physician will not have the opportunity to include the patient in medical research (Devendorf et al., 2019).

The lack of international consensus on how to define recovery from ME/CFS also makes it difficult to differentiate between those in the process of recovery and those who regard themselves recovered from ME/CFS. In previous research, children and adolescents with ME/CFS have revealed very different perceptions of recovery, and have often found it difficult to describe what recovery involves (Harland et al., 2019). One reason for this lack of clarity is that when children and adolescents are ill for long periods, illness may become the "new normal", making it difficult to consider what complete recovery might mean (Harland et al., 2019).

Given the complexity of ME/CFS, and the fluctuating character and intensity of symptoms over time (Parslow et al., 2018; Rowe et al., 2017), a child or adolescent patient can experience improvement in some symptoms while others remain unchanged.

With two exceptions (Harland et al., 2019; Jelbert et al., 2010), few studies have examined children's and adolescents' experiences of recovery (Moore et al., 2021). Harland et al. (2019) found essential elements of recovery to include resuming meaningful activities with peers, avoiding setbacks and enjoying flexibility in life. Jelbert et al. (2010) found that adolescents experienced personal growth, including increased confidence and maturity, as a result of their illness and recovery. Their illness experience also strengthened their relationships with family and friends. However, returning to everyday life and being with others was also experienced as difficult and scary, especially at a time when adolescents were facing the challenge of transitioning from being ill to getting better (Jelbert et al., 2010).

Despite such research, there remains a gap in the literature regarding what the process of recovery means and entails for young individuals with ME/CFS. What nuances and variations do their experiences reveal in terms of bodily changes and everyday life? Given the lack of consensus on what constitutes recovery in children and adolescents, there is a need to focus on this process as narrated and experienced by those who have first-hand knowledge of it (Moore et al., 2021).

For our study, we gathered and explored narratives told by young women in recovery from ME/CFS who had been severely ill since childhood or adolescence. We sought to identify what they found significant and meaningful in their recovery process by posing the following question:

What and how do young women previously suffering from ME/CFS during childhood and adolescence tell about their bodily experiences of becoming better from the present position of being in recovery or being recovered?

Theoretical framework

In terms of theoretical perspective, our research was inspired and informed by the insights of the French phenomenologist Maurice Merleau-Ponty (1962), in particular his understanding of the lived body as the basic source of all our experiences and perceptions. We argue that a phenomenological perspective can illuminate the lived experiential meanings embedded in individual stories of bodily phenomena: still acknowledging that there are also pre-conscious and embodied meanings at play that are not immediately apparent to the person narrating their story. In our study, we explore young women's lived experiences of recovery from ME/CFS as narrated in retrospect, focusing especially on bodily changes and everyday life. For Merleau-Ponty (1962), humans are at once individual, relational and situated bodily beings. Here, the body, far from being the passive object of our consciousness, is understood as an inseparable, interpersonal, sensitive, interpretive and significant embodied and embedded lived body (Merleau-Ponty, 1962). Our existence is a situated, intersubjective co-existence: we see and are seen, we hear and are heard, and so on. As Merleau-Ponty (1962) explains, this interactive bodily existence means that we both are and have our body—we are always both subject and object, never either-or. In line with Merleau-Ponty (1962), we argue that it is through their bodies that the young women in our study perceive themselves and their surroundings, express themselves and communicate with others.

Our study is also influenced by ideas developed by Fredrik Svenaeus (2001), himself inspired by the German phenomenologist Heidegger, regarding experiences of being-in-the-world during illness. When people fall ill, Svenaeus (2001) argues, they experience a constant sense of obtrusive unhomelikeness in their being-in-the-world (Svenaeus, 2000, 2001). This can involve feeling disorientated, helpless and despairing, in contrast to finding oneself "at home" in one's being-in-the-world. Such feelings contrast with the parallel notion of "homelikeness": the normal, everyday flow of life to which we rarely pay explicit attention to (Svenaeus, 2000). The experience of recovering can be understood as slowly regaining or coming to terms with a more homelike being-in-the-world. While this may not necessarily mean a return to the old, pre-illness homelike being-in-the-world, it involves the individual actively exploring and discovering new ways of being-in the world, towards creating a new "homelikeness".

In our study, we sought to explore recovery as a process that changes over time. For this reason, we applied a narrative methodological approach. Since storytelling is understood as our fundamental way of making sense of our experiences (Polkinghorne, 1988), we argue that retelling the story of their illness and recovery offers the young women in our study a way of "repairing" their biography as well as involving them in a profound meaning-making process (Riessman, 2008).

When retrospectively making sense of recovery in relation to the past, present and with expectations for the future, we do so in a particular way: we structure our experiences in the form of stories (Mattingly, 1998). Storytelling is a meaning-making process, where events are linked together in a temporal way to create a coherent whole. The perspectives of those who have recovered, or are in recovery, from ME/CFS, are unique and valuable. Such individuals are in a position to narrate coherent stories and give meaning to their former experiences by connecting the past with the present and onto a possible future.

Mattingly and Lawlor's (2001) descriptions of "healing dramas", where moments stand out as significant for the person, can contribute to an understanding of recovery as an inter-personal process. Within this understanding, recovery might not be about returning to the healthy body one once was but rather about reclaiming the body and exploring the body-related possibilities that are now conceivable (Mattingly & Lawlor, 2001). Viewed from the perspective of being in recovery, these could be healing moments — although ones that might remain invisible to others (Mattingly & Lawlor, 2001).

In this study, then, we combine a phenomenological theoretical perspective with a narrative approach to explore and comprehend the lived experiences of recovery over time.

Methods

Recruitment and participants

Participants for this study were required to be women aged between 16 and 30 who had fallen ill with ME/CFS during childhood or adolescence. Women were chosen because of the higher incidence of ME/CFS among females. The 16–30 age range was chosen in order to recruit participants who had been ill during childhood and adolescence but who were currently considering themselves to be in partial or full recovery from ME/CFS. Participants had to have been diagnosed with ME/CFS by a physician, to have been ill for more than a year, and to now consider themselves to be considerably better or without symptoms. They were also required to speak, read and write Norwegian fluently.

We recruited participants by placing an advertisement on two Norwegian websites concerned with women's health care and rights in society. Potential participants contacted the first author directly by phone or email, and those who met the criteria received detailed information about the study and a consent letter by email. A total of 17 women made contact, of whom only 13 took part in the study. Of the four women who did not participate, three decided not to take part in the study and one did not meet the criteria (she had not been diagnosed with ME/CFS by a physician). The interviews were conducted shortly after each participant made contact with the first author.

Our 13 participants were aged between 16 and 29 years (median age 24). Three of them had fallen ill before the age of twelve; nine had fallen ill during adolescence; and one had become ill in late adolescence/early adulthood. While some considered themselves to be in significant recovery, most considered themselves to be fully recovered from ME/CFS. At the time of the interviews, the women were either engaged in full- or part-time education or were working full- or part-time. Six were married or living with a partner, and one had a child. The women lived in different parts of Norway, both rural and urban, and all described themselves as having grown up in 'middle class's homes. None of the participants was previously known to the first author.

Prior to the interviews, participants were informed about the aims of the study and what their participation involved. They were told that they would be interviewed by a female paediatric nurse with extensive experience of clinical work with children and adolescents.

Narrative interviews

Interviews were conducted by the first author between May and September 2019, at participants' homes, the local library or in a university setting. Each interview lasted from 60 to 150 minutes, was digitally audio-recorded and was transcribed verbatim by the first author shortly after its completion.

In line with the recommendations of Riessman (2008), participants were encouraged to speak freely and with minimal interruption about the changes and improvement in their condition they had experienced over time. The first author began by asking open-ended questions such as "Can you tell me about the time before you experienced starting to become better?" Typical follow-up questions included "Can you tell me about how you first became aware there was an improvement in your condition?" and "Can you tell me about the experience of becoming better?"

Throughout the interviews, participants were encouraged to take their time, reflect and rephrase. This gave the first author the chance to follow up unexpected comments or changes of direction. It also facilitated the generation of extended narratives, as described by Riessman (2008), and gave participants space to create meaning and coherence during their storytelling. Having experienced major disruptions to their lives, the women were ready to offer extended, in-depth descriptions, sometimes with unexpected turns (Riessman, 2008). Additionally, encouraging participants to speak freely and retain control may have contributed to some equalization of the power relation in the interview situation.

Analysis

Data analysis was conducted by the first author in close collaboration with the four co-authors having professional backgrounds of nursing, occupational therapy and physiotherapy and experienced with various qualitative research methods. The narrative analysis was inspired by the work of Riessman (2008), specifically her thematic and structural way of analysing narratives, and by Mattingly's (1998) concept of healing dramas and telling moments. Throughout, our focus was on the events participants had found especially meaningful during their process of becoming better. In line with Mattingly (1998), we understand events as telling moments, ones when individuals understand themselves and their situation in new ways, enabling them to take new forms of action.

First, the audio-recorded interviews were listened to several times. This was followed by a close reading of each interview to get an overall impression of what the narrative was about.

In line with Riessman (2008), what was told was analysed with narrative thematic analysis. At this stage we posed the following analytic questions:

- What are the young women telling about the experience of being in recovery?
- What kind of telling moments or events emerge from their accounts?

In our narrative structural analysis, the focus was on the temporal structure of each story: its beginning, middle and end (Riessman, 2008). Furthermore, how the stories were told entailed organizing participants' events seeing how they were interconnected and trying to reach a meaningful whole (Mattingly, 1998). By comparing and contrasting across the analysed interviews, we gradually enabled to develop two storylines. During this process of analysis, we found differences in how the recovery process was narrated, which is illustrated in the two storylines. While some stories involved events that were ordered temporally (making the narrative easy to follow), other stories included elements that were more challenging to comprehend. This tended to be the case with stories that seemed incomplete or tentative, often told in a hesitant way. Events representing telling moments (whether ordinary events that were suddenly experienced in new ways, or totally unexpected events) were coded and further explored (Mattingly, 1998). The stories, while various and unique, shared some common patterns and themes.

In line with the narrative tradition (Riessman, 2008), we present our in-depth analysis of two such stories, which we regard as especially nuanced and illuminating. At the same time, although different in details, these storylines are also seen in the stories of the other participants. The first storyline, a structured, finished, and coherent piece of storytelling, contrasts with the second, which presents a more unfinished, not fully developed storyline. The two storylines, however, share a common plot: struggling from being "unhomelike" to gradually becoming a homelike being-in-the-world. We argue that this narrative plot provides one possible way of understanding what a personal recovery process from ME/CFS can be like.

Ethical considerations

The study was approved by the Norwegian Regional Committee for Medical and Health Research Ethics, Social Science Data Service, and 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 main supervisor (KSG) and the first author have had full access to the interviews and the transcribed material; the three other authors have had access only to excerpts from the anonymized transcribed material. Informed consent was given by the participants prior to each interview.

Findings

Eight out of our thirteen young women participants considered themselves to be completely recovered from ME/CFS and were either working or studying full-time or planning to work or study full-time at the time of the interview. The remaining five considered themselves to be much better, but still to some extent experiencing fatigue and aware of the need to get enough rest. All the women described how they had a greater need for structure and routine in their daily life (for example, in relation to meals and sleep) than they had experienced prior to illness. All told of how, when they fell ill, their parents had sought different kinds of treatment for them, and how they themselves tried different treatments in the hope of getting better.

When it came to how they told their stories, however, participants varied considerably. Some of those who had recently recovered or had a sudden recovery told their stories by jumping back and forth in time and adding remembered details along the way. This was storytelling that was a bit difficult for the interviewer to follow; as researchers, we understand it as an unstructured form of storytelling. Others told their stories by describing their current situation before moving back in time. But most of the women started by telling about their life prior to illness, then moving on to describe falling ill and eventually becoming better.

In the excerpts from transcripts presented below, all participants appear under pseudonyms. Any quotation that might disclose a particular participant's identity has been omitted. The stories are written in the present tense, even in relation to past experiences, in an attempt to underline the developing nature of the narratives.

The first story, told by Cornelia, is that of a young woman who considers herself to be fully recovered from ME/CFS. The story is an example of structured, finished, and coherent storytelling: Cornelia begins by describing her life prior to her illness, then moves on to describing her experiences of falling ill and, eventually, becoming better.

The second story is told in a different way. Hedda is a young woman who considers herself to be in the process of recovery from ME/CFS, rather than fully recovered. While her narrative reveals elements of structured storytelling, it appears somewhat unfinished and chaotic when compared with Cornelia's account. While narrating her story, Hedda jumps back and forth in time as she seeks to make sense of her recovery. This may be related to the fact that she experienced a sudden awakening after a long period of being bedridden with ME/CFS.

While both Cornelia and Hedda recount a long process of returning to everyday life, a struggle to come to terms with a changed and changing body in order to find a way to rebuild one's body and everyday life, they deploy different storylines.

We characterize the theme of the first storyline as "Exploring and building an understanding of bodily limits and capacities". Here, a woman who considers herself to be fully recovered from ME/CFS describes a recovery process in which she tests her body's tolerance and seeks to build a more confident self.

The theme of the second storyline is "Bodily awakening of the self: From a dark place to a fragile and unfinished process of reuniting with one's own body and world". While this woman considers herself to be significantly better from ME/CFS, her recovery process remains ongoing. In her narrative, she describes how she wakes up to a world of possibilities for action, after being isolated and severely ill for years.

In the excerpts from transcripts presented below, the symbol [...] signifies that two identified sequences were found to be related, while three dots ... indicate a pause in the narrative.

Exploring and building an understanding of own bodily limits and capacities

At the time of her interview, Cornelia is 25 years old. She is about to become a full-time student after being ill for nearly ten years. When she first fell ill, she was diagnosed with Mononucleosis. She never seemed to recover from it, but despite this, she was advised to stay physically active and keep up full-time schooling. It was only after nearly two years of seeking medical help and struggling with exhaustion and malaise that she was finally diagnosed with ME/CFS. During her illness, Cornelia experienced symptoms that fluctuated from moderate to very severe. For a long time, she attempted to keep up with her schoolwork but found doing so took all her energy. In the end she was forced to quit school because of her high absenteeism. She describes her years before recovery as a downward spiral in which her condition always worsened and she suffered "collapses" which left her bedbound, isolated, and severely ill for months. She would get somewhat better, only to collapse again.

During her collapses, Cornelia experienced profound fatigue, diffuse pain, memory loss and loss of appetite. She described how her parents struggled to help her, searching for treatments, and battling to provide her with sufficient nutrition. She went through a variety of treatments, including physical therapy, psychotherapy, diets, and the Lightning Process (a three-day personal training programme developed and trademarked by British osteopath Phil Parker). But while these treatments gave her some tools to cope with her situation, she continued to get worse.

However, during a period of more moderate symptoms when she was able to leave her bed, she made one final attempt to get treatment, at a public health out-patient clinic for people suffering from different kinds of exhaustion disorders. As she explains:

> We (the family) understood I had to try something completely different ... I couldn't stand another collapse ... My first meeting at the clinic ... well, I got a good feeling as if they knew what they were doing. I was together with people of all ages, and everyone got their own exercise plan ... we met like four times a week [...] There was nothing left of my body, I couldn't do a thing ... but you were supposed to take it very slowly ... not overdoing activity, ... kind of get in touch with your body ... very gently ... slow Yoga or Pilates. They helped me to find the level I could do without getting worse the next day.

For the first time in years Cornelia was outside her home, in a safe place with others who somehow understood her situation. Her embodied way of being had changed dramatically during the illness, leaving her with little strength to do anything. Despite this, she was guided to slowly explore her body and possibilities for action. She gained an understanding of how much her body can tolerate without experiencing exhaustion afterwards. This is how Cornelia describes the change she experienced:

> It was wonderful to be social again … but man, we were a bounce of tired people (laughs). For the first time in years, I had like a schedule, and I could go through with it […] I focused on my body and movement … stretching … Not pushing myself … It was so nice to find the right level … and wake up the next day with a good feeling … and after some time at that level, slowly challenge myself and do a bit more. I learned to listen to my body … and it went well. I had to learn my new limits and accept them. I was done with pushing myself and this was how I wanted to do it […] You could say this was a turning point for me …

Sharing her experiences with others in a similar situation and meeting on a regular basis prove especially important to Cornelia. Together, they create a kind of supportive community. Exploring what her weak body can achieve, with support from others, is like balancing on a tightrope, with little room for mistakes: she knows that if she overdoes a particular exercise, she will feel exhausted the following day. All the same, she knows she has to test her body so as to understand what she might be capable of. Without that testing, she cannot know what her body can tolerate. Cornelia senses she had started something within herself. By doing these slow movements she is on her way to reconnecting with her body, and it feels good.

In the past, Cornelia had been determined not to show others how ill she was. Additionally, she had pushed herself to attend school, knowing that otherwise she would be forced to quit. But at the clinic she does not need to hide her illness:

> It's always been the social things that have worn me out … and I could never reveal any weaknesses. People never understood I was ill … because I didn't look ill and when I got worse, I was not at school … at school I continued wearing my "mask" and played the healthy Cornelia … with perfect makeup, a smile and always social … It was exhausting to play that role. After a while I had to quit school because of my absenteeism and I became severely ill … isolated, lost all my friends (swallows). I didn't understand that I pushed myself beyond […] No one else at the Clinic was wearing "a mask" so I just stopped … was honest with myself … I stopped pretending I was healthy … which saved me a lot of energy.

Despite her illness, Cornelia had tried to conform with social expectations. She sought to present herself as a healthy person and a perfect version of herself, instead of paying attention to her own needs and limits. She adopted a "mask" to fend off questions from others, and continued attending school, telling herself "If I just play healthy, I am healthy". This situation proved unsustainable, and Cornelia found herself bedridden for months at a time.

A breakthrough is achieved when Cornelia is able to reveal the fact that she is ill in the presence of supportive others with whom she feels safe. Patiently following the advice she is given at the clinic, she now pays attention to her body. At last she can concentrate her energy on getting well. Cornelia attends the clinic for nearly three years. At times she is uncertain whether she is getting any better. But then, something happens which helps her discover how much better she actually has become:

> I think it was a year after I started the treatment that we (the family) went to our cabin and everyone wanted to go skiing, I was a bit insecure; should I try? My family didn't want to push me … but then I went on an 8 km roundtrip on my skis … slow, and my dog pulled me a little but still … such a wonderful experience … a relief … I got tired, but it was a good feeling … For the first time I knew there was a big change … that I had done something right. When things are changing slowly you don't always see the progress …

The event stands out as a long-awaited confirmation, a quiet moment of understanding and a certainty that she has regained sufficient strength in her body to restart everyday activities. She is heading in the right direction. Tiredness used to be something she feared, but for the first time in years, she experienced tiredness as a positive and natural part of being. Her body used to be experienced as an obstacle, but now she has reclaimed a sense of its possibilities for action. Cornelia reflects on her illness and recovery process thus:

> The further I get, the more confident I am … I learned to understand myself … now I know how to handle my illness […] If you want to get well, you need support from others and without my family, I would't be here … and the folks at the clinic (smile) .. . and you must make some hard choices, like if a person wears you out, you have't let go … you must cherish your energy … decide how you would like to spend it […]
>
> I need my routines … the balance between sleep, rest and activity, I need to eat regularly so I need to plan … do things that makes me happy! I can even do things that are socially exhausting for me … like going to a party … I know it costs and I'll need to rest afterwards … but it's worth it and I know I`ll be fine. I think I'm as healthy as I could get … from my perspective then … mm … I'm done comparing myself with others … I've been ill for more than ten years … of course I wish I hadn't been ill … but my life took a turn … and I learn to look on the bright side.

With the help of others, Cornelia gains an understanding of what her body can tolerate and how to live with the illness. She still needs to prioritize so as to manage her life but she has learned to embrace the future, avoid dwelling upon the past, focus on the good things in her life, and limit what drains her of energy.

Cornelia's recovery storyline tells of a growing understanding and awareness of body and self. Left with a vulnerable and strange body by her long-term illness, Cornelia experienced a kind of disconnection from her body. When placed in a safe world shared with others, she slowly begins to explore her body through movement. Aided by significant helpers, she becomes more aware of her bodily self and who she wants to be. Slowly an experience of confidence and belongingness in her own self develops. The illness is slowly fading into the background, and she makes various adjustments. More than ever, however, she is does focusing on her future.

Bodily awakening of the self: From a dark place to a fragile and unfinished process of reuniting with one's own body and world

At the time of our interview, Hedda is 27 years old and living in her own apartment. She explains that she had little experience of illness prior to ME/CFS. Unlike Cornelia, she had no infection or other explanation for why she became ill in the first place. She was diagnosed with ME/CFS at the age of twelve after a long period of pain, exhaustion and sensitivity to light and sound. For the next seven years she was severely ill and bedridden most of the time. Eventually she became unable to eat or go to the toilet by herself, spending her days lying completely still in bed in a darkened room.

Looking back, Hedda recalls feeling very fragile but also alert during this period. Her parents did all they could to spare her distress, for even the smallest thing, such as eating or changing her diaper, was painful and stressed her out. She was too ill to receive any kind of treatment. She describes it as a challenging situation for her family: they knew she is suffering but didn't know how to help her. Naturally, it was an extremely difficult situation for Hedda herself and for a long time she showed no signs of improvement.

From the perspective of today, Hedda describes how severely ill she was:

> The last year was quite serious … I could barely be fed via the nasogastric tube (swallows). So nauseous … I didn't think it was possible to suffer this much and still be alive (pause, looks out the window) time was moving slowly … I wanted to die … I was done living. I think it was hard on my parents […] mm how should I continue … (pause) In the beginning it was difficult for me to talk about it … I could easily start to hyperventilate, it was traumatic … it's a bit easier now … like telling you about it.

For Hedda, her illness was like living in a kind of borderland, a place of stagnation between life and death. It was as if time had stopped, as if everything in her body had stopped, so that her body could hardly absorb food. Life was transformed into merciless, unbearable and eternal torment. All she wanted was an end to her misery. Even later, during recovery, merely thinking about her illness could easily take over Hedda's entire being. But today she is able to control the feeling, making it possible for her to share her story.

After years of lying still in a darkened room, Hedda experienced a sudden turning point in her life:

> I remember there was a change that summer … small change … I remember I started to move … that I felt like moving my arm and … maybe I turned around … because I had been lying on my back the entire time … I didn't dare to believe … but from time to time I dreamed about becoming better … I didn't believe I could get well, but that I could be able do something … but sometimes I didn't believe there was any improvement at all.

Out of the blue, Hedda experiences an inner urge to move herself. She slowly begins to make small movements, carefully and cautiously trying to reconnect with her body after being totally disconnected from it for a long time. Her small movements make her think and hope about getting better, although such hope is fragile and filled with ambivalence: she lacks any confidence in her body and fears it may fail her. She does not dare to hope too much.

However, Hedda's parents are more optimistic. Following this event, they invite therapists experienced in the treatment of ME/CFS to their home. Her parents have heard about another girl who had been severely ill with ME/CFS but who is no longer bedridden following treatment of this type. This is how Hedda describes what happened when the therapists arrived at her home:

> I was told someone was coming to see me, but my parents didn't tell me much … then they came and I remember one of the women asked me: "Do you want to get well?" I did not understand … was this an option? … to get well? I was supposed to press her hand if I wanted … it took a long time … but then I pressed her hand.

Hedda finds herself confronting a challenge. After being "sheltered" for years in her unpredictable and traumatic state, she is asked to make a decision. Does she want to get well? Such a prospect is so far away from where she is that it is incomprehensible. She wants to get well, but at the same time she is reluctant to commit herself. She hesitates. What does the question even mean? What does it demand of her? Can it actually mean that she can get well? After Hedda signals she wants to get well, the therapists do something totally unexpected:

> They (therapists) drew the curtains and opened the window … helped me so I could sit up in bed … I saw the faces of my family which I hadn't seen in years. I recall the lovely feeling … and letting the daylight into the room … light used to make me suffer […] The next day they held (supported) me and I tried to walk … mm … and I think I sat outside on the terrace, so human in a way.

By saying "yes", Hedda enters into an alliance or contract with the therapists, enabling them to take the initiative and begin therapy. It is as if Hedda has woken up from long-term hibernation as she is literally as well as symbolically lifted into the daylight. It is the start of an awakening. Hedda has committed herself to re-entering life beyond her bed and darkened room. There is no turning back. Just sitting up in bed and being able to see her family becomes a dramatic, observable healing moment.

As Hedda starts on the long road to reuniting with her body and the wider world, she experiences joy. But at times she is also overwhelmed by exhaustion, resulting in setbacks:

> In the beginning it was such a pleasure waking up in the morning … taking part in life and spending time with others. I recall how others would complain about being tired in the morning, and I just thought 'it's fantastic to be able to leave the bed!' It's like I've heard from others (with ME/CFS), that it was like rising from the grave … to get my life back. I can remember the feeling very well […] I had a physical therapist who helped me, we went for short walks … besides that nothing special … I was surprised how quickly my body rebuilt itself after so long a time … mm … in time I was kind of bored of being home and I started going to lectures at school … I felt very grateful […]
>
> But I had several periods when I felt down and thought 'this is not going my way' … I had like setbacks (exhaustion) and became terrified … not that I became totally bedridden, but I remember I had to spend days on the couch … terrified I was falling ill again … think it made me worse. What if I don't get any better! I was so stressed. The negative thoughts kind of pulled me down again … I had to pause for weeks, maybe months, before I could return to where I had been.

Hedda experiences a tremendous sense of gratitude of being alive. She compares being finally able to leave her bed to a kind of resurrection, using a powerful metaphor, "like rising from the grave", to emphasize the extraordinary experience. But awakening after severe illness is not easy. Hedda is still fragile; her strange body is recurrently tired or exhausted. All this makes Hedda insecure. What is happening and what is she supposed to do? She fears she is falling ill again, and she does not know how to navigate her way so as to avoid getting worse again. She finds herself repeatedly forced to take a step back and withdraw from those around her.

All her life, Hedda explains, she has battled excessive self-criticism:

> I used to be so self-critical, you know, ever since I was a child … it took most of my time and I could never say no to anyone … wore me out … I didn't understand it at the time … I had to learn to get to know the feeling and understand that it stressed me out […] I remember the first time I failed to use the technique (from the therapist): you know, I tried to picture myself in a comfortable state … tried to relax and told myself nice things … but then I totally lost focus and told myself I couldn't do it! Same thing, over and over … frustrating … after a while I managed to use the technique to stop the negative thoughts and kind of stop the stress … it's what I need to do when I kind of lose direction … I could easily end up in the ditch again. At one point it became very clear to me: okay, I am exhausted, but it's not all about the lack of energy … the only thing I need is actually peace and quiet … I need to be at peace with myself. Then I gain energy and do what I want … and be with others.

Before Hedda fell ill, she was already giving herself a hard time. She spoke of always prioritizing others' needs and desires over her own. In retrospect, she understands how this may have contributed to her experience of exhaustion. She learns to pay attention to her body so she can better understand her own needs and desires. This enables her to find some balance in her life and reach towards inner peace.

Hedda uses the metaphor of "the ditch" to describe her setbacks: times when she experiences symptoms and loses faith in getting well. She tries to help herself, but it is a lonely and difficult process. Today, Hedda considers herself to be significantly better but still in recovery:

> It's been a long way of rebuilding myself and returning to life (swallows) […] I tried to regain contact with my friends, but I think it was difficult for them … made them uncomfortable … because I had been so ill … I figure they didn't understand .. . I was at a totally different place … they were deciding which school to go to, and I was most concerned about rebuilding my legs […] I try to liberate myself; my family means well - but I'm not a child anymore … I must try and fail on my own … otherwise, I will never move on […] My doctor told me to stop comparing myself with others who have never been ill and focus on how far I have come, despite being so ill … I need to compare myself with myself.

No longer sheltered from the outside world, Hedda explores ways of becoming an adult and gaining a new, independent way of being. This involves great effort and it's a process she is doing on her own. She knows that others cannot possibly understand what she has been through or how ill she actually has been. She must rebuild herself and her life from scratch.

When Hedda enters adulthood, she does so without having passed through the possibilities and experiences that are characteristic of adolescence.

Hedda's storyline is one of resilience but also of continuing fragility. Awakened from her long, merciless hibernation, Hedda still battles to create an understanding of what she has been through and make meaning out of the experience. Her first experience of hope and recovery was her inner urge to move. Then she received help to understand that there were possibilities waiting for her. Now, finally, she is in the process of reuniting with her body. From the perspective of today she understands recovery as an ongoing, self-driven process that takes time. While she needs support from others, no one can tell her exactly what to do.

For Hedda, her current being is at the same time familiar and unfamiliar. She is still on guard worrying about setbacks. She needs to experience a greater sense of familiarity if she is to gain a sense of belongingness in her being and be able to explore her possibilities in life. She must draw herself a new map in order to navigate a way home.

Discussion

The two storylines presented here reveal being in recovery from ME/CFS as an inter-personal, contextual, fragile and nonlinear process in which the individual slowly and persistently builds a more homelike being, in both the body and the world. Recovery emerges as a continuously demanding process, one that requires determination, bodily based self-awareness and self-knowledge. In this discussion, we elaborate on this fragile process of (bodily) homecoming experienced by women recovering from ME/CFS.

As our participants reveal, the process of recovery entails searching for ways to make one's being understandable and bearable again. After long periods in which they were bedridden and disconnected from the body and the world, the young women were in search of a new order. They searched for ways to gain bodily knowledge and trust; they strove to unite with a fragile body in a shared world of others. In line with Svenaeus (2011), this can be interpreted as a way of re-gaining belongingness by moving from an "unhomelike" being-in-the-world to one that is more "homelike" (Svenaeus, 2011). Rather than following a particular route it is an explorative process of searching for possible routes towards a new kind of homelikeness. For these young women, all of them living with a changed and changing body, the quest for homelikeness involved immense challenges.

Their fragile process of homecoming entailed searching and reaching for belongingness and reuniting with their bodily being. They embarked on a long and strenuous journey, a struggle to make sense of their strange body and how it reacted to movements and stimuli such as bright light and sound. Moving forward, exposing themselves to new experiences they regained a sense of belongingness in their being-in-the world. New possibilities and hope increasingly came in the foreground of their focus. But they also suffered moments of doubt—setbacks that could leave them feeling lost again and losing hope. Throughout this journey, the women sought to re-establish a kind of equilibrium and harmony in their being-in-the-world (Gadamer, 1996/2018).

Trying and failing formed part of this process of exploring the body during recovery. As they explored, the young women learned more about their bodies and bodily limits. This bodily exploration required strong self-motivation and a readiness to take risks: there was always a possibility of becoming worse, but also an opportunity of rising again, even if this involved great effort. Additionally, this bodily exploration entailed gaining knowledge and learning from setbacks. As the women persisted their exploring, past experiences of their bodies gradually faded away; they gradually regained trust in a body which, aided by growing self-understanding, was on course to become a new, habitual one. However, the fragility of this process was very much present in most of the stories, with the threat of relapse lingering in the background.

Over time, everyday routines and actions in the world gradually became pre-reflective: products of habit to which the women did not consciously pay attention (Merleau-Ponty, 1962). At the same time, the "new" habitual body called for attention in the sense that the women needed to be on guard for bodily signs and reactions. They sought to pick up on signs of exhaustion or other indications that they had pushed themselves too much. The new habitual body could manage to stay in balance and avoid setbacks when specific adjustments were made, new routines established, and some degree of balance achieved in respect of sleep, rest and meals. These specific and individual adjustments were entailed balancing on a thin line and emerges as the very essence of the recovery process in ME/CFS. In recovery, developing bodily self-knowledge emerges as an ongoing process of exploration, a constant effort to make sense of bodily limits and possibilities. This effort to make changes in one's life and focus on possibilities has also been highlighted in previous research (Kalla & Simmons, 2020).

For our participants, a crucial moment in their recovery was their decision to reveal to others the extent of their illness. Through such self-exposure, the women were able to share common experiences, support one another, enrich their understanding, and create a sense of belongingness (Leder, 1990). Through others we widen our perspective on the world and in this way supplement our own embodiment (Merleau-Ponty, 1962). When we are in recovery, the experience of a fragile body may seem less alienating when shared with others who have similar experiences, as narrated in the first storyline. During recovery, shared experiences can contribute to our gaining knowledge about our being-in-the-world and make it less uncanny. The metaphor "letting go of the mask" describes this risky moment of revealing oneself as ill to self and others. Even though there is an aspect of existential loneliness in the experience of being severely ill, experiences of body and self, have a profoundly social dimension, one arising out of the presence of others and their gaze back upon us. As Leder puts it, "My self-understanding always involves the seeing of what others see in me" (Leder, 1990, p. 96). Exposing to others the extent of one's illness may result in acceptance or rejection. But more importantly a step has been taken towards being honest with oneself, to being accepted by oneself without "the mask".

Some participants gradually found themselves with sufficient energy to perform simple tasks, such as knitting, watching a film, or drawing (parents often played an encouraging role here). For others, their recovery experience was more of a sudden waking up. Whatever its form, this bodily awakening can be likened to being brought back, or reconnected, to life, to feeling the presence of life in a shared world of others. Uncertainty persisted. Participants were aware that their attempts to reconnect with body and outside world might fail. As narrated by the participants, these awakening experiences can be understood as "healing dramas" (Mattingly & Lawlor, 2001). As described by Mattingly (2010), small events or healing dramas can bring hope and therefore be of great importance. For our participants, new possibilities for action were opened up and new meanings arose as events unfolded (Mattingly & Lawlor, 2001). At the same time, these small events and dramas might be fleeting and fragile, their outcome uncertain. One participant used the metaphor "like rising from the grave" to describe her bodily awakening. The metaphor conveys not just the act of resurrection but also the unhomelike nature of the place from which one is rising: the bleakness of the grave. In the awakening storyline, there are glimpses of hope, of escape from the uncanny, unhomelike being in one's own body and world, which has permeated every aspect of the individual's being. There is the prospect of moving, of inching towards a more homelike being-in-the-world—one that is different from that experienced prior to falling ill.

During recovery, participants struggled to make sense of setbacks, with some experiencing a kind of collapse. Lack of comprehension and coherence, combined with difficulty in finding the words to describe such experiences to others, could undermine their attempts to build greater self-understanding. In order to cope with such reversals, which one participant likened "ending up in the ditch", the need is to re-establish equilibrium, to regain balance in one's being (Gadamer, 1996/2018/2018).

During the fragile recovery process described in the storylines, both illness and wellness seemed to be present. The daily need to make adjustments might help explain why for participants found it difficult to describe themselves as recovered from ME/CFS (Cheshire et al., 2020). Adults' experiences of feeling healthy but at the same time adjusting to illness are described by Brown et al. (2017) as akin to living in a kind of borderland between illness and wellness: a threshold or liminality which could be understood as even less legitimate than actually being ill (Brown et al., 2017). This constant adjusting is in line with Paterson's (2003) Shifting Perspectives Model of Chronic Illness. Here, Paterson argues that living with chronic illness involves an ongoing shift in perspective between illness-in-the-foreground and wellness-in-the-foreground, with the two perspectives co-existing and serving specific functions in the person's world. This ongoing shift between wellness and illness is also described by Frank (1995). When being in recovery or member of "the Remission society", there is a shift when wellness is in the foreground and illness in the background and the other way around depending upon the circumstances (Frank, 1995). For the participants in our study, it was crucial to create a feeling of certainty, increase their sense of control, and make sense of setbacks while seeking to avoid them. It was important that a sense of wellness prevailed over a sense of still being ill, even when they were still suffering from a disease.

Gadamer (1996/2018/2018), too, describes the importance of working one's way back from the social disruptions caused by illness and returning to life, with all its challenges. The existential loneliness experienced by the participants while they were bedridden, isolated and detached from life contrasts sharply with their being in the process of recovery. Rather than being simply a matter of physical recovery from illness, this involves returning to where we belong, to where we truly live our lives (Gadamer, 1996/2018/2018). For our participants, the fact that many years had passed since they had last taken part in social activities, together with their restored ability to be part of activities associated with a healthy life, encouraged them towards a greater focus on wellness.

The fragile process of moving from an unhomelike being-in-the-world towards a new, different homelike being-in-the-world seems to rest on hard-fought-for knowledge about one's body and its new ways of relating and acting. The body slowly becomes a new-habitual body, making it possible for the individual to carry out new habitual actions. During this interpersonal, contextual, fragile and nonlinear homecoming, illness slowly fades into the background and there is the prospect of a healthier tomorrow.

Methodological considerations

In terms of robustness and trustworthiness, the findings of this study are reinforced by the transparency of the analysis and also by the fact that the authors have different professional backgrounds and scientific experiences, enabling us to challenge and question each other's preunderstandings and interpretations. The collaboration between the authors allowed us to reflect and discuss across narrative methods and phenomenological perspectives. The authors brought different preunderstandings regarding ME/CFS treatments and the concept of recovery, resulting in much discussion, clarification and raising of critical questions. Throughout the research process we sought to maintain a reflexive, open and curious attitude while remaining critically conscious of our preunderstandings (Finlay, 2008). Throughout the process of analysing and writing, we benefited from discussions within the group. For instance, when analysing the stories, especially those involving "awakenings", it was not always easy to understand what the recovery process was about. But through repeated reading and group discussions, we were able to gain a better grasp of the "awakenings" phenomenon and its nuances. What we first coded differently, eventually seemed to revolve around the same phenomenon.

The participating young women formed a relatively heterogeneous sample, drawn from different parts of Norway and with varying family backgrounds and educational levels. We considered the heterogeneous sample a strength, given that it yielded a variety of recovery stories and meaning-making strategies. The stories narrated by our participants share common features, underlining their relevance for a broader understanding of the experience of being in recovery. But despite the similarities across our interviews, our study does not claim to have revealed all possible recovery narratives; indeed, such a claim would be inconsistent with the narrative approach we have employed. However, we would argue that our study is an important contribution to understanding the effortful, complex, and fluctuating healing process undertaken to recover from ME/CFS.

Clinical implications

This study highlights young women's recovery from ME/CFS as a continuously demanding process that requires an explicit focus on bodily based self-awareness, self-knowledge and self-motivation. Our findings underline the importance of listening to, and learning from, the stories of women who are in recovery or have recovered from ME/CFS, if we are to gain richer, more nuanced understanding of what recovery involves and demands. In addition, our research suggests that it is vital for individuals in recovery to make sense of setbacks along the way. It is crucial to underscore the fact that the process of recovery usually takes years, with unavoidable setbacks along the way. Explaining the time dimension may help those in recovery by underlining the value of patience, openness to learning, and determination never to give up. That healthcare professionals should convey this message to patients striving to recover from ME/CFS seems of paramount importance. Healthcare professionals also need to remain aware of the possible discrepancy between their own understanding of what recovery entails and the perspectives and insights of their patients. Acknowledging this discrepancy, health care professionals can take more active part in their patients' explorative, meaning-making process towards a new kind of homelikeness, thereby easing their challenges and burdens somewhat.

Concluding remarks

Recovering from ME/CFS emerges as an inter-personal, contextual, fragile and nonlinear homecoming, based on a gradual rising bodily based self-knowledge. Crucial to such recovery is an individual's ability to reach a state of being in which wellness predominates over illness. Recovery seems to be an ascending process, one in which illness slowly fades into the background as the healing patient moves on and looks ahead towards a healthier tomorrow.

In terms of further research, the authors highlight the need for more exploration of the specific health needs of children and adolescents in recovery from ME/CFS as they navigate a path to their own homecoming.

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Errataliste

Navn på kandidat: Silje Helen Krabbe

Avhandlingstittel: The long, arduous road to recovery: an exploration of the experience of young Norwegian women falling ill with ME/CFS during childhood and adolescence.

Celtf -endring av sidelayout eller tekstformat

Side	Linje	Originaltekst	Type rettelse	Korrigert tekst
0	I «Summary» Avsnitt 4, setning 2	*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.*	Celtf	Endre til Times New Roman Størrelse/Font size 11
0	I «Summary» Avsnitt 4 setning 3 - 6	Together, the storylines build a picture of participants' overwhelming bodily discomfort and long-term, seemingly endless isolation. The women's limited access to others brings with it profound loneliness and suffering; it disrupts their sense of belonging to the world and pushes them closer to the edge of life. These results underline the existentially challenging nature of being long-term bedridden and severely ill with ME/CFS.	Celtf	Endre til Times New Roman Størrelse/Font size 11