The Use of the Telepresence System Avatar AV1 as a Therapeutic Tool for Social Inclusion in a 10-year-old Girl Treated for a Brain Tumor

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Abstract

Background: Children with brain tumors are at increased risk for experiencing loneliness, a lack of close friendships, lower academic achievement, and diminished school motivation. To counteract these negative effects, telepresence systems and their ability to maintain school and social participation as well as a sense of belonging are recently being discussed as promising approach. Despite the use of these systems throughout many countries, studies examining their effects are scarce.

Objectives: The aim of this article is to illustrate effects of one telepresence system, called avatar, in a pediatric patient, to analyze possible benefits and challenges and to open up further research topics.

Patients and Methods: In this report, the case of a 10-year-old girl named Sarah, suffering from a brain tumor (medulloblastoma), is described. The girl received the avatar because of her reduced ability to attend school due to her medical condition. The avatar had been in use for seven months, acting as a therapeutic tool to promote social inclusion and to keep up with school. Qualitative interviews were conducted with Sarah, her mother and her teacher, illustrating the relationship between social and learning aspects of telepresence systems.

Originality and Clinical Relevance: The case report indicates that the avatar has the potential to act as an essential supportive means for pediatric patients, maintaining social participation, sense of belonging and academic motivation. The novelty of this telepresence system, the lack of studies in this research area, and the probable positive influence emphasize the originality and clinical relevance of this case report.

Keywords: telepresence system, chronic illness, brain tumor, social inclusion, avatar, pediatrics

1 Introduction

As a result of the Corona pandemic, distance learning and e-learning have become an integral part of the daily lives of many young people (Alqahtani & Rajkhan, 2020; Goldschmidt, 2020; Petretto et al., 2021). For example, approximately 80 to 90% of the pupils in Austria (primary and secondary school) were reached through distance learning in the years 2019/2020 during school closures (UNESCO, 2017). While the absence from school is a new challenge for many healthy children, for children with chronic illnesses it was often already part of their everyday life. Chronic conditions do not only lead to learning and school difficulties (Upton & Eiser, 2006), but in many cases long absences from school due to inpatient medical treatments or a weakened immune system result in social isolation, loneliness, fewer close friendships or a lacking sense of belonging in school (Maes et al., 2017; Hocking, Noll & Kazak, 2020; Pinquart & Teubert, 2012; Pletschko, 2014). Chronic illnesses in children are also associated with an increased risk of bullying and rejection by peers (Holland et al., 2019), peer-victimization (Sentenac et al., 2012), internalizing and externalizing behavior problems (Pinquart & Teubert, 2012), limited career and future prospects (Etschenberg, 2001), higher class-repetition rates (Pletschko, 2014), difficulties in equaling their classmates in school performance (Pletschko, 2014), lower self-esteem (Pinquart, 2012) and a lower health-related quality of life (HRQOL) (Varni, Limbers & Burwinkle, 2007).

One of the protective factors that may counteract some of these negative consequences of chronic illnesses is the sense of belonging (to school), which occurs when students see themselves as a part of their school and feel attached to their peers and the staff (Lohmeier & Lee, 2011). It has been shown to be

positively correlated with important school outcomes including higher academic achievement, academic engagement, peer acceptance, well-being (Anderman, 2002), self-efficacy, and engagement in school (Furrer & Skinner, 2003) as well as higher motivation (Kirkpatrick, 2020). Children with chronic conditions often report lower levels of sense of belonging to their school and lower positive feelings about their school (Kirkpatrick, 2020; Svavarsdottir, 2008), which in turn may affect their academic performance.

To improve the sense of belonging, social participation, and subsequently academic performance for children with chronic illnesses, telepresence systems like robots or avatars are currently being discussed as a promising approach (Weibel et al., 2020). Although telepresence systems are already in use in some European countries, their effects have not been sufficiently investigated. One of these telepresence systems specifically designed for chronically ill children is called the avatar and shown in figure 1. It is connected to the tablet of the child by an app and can transmit sound in both directions. Video transmission only works in one direction, so that the user can see their class or classmates but not vice versa. The avatar is handy, can easily be carried and taken along on school trips. The few existing studies indicate that telepresence systems in general and the avatar as a form of these telepresence systems create opportunities for school and social participation that are significant for the development of children and adolescents with chronic illnesses (Weibel, et al., 2020). Therefore, the use and possible effects of avatar in a 10-year-old girl in a chronic health condition are illustrated in the following case report.

Figure 1: Avatar of the Norwegian company "No isolation".

2 Patient information and clinical findings

Early childhood development and school performance prior to the disease-onset of the 10-year-old patient, we call her Sarah, were inconspicuous. After a deterioration of her general condition including high intra-cranial pressure and moderate ataxia, Sarah was diagnosed with a brain tumor of the fossa posterior (medulloblastoma, WHO grade IV (Louis, Ohgaki, Wiestler

& Cavenee, 2007)) in November 2020. A tumor resection was performed shortly after diagnosis followed by chemotherapy according to the HIT-Med-Guidance-protocol (Juhnke et al., 2017), and proton radiation therapy in spring 2021. During avatar implementation, the patient was in the second cycle of maintenance chemotherapy regularly attending the outpatient clinic. Despite good toleration of the chemotherapy, the girl could rarely visit school due to side effects or hospital appointments. In December 2020 the avatar was assigned, after Sarah had not visited school for 2 months and had no home tuition.

3 Diagnostic assessment

A post-operative neuropsychological diagnostic assessment was performed as a standard of care and questionnaires regarding school and social participation and sense of belonging were administered before Sarah received the avatar. Sarah's visuomotor skills (Beery VMI; Beery, Buketnica & Beery, 2010), her memory (VLMT; Helmstaedter, Lendt & Lux, 2001) and executive functions (BRIEF; Drechsler & Steinhaußen, 2013), as well as her behavior (SDQ; Goodman, Meltzer & Bailey, 1998) were in the average range at the time of diagnostic assessment. In the School Participation Scales 24/7 (Pletschko, 2014) Sarah's mother rated her daughter's school and social participation capabilities as average, while Sarah herself stated that, compared to her peers, she felt restricted in the areas of communication, energy and drive functions as well as information processing speed and logical thinking. Overall HRQOL as assessed by the KINDL (Ravens-Sieberer & Bullinger, 2000) was in the average range, although Sarah reported low HRQOL in the areas of friends and physical well-being. At the time of the assessment, Sarah reported an above average self-esteem (ALS; Schauder, 2011). Lastly, Sarah reported a strong feeling of belonging to her school in the School Connectedness Scale (Lohmeier & Lee, 2011) and in the Austrian nationwide "PISA survey" of sense of belonging (Mang et al., 2019). See table 1 for exact results of the diagnostic assessment.

4 Therapeutic intervention and patient perspective

The avatar was provided by the company "die Berater", which together with the Medical University of Vienna, the Vienna Hospital School and the University of Klagenfurt are partners in the project "Life happens wherever you are – Use of avatar AV1 to enhance school participation in children and adolescents with chronic illnesses". Before the avatar was assigned, Sarah's classmates and teachers were educated about her illness by the Vienna Hospital School and the avatar was presented in class. Informed consent to the study was given by Sarah, her mother, her teachers, and the parents of her classmates. Before the avatar was brought to the school, Sarah had the opportunity to per-

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sonalize and decorate it. Sarah was one of the pilots who used the avatar and described her experience with it. The following quotes and content are retrieved from interviews with Sarah, her mother, and one of her teachers, illustrating one of the first avatar deployments in Austria and raising issues for further research on telepresence systems.

As described by all parties, Sarah remained an integral part of class and could continue to participate in academic and social life. Switching on the avatar for the first time in a music lesson worked without any problems. Both she and her mother were particularly enthusiastic about the fact that the avatar transmitted Sarah's voice rather than a robot voice. Furthermore, personalization of the avatar was crucial for Sarah to identify with it as she stated, "my first idea was to glue eyelashes on him, because that is so typically me". The teacher reported that getting used to the avatar took only a short time and it was easy to use from the beginning. According to all participants, the assumption of responsibility for the avatar by a classmate was particularly important to draw the teachers' attention to visual signals and to ensure that the teacher notices Sarah wanting to say something.

In terms of social participation, Sarah reported that she "was actually there just like the other students" and "didn't feel different from the others". She felt as if "she still belonged to the class" and stated that through the avatar she did not miss anything and could even whisper or chat with her seat neighbors without the teachers noticing. When asked if it is different to be at school with the avatar, Sarah stated that "of course it's different", but "it's both cool and I'm happy on both sides", meaning she is happy to be at school with the avatar as well as in real life. Moreover, her mother and teacher describe that Sarah is addressed like a regular pupil, also during breaks or when the pupils are standing outside the classroom waiting for the teacher. Sarah's mother describes situations during breaks when Sarah's avatar stood in the middle of the students, and they asked her "if she will also be present in the next lesson" or "if she has to go somewhere else now". Furthermore, Sarah and her mother described taking part in various events at school as particularly enjoyable experiences. For example, Sarah was able to take part in the school Christmas party which Sarah found "very nice". Her mother also described "that was kind of nice because she was kind of there, in the middle of it."

Sarah also benefited from the implementation of the avatar in school and learning aspects. After pausing the use of the avatar during the lockdown due to the COVID-19 pandemic, Sarah said that she "participated normally [with the avatar in class]" and took part in group work as well as in tests. It is particularly noteworthy that both the teacher and the mother stated that Sarah's academic motivation was very high and that she wanted to participate in all subjects as much as possible, even if this was not required. Furthermore, Sarah's mother reported that she "was awarded best in class at the school graduation ceremony" and that this was only "possible with such a tool [like the avatar]". The teacher also perceived the avatar and its functions as enriching and superior to regular communication soft-

ware when she says "what I also experienced as positive with the avatar is that she can give signals" if Sarah does not want to be addressed, for example. According to the teacher, a possible challenge arose from the additional preparation for the lessons and the matching of the material to the avatar, as she had to consider "whether this is feasible for Sarah". Another challenge were technical difficulties, for example when the picture was distorted or the connection broke. However, according to Sarah's mother, these difficulties could always be solved quickly by the technical support of the company "die Berater".

5 Discussion

In summary, all parties (Sarah, her mother and teacher) described predominantly positive experiences with the avatar. Identification with the avatar was strongly present and the avatar was mainly used to stay in contact with classmates, to participate in class activities and also school lessons, which becomes an extraordinary experience in the context of chronic illnesses. In Sarah's case, at the time of diagnosis, no cognitive deficits were apparent while her self-reported HRQOL was already diminished in the areas of friends and physical well-being. In contrast, no limitations were reported in Sarah's sense of belonging indicating that the reduction in personal contacts occurred faster than that of the sense of belonging. Although a decrease in close friendships is typical for brain tumor patients (Hocking et al., 2020), Sarah's experiences with the avatar show that at least for a period of seven months she could stay in contact with her classmates and maintaining her sense of belonging to school, despite not being able to attend classes physically.

Legally, chronically ill children are not obligated and sometimes even not permitted to attend school, and only in the case of a prolonged illness, the children and adolescents are entitled to hospital or home tuition, which is crucial for academic success but does not foster social inclusion. The avatar as a tool enabled Sarah to participate in group work, supporting social participation, sense of belonging as well as academic motivation. However, it must be emphasized that the avatar is intended to improve social inclusion, but it is not meant to replace home schooling, nor does it imply an obligation to perform schoolwork, since this may place an unnecessary burden on the patient and the family.

While the use of the avatar is associated with many advantages, we recommend certain requirements, gained from our experiences. To maintain social participation, it is necessary that the users have already met their classmates and teachers and gained insight into everyday school life before using an avatar. Furthermore, it is necessary to define people who are in charge of the avatar (e.g. classmates) whose task is to recharge it and take it to different classrooms. Moreover, additional preparation time for the teachers besides their willingness to implement the avatar into daily routine may be necessary to optimize the use of telepresence systems.

One limitation of this case study is the lack of a follow-up survey, as Sarah continues to use the avatar. Changes in the sense of belonging or HRQOL could therefore only be described qualitatively. Also, comparative data regarding sense of belonging are currently only available for children over the age of 14, limiting the interpretability of the results. A standardization of the questionnaires regarding sense of belonging in a german-speaking population of pupils at or over the age of 10 is planned as part of the further studies, in order to allow for more valid comparisons.

Sarah was chosen for this case report because children with medulloblastoma are known to suffer from long-term-effects including cognitive impairments as well as changes or restrictions in communication and social participation (Maes et al., 2017; Noll & Wefel, 2015; Pinquart & Teubert, 2012), which may not be apparent at the beginning of the illness. This case report indicates that early interventions, regarding the maintenance of the sense of belonging, may help pupils to stay connected. However, the relationship between the avatar, the sense of belonging and academic performance has not yet been sufficiently clarified. Future studies should further investigate the relevance of the personalization of avatars as a prerequisite for the identification with telepresence systems and their use as therapeutic tools to ensure social inclusion. Focus could also be placed on whether, for example, the children's self-esteem or sense of belonging remain stable or possibly even improve during the avatar use. The diagnostic recording of the sense of belonging may provide additional information about how connected pupils feel and in which areas work could be done to improve the sense of belonging. Additionally, including the perspective of classmates may also shed light on the social situation of a patient in class before a longer absence, which may be particularly important when using avatars not only for patients in a chronic physical condition but also for young patients with psychiatric disorders.

As a pilot, this case report can be groundbreaking for the use of technical, therapeutic tools in children with chronic illnesses by illustrating the use of the avatar in everyday life and opening up future relevant research topics and questions, which, to the knowledge of the authors, have not yet been sufficiently investigated.

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Declaration of interest

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Table 1: Results of the diagnostic assessment of Sarah

Assessment (name; author, year of publication)	Subscales	PR Sarah's mother	PR Sarah	M Sarah's mother	M Sarah	Rating
WHO Multiaxial classification scheme for mental disorders of children and adolescents – (Remschmidt, Schmidt & Poustka, 2017)	Axis 3 – Intelligence level					average (expert rating[a])
Beery VMI (Beery-Buktenica Developmental Test of Visual-Motor Integration, 6th edition; Beery, Buktenica & Beery, 2010)	–		54			average
VLMT (Verbaler Lern- und Merkfähigkeitstest; Helmstaedter, Lendt & Lux, 2001)	Overall performance		25			average
BRIEF (Verhaltensinventar zur Beurteilung exekutiver Funktionen, Drechsler & Steinhaußen, 2013)	Global Executive Composite	18				average
SDQ (Strengths & Difficulties Questionnaire; Goodman, 1999)	Total difficulties					average (rating of Sarah's mother)
The School Participation Scales 24/7 (Pletschko, Schwarzinger, Weiler & Leiss, 2015)	Attention functions	30	22			average
	Memory functions	38	18			average
	Thought functions	62	6			below average
	Higher-level cognitive functions	74	30			average
	Energy and drive functions	73	13			below average
	Learning and applying knowledge	59	27			average
	Communication	53	<1			below average
	Interpersonal interactions and relationships	76	44			average
	Fine hand use	>99	40			average
	Moving around	>99	40			average
	Temperament and personality functions	68	76			average
KINDL (Fragebogen zur Erfassung der gesundheitsbezogenen Lebensqualität bei Kindern und Jugendlichen, Ravens-Sieberer & Bullinger, 2000)[b]	Physical well-being			50.00	50.00	below average
	Psychological well-being			81.25	81.25	average
	Self-esteem			75.00	62.50	average
	Family			87.50	75.00	average
	Friends			25.00	62.50	below average
	School			87.50	87.50	average
	Illness			54.17	66.67	average
	Overall HRQOL			67.71	69.79	below average
ALS (Die Aussagen-Liste zum Selbstwertgefühl für Kinder und Jugendliche; Schauder, 2011)	Self-esteem regarding school		85–90			above average
	Self-esteem regarding family		90–95			above average
	Self-esteem regarding leisure		85–90			above average
	Overall self-esteem		90–95			above average
SCS (School Connectedness Scale; Lohmeier & Lee, 2011)	-				4.25[c]	above average
PISA Survey (Mang et al., 2019)	Sense of Belonging			3.60[e]	3.66[d]	average

Note. Results are indicated in Percentile Ranks (*PR*) and Mean Values (*M*). The average range (in which the values are considered statistically normal for percentile ranks (PR) is from PR=16 to PR=84. Mean values (*M*) are given separately for each assessment including mean and +/- 1 standard deviation. [a] Sarah's intelligence level was rated by two psychologists from the clinic according to the WHO classification scheme. [b] Sarah's results are compared to a sample of 7- to 10-year-old girls (Physical well-being $M = 74.43$, $SD = 14.19$; Psychological well-being $M = 83.11$, $SD = 11.33$; Self-esteem $M = 66.68$, $SD = 17.83$; Family $M = 84.40$, $SD = 12.85$; Friends $M = 78.10$, $SD = 13.78$; School $M = 74.10$, $SD = 12.29$; Illness $M = 60.56$, $SD = 15.25$, Overall HRQOL $M = 76.83$, $SD = 8.63$). [c] Sarah's results are compared to a sample of suburban 9th to 12th grade students ($M = 2.955$, $SD = 0.17$, scale ranges from one to five) and [b] to 15-year-old German-speaking pupils ($M = 3.19$, $SD = .64$, scale ranges from one to four). [e] Currently, there is no comparison sample for the parents' assessment of sense of belonging available.