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RESEARCH ARTICLE

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Back to school with telepresence robot technology: A qualitative pilot study about how telepresence robots help school-aged children and adolescents with cancer to remain socially and academically connected with their school classes during treatment

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Abstract

Aim: To explore how an AV1 telepresence robot helps school-aged children and adolescents with cancer to remain socially and academically connected with their school classes during cancer treatment.

Design: Qualitative pilot study.

Methods: Data were collected through semi-structured interviews with school-aged children and adolescents (*N* = 3, 12–14 years) diagnosed with cancer, their parents (*N* = 3), teachers (*N* = 2), classmates (12–14 years, *N* = 15, focus group interviews) and healthcare professionals (*N* = 4). Participant observation was performed in the child or adolescents' homes and in the classrooms during education participation via an AV1 telepresence robot.

Results: Five themes emerged: expectations, sociality, learning, spatiality and technology. Participants experienced the robots as facilitating social interaction processes with classmates and inclusion in learning activities, reducing their sense of loneliness and lacking behind educationally. Nevertheless, multiple factors determine whether

the robot is perceived as exclusive, including the technical functionality of the robot, spatiality in the classroom and mutual expectations of the parties involved.

KEYWORDS
cancer, childhood illness, education, school nursing, technology

1 | INTRODUCTION

School absenteeism of more than 40% is experienced by children and adolescents diagnosed with cancer when undergoing treatment. The absence is related to hospitalization, adverse effects, protective isolation, etc. leading to academic challenges and limited interaction with classmates (Charlton et al., 1991; Helms et al., 2016; Sandeberg, Johansson, Bjork, & Wettergren, 2008).

On return to school after cancer treatment, 50% of children and adolescents experience social, psychological or school-related problems, necessitating 20% repeating a grade (Beeman & Henderson, 2012; Boonen & Petry, 2012; Charlton et al., 1991; Helms et al., 2016; Sandeberg et al., 2008). Psychosocial problems, such as social exclusion, fear of peer rejection and bullying, are some of the foremost reasons for their educational difficulties (Butler et al., 2008; Danske-Patienter, 2016b; Gregory, Parker, & Craft, 1994; Helms et al., 2016; Schultz et al., 2007). Use of telepresence robots in hospital settings can change everyday hospital life for schoolchildren and adolescents with cancer and how their care and treatment is organized.

2 | BACKGROUND

Danish school-aged children and adolescents (secondary school) with a long-term illness have a statutory right to receive home schooling after 15 school days from their first day of absence. However, a Danish study shows that only 8% receive such home schooling, mainly due to parents being unaware of the right and schools infringing this right (Danske-Patienter, 2016a). Recent developments in technology give children and adolescents with cancer new opportunities to stay academically and socially connected with their school despite being physically absent (Danske-Patienter, 2015; Newhart, Warschauer, & Sender, 2016; Soares, Kay, & Craven, 2017; Wilkie, 2012).

In theory, telepresence robots provide the flexibility needed to maintain school education by bridging the transition between school and hospitalization and being at home during treatment (Beeman & Henderson, 2012; Danske-Patienter, 2015; Soares et al., 2017). Telepresence robots, for example AV1 robots, mimic presence by the robot's "body" acting as a physical representation of the child or adolescent in the classroom.

Only few studies have explored how technologies can assist children and adolescents with a long-term illness in staying connected with their school class (Beeman & Henderson, 2012; Danske-Patienter, 2015; Lim & Shorey, 2019; Newhart et al., 2016; Soares et al., 2017). These studies show promising trends and indicate that technologies can help children and adolescents participate in education and facilitate social interactions with classmates (Beeman & Henderson, 2012; Danske-Patienter, 2015; Fels, Waalen, Zhai, & Weiss, 2001; Newhart et al., 2016; Soares et al., 2017). However, knowledge is sparse on the effects of telepresence robots on psychosocial and educational development in children and adolescents with cancer. This article reports findings on how telepresence robots help school-aged children and adolescents with cancer to remain socially and academically connected with their classes during treatment.

3 | THE STUDY

3.1 | Design

We used a qualitative approach with individual interviews, focus group interviews and participant observation.

3.2 | Telepresence robots, AV1

AV1 is a telepresence robot designed by No-isolation. The AV1 is activated via an app on a mobile device. AV1 allows the user (the child or adolescent with cancer) to connect with the school class (Figure 1). AV1 has a two-way auditive communication channel and a one-way camera, enabling the child or adolescent to see his or her classmates.

3.3 | Description of the telepresence robot intervention

3.3.1 | Establishment of contact with the children and adolescents

Information: The child or adolescent with cancer and their parents received oral and written information about the AV1 intervention and instruction in the technical functions of the robot.

Delivery of the robot: The child or adolescent with cancer received an AV1 and password for the app.

Implementation of AV1 in school-based education: Teachers and classmates received oral instruction on the use of AV1. All teachers, except one, received written information about the technical functionalities of the AV1.

Ongoing contact: The participants had the opportunity to contact the first author MW if any questions or technical problems arose.

FIGURE 1 AV1 robot. Example of an AV1 telepresence robot. *Source*: No-isolation.com. *Note*: Image is not an actual school class

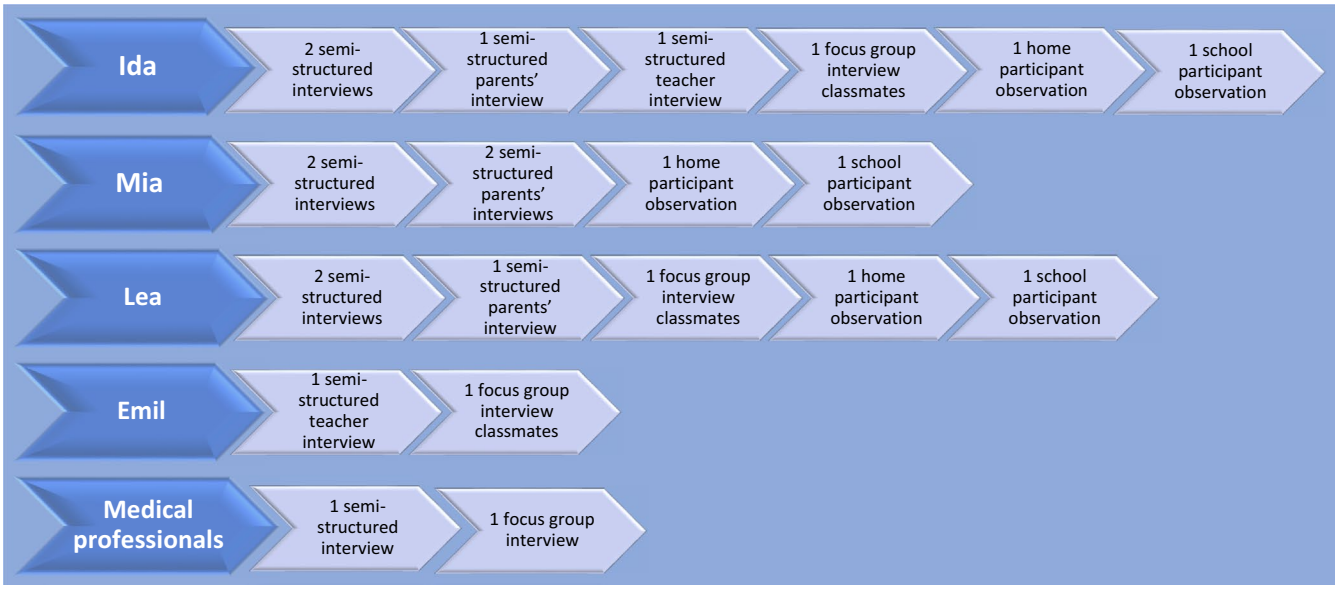

FIGURE 2 Data collection: A list of participants and their relationships

When technical problems occurred, No-isolation provided technical AV1 support to MW.

Intervention period: The child or adolescent decided the duration of the intervention before returning the AV1.

3.4 | Participants

We included 27 participants in this qualitative study. Data were collected through semi-structured interviews including children and adolescents with cancer (*N* = 3), their parents (*N* = 3) and their teachers (*N* = 2), and focus group interviews with their classmates (*N* = 15) and healthcare professionals (*N* = 4). Additionally, 12 hr of participant observation in the child or adolescents' homes and classrooms was performed during the AV1 intervention (Figure 2).

3.5 | Sampling strategy and recruitment

Participants were recruited through the Department of Pediatric and Adolescent Medicine from October 2017 to May 2018. Additionally, we gained access to the patients through the RESPECT project (a school intervention for children with cancer and their classmates at Rigshospitalet in Copenhagen, Denmark) (Thorsteinsson et al., 2013).

The inclusion criteria were as follows: (a) being a school-aged child or adolescent ≤ 18 years of age; (b) having a diagnosis of cancer or a cancer-related illness; (c) hospitalization at the Department of Pediatric and Adolescent Medicine at Copenhagen University Hospital, Rigshospitalet or being in protective isolation at home; (d) having a high level of school absence; or (e) participating in the RESPECT project. The selection criteria were based on convenience sampling and on the number of AV1 robots (*N* = 3) available during the study.

Four patients meeting the inclusions criteria in the selected period were invited to participate.

Three girls (Ida, Lea and Mia) participated. One participant (Emil), who had already tested the AV1 for two months, declined participation because he had returned to school, but he gave permission to interview his classmates and teacher about their experiences—these are included in this study. All three girls received oral and written information about the robot intervention before inclusion in the project.

The informant group for the focus group interview with classmates were sampled in cooperation with the child or adolescent with cancer's teacher, ensuring heterogeneity in the group.

3.6 | Data collection

This study followed the COREQ checklist for reporting qualitative research (Tong, Saninsbury, & Craig, 2007).

The interview guide was based on a continuum from the semi-structured interview approach, where the researcher uses only a few themes and questions (Tanggaard, 2015). Data credibility was established by the open-ended questions offering the participants the opportunity to elaborate on spontaneous narratives and experiences of the robot intervention (Staunæs, 2005).

The interviews with the children or adolescents with cancer were based on the following open-ended questions: (a) "Would you describe the first day you participated in school-based education through the AV1?" (b) "What were your thoughts and feelings when participating in your school class through the AV1?" (c) "Did you experience any difficulties when you participated through your AV1?" (d) How did your teacher and classmates respond to the AV1 in the class?" etc. The questions were followed by probing such as "Could you explain more?"

In the semi-structured individual interview with parents and healthcare professionals and in the focus groups interview with classmates, we also asked about similar personal experiences with the AV1.

The overall focus in the semi-structured individual interviews and in the focus groups was the narratives on how humans (children or adolescents with cancer and classmates) and non-human (AV1 robots) forces interact with each other in school-based education.

The participant observations were performed in the child or adolescent's school classes and private homes by first author MW. Observation notes were collected and analysed the same day they took place. In the observations, the researcher focused on how the children and adolescents used the AV1 and which intra-action processes were offered across virtual and real platforms. Accordingly, the observation focus was on both human and non-human forces and their relationship with each other.

Further, the participant observations were used to create a common reference between the child or adolescent and MW in the interview situation. This allowed MW to ask the child/adolescent about specific situations where they had both participated (Eide & Eide, 2007).

This study can be criticized for the impact MW had on the robot intervention and behaviours in the classroom when she helped restore the robot's function when it lost the connection in the classroom. From the ethico-onto-epistemology perspective, it can be argued that a researcher always has an ethical responsibility for the relationships where that researcher enters into and thereby it becomes a duty to help and give something back to the actors involved in the research field (Barad, 2007).

3.7 | Theoretical approach, analysis strategy and rigour

The philosopher and physicist Karen Barad's new-material theory "agential realism" inspired the study. We used the theory concept of agential realism to develop the research question, interview guides and participant observation notes and also as an analytical strategy.

Nina Hein's use of Adele Clarke's "Situational Analysis" (Hein, 2012, 2018) combined with perspectives from a poststructuralist and new materialistic thinking was applied for the (meta)theoretically perspective (Adrian, 2016; Clarke, 2005; Hein, 2012, 2018). The main focus was on the complex production of agency in the local situation. This approach for processing empirical data gives an insight into complex social dynamics where the subject is not the centre of the analysis (Hein, 2018).

In the analytical work, we drew connecting lines between elements from the empirical material (human and non-human forces) that affected the AV1 intervention. We started the analytical work by listing all the elements from the semi-structured interviews and participant observation that seemed to affect the robot intervention for the specific child or adolescent with cancer. After listing all the elements in three different "messy-maps" (Clarke, 2005), we compared the child's or the adolescent's situations with each other. The themes that emerged from the semi-structured interview and participant observation notes across the children's or adolescents' situations formed the result section. Five themes were identified across the three situations/"messy-maps": (a) *expectations*, (b) *sociality*, (c) *learning*, (d) *spatiality* and (e) *technology*. The structure of "Situation Analysis" provides a basis for comparison across different data, which enhances the internal validity of the study (Graneheim & Lundman, 2004).

The theory concept of agential realism has contributed to a rejection of knowledge as an objective one-to-one mirroring of reality (Plauborg, 2015). In this study, it was an ambition to contribute to a nuanced perspective of the AV1 intervention. Validity was ensured by analysing the robot intervention from several perspectives, that of the child or adolescent with cancer, parents', teachers', classmates' and healthcare professionals', which increased the likelihood of trustworthiness and nuanced perspectives. This creates a shift from focusing on essence and stability towards constituent processes (Søndergaard, 2000). Accordingly, the quality of this research should be understood by its ability to create reflexivity about the different perspectives of the AV1 intervention. Credibility was ensured through an audio recording of all interviews followed by transcribing.

4 | FINDINGS

Three girls aged 12–14 years and diagnosed with cancer were recruited (Figure 3) and the teacher and classmates of a boy aged

Name	Age	Sex	Grade when interviewed	Delivery of the AV1
Ida	12	Female	5th	Delivery date: October 2017 Expiry date: January 2018 Intervention period = 3 months
Mia	14	Female	8th	Delivery date: January 2018 Expiry: April 2018 Intervention period = 3 months
Lea	13	Female	7th	Delivery date: January 2018 Expiry: May 2018 Intervention period = 4 months

FIGURE 3 Information about the adolescents with cancer

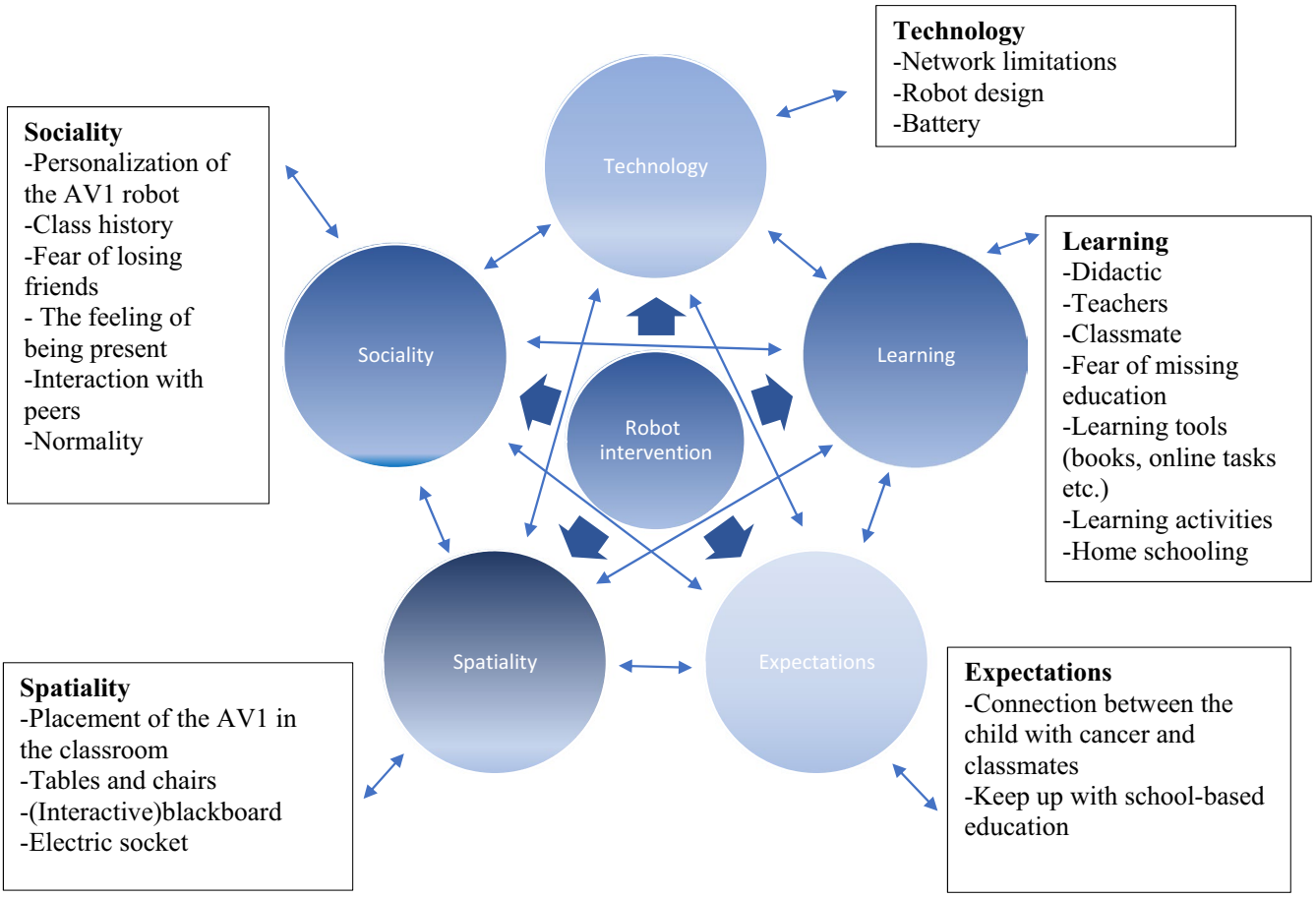

FIGURE 4 Themes and sub-themes from the analysis (human and non-human forces that affect the AV1 intervention)

14 years. The adverse effects of the cancer treatment prevented them from participating in their school classes; accordingly, they received an AV1. *Themes*: Five themes were identified across the children and adolescents' experiences with the AV1 (Figure 4). The themes were (a) *expectations*, (b) *sociality*, (c) *learning*, (d) *spatiality* and (e) *technology*.

4.1 | Theme 1. Expectations

The participants described how the cancer had created a distance between them and their classmates and how the treatment-related school absence created a longing to return to their everyday life. They described how AV1 provided a connection between them and the school class:

I can join in the class, I can see the other girls and feel I still belong. I can hear what the teacher says and that helps me keep up. Instead of just sitting here not knowing anything about anything. The robot helps me to know what's going on.

(Lea, 13 years)

In this way, the AV1 intervention helps bridge the distance.

4.2 | Theme 2: Sociality

The AV1 becomes a substitute for the child or adolescent with cancer in the school class and is personalized by being called the name of the child or adolescent and the children and adolescents uses terms like "me" and "I" when talking about the AV1. Moreover, the classmates regard for the AV1 as if it were a human as this observation illustrate:

Liam [Ida's classmate] gently touch the cheeks of the AV1.

(participant observation notes)

The physical presence and personalization of the AV1 creates an inclusive process, where the AV1 allows the classmates to include the child or adolescent with cancer in their social activities. For example, the classmates invite the child or adolescent to participate in informal conversations, playing in the schoolyard, learning activities, etc. Furthermore, the classmates describe how the physical presence of the AV1 makes it possible for them to participate in the child or adolescent's treatment trajectory. They describe how they have asked the child or adolescents about their well-being and cancer treatment. This possibility for first-hand participation reduced their concerns about the cancer disease and allowed them to show empathy, as Ida's classmates explain:

Int: But why was it important for you to do these things? [build a house for the AV1 and talk to it]
M: It was just nice to have done it.
L: Because it made me feel like I'd helped Ida.
Int: Yeah and so you tried to make it nice for her?
M: Yeah, the first day it was here it felt like Ida had come back. (focus group interview, classmates)

The quote indicates how the classmates feel they are supporting Ida when they take care of the AV1 and that they feel her presence when the AV1 is physically placed in the classroom. Two participants with cancer, Lea and Ida, expressed how the social invitations made them a part of their classmates' social environment again: *"…I was just, like, SO happy and I felt warm all over" (Ida, 12 years old)*. However, another participant with cancer, Mia, did not feel the same joy from her classmates' invitation to social activities through the robot:

I just thought it was kind of awkward because there wasn't so much to talk about. We just talked rubbish, like "do you remember this?" yes, of course I remember. It's not like I've forgotten school

(Mia, 14 years)

This participant interpreted the interaction as pointless and described her classmates as being uninterested in talking to her through an AV1. During her cancer treatment, she started in a new class at her school, which seemed to create a feeling of insecurity, causing Mia to feel excluded or absent when attending the new class through the AV1.

4.3 | Theme 3: Learning

In the classrooms, the teachers perform different actions which are transferred to the AV1 to allow the child or adolescent to feel included in the classroom's learning community. For example, teachers placed the AV1 among the classmates, involving the child or adolescent in academic discussions and group work and including the child or adolescent through the AV1 in the annual class photograph. Two participants with cancer, Lea and Ida, described how the teacher's interaction with the AV1 created a feeling of being present and included in the learning environment. However, the third participant, Mia, describes how the AV1 intervention made her feel overlooked in the classroom because the teachers and classmates overlooked her AV1 presence:

I don't know if it's because my teachers don't take it seriously, but to me, they don't seem to care so much. They don't really ask if I've understood. It feels like I am just sitting and watching.

(Mia, 14 years old)

Observation notes from Mia's classroom showed that her teacher was performing didactic actions to make Mia feel included in the social environment of the new class. For example, the teacher allowed the classmates to take the AV1 in the school yard and on a tour around the school. However, in the interview Mia explains that she does not like the social initiative and prefers only to participate in lessons. Accordingly, there is incongruence between Mia's and her teacher's expectations and understandings related to the use of the AV1 as a socially or academic tool.

Parents explained how they think AV1 has both a social and an educational value for their children:

Mom: She can get in contact with them [classmates] and be together with them in education when she feels like it (..).
Int: So you think it [AV1] can provide something social and educational?
Mom: Yes, exactly, both. (parents' interview)

Some teachers explained how they think the robot has potential of being used as a learning tool for children with cancer, but that it was difficult to know how to include the child or adolescent through the AV1 because they did not know the way the child or adolescent wished to participate.

Furthermore, one teacher who received the AV1 without a manual or explanation about its use recounted how it made him unsure of how to deliver his teaching: "*There was no manual, it was just – here is a robot and some wires*" (teacher interview).

4.4 | Theme 4: Spatiality

The physical placement of the AV1 in the classroom affected the child or adolescent with cancer's feeling of being present via the AV1. Placement of the AV1 among classmates created a feeling of being present and included in the social environment: "(..) *it kind of felt like I was in the class*" (Ida, 12 years). However, the placement of the AV1 away from the centre of the classroom could generate a feeling of being overlooked and excluded: "*(..)they don't really notice whether you are there or not. Like she* [the teacher] *didn't even notice when I switched it* [AV1] *off*" (Mia, 14 years). The placement of desks, chairs and power sockets affected the child or adolescent's possibilities as these elements influenced the feeling of being included as a "present" student. How the classmates and teachers handled and placed the AV1 in the classroom affected the child or adolescent's possibilities of being included in the learning environment.

4.5 | Theme 5: Technology

All participants (children and adolescents with cancer, classmates, teachers, parents and healthcare professionals) regarded an unreliable AV1 WIFI connection as a limiting factor. As one participant with cancer describes:

> *Well, I think that it [AV1] is good when you can hear what's going on and stuff. Then I think it's really god. But when it's not working properly then I actually don't think it's (pauses) then I just think it's useless.*
>
> *(Lea, 13 years)*

Classmates also explain how the disconnection creates a feeling of disappointment: "*Ida couldn't connect [to the AV1] (..) I was really disappointed*" (focus group interview, classmates).

A teacher explains how the AV1 lost online connection in certain areas of the school: "*I was told that it could be used outside. But then it could barely keep power or a signal (..) It was a bit of a disappointment*" (teacher interview). Healthcare professionals also said there were dead spots at the hospital where the AV1 disconnected:" *(..) there is a lot of concrete in the walls, so there is no signal*" (healthcare professional interview). Across the experiences of the three participants with cancer, the unstable network connection was a non-human force that created exclusionary processes from social and educational activities. The children and adolescents described the network connection limitations as disappointing for themselves, their classmates and their teachers and it limited the experience of being present in the classroom. Ida explains: "*…it's not like reality when you talk to someone* [through the AV1]" (Ida, 12 years).

5 | DISCUSSION

This qualitative study showed that the telepresence robot, AV1, allowed hospitalized children and adolescents with cancer to remain socially and academically connected with their classes despite being physically absent. Disconnection occurs as a consequence of cancer and cancer treatment and affects the children and adolescents' academic achievements, social integration and quality of life both during and following treatment (Helms et al., 2016).

Furthermore, for children and adolescents with cancer it is important that classmates show empathy and care about their situation as they are an essential part of children's and adolescents' social network support (Danske-Patienter, 2016b). We showed that the AV1 provided the classmates with such an opportunity. Further, the AV1 supported classmates in coping with the child or adolescent and his/her cancer disease as an integrated part of everyday school life. The AV1 created inclusive processes allowing the child or adolescent with cancer to be invited into social interactions, such as informal conversations and playing in the school yard, which potentially reduces the sense of loneliness. Beeman and Henderson (2012) point out that socialization with peers is crucial to children's and adolescents' academic and psychosocial development and that interactive videos, such as telepresence robots, can provide a possibility to achieve these development tasks.

Exploring ways to remain academically and socially connected is important since one in two children and adolescents with cancer reports educational and peer-related problems, which affects their quality of life when returning to school after the cancer treatment (Beeman & Henderson, 2012; Boonen & Petry, 2012; Charlton et al., 1991; Helms et al., 2016; Sandeberg et al., 2008).

The peer-related problems children and adolescents face after cancer treatment often include how to re-enter into the peer-dynamic and friendship relations after being absent for long periods.

Explorative studies including children or adolescents with a long-term illness show that telepresence robots are often personified (Newhart et al., 2016; Soares et al., 2017). Similarly, we showed that the AV1 became a substitute for the child or adolescent with cancer. However, the child and adolescent experienced this personalization differently. To some, the personification made them feel integrated in the social environment of the class. But for another, participating through the AV1 underscored the dis-belonging to the school class and generated feelings of uncertainty and exclusion, which ultimately resulted in a dislike of being personified through the AV1. Children and adolescents undergoing cancer treatment are

already vulnerable; accordingly, robot intervention necessitates ethical considerations regarding who will benefit from an AV1 robot and in what circumstances.

Technologies and online services can facilitate education for individuals with long-term illness by connecting the child or adolescent with the classroom (Newhart et al., 2016; Soares et al., 2017). This study suggests that a telepresence robot has the potential of being a learning tool if the teachers and classmates include the child or adolescent with cancer when participating through the AV1. The power behind the use of telepresence robots in education is the control the child or adolescent with cancer has on the camera and microphone in the classroom, which can provide a visual present (Beeman & Henderson, 2012). The child or adolescent can participate virtually in educational activities and interact with classmates, despite being physically absent.

Moreover, the study showed that the teachers' and classmates' ability and willingness to involve the child or adolescent as a full member of the classroom's learning community, for example by participating in learning activity and accepting the child or adolescent's contribution to educational discussions, have an impact on the child or adolescent's feeling of being included and present in the learning situation. To achieve integration, it is important that teachers are trained in the use of new technology and feel confident in using the robots. Telepresence robots can potentially facilitate children and adolescents with cancer remaining academically connected with their classes, but further research is needed on how telepresence robots can support and further the child or adolescent's academic level during treatment.

Robot interventions require consideration regarding the physical environment of the classroom, the physical placement of the AV1 in the classroom and how it has an impact on the child or adolescent's feeling of being present. Non-human forces, such as spatiality in the classroom, technology, robot design and network connection, are forces that interact with the AV1 and the child or adolescents with cancer.

The child with cancer can control the "head" of the robot and thereby the direction of the camera in the classroom and the microphone and decide whether it is open for communication or mute and "raise the hand" by turning on the light in the top of the robot's head. The design of the AV1, without wheels, implies that the child or adolescent cannot control the full movement of the robot; accordingly, classmates must carry the AV1 around the school if relocation is required. This can potentially teach classmates to show care for the child's or adolescent's situation, which is a behaviour they can use when the child or adolescent returns to school. Conversely, this lack of control may lead to a feeling of being dependent on others. Telepresence robots with wheels exist; however, further research is needed on how different robot designs affect the child's or adolescent's opportunities in the classroom.

The participants further described how the AV1 network problems limited its use, acting as an excluding factor. Similarly, a feasibility study on implementing a mobile robotic telepresence (MRT) for hospitalized schoolchildren showed network disruptions in certain areas of the hospital and school buildings (Soares et al., 2017). This study highlights the need to carefully consider how new technology should be implemented before interventions are established because disparities between expectations and understandings and technological challenges potentially cause disappointment for those involved.

Telepresence robots can provide a transition between hospital and school settings (Soares et al., 2017). Based on the result of this pilot study, we believe that telepresence robots can enhance the everyday hospital life of children and adolescents with cancer. However, to ensure this possibility, nurses need to include the use of telepresence in the planning of the care of the child and adolescent. For example, planning should be considered in the timing of personal care, taking of blood samples, IV treatment, doctors rounds, etc., so that the child or adolescent has the best possibilities to stay connected through telepresence robots.

5.1 | Strengths and limitations

This study contributes with different perspectives on how an AV1 intervention works in practice. Despite the small sample size, this study gives a perspective of the many forces forming the robot intervention for the specific child or adolescent. Further research is needed on how an AV1 intervention influences the return to school process and the psychosocial and educational development of the children and adolescent with cancer.

6 | CONCLUSION

An AV1 has the potential to help children and adolescents with cancer to remain socially and academically connected with their classes during cancer treatment. The potential is influenced by multiple factors that determine whether the robot technology is an inclusive or exclusive factor for the children and adolescent with cancer, including the technical functionality of the robot, the well-being of the child or adolescent, spatiality in the classroom, expectation congruence and cooperation with several involved parties. Robot interventions call for considerations regarding which children and adolescents will benefit from an AV1. The use of telepresence robots in hospital settings can enhance the everyday hospital life of schoolchildren and adolescents with cancer and the organization of their care and treatment.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the author(s).

AUTHOR CONTRIBUTIONS

Mette Weibel: contributed to the concept, data collection, data analysis and manuscript drafting. All interviews and participant observations were performed by MW. Martin Fridh Nielsen: contributed to the concept, data analysis and manuscript drafting. Martha Krogh Topperzer: contributed to the data analysis and manuscript drafting. Nanna Maria Hammer: contributed to the data analysis and manuscript drafting. Sarah Wagn Møller: contributed to the data collection, data analysis and manuscript drafting. All interviews with healthcare professionals and teachers were undertaken by MW and SWM. Kjeld Schmiegelow: contributed to the concept, data collection, data analysis and manuscript drafting. Hanne Bækgaard Larsen: contributed to the concept, data collection, data analysis and manuscript drafting. All authors have given final approval of the version to be published.

ETHICAL APPROVAL

The Regional Ethical Scientific Committee for the Capital Region approved the study (file. H 3-2012-105), and the Danish Data Protection Agency (file. 2007-58-0015/nr.30-0734) approved the study and the data protection structure. The study used the described criteria for informed consent and the principles outlined in the Declaration of Helsinki II. Informed consent was obtained from all participants' parents before participation in the interviews, and all identifying patient information was anonymized.

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