THE ROLE OF THE AVATAR AS PEDAGOGICAL AGENT FOR SCHOOL INTEGRATION AND INCLUSION IN PEDIATRIC LONG-TERM CARE UNITS: A PROJECT PROPOSAL

IL RUOLO DELL'AVATAR COME AGENTE PEDAGOGICO PER L'INTEGRAZIONE SCOLASTICA E L'INCLUSIONE NEI REPARTI DI LUNGA DEGENZA PEDIATRICA: UNA PROPOSTA PROGETTUALE

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ABSTRACT

Treatment of both benign and malignant pediatric tumors requires long periods of hospitalization. To foster connections with peers, hinder isolation and reduce school drop-out during and after treatment, we have structured a project proposal aimed at studying an educational path that involves the use of a virtual avatar as a facilitator of the processes of social interaction and inclusion in learning activities, with the aim of maintaining the patient's school routine.

Il trattamento dei tumori pediatrici, sia benigni che maligni, richiede lunghi periodi di ospedalizzazione. Al fine di favorire connessioni con i pari, ostacolare l'isolamento e ridurre il drop-out scolastico durante e dopo il trattamento, abbiamo strutturato una proposta progettuale finalizzata allo studio di un percorso educativo che preveda l'utilizzo di un avatar virtuale nella veste di facilitatore dei processi di interazione sociale e inclusione nelle attività di apprendimento, con lo scopo di mantenere la routine scolastica del paziente.

KEYWORDS

Introduction[1]

The medical-scientific advances that have characterized the last decade are the basis of the significant reduction of the phenomenon of infant mortality at a global level, the overall decline of which has seen a simultaneous increase in the number of children suffering from chronic diseases (Klunder et al., 2022). This has led to an increase in the number of young people hospitalized, whose forced removal from school activities (especially those in presence) is the basis of the considerable gap often recorded compared to healthy peers (Lum et al., 2019) with significant repercussions on the quality and continuity of education (Fairfax et al., 2019). In fact, a high percentage of hospitalized children, due to acute or chronic problems, cannot regularly go to school (LeHo Project, 2015) and the educational environment is far different from that to which children are accustomed (Capurso & Dennis, 2017; Csinády, 2015). In this sense, as regards the Italian context, the possibility of studying in hospital is now widespread in the main pediatric departments, allowing admitted pupils to proceed with the increase of skills and competencies in order to facilitate and promote reintegration into the various school contexts and prevent social isolation (LeHo Project, 2015; Belpame et al., 2016; Caggiano et al., 2021). Both in Europe and in Italy, at the legislative level, there are indications in order to ensure school continuity also for hospitalized children. However, this is often not the case, as there are complex organizational obstacles in daily application. Despite the centrality of the theme of inclusion in education, today there are still several critical issues that do not allow the full application of policies to support students in difficulty. The approach to heterogeneity and the difficulty with which some diseases manifest, leads to the need to structure different types of interventions to be implemented when the school is not what we are used to thinking. It is of fundamental importance, in these situations, to develop the ability to personalize teaching activities through continuous actions of problematization and transformation (Fabbri & Romano, 2017).

The project proposal presented fits into this framework through the setting of an educational path within a research project in which it is proposed to carry out two types of teaching: one online in simultaneous mediated avatar and one in simultaneous online without the avatar, in order to evaluate the differential impact of the two types of educational paths. The theoretical context within which this

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study takes place is that of collaborative learning and both teaching methodologies should be based on learning through the use of the class group as an educational tool.

1 School attendance and hospitalization: an impossible challenge?

1.1 School education in long-stay wards

The rights of children who are forced into a hospital room due to a long illness are enshrined in various international and national legislative documents. Despite this, data in the literature report that these young people are still facing problems of the school system and significant repercussions of social integration (UNESCO, 1994). The needs of those suffering from chronic diseases in children can remain unheard even in highly advanced countries. In this context, the innovations coming from different sectors of technological scope can make an important contribution to the reduction of educational inequalities particularly evident in children seriously affected by health. Inwards, the treatment of the disease takes priority over the maintenance of a complete training path. The consequence of a prolonged absence, however, together with the lack of daily life in the classroom and with classmates, affects both the group of friendships and the post-illness reintegration (Newhart et al., 2016). The high impact of hospitalization on the quality of life and the long days spent in the ward cause an overall decrease in autonomies with strong repercussions on the whole of life (Nijhof, et al., 2018). The friendships at this age develop rapidly and if the patient is absent for some time from his main place of aggregation, reintegration can be very difficult. A chronic childhood disease, unfortunately, compromises the normal school performance, self-esteem, affective life and social participation, both present and future (Kirkpatrick, 2020), of the hospitalized boy. The long period of hospitalization is a shocking and stressful event for the patient who, at such a delicate time, when social involvement with peers is particularly important (Runions et al.,. 2020), in addition to a sharp break in friendships, causes a heavy impact on motivation and learning (Azevedo et al., 2019), placing it at risk of isolation from the school community. Even the sense of belonging has been widely studied, as, the guys who experience it, are less likely to drop out of school because the possibility that they are allowed to interact with peers and teachers makes them able to respond positively to school tasks (Nuzzaci & Marcozzi, 2019) that are constantly described as difficult to achieve due to low levels of motivation, feelings of insecurity and high levels of loneliness and isolation compared to peers (Lum et al., 2017). The benefits that come from the school institution go far beyond the cognitive

dimension (Thompson et al., 2015), as they prevent and reduce long-term negative psycho-social consequences (Pradhan et al., 2018). Despite this, evidence in the literature shows that hospitalized children tend to develop problems related to learning and social integration caused by the testing of physical changes, mental and environmental that interfere with school success and produce a lowering of self-esteem (Capurso & Dennis, 2017). In the case of oncological diseases, the return to school occurs after months or, sometimes, after years and the possibility of not losing contact with the class to which it belongs has important benefits of a cognitive and affective-relational objectives which go far beyond the attainment of the objectives set out in the curriculum (Stam et al., 2006; Woolfolk, 2010). The psychological and pedagogical management linked to the relationship with the class is crucial for the hospitalized boy, because it is possible that, After the illness, the physical body has undergone significant transformations that lead the young person to develop difficulties at the social level due to the expectation placed in the behavior of the companions, which often result in bullying (Maes et al., 2017). Both the school integration and the desire not to leave these children behind are important quality indicators for the SSN (Piro, 2005). Protecting the right to education also guarantees continuity between the outside world and the long days spent in hospital, ensuring the possibility of detaching themselves even for a short time from hospital rhythms. For children, school attendance represents everyday life and projects them towards a future of hope, allowing them to no longer perceive themselves only as patients but as subjects able to live and develop regularly (Capurso, 2014). When working in these areas, it is necessary to define anew the meaning of the different educational processes, always trying to consider the boy in his entirety (Capurso, 2008a), giving him a positive reinforcement in terms of school performance (Boles et al., 2017). In the literature, ample space has been given to post-disease school integration programmes, trying to limit as much as possible the barriers that these young people may encounter due to the long marginalization (Hen, 2022). The same thing, unfortunately, cannot be said about the empirical research that, to date, is very lacking on programs that can reduce the feeling of inadequacy that the disease creates in patients (Stage, 2022).

2   Psychophysical changes associated with oncological diseases

Chronic diseases represent a criticality of the first order in the world and, although the purely clinical front is the primary subject of discussion and intervention, the educational aspect related to long-term hospitalization has not been treated with the same attention over time. Among chronic diseases, oncological ones are among

the most problematic, especially in relation to the numerous negative outcomes and the direct or indirect relapses of treatment (Sung et al., 2021; Berríos-Rivera et al., 2008). Cancer can cause particularly noticeable physical changes and negatively affect the patient's perception of his body. In this sense, such alterations on the somatic plane manifest themselves with particularly serious effects on a psychological level (Pradhan et al., 2018; Fabbri & Romano, 2017). In particular, in the literature are reported effects of wide relevance regarding the onset of anxiety and depressive symptoms, as well as those concerning sleep disorders (Nunes et al., 2017). The most common body modifications are identified in hair loss, lymphedema, weight gain and skin irritation (Newhart et al., 2016). The presence of such problems is associated in the literature with an increase in levels of social isolation that contribute to aggravate the burden of a particularly complex educational path to manage both the patient and the teachers (Nijhof, et al., 2018). Therefore, it is of primary importance to structure educational strategies that enhance the role of the virtual presence of the boy in class going to implement the concept of telepresence. Cancer often causes significant physical changes, negatively impacting the patient's perception of their body image (Docherty et al., 2015; Grinyer, 2007). In the long term, many patients experience a wide spectrum of psychological issues that complement physical alterations. Such pathological deviations are concretized in the symptomatology of anxious and depressive nature and are often associated with the dysfunctional perception that the patient develops of his own body image (Kestler & LoBiondo, 2012; Brederecke et al., 2021). The latter can be defined as a multidimensional construct that includes thoughts, feelings and perceptions associated with one's own body (Larouche & Chin-Peuckert, 2006). This construct is the subject of psycho-oncology and is often analyzed in relation to irreversible changes in the body post-traumatic or resulting in long and burdensome treatments (e.g. chemotherapy and radiation therapy). In particular, in the case of oncological patients, there are changes related to: hair loss (Dua et al., 2017), lymphedema (Chien et al., 2020), skin irritations (Berríos-Rivera, 2008), changes in weight (Nunes et al., 2017). These consequences have negative repercussions also on the social life of the patient with all the baggage of psychological alterations that this condition entails (Belpame et al., 2016). These assumptions are particularly relevant in the case of hospitalized children and adolescents, who experience a more marked imbalance in the perception of their own identity with the consequent development of coping strategies often dysfunctional that often aggravate the burden that young patients have to bear daily. The latter can result in a generic escape from the possibilities of interaction

with peers and a withdrawal from activities that require a high involvement in the first person, primarily the school (Docherty et al., 2015; Chen et al., 2015).

3   Social inclusion tools in the digital environment

Technological advances in recent decades have enabled the creation of tools to overcome geographical and cultural barriers that are particularly binding in the field of education. In fact, the digitalization of training processes presents interesting development prospects, aimed at structuring strategies that allow hospitalized children to feel normal and connected despite hospitalization (Scott et al., 2017). The achievement of these goals lies in the possibility offered to the children admitted to school and socially connected with the class despite their absence (Danske-Patienter, 2015), preserving the sense of belonging to it. In fact, if students do not feel this sense of closeness to the school community, they may in the future become reluctant to return (Celia et al., 2014). The use of technology offers many advantages that ensure young patients a continuation of the emotional bond with classmates and teachers, ensuring greater autonomy (choice of connection times) and thus facilitating socialization while hindering isolation, supporting hope for the future and preventing school dropouts or repeats. In this perspective, technologies can be an important facilitator and above all a valuable support (McCarthy et al., 2017). The school carried out in the hospital is an "element of normality" just where everything is confused and enormously uncertain (Kanitza, 2006 p. 37); and it is precisely here that it becomes necessary to build a collaboration between the different figures who participate together both in the educational and health care of the boy (Caso, 2015). The analysis of the dynamics of use of state-of-the-art technological systems, aimed at maintaining relations with the outside world, represents a research strand of primary importance, because, to date, one in two patients reports educational problems and relational problems with peers and this affects the quality of school resumption after long hospitalization (Maor & Mitchem, 2015). Through the application of new technologies, the role of children is made active with an increase in global personal autonomy (Leon et al., 2016). Through the concept of telepresence (Weibel et al., 2020) the distance is reduced and the long absence has a lesser impact on the lives of children allowing them to remain connected both socially and scholastically (Maor & Mitchem, 2020).

4   Virtual learning environments: the role of the avatar between school and hospital

The term telepresence is used to indicate those technologies that allow the user to establish a virtual presence in relation to a defined interaction target (Weibel et al. 2020).

The theoretical educational framework in which this project proposal fits belongs to the strand of collaborative learning and, in particular, of computer-supported collaborative learning (CSCL). Collaborative learning plays a fundamental role in building learning environments that promote the processes of self-regulation and individual development through the implementation of educational paths based on sharing and collective construction of knowledge (Peramunugamage et al., 2023). This teaching methodology is based on the mutual collaboration between all the actors that make up the microcosm of the class, of particular importance is the role of the teacher who acts both as a mediator of the interactions between students and as a dispenser of knowledge in a format that provides for the separation of knowledge in units manageable by all pupils in a shared way (Page et al., 2009; Peramunugamage et al., 2023). In this sense, the effectiveness of collaborative learning has been studied in different contexts, also comparing the teaching methods in presence and telematics (Wang et al., 2018). The latter have shown particular effectiveness in the paths that did not exclusively involve social interaction related to a specific learning task (informal socialization) (Page et al., 2009). Another important aspect to consider in this framework is the need to provide both synchronous and asynchronous learning modes in the online pathways. This is because it is necessary to provide students and teachers with immediate feedback on the learned knowledge, while ensuring some flexibility in the management of the educational process, mainly in the area of content analysis and the implementation of learning strategies in the field of collaborative learning are largely based on social interaction (Biasi et al., 2017; LeBlanc & Posner, 2022). The environment in which this interaction takes place plays a fundamental role in mediating the learning process and in this case we talk about virtual environments that provide the presence of a series of constituent elements that vary according to the type of digital infrastructure choice and method of delivery (e.g. blended or exclusively telematic). Among these elements, the presented work aims to focus on the virtual avatars that the user has the ability to create to interact in the learning environment. An avatar can be defined as the virtual representation of a subject who poses as an alter-ego in a digital environment, presenting more or less human-related characteristics. In particular, the avatar can present different levels of communicative accuracy that are mirrored in body language (Löllgen et al., 2022; Petrakou, 2010). These tools are particularly useful to increase students' involvement in educational activities by acting on the individual's motivation to

learn, becoming innovative pedagogical agents in a rapidly expanding technological society (Palecza, 2020). As for the treatment here, the avatar plays a leading role in mediating school training in hospital for long-term patients in oncology wards. In fact, many platforms allow you to customize your alter-ego at will. Such human-like avatars are particularly useful for creating a learning environment in which the hospitalized student can act in greater freedom, limiting the embarrassment related to the bodily changes that the subject experiences in these conditions (Wonggom et al., 2016). The potential of the avatar can be inscribed within the theoretical paradigm of Embodied Social Presence (ESP). In fact, the use of these tools allows to reproduce in virtual environments a communicative form through the elicitation of a sense of presence resulting from the perception of a body control (virtual)in order to reproduce the interaction in vivo as closely as possible while maintaining the student's cognitive involvement (Page et al., 2009; Yung-Hsiang et al., 2023). According to the model of Wang et al. (2016) to build an embodied virtual environment, it is necessary that all the components of the ESP are present both at the individual level, with the spatial perception of their avatar, and at the collective level, by developing a sense of closeness with other learners and teachers who may or may not use an avatar themselves. Finally, a last element that characterizes the ESP is the presence of a collaborative involvement in the activities that take place in the learning environment (basic structure of a collaborative virtual learning environment) (Löllgen et al., 2022; Yung-Hsiang et al., 2023). The aim of educational paths based on the principle of collaborative learning allows the class in its entirety to stimulate decision making processes. This educational methodology has particularly important implications in the context of telematic learning, in which learning spaces are dispersed and group activities are difficult to apply. In this sense, most educational platforms do not allow real-time interaction and, Above all, there are not the tools necessary for the implementation of collaborative paths and in which the teacher can be inserted and perform his function as a mediator of activities. On the basis of these assumptions, the project proposal presented involves the use of the Gather Town platform that allows the creation of its own avatar to be customized (while presenting some technical limitations in this regard) and in a virtual learning environment where students can actively act in different settings that simulate face to face interaction as likely as possible (Kogilathah et al., 2019; Yung-Hsiang et al., 2023; Tongpeth et al., 2018). This educational platform allows students to experience greater involvement in educational activities through real-world interaction with other users in a virtual environment that allows you to stimulate the motivation to learn in a highly stimulating and constantly changing context.

5   Materials and methods

The project proposal presented fits into this framework through the setting of an educational path inserted within a longitudinal research project conducted on a single case (16-year-old girl suffering from widespread glioma of the middle line). The experiment will be articulated over 3 months, in which two types of teaching will be carried out: one online in a simultaneous mediated avatar and one online simultaneously without the avatar. Before proceeding with the experimental procedure, a period of training in digital literacy will be organized for teachers and students, as well as a training for the use of digital platforms that will be used in the study paths mentioned. The theoretical framework within which this study takes place is that of collaborative learning and both teaching methodologies will be based on learning through the use of the class group as an educational tool. In fact, both teachers and learners will be trained in the use of concept maps and GitMind for their construction. Before proceeding with the experimental protocol will be organized a period of training in the field of digital literacy (digital use, digital collaboration, digital communication and digital content creation) for teachers and students, as well as training for the use of digital platforms that will be used in the mentioned study paths.

Students will be specifically trained in the following fields:
- Training in the use of concept maps.
- Basic principles of collaborative learning.
- Basic notions in digital literacy.
- Training in the use of the platforms (Zoom and Gather Town).
- GitMind usage training.

The protocol will be divided into three phases. The first will see the administration of the Questionnaire on Motivation and Learning Strategies (Moretti et al., 2018) for the evaluation of learning motivation, the Scale of perceived school self-efficacy (Pastorelli & Picconi, 2001), of the Beck Depression Inventory (Beck et al., 2014) for the evaluation of depressive symptomatology, of the STAI-Y (Franceschina et al., 2004) for the evaluation of state and trait anxiety, of the Body Image Scale (Chieli et al., 2016) and of the Rosemberg self-esteem Scale (Prezza et al. 1994). The median phase will consist in the implementation of the learning path conducted through the use of concept maps by the teacher and students in shared mode. During this phase, students must engage in the construction of concept maps for each lesson being studied, both individually and collectively. In this sense, teaching will be carried out both through the Zoom platform and through Gather Town,

therefore building avatars and customizing learning spaces. In the final phase, the administration of the previously mentioned tests will be repeated and the knowledge learned during the course of the study will be evaluated.

Discussion

The goal of the project is to analyze the effects of using the avatar in mediating learning processes. In this sense, the use of collaborative techniques is expected to reduce levels of anxiety and depression in the patient and increase levels of learning motivation, self-esteem and self-esteem. Ultimately, the aim of the project is to reduce the gap between the hospitalized patient and the class group. Analyzing the differential effects on the two domains mentioned, it is possible to summarize the main consequences at the educational level, with an emphasis on the high fragmentation of training during the school year, which results in a series of difficulties regarding post-disease integration and a progressive impoverishment of the friendly relations with classmates (Capurso, M., & Dennis, J. L., 2017; Csinády, R., 2015). On the other hand, as regards the psycho-social plan, the long hospitalization has as immediate consequence a negative impact on self-esteem levels, which is often accompanied by a marked difficulty in the strategies of emotional regulation and in the alterations of the learning processes, involving in this sense both the cognitive and the affective components (Fabbri & Romano, 2017).

The intervention policies useful for the inclusion of hospitalized children in the school context are characterized, within the Italian panorama, by a remarkable bias in terms of rational and fragmented interventions on the territory. In fact, only the most advanced healthcare structures can afford to implement strategies based on the integration within the hospital framework of training strategies that promote triadic collaboration between hospitals, school and family, through the application of educational paths that ensure a certain school continuity in respect of individual needs. Obviously, this objective requires the complementary work of several specialised figures belonging to the school and health care staff who make use of the technologies available in this context.

Conclusions

Despite the growth of young people with chronic health conditions, the education sector has not responded promptly to the increasing demands of these students (Pufpaff et al., 2015). It is a shared opinion that these children deserve specialized

help in the field of education despite the fact that to date research is lacking in proposing effective interventions (Rogers & Johnson, 2018). Future research should investigate the two aspects in comparison, namely children with chronic diseases studying at a distance and those studying through the use of technology in order to find methods that can help reduce educational disparities. However, the use of technological tools in teaching sick students can be hampered by various reasons, not least the skills needed to use them effectively (Benigno et al., 2017). It is no longer conceivable today that there is a lack of awareness that both advanced technologies and advances in teaching can enable students with serious health problems to have the same learning opportunities wherever they are in the world. In order to avoid, in the long term, negative psychological and social repercussions, the school services provided must adapt to the needs dictated by the sensitivity inherent in the context in question (Pradhan et al., 2018). Providing good educational services entails the improvement of both present and future social life and, of course, this is worth every effort. One of the most burning issues for the near future is represented by ethics in the use of advanced technologies, as we cannot but confront its many impacts. New technologies are changing our lives, and while these changes can often be highly beneficial, they can expose people to risks that are not even known to exist (Borenstein & Howard, 2021).

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