Use of Telepresence Systems to Enhance School Participation in Pediatric Patients with Chronic Illnesses Involving the CNS

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Abstract: *Background:* Due to hospitalization, medical treatment and/or rehabilitation stays, children and adolescents with diseases of the central nervous system (CNS; e.g. tumors, epilepsies or traumatic brain injuries) often cannot participate in everyday school life to the same extent as their peers. To counteract social isolation and negative consequences (e.g. lack of a sense of belonging, reduced well-being and self-esteem, more frequent class repetitions or low educational attainment) telepresence systems are increasingly being discussed as a way to enable participation for children and adolescents with chronic illnesses. *Method:* This paper presents different telepresence systems and their advantages and disadvantages, effects of use, and potential difficulties. *Conclusion:* Telepresence systems offer an innovative and promising perspective to enable patients with CNS-associated diseases to participate in everyday school life.

Keywords: telepresence system, illnesses of the central nervous system, pediatrics, social inclusion, sense of belonging

Einsatzmöglichkeiten von Telepräsenzsystemen zur Verbesserung der schulischen Teilhabe bei Kindern und Jugendlichen mit Erkrankungen des Zentralnervensystems

Zusammenfassung: *Theoretischer Hintergrund:* Kinder und Jugendliche mit Erkrankungen des zentralen Nervensystems (ZNS; beispielsweise Hirntumoren, Epilepsien oder Schädel-Hirn-Traumata) können aufgrund von Krankenhausaufenthalten, Behandlungen und/oder Rehabilitationsaufenthalten oftmals nicht im selben Ausmaß am schulischen Alltag teilhaben wie Gleichaltrige. Um sozialer Isolation und negativen Folgeerscheinungen wie einem fehlenden Zugehörigkeitsgefühl, reduziertem Wohlbefinden und Selbstwert, häufigeren Klassenwiederholungen oder niedrigen Bildungsabschlüssen entgegenzuwirken, werden zunehmend Telepräsenzsysteme als Möglichkeit diskutiert, um Partizipation für Kinder und Jugendliche mit chronischen Erkrankungen weiterhin zu ermöglichen. *Methode:* In diesem Beitrag werden unterschiedliche Telepräsenzsysteme vorgestellt und deren Vor- und Nachteile, Effekte des Einsatzes sowie potenzielle Schwierigkeiten diskutiert. *Schlussfolgerung:* Telepräsenzsysteme bieten eine innovative und vielversprechende Perspektive, um Patient_innen mit ZNS-assoziierten Erkrankungen die Teilhabe am schulischen Alltag zu ermöglichen.

Schlagwörter: Telepräsenzsystem, Erkrankungen des Zentralnervensystems, Pädiatrie, soziale Inklusion, Zugehörigkeitsgefühl

In Austria, about 200 children and adolescents are diagnosed with cancer every year, with tumors of the central nervous system (CNS) accounting for 20 % in children up to the age of 14 and 10 % in children from the age of 15 (Hackl & Ihle, 2020). Affected children and adolescents experience frequent and long absences from school and social activities because of CNS tumors, other illnesses or injuries of the CNS (e.g., epilepsy, traumatic brain injuries, or inflammatory diseases such as multiple sclerosis), associated treatments, and inpatient hospitalizations. These absences can lead to a reduced health-related quality of life, a diminished sense of belonging to school, and a lack of social inclusion (Hocking et al., 2020; Maes et al., 2017; Pinquart & Teubert, 2012; Pletschko, 2014). Lum and colleagues (2019) state that pupils with chronic illnesses experience higher levels of emotional distress, face more ac-

ademic challenges (e.g., poorer academic performance, frequent grade repetitions, and reduced educational attainment) and feel less confident in social contexts than their peers.

To prevent falling behind in academic performance, some federal states in Austria have implemented so-called "homeschooling," where children and adolescents with chronic illnesses receive lessons at home or at the hospital from teachers (e.g., from the hospital schools located in the respective states). Although homeschooling is an important factor for the children's academic performance and reintegration into school, it does not necessarily satisfy their need for contact with peers, friendships, and a sense of belonging. Telepresence systems represent means of fulfilling this need – at least partially – and to promote the sense of belonging, which has already been identified in some studies as a protective factor in children and adolescents with chronic illnesses (Gilmour et al., 2015; Kirkpatrick, 2020). But what are telepresence systems and how can they contribute to social inclusion and school reintegration in children and adolescents with CNS tumors?

To answer this question, we discuss different forms and possible applications of telepresence systems as well as their potential effects on children and adolescents with chronic illnesses (especially CNS tumors or other diseases involving the CNS). We briefly report experiences with a telepresence system and provide an outlook for future research.

Telepresence Systems

Telepresence systems can be defined as "the experience of presence in an environment by means of a communication medium" (Steuer, 1992, p. 75) and are used to enable social interaction between people (Kristoffersen et al., 2013). While this general definition includes common tools for video conferencing (e.g., Microsoft Teams, Zoom, etc.), which have become a booming trend especially since the COVID-19 pandemic, Newhart (2018) refers to the notion of *virtual inclusion*, describing it as "[...] educational practice that provides the homebound student a physical presence (i.e., telepresence robot) in school via virtual means (i.e., internet connection to the robot)" (p. 6). To provide this presence, despite physical absence, various telepresence robots or telepresence systems are available, two of which are described here in more detail.

A virtual learning environment (VLE) is computer software that provides virtual access to classes, class content, tests, homework, and other learning resources. Additionally, it is a social space connecting remote students with their classmates and teachers, providing a two-way audio and video connection between the patient's home or hospital room and the classroom (Zhu & Van Winkel, 2016). An example of such a VLE is Bednet, which is mainly used in Belgium (see Figure 1). It consists of a rotating camera, a keyboard, a microphone, and a tablet/Chromebook on which the child can be seen in class. In addition, there is Bednet software with which the child can connect to the class via a computer or a laptop and, if necessary, request IT support from Bednet. Unlike telepresence robots (see below), the classroom component of VLE consists of a tablet/screen (as well as a keyboard and/or camera, etc.) rather than a robot or robot-like component.

Telepresence robots consist of a robot-like unit placed in the remote student's classroom, which can usually be remotely controlled by the student from home or the hospital, and allows for real-time, two-way/one-way audio and video transmission via a connection with a tablet or computer. Models differ in their range of mobility, remote-controlled features, type of communication medium, and overall design. While most telepresence robots currently in use are off-the-shelf telepresence robots originally developed for adult use in office settings, newly developed telepresence systems are specifically designed for children and adolescents with chronic illnesses. One example is the "Avatar" AV1, which can be controlled by the remote student, allowing it to be rotated completely on its own axis, while not transmitting video material of the remote student into the classroom (Børsting et al., 2019; Weibel et al., 2020). Some of the well-known telepresence systems are illustrated below (see Figure 2).

Advantages and Disadvantages of Different Systems

VLE are suitable tools for homebound or hospitalized students to engage in education, participate in classroom work, and engage in social interactions during classes. Compared to telepresence robots, VLE like Bednet offer the advantage of high-quality microphones and speakers. In contrast to telepresence robots, the installation of VLE is often simple and operation is intuitive and easy for children and adolescents (Zhu & Van Winkel, 2015, 2016). Nevertheless, they sometimes offer limited mobility because of many components (camera, tablet, keyboard, etc.), making it difficult to participate in events outside the classroom, like school trips or even lunch breaks. Furthermore, two-way video transmission is not always appropriate in this context, since private spaces like the home or hospital room might be displayed and visible sequelae might cause insecurities (Ahumada-Newhart & Olson, 2019).

Figure 1. Components of Bednet (©Bednet).

Figure 2. Different telepresence systems (from left to right): Ohmni (©Ohmnilabs), VGo (©VGo Communciations), Pepper (©Softbank Robotics), Avatar AV1 (©No Isolation).

Telepresence robots offer increased mobility, enabling the remote student to attend lectures as well as other activities in school. Robots designed for adult use offer features that are considered appropriate in a school environment. Remote-controlled mobility, while providing a certain amount of independence, can be difficult to use and requires a high amount of energy and concentration. Sometimes these robots must be carried when they lose Wi-Fi connection, run low on battery, or get stuck because of obstacles, possibly incurring a burden of implicit social debt to peers. The AV1 does provide limited mobility and has been shown to increase social connections to peers instead of incurring implicit social debt – provided its shape, size, and weight allow it to be carried around easily (Børsting et al., 2019), even to events outside a classroom setting, school breaks, and field trips, thus augmenting the experience of social inclusion (Weibel et al., 2020). Moreover, robots specifically designed to include students with chronic illnesses in school are aware of privacy factors; hence, the AV1 only transmits video and audio from the classroom to the remote student but does not transmit an image of the remote student to the class to preserve privacy and security (Børsting et al., 2019; Weibel et al., 2020). The cost of telepresence robots is usually higher than that of VLEs, which presents a major challenge to institutions or organizations that want to put telepresence robots into use and have to provide their own funding or rely on donations and funding requests. Also, the first setup of a telep-

resence robot requires extensive training in the handling and operation of the system, which often demands manpower and time. Lastly, the attractiveness and "coolness" of the telepresence robot can motivate peers to engage with it and can be important for establishing social relations with the robot. For example, the Avatar AV1 can be personalized by children and adolescents by painting or pasting decorations on it. This, in turn, ensures meaningful interactions and allows the robot to be perceived as an extension of the remote student, creating a positive experience for the children and adolescents connecting with the school (Børsting et al., 2019). To further illustrate the differences between VLE and telepresence robots, we present two examples in use in Figure 3 and Figure 4.

As Powell and colleagues (2021) describe, not every telepresence system is appropriate for every child. Children and adolescents with CNS-associated illnesses often have motor or cognitive impairments as well as sensory impairments (vision, hearing, etc.). Motor impairments are a particular hurdle when the upper extremities are affected, as these are usually essential for operating telepresence systems such as laptops or the tablet of Avatar AV1. Possible barriers and obstacles can be identified at the beginning, or a trial phase can be offered to evaluate again whether and which telepresence system is best suited to counteract these problems (Powell et al., 2021). This can help to facilitate the use of telepresence systems despite existing difficulties. However – if not otherwise possible – in severe cases of cognitive, sensory, or motor impairment, it may be necessary to refrain from using a telepresence system, as this may lead to negative effects, such as severe frustration or excessive demands for the children and their environment. Table 1 summarizes the advantages and disadvantages of telepresence systems.

Social, Educational, and Neuropsychological Outcomes

All telepresence systems are successful in stimulating a mutual sense of presence and minimizing the sense of disconnection with school as well as reducing social isolation and improving well-being and mood of pediatric patients to a certain degree (Ahumada-Newhart & Olson, 2019; Børsting et al., 2019; Chubb et al., 2021; Pletschko et al., 2022; Vetere et al., 2012; Wadley et al., 2014; Weibel et al., 2020; Zhu & Van Winkel, 2016). Results from using VLE and telepresence robots showed that remote students felt they had improved their social relations and increased social interactions with teachers and classmates, including more frequent attendance at school (Zhu & Van Winkel, 2016). Furthermore, participants reported a reduced sense of isolation and loneliness as well as an increased sense of belonging; feeling like a part of

Figure 3. Left: Computer software of Bednet installed on a laptop of the child/adolescent with a chronic illness (©Bednet). Right: Bednet in the classroom (©Bednet).

Figure 4. Left: Avatar AV1 in the classroom (©Estera K. Johnsrud). Right: Components of the Avatar AV1 explained to a teenager.

Table 1. Advantages and disadvantages of VLE and telepresence robots

Domain	VLE	Telepresence robots
Privacy	– Two-way video transmission	+ Telepresence robot (Avatar AV1) with one-way video transmission, specially designed to meet the needs of children with chronic illnesses
Mobility	– Sometimes limited mobility (because of many components like tablet, keyboard, camera etc.)	+ Good mobility for robots that can be carried (Avatar AV1) or completely remote controlled (e.g., Ohmni, VGo)
System setup	+ Easy installation of the software and intuitive operation of the system	– Setup usually needs training on how to use the system, time and manpower
Costs	+ Cheap	– Expensive
Appearance	– Often no special features or options for personalization	+ Are often perceived as „cool," offer partial possibility for personalization

the class and being supported by classmates and teachers, which in turn contributed to their mental well-being; reduced distress and anxiety, enhanced social and academic self-esteem including motivation and interest in school activities (Ahumada-Newhart et al., 2016; Børsting et al., 2019; Powell et al., 2021; Weibel et al., 2020; Zhu & Van Winkel, 2016). Both parents and children described keeping up with schoolwork and participating in lessons with Avatar AV1, although not legally obligated for children and adolescents with chronic illnesses in Austria, as particularly important and relieving for the overall situation (Pletschko et al., 2022).

The student's virtual inclusion experience was shaped by the social interactions they received while using the telepresence robot. Ahumada-Newhart et al. (2016) state that, while the use of telepresence robots may help students academically by permitting them to participate in lectures and activities, these benefits might be influenced by the social acceptance of the robot as a classmate, which in turn was linked to social attachment to classmates and a sense of normalcy (Ahumada-Newhart & Olson, 2019; Børsting et al., 2019; Weibel et al., 2020). The robot was commonly seen as an extension of the remote student, although this perception varied between schools, depending on the amount and regularity of exposure and informal interactions between peers and the robot as well as the level of individuation and personalization of the robot (Børsting et al., 2019).

While most students using a telepresence robot reported mainly positive experiences, some did not enjoy using the technology as much, even deciding to stop using the telepresence robot altogether. Negative experiences included physical bullying, negative actions, verbal harassment from classmates, excessive attention from other students, and not being noticed in class because of the placement of the robot, or an unreliable WIFI connection (Ahumada-Newhart et al., 2016; Page et al., 2021; Weibel et al., 2020). Remote students' responses also varied and were influenced by the experienced acceptance, social inclusion, and support from peers, teachers, and parents (Ahumada-Newhart et al., 2016). Børsting et al. (2019) hypothesize that, especially with AV1, the perceived attractiveness of the robot is a factor that helps to integrate the technology as well as the children and adolescents with a chronic illness into the school environment. The different outcomes and moderating factors are illustrated in Figure 5.

Discussion and Future Directions

Children and adolescents with CNS tumors are often unable to regularly participate in everyday school life. Low attendance rates can lead to a lack of academic continuity and poor social connections with peers, which subsequently facilitates poor academic outcomes and social isolation. For example, in addition to neurocognitive or motor deficits, children and adolescents with CNS illnesses often experience particularly severe social isolation, as rehabilitation often takes up a lot of time and increases the amount of time children and adolescents are unable to meet their classmates and participate in school. Virtual inclusion of students with chronic illnesses via telepresence systems has proved to reduce feelings of social isolation, anxiety, and depression, whereas an increase in social interactions facilitates a sense of belonging and normalcy and improves motivation and performance in school. The potential for telepresence robots to help students with a chronic illness to remain socially and academically connected with their class is influenced by multiple factors such as the technical functionality of the robot, the well-being of the child or adolescent, placement of the robot in the classroom, and congruence between the student's expectations (Weibel et al., 2020).

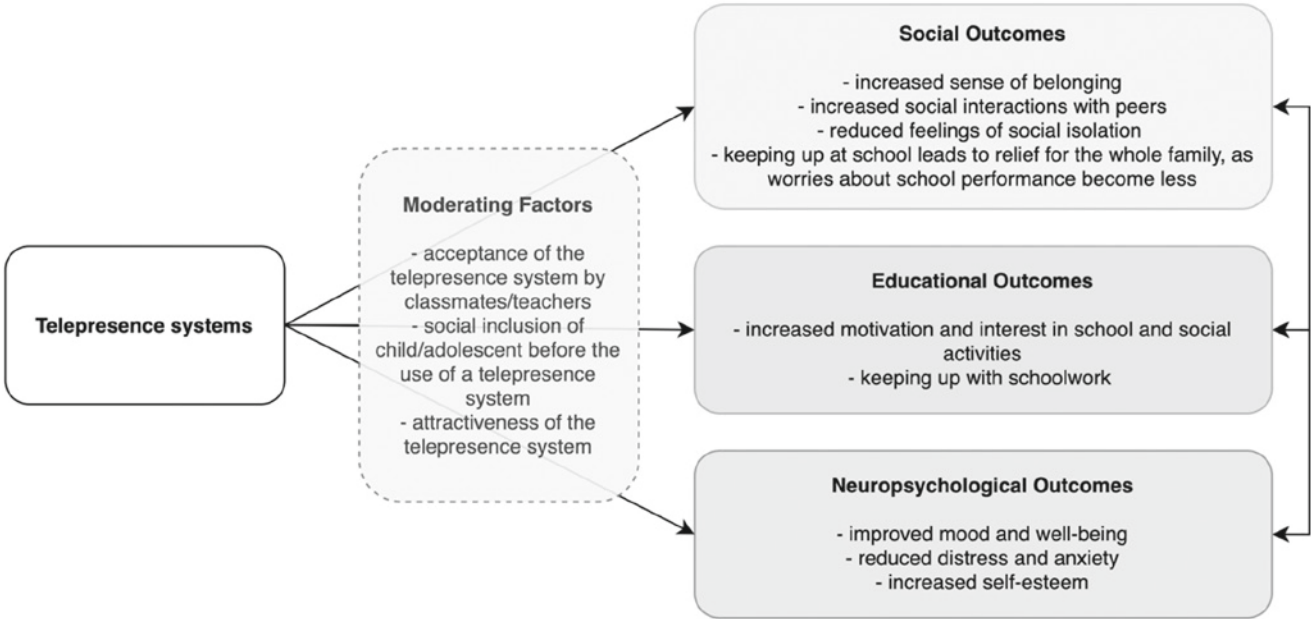

Figure 5. Illustration of the social, educational, and neuropsychological outcomes as well as moderating factors.

Some important aspects must be considered when using telepresence systems. For example, if too little time is invested in managing the telepresence system (e.g., charging, turning it on, carrying it to different locations) or if teachers are skeptical or ambivalent about the system, the children's positive experience with the telepresence system can significantly be diminished. However, a high level of commitment from all involved can have the opposite effect and contribute to a successful experience. Technical difficulties, which can occur with all telepresence systems (e.g., connectivity issues, bad audio transmission, difficulties moving the telepresence system), can also lead to frustration and a loss of self-confidence among children and adolescents as well as teachers (Powell et al., 2021; Wernbacher et al., 2022). Therefore, a support service that timely communicates with individuals and resolves technical issues is of particular importance. Proper training of school staff for using the telepresence system of choice as well as education of classmates are also recommended to reduce bullying and fear of social interaction among chronically ill children, and to promote acceptance in the school environment as well as competence in managing a chronic illness (Powell et al., 2021). For example, when the Avatar AV1 is used in Austria, teachers and classmates are informed about the chronic illness and the telepresence system prior to use. This education and the subsequent use of the telepresence system as well as the technical support can help facilitate a smooth school reintegration and better adjustment of the children and adolescents after their absence (Tollit et al., 2015). As a final consideration, the cost of the various telepresence systems must be taken into account. The price of a telepresence system is usually high, and the financing of the systems varies greatly, depending on the telepresence system used and the country in which the system is used. However, with the Avatar AV1 in Austria, for example, care is taken to ensure that there are no expenses for the families. To meet the need for telepresence systems in the long term and thus ensure psychosocial care and social inclusion for children and adolescents with chronic illnesses, the financing of telepresence systems should become part of health policy considerations.

The summarized reports on experiences with telepresence systems show a strong potential for including children and adolescents with CNS tumors and other CNS-related illnesses and subsequent positive effects on their socioemotional and educational development. Negative experiences highlight factors that should be considered when improving telepresence systems and their application to facilitate positive outcomes. Further longitudinal research is necessary to investigate the long-term effects of telepresence systems on mental health factors such as the sense of belonging, health-related quality of life or self-esteem, and their interaction with cognitive and educational outcomes, especially in patients with CNS-associated illnesses. This article clearly shows that the use and further development of telepresence systems offer major benefits for the psychosocial care of children with chronic illnesses and especially with illnesses of the CNS, with the Avatar AV1 being one of the most promising examples for this innovative technology.

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History
Eingereicht: 2. August 2022
Akzeptiert: 31. August 2022

Acknowledgment
This work was supported by a CCP starter grant from the Medical University of Vienna, the "Occursus" Award for Communication in Oncology, and grants from the Pfizer Corporation as well as the "Innovationsstiftung für Bildung".

Conflict of Interest

„Die Berater Unternehmensberatungs GmbH" is a private educational institution, which has been active in the areas of distance learning, virtual learning and robotics for many years. They focus more and more on telepresence systems which „Die Berater Unternehmensberatungs GmbH" are distributing in Austria, with Martin Röhsner as co-author being the managing director of this company.

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