

BMJ Open Factors related to educational adaptations and social life at school experienced by young people with CFS/ME: a qualitative study

Wenche Ann Similä ^{1,2}, Torunn Hatlen Nøst ³, Ingrid B Helland,⁴
Torstein Baade Rø^{1,2}

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¹Children's Clinic, St Olav's Hospital, Trondheim University Hospital, Trondheim, Norway

²Department of Clinical and Molecular Medicine, Norwegian University of Science and Technology, Trondheim, Norway

³Department of Mental Health, Norwegian University of Science and Technology, Trondheim, Norway

⁴Division of Pediatric and Adolescent Medicine, Oslo University Hospital, Oslo, Norway

Correspondence to

Mrs Wenche Ann Similä;
wenche.a.simila@ntnu.no

ABSTRACT

Objectives To explore factors perceived as positive or negative among young people with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) in relation to school and everyday life.

Design A qualitative study with semistructured individual interviews performed at the local hospital or at the informants' homes between September 2017 and January 2018, with an additional telephone interview to collect data on experiences from the COVID-19 pandemic, conducted in September 2020. Data were analysed using a grounded theory approach.

Setting The informants were recruited from two university hospitals that offer interdisciplinary assessments of young people with CFS/ME from various parts of Norway.

Participants Five males and 13 females aged 13–21 years with CFS/ME diagnosed 3–56 months prior to the interviews participated.

Results The informants were concerned about a lack of educational adaptations and missed social life at school. Educational and social adaptations could improve schooling and health among young people with CFS/ME. Negative experiences were related to a lack of knowledge about CFS/ME among school personnel and young people's difficulties to limit activities. Online teaching as experienced during the COVID-19 pandemic was described as positive both for education and social life.

Conclusions Young people with CFS/ME can benefit from better educational adaptations and increased social interaction with peers. From the participants' view, factors that limit learning and socialisation include a lack of knowledge about CFS/ME among teachers and school personnel, expectations from teachers of doing more than they could manage at school, feeling alone coping with the disease and not recognising their own limitations regarding what they are able to do. Suggested factors perceived to enhance learning and socialisation were a better understanding of the disease among school personnel and peers, suitable educational adaptations and being able to socialise with peers.

BACKGROUND

Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) is a disease characterised by general fatigue and post-exertional

Strengths and limitations of this study

- The assessment of young people with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) was similar in the two university hospitals from where informants were recruited.
- All interviews were performed by a person who had cared for young people with CFS/ME to ensure attention to the specific needs for this patient group.
- A limitation to the study was that precise information about what adaptations the young people had received at school was not provided.
- A limitation was also that findings may not be directly transferable to countries with other educational and healthcare systems as the study was set in Norway.
- A third limitation was that the parents' involvement in adaptations at school was not explored.

malaise (PEM) for the duration of at least 3 months.¹ CFS/ME occurs three to four times more frequently in females than males with an estimated prevalence of 0.1%–1.0%.² The incidence rate of CFS/ME among Norwegian students is 43 out of 100 000.² The aetiology of the condition is unknown and there is currently no curative treatment.³ Young people with CFS/ME usually have impaired physical and cognitive functioning, which may lead to disruption of education, as well as social and physical activities during a critical period of life.^{4 5} Depressive symptoms are common, possibly due to the loss of education and social interaction,⁶ and a lack of awareness about the disease may cause anxiety.⁷ Young people diagnosed with CFS/ME often find it difficult to limit activities.⁴ They tend to put too much energy into activities like schooling, potentially leading to increased fatigue.⁸ Previous studies found that young people with CFS/ME can benefit from educational adaptations and advice on

how to master school and everyday life.^{5 9 10} Knowledge about which educational and social adaptations young people with CFS/ME find useful is still limited.

In a previous study, we found that good relationships with school and teachers were associated with higher levels of health-related quality of life (HRQoL) in young people with CFS/ME.¹¹ The aim of the present study was to explore factors perceived as positive or negative among young people with CFS/ME in relation to school and everyday life.

METHODS

Design

A qualitative study using semistructured individual interviews was conducted between September 2017 and January 2018. Supplementary interviews related to the new situation in schools created by the COVID-19 pandemic were conducted in September 2020.

Setting

The informants were recruited from two university hospitals that offer interdisciplinary assessments of young people with CFS/ME from various parts of Norway. After the assessment, medical doctors, occupational therapists, and specialised nurses usually communicate with primary healthcare providers and school personnel to inform them about the disease and educational or other adaptations the individuals might need.

In Norway, most schools are public with compulsory schooling for 10 years and with a right to complete additional 3 years of high school before the age of 24 years. At high school, students can choose between academic and vocational tracks. It is mandatory for all schools regardless of level to assess individual needs and adapt education. To obtain a high school diploma, most students must attend school 85% or more of the time. With a doctor's declaration documenting illness as the primary cause of school absence, exemption to this limit is possible. During the COVID-19 pandemic, schools offered teaching via online platforms beginning from March 2020.

Informants and recruitment

Informants were recruited by mail for the current study and a preceding HRQoL study.¹¹ Inclusion criteria were (1) a diagnosis of CFS/ME from St Olav's Hospital, Trondheim University Hospital or Oslo University Hospital in Norway and (2) age 12–18 years at the time of diagnosis. Exclusion criteria were (1) inability to understand Norwegian or (2) not able to participate in interviews. Among 33 informants contacted, 18 consented to participate in the interviews. Reasons for not participating were not wanting to or being able to participate in interviews.

The first author contacted all consenting participants consecutively after replying to the HRQoL study. All informants were diagnosed with CFS/ME according to Jason's paediatric diagnostic criteria.¹² Informants were included until preliminary analysed data were repeated by new

informants and saturation was considered achieved.¹³ Three of the informants had recently entered university. However, they primarily talked about their experiences from secondary and high school. Three of the informants had previously met the interviewer in a meeting or course at one of the hospitals.

Data collection and interview guide

The first author, a female PhD student and specialised nurse, interviewed all informants face-to-face. All the informants were offered interviews at home to avoid potential worsening of fatigue due to travel. Fourteen of the interviews were completed at the local hospital in a regular office, with comfortable chairs and dim light. Four informants were interviewed at home. Due to age and the potential negative cognitive impact of the disease, informants could bring a parent to the interview, which 11 of the informants did. The informants were told that they could pause or stop the interview at any time. Parents were informed that they should only comment on the informant's or interviewer's request.

The semistructured interview guide was developed by a group consisting of two medical doctors, two psychiatrists, one health economist and a specialised nurse. All were experienced with the patient group. The questions were based on previous knowledge about perceived challenges for young people with CFS/ME, especially factors important for education. Subsequently, the questions were discussed by the research group and informed by previous research. The interview guide consisted of two parts: the first part addressed being fatigued and the second part addressed healthcare and support from school, family and friends. The central questions were about 'How has your school curriculum been adjusted and how have the adjustments worked out for you?' and 'How do people you relate to perceive your disease?'. The interviewer did not have any information about provided adaptations for the informants from school personnel or healthcare providers. Interviews were audio recorded and lasted between 59 and 116 min. A pilot telephone interview with a young female with CFS/ME was performed. Comments were considered and resulted in minor changes to the questions, order of questions and a few additional questions.

The COVID-19 pandemic led to a new way of schooling for all young people in Norway. To study experiences from the COVID-19 pandemic, the first author conducted supplementary interviews by phone in September 2020. The central questions were about how the informants perceived the switch to online schooling and altered contact with school following the COVID-19 pandemic. Sixteen of the 18 informants participated in the supplementary interview.

Data analysis

The interviews were consecutively transcribed verbatim by the first author, and analyses were based on a grounded theory approach.^{14–16}

Data were initially open coded by the first author into seven categories: (1) health, (2) own perception and acceptance of the disease, (3) others' perception and acceptance of the disease, (4) healthcare and support, (5) school adaptations, (6) emotional challenges, and (7) loss and sorrow. The open coding showed differences in how the participants experienced school adaptations, and educational adaptation was the main concern emerging from the data. Subsequently, the main concern was axially coded with the seven categories from open coding. In axial coding, own and others' perception and acceptance of the disease (categories 2 and 3) were considered important to how the need of school adaptations was resolved. These two categories were leading when data were selectively coded in new categories and described in a storyline and a conditional matrix. Following selective coding, loneliness emerged as a second important concern among the informants, where school contact seemed important to resolve the main concerns. Selectively coded data were passed from the first author to the coauthors. A research group at the university read and gave their view and perspectives to the preliminary results of the analysis.

Patient and public involvement

The patient perspective was included in the planning of the project by obtaining approval from the patient organisation. A patient representative was involved in the conduct of the study by commenting on the interview guide after participating in pilot testing.

RESULTS

A total of 18 informants, 5 males and 13 females, aged 13–21 (median age 19) years were interviewed (table 1). The informants were diagnosed with CFS/ME 3–56 months prior to the interviews, and two of them had recovered. Ten of the 18 informants attended more than half of the classes in the 4-week period before the

interview. Five out of 18 informants did not attend school at all in the 4-week period before the interview, but three had contact with school personnel and received home assignments.

The participants experienced a range of symptoms. As expected, the most common symptom was fatigue, which typically worsened if they pushed themselves to do more than they could manage. Furthermore, insomnia/unrefreshing sleep, headache, joint and muscle pain, and hypersensitivity to light, sounds, or smells were recorded. Other symptoms mentioned were neurocognitive manifestations (ie, memory and concentration difficulties), autonomic, neuroendocrine and immune manifestations. Symptoms could vary and fluctuate over time. They had all been advised by healthcare providers to follow a daily plan with fewer activities. Most of them experienced this as useful, but two said that a daily plan did not work out for them. Some received assistive devices like noise-cancelling headphones, special sunglasses or a wheelchair.

Lack of adaptations at school was a main concern among the informants. Management of the school day seemed to depend on how the young people themselves and others perceived and accepted their disease. Many felt that they were not understood by school personnel, and some said it was difficult to know how to initiate and handle school adaptations. In addition, they felt lonely because they were not able to participate as normal in social life with peers.

Words and phrases like 'terrible', 'tough' and 'locked in and trapped' were used by informants to describe how it was to live with CFS/ME. They said they felt angry, irritated and sad about not being able to go back to school and their regular social life. Some of their everyday life experiences from living with CFS/ME are shown in figure 1.

Fewer spoke about negative experiences regarding school adaptations among the most recently diagnosed than those who had been diagnosed years ago. Factors that the informants perceived as positive or negative in relation to school were categorised into the following four themes: *Educational adaptations and challenges*, *Focus on what you can do or focus on the illness*, *Social life and support*, and *Adaptations following the COVID-19 pandemic*.

Educational adaptations and challenges

Adaptations that worked

Some informants said that they were taken seriously by their teachers and received adaptations to accommodate their needs. One example was an educational plan with fewer lessons where the balance between activity and rest during the school day was taken into consideration. Some received fewer tests, or tests at home, and an adjusted overall academic progression plan. They had an opportunity to socialise with peers at school, and they were supported by teachers, counsellors, and school nurses. Two participants who attended special education schools received all these adaptations and were content with their

Table 1 Characteristics of informants	
Characteristic	N
Gender	
Female	13
Male	5
School level	
Secondary school	5
High school	10
University	3
School attendance	
0%	5
1%–50%	3
51%–100%	10

School level and school attendance are at the time of the interview.

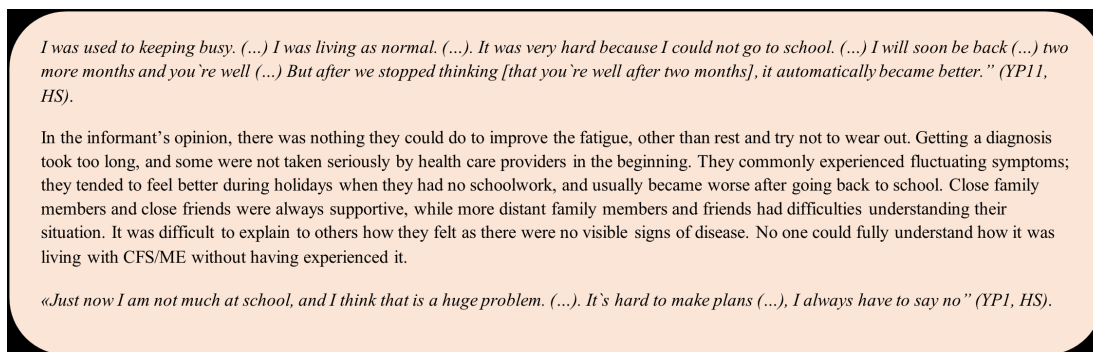


Figure 1 Everyday life experiences from living with CFS/ME. CFS/ME, chronic fatigue syndrome/myalgic encephalomyelitis.

school situation. They especially valued the good atmosphere, alternative educational tasks, and close contact with teachers and counsellors. Informants who received adaptations that worked talked about more regular school attendance than other informants.

I have the same plan as the rest of the class, but I have the possibility to extend deadlines or miss out on some projects (...) because it is too demanding, but I am able to attend my class, and that is also what I want. (YP12, high school (HS))

A struggle to get educational adaptations

Regular school days were difficult to handle for all the informants in the beginning of their disease. Some said that they were not listened to and had to struggle to get the educational adaptations they needed. Some even studied at home without any communication with a teacher and had to ask friends to provide notes from lessons.

A plan for school attendance was useful, yet many experienced that the plan often included more items than they could cope with. Overambitious plans could be made by teachers, but the informants also said that it could be difficult for themselves to recognise their own limitations. They would overestimate their capabilities to attend school, resulting in worsening of fatigue, PEM and increased school absence.

Yes, I believe it's just a matter of knowing your limitations, like when I have a very good day, I can't use all the energy, because then I know that I will have a bad day tomorrow somehow (...). (YP7, HS)

Some of the informants said they felt overlooked and disbelieved by their teacher. If they did not manage to follow the plan or if they missed school, teachers questioned the reason for their absence and did not contact them or update plans as previously promised. Often this meant that their parents were left with the responsibility to request meetings with the school to update plans.

Presently I don't attend school (...). Some [teachers] understood, while some didn't understand completely, and some didn't understand at all. (...) Those who understood some, promised a lot, and then it wasn't possible to carry through. (YP5, HS)

The informants said they wanted to go to school but were not always able. They said it felt like a total defeat when they realised that they could not progress through school normally. Two of the informants who eventually had started in special education schools said it was hard to accept for them at first, after a while they felt it was the best thing that happened to them. Now they could attend school even on a bad day and get the help they needed.

So, returning [to school], just for a bit at least, that is really important. It's more about considering that the school takes an initiative. (...) I haven't heard from them since long before Christmas. (YP10, secondary school (SS))

Before being diagnosed, several informants said they were not always believed by their teachers thus, they received no adaptations for education nor social life at school. They did not manage to keep up with the rest of the class, and some of them started feeling stupid. One said that this led to low self-esteem and resistance towards attending school. After receiving a diagnosis, many said it was easier to be believed by teachers. Others said that it did not lead to improvements, even after healthcare providers had informed the teachers. Some of the informants said that they perceived the lack of understanding from teachers to be caused by a lack of knowledge about CFS/ME.

Before we got a really good collaboration with school there were uncertainties in a way, and particularly before I was diagnosed, (...) it was more like I come [to school] when I come, and the teachers choose not to ask. (YP12, SS)

Focus on what you can do or focus on the illness

Some informants said that if they focused on their fatigue and what they no longer could do, it made them feel depressed. Focusing on what they were able to do, accepting life as it was, staying positive minded and socialising when they were able made them feel better. Diversions like television or a pet were also helpful for some. One said that for a while, it had worked well not to think about the help she hoped for but did not get from the school.

If I must consider how difficult and hard and strenuous and tiring and hurtful and miserable everything really is, with my disease and my diagnosis and how I experience this. If I focus on that, so, you know, I simply don't think I would stay alive. (YP11, HS)

The informants said they mostly focused on the present. They did not like to think about the future because of the uncertainties concerning the duration of the disease and the difficulties they had experienced with educational adaptations. One feared that the future could bring more experiences of being alone with her disease challenges. To think about major transitions between school were especially worrying, as they previously had experienced those changes could lead to worsening of the disease. If good communication between educators was assured, major transitions felt safe.

Standing there alone, is what I fear, because I have been [alone], and I remember how terrible it was. I don't want to stand alone, because I have worked hard for the things I have now, (...) the transition, I fear that, it can go terribly wrong (...) I have no idea. I don't know my opportunities. I don't know who can be there, what titles, or functions or I don't know, (...) and that has been a huge problem through my illness, that I don't know. I don't know where to get information. I don't know who I can ask. (YP11, HS)

Social life and support

All informants said that they missed meeting peers. Socialising with peers was difficult both due to fatigue and to school absence. Some were able to prioritise socialising during the school day, that is, with a plan that included attending one or more breaks with peers. Others said that school did not prioritise social interactions with peers in the educational plans. Some had friends they met with regularly in their leisure time, while for others it could go months without socialising with peers. At home they socialised with family when they managed. Some feared they would enter adult life without having developed socially among peers either at school nor in everyday life.

(...) In many ways I haven't been able to develop socially like other teenagers, because I don't have the freedom to go where I want or do what I want (...).

(YP1, HS)

The informants noticed that it was difficult for family and friends to understand the implications of the disease. In the beginning, family members could push them to school without knowing when they had to stop. This eventually improved, and the participants experienced that close family members accepted and respected them and were very supportive. The informants had experienced that close friends tried their best to understand and to support them, and that those friends could feel powerless because there was no improvement. Some friends who

had trouble believing or accepting withdrew and eventually disappeared.

Someone to talk to

Many believed that family, friends, teachers and school nurses could all help them to cope with their disease. Most informants talked with close family and friends about frustrations regarding the disease. Only a few informants said they talked to their teachers or school nurses, and the reason for those who did not was that they expected the school nurses or teachers would not understand. Subsequently, this made them feel alone regarding how to handle the disease and challenges at school. Some suggested the potential helpfulness in a school counsellor who understood their situation, who could help them if the disease worsened and counsel them regarding future education and realistic job opportunities.

Maybe someone can help me plan in a way, maybe about the future, when I leave high school. (...) a type of counselor, maybe a school counselor or something or someone and just see opportunities and what I can do, so one doesn't feel that this is what I am going to do the rest of my life. (YP15, university)

Online teaching might be a useful adaptation for young people with CFS/ME

Online teaching became a necessity during the COVID-19 pandemic. The informants described online teaching as helpful because everyone had to stay at home, plans had to be made, and thus, the informants could participate on equal footing with their peers. One informant said that online tasks, often with a completion deadline set later than before, gave him the freedom to do schoolwork whenever he managed to, so he felt more in control. A second informant said that online teaching had enabled her to complete the school year even though she was housebound. The informants reported that teachers who did not manage to adapt teaching to their needs previously were able to do so during the COVID-19 pandemic.

Online teaching was almost the same as meeting one-on-one at home. It was in a way nice that everybody was in the same situation with online teaching. Everyone was stuck together. Doesn't feel so different, I was like most others. The opportunity of online teaching would be better if I had it from first year of high school. (...). I think it's a good solution for the chronically ill. (YP1, HS)

Communicating online with teachers through chat was described as easier and more direct than the previous use of email. One informant thought that if she had been taught via online platforms earlier, she could have kept in contact with peers and teachers more directly, and that this would probably have made it easier to attend physical school again later. However, some said they still preferred to meet physically with teachers and peers rather than via online platforms. These participants felt it was easier to

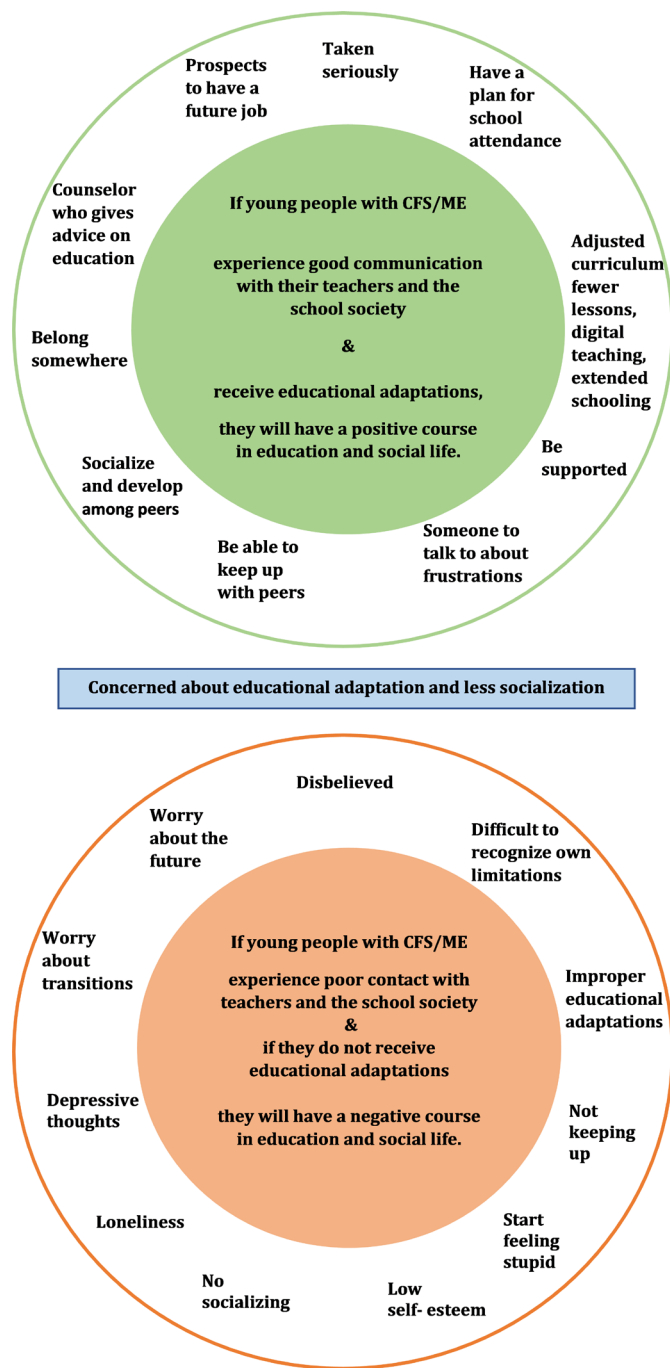


Figure 2 How the informants experienced that their main concerns, for example, adaptation of education and social life was resolved and how the resolving factors resulted in positive (green) or negative (red) course. CFS/ME, chronic fatigue syndrome/myalgic encephalomyelitis.

follow lessons when they met physically at school and had the possibility to ask the teachers questions more directly.

I liked better to meet people. I was fine being at home. It was a bit more difficult because the teacher can't come over and explain to you. (YP4, SS)

In figure 2, the overall results are summarised in a twofold conditional matrix. A conditional matrix can be visualised as a set of concentric circles with actions

and interactions at the centre, and where each level of circles corresponds to a different unit of influence on these actions. In this conditional matrix, the inner circles show how the participants experienced interaction with their teachers, how teachers acted to adapt education and social life at school for them, and how this resulted in a positive or negative educational course. The outer circles show the factors that were experienced as positive or negative regarding education and social life at school, and how the factors impacted the educational course.

DISCUSSION

This study explored factors perceived as positive or negative among young people with CFS/ME in relation to school and everyday life. The main findings were the informants' concerns about educational adaptations and social life at school. Positive factors were appropriate measures that could lead to improved learning and a better social life. On the other hand, a lack of measures or maladaptive measures could limit learning and in the worst case cause dropout from school. A novel and potentially important finding was that online teaching improved learning and made young people with CFS/ME feel more socially connected with both teachers and peers.

A strength of this study was that assessment and follow-up of young people with CFS/ME were similar in the two university hospitals included. All interviews were performed by one person experienced with young people with CFS/ME to ensure attention to the specific needs for this patient group. It was a limitation to the study that we did not register precisely what adaptations the young people had received at school. Furthermore, parents' involvement in adaptations was not explored. Another limitation was that the findings may not be directly transferable to countries with other educational and healthcare systems than Norway. This was the first study in Norway to explore perceived factors related to school functioning among young people with CFS/ME.

Some of the informants had experienced satisfying educational and social adaptations at school and managed to maintain their education. Factors related to satisfaction were typically being taken seriously, good communication with school, and individually tailored educational and social adaptations. Most young people with CFS/ME manage to keep up with their peers if they are given an adjusted curriculum.³ Educational adaptations responding to the needs of young people with CFS/ME require that health and school personnel have knowledge about how CFS/ME impact learning,³ and how to address the need for adaptation in school.⁴ This requires sound scientific and practical knowledge among healthcare providers, and that information on individual educational and social challenges is communicated to school personnel.^{17 18} This includes the important engagement from occupational therapists in identification of potential obstacles, solutions and subsequent advice to teachers

on individualised adaptations.¹⁹ Teachers' genuine concern about their students' needs is valuable, nevertheless, attitudes towards CFS/ME might impact experiences in students with CFS/ME.¹⁷ Advice from healthcare providers is usually necessary to prevent a course of intuitive trying and failing when adapting education for young people with CFS/ME.²⁰ Teachers also need acceptance and resources from their leaders to be able to adapt education adequately to the student's needs.²¹ Conversely, if the teachers do not see any reason for adapting the education level, the school leadership should take actions to secure individual educational adaptations for students with CFS/ME.²¹ The current study confirms that adequate and individualised educational and social adaptations at school may facilitate school progression for young people with CFS/ME.

Other informants described several negative factors related to educational and social adaptations in school. Negative factors included disbelief and distrust from teachers, overambitious educational plans and difficulties in recognising their own limitations. Not all schools have previous experiences of students with CFS/ME. In addition, the adolescents might try to conceal their symptoms when they attend school, potentially making it difficult for teachers to understand their adaptation needs.¹³ Also, the uncertainties surrounding CFS/ME diagnosis and especially CFS/ME aetiology could further contribute to a lack of understanding and disbelief from schools.¹⁷ This may lead to overambitious plans for school attendance.⁴ One reason for why overambitious or inadequate plans are made can be to reduce the negative consequences for healthy students.²¹

Nevertheless, in Norway, schools are required by law to adapt education for young people with chronic health conditions. There is however a gap between ambitions and realities when adaptations of education for young people with chronic health conditions are managed in mainstream classes.²² The current finding confirmed that the informants' experienced that promised adaptations were not always possible to carry through. Special classes have been described as preferable for young people with other chronic health conditions.²³ This was also preferred by some informants in the current study.

How the interdisciplinary management of adaptations for young people with chronic health conditions in mainstream classes is handled and how they work out is poorly explored. Thus, young people with CFS/ME might not be the only ones who struggle with educational and social adaptations at school. It is previously explored how healthcare providers' support schools regarding the needs in young people with chronic health conditions,²⁴ and it is found that social teachers can facilitate social connectedness with peers for young people with disabilities.²⁵

Some informants found it difficult to recognise their own limitations regarding activities at school and suggested that an advisor perhaps could help them to find a more appropriate activity level. Young people with CFS/ME commonly spend most of their energy trying to

keep up with schoolwork early in their disease,⁸ motivated by their previous experience of being able to participate and master school when healthy.²⁶ The need of young people with CFS/ME for educational adaptations is previously described as important.^{4 27–29} However, educational adaptations are often delayed due to the long time it takes to establish a CFS/ME diagnosis.²⁹ The current study confirms that young people with CFS/ME often lack early adaptations of education. It also confirms that young people with CFS/ME appreciate guidance on how to adjust to their limitations to ensure the best possible school progression and socialization with peers.

Disbelief from teachers and missed opportunities to develop both academically and socially among peers make young people with CFS/ME feel lonely.⁴ An uncertain prognosis, increased emotional vulnerability, and lack of awareness and acceptance of CFS/ME also impact their mood.^{6 7} It is challenging for young people with CFS/ME to accept that loneliness and dependency on close relatives often become the new everyday life instead of developing independence and their own social network.^{26 30} The change in everyday life due to CFS/ME has previously been found to cause fragility and vulnerability as well as undesired emotions like irritability, worry, anxiety, sadness and depression.^{4 26 31} Supportive relations and socialising in school are found to enhance understanding of the identity and loneliness challenges they meet.^{4 7} The classroom might be the only place young people with CFS/ME meet with peers, and thus, social adaptation in school to allow for this is highly valued.³ The current study confirms that young people with CFS/ME find it challenging to accept their new situation, that they experience loneliness and that this impacts how they feel.

Online teaching was perceived as helpful by most informants. It put them on equal footing with peers, and they experienced increased contact with teachers and peers. There are, to our knowledge, no studies examining experiences with online teaching for young people with CFS/ME, but it has previously been found that they can benefit from online healthcare treatment programmes.³² Students with concentration impairments have benefited from being able to study without distractions from the physical classroom environment and from being able to study at their own pace.³³ Furthermore, previous studies have found that young people with CFS/ME find ways to adapt and maintain a sense of normality through online connectedness.³⁴ One study found that young people with CFS/ME do not perform academically to their full potential despite receiving external educational adaptation and support. Poor school-related quality of life and poor connectedness with school place them at risk of developing long-term maladjustment of cognitive, academic and social skills.³⁵ The current study adds to this by showing that young people with CFS/ME may benefit from online teaching both academically and socially.

Clear information on adaptive measures from healthcare to schools is an important factor to increase

knowledge about CFS/ME in schools. Young people with CFS/ME need early guidance and adaptation of education to adjust to their limitations. Online teaching may be an important factor both to improve learning and to improve social connectedness for young people with CFS/ME. Further research should focus on preventing loss of function among young people during the period before a CFS/ME diagnosis, in specific in regard to providing educational and social adaptations for young people with CFS/ME.

CONCLUSION

Young people with CFS/ME can benefit from better educational adaptations and increased social interaction with peers. According to young people with CFS/ME, factors that limit learning and socialisation include a lack of knowledge about CFS/ME among teachers, school personnel and in the educational system. Young people with CFS/ME feel alone coping with the disease and how to recognise their own limitations regarding what they are able to do. Factors that may facilitate learning and socialisation are a better understanding of the disease among teachers, school personnel and peers; suitable educational adaptations and being able to socialise with peers.

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Contributors WAS collected, analysed and interpreted the data, and was the main author of the manuscript. TBR supervised the project, analysed and interpreted the data, contributed to writing of the manuscript, and was the guarantor of this work. THN supervised interpretation of data and contributed to writing of the manuscript. IBH facilitated and supervised the data collection from Oslo University Hospital. All authors read and approved the final manuscript.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Obtained.

Ethics approval All procedures performed were in accordance with ethical standards and approved by the Regional Ethical Committee for medical and health profession research in South-East Norway (REK 2017/749) and performed according to the Declaration of Helsinki. Specifically considered protection for the participants was made. Participants were allowed to have their interviews at home to avoid worsening from travelling, to stop the interview if they needed, to voluntarily bring a parent, and to be seated in comfortable chairs and with dim light during the interview. The informants were also offered supportive healthcare after the interviews. Informed consent was obtained from all participants included in the study. Parents signed on behalf of informants below legal age (16 years). All informants received verbal and written information about the study. Informed consent obtained from all individual participants included consent for publication of anonymised data.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. The datasets generated and analysed during the current study are not publicly available. The raw data supporting the findings of the manuscript can be found at the Children's Clinic, St Olav's Hospital, Trondheim University Hospital, Trondheim, Norway. Due to regulations of the Regional Ethical Committee for medical and

health profession research in Norway, REK, the anonymity of the informants must be secured. In the raw data, it is possible to identify the informants, and restrictions therefore apply to the availability of these data. Reasonable request concerning the data can be sent to the corresponding author.

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ORCID iDs

Wenche Ann Similä <http://orcid.org/0000-0001-7591-178X>

Torunn Hatlen Nøst <http://orcid.org/0000-0003-1149-7238>

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