**PEER REVIEW HISTORY**

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**ARTICLE DETAILS**

| TITLE (PROVISIONAL) | Factors related to educational adaptations and social life at school experienced by young people with CFS/ME: A qualitative study |
|---------------------|---------------------------------------------------------------------------------------------------------------|
| AUTHORS             | Similå, Wenche Ann; Nøst, Torunn Hatlen; Helland, Ingrid; Ro, Torstein |

**VERSION 1 – REVIEW**

| REVIEWER             | Chu, Lily |
|----------------------|-----------|
|                      | Independent Consultant, Burlingame, CA, USA |
| REVIEW RETURNED      | 08-May-2021 |

**GENERAL COMMENTS**

This paper addresses an important topic: how children/young adults with ME/CFS perceive their experiences in school. Direct, open-ended questioning of the study participants - without the interference of parents, guardians, or other authorities - makes this article unique. I do not recall another paper which focuses on asking this population directly about school accommodations.

Nevertheless, I found the paper somewhat superficial because important details appeared to be missing, unclear, or spread throughout the paper. My experience has been qualitative papers utilizing interviews are often rich in detail. The Discussion did not focus on the research questions and analysis of results was lacking. Some publications concerning the subject of the paper do not appear to be cited.

The paper would also benefit from an editor experienced in English. Grammatical issues coupled with awkward phrasing distracted from the content of the paper. I have included an attachment highlighting some of these areas. While some repetition is expected to emphasize the main findings of paper, I believe the Discussion can also be made more concise.

1. Details about whether educational adaptions were provided, what those adaptations were, and how effective they were are sparse or scattered throughout the paper. One of the two major questions asked was “How has your school curriculum been adjusted and how have the adjustments worked out for you?”, I expected more elaboration.

If the message is that most students did not receive any adaptions or that the scarce adaptions provided were not adequate, that message should be highlighted. The lack of adaptions perhaps is exemplified by the short paragraph on page 9 regarding what accommodations were helpful, i.e., fewer lessons, extended deadlines, ability to rest during the day, opportunity to talk to school professional whenever they want. However, helpful
measures brought up by students or which could be inferred are also scattered throughout the text. For example: adjusting overall academic progression (page 10, line 223), exploring what is being done in special education schools that could assist students affected by ME/CFS (p. 10, 224), assuring good communication between educators during major transitions (p. 12, line 252), planned breaks with peers (p. 12, 268), school counselors designated as resources for students affected by ME/CFS (p. 13, 281). These measures could be advanced as possible solutions or areas to research in the Discussion section.

In contrast, the section about “digitalization” of education on pages 13-14 is excellent. Minor suggestions: change the title of the section to focus on this topic (other COVID-19 adaptations are not discussed) and consider using a more international term. I am not sure but what is the best term: in the US, I have seen “virtual” or “online” classrooms, learning, etc. used.

2. Details about the social lives of students and other people students encountered at school were sparse or nonexistent. The title of the paper includes the words “social life at school” and a major interview question was “How do people you relate to perceive your disease?” (p. 7, 139) Yet, only a few lines directly address social activities at school. Two important groups appear to be missing when students were asked about others’ perceptions: their parents (in relation to schooling) and their peers at school. Both these group influence provision/ use of any adaptations. For example, parents may hold unrealistic expectations as well and peers may pressure students to do more than they are able.

3. Provide more context about the participants’ situation and the educational/ health environment in Norway. I appreciate that the authors pointed out the limited generalizability of their work across countries and described the Norwegian educational system (p. 4, 104-109). There are some questions I am left with though which may also assist readers outside Norway.

a) In some European countries, students are placed into separate tracks in high school (e.g., college-bound vs. technical vocation-bound). Is this true of Norway and if so, how does it affect students’ overall education/ struggles? In the United States, at the high school level, schools are legally responsible for assessing students and adapting to their needs. Thus, schools have to take a proactive role even if parents/ students do not. In contrast, at the university level, schools are not as longer responsible (university education is not compulsory) and parents/ students must advocate for themselves. Consequently, for the United States, it would not make sense to study university and high school/ secondary students together as one group. Is the situation different in Norway?

b) On p. 5, lines 100-103, the authors write that medical professionals “usually” educate the student’s primary doctor and educators about ME/CFS the accommodations a student might need. Do the authors know what general information and suggestions were conveyed? Better yet, is there any information about the suggested accommodations for individual students? This information may not be available to the authors. Information about suggested accommodations provides an objective measure against which to assess the reality students faced, i.e., whether adaptations were provided or not, to what degree, etc.
c) Accommodations do not exist in a vacuum but are matched to the functional limitations, symptoms, etc. an individual student faces. The paper mentions inquiring about fatigue (p. 7, 136) as part of the interview and then the Discussion mentions cognitive impairment. It is not clear whether the authors probed for symptoms beyond fatigue. The key symptom of ME/CFS is post-exertional malaise yet it is mentioned nowhere in this article, barring one quote from a student which hints at it (p. 11, 207-213). Other symptoms that students have brought up interfere with school include orthostatic intolerance, pain, and hypersensitivities. It would be helpful for readers to have some idea of the symptoms participants found the most challenging as the degree and type of adaptations would vary.

d) For the Discussion, consider comparing the situation of students affected by ME/CFS vs. other chronic medical conditions in Norway. Are those with other conditions treated better or do they face the same struggles?

4. There are several article and resources concerning pre-university education the authors could review and incorporate – as appropriate – in their paper. Some are listed below:

a. Papers by Dr. Faith Newton (United States):
Newton FR. Meeting the Educational Needs of Young, ME/CFS Patients: Role of the Treating Physician. Front Pediatr. 2019;7:104. Published 2019 Apr 2. doi:10.3389/fped.2019.00104
Faith Newton (2015) Improving academic success for students with myalgic encephalomyelitis/chronic fatigue syndrome, Fatigue: Biomedicine, Health & Behavior, 3:2, 97-103, DOI: 10.1080/21641846.2015.1004831

b. Paper by Dr. Esther Crawley (UK):
Brigden, A., Shaw, A. & Crawley, E. “it’s a medical condition … you need to support as much as possible”: a qualitative analysis of teachers’ experiences of chronic fatigue syndrome / myalgic encephalomyelitis (CFS/ME). BMC Pediatr 21, 6 (2021). https://doi.org/10.1186/s12887-020-02461-7

c. The Young ME Sufferers’ Trust (The TYMES Trust; UK): has several publications on education
https://www.tymestrust.org/tymespublications.htm

d. Massachusetts CFS & FM pediatric page:
https://www.massmecfs.org/information-for-schools

At the university level, my colleagues and I published a paper on environmental accommodations:
Chu, Lily et al. ‘Environmental Accommodations for University Students Affected by Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)’. 1 Jan. 2020 : 315 – 326. https://content.iospress.com/articles/work/wor203176

One way of categorizing accommodations per Canadian occupational therapists is a) personal assistive devices (e.g., noise-cancelling headphones, sunglasses), b) behavioral modifications (e.g. flexible hours, alternating physical and mental activity), and c) environmental accommodations (e.g. no strong cleaning agents). The authors might consider thinking about how these categories fit different types of accommodations.
5. In the Discussion, it was not clear what the main findings of the paper were and analysis/interpretation of data was superficial. For example, the authors took it at face value from the interviews that lack of/inadequacy of adaptations were due to lack of knowledge among teachers. First, knowledge is only part of the issue: some people may be knowledgeable but still hold the view ME/CFS is not a serious condition. Second, while students’ main interactions with school personnel are with teachers, teachers are often not the only factor influencing adaptations. For example, local regulations/funding may limit what teachers can do, logistical challenges (e.g., would some adaptations interfere with other students’ education?), teachers may be willing to adjust but the school leaders may not, etc. Conversely, school leadership can implement/reinforce accommodations school-wide when individual teachers refuse to accommodate. This is one example but is the type of deeper analysis I expected.

6. Discussion of weaknesses: I recognize that with open-ended interviews, there is intentionally less control over what/how much participants say but I wonder if the authors probed the participants enough. If so, the paper did not reflect the richness or detail most qualitative papers offer. Some items I mention may not have been planned as part of the study (e.g., asking students about their parents’ views) or were not accessible to researchers (e.g., clinician recommendations for accommodations). These aspects could be mentioned as potential limitations, future research directions, etc.

7. Research ethics/consent: In the Methods section, the authors should explicitly mention what regulations the study adhered to and what processes were involved to assure compliance with regulations (e.g., Declaration of Helsinki, institutional review board approval). This is especially important for a study conducted on children, considered an especially vulnerable population.

8. Explain Figure 2 further in the text and figure legend. For readers unfamiliar with qualitative research, explain what a conditional matrix is and what the Figure is meant to display. I found this Figure confusing. Is the red and green circle meant to illustrate different situations, e.g., less and more knowledge among personnel? Are the words connected by the red and green lines meant to be current or future consequences of the situations? The connected words are also confusing because some appear to be consequences whereas others seem to be processes that result in the consequences (e.g., improper educational adaptations, counselor).

**REVIEWER**
Newton, Faith  
Delaware State University, Education

**REVIEW RETURNED**
19-Jul-2021

**GENERAL COMMENTS**
This journal article was very well written. It was clear and to the point. The research the authors conducted was focused and the questions accurately assessed the issues adolescents may face with ME/CFS. The journal article offers some important insights into the educational and social adaptations that are or are not being made in some of our schools. It was interesting to read young people’s experiences with living with ME/CFS during COVID-19.
There were minor grammatical errors. The reviewer made suggestions that the authors can choose to accept or reject. The suggestions/corrections are on the uploaded file.

Minor General Style Comments:
References cited in text should use brackets, not parentheses. The CDC capitalizes COVID-19, though "Covid-19" is probably fine as long as keep consistent. Seem to use “’” (left single open quotation mark) rather than “‘” (apostrophe) sometimes (e.g. page 8 line 152 vs. page 7 line 130). Is it standard to use acronyms for author contributions? (Page 19) Last names would be less confusing.

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1
Dr. Lily Chu, Independent Consultant, Burlingame, CA, USA
Comments to the Author:
Comment: This paper addresses an important topic: how children/young adults with ME/CFS perceive their experiences in school. Direct, open-ended questioning of the study participants - without the interference of parents, guardians, or other authorities - makes this article unique. I do not recall another paper which focuses on asking this population directly about school accommodations.
Reply: Thank you for your positive comments.
Comment: Nevertheless, I found the paper somewhat superficial because important details appeared to be missing, unclear, or spread throughout the paper. My experience has been qualitative papers utilizing interviews are often rich in detail. The Discussion did not focus on the research questions and analysis of results was lacking. Some publications concerning the subject of the paper do not appear to be cited.
Reply: We appreciate your constructive and helpful comments. Both the results and the discussion sections are changed according to suggestions where it has been possible. The changes are listed below. Grammatical corrections are listed under the minor revision part.
Pages and Line numbers are referred to as in the version with track of changes
Comment: Details about whether educational adaptions were provided, what those adaptions were, and how effective they are sparse or scattered throughout the paper. One of the two major questions asked was “How has your school curriculum been adjusted and how have the adjustments worked out for you?”, I expected more elaboration.
If the message is that most students did not receive any adaptions or that the scarce adaptions provided were not adequate, that message should be highlighted. The lack of adaptions perhaps is exemplified by the short paragraph on page 9 regarding what accommodations were helpful, i.e., fewer lessons, extended deadlines, ability to rest during the day, opportunity to talk to school professional whenever they want. However, helpful measures brought up by students or which could be inferred are also scattered throughout the text. For example: adjusting overall academic progression (page 10, line 223), exploring what is being done in special education schools that could assist students affected by ME/CFS (p. 10, 224), assuring good communication between educators during major transitions (p. 12, line 252), planned breaks with peers (p. 12, 268), school counselors designated as resources for students affected by ME/CFS (p. 13, 281). These measures could be
advanced as possible solutions or areas to research in the Discussion section.

Reply: We restructured the results as delineated below. Since we did not have complete information about the adaptations provided, and that the participants sometimes did not remember or describe them in detail, it was difficult to analyze how effective they were.

P7, L157-158: Added “The interviewer did not have any information about provided adaptations for the informants from school personnel or health care providers.”

P11, L229-242: Added:

“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 socialize with peers at school, and they were supported from teachers, counselors, and school nurses. Two participants who attended special education schools received all these adaptations and were content with their school situation. They especially valued the good atmosphere, alternative educational tasks, and close contact with teachers and counselors. Informants who received adaptations that worked talked about more regular school attendance than other informants.”

P11-12, L247-251: Added the highlighted words: “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 get them notes from lessons.”

We have advanced the measures that worked as possible solutions in the discussion. (P17, L 417-438), and in regard to further research (P23, L 530-537).

Comment: 2. Details about the social lives of students and other people students encountered at school were sparse or nonexistent. The title of the paper includes the words “social life at school” and a major interview question was “How do people you relate to perceive your disease?” (p. 7, 139) Yet, only a few lines directly address social activities at school. Two important groups appear to be missing when students were asked about others’ perceptions: their parents (in relation to schooling) and their peers at school. Both these groups influence provision/ use of any adaptations. For example, parents may hold unrealistic expectations as well and peers may pressure students to do more than they are able.

Reply: We have made changes to several sections in the Results section, particularly to the “Social life and support” section.

P 10, L235-236. Added: “They had an opportunity to socialize with peers at school, and they were supported from teachers, counselors, and school nurses.”

P13, L 279-280: Added the highlighted words: “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.”

P15, L 320-338: Added:

“All informants said that they missed meeting peers. Socializing with peers was difficult both due to fatigue and to school absence. Some were able to prioritize socializing during the school day, i.e. with a plan that included attending one or more breaks with peers. Others said that school did not prioritize 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 socializing with peers. At home they socialized with family when they managed. Some feared they would enter adult life without having developed socially among peers neither 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 had 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 got better, 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 support. They had also experienced those friends could feel powerless because there was no improvement. Some friends who had trouble believing or accepting, withdrew and eventually disappeared.

Comment: 3. Provide more context about the participants’ situation and the educational/health environment in Norway. I appreciate that the authors pointed out the limited generalizability of their work across countries and described the Norwegian educational system (p. 4, 104-109). There are some questions I am left with though which may also assist readers outside Norway.

a) In some European countries, students are placed into separate tracks in high school (e.g., college-bound vs. technical vocations-bound). Is this true of Norway and if so, how does it affect students’ overall education/struggles? In the United States, at the high school level, schools are legally responsible for assessing students and adapting to their needs. Thus, schools have to take a proactive role even if parents/students do not. In contrast, at the university level, schools are not as longer responsible (university education is not compulsory) and parents/students must advocate for themselves. Consequently, for the United States, it would not make sense to study university and high school/secondary students together as one group. Is the situation different in Norway?

Reply: P5, L 111-114: Added information about the school context:
“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.”

P6, L134-135 Added information regarding participants who had recently entered university: “Three of the informants had recently entered university. However, they primarily talked about their experiences from secondary and high school.”

P6, L132-133: Revised to, “Informants were included until preliminary analyzed data were repeated by new informants and saturation was considered achieved” to show how we defined saturation.

Comment: b) On p. 5, lines 100-103, the authors write that medical professionals “usually” educate the student’s primary doctor and educators about ME/CFS the accommodations a student might need. Do the authors know what general information and suggestions were conveyed? Better yet, is there any information about the suggested accommodations for individual students? This information may not be available to the authors. Information about suggested accommodations provides an objective measure against which to assess the reality students faced, i.e., whether adaptations were provided or not, to what degree, etc.

Reply P3, L71-72: Added: “A limitation to the study was that precise information about what adaptations the young people had received at school was not provided.”

P7, L157-158: Added: “The interviewer did not have any information about provided adaptations for the informants from school or health care providers.”

P18-19, L411-415: Added: “It was a limitation to the study that we did not register precisely what adaptations the young people had received at school. Furthermore, there was a weakness that parents’ involvement in adaptations were not explored. Another limitation was that the findings may not be directly transferable to countries with other educational and health care systems than Norway.”

Comment: c) Accommodations do not exist in a vacuum but are matched to the functional limitations, symptoms, etc. an individual student faces. The paper mentions inquiring about fatigue (p. 7, 136) as part of the interview and then the Discussion mentions cognitive impairment. It is not clear whether the authors probed for symptoms beyond fatigue. The key symptom of ME/CFS is post-exertional malaise yet it is mentioned nowhere in this article, barring one quote from a student which hints at it (p. 11, 207-213). Other symptoms that students have brought up interfere with school include
orthostatic intolerance, pain, and hypersensitivities. It would be helpful for readers to have some idea of the symptoms participants found the most challenging as the degree and type of adaptations would vary.

Reply:
P10, L202-211: We added information about symptoms among the participants, advise from health care, and assistive devices the participants talked about.

“The participants experienced a range of symptoms. As expected, the most common symptom was fatigue, typically getting worse 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 (i.e. memory and concentration difficulties), and autonomic, neuroendocrine, and immune manifestations. Symptoms could vary and fluctuate over time. They had all been advised from health care 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 for them. Some received assistive devices like noise-cancelling headphones, special sunglasses, or a wheelchair.”

Comment: d) For the Discussion, consider comparing the situation of students affected by ME/CFS vs. other chronic medical conditions in Norway. Are those with other conditions treated better or do they face the same struggles?

Reply: We have discussed our findings in relation to similar studies on other chronic conditions. P20, L459-463: Added: “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. The current finding, that the informants’ experienced to be promised a lot that were not possible to carry through, confirmed this. Special classes have been described as preferrable for young people with other chronic health conditions. 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 are 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.”

Comment: 4. There are several article and resources concerning pre-university education the authors could review and incorporate – as appropriate – in their paper. Some are listed below:
Reply: Thank you for making us aware of these publications. We have incorporated these publications in the references (Ref 18, 19, and 20).

One way of categorizing accommodations per Canadian occupational therapists is a) personal assistive devices (e.g., noise-cancelling headphones, sunglasses), b) behavioral modifications (e.g. flexible hours, alternating physical and mental activity), and c) environmental accommodations (e.g. no strong cleaning agents). The authors might consider thinking about how these categories fit different types of accommodations.

Reply:
P10, L208-211: Added: “They had all been advised by health care 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.”
P19, L 424-428: Added: “This requires sound scientific and practical knowledge among health care 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 individualized adaptations (19).”

Comment: 5. In the Discussion, it was not clear what the main findings of the paper were and
analysis/interpretation of data was superficial. For example, the authors took it at face value from the interviews that lack of/inadequacy of adaptations were due to lack of knowledge among teachers. First, knowledge is only part of the issue; some people may be knowledgeable but still hold the view ME/CFS is not a serious condition. Second, while students’ main interactions with school personnel are with teachers, teachers are often not the only factor influencing adaptations. For example, local regulations/funding may limit what teachers can do, logistical challenges (e.g., would some adaptations interfere with other students’ education?); teachers may be willing to adjust but the school leaders may not, etc. Conversely, school leadership can implement/reinforce accommodations school-wide when individual teachers refuse to accommodate. This is one example but is the type of deeper analysis I expected.

Reply:
P17-18: We have revised the discussion as suggested.
P19, L428-436: “Teachers’ genuine concern about their students’ needs is valuable, nevertheless, attitudes towards CFS/ME might impact experiences in students with CFS/ME. Advice from health care providers is usually necessary to prevent a course of intuitive trying and failing when adapting education for young people with CFS/ME. Teachers also need acceptance and resources from their leaders to be able to adapt education adequately to the student’s needs. 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.”

P3, L57: Added: “From the participants view, factors that limit learning and socialization include a lack of knowledge about CFS/ME among teachers and school personnel…”
P24, L540: Added: “According to young people with CFS/ME, factors that limit learning and socialization include a lack of knowledge about CFS/ME among teachers…”

Comment: 6. Discussion of weaknesses: I recognize that with open-ended interviews, there is intentionally less control over what/how much participants say but I wonder if the authors probed the participants enough. If so, the paper did not reflect the richness or detail most qualitative papers offer. Some items I mention may not have been planned as part of the study (e.g., asking students about their parents’ views) or were not accessible to researchers (e.g., clinician recommendations for accommodations). These aspects could be mentioned as potential limitations, future research directions, etc.

Reply:
P3, L71-72 & 74-75: Added:
“A limitation to the study was that precise information about what adaptations the young people had received at school was not provided.”
“A third limitation was that the parents’ involvement in adaptations at school were not explored”
P18-19, L411-415: Added: “It was a limitation to the study that we did not register precisely what adaptations the young people had received at school. Furthermore, there was a weakness that parents’ involvement in adaptations were not explored. Another limitation was that the findings may not be directly transferable to countries with other educational and health care systems than Norway.”

Comment: 7. Research ethics/consent: In the Methods section, the authors should explicitly mention what regulations the study adhered to and what processes were involved to assure compliance with regulations (e.g., Declaration of Helsinki, institutional review board approval). This is especially important for a study conducted on children, considered an especially vulnerable population.

Reply:
The Ethic approval is provided in the section after the discussion, in line with the author guidelines (P25, L557-568) and covers the issues raised by the reviewer.

Comment: 8. Explain Figure 2 further in the text and figure legend. For readers unfamiliar with qualitative research, explain what a conditional matrix is and what the Figure is meant to display. I found this Figure confusing. Is the red and green circle meant to illustrate different situations, e.g.,
less and more knowledge among personnel? Are the words connected by the red and green lines meant to be current or future consequences of the situations? The connected words are also confusing because some appear to be consequences whereas others seem to be processes that result in the consequences (e.g., improper educational adaptations, counselor).

Reply:
P17, L 379-386: Figure 2 has been revised. In the results section, the following explanation to Figure 2 is provided:

“In Figure 2, the overall results are summarized in a twofold conditional matrix. A conditional matrix can be visualized as a set of concentric circles with actions and interactions at the center, 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.”

Reviewer: 2
Dr. Faith Newton, Delaware State University

Comments to the Author:
This journal article was very well written. It was clear and to the point. The research the authors conducted was focused and the questions accurately assessed the issues adolescents may face with ME/CFS. The journal article offers some important insights into the educational and social adaptations that are or are not being made in some of our schools. It was interesting to read young people’s experiences with living with ME/CFS during COVID-19.

Comment: There were minor grammatical errors. The reviewer made suggestions that the authors can choose to accept or reject. The suggestions/corrections are on the uploaded file.

Reply: We appreciate your positive and constructive comments. We have accepted and corrected grammatical changes according to both reviewers’ suggestions. The changes are listed below under minor revisions.

Minor revisions:
Abstract
P2, L36: We removed “…using a qualitative design.” from objectives, because it was repeated in the design paragraph. This was our own suggestion.

P2, L 40 …: “Covid-19” was replaced with “COVID-19”. This was repeated through the document.

P3, L50:
- “…social life in school” is changed to “…social life at school”.
- “Educational and social adaptations improved schooling…” is changed to “Educational and social adaptations could improve schooling…”.

P3, L 53: “Digital teaching…” is changed to “Online teaching…”. This is repeated through the document.

Article summary
P3, L 66-67: “were” changed to “was”, and “were” changed to “where”.
P4, L 68-69: “with experiences from caring for…” changed to “who had cared for…”

Left single open quotation marks are replaced with apostrophe through the document.

Background
We moved a sentence from the section describing the Section to the Background
“The incidence rate of CFS/ME among Norwegian students is 43 out of 100,000” This was our own suggestion. So was the added word in L84: “…as well as social and physical…”
P4, L 81: Added: “may” to the sentence “…the disease may cause anxiety”. 
Setting
P5, L107: Added: “providers”
P5, L107: Added: “them” to the sentence “…to inform them about the disease…”
P6, L117: Added: “beginning” to the sentence “…beginning form March 2020”
Informants and recruitment
P6, L123: Changed: “not able to” to “inability to”.
P6, L127: Added: “The” to “The first author….”
Data collection and interview guide
P7, L140: Removed: hyphen in “PhD student”.
P7, L153: Removed: hyphen in “interview guide”
P7, L155: Added: “The” and “about” to “The central questions were about…”
P7, L159: Changed: “First a pilot interview…” to “A pilot interview…”, our own suggestion.
P7, L163: “made” was replaced with “conducted” as suggested.
P7, L164: Added: “The” and “about” to “The central questions were about…”
P8, L167: Changed: “…participated with…” to “…participated in a supplementary interview…”
Data analysis
P8, L169: “verbatim transcribed” was rephrased to “transcribed verbatim”.
P8, L171-173: Changed: 1), 2), 3) etc to (1), (2), (3) etc for all 7 categories
P9, L188: To be consequent, changed three to 56 months to 3-56 months
Results
P9, L193-194: Changed the sentence: “Ten of the 18 informants attended school 50-100% in the four-week period before the interview” to “Ten of the 18 informants attended school more than half of the classes in the four-week period before the interview” and rearranged the paragraph.
P9, L198: Table 1 was revised and embedded
P10, L214: Changed: “...accepted the disease.” to “...accepted their disease.”
P10, L217: Added: “and phrases” to “Words and phrases…”
P10, L222: Changed: “Fewer spoke about…” to “Few, but still some, spoke about…”
P10, L222-225: Rearranged the four themes to: “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.”
P11, L248. Deleted: “They talked about physical, cognitive, social, and emotional challenges”, since this was included in the paragraph with the symptoms.
P11, L249: Added to the sentence: “Some said that they were not listened to and had to struggle…”
P12, L250: Added: “Some even studied at home without any communication with a teacher and had to ask friends to provide notes from lessons.”
P12, L254: Added to the sentence: “…informants also said that it could be difficult for themselves to recognize…”
P12, L255: Changed: “They could…” to “They would…”, and revised the whole sentence to “They would overestimate their capabilities to attend school, resulting in worsening of fatigue, PEM, and increased school absence”
P12, L271-272: Rephrased as suggested to: “could not progress through school normally”.
P12, L272-274: Changed the sentences to: “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.”
P13, L279-280: Changed: “got” to “received”, and added to the sentence “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.”
P13, L284: Removed: “not”
P13, L289-290: Removed: “But now its fine, and all the teachers…”, to make the quotation more to the point.
P13, 294-296: Rephrased as suggested to: “Focusing on what they were able to do, accepting life as it was, stay positive minded, and socialize when they were able made them feel better”.

P13, L 296 “TV” written out to “television”.
P14, L 298: Deleted comma in “the help she hoped for”
P14, L 304: Removed: “,” and added “the” to “…because of the uncertainties…”
P14, L 308: “transferring from secondary to high school” changed to “transferring to a new school”
P14, L 305-309: Rearranged sentences, and deleted the sentence “Their present support personnel…”.
The new paragraph is:
“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.”
P15, L 320: “with peers” to “Socializing with peers was difficult…”
P16, L 343-344: Added: “for those who did not”, changed “were” to “was”, and changed “they” to “school nurses and teachers”
P16, L 353: Changed the heading to: “Online teaching might be a useful adaptation for young people with CFS/ME”
Comment: In contrast, the section about “digitalization” of education on pages 13-14 is excellent. Minor suggestions: change the title of the section to focus on this topic (other COVID-19 adaptations are not discussed) and consider using a more international term. I am not sure but what is the best term: in the US, I have seen “virtual” or “online” classrooms, learning, etc. used.
Reply: Thank you for your positive comment.
P16, L 355: The heading is renamed to “Online teaching might be a useful adaptation for young people with CFS/ME”
“Digital” is replaced with “online” through the document.
P16, L 357: Changed: “…more in line with…” to “…on equal footing with…”
P16, L 359: Added: “him the” to “…gave him the freedom to…” as suggested.
P16, L 362: Changed from: “The informants had experienced…” to “The informants reported…” as suggested.
P16, L 363: Removed: “,”
P17, L 372: Added: “this” to “…that this would probably…”
P17, L 373-375: Changed: “meant” to “felt”, and revised with a split into two sentences as suggested. The second sentence was not changed as suggested due to what some of the participants preferred, which was physical school. Therefore, the sentences were changed to:
“However, some said they still preferred to meet physically with teachers and peers rather than via digital platforms. These participants felt it was easier to follow lessons when they met physically at school and had the possibility to ask the teachers questions more directly”.
P17, L 379: Figure 2 is explained in a revised version, see major revision.
Discussion
Major revision was provided for the discussion. Minor revisions that remained in the final text is listed below.
P18, L 405: Changed: “were” to “was” as suggested
P21, L 431 Changed: “opportunity” to “opportunities”
P21, L 475 Added: “trying” to “trying to keep up” as suggested.
P21, L 484 Changed: “opportunity” to “opportunities”
P22, L 509 Added: “and” to “and thus”
P23, L 515-516: Rephrased from: “It made them feel more in line with peers” to “It put them on equal footing with peers”.
P23, L 524: Deleted: “of” from “despite of”
P23, L 526: Added “developing” to “place them at risk of developing long-term…”
P23, L534-536: Sentence changed as suggested to: “Further research should focus on preventing loss of function among young people during the period before a CFS/ME diagnosis”, and added “…, in specific in regard to the providing of educational and social adaptations for young people with CFS/ME.”

Conclusion
P24, L 529-545: Changed as suggested to: “…factors that limit learning and socialization include a lack of knowledge about CFS/ME among teachers and school personnel,…”, and revised the sentence to this: “According to young people with CFS/ME, factors that limit learning and socialization include, a lack of knowledge about CFS/ME among teachers, school personnel, and in the educational system. Young people with CFS/ME feeling alone coping with the disease and how to recognize their own limitations regarding what they able to do”

P24, L545-547: Added semicolons.

References
Minor General Style Comments:
References cited in text should use brackets, not parentheses
The CDC capitalizes COVID-19, though “Covid-19” is probably fine as long as keep consistent
Seem to use “” (left single open quotation mark) rather than “” (apostrophe) sometimes (e.g. page 8 line 152 vs. page 7 line 130)
Is it standard to use acronyms for author contributions? (Page 19) Last names would be less confusing.
Reply: References cited changed from parentheses to brackets.

Figures and Tables
Comment:
Formatting Amendments (where applicable):

● Table/s should be embedded
Kindly embed your table (should be editable and in table tools format). Tables should be placed in the main text where the table is first cited.
Reply: Table is revised and embedded
● Required figure/s format

Figures can be supplied in TIFF, JPG or PDF format (figures in document, excel or PowerPoint format will not be accepted), we also request that they have a resolution of at least 300 dpi and 90mm x 90mm of width.
Reply: Figures are revised and supplied in the requested format.

VERSION 2 – REVIEW

| REVIEWER     | Chu, Lily |
|--------------|-----------|
| Independent Consultant, Burlingame, CA, USA |
| REVIEW RETURNED | 01-Oct-2021 |

GENERAL COMMENTS
I appreciate that the authors attempted to address most of the comments and questions I submitted during my initial review. For example, they further described the Norwegian educational system, emphasized the benefits of online schooling, clarified the Ethics section, and included limitations. (1) Throughout the paper, the authors placed a comma before every bracketed citation number at the end of a sentence. I have
marked several - but not all - of these in the attached "Grammatical and Phrasing" file. The comma is confusing for readers. The authors and editors of the journal should check that citations are formatted correctly as a quick look at published BMJ Open articles show superscripted numbers are used instead.

(2) Some grammatical errors, awkward phrasing, and informal language use persists in the article I have highlighted these issues in the attached file. In a few areas, I was not sure what the authors were trying to convey. In the future, the authors may wish to consider consulting a professional editing service or colleagues skilled in written English.