A ROBOT-AVATAR: EASIER ACCESS TO EDUCATION AND REDUCTION IN ISOLATION?

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ABSTRACT

This paper presents a qualitative study of deployment and use of a robot as a sick child's avatar at school. Many children and youth suffer from a range of chronic illnesses that make them, often for long stretches of time, deprived of normal education and social life. The participants in our study are adolescents who have been diagnosed with, and suffered from, Myalgic Encephalomyelitis (ME/CFS) for at least one year. They attend school typically between 1 – 3 hours per week, and the robot-avatar is intended as a way for them to extend the time spent in the classroom and to increase their social presence. The paper discusses tools made to help us understand these young people and their relation to technology (concerning their physical and mental condition) and their connectedness to others (friends, family, teachers and other relevant connections). Further, the paper reports on experiences with the use of robot-avatars by participants, their parents, and their schoolteachers.

KEYWORDS

e-health; e-learning; robot-avatar; adolescents; ME/CFS.

1. INTRODUCTION

This article is concerned with how well can the technology support access to school or alleviate isolation for adolescents who are, due to a chronic illness, forced to stay at home or in the hospital. The chronic illness is defined as in (Mokkink et al., 2008) and entails 1) medical conditions lasting longer than six months, 2) are not (yet) curable, 3) affect the child's daily functioning and well-being, and 4) require a disproportionate amount of health care resources. In the case of children and adolescents, the latter point also implies resources of parents and others in the immediate family, as well as those of the educational system.

The case explored in this paper is that of adolescents suffering from Myalgic Encephalomyelitis, also known as the Chronic Fatigue Syndrome (ME/CFS) and their use of a robot-avatar as a tool that could help increase school attendance and, perhaps, decrease social isolation that is often a consequence of their condition. The use of robot-avatars with adolescents suffering from ME/CFS is part of a larger study concerned with avatar's use by children and adolescents suffering from other chronic conditions, such as cancer, heart diseases, asthma and others. The aim of the larger study is to see how different illnesses affects the use of the robot and if there are special needs related to some conditions that require additions, modifications, customizations, etc. of the robot. ME/CFS, as a multi-system ailment, certainly has aspects that are different from other chronic conditions, for example, the energy modulation mentioned in the literature review. Increased care regarding ethical concerns while doing research with youth suffering from this condition is also needed. While they do not necessarily show visible signs of illness, their efforts to participate may have health-related consequences. The condition is also often misunderstood and stigmatized.

Ten robot-avatars used in the study with ME/CFS adolescents are high-fidelity prototypes, currently under development by a startup *No Isolation,* see ("No Isolation," 2015). For the duration of our qualitative use study (from September 2015 – August 2016 when the robots are to be launched as commercial products), they may be considered as research products (Odom et al., 2016), placed in the context of everyday lives of

adolescents with ME/CFS. The specific research concern discussed in this paper is how well robot-avatars meet school needs, and how they affect the social arena related to schools. So far, the robots were given to nine families with youth suffering from ME/CFS, and arrangements have been made with their schools around the use of the robot in the classroom. These arrangements entailed school's permission (principal's), agreement with teachers, and last, but not least, consent of other children and their parents to the use of the robot in the classroom. For this paper, because of space limitations, we report on findings from two cases that stand out as complementary and representative of findings otherwise. The first case focuses on the use of the very first prototype made and placed with an adolescent whom we call Jon (age 14). This case alone illustrates best diverse usability issues that have had an impact on how the robot-avatar did at school. The second case is that of a boy whom we call Peter (age 13) and his robot-avatar. Peter's case is representative of several other participants who could attend school very seldom during this school year.

The paper is structured as follows. In the next section, the literature review on adolescents with ME/CFS is presented. The subsequent section briefly describes robot-avatars and then addresses the research design. Experiences with the robot, from both the participant's and the school's perspective, are described in Section 4. Section 5 presents our findings. Conclusions and future work end the paper.

2. THE LITERATURE REVIEW

This literature review is divided into three parts. The first part offers an insight into what ME/CFS is and how are adolescents suffering from it affected. In recent years, the increase in chronic diseases, in particular among youth, has been significant (Perrin et al., 2014). Among these diseases, ME/CFS has become a growing concern (Farmer et al., 2004), not only for those suffering from it and their families, but also for the medical science, health management, and society at large. It is no longer a rare disease, and it affects children from about the age of 11 at the same rate as adults, which is well over 3% of the population by some definitions of the disease (Jason et al., 2012). Understanding this is crucial for understanding adolescents with ME/CFS, their abilities, and expectations, also with and of technology. The second part relates the condition with the issue of social isolation. The last section relates previous research on ME/CFS and technologies designed, or used, to help sufferers.

2.1 What is ME/CFS and how it affects adolescent sufferers?

ME/CFS is a debilitating multisystem illness resulting in a number of symptoms that include severe physical and cognitive exhaustion, confusion, difficulties with memory, concentration, sensitivity to light and noise among others, see (Afari and Buchwald, 2003; Bringsli et al., 2014). In order for someone to be diagnosed with ME/CFS, the symptoms need to be present to such a degree that they clearly limit person's ability to carry out ordinary daily activities (National Collaborating Centre for Primary Care (UK), 2007). Sufferers are classified in four groups: mild (an approximate 50% reduction in pre-illness activity level), moderate (mostly housebound), severe (mostly bedridden) or very severe (totally bedridden and in need of help with basic functions) (Carruthers et al., 2011).

The origin of the disease remains an enigma. Treatments are highly individualized, often symptom-based, and include both pharmacological and behavioral strategies. The most common form of help to those suffering from the illness in Norway is provided through self-management courses. These courses teach people how to stabilize symptoms, balance rest and activity etc. (Bringsli et al., 2014). This is in line with a more general trend to promote self-management, especially for patients with chronic diseases (Holman and Lorig, 2004). Self-management generally implies medical management, behavioral management, and emotional management (Corbin and Strauss, 1988; Lorig and Holman, 2003). For ME/CFS sufferers, it also includes a so-called *energy modulation*, where a sufferer is considered to have a limited amount of energy to use per day and that amount needs to be distributed carefully. Research shows that energy modulation has an effect on the illness (Jason et al., 2009). Overuse implies extra exhaustion lasting between several hours to several days, leading to increased pain, sensitivity and overall worsened physical and cognitive condition. A person with ME/CFS, however, often does not know in advance effects of activities, such as meeting a friend. Thus, energy modulation is challenging and difficult. For us as researchers, it was crucial to learn about this and behave accordingly while doing our research at homes of these young people.

For children and adolescents, symptoms are often ascribed to other causes, making their position more difficult, as Dowsett and Colby reported already in 1997 (Dowsett and Colby, 1997) and still true today:

"Do children and adolescents suffer from ME/CFS? Simple common sense tells most parents, teachers

and doctors that they do and often more severely than adults. Yet there remains a sizeable proportion of professionals in Health Care, Education and Social Services who are still prepared to ascribe the numerous, disabling but seemingly unconnected symptoms of this illness in young people to anorexia, depression, school phobia or a dysfunctional family background. All are, at least, agreed that the illness presents a considerable economic, educational and social problem", (Dowsett and Colby, 1997).

2.2 ME/CFS and social isolation

Social isolation is often associated with people suffering from ME/CFS (Best and Butler, 2014; Drachler et al., 2009; Roche and Tucker, 2003). Drachler reviewed thirty-two quantitative and qualitative studies, including the views of over 2500 people with ME/CFS. They found seven issues in need of major support. One of these seven was the need to support ways to develop strategies to maintain/regain social participation. They further stated that "outside the family, education was the major focus of social participation for many young people" (Drachler et al., 2009). However, because of their illness symptoms they could not attend school, and therefore some reported having lost connection with friends and teachers (Roche and Tucker, 2003). Home tuition is an often used alternative to attending regular education for young people suffering from ME/CFS (Garralda and Rangel, 2004). Drachler found that home tuition "allowed a flexible schedule of learning within the limits of their condition, but reduced social participation at an important stage of social development" (Drachler et al., 2009). Asbring finds that for ME/CFS sufferers just attending school, or having a job for an adult, signifies living 'normally', and further, "providing purposeful activity, an opportunity for social interaction, a sense of achievement, self-value and social recognition, income and social security" (Asbring and Närvänen, 2002; Clarke and James, 2003; Schoofs et al., 2004) are important.

2.3 Adolescent ME/CFS and technology

There is little in the literature on supporting children and adolescents with ME/CFS through the use of technology. As mentioned, ME/CFS sufferers have multiple challenges, at the physical and cognitive level, coupled with reduced tolerance to light and noise. These challenges affect their experiences with technologies. Special attention is required when introducing a new technology into to the life of these adolescents; one needs to take care not to introduce new problems. However, social and educational challenges are very important, as was also found by (Wadley et al., 2014), whose study with hospitalized children concludes that mediated communication between hospitals, homes and schools is beneficial. Very few other examples of previous research that we could find, are also related to educational and social arenas. General use of social media was described in (Grajales et al., 2014), where authors have analyzed and synthesized 76 articles, 44 websites, and 11 policies/reports and presented findings according to 10 different categories of social media: (1) blogs (e.g., WordPress), (2) microblogs (e.g., Twitter), (3) social networking sites (Facebook), (4) professional networking sites (LinkedIn), (5) thematic networking sites (e.g., 23 and Me), (6) wikis (Wikipedia), (7) mashups (HealthMap), (8) collaborative filtering sites (Digg), (9) media sharing sites (YouTube, Slideshare), and others (SecondLife). Some of their results, in particular, those related to the second life, are relevant for adolescents with ME/CFS and have been described in the work of Best and Butler (Best and Butler, 2013a, 2013b). Literature addressing education for adolescents with ME/CFS is scarce as well, and papers found mostly focus on e-learning, see (Sheridan et al., 2013). Diverse e-learning platforms are seen as an opportunity for children with ME/CFS to participate in classroom activities even though they are staying at home. However, the access to school and educational materials is only one of the challenges that sufferers meet, thus, it does not address, for example, the cognitive problems.

In summary, there is a great need for research exploring design and use of technology for ME/CFS adolescents that does not worsen their condition and supports, in particular, education and social presence.

3. ROBOT-AVATARS AND THE RESEARCH DESIGN

The participants for the study were recruited in collaboration with the Norwegian ME/CFS association ("Norges ME-forening," 2016). Nine adolescents, over 12 and under 16 years of age, were chosen to participate in the study. The recruitment choices were made based on the insight that ME association had on participant's condition (only mild or moderate cases were considered) and difficulties related to school attendance. Five boys and four girls were recruited. The tenth robot was given to Jon, replacing the very first prototype made. This paper then shows the trajectory of deployment of two robot-avatars at Peter and Jon's schools. Working with them has helped shape our methods, discover problems related to the classroom use

and uncover some interesting leads for our current and future research. The work with *No Isolation,* discussing the research design, took about three months, while the work with participants started in early January of 2016. Jon got his robot in early February, and Peter shortly after. Jon and Peter could use their robots for about a week, and after that, the robots were placed into the classroom where, at the time of this writing, they have been for over four months. Peter lives close to school (ca. 2 km), but was capable of attending at most one school class per week. Jon lives far from school (ca. 24 km), but was capable of attending one class every second day. Both Peter and Jon live with their parents and a younger sibling.

3.1 Robot-avatars

Robot-avatars are intended for a single person's use. They are to be controlled by their owners, allowing the avatars to become their eyes, ears, and voice. An avatar is controlled using touch on a smartphone or a tablet. It has a microphone, speakers and camera installed, but it does not have the ability to store any data, it simply streams, see Fig. 1, without any recording capabilities, between a sick adolescent and their school. An app, installed on a personal mobile device such as a smartphone or a tablet, is used to control the robot in real-time, see Fig. 1d). This control is simple and implies signaling presence when the contact between the adolescent and the classroom is established (the eyes light up), using touchpad to move the avatar's head in the desired direction and touching the light button, signaling that they would like to speak (the light on top of avatar's head lights up, Fig. 1a)). A robot-avatar is using 4G so that it can be taken to class trips or places where there is no Wi-Fi, ensuring access everywhere.



Fig. 1. a) Jon's old and new avatars. The old, black one, has a red sticker from the class trip to the museum, b) Peter's classmates made a smile for his avatar, c) the inside of an avatar, d) the app showing how Jon sees a remote location.

An adolescent can see his peers and teachers. He/she is not visible. The intention is for others to see the robot as a physical representation of a sick person. While this is not crucial for ME/CFS adolescents (much more relevant for other illnesses where a child may be in a hospital), they also are often not in a shape they want others to witness.

3.2 Methods

As discussed in Section 2, we used the literature review to gain an understanding of what has been done in terms of design and use of technology for ME/CFS sufferers. To gain an understanding of the user group itself, we have organized an expert sense-making session on ME/CFS. The participants have a deep knowledge of ME/CFS, having daily contact with children, youth and adults with ME, and their families. The group consisted of representatives from the Norwegian ME organization, the organization that provides support to families of ME/CFS sufferers, the youth ME/CFS organization, and a medical doctor. The insights from this session were very important and reported in (Børsting and Culén, 2016). For present paper, it suffices to say that it has helped us understand better the concept of energy modulation and many other issues relevant to everyday living with ME/CFS.

Our choices of methods and tools to use with participants were guided by our previous experiences in working with vulnerable children and youth (Culén, 2015; Culén and Karpova, 2014; Culén and Velden, 2013), where vulnerability is to be understood as a set of risks that should be reduced by new technologies such as the robot-avatar. Thus, on the one hand, we needed to develop methods and tools to collect data on participant's habits around school and social connections related to school, enabling us to see changes in behavior and social patterns. Their condition was not to deteriorate due to increased school attendance and

social activities via the avatar, or efforts to participate in this research. On the other hand, we needed to collect data on the robot use in the classroom, diverse usability issues and opportunities for re-design. The first part required great sensitivity to ethical issues. Firstly, as part of the research was done at participant's homes, if they got tired, or their pain increased, it was harder for them to tell us to leave, so we needed to observe them closely and ask several times if they are still ok with participation. Secondly, as mentioned, the energy modulation is challenging, and sometimes even the participants do not know how some activity will affect them. We have, thus, made every effort to be fast and efficient beforehand. Finally, some ethical concerns were related to other classroom peers and their parents. Even though they were thoroughly informed about the study, aware that robot-avatars do not store any information and that all data is encrypted, some still felt uneasy with the possibility that their child could be seen from a remote location. In one case, a request was made that the parents of a participant sign that only their child will ever use the robot-avatar and that no one else would ever observe the classroom with their child.

When delivering an avatar to participant's home, we first interviewed the participant and then helped them to install the app and bring the avatar to life and made sure that they would know how to use them later. When the robot-avatar was delivered to Jon, our first participant, this initial visit took a long time (approximately three hours) due to diverse technical problems. Visiting Peter, and especially more recent participants, it took much less time. Interviews typically lasted about 30 minutes.

Tools such as the cool wall (Fitton et al., 2012; Read et al., 2011), social mapping and the technology use mapping, described in (Culén, 2015), were used, see Fig. 2. The interview was audio recorded, and the photos, as per consent allowed, taken.

The cool wall, shown in Fig. 2 a), was used as an ice-breaker technique that at the same time allowed us to discuss what they consider cool in terms of technology and games, and why. Large magnets and the board allowed for easy movement of items and ease in changing categories, if needed. Some icons that we considered likely to be used by our participants were made a-priory. We left some magnets white, and participants easily add their own items. We also asked if any of these things that they consider as cool or neutral tire them.



Fig. 2. Tools used: a) the cool wall b) the communication map c) the future technology map.

Fig. 2 b) shows a social map that places the participant in the center (the green square marked as me), then a circle of close relations with daily contact was drawn, and then the circle with people with whom the communication is occasional. Small people cutouts, in different colours to separate people into categories such as friends, family, really close friends, doctors, teachers etc., were provided. Each participant could define their own categories, as well as choose colours for each category. A similar map was used to see what kind of technologies they use daily and for what (this map is not shown in Fig. 2). Here, we also aimed to find out if some technology platforms had a negative impact on their health, that is if they increased their illness symptoms. The same icons as for the cool-wall, as well as the self-made ones, were used to discuss their habits around technologies such as Skype, smartphones, computers, TV and others. Finally, a map of envisioned use of the avatar was presented, see Fig. 2c). Here, participants could write directly on the map any thoughts around how the robot-avatar will be used. The same procedure was used with all nine participants, but as mentioned, this paper focuses on Jon and Peter's case.

After this initial visit, data on Jon and Peter's cases was gathered through frequent email contacts with their parents. In total, 69 messages were exchanged. 37 of these handled organizational matters, while 32 were the actual feedback on use, technical problems and design and personalization suggestions. After a period of 6 weeks of use, an online interview was done with Jon and Peter. The online format was chosen in order to allow Jon and Peter to answer 17 open questions at the time of their own choosing. After ten weeks

of use, 14 open questions interview was done with three schoolteachers, two from Jon's school and one from Peter's school. Thereafter, observations were carried out at both schools, while Peter and Jon attended their classrooms remotely. At the end of the class observations, we administered a nine questions questionnaire to their classmates. Lastly, a closing interview with Peter and Jon, using the same tools as the initial one, was done.

In summary, this is an interpretative study, where data was collected through face-to-face and online interviews with our participants, classroom observations, classmates' questionnaires, as well as feedback from parents in the form of email and teachers through online interviews.

4 FINDINGS AND DISCUSSION

It is appropriate to mention, prior to discussing findings, that there were some issues with these first prototypes. For example, one had to take the battery out of the robot and charge it daily, see Fig. 1c). One also needed to charge the modem. Furthermore, 4G coverage was supposed to work everywhere, but this was not the case. These two problems have, naturally, affected the experiences with avatars. Coping strategies that emerged to address these issues were interesting for this research.

The amount of data collected in this study is large, and themes that emerged rather diverse, i.e., we could discuss design, personalization, technical issues and other issues based on the collected data. We focus only on access to school and social relations findings that emerged from interviews, classroom observations and student questionnaires regarding access to education and social connections at school.

4.1 Findings from interviews

We start by reflecting on the usefulness of the tools for the purpose of interviews. The cool wall served well as an icebreaker and conversation starter. It was an easy exercise to do and allowed us to address a wide range of topics on technology use, and more importantly, their personal likes and dislikes. It was also useful when addressing topics that could be perceived as difficult to talk about, such as how long they can play before they get tired, or how many close or distant friends they have. We found out that the use of these tangible magnets, pens and maps enabled us to collect more and richer data than we would have gotten if we just asked questions, addressing these same topics directly. Jon and Peter found these exercises to be fun. Since Jon's mother (and both parents in Peter's case) was present during the interview, these tools enabled us to have a more direct dialogue with the interviewee only. They also enabled an easy overview of changes between the initial and final interviews.

Some concerns regarding computers were raised during the initial interview. Jon stated that he gets worse when using a stationary computer. Peter's parents reported that it was their impression that Peter gets worse with prolonged use of the stationary computer. In particular, that he gets worse if sound levels in games he plays are high. The adverse reaction to noise was an important issue at school also. The parents pointed out that lots of noise in the classroom could also be a problem when using the robot-avatar. Peter did not comment, rather, he said that he favored the computer for playing the game of Minecraft. That game connects him to the three friends he has. Minecraft and Skype, on the computer, were the primary routes to social contacts for Peter. Jon was also using his phone, SMS, Skype and diverse games to connect daily with his friends and actively keep close contacts. When using the future avatar use map, Jon was quick to point out that the categories we set should be mixed, see (Fig. 2 c). We have separated home, school and friends, but Jon insisted that school friends are very important.

In online interviews, both Peter and Jon reported that they have been able to tend to their education much more frequently than before. Peter reported that he was able to attend remotely in one week, as much as he had been able to attend during the three months period prior to the use of the avatar. He also stated that in periods of increased illness symptoms, he was still able to attend school, something that would not be possible without the robot-avatar.

Jon wrote in the online interview *"I have had great pleasure from using the robot. I've learned something new and feel that I am more included".* Jon has used the robot to talk to some of his classmates during breaks at school when the teacher was not present. In addition, he could use it during the group work in the class.

All three teachers found the current prototype setup with daily charging to be problematic. It took time and it was an easily forgettable task. The mentioned 4G coverage problems affected negatively the answers from two teachers at Jon's school. They, however, still saw a potential for the robot to work well when these technical issues were eliminated. One of Jon's teachers stated that the robot had been mostly out of working

order, but still, when asked if it was perceived to be useful for Jon, the answer was "Yes, exciting". The other teacher answered "Currently, not much" to this question. Peter's teacher, from school that had good 4G coverage, reported much more positive experiences. Her answer to the question related to robot's usefulness was *"Yes, I find it very useful. He gets a feeling of being a bit more included, although he is not physically present."*

Many issues addressed by teachers were also brought up by Jon and Peter, i.e., the need for a signal when they want to say something, or another signal if illness symptoms on that specific day were worse and they wanted to observe only, rather than participate. Peter's teacher said that it was easy to forget that Peter was present and that she is trying to be more aware and include him in the work just like his classmates.

4.2 Findings from classroom observations

We attended a lesson in English at Peter's school. Fifteen students were present. After the greetings and explanation as to who we are, the focus shifted to the avatar. There was a lot of confusion about whether Peter was present via his avatar, or not. This unsureness was something that Peter reported previously in his online interview. When it was confirmed that the robot was on, the teacher greeted Peter: "Can you hear me? Hi!" "Yes", answered Peter. Then the class proceeded as usual. The teacher gave some examples of what prepositions in English are, and proceeded to do exercises from the book. She also directly addressed Peter: "Peter, do you know where we are?" Peter confirmed. The teacher asked him if he could read from the book. He did. "Perfect, totally correct, perfect!" Then just like everyone else was called to answer questions, so was Peter. His responses were always correct. The teacher also made sure that Peter had no problem seeing the text on the blackboard. The dialogue went well, and we felt that Peter was included in line with other students. However, Peter did not interact much with the robot-avatar. That is, the robot never moved, it did not turn to follow who spoke in the class. Peter did not request to speak on his own. He spoke low when he spoke. The robot was positioned on a school bench, where just one other student was sitting. At some point, the student asked the teacher if she could move to sit with a friend saying "It is the most boring thing to sit alone". Another student offered to move 'Peter' to his desk at the start of the class, but this was not approved.



Fig. 3. a) Peter's classroom, b) Jon's classroom at the start c) Jon's classroom at the end of the semester

The experience in Jon's classroom was in strong contrast with this one. Jon's mother has picked up the avatar the day prior to our visit and charged it overnight. She delivered it fully charged to school the next morning, in order to make sure that everything works. She has experienced problems with charging routines at school before. The following little digression illustrates this point: *several times both Jon and Peter had substitute teachers. Since substitute teachers had no training in handling the robot-avatar and they did not know that it had to be charged, the communication was not possible. One of the substitute teachers in Jon's class refused to have the robot – something that was not expected, so again, Jon could not take part in the class as scheduled. This happened at a point when the avatar has been used for some time already and when Jon started to expect flawless access to teaching. So, it was very frustrating that he could not attend school through the robot as expected. The outcome at Jon's school was to take the robot away from the classroom and keep it locked in a closet. At Peter's school, the routines around charging were changed, and responsibility for charging the robot delegated to students. This has worked perfectly.* On the morning of our visit, the principal walked us to Jon's classroom. We attended a math lecture. The avatar was not there. We greeted the class and the teacher, while the principal went to pick up the avatar from the closet (even though the mother returned it just some minutes earlier, specifically so that it could be ready). The avatar was placed next to the blackboard, see Fig. 3c), where the 4G coverage was weak. The teacher did not greet the student

but proceeded with solving an equation and explaining principles behind what he did. Avatar's eyes light up when it is on. Sitting at the back, we could see the light (the connection) fluctuating. One of us went to the teacher and asked if he could make sure that the student is actually present. The teacher checked and Jon answered. The teacher then told students to do exercises from their book. The avatar's connection continued to flicker. One researcher got up and placed the modem in a different location, where the connection was decent. Not much more happened in terms of interaction with Jon during the hour.

4.3 Findings from questionnaires

There were six out of nine questions that are relevant for this paper (the remaining three questions addresses the personalization and design issues). These were the following: 1) Does it feel like Jon (Peter) is present in the classroom when he uses the robot-avatar? 2) What is good with the robot-avatar in the classroom? 3) What is it that you do not like with the robot-avatar in the classroom? 4) Have you used the avatar to talk to Jon (Peter) at breaks? 5) What do you think, how is it to have the robot-avatar in the classroom? 6) If the robot-avatar were yours, how would you use it? The first and the fourth questions were yes/no questions, while the fifth was a 5 point smiley scale. The remaining two questions were open.

In Jon's classroom, 23 students filled the questionnaire. In Peter's classroom 15. The first question in Jon's classroom was answered in positive 8 times and 15 times in negative, while in Peter's 5 were negative, 7 positive and 3 undecided.

So, in Jon's classroom, most students did not feel like he was there. Answers to other questions clarified why this was so. For the second question, students wrote: "That Jon can attend the school", "When he is not here, he can be here using the avatar", "It is good for him, he can get some teaching and be social", "I do not think over it, but it is nice that he can attend the school from home", "Nothing special, he does not use it much", "It is special, not many classrooms have a robot", "It is cool to have something nobody else has", "Nice for him". The negative aspects were: "It is scary", "It should be used more", "It is missing hands!", "Noise from his home is heard", "Black and boring". However, six friends reported that they did talk to Jon during breaks (before the robot went to live in the closet).

One student found the robot to be very negative, the majority (11 students) gave it the biggest smile, and 5 a smile. As for the last question, they had many ideas, some along the line of current use (go to school when sick), and others different: "Pretend to work", "Watch others learn", "Talk", "Joke", "To cheat on tests", "Be with people when they are sick".

Many in Peter's classroom gave very similar answers as to what is good with the robot. For the negative aspects, three students added that the robot is fragile (it actually fell to the ground and the shell broke, but the functionality was not affected), it needs to be handled with care. One student wrote that the voice is too low and it is hard to hear Peter talk.

Nine students answered the fifth question with the biggest smile, 5 with a smile, one person did not care (neutral), and one was mildly frowny.

In summary, here too, technical problems with robot-avatars were mentioned, its fragility, noise it can be transmitted from Jon or Peter's home, the noise the robot makes when it turns from. It was not experienced as a true representation of Jon or Peter. In spite of all this, teachers, participants, and parents were very positive towards the future possibilities of robot-avatars, once all technical problems were eliminated. Most positive statements pertained to the exact purpose for which avatars were made.

DISCUSSION

This paper focus on how the robot-avatar provides access to education, social participation at school and some important ethical considerations when doing research with youth suffering from ME/CFS.

As mentioned in the introduction, increased care regarding ethical concerns while doing research with youth suffering from ME/CFS is needed. Special considerations need to be taken to ensure that the use of the robot in everyday lives does not worsen their condition. When introducing or developing technology for youth with ME/CFS, it is especially important to be aware of and sensitive towards the challenges related to the energy modulation in order to avoid post-exertional malaise. Any sensory inputs, cognitive or physical activities related to the use of the robot, which exceed individual boundaries, can worsen their condition, often experience over several days post-exertion. Therefore, it is also important to know that youth with ME/CFS could easily surpass their own limits, in order to comply with demands from others or, simply because the robot is fun to use. This highlights the importance of carefully evaluating the design and use of the robot

and how it affects the user. We now recommend the youth and their parents to be careful and design strategies for use that suit their child.

Peter has had days of increased illness symptoms during this period. Neither he nor his parents attribute these health-related problems to the robot. They said that Peter periodically gets better or worse. The robot-avatar continued to be used on the days that he could. Jon, on the other hand, has designed a use strategy in line with the energy modulation strategy, consisting of 'small doses' of use. However, to be sure that it is not the robot that causes an increase in illness symptoms, it would be wise for Peter also to adopt a strategy for use, like Jon's, based on energy modulation (Jason et al., 2009).

If robot-avatars are to provide access to schools successfully, they need to be in perfect functioning order, easy to use and useful. The level of "being finished" that our avatars had, could not work for a commercial product. But they were absolutely amazing as research products (Odom et al., 2009). We got a lot of great data, in particular, related to design and personalization because avatars were indeed seen as something that can be improved, and thinking about suggestions worthwhile. However, when it comes to access and socializing, they were somewhat impeded by this "prototype" status. In fact, we heard the teacher at Jon's school tell the students just before they started filling the survey: "Remember, this is just a prototype, so you need to be VERY honest!"

As mentioned in the literature survey, there were attempts to use tablets and similar to ensure access to school (Sheridan et al., 2013). However, considering tablets as representatives of a child were not the issue brought up. The emotional aspect that physical representation of a child by avatar opens up for was important to explore. The stronger the emotional connection with the avatar as a representative of the child, the better outcomes can be expected from its use in terms of social connections. A good example of this is the fact that Jon's teachers, and in particular, the substitute teacher mentioned earlier, do not see the robot as Jon. If they did they most certainly would not lock him in the closet whenever Jon did not attend a lesson. Jon's mother did make an emotional connection with the avatar, and voiced her opinion as "it is like locking him (Jon) in a closet", identifying Jon's ability to access friends and teaching with that of the avatar. Jon has increased the number of closest friends by one and added a few more to the group of occasional contacts, and he thinks that this is due to the use of the robot, despite the fact that lately, it has been living in the closet. This increase he attributes to the ability to talk to them more often and participate in social interactions with peers in breaks. Jon was much more positive towards the robot when he could use it to talk to friends in the breaks, than after this possibility was eliminated. When Jon was able to participate in breaks with the robot, he described that he felt more included socially in his class (as was reported through the online interview). His parents also noted that, in general, he seemed more emotionally satisfied and happy.

For teachers, it was naturally easier to see the robot as a prototype, because they were the ones having to do extra work, where charging the robot, or placing the modem where there is reception are only one aspect of it. They also had to think how not to forget the child, as Peter's teacher pointed out. They had to find natural ways to include the child properly in a conversation, also when what they do in the classroom is really not easy to attend remotely. How willing they are to address these issues determines how well the robot can be used. In our cases, at one school, teachers used a workaround, where students performed the charging activities, while at the other school the robot-avatar was used less and less.

Do robot-avatars enable easier access to education and reduce isolation? They need to be completely functional, but all our participants believe in the potential they promise.

CONCLUSION

We argue that focusing on the needs of youth suffering from ME/CFS is needed. Our study does so by researching how a technology could support these youth in their everyday lives. Access to education and social connectedness are identified as particularly relevant part of the everyday life for this user group. The technology in our study is a robot-avatar, which is intended as means to reduce social isolation and increase possibilities of getting access to education. It acts as an avatar for children at risk of isolation and represents them in social contexts at school and within friends and family. Already at this stage of prototyping, the robot-avatar represents the solution that solves the problems of access to education for ME/CFS sufferers better than any of the technical solutions discussed in the literature section. In addition, the first trials in real life show huge potential of the avatar, both in terms of ease of use, and because lessons learned from these two cases most certainly generalize to many of those suffering from ME/CFS. This because the participants had many problems common to ME/CFS, and the feedback from the study is that using the avatar has

worsened none of the symptoms. On the contrary, very positive feedback from participants, school and parents were received. It is still important to adopt strategies for use that are in line with the need for energy modulation related to the ME/CFS illness. Being aware of and sensitive to issues related to the energy modulation is highly important through the whole process of doing research or developing technologies for and with people suffering from ME/CFS. Our research indicates that the robot-avatar, the added work tasks for teachers and organizational issues still needs more work, but the technology has the potential to support youth suffering from ME to access school and reduce their exposure to social isolation.

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