

Development and evaluation of an interactive electronic game for the learning process of the treatment of children and adolescents with Duchenne muscular dystrophy*

Desenvolvimento e avaliação de jogo eletrônico interativo para o processo de aprendizagem do tratamento de crianças e adolescentes com distrofia muscular de Duchenne

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ABSTRACT: This paper aims to present the development and evaluation process of an interactive video game created to promote the construction of knowledge about the rehabilitation program of children and adolescents with Duchenne Muscular Dystrophy (DMD). The game content data collection was done by brainstorming with a multidisciplinary team of health professionals (physiotherapists and occupational therapists) and patients with DMD. Data were analyzed and separated into three categories: genetic, pathophysiology and stretching programs. This information was transformed into a storyboard and a team of engineers made the programming and implementation of the game. Lastly, the electronic game was tested by DMD patients by a pre-post-game questionnaire. The results showed an increase in the repertoire

related to rehabilitation after they played the game. The interactive electronic game DuchsVille was created, evaluated and was able to be used as a tool of information technology applicable to favor processes of teaching and learning about rehabilitation aspects of DMD, bringing the technical and scientific logic of health care providers closer to the logic of common sense of the population.

KEYWORDS: Muscular dystrophy, Duchenne/rehabilitation; Health education; Physical therapy specialty; Occupational therapy; Games, experimental.

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RESUMO: O trabalho visa a apresentar o processo de desenvolvimento e avaliação de um jogo eletrônico interativo

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Corrêa AGD, Klein NA, Savioni CC, Ficheman IK, Lopes RD. Desenvolvimento e avaliação do Jogo DuchsVille para apoiar o processo de aprendizagem nutricional: estudo de caso com adolescentes com distrofia muscular de Duchenne. *RENOTE. Rev Novas Tecnol Educ*. 2013;11:1-10.

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criado para favorecer a construção de conhecimento sobre o programa de reabilitação de crianças e adolescentes com Distrofia Muscular de Duchenne (DMD). A coleta de dados do conteúdo do jogo foi feita por *brainstorms* com equipe multidisciplinar de profissionais da saúde (fisioterapeutas e terapeutas ocupacionais) e pacientes com DMD. Os dados foram analisados e separados em três categorias: genética, fisiopatologia e programas de alongamento. Essas informações foram transformadas em um *storyboard*, e uma equipe de engenheiros fez a programação e execução do jogo. Por fim, o jogo eletrônico foi testado por pacientes com DMD por meio de um questionário pré-pós-jogo.

INTRODUCTION

The Duchenne muscular dystrophy (DMD) is an inherited disease characterized by progressive and irreversible degeneration of the skeletal muscle, resulting in a generalized muscle weakness as a result of mutation of the Xp21 chromosome, a factor limiting the production of dystrophin, a protein which is essential for the function of striated muscle^{1,2}. It is a recessive inheritance pathology that affects males with an incidence of 1 in 3,500 live births².

The first symptoms of DMD are initiated from the age of three, when the symmetrical compromise of the pelvic girdle muscles reflects the difficulties that the child has to climb stairs, jump and run^{3,4}. Between 9 and 12 years, usually occurs the loss of walking ability, and the person starts to need a wheelchair³. From this stage, the greater compromise of respiratory capacity occurs⁴.

With all this clinical situation described, it is known that the person with DMD will progressively lose the ability to perform, independently, the activities of daily living (self-care, feeding, locomotion, etc.) and of practical life (community activities)^{2,4}. The families of these patients become responsible for many everyday tasks such as, for example, administer prescribed medications, perform breathing exercises and muscle stretching, insert and remove the orthoses for lower and upper limbs, correctly position the person in the wheelchair, perform the necessary transfers, connect and monitor ventilatory support devices⁵. Moreover, they must also follow the routine of care in rehabilitation centers, medical appointments, and periodic examinations⁶.

The approach to a complex disease, like DMD, requires effective communication for the transmission of information and health care. Since it is a chronic,

Os resultados demonstraram aumento no repertório relacionado à reabilitação após o jogo. O jogo eletrônico interativo DuchesVille foi criado, avaliado e pôde ser utilizado como uma ferramenta de tecnologia de informação aplicável para favorecer processos de ensino e aprendizagem sobre aspectos de reabilitação na DMD, aproximando a lógica técnico-científica dos profissionais da saúde da lógica do senso comum da população.

DESCRITORES: Distrofia muscular de Duchenne/reabilitação; Educação em saúde; Fisioterapia; Terapia Ocupacional; Jogos experimentais.

progressive disease and the first clinical signs are present from three years of age, counseling focused on a child patient is difficult. Therefore, at the first signs and symptoms and closing of diagnosis, all counseling actions including stimulation of genetic counseling are directed to the families of children with DMD^{3,6}.

From the age of six, it is interesting to think of teaching strategies concerning the DMD disease, to achieve greater understanding and adherence of the child in the treatment routine; however, some studies suggest that about 30–50% of people with DMD have some degree of cognitive impairment whose cause is not yet identified or conclusive. The reason is that the dystrophin protein is also found in the brain and its deficiency is associated with intellectual deficits^{7,8}, a factor that may further undermine the educational processes in health.

Although there are no representative data, it is known that there are many people with DMD still without assistance and others that are attended only on an outpatient system by the health care team. The time spent on care may not be sufficient to ensure that information about the disease and its management are transmitted across the whole interdisciplinary team involved^{9,10}. Thus, the creation of an interactive electronic game proposes to facilitate the teaching-learning of information about rehabilitation that must be adopted in daily life; added to the fact that the game is available on the Web, the interactive tool can reach a larger number of patients with DMD, their caregivers and family members throughout Brazil.

The video game was funded by the program to support projects in the final stage of technological development of technical support of the National Center for Assistive Technology – Studies and Research to prepare Implementation Proposal – CNPq process No. 48.6257/2007-0.

OBJECTIVES

Overall Objective: To present the process of development and evaluation of an interactive video game created to promote the construction of knowledge about the rehabilitation program for children and adolescents with DMD.

Specific Objectives: To identify the knowledge of professionals and patients about aspects related to rehabilitation in DMD; To address the transdisciplinarity; Allow the active participation of patients in the construction and review of Game.

METHODS

To develop this research, we followed the ethical aspects of Resolution 196/96 of the National Health Council (CNS), which regulates research involving human subjects. Research Ethics Committee of the Federal University of São Paulo, under number 0488/10. All participants signed an informed consent.

This is an exploratory prospective study, which lasted from December 2010 to December 2012, and the game DuchsVille was made available on the Web in January 2013.

Data collection for the creation of educational content

Seven rehabilitation professionals (physical and occupational therapists) participated in the collection of data, with minimum training of specialist or master of the Brazilian Association of Muscular Dystrophy (ABDIM) and at least two years of experience in the care of patients with DMD and ten patients with DMD from ABDIM, ambulatory patients and wheelchair users, literate (primary school to higher education) and aged between 11 and 29 years. A brainstorm – a tool for generating new ideas, concepts and solutions to solve specific problems and stimulate creative thinking – was conducted on which content related to the rehabilitation of patients with DMD would be important to be contained in the educational game. All speeches were recorded and transcribed into tables.

Data analysis for creation of educational content

Collected data were separated into four categories, namely, genetics, pathophysiology, stretching programs, and use of wheelchair and orthoses, because of the frequency of references to these in the speeches of professionals and patients interviewed.

Implementation of the electronic game

At this stage, the categorized content was transformed into a storyboard (drawings) by a team of two engineers, a designer student, and an occupational therapist. The illustrations were made with use of tablet Intuos PTK-440. For illustration and design of the drawings, Adobe Photoshop and Adobe Illustrator software were used, which enable exporting files in the format supported by Adobe Flash (TIF). Some vectors were exported in PNG, a format chosen due to supporting transparency.

The game was implemented with Adobe Flash CS5, which allows access through the Internet by use of a web browser with Flashplayer (version 10 or higher) installed. The game programming (linking the screens, animations, and user interactions) was created in the programming language ActionScript 3.0 (AS3), supported by Adobe Flash CS5.

Method of evaluation of the electronic game with DMD patients

Once developed and implemented, the game was tested directly with ten patients with DMD for a week; five wheelchair users and five ambulatory patients aged 11–29 years, literate or not, and who were not part of the initial brainstorm. A qualitative and quantitative illustrated questionnaire was applied to register the user's prior knowledge on aspects related to rehabilitation. Then, the user was invited to play and, at the end, the questionnaire was reapplied to assess whether the information was assimilated postgame. Some other information was also collected through Likert scale to assess issues related to aesthetics (contrast of colors, setting art, the main character), audio (vocalization, soundtracks, and sound effects), and usability (ease of interaction, simplicity of screens and memorization). Finally, the players were invited to opine freely on the perceptions of the game.

Method of evaluation of the electronic game with professionals

Evaluation of usability of the rehabilitation game was submitted to five professionals of engineering and two professionals of rehabilitation (physiotherapist and occupational therapist) using a semi-structured questionnaire based on heuristics of Nielsen¹¹, including visibility of the game state, simple and natural dialog, control and freedom of the user, minimizing the memorization load for the user, consistency and adherence

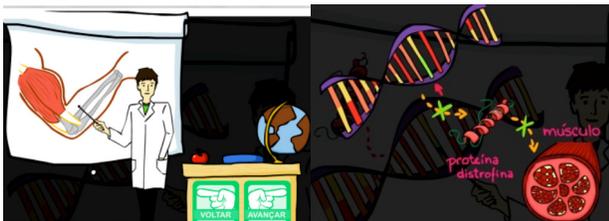
to standards, aesthetic and minimalist design, precise and constructive error messages, prevention of errors, help and documentation.

RESULTS

Development of the electronic game DuchsVille Rehabilitation

The video game was developed with collected and analyzed data from the four physiotherapists and three occupational therapists, with a mean of 5.4 years of experience in the care of patients with DMD and 10 patients with DMD, mean age of 17.1 years (11–29 years). The main character was “characterized” as a male teenager who can be ambulatory or wheelchair user, depending on the user’s choice; the therapist character is responsible for explanation of the pathophysiology of DMD; the dog illustration interacts and complements some information at various stages of the game.

The initial game animations explain about the origin, the cause and the main clinical symptom of DMD (Figures 1 and 2). In the next step, the user must choose whether to start the game with the ambulatory or wheelchair user character.



Figures 1 and 2 – Explanation on genetics, pathophysiology, and symptoms of DMD

Depending on the aforementioned user’s choice, in the first game the user must click on the main regions of the body that need to be primarily stretched with visual and auditory information, and in case all those that should receive interaction are hit correctly, the user passes to the second game.

The second game is Ortheses, in which the user is instructed on the importance of these rehabilitative devices, and the challenge is to fit them according to the need of the character – whether wheelchair user (Figure 3) or ambulatory patient (Figure 4) – to move to the third stage.



Figures 3 and 4 – Ortheses game settings

In the third and final game, the user moves through the setting of a house with six rooms and must find the hidden rehabilitation equipment (Figure 5). This game reinforces the learning about the use and care with ortheses which are part of daily routine.



Figure 5 – Messy house game setting

At the end of all stages, the user receives positive feedback in relation to stretching in the right areas, the proper fitting of ortheses, and being careful with the rehabilitation equipment. On the final screen, the player may leave his/her name registered and interact with other users.

Results from the impact of the learning process of patients with DMD - Pre and postgame test and qualitative perceptions

Comparative analysis of pre and postgame results related to the theme “stretching” demonstrated that wheelchair user patients had an increased repertoire of the areas in 62%, and 38% maintained the same repertoire. Regarding ambulatory patients evaluated for this same theme, 50% showed some increase in the previous content, 33% showed the same repertoire pre and postgame, and 17% could not be classified.

Analysis of results of the theme “ortheses” showed that 50% of wheelchair user participants had increased

postgame repertoire and 50% had no differences. Regarding the ambulatory patients evaluated, 33% showed increased postgame repertoire, 50% had the same answers pre and postgame, and 17% could not be classified.

As for the opinion of players regarding the game's aesthetics: 29% evaluated as excellent, 33% as very good, 26% as good, 9% as regular, and 2% as poor. As for the game's audio: 36% evaluated as excellent, 26% as very good, 33% as good, and 5% as regular. As for the game's usability: 40% evaluated as excellent, 18% as very good, 32% as good, 8% as regular, 2% as poor, and 2% as very poor.

Finally, the analysis of the ten qualitative speeches enabled the selection of key terms, and, of these, four central ideas were extracted, which had their frequencies calculated: 50% of the opinions were positive affirmations (general praise) related to the game, 50% of the answers were opinions related to the extent to which the game favors learning processes concerning DMD, 20% were opinions related to the increase in the repertoire of the participant, and 30% of the opinions were suggestions to improve the game in different aspects.

Results of the experts' evaluation (Adjustments carried out and Educational tool)

The analysis of the experts' opinions demonstrated various problems in the aspects of technology and usability, such as errors in the speed of animations, lack of option to repeat the sequences, difficult to access parts of the game or exit the game, and malfunction of access buttons.

The information above was added to the qualitative feedback from patients and the team implemented the corrections and adjustments to the software. The game was hosted on the Abdim website (www.abdim.org.br) and is available to the general public.

DISCUSSION

With the significant advances in education technology, new forms of teaching and learning processes have become possible¹². The interactivity of technology, as a transmitter of information, makes the user build his/her own knowledge using the computer/tablet/smartphone¹³.

In this same way, several studies try to prove the effectiveness of educational programs related to health via the Internet; however, one of the challenges is the reliable source of information¹⁴. Some studies demonstrated advantages in this type of educational technique, such as in rheumatoid arthritis¹⁵ in fibromyalgia^{14,16} and in amyotrophic lateral sclerosis¹⁷.

Use of electronic games via WEB as a mediator of learning for children and adolescents has been an emerging issue as a teaching strategy for health education processes¹⁸. Applicability of the games has a ludic and informative nature, provides human interaction¹⁹ and turns the participant into an active agent in the learning process²⁰.

Teaching children and adolescents about their disease is a major challenge. Since it is a progressive disease, the approach must be very careful²¹. In many developed countries, there are summer camps for children with muscular dystrophy²², and in Japan some specialized hospitals are collective housing for these patients, where they have social and educational activities directed to fighting the disease²³. In Brazil, there are no reports of these practices, and government health programs earmark no investment in education for neuromuscular diseases, with actions reduced to providing ventilatory equipment for life support and medications that have some efficacy²⁴.

The strategy of creating a video game to explain the Duchenne muscular dystrophy proved didactically interesting, since the pre and posttest analysis resulted in increased repertoire, except for the theme "orthoses" in ambulatory patients; this fact may be related to the stage of the disease in which they are, in which the use of orthoses for lower limbs is extremely encouraged by the rehabilitation team, due to preventing the evolution of muscle shortenings²⁵ and, thus, prolonging the ability to walk.

Analysis of the qualitative speech²⁶ of the patients about the game showed satisfaction and interest by them, and it can be a tool for this population to disseminate information and break paradigms concerning the Duchenne muscular dystrophy.

The whole process of creating the video game DuchsVille was conducted by the interdisciplinary team, and all implementation adjustments were based on the opinions of patients tested, bringing engineering and design students closer to the health professionals and to the target population.

CONCLUSION

The interactive electronic game DuchsVille was created, evaluated, and can be used as an information technology tool applicable to favor processes of teaching and learning about rehabilitation aspects in Duchenne muscular dystrophy, bringing the dialog of scientific and technical logic of health professionals closer to the common sense logic of the population.

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