

‘It’s like being a slave to your own body in a way’

A qualitative study of adolescents with chronic fatigue syndrome

Abstract

Background: Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) is a relatively common disabling illness in adolescents that may limit participation in daily life. **Aim:** This study explored interactions between the illness experiences of adolescents with CFS/ME, their occupational lives and expectations for the future. **Methods:** Seven adolescents with CFS/ME were interviewed. The interviews were analysed using thematic analysis. **Results:** Three themes were developed. ‘Being ruled by an unfamiliar and inexplicable body’, which illustrated that altered and strange bodies seemed to separate and disrupt the participants from their former occupational lives. ‘On the sideline of life with peers’, which demonstrated that the informants spent time at home, doing undemanding activities instead of participating in activities with peers. ‘A coherent connection between present and future life’, which was reflected by how the participants eventually accepted their situation and rebuilt a meaningful occupational life and value of self. **Conclusion:** CFS/ME made the body unfamiliar and disconnected informants from participating in their usual daily occupations. A coherent interaction between body, occupational life and social self was achieved by taking their new body into account and adjusting their occupations accordingly. This practice enabled the participants to hope for a better future life.

Keywords: CFS/ME; illness experience; interactions; occupational life trajectory; recovery; young

Introduction

Chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME), exhibits an estimated prevalence of 1% in children and adolescents [1, 2]. The aetiology of CFS/ME is not known, and objective findings in medical examinations do not support the diagnosis [3]. CFS/ME is characterized by a persistent, unexplained fatigue that is not alleviated by rest. Patients also report symptoms, such as muscle and joint pain, headaches, unrefreshing sleep and post-exertional malaise [3, 4, 5]. Young people living with CFS/ME experience substantial limitations in daily activities [1, 6, 7, 8], such as being unable to walk and problems to concentrate, which may lead to inactivity and school absences [1, 9, 10]. Adolescents may become increasingly dependent on their parents during a life period when their peers free themselves from home. So far, there are no curative treatments for CFS/ME, and patients must learn to live with the condition. Therefore, CFS/ME represents an important health-related challenge in the Western world today [8, 12, 13].

A recent metasynthesis of 10 qualitative studies of young persons with CFS/ME revealed that children/adolescents experienced considerable losses related to their everyday life. Children/adolescents reported experiences about their diagnosis and illness beliefs/attributions [14]. Some adolescents initially considered their symptoms to have a somatic cause but later adjusted their previous views and assumed that symptoms could also have psychological causes [15]. Other adolescents reported that family, friends and school teachers thought they were lazy or that their illness was faked because their symptoms were not visible to others [8, 16].

Adolescents talked about illness symptoms, and the consequences for their everyday life [8, 14, 15, 16]. Nausea together with changes in taste and smell, were followed by weight loss [17]. Some adolescents described worry and high levels of anxiety [14]. They expressed

frustration about fluctuations in symptoms, which made their everyday lives unpredictable [8]. The illness hindered participation with their peers, and they felt sad for the loss of their former lives. They also felt alienated in their own bodies and forgotten by friends [16]. Some adolescents experienced a loss of academic life as well as less hope for the future [16]. However, some reported that they had gained something positive from being ill and experienced personal growth [16, 18]. They developed management strategies to cope with their new life situation by balancing their daily lives and hoping for recovery and future education and work [15, 16, 17, 18]. Mostly, previous studies explored how patients experienced their symptoms or how CFS/ME had consequences for participate in specific activities of everyday life. However, more in-depth knowledge is needed for occupational therapists to more fully understand how symptoms interfere with adolescents' daily lives during an important time of personal maturation and growth. Such knowledge can enable occupational therapists to provide adequate health care and support and contribute to the identification of appropriate strategies to ease the burden of the illness. Thus, this study explored interactions between the illness experiences of adolescents with CFS/ME, their occupational lives and their expectations for their future lives.

Theoretical framework

Occupational life is a crucial concern for occupational therapists as it is assumed that to be occupied in life is a fundamental human need [19, 20]. Perceptions of low energy and other symptoms related to CFS/ME, as shown above, may change the activities of daily life for affected individuals. Occupational life comprises what kind of activities people are involved in as well as how activities in various situations and contexts constitutes a social life [10, 19]. Hence, this study interpreted occupational life as including the kind of everyday activities one

is engaged in, as well as how this engagement relates to various social contexts and connects adolescents with CFS/ME to other people around them. This means that we also assumed that social identities and roles are shaped by engaging in occupations and vice versa. These assumptions align with social constructionism where social life, human roles and identities are considered to be constructed through interactive processes between the individual, their particular life situations and the contexts in which individuals live their lives [22, 23]. This also means that we understand occupational life, social identities and roles as changeable and fluid phenomena, depending on who people are together with and what social expectations are nested to particular situations within various social contexts. Occupational life unfolds as a trajectory [24], which may be understood as a path resulting from a dynamic process in which human beings engage in a set of occupational activities over time. It may also be understood as a life project that may change course over time, depending on the current life situation, past experiences and visions for future life [24, 25], which also depends on who one is and wants to be.

Materials and methods

Design

A qualitative study design with in-depth semi-structured individual interviews and an inductive thematic analysis was chosen for this study. Each person was interviewed once. The present study was part of the NorCAPITAL Trial (the Norwegian Study of Chronic Fatigue Syndrome in Adolescents), (Clinical Trials, NCT01040429)[26]. The NorCAPITAL Trial was approved by the Regional Committee for Medical Research Ethics (approval number 2009/2541).

Participants

In the present study, seven patients were included consecutively from those included in the NorCAPITAL Trial. Participants for the present study were included between November 2010 and May 2011. All patients should fulfil the modified version of the Centers for Disease Control (CDC) criteria for CFS/ME [3]; they should be within the age range of 12-18 years old, having unexplained persistent fatigue for more than three months and inability to attend school at a normal level.

Most of the participants lived with both of their parents and one or more siblings. All of them had reduced school attendance, except for one participant who was on sick leave. The school schedule varied from 2-3 hours for three days per week to 4 hours every day. Some participants also received home-schooling one or two days per week. Although two of the participants had chosen vocational directions, the majority attended a general secondary school. At the time of the interviews, they spent time with friends when they had sufficient energy. Participant demographics are shown in table 1.

[Table 1 near here]

Interviews

An occupational therapist (BWN) with extensive clinical expertise in adolescents with CFS/ME performed the interviews, but she did not know the participants beforehand. A semi-structured interview guide [27] was developed based on her clinical experience with a focus on illuminating experiences about the interaction between illness experiences and occupational life. The interview guide comprised semi-structured, open-ended questions

organized under the following themes: the adolescents' illness experiences, including their own perceptions of CFS/ME; their daily lives before they became ill; initially when they were ill, and their lives now with regard to occupational life, school and friends. In addition, they were asked how they anticipated the future and whether they believed that they would recover and become well again.

The interview guide was used as a reminder to ensure that all of the themes were elaborated. Follow-up questions, such as 'What are you concerned with?' or 'What do you like to do during leisure time?' were asked if appropriate to ensure a broader description and to enrich the data further, as well as 'Will you tell me more?' or 'How did you experience that?' to obtain more in-depth data. The interviewer tried to listen carefully and to follow the participants' stories by encouraging them to describe their experiences. The interviews were conducted in a hospital, in a quiet room, and they lasted from 40 to 70 minutes.

Analysis

The interviews were tape recorded and consecutively transcribed verbatim a few days after completion by the first author (BWN). We analysed the texts using inductive thematic analysis [28]. The transcripts were read several times to become familiar with the data and discussed with the last author (US). Words, statements and initial thoughts were noted, and we developed general impressions about the content. We initially agreed that the transcripts were about the body, everyday life and the informants' reflections on their situations and changes in insights over time. These issues were explored more in-depth in the process of coding and development of the themes. It became obvious during this reading that the informants compared their experiences with what life was like before, when they were

healthy, and to the lives of their peers. Hence, the first step of the analysis was to sort the data into what it was like initially when ill and what it was like at present. The data material constituted rich and varied descriptions of the participants' experiences, in particular about bodily suffering and its interaction with everyday life and prospects for the future. Thereafter, words and phrases informing these issues were coded, for example, *being tired as healthy and ill*, *body perceptions as healthy and ill*, *present school life in comparisons with their peers*. The transcripts were closely read again to collate data relevant to each code. Then, a new search was performed across the data material to group the coded extracts into subthemes and sort the different subthemes into potential themes, for example, *not being believed or taken seriously*, *everyday life* and *missing friends*. During this process the transcripts were re-read several times. To enhance the reflexivity the analysis was discussed with both co-authors (US and AMM) who have a professional background in occupational therapy and physiotherapy respectively, as well as having theoretical understandings.

Gradually, an understanding of the data material as a whole developed and the themes were refined. Finally, three themes were named. The two first are displaying early time of illness; 'Being ruled by an unfamiliar, inexplicable body' and 'On the sidelines of life with peers', while the third is describing the present situation for those who had been sick for some time; 'A coherent connection between present and future life'. The analysis is presented in a step-wise manner. However, the analytical process involved a constant moving back and forth between the entire data material, the coded extracts, the refinements of themes and the writing of the results. The findings are presented in a descriptive manner, and in the discussion, the findings are interpreted and abstracted in light of theory.

Results

Three themes were developed in the analysis. The adolescents described how the illness affected their bodies and disturbed their occupational lives. The last theme illustrates how the participants managed their new life and expressed hope for the future. This theme is primarily based on interviews with the participants who had been ill for several months and years and, therefore, had long experiences being ill. Significant quotations are given, and the participants were given fictional names to illustrate who is talking and thus, showing the variety of the data material.

Being ruled by an unfamiliar, inexplicable body

‘It would be great to just live my life without thinking about my body, because I kind of feel that ... my body limits me a lot’. [Andreas].

The adolescents told that life was turned upside down when they became ill with CFS/ME. They experienced how their usually taken-for-granted bodies now had become more noticeable and required more attention than before. Their bodies felt different and alienated in an incomprehensible manner. When they described their illness experiences, the adolescents talked about the body and mind as two separate phenomena. The body was described as an unfamiliar object that they had under observation and not any longer being an integrated part of themselves. The body even overruled what they wanted to do: *‘Not everyone understands. It’s sort of ... like your body says “now you’re tired”’.* [Andreas].

The participants expressed that, when they became ill, they did not understand what occurred to their bodies, and this incomprehensible body interacted with their occupations and made their lives chaotic. They became confused when their usually ‘silent’ and taken-for-granted body limited their usual daily activities. Their changed bodies felt weak and did not

obey when they wanted to go to school or to play football with friends. Sometimes the body felt heavy, rendering it difficult to get out of bed or to take a shower. They could feel disconnected with their bodies and completely unable to move and perform occupations: *'I feel like my legs just kind of fail, like they're not really there'*. [Charlotte]. The informants also experienced that the body did not recover in the same manner as before. Before they became ill, they knew that a night's sleep would be sufficient to recover when they felt tired or had been performing demanding activities. Now, the situation had changed: *'The worst thing I know is when I've slept, slept really well ... slept for almost ten hours one night, and then I wake up, and I'm still really tired ... that's exhausting'*. [Andreas].

The perceived changes of the body were invisible to other people and hence not recognized. The participants found it difficult to explain to friends and family what this experience was like. They were unable to explain why they could not participate in occupations as they did before because the participants did not understand why they felt so tired and worn out. They had the feeling of not being believed when they attempted to explain their situation. Mistrust of others became evident as the informants reported having been told that they were lazy and that they needed to pull themselves together. Even medical doctors seemed to question their unfamiliar body experiences when the informants talked about their symptoms: *'Then, he [the doctor] said that it was just ... anxiety ... and that I sort of wanted it, you know, and I denied that'*. [Charlotte].

The body had also become strange in terms of being perceived as unpredictable. What the body could tolerate differed from day to day, which made it difficult for the participants to rely on their bodies because they never knew how the day would turn out and how their bodies would behave. It felt frustrating that the body interacted that significantly with daily activities. The participants described how their bodies disturbed them some days by letting them know that they did not have sufficient energy to get out of bed or get dressed in the

morning. They were forced to consider bodily limitations when planning to participate in social events or other demanding occupations. Moreover, even if they felt prepared by having saved energy to perform planned activities, they might have to disrupt the activity and go home to rest. Sometimes, it almost felt like their bodies took revenge after having done nice and pleasant things. It could be described as one of them did: *'It's like being a slave to your own body in a way. It's like your body says, "well, you've had a lot of fun: you're doing things you enjoy ... so that's it ... you have to go home and sleep"'*. [Andreas].

On the sideline of life with peers

'They've got girlfriends, boyfriends, new friends, and even kind of new in-jokes that I don't get, you know'. [Sara].

Unfamiliar perceptions of the body interacted tremendously with participation in occupational life. The adolescents described their typical everyday lives before and after they became ill. Like their peers, they had earlier been active and performed leisure activities, such as dancing, horseback riding, playing music or football or participating in other sports activities *'I love to dance! It was ... it really was what I used to do'*. [Christine]. Some of them previously had high ambitions within their favourite activities, and they had struggled to accept that these goals now seemed unachievable. Alternatively, they now were performing quiet and less demanding activities, such as using a computer, watching television and movies, and knitting and embroidery. Such changes in occupational life separated them from their friends, who did not share the informants' new interests. The new interests and occupations in everyday life represented a contrast to their lives before they became ill and what they had expected their lives to be. They missed casual and, for some, also apparently insignificant, taken-for-granted

occupations and all the activities they used to do. They missed living an ordinary life and being spontaneous without having to consider their bodies and thereby continuously be reminded of their occupational limitations. *'Definitely... there are lots of things I miss. I kind of miss being able to do something spontaneously! And I miss ... I kind of miss, well, not having any worries at all'*. [Sara]. They also felt sad for not being able to participate in leisure activities, such as playing football: *'Well, it was a bit hard because it was my favourite sport, after all. Well, my dad and uncles and well, everyone ... it's kind of part of everyone's genes being active, so it is not easy'*. [Martin]. The participants shared experiences of time passing, even months, without even noticing. All of their attention was drawn towards the daily challenges with which they had to deal, and they had no capacity to keep up with the ordinary lives of their peers.

The adolescents in the present study usually earned high grades before they became ill, but when they became ill with CFS/ME memory and attention problems began to influence school attendance. Increased school absence resulted in poor grades, and they fell behind their peers in performance. They expressed how school gradually became a major stressor in their lives. They experienced to become easily distracted, and they had problems to focus and concentrate on school tasks. When several things were happening, and there were many people around them, they became overwhelmed. In such situations, their exhaustion often felt worse, and they considered it similar to being exhausted after performing strenuous occupations. It was easier to accept feeling tired after a walk than becoming exhausted by doing nothing at all. To avoid the pressure, they also dropped out of school for shorter or longer periods of time. *'Well, I'm tired a lot, and then everyone thinks immediately that my body's tired ... but that's not really it ... it is more that there's so much going on in my head. Like I can't focus on everything at once, and I get stressed out by sounds and light, and then I sort of have to ignore whatever's happening'*. [Ingrid].

Everyday life was disturbed and became the visible consequence of the illness. The days were unpredictable, and the adolescents found it difficult to plan to meet friends or to go to a party: *'Keep in mind that I'm ill, quite a lot, so it might be that I have to cancel ... for some reason, because if I'm having a bad day, I won't have the energy'*. [Ingrid]. The bad days became visible to others through their absences in participating with peers, and the adolescents were not considered by their friends and peers as they had been before. As a consequence, they were separated from their former social lives with their peers. One girl became aware of this effect; for her, the time had stopped for three or four months while her friends continued with their lives: *'And then, I kind of had this shock that ... man ... they've still got their own lives'*. [Sara].

Through the significant changes in the lives of the participants, they were in a way placed on the sidelines of the life that is socially expected for adolescents. With long school absences, they were also excluded from school as a social arena. *'School was where I had most of my social life, you know. That's where all my friends were ... so, school was important in that way too'*. [Christine]. Even if they were able to spend a few hours at school every week, they were cut off from sharing time with their peers and were unable to behave as spontaneously and creatively as their peers. They felt forgotten and often left alone and shut out, and they were sad for the loss. Some friends also rejected them by not being interested in talking to them any longer and simply going away. *'But I suppose this is the point where you find out who your real friends are'*. [Marianne].

A coherent connection between present and future life

'I don't think I would, even if I could, choose not to have gotten ill, you know. I don't think I would turn back time to change that because then, I wouldn't be the person I am now'.

[Andreas].

Over time, the adolescents involuntarily had much time to reflect on their own situations, thus obtaining an enhanced understanding of themselves, and eventually, they felt that they became more mature than their peers. By accepting how things had occurred, they did not spend as much energy being frustrated about how the situation had turned out. Instead, they attempted to find new ways to live their lives. They were in the process of rebuilding an everyday life by bridging the former disrupted interactions between their bodies, occupational and social life and themselves. This process might be regarded as a way of developing a unified and meaningful wholeness, including complex processes of adapting to and accepting that they had to take their bodies into account, adjust their everyday lives, adopt new social roles and thereby create a valued and social self.

They illustrated how they adapted to their changed capacities by being able to appreciate small things that they had taken for granted before they became ill. Even things and situations they previously found meaningless and boring now were considered differently, as one girl said: *'Before I would have considered it a boring day, but now it's great. Not doing anything, I never used to like it. I just kind of felt guilty for sitting around doing nothing, wasting the day'*. [Sara]. New and valued activities might now include waking up early, eating breakfast, spending some time in the living-room, going for a walk, or perhaps calling a friend and then do some drawing or doing other undemanding activities. They also simply enjoyed feeling hungry or not having a headache as this was not taken for granted anymore.

The participants used various strategies to manage everyday life. They learned ways to make sense of the bodily sensations that they perceived. Problems with speech, memory and concentration were interpreted to signify tiredness, which indicated that it was necessary to take a rest. Thus, worries about such sensations were not in the fore any longer, and the participants used these experiences to guide them in how to manage everyday life situations. In turn, this strategy provided them with some control over both the illness and their everyday lives. They had learned to choose some activities over others, to take breaks to regain energy and to rest before and after demanding activities. In this way, they were rebuilding another occupational life. Predictable and limited participation in activities now became important to be able to maintain an acceptable way of living.

The importance of having relationships and interactions with friends was recurrently talked about; not only now when the participants were ill but also in the future, when they had recovered and were well again. Due to long-term illness, the participants over time adopted new roles among peers, friends and family. For example, one girl underwent a major personal change during this period. From being popular among her friends, always having a quick reply and playing a leading role, she began to behave more quietly and to play a less dominating social role. She used to have control in most areas of her life, at school and among friends, and she called herself a 'control freak'. The illness, however, forced her to let go this control, which she to her surprise found liberating and meaningful. All participants were concerned about their relationships with friends, and that being ill over months might have changed what they considered to be valuable when being together with friends. Accordingly, new friendships matching their new values could be established: *'She's the type of person you can just be silent with. If I'm having a bad day, she'll just kind of lie beside me on the bed and watch TV or something'*. [Sara]. To build a network was therefore prioritized and was considered important both for the present and the future.

By relating to friends valuing the same occupations in life as themselves, the informants spent less time speculating and reflecting. Previously, they had spent hours lying on the sofa, speculating on what was wrong. *'And you're lying there, half asleep ... and then you get these strange ideas and ...'* [Martin]. Now, they would rather attempt to think of something else than be occupied with difficult thoughts, or they would spend time with friends. When asked to describe a good day, they reflected on the present situation. The notion of 'a good day' had changed over the months and even years with illness. A gradual change had occurred, from being very active young people to finding other values for alternative and meaningful occupational lives. Rather than attempting to catch up with peers and not succeeding in performing demanding activities, they had rebuilt alternative lives through which they could create new roles and identities as adults that were still normal for a young person.

The participants had learnt to engage in tolerable and achievable occupational activities. Even if they had been ill for months, they were able to take a step back and reflect on and value their own illness experiences. Some still experienced a very unstable condition, with ups and downs that in turn influenced their thoughts about the future. Nevertheless, all of the participants believed that they would be well in a few years, as one of them said: *'So when I'm 25, maybe I'll think, "oh man, I had ME when I was ... ten years ago". You know, I want to study music. Becoming a musician's my dream, you know, being able to make a living like that'*. [Andreas].

One participant considered herself to have recovered over a five year period: *'Well, I just have to do it ... because if not, I guess I would ... because I think I would go crazy, to be honest, if I ... because I just have to believe that I'll get better'*. [Christine]. Their future life plans could be to work as a journalist, to study medicine abroad, to work at a garage or to sail around the world: *'I actually think that I, someday, at some point in life ... that I'll, you know,*

get a sailboat and sail around most of the world. I hope I'm not ill then, that I'm completely well and able to study and ... move on with life'. [Marianne].

Through their illness experiences, the adolescents sensed a change in identity, by which they gained new future opportunities. Altogether this showed the complex and profound personal processes they had undergone in developing valued social selves. The adolescents had accepted their new social roles and considered their illness experiences valuable in terms of becoming more reflective and mature, compared to before these experiences. Certainly, they had lost something important by being ill, but something had also been gained from it, indicating that their personal development and growth had turned out differently than what they had expected but in a meaningful manner. This could be illustrated by quoting one of the participants comparing her transition to adulthood with that of her friends: *'Yeah ... I think so. When it comes to knowing myself I think I've grown up, have become more mature and not as insistent as I used to be. That I sort of have more time to take a break and more time to think about life, you know. Generally, well perhaps I've got more self-insight but also lower self-esteem, I guess'. [Sara].*

Discussion

The present analysis illustrates how inexplicable perceptions of the body intruded the occupational lives of patients with CFS/ME in a rather profound way. The adolescents used to be active and spent time with their peers. Now, they did not have energy to live their previous lives, and they were somewhat sidelined from their lives with friends. Over time, however, they reportedly experienced personal growth and maturation. By accepting their situation and, taking their bodily limitations into account, they adjusted their everyday lives

and adopted new social roles, which in turn helped them to create new, valued social lives and selves.

Currently, the participants experienced their bodies as unfamiliar objects that had changed and transformed into bodies they could no longer recognise, as described in the first theme, *'Being ruled by an unfamiliar, inexplicable body'*. This finding is in agreement with the findings of other studies reporting adolescent experiences of the body as strange and different from how it used to be [8, 16, 17, 18]. The study participants also distinguished between what their bodies wanted and what they themselves wanted. Thus, they talked about their bodies as an 'it' or, in other words, as an object separated from the experiential body with which they were familiar. Merleau-Ponty claimed that it is through the body that humans can be and experience the world, that the body is something we *have* that we can observe as an object, and at the same time, we learn and experience living in the world through our body [29]. According to body phenomenology, the body object and subject are unified [30], but during illnesses, the unfamiliar body that we *have* comes to the fore, and new experiences about being in the world must be developed to recreate a connection between the body object and subject. When body experiences no longer provide any sense of meaning, as illustrated in our study, it becomes tremendously different to be in the world. In agreement with Svenaeus [31], one might say that the patients had become 'homeless'.

The adolescents with CFS/ME, due to their experience of exhaustion as described in the second theme, *On the sideline of life with peers*, were no longer able to perform their usual everyday occupations, either at school or during leisure time. This inability caused dramatic changes in their ordinary lives, in which they were used to live without worrying about becoming ill or about how to best manage their everyday lives. Everyday life routines and habits are usually taken for granted [32], just as our bodies are taken for granted when they are functioning normally. However, when the participants' bodies actively restricted them in

performing occupations, their habits were disturbed. Their previous bodily experiences were no longer valid to guide them regarding what they could tolerate doing. The unpredictable lack of energy disturbed their daily functioning and disconnected them from previous experiences about how to live their lives, as well as leaving them on the sideline of their occupational lives of their peers.

Several occupational therapist researchers have used the metaphor ‘rhythm of daily life’ when discussing the notion of everyday life [33, 34, 35]. For the adolescents in our study, this rhythm of daily life was disturbed by the illness. Their normal routines had changed; they slept during the day rather than at night, and they did not eat regular meals. Time passed slowly when they were not actually doing anything but staying home, puttering around many hours per day, which contrasted strikingly with how they had previously experienced time when they were together with friends, horseback riding or playing music, having fun and losing track of time.

The adolescents in our study became ill during a vulnerable period of life: a time of transition from childhood to adulthood. They experienced that the illness separated them from their taken-for-granted bodies, their usual lives and being as a young person [36], and, as a consequence, their everyday and social lives were disrupted. Additionally, their former sense of coherence between the body, occupational life and social life had been disrupted. One might say that this disruption results in a disrupted biography [37] that must be healed [38]. Accordingly, it is not only a disease or an illness that must be healed, but it is also the person’s being and acting in the world. Being ill for a long period of time often means living a restricted life with limited participation in social settings and less shared activities with other people [39]. In particular, the transition from being an adolescent to adult roles and identities is highly shaped by relationships with other people. Typical for adolescent life is to break out from the family, to spend time with friends rather than parents and to create new social

identities and roles. Friends and other adults than parents then become significant for the transition of identity [40]. However, because of illness and a lack of energy to participate in everyday life as before, the participants had fewer opportunities to develop a valued self when homebound. The adolescents became disconnected, not only from their bodies but also from their occupational lives as young people. Similar consequences of the illness have been described in other studies in which adolescents missed school and lost contact with friends [16, 18]. In turn, this is leading to loneliness and difficult feelings [16]. Another study reported worries about school exams, falling behind and missing social interactions [8]. The participants in our study missed the ordinary adolescent identity about which their peers did not even think. In some way, it looked like the occupational lives of the adolescents had turned out to be more like an adult life. Rather than considering it to be a loss of adolescence, they eventually viewed it positively, by regarding themselves as members of the adult world.

Our study illustrated how the adolescents eventually developed strategies to manage their changed occupational lives, as the third theme, '*A coherent connection between illness, present and future life*', indicated. Some reported that they had changed their own perspectives about themselves, thanks to their illness experiences. Similar illness-related gains have been described in other studies, including maturation and personal growth [16, 18], as well as finding a good balance between doing enough but not too much [8]. Optimism and hope about the future have also been reported [15, 16, 17, 18]. The participants in our study spent hours and weeks reflecting on their own situations, attempting to make sense of their bodies and occupational lives and applying this understanding to create coherence between their changed bodies, their social lives and who they were and wanted to be in the future. From feeling confused and, not understanding what was happening to their bodies, they eventually began to take charge of everyday life and thereby reconnected with their present social lives and created positive expectations for the future. Such a process has been described

as one of several management strategies in the recovery process understood as a personal healing process [34, 41, 42]. By finding alternative, meaningful activities and new values, the present participants connected with life in new ways and recreated valued new ways of living.

The process of transition of social identity [36] that the adolescents underwent can be understood in the light of the recovery as a personal healing process [43, 44, 45]. Recovering from illness, as our participants reported, can be described as a process [33] intertwined with a transition from childhood to adulthood. This implies that illness has made this transition into a particular trajectory that leads to a change in their valued selves and lives and thereby becoming another person than they likely would have become without being ill. Illness, and especially a chronic illness such as CFS/ME, is complex and can have a profound impact on everyday life. To recover indeed indicates a complex personal process for those who are ill. It comprises building bridges between the body, social life and self, creating a sense of coherence in a meaningful manner and a new understanding of the self and what is found valuable in occupational life.

Methodological considerations

The present study contributed with rich, in-depth data about illness experiences and the occupational lives of adolescents with CFS/ME, allowing us to develop a nuanced but comprehensive understanding of what it is to live with CFS/ME. Although a small number of participants with a small variation in age, the participants differed regarding illness duration, gender, family background and school priorities, indicating that we had in-depth data from a rather heterogeneous sample of adolescents. However, the participants were recruited from an intervention trial. Intervention trials incur the risk of including skewed samples. First, this

study was performed in a hospital and accordingly recruited informants among clinical cases, and, second, patients who were severely affected might not have had the energy to participate in the trial. Thus, our findings might not be transferable to adolescents with CFS/ME who are more severely affected or those not using health services.

We used inductive thematic analysis, which provided a robust, systematic method for the data analysis [28]. The first author (BWN) had worked for many years as an occupational therapist with young people with CFS/ME and, thus has broad knowledge in the field. To enhance the reflexivity during the process of analysis, regular discussions were held with the co-authors, which also challenged the preconceptions of the authors. All authors reflected on the coded data and the developed themes, seeking alternative coding and other possible themes and thus, attempted to increase the credibility of the analysis. We do not claim that our interpretation is the only way to understand our data material, but due to the thorough reflexive process of analysis with the support of theory we believe that our findings and interpretations offer a plausible, trustworthy understanding of what it is like to live with CFS/ME from an adolescent's point of view.

Conclusion and implications

The findings of this study illustrated how CFS/ME disconnected the adolescents from their bodies, from their occupational lives, and from the usual process of transition from adolescence to adult life. In this way, the adolescents' identities developed differently than anticipated for young, healthy and active people. It was difficult for the adolescents to understand the relationship between their unfamiliar bodies and occupational life. When they finally seemed to accept the situation and adjust their occupational lives, they were able to

rebuild meaningful occupational lives and valued social selves and to express hope for the future. This finding indicated how complex long-term illness processes are. Occupational life was not permanently ruined but differed from what it could have been if not illness had occurred. An alternative occupational life emerged, which was experienced as meaningful. One might say that the informants had undertaken a profound, complex process of personal maturation and growth. They had turned a situation with chaos and confusion into eventually making sense of the situation and hoping for a better future life. This indicates how important it is for occupational therapists and other health professionals, to listen to adolescents with CFS/ME to attempt to understand this complexity and to support the patients in their endeavours to reconnect with their body and create a meaningful occupational life.

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Declarations of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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