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Alfa test of a gamified technology for children and adolescents in hemodialysis

Teste alfa de uma tecnologia gamificada para crianças e adolescentes em hemodiálise

Prueba alfa de una tecnología gamificada para niños y adolescentes en hemodiálisis

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ABSTRACT

Objective: to present the alpha test of a prototype of a gamified technology, the Nefro Hero®, focused on the Health-Related Quality of Life of pediatric patients on hemodialysis treatment. **Method:** a methodological, evaluative research, through the alpha test, with quantitative approach, carried out with eight patients on hemodialysis treatment aged between eight and 16 years. It was developed in four stages: first application of the DISABKIDS® HRQoL inventory; nine game sessions with the patients, individually, during the hemodialysis sessions; second application of the inventory; two brainstorming sessions. **Results:** between the first and second applications of the inventory, improvements were identified in the mental domain in the patients' HRQoL, indicating the potential of the primary function of the strategy. Points to be reviewed in the technology before the validation stage were raised. **Conclusion and Implications for Nursing**: as it is an alpha test, the results cannot be generalized, but they indicate the potential of the strategy. The article presents an evaluation stage prior to validation, fundamental to the development of game-format technologies and still little explored.

Keyword: quality of life; kidney dialysis; games and toys; child, adolescent.

RESUMO

Objetivo: apresentar o teste alfa do protótipo de uma tecnologia gamificada, o *Nefro Hero*®, com foco na Qualidade de Vida Relacionada à Saúde de pacientes pediátricos em tratamento hemodialítico. **Método**: pesquisa metodológica, avaliativa, por meio do teste alfa, com abordagem quantitativa, realizada com oito pacientes em tratamento hemodialítico com idades entre oito e 16 anos. Foi desenvolvida em quatro etapas: primeira aplicação do inventário de QVRS DISABKIDS®; nove sessões de jogo com os pacientes, individualmente, durante as sessões de hemodiálise; segunda aplicação do inventário; duas sessões de *brainstorming*. **Resultados:** entre a primeira e a segunda aplicações do inventário, foram identificadas melhorias no domínio mental na QVRS dos pacientes, indicando o potencial da função primária da estratégia. Foram levantados pontos para ser revistos na tecnologia antes da etapa de validação. **Conclusão e implicações para a Enfermagem:** por ser um teste alfa, os resultados não podem ser generalizados, mas indicam o potencial da estratégia. O artigo apresenta uma etapa de avaliação anterior à de validação, fundamental ao desenvolvimento de tecnologias em formato de jogos e ainda pouco explorada.

Palavras-chave: qualidade de vida; diálise renal; jogos e brinquedos; criança; adolescente.

RESUMEN

Objetivo: presentar la prueba alfa del prototipo de tecnología gamificada, *Nefro Hero*®, con foco en la Calidad de Vida Relacionada con la Salud en pacientes pediátricos en hemodiálisis. **Método:** investigación metodológica, evaluativa, mediante la prueba alfa, con abordaje cuantitativo, realizada con ocho pacientes en hemodiálisis con edades comprendidas entre los ocho y los 16 años. Se desarrolló en cuatro etapas: primera aplicación del inventario HRQL DISABKIDS®; nueve sesiones de juego con pacientes individualmente durante las sesiones de hemodiálisis; segunda aplicación del inventario; dos sesiones de *brainstorming*. **Resultados:** entre la primera y la segunda aplicación del inventario, se identificaron mejoras en el dominio mental de la CVRS de los pacientes, indicando el potencial de la función primaria de la estrategia. Se plantearon puntos para ser revisados en la tecnología antes de la etapa de validación. **Conclusión e implicaciones para Enfermería**: al tratarse de una prueba alfa, los resultados no pueden generalizarse, pero indican el potencial de la estrategia. El artículo presenta una etapa de evaluación previa a la validación, fundamental para el desarrollo de tecnologías de formatos de juego y aún poco explorada.

Palabras clave: calidad de vida; diálisis de riñón; juegos y joguetes; niño; adolescente.

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INTRODUCTION

Chronic Kidney Disease (CKD) is characterized by slow, progressive and irreversible loss of kidney function, which occurs with the destruction of the nephrons, functional units of the kidneys, which have no regenerative capacity. In its terminal phase, CKD presents, as one of the treatment modalities, hemodialysis, a renal function replacement therapy performed through an extracorporeal system connected to a vascular access[1].

CKD can affect individuals in various age groups, bringing significant changes in their Health-Related Quality of Life (HRQoL), considering its subjective and multidimensional nature. When it affects children and adolescents, besides its clinical severity, it affects an organism in the process of growth and biological, cognitive, social and emotional development, triggering a series of musculoskeletal dysfunctions, pubertal delay, malnutrition, increasing thirty to fifty times the mortality rate in this age group. The life expectancy of children and adolescents from zero to 14 years old who undergo hemodialysis is only 20 years[2,3].

Therefore, children and adolescents on hemodialysis demand assistance consistent with the specificities of their age group, which goes beyond care with the physical domain, being essential the development of strategies that seek to achieve social and emotional needs and thus contribute to their adaptive process in the face of limitations imposed by CKD and hemodialysis[4].

CKD requires, therefore, adaptation to changes and to the new lifestyle imposed by the pathology and treatment. Thus, this requirement goes back to Calista Roy's Adaptation Theory, which considers the attribution of Nursing in the process of adaptation of the individual for better health care and HRQOL. For Roy, the individual maintains continuous interaction with the environment, developing responses according to the stimuli they experience, so that when stimulated efficiently, they develop favorable responses that contribute to the improvement in their health status and, consequently, in their HRQoL[4].

One type of strategy that has been used successfully in the acquisition and modification of behaviors is gamification. This type of intervention strategy seeks to apply the fun and engaging elements of games to common real-life activities, generating motivation and engagement, contributing to favorable behavioral changes[5].

Regarding the aforementioned "game elements", there are different conceptions of what they would be in essence. There are definitions in which the games are characterized by the existence of goals, rules, feedback system, and voluntariness[6] and structural definitions in which they are characterized from dynamics, mechanics, and components[7]. These conceptions are complementary and can be used to characterize games like chess and poker, sports like soccer and volleyball, as well as electronic games in all their forms.

Thus, developing a gamified health intervention strategy involves identifying a demand and listing the behavioral aspects related to this demand that will be targeted by the intervention. From this, define the game elements to be used to increase or reduce the relevant behavioral patterns and then create the technology prototype. In this study, the prototype is characterized as a Care-Educational Technology (CET), because it is a product for professional practice with convergence between care and education[8].

The production of an CET involves steps that start with the creation of a prototype, go through the validation process, and then reach the stage of applying the final version[9]. When it comes to game-format CET, however, it is recommended that the validation stage be preceded by an alpha test that allows the evaluation of its playability while checking whether the prototype meets the objectives for which it was developed, contributing to the identification of points that can be reviewed and corrected before the validation stage[10].

Based on these premises, a prototype of a gamified CET was developed in the format of an analogical Role Playing Game (RPG), aimed at children and adolescents on hemodialysis treatment, with the main objective of improving their HRQoL. The game in question was called Nefro Hero®[11] and followed the core precepts of an RPG, which involve role-playing in interactive and participatory narratives while stimulating problem-solving and allowing reflections and recreations[12].

The game portrays - in a fantastical way and in a fantastic narrative - situations experienced by children and adolescents who undergo hemodialysis. The scenario represents a fantasy world composed of seven kingdoms that needed to be crossed; each of these kingdoms is related to a condition of adaptation, namely Kingdom of Troubled Waters - not getting the catheter dressing wet; Kingdom of the Desert - maintaining water restriction to avoid edema and intercurrences during treatment; Kingdom of Giants - having growth deficits, causing them to have smaller stature than their peers; Kingdom of Vertigo - having intercurrences and adverse effects from hemodialysis; Kingdom of Chips - keeping the hyposodium and restrictive diet; Kingdom of the Black Needles Swamp - going through painful procedures; Kingdom of Garbage - keeping hygiene care and prevention of infection from the venous access. The creation process, which interfaces with Calista Roy's Adaptation Theory, and the details of gameplay would be beyond the scope of this article, but can be found in the first author's dissertation[11].

This paper aims to present the alpha test of the prototype of a gamified technology, the Nefro Hero®, focused on the Health-Related Quality of Life of pediatric patients on hemodialysis treatment.

METHOD

This is a methodological, evaluative research with a quantitative approach. It was developed in four stages: first application of the DISABKIDS® HRQoL inventory; nine game sessions with patients, individually, during hemodialysis sessions; second application of the inventory; two brainstorming sessions.

With regard to the evaluative perspective, performed by means of the alpha test, repeated measures of the pre- and post-intervention type were used. In an alpha test of a game with applied purpose, the researcher must select one or more

variables that are expected to be affected by the game[10]. To meet this requirement, it was chosen to assess HRQoL. Repeated-measures designs are used, among other reasons, when there is a potentially low number of participants; in early studies for which there are not yet clear parameters; and in studies in which there is no pretension of data generalization[13], which is the case of this study.

In order to raise the less functional aspects of the game that would need to be modified before the validation stage, the brainstorming technique was used, in which a group of people with different perspectives needs to reach a common denominator for a given situation, seeking a solution together[14].

The research was conducted in the Pediatric Renal Replacement Therapy Sector of a reference hospital in Belém, Pará, Brazil, from March to May 2019. The site was chosen because it is the only pediatric hemodialysis sector in the metropolitan region of Belém.

The inclusion criteria for participants were: undergoing regular hemodialysis treatment at the institution for at least three months and being between eight and 18 incomplete years of age. The exclusion criterion was not being cognitively able to participate in the game. At the time of the survey, there were 23 patients in the sector, ten of whom did not meet the inclusion criteria. Among the remaining 13, two gave up on participation, one was transferred, one was discharged, and one died. Thus, the final sample was of eight participants, following a convenience sampling in which all members of the possible universe were considered as possible participants and all who agreed to participate and met the criteria were included.

In the first stage, we applied the HRQoL questionnaire DCGM-37 of the DISABKIDS® group, which consists of three domains distributed into 37 items, organized on a Likert scale. The scores for each domain range from six (minimum value) to 30 (maximum value); the higher the score, the less affected is the QL in the respective domain. The instrument has been translated and validated into Portuguese[15,16] and was used with the permission of the Brazilian representative of the DISABKIDS® group. The questionnaire was given to the children during a hemodialysis session and was self-applicable, being completed by the participants themselves, but with the help of the researchers at times of difficulty in understanding terms or premises. This step occurred in March 2019.

In the second stage, carried out in nine game sessions with the patients, individually, during hemodialysis sessions, the prototype of the Nefro Hero® gamified strategy was used. The eight children and adolescents selected used the Nefro Hero® game with the following items: three stickable avatar images chosen by the children themselves; 24 printed maps, including a world map, a map of the main village, and 22 "phases" distributed among the seven kingdoms; two ten-sided dice; a printed character sheet where their characteristics, evolution, and story progress were recorded; 49 miniatures of the villains in Medium Density Fiberboard (MDF); colored pencils; cubes and colored plastic cylinders.

The games occurred through adventures narrated by the researchers with each patient, in particular, during the hemodialysis sessions, and adaptations were made in the narrative to adapt it to the different age groups and particularities of each participant. Before starting the first game, the participants were explained the rules of the game, the materials that would be used, and were asked to choose their avatar and start filling out the character form. The records of this stage were made in a field diary in which observations and occurrences during the games were noted. Information regarding the behavior of the participants throughout the game, their mood while playing, as well as information about the environment, such as, for example, noises or interruptions that might jeopardize the participant's interest in the game, were grouped together. Each game lasted an average of 30 minutes. This stage occurred between the months of April and May 2019.

In the third stage, after the last game of each participant, the inventory was reapplied, following the same parameters of the application of the first stage.

In the fourth stage, the researchers organized two brainstorming sessions in order to: evaluate the gameplay; identify difficulties in the application of the game; raise points of greatest confusion for children, kingdoms, less interesting and attractive characters and elements, and other potentially negative aspects of the prototype. The researchers based themselves on their own experience as narrators of the adventures and on the field diary entries. The points mentioned by all the researchers were listed and a list of changes needed for the next version was elaborated. A summary of the four steps can be seen in the following flowchart (Figure 1):

For the analysis of the data obtained through the responses to the inventory before and after the educational intervention, the responses were organized in a database modeled in Microsoft Office Access® 2016. Statistical analysis was performed using GraphPad Prism 6.0® and Biostat 5.0®. The paired parametric t-student test was applied for the correlation of the scores obtained before and after the intervention. A 5% significance level was used. Since this is an alpha test, we do not intend to generalize the data, so that the analyses are not inferential but correlational, seeking to investigate whether any changes in scores after the intervention are significantly different from those found pre-intervention in order to assess whether these changes would be potentially correlated to the introduction of the game.

The research project was approved by the Ethics Committee of the University of the State of Pará under number 2.992.715 and by the Ethics Committee of the Santa Casa de Misericórdia Foundation of Pará under number 3.159.510. To comply with the ethical precepts, those responsible for the children and adolescents signed the Free and Informed Consent Term (FICT) and the minors signed the Free and Informed Consent Term.

RESULTS

The group of participants was composed of eight children and adolescents, five male (62.5%) and three female (37.5%), aged between eight and 16 years, with a mean of 12.25 years (SD= ± 2.71). As for the number of siblings, five (62.5%) participants

reported having one to two siblings. Regarding schooling, three (37.5%) did not study and five (62.5%) were in elementary school. Regarding the city of residence, three (37.5%) lived in Belém and five (62.5%) lived in cities in the interior of the state. Regarding venous access, four (50%) presented AVF and four (50%) presented CDL. Regarding the underlying pathology, four (50%) had, as a cause of CKD, congenital malformation.

Table 1 shows the results related to quality of life scores before and after the gamified educational intervention. Post-intervention scores increased in the mental domain, with a significant association in the emotional dimension.

In the mental domain, independence dimension, before the intervention, we obtained a mean score of 21.0 (the score in this dimension varies from 6 to 30, and values closer to 30 are considered "satisfactory"). In the post-intervention moment, the score was 24.5 (p = 0.0524). In the emotional dimension, the average pre-intervention score was 26.1 (the score in this dimension ranges from seven to 35, and values closer to 35 are

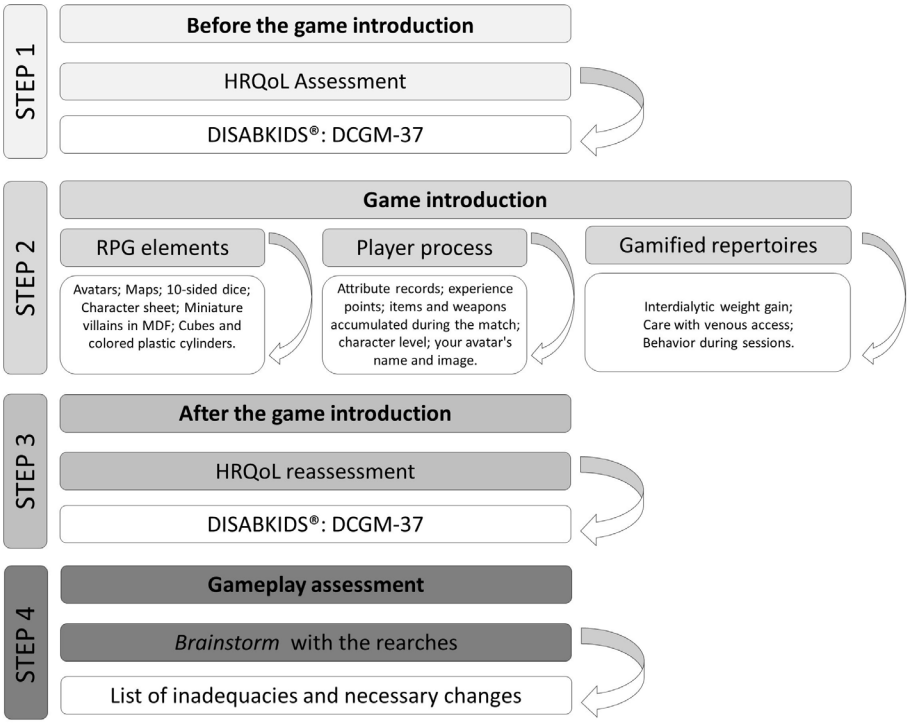

Figure 1. Flowchart with the method steps.
Source: Elaborated by the authors.

Table 1. Quality of life scores of participants in the pre and post stages of the gamified educational intervention. Belém, Pará, Brazil, 2019. (N=8)

Domain	Dimension	Before	After	Mean of diferences	95%CI Means diferences	p value[1]
Mental	Independence	21.0	24.5	3.5	(-0.05 a 7.05)	0.0524
	Emotional	26.1	28.8	2.6	(0.10 a 5.15)	0.0436
Social	Social inclusion	21.6	23.3	1.6	(-1.30 a 4.55)	0.2308
	Social exclusion	24.3	23.3	-1.0	(-4.16 a 2.16)	0.4786
Physical	Physical limitation	22.4	22.9	0.5	(-1.50 a 2.50)	0.5727
	Treatment	22.9	23.3	0.4	(-4.12 a 4.89)	0.8498

(1) Parametric paired Student's t-test (p value <0.05)

considered "satisfactory"). After the intervention, the score was 28.8 (p= 0.0436).

In the social domain, social inclusion dimension, before the intervention, the score was 21.6 (the score of this dimension varies from six to 30, and values close to 30 are considered "satisfactory"). After the intervention, the score was 23.3 (p=0.2308). In the social exclusion dimension, before the intervention the score was 24.3 (the score in this dimension varies from six to 30, and values closer to 30 are considered "satisfactory"). After the intervention, the score was 23.3 (p=0.4786).

In the physical domain, the physical limitation dimension presented a pre-intervention mean score of 22.4 (the score in this dimension varies from six to 30, and values closer to 30 are considered "satisfactory"). After the intervention, the score was 22.9 (p=0.5727). The treatment dimension had a pre-intervention mean score of 22.9 (the score in this dimension ranges from six to 30, and values closer to 30 are considered "satisfactory"). After the intervention, the score was 23.3 (p=0.8498).

In relation to the gameplay evaluation, the negative points listed by the researchers were organized into three axes: structural, mechanical, and components. As structural problems, the following were cited: the absence of a manual that could better guide the user; the extension of the age range, which required substantial adaptations in the narratives depending on the participant; and the existence of realms where the narrative did not maintain the expected parallel with the health/treatment situation of the participants. The problems related to mechanics focused mainly on elements with no clear function, including items, characters and attributes that had no impact on the narrative or character evolution. Regarding the components, the criticisms focused on the monotony in the narrative of some worlds (Garbage, Chips and Swamp) and the graphic presentation of the maps in general, which did not present a standardized size and style, and often did not follow the content of the narratives.

DISCUSSION

Studies on the epidemiological profile of children and adolescents with CKD are scarce, however, the profile of the study participants shows similarities with other studies conducted that also demonstrated the predominance of males and similar mean age and the cause of CKD[1-3,17]. A survey conducted in Belgium revealed that 59% of patients had congenital anomalies as the cause of CKD, a result very similar to this study in which 50% of the participants had the same underlying pathology[18].

As for the residence of the participants, 62.5% live in cities in the interior of the state, which reveals the need for frequent travel of the patient and his family for the hemodialysis sessions and other procedures necessary for the treatment, making the treatment tiring and exhausting[1-3].

As for the schooling of the participants, it was observed that 37.5% of them were not attending school at the time of the survey. This points to the interruption of school life, one of the implications that hemodialysis treatment brings to the lives of children and adolescents, because the frequent routine of procedures that they are submitted to and the schedule of hemodialysis sessions prevent them from maintaining their normal routine, such as going to school or participating in other social activities[1-3,17].

Regarding the impacts of the game on the participants' HRQoL, positive results were found in the mental domain - which corresponds to the independence and emotional dimensions - which presented the best post-intervention scores, which is consistent with the focus of the game, which were aspects related to self-perception and the strengthening of resilience. The emotional dimension is related to emotional concerns and feelings. Independence, on the other hand, refers to the autonomy the individual feels in relation to his activities and treatment. The results found in this domain, with a significant association in the emotional dimension, reinforce the notion that individuals are adaptable and that, when stimulated, they can reveal favorable behaviors[4,6].

The positive change described above can be explained by the effect of gamification, which is able to make the individual add, to the real context, the characteristics that the player presents when playing, such as optimism and determination, reiterating one of the expected functions of gamification and games in applied contexts[5-7].

As for the physical domain, there was no significant improvement with the intervention. This domain is composed of the limitation dimension, which focuses on the functional limitations felt by patients in relation to their pathology and treatment, and the treatment dimension, which addresses questions about the emotional impact related to the multiple invasive and painful treatments and procedures experienced by children and adolescents.

The changes concerning the domain limitation were addressed in one of the realms, bringing sensitive points such as the effects felt during hemodialysis intercurrences. When considering that this domain was not affected by the game, the researchers, during the brainstorming stage, considered this as one of the weaknesses of the game to be corrected for the next version.

The game brought, in its narrative, points focused on the resignification of negative experiences of the participants in relation to their treatment - which includes better acceptance and resilience towards the need to use injectable drugs and multiple venous punctures that are part of the treatment. Again, the researchers considered that this is an aspect that needs to be further developed, including more reinforcing narratives in which analogous procedures in the game can bring greater benefits and the development of adventures more directed to this dimension.

Regarding the social domain, the social inclusion dimension addresses issues related to children and adolescents in being part of a group and being accepted by their peers. The social exclusion dimension, which showed a worsening in the post-intervention score, refers to the stigma and feeling of exclusion from society felt by patients, which may be related to the presence of vascular access and the physical changes caused by the disease. Other studies on the HRQoL of children and adolescents on hemodialysis have revealed that the low adaptation to limitations related to the pathology and the treatment are caused mainly by feelings such

as shame and discrimination, triggered by physical changes, such as short stature and the presence of vascular access, which make children/adolescents feel different from their peers[11,15,16].

This domain did not show statistically significant improvement, probably because the game contains few elements of socialization, with interaction only between the player and the narrator, represented by the researcher. As the game sessions take place during the hemodialysis sessions, collective games with two or more players are not feasible, so this weakness identified in the alpha test has not been solved yet.

The different maps produced for the game emphasized the challenges of adaptation of children and adolescents to treatment. Studies on the difficulties of acceptance of hemodialysis indicated that the main difficulties faced by this public are related to adherence to diet, water restriction imposed by the disease, and having to experience frequent therapeutic interventions, which prevents them from enjoying a routine common in this phase of life[2,11].

The assessment of HRQoL scores allowed us to evaluate Nefro Hero® in terms of its potential to intervene in the motivation and resilience of children and adolescents to adhere to hemodialysis treatment and, consequently, to develop positive responses in their perception of HRQoL. The alpha test was also important to evaluate the suitability of gameplay and the time previously set for the games, points that are not evaluated in the validation process.

The brainstorming raised the points considered necessary for change in various aspects of the game related to gameplay, revealed the need for the formulation of an instruction manual, the strengthening of aspects addressed in the narratives and these with the maps, the change of the villains' names and the non-playable characters (played by the narrator/researcher).

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

Each person is considered an adaptive system that develops responses to internal and external stimuli. Children and adolescents with CKD experience changes in their lives in various aspects (environmental, physical, and social), which impose on this population daily changes that have an impact on their social relationships, in addition to psychological ones, because they have to deal with the chronicity of the disease, with the burden of treatment, and with the expectation of a kidney transplant, which involves a lengthy process.

Therefore, it is important to develop technologies that consider all these aspects and that go through a rigorous process in all its stages. The alpha-testing of Nefro Hero® was important to evaluate and list improvements in the prototype before the validation stage, evaluating aspects of playability and its potential to develop changes in the HRQoL of children and adolescents undergoing hemodialysis.

The improvement in the emotional score demonstrated the potential of gamification in a possible re-signification of treatment-related aspects, strengthening resilience.

Since this is an alpha test of a technology prototype, this study has the limitation of not generalizing the data. It is noteworthy that the weaknesses identified in the alpha test will be strengthened and corrected in the new version of the technology and, subsequently, submitted to the validation process.

AUTHORS' CONTRIBUTIONS

Study design. Fernanda de Nazaré Almeida Costa. Elizabeth Teixeira. Paulo Elias Gotardelo Audebert Delage.

Data collection or production. Fernanda de Nazaré Almeida Costa.

Data analysis. Fernanda de Nazaré Almeida Costa. Paulo Elias Gotardelo Audebert Delage. Elizabeth Teixeira. Mary Elizabeth de Santana.

Interpretation of results. Fernanda de Nazaré Almeida Costa. Paulo Elias Gotardelo Audebert Delage. Elizabeth Teixeira. Marcia Helena Machado Nascimento. Mary Elizabeth de Santana.

Writing and critical revision of the manuscript. Fernanda de Nazaré Almeida Costa. Paulo Elias Gotardelo Audebert Delage. Mary Elizabeth de Santana. Marcia Helena Machado Nascimento. Elizabeth Teixeira.

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