Supporting Social Inclusion for Children with Hemophilia by Video Gaming

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ABSTRACT

Hemophilia poses a paradox: if physical activity is recommended for children with hemophilia for the sake of their health and to promote social inclusion, teachers, peers and sometimes parents are reluctant to involve them in physical activity at school. To support physical activity and sports for children with hemophilia, we created a video game called "HEMO-GAME" (https://hemogame.itch.io/play). This paper is aiming to present a quasi-experimental study to assess if the use of this video game has impacts on social inclusion for children with hemophilia. To assess social inclusion of twelve children with hemophilia recruited in this pilot study, two complementary tools have been used: The Playground Observation of Peer Engagement scale (POPE) and the coding social network centrality scale. Results show that successful initiations and positives responses for the child with hemophilia increase significantly in the classrooms where our video game HEMO-GAME has been used, while these indicators remain stable for the child with hemophilia in the classrooms where no specific educational intervention has been introduced. Moreover, social network centrality has two different ways: In the classrooms where our video game HEMO-GAME has been used, the child with hemophilia is more and more connected with his peers; In the classrooms where no specific educational intervention have been introduced, the child with hemophilia has always peripheral and moderate connections with his peers. Finally, the main objective of our work is to influence the mental representation of parents, peers and teachers regarding the importance of physical activity and sports at school for hemophiliacs by using a specific video game, to support social inclusion of children with specific needs. So the use of our video game called HEMO-GAME seems to have positive and significant impact on social interactions between children with hemophilia and their peers.

*Both authors contributed equally to this research.

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CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in HCI**.

KEYWORDS

Human computer interaction (HCI), User studies, Empirical studies in HCI

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1 INTRODUCTION

Approximately 300 million people around the world are living with a rare disease. A disease is considered rare if it affects fewer than, or equal to, 5 in 10 000 people, rare disease including some of the most serious of all illnesses and impacts millions of patients worldwide. More than 295,000 people have been identified with bleeding disorders worldwide, the majority being hemophiliacs (257 000; data from the World Federation of Hemophilia, 2022). Hemophilia is a rare disease and is an inherited bleeding disorder caused by abnormalities in the genes for factor VIII (FVIII) or factor IX (FIX). Hemophilia poses a paradox: Physical activity is recommended for children with hemophilia for the sake of their health and to promote social inclusion, but teachers, peers and sometimes parents are reluctant to involve them in sports at school.

One of the main problems is that children with hemophilia have difficulties describing their conditions, the activities they can or cannot practice, and the cause of their concerns. Physical or functional limitations can make young children with hemophilia feel shy and embarrassed or lead them to be teased by others. It should not be not necessary for children with hemophilia or their teachers to make a special point of telling the class about the disease every year, but it is important for children with hemophilia to be able to explain their bruises or health factors that may cause them to miss school occasionally. Therefore psychosocial support is an important part of comprehensive care for people with hemophilia. Beyond the medical condition, these individuals commonly face a number of psychosocial challenges.

1.1 Social Inclusion of Children with Hemophilia by Physical Activity

The care of children with haemophilia has been greatly improved in most countries in the last decades due to the availability of factor VIII (FVIII) and IX (FIX) concentrates [27] [3] [22] [20]. But the consequences of hemophilia is not only physical [28] because the consequences of hemophilia can affect a broad range of social and academic activities among school-aged children [12]. For instance, the effect of hemophilia on academic achievement also has been of interest to a number of investigators. Frequent absences from school, such as those experienced by children with chronic diseases, can interfere with the academic and social development of children [32] [26]. Several reports in the literature document higher rates of school absenteeism in children with hemophilia than in others [23] [33] [25] and discrepancies between children's potential and achievement as they progress through the upper grades [6]. In the same way and more recently, some studies have investigated the impacts of hemophilia on family [9]. The impact of hemophilia, or any chronic disease, on a young child (i.e., aged <11 years) is not an isolated impact. It is generally understood that the ability of a family to adapt and cope with a child with a chronic illness is associated with the health outcomes for the child, a concept that has been well studied in other conditions such cancer [30] and asthma [21].

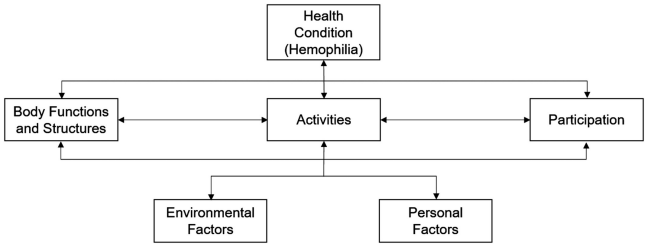

Figure 1: Relationships between health conditions of people with hemophilia and contextual factors, both personal and environmental, according to [5].

Today, physicians and professionals are agree that participation in sport helps children with hemophilia to develop skills, strength, endurance, and agility, vital for healthy physical development. Understandably, parents are concerned about the risk of injury but it is essential that children with hemophilia learn what they can and cannot physically do. If a child is forbidden to participate in a sport he or she wants to play, there is a good chance that he or she will play it anyway without the parents' knowledge. In other words, it has been demonstrated clearly throughout the scientific literature that sports and physical activity for those with hemophilia are recommended [8] because links between physical activity and social inclusion are very strong (Figure 1; [5]). And finally, several results support that exercise and sports improve the physical aspects of the children with hemophilia as well as the psychosocial aspects [8]. Their better social interaction assists them in creating a better image of themselves and the ability to control their disease. If teachers in primary schools are not always comfortable educating pupils with bleeding disorders or allowing them to participate in sports, their reluctance may be related to a lack of knowledge about hemophilia. Caution and injury prevention are important for people with hemophilia; However, it is important to distinguish between injury prevention and overprotection.

Whatever the child, sports and physical activity are necessary for his/her development, from a physical and psychological point of view because they contribute also to social inclusion [10][1]. Social participation of children with hemophilia is an ancient research topic. Several studies have demonstrated the positive benefits of sports activities in children with hemophilia in terms of both physical and psychological wellness [24]. Whatever the child, sports and physical activity are necessary for his/her development, from a physical and psychological point of view because they contribute also to social inclusion [10][1]. Social participation of children with hemophilia is an ancient research topic [5]. Several studies have demonstrated the positive benefits of sports activities in children with hemophilia in terms of both physical and psychological wellness [24]. Sports and physical activity is necessary for children with hemophilia to preserve joints' range of motion, reduce joint bleeding, improve muscle mass and strength, enhance proprioception and prevent secondary chronic diseases (i.e., cardiovascular disease, diabetes, cancer) [13] [29]. To prevent joint and muscle bleeding, parents put their children with hemophilia through various exercise programs [7]. Muscle atrophy, instability and restriction of motion are the first visible signs of sedentarism [6], whereas early subclinical symptoms such as tender ligaments are found even in clinically healthy young people [11]. This leads to a lack of physical activity and exercise that results in a poor physical condition with diminished muscle strength, aerobic/anaerobic power, proprioception and flexibility [31]. Furthermore, sports and physical activity can improve bone mineral density, which is lower in children with hemophilia than in healthy peers [15]. In the past, because of bleeding risk, sports activity was discouraged in children with chronic disease [9]. However, nowadays, due to new improvements in medical treatment, the participation of children with hemophilia in sport has improved [13] [34].

In other words, such a proposal implies the following educational and formative purposes: - to enable pupils with hemophilia to come into closer contact with their body; - to gain a better body coordination and a more effective ability to move in an adapted context - to promote socialization in order to build an interacting group. The physical activity stimulates growth through relationship in the group, and also the educational value and the learning opportunities that occur within it

1.2 The Use of Video Game for Children with Hemophilia

If there are a lot of video games existing for rare diseases to help manage pain, boredom, anxiety, sadness, and cognitive impairment [14] [2], very few video games have been created for people with hemophilia. We can distinguish two kinds of video games in relation to rare diseases:

- Video games dedicated for professionals and physicians. For instance, SUPER-HEMO is a game to help health students better understand hematology - a discipline often perceived as difficult by students -, notably through the interpretation

of the blood count. Indeed, the hemogram (or CBC) constitutes one of the most prescribed biological tests, because it is indicated both in the diagnosis and monitoring of numerous pathologies as well as to assess the general state of health of a patient;

- Video games dedicated for the patients. For instance, HEMOCRAFT was created by Pfizer in partnership with the Entrepreneurial Game Studio at Drexel University and representatives from the hemophilia community. This video game aims to help younger individuals with hemophilia, 8-16 years of age, learn the importance of integrating treatment into their routine in an educational and fun gaming environment. In HEMOCRAFT, players go on a quest and interact with the village doctor–a fictional health care professional character–to learn how to stick to their treatment plan, stay prepared, and understand how treatment works. Throughout the game, players are challenged to monitor factor levels and self-infuse to help control bleeding, if needed;

These two video games are absolutely relevant for their audiences who are adults (i.e., medical students for SUPER-HEMO and adults patients for HEMOCRAFT), with a specialized vocabulary for experts and a series of complex activities and a complex gameplay. So to our knowledge and after an extensive analyses of the scientific literature, there is no video game dedicated to young children with hemophilia. It is the reason why we proposed an innovative video game.

1.3 Our Video Game HEMO-GAME

HEMO-GAME is a proof of concept for a serious game designed to facilitate the social integration of children with hemophilia [16]. A prototype can be tested by using this link: https://hemogame.itch.io/play. It is not aimed at carriers of the disease, but at the school environment, such as pupils in a class, teachers, and administration. It is designed for use in the classroom, either individually or in groups. The child with hemophilia is sometimes the protagonist, and sometimes an element of the game. The scenario is based on a typical day in the life of a secondary school student. It was originally intended to start with the child going to school and end with the child returning home. Depending on the situation, the behavior of the other students, and whether or not they take part in the various activities, the child with hemophilia will see his "physical" and "moral" levels change. In our video game HEMO-GAME, three scenes have been developed, each scene highlighting three different high-risk situations and activities:

- Sport Lesson (Figure 3. Risks: shocks, blows). In this scenario, the teacher introduces the activity of the day. The class decides to include the child with hemophilia in the sports activity. If the child is excluded, his/her morale and physical condition will decrease. The class organizes the playing area, chooses the balls, and starts warming up by throwing the ball. During the activity, children with hemophilia can be injured, for example, by a ball hitting the face and causing a nosebleed. The players are given several suggestions on how to behave. Four suggestions are shown, ranging from 'tilt your head back' to 'call the fire brigade'. The choice of behavior will change the moral and physical scales of the sick child.
- Recess (Figure 4. Risks: falls, shocks). In this scenario related to a life science lesson, the child with hemophilia is in the playground with his/her classmates. The bell tells them to go to their classrooms. They have a limited time and must cross the playground as quickly as possible to avoid being punished. The course is a labyrinth with many obstacles. Here too, in the event of injury, they are given suggestions on how to behave ("call a teacher", "go to the infirmary", etc.).
- Science lesson (Figure 5. Risks: cuts). In this scenario, the teacher presents the day's lesson about life science, which is the dissection of flowers. The work is done in pairs and the child with hemophilia chooses another pupil (i.e., a peer) from the class to work with him/her. The reward is inversely proportional to the academic level of the chosen pupil. Depending on the physical and moral condition of the pupil with hemophilia, some peers cannot be chosen. The activity takes place in two stages. First, the child with hemophilia holds the flowers and the pair cuts them with the chosen tools (scalpel, scissors, etc.). In the second stage, the child with hemophilia makes the cuts and his/her partner holds the flowers. Again, if the child with hemophilia is injured, several behavior suggestions are shown on the screen.

These three different scenes are designed to teach the children in a class the limits of what a child with hemophilia can do and how to act in situations of problems to reduce the social exclusion of a child with hemophilia. The game was created using the Unity development environment and the CSharp language. The 3D modeling, camera management, and light sources were created by using Blender and then exported to FBX format in Unity. A prototype of the video game called HEMO-GAME exists and can be tested her: https://hemogame.itch.io/play.

1.4 Main Objectives

This paper is aiming to describe a 10 week intervention with our game-based learning activities using our video game HEMO-GAME with the following main question: What are the impacts on social inclusion for children with hemophilia? Control schools have been included in the study to compare results.

2 METHOD

2.1 Participants

We conducted a quasi-experimental pre-posttest school-based intervention study, quasi-experimental design being the most relevant method for evaluating the effects of educational interventions, programs, or policies.

Our study compared, in twelve French elementary schools, pre and post differences about social inclusion of twelve children with hemophilia (mean age = 7.5 years-old, SD = 0.8 months). For six children, there is no specific educational intervention ("Without HEMO-GAME"); For the other six children, the teachers and the peers were asked to use our video game HEMO-GAME during 10 weeks. Among our twelve children with hemophilia, 10 were with hemophilia A which is this is the most common type of hemophilia

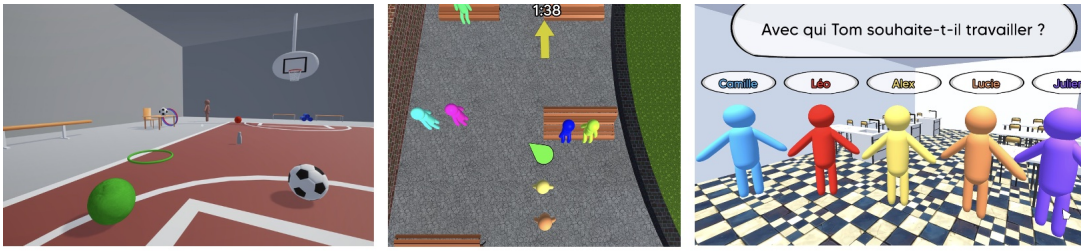

Figure 2: Screenshots extracted from HEMO-GAME for the sport course (left), recess activity in the playground (middle), and in the life science course (right).

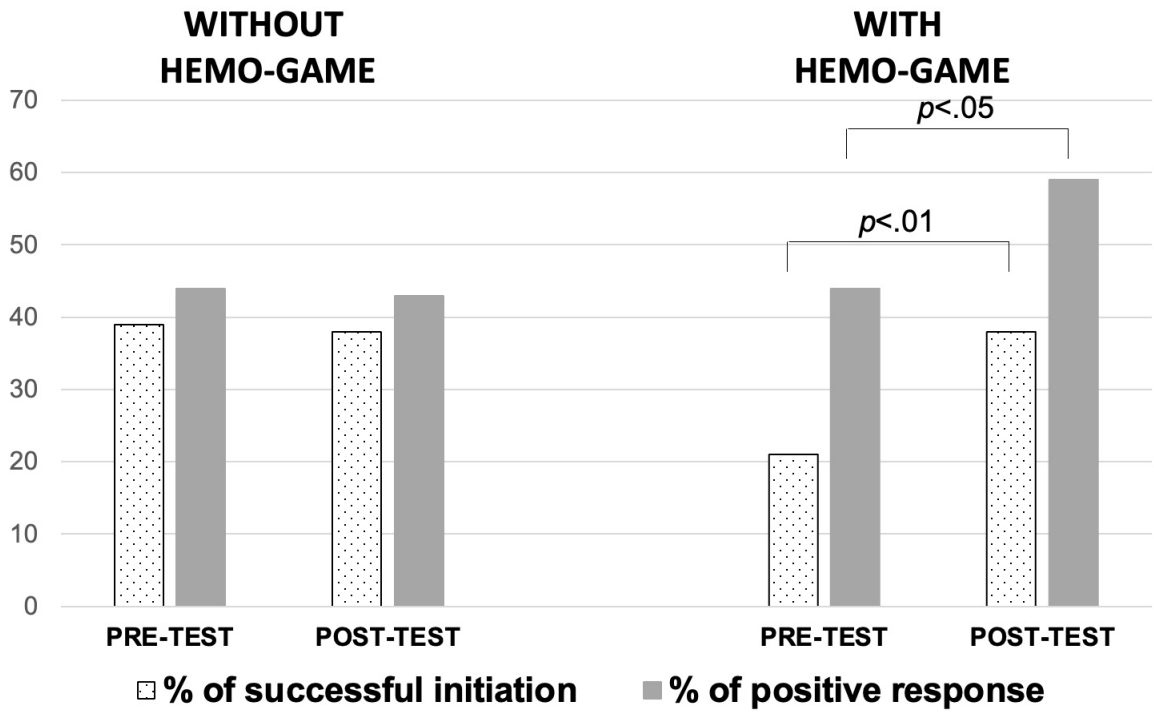

Figure 3: Evolution, after 10 weeks, of social interaction for the twelve children with hemophilia, assessed by using the POPE scale: Top = Without HEMO-GAME; Bottom = With HEMO-GAME.

(related to factor VIII). And 2 children were with hemophilia B (related to factor IX).

2.2 Procedure and Design

To assess social inclusion of our twelve children with hemophilia, two complementary tools have been used: The Playground Observation of Peer Engagement scale (POPE) and the coding social network centrality scale (see below). In the classrooms "Without HEMO-GAME", no specific educational intervention has been introduced. In the classrooms "With HEMO-GAME", the teacher has been encouraged to use the video game HEMO-GAME two or three times a week, with each session involving 4 or 5 pupils (https://hemogame.itch.io/play).

2.2.1 Playground Observation of Peer Engagement. . The Playground Observation of Peer Engagement (POPE) is a timed-interval behavior-coding system. Independent, blinded observers rated children on the playground for 40 consecutive seconds and then coded for 20 s during the recess or lunch play period [17]. Observers were trained in vivo by one of the developers of the POPE and considered reliable with a criterion alpha > 0.80. Reliability was collected on 20% of sessions during the study with an average percent agreement score of 0.87 with a range from 0.82 to 0.93. Playground engagement states were expressed as the percentage

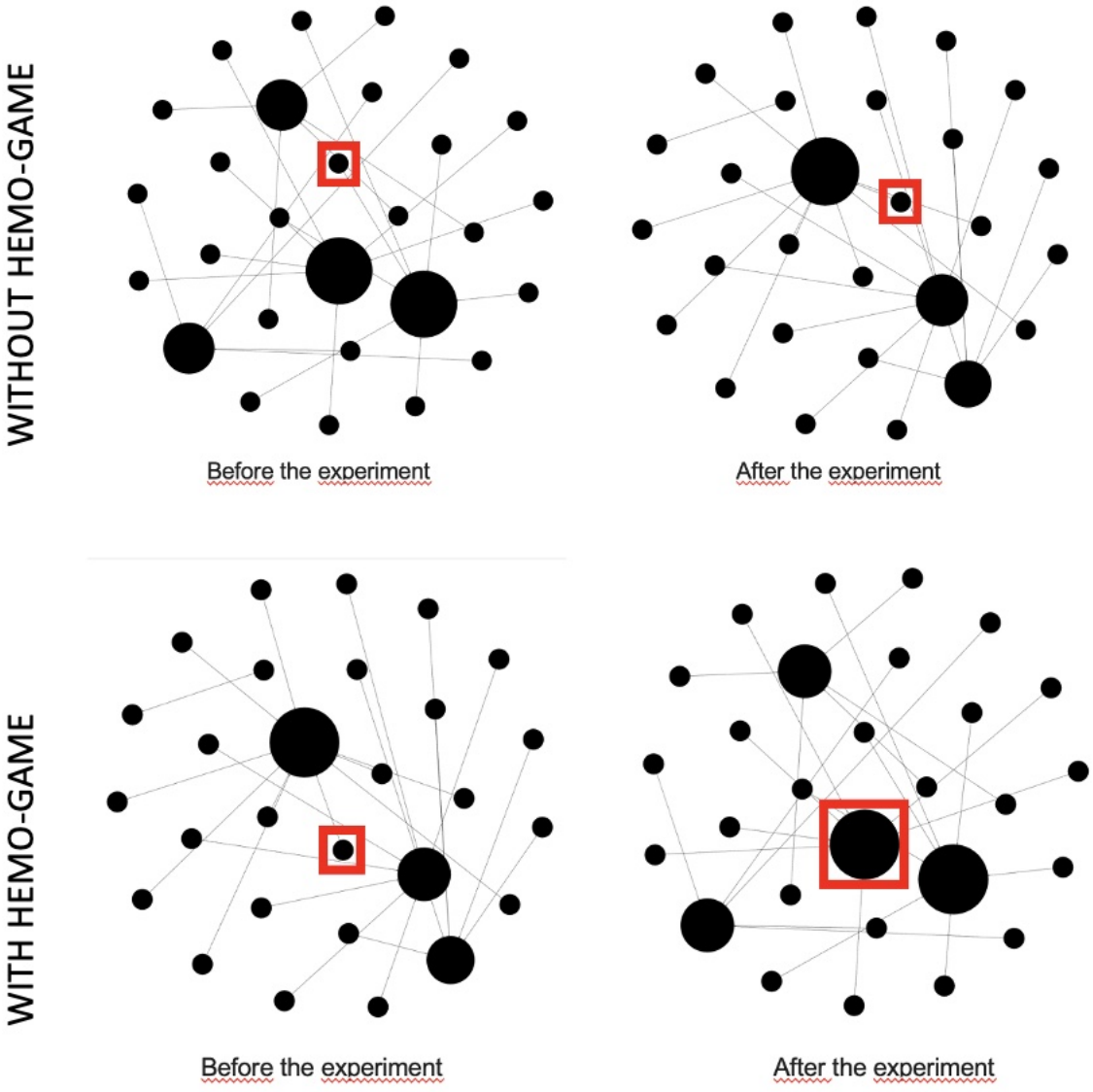

Figure 4: Social network centrality for the twelve children with hemophilia (in the red square), before and after ou experiment; Top = Without HEMO-GAME; Bottom = With HEMO-GAME. Data are based on Gephi 0.8.2 beta, and the layout algorithm Fruchterman-Reingold for the visualisation.

of intervals children spent in solitary play (i.e., unengaged with others) and jointly engaged with others (i.e., turn-taking in a game or reciprocal engagement in conversations or joint activities). In addition, coders noted two types of initiations toward other children. First, observers coded successful initiations to peers where the target child directed nonverbal or verbal communication to a peer or group of peers who then responded with a nonverbal gesture (e.g. head nod/shake, follows the child, laughs, etc.) or verbal language. Second, observers rated children's unsuccessful initiations where the target child directed communication to a peer/peers and there was no verbal or nonverbal response. Coders also noted two types of responses to others including the target child's appropriate responses to a peer's initiation (e.g., a peer asks, 'how are you?' and the child says, 'fine') as well as missed responses to a peer's initiation (e.g., a peer asks the child, 'how are you?' and the child does not respond). Six variables were computed and used for analysis (Figure 5): successful initiation rate (successful initiations/total length of time observed), total initiation rate (total initiations/total length of time observed), percentage of successful initiations (successful initiations/total initiations), positive response rate (positive response/total length of time observed), response rate

(total responses/total length of time observed), and percentage of positive responses (positive response/total opportunities).

2.2.2 Coding social network centrality. . Social network centrality refers to the prominence of each individual in the overall classroom social structure [4][18][19]. A series of social network analyses were conducted to obtain each child's social network centrality score following the procedures outlined by Cairns and Cairns (1994). Four categories of social network centrality were generated: isolate (no social connections in the classroom), peripheral (children in the bottom 30% of social connections in the classroom), secondary (children in the middle 40% of social connections in the classroom), and nuclear (children in the top 30% of social connections in the classroom). In our study, the main program used was Gephi 0.8.2 beta (Gephi Consortium 2014), an interactive visualization and exploration platform for all kinds of networks and complex systems, dynamic and hierarchical graphs. As layout algorithm in Gephi, Fruchterman-Reingold was used (Figure 6).

2.3 Ethics

All adults' participants provided written informed consent for their participation in this study, and all legal parents of children provided the same informed consent. Moreover, the responsible of the school provided also her consent. Before providing the written consent, all adults' participants, legal parents of children and the director of the school where the research has been conducted received the same information relating to the following points: A statement that participation is voluntary and that refusal to participate will not result in any consequences or any loss of benefits that the person is otherwise entitled to receive; The precise purpose of the research; The procedure and material involved in the research; Benefits of the research to society and possibly to the individual human subject; Researchers ensured that those participating in research will not be caused distress; Subjects' right to confidentiality and the right to withdraw from the study at any time without any consequences.

3 MAIN RESULTS AND DISCUSSION

As Figure 5 shows, successful initiations and positives responses for the child with hemophilia increase significantly in the classroom where our video game HEMO-GAME has been used (respectively: from 21% to 38% and from 44% to 59%), while these indicators remain stable for the child with hemophilia in the classroom where no specific educational intervention has been introduced (respectively: from 39% to 38% and from 44% to 44%). In other words, the use of our video game called HEMO-GAME seems to have positive and significant impact on social interactions between children with hemophilia and their peers.

Moreover, as Figure 6 shows, social network centrality has two different ways: In the classroom where our video game HEMO-GAME has been used, the child with hemophilia is more and more connected with his peers; In the classroom where no specific educational intervention has been introduced, the child with hemophilia has always peripheral and moderate connections with his peers.

Several limitations prevent to generalize our results. For instance, only twelve children with hemophilia participated in our study. Moreover, our study has been conducted in twelve different elementary schools. It could be relevant to control socio-demographics and educational characteristics in future studies. Be as it may, the preliminary results obtained in our quasi-experimental study show that successful initiations and positives responses for the children with hemophilia can increase significantly in the classroom where our video game HEMO-GAME is used.

Physical activity and exercise have many positive benefits for health and can improve self-esteem, learning, and inclusion in schools, and even if such activity holds particular risks for children with hemophilia, there are also particular benefits for them. Physical activity is almost as important from a psychological point of view, because it has positive benefits with respect to inclusion, self-esteem, and social relationships between peers. Finally, the main objective of our work is to influence the mental representation of parents, peers and teachers regarding the importance of physical activity and sports at school for hemophiliacs. It is sometimes easier for parents to deal with the diagnosis in families with a known history of hemophilia. However, there can be challenges, such as generational differences and new developments in understanding hemophilia and its management. Past generations of children with hemophilia who did not have access to factor therapy were discouraged or prevented from participating in sports or supportive activities, and were often overprotected and somewhat isolated. So future investigations are necessary to complete our own research to help social inclusion of children with specific needs.

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