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Validation of an Oral Health Pamphlet for Children and Adolescents with Chronic Kidney Disease

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Abstract

Patients with chronic kidney disease (CKD) are candidates for kidney transplantation and therefore the presence of any source of infection must be avoided. Consequently, awareness to maintain oral health is very important for these patients. The aim of this study was to validate the contents of a pamphlet dealing with the subject of oral health for children and adolescents with CKD. The pamphlet was elaborated by a team of Pediatric Dentists at the Federal University of Rio de Janeiro (UFRJ), Brazil. Validation was carried out in 4 stages: 1) evaluation of the technical content by 8 university professors in the field of Pediatric Dentistry and 6 researchers in the area of renal diseases. At this stage, replacement of some terms and inclusion of new topics, such as the use of fluoride toothpaste, were suggested; 2) the suitability of communication and language was evaluated by 2 experts in the Educational area and the adequacy of language for the age group and the general interest in the subject raised by the pamphlet was assessed; 3) 14 adolescents without CKD were asked to evaluate it, of these 12 considered the pamphlet "good", but recommended that the black and white figures were changed to color ones, without any other changes; 4) 4 caretakers responsible for children and 2 adolescents with CKD were asked for their opinions and all 6 participants rated the pamphlet as "very good" and 5 had not been aware that poor oral health could delay a transplant operation. After qualitative analysis of the results, alterations considered relevant were included in the final version of the pamphlet. The validation process was considered important to enhance the content and organization of the pamphlet, making it clearer for the understanding of children and adolescents with CKD.

Keywords

Chronic Kidney Insufficiency, Oral Health, Child, Adolescents, Pamphlets

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1. Introduction

Children and adolescents suffering from chronic kidney diseases (CKD) often present oral manifestations, such as increased plaque accumulation (Klassen & Krasko, 2002), high calculus formation (Martins et al., 2008; Martins et al. 2012), gingival inflammation and periodontal attachment loss (Davidovich et al., 2005). Some authors have reported that patients undergoing hemodialysis have inadequate oral hygiene habits (Souza et al., 2008; Naugle et al., 1998) and that the progression of periodontal disease is related to these habits (Davidovich et al. 2005). Drugs used by individuals with CKD and the different orientation about diet can contribute to changes in the oral tissues (Proctor et al., 2005; National Kidney Foundation, 2007). Furthermore, CKD patients are candidates for transplantation and surgery will only occur if the patient is free from any infections, including oral ones. After transplantation, immunosuppression can turn any source of infection into a severe infection, which can be fatal or lead to failure of the donated organ (Costa Filho et al., 2006).

An educational program to motivate good oral hygiene practices is necessary so that possible dental problems can be prevented and consequently the quality of life of these individuals can be improved. Studies related to pamphlets exclusively about oral health for patients with CKD were not found in the Pubmed database during a search performed in September 2015. With this concern in mind, a team of pediatric dentists as a part of a dental program developed a pamphlet specifically for children and adolescents with CKD. The aim is to alert them and their parents/caregivers of the effects of CKD on oral health and strengthen the practices of toothbrushing and flossing.

The preparation of pamphlets in the medical field shows the importance of validation of the educational tool prior to distribution (Hill & Bird, 2003; Garcia et al., 2010; Reberte et al., 2012). Based on this, the purpose of this study was to describe the validation process of the written and illustrative content of a pamphlet on oral health practices for children and adolescents with CKD undergoing dialysis treatment.

2. Methodology

The Local Ethic Committee approved the project. The study population was children and adolescents with CKD undergoing dialysis or their parents/caregivers, when the children were too young or did not feel able to assess the pamphlet.

The validation process of the pamphlet “Oral Health Orientations for Children and Adolescents with Chronic Kidney Disease” was carried out in four stages:

2.1. Professors and Researches

Professors and MSc or PhD students in Pediatric Dentistry at UFRJ, whose field of research was in CKD patients and who had completed their theses or dissertations on the topic, evaluated the pamphlet. At this stage, the pamphlets were distributed individually for reading and evaluation in a silent room without a pre established time set. On distributing the pamphlet, the authors explained that the technical content should be analyzed, and asked the participants to make their remarks, modifications, suggestions and point out any possible doubts.

The participants read the pamphlet silently, wrote their comments and then handed it back to the researchers, guaranteed that they were not influenced by the authors, nor for others comments. Thereafter, the authors gathered together to discuss the comments and assess them.

2.2. Educational Professionals

The pamphlet was submitted to education professionals working in health educational psychology and health education. An email elucidating the objective of this study was sent for the educational professionals, inviting them to evaluate the pamphlet. After their acceptance, the pamphlet was given personally and the professionals assessed it within a week and sent back a report with their comments based on the concept of developmental psychology and the psychology of perception.

2.3. Children and Adolescents without CKD

At this stage, the pamphlet was evaluated by adolescents without CKD but who were under dental treatment at the Department of Pediatric Dentistry and Orthodontics at UFRJ.

2.4. Target Population

This stage was carried out at one of the CKD clinics in the city of Rio de Janeiro (RJ) with the children and adolescents who were undergoing hemodialysis (HD)/peritoneal dialysis (PD), or with their parents/caregivers.

At these last two stages, the pamphlet was read aloud and the participants were asked to assess it regarding its content: if it was easy to understand, if there were any questions about some point and also to give any suggestions that they felt were relevant to the topic. In the case of children who could not understand the purpose of the study, the pamphlet was presented to their parents/caregivers. The intention was to encourage the participants, either directly with the adolescents or through the parents/caregivers of the children, to be autonomous and independent in terms of taking care of their oral health.

After each evaluation, all suggestions/corrections were reviewed, and those considered relevant to the proposition of the study by the lead investigators were included in the pamphlet, generating new versions before the start of each evaluation stage.

3. Results

Considerations and suggestions made by participants are described below.

3.1. Professors and Researches

A total of 14 pediatric dentists, 8 professors of the Department of Pediatric Dentistry at UFRJ and 6 MSc or PhD students who had developed research in kidney patients, evaluated the pamphlet. Among the Pediatric Dentistry professors, two were professionals who worked with special care children. After the professionals made the suggestions (n = 18) a new version of the pamphlet was generated to incorporate the suggestions considered relevant (n = 11) (**Table 1** and **Table 2**) according to the proposition of the study.

Table 1. Suggested replacement terms for the first validation stage.

Terms for replacement	Suggestions	Incorporated suggestions
1. “Children and adolescents”	“People”	Yes
2. “Teeth problems”	“Buccal disease”	Yes
3. “Dental changes”	“Buccal problems”	Yes
4. “Plaque”	“Dental plaque”	Yes
5. “Polish”	“teeth cleaning”	Yes
6. “Delay possibility of transplanting”	“Delays the release for transplantation”	Yes
7. “Delay possibility of transplanting”	“Prevents the transplantation”	Yes
8. “Visit your dentist every 4 months”	“Visit your dentist according to his recommendations”	No

Table 2. Suggestions made by the participants in stage one.

Suggestions	Incorporated suggestions
1. Use of fluoridated toothpaste	Yes
2. Young children should use a reduced amount of paste	Yes
3. Healthy eating	No
4. Presence of uremic breath	No
5. Presence of pigmentation in teeth, changes in salivary flow, presence of oral lesions	No
6. Disclosure of referral centers for dental care of patients with CKD	No
7. Information from the 1˚ and 2˚ paragraph were written in topics	Yes
8. Add to the final part of the sentence: “Find the dentist closest to you	Yes

3.2. Educational Professionals

Two education professionals who rated the pamphlet: a PhD professor of educational psychology and a PhD professor in health education. Suggestions and comments (n = 6) were:

- The pamphlet is sufficiently clear and the language is suitable for the intended population;
- The information was organized so as to provoke curiosity and made it readable and informative;
- Overlapping of figure and text by placing the figure on the background and content on foreground;
- Replacing the black and white figures for colored ones.
- The CKD abbreviation should be replaced for the term “chronic kidney disease”.

A new version of the pamphlet was created by incorporating the suggestion considered relevant (n = 1). For this stage, the only modification incorporated was the last comment.

3.3. Children and Adolescents without CKD

A total of 14 adolescents participated in this stage: 6 boys and 8 girls aged between 12 and 17 years old. Suggestions and comments at this stage (n = 9) are shown in **Table 3**.

A new version of the pamphlet was generated to incorporate the suggestions considered relevant (n = 2) according to the proposition of the study. The reviews of this stage and the first and second stages indicated the need to change the visual programming of the pamphlet, which was rebuilt at this stage.

3.4. Target Population

This phase was conducted with a total of 6 participants, 4 parents/caregivers and 2 adolescents on dialysis. One child was undergoing peritoneal dialysis and the other hemodialysis. The age of the children and adolescents was from 7 - 17 years old. Suggestions and comments (n = 6) at this stage are shown in **Table 4**.

The version of the pamphlet remained the same as the third stage with the new visual programming and no additional stage was necessary.

4. Discussion

The elaboration of the pamphlet was based on specific scientific literature of the area, which describes oral manifestations of chronic renal disease, professional experience and the observation that greater oral care is needed for children and adolescents with CKD. The pamphlet contains information about the main dental problems presented by patients with CKD, and how these issues may affect their life and treatment. The pamphlet also contains guidelines for buccal hygiene practices and flossing as a form of maintaining buccal health and the importance of visiting the dentist for treatment and prevention.

Considering the wealth of information about dentistry related to chronic renal patients, this pamphlet could not cover all areas. However, its aim is to motivate patient autonomy in favor of their oral health. Therefore this

Table 3. Suggestions and comments made by the participants in the third stage.

Suggestions	Incorporated suggestions
1. Using color images instead of black and white ones.	Yes
2. Considered the pamphlet “good”, requiring no change.	-
3. The words used in the pamphlet were easy to understand.	-
4. Found the pamphlet objective, direct, and considered the organization “good”.	-
5. Commented that they did not know that buccal infections in CKD patients could delay or prevent the surgery for kidney transplantation.	-
6. Commented that they did not know that people with CKD may have a greater accumulation of dental plaque and calculus on their teeth.	-
7. Noted that something was missing from the cover of the pamphlet.	Yes
8. Liked the size of the content: “neither too big nor too small”.	-
9. Found the idea of testing the booklet before “very cool”.	-

Table 4. Comments made by the participants in stage four.

Comments	N° of parents/caregivers (n)	N° of adolescents (n)
Unaware that oral infections could interfere with transplant	03	02
Found the pamphlet interesting/very good	04	02
Reported not receiving guidance on oral health by the medical staff	02	02
Reported that the pamphlet brought information that they did not know	01	01
Reported that they did not take the child to the dentist	03	--
Reported that they did not go to the dentist	--	02

pamphlet avoided excessive information in order not to shift the focus away from motivating self-care attitudes and the pamphlet was made readable, considering the age of the target audience.

Patients remember between 29% - 72% of the information verbally presented by health professionals, according to Houts et al., 1998. In this way, pamphlets are important tools to enhance the understanding and recall of healthcare instructions. Many written materials, however, may be difficult for low-literate caregivers and patients to comprehend, therefore validation is an essential process for the adequacy of the material for the target population. Well-crafted materials and information easy to understand improve knowledge and patient satisfaction. Thus, we tried to bring relevant information through simple language and short sentences.

In the first stage of testing, the terms suggested for replacement: “teeth problems” for “buccal disease” and “dental changes” for “buccal problems” were considered relevant, since the oral changes in CKD patients are not restricted to the teeth but may also affect the oral tissues in general.

In addition, others terms were replaced, such as “polishing” for “teeth cleaning” and “plaque” for “dental plaque”. In the first case, “polishing” was considered a technical term, while “teeth cleaning” was easier to understand. In the second case, dental plaque is the appropriate expression and facilitated the understanding of the message.

One participant found that the phrase “delays the possibility of transplant” could mean that donors would not donate because of buccal problems and suggested it was changed to “delay the procedure for transplantation.” Another participant suggested that it was more appropriate to place “prevent the possibility of transplant” to emphasize the risk of dental problems in transplant surgery. Based on these comments “prevent or delay the procedure for transplant surgery” was added. In patients with CKD, transplantation is only undertaken if the patient is without any infection, including oral ones. Any infection can increase the risk of generating a severe infection in these patients. Thus, it is essential to emphasize the importance of maintaining buccal health.

In relation to the frequency of visiting the dentist, the proposal of “visiting your dentist every four months” was suggested to be changed to “visit your dentist according to his recommendations”. However, this suggestion was not incorporated, based on scientific literature. Martins et al. (2012), in a study that analyzed the dental calculus formation rate in children and adolescents undergoing HD, observed that the dental calculus accumulation had reappeared three months after its removal. In addition, Davidovich et al. (2006), a study that analyzed the dental calculus in a child with end-stage kidney disease, found that four months after removal, there was a new accumulation of calculus in the same locations. This information reinforces the indication that fixed periodic visits to the dentist should be made.

Some participants suggested including terms such as tooth pigmentation, salivary flow, uremic breath and healthy eating; however, these terms were not incorporated as they would make the pamphlet too long, with excessive information and could deviate the reader from the main objective that is to encourage basic oral hygiene therapy to prevent oral problems. However, a pamphlet containing more comprehensive information on this topic could also be produced.

The expert in the educational area considered the concept of developmental psychology and the psychology of perception. The first point highlighted was that the material aims to reach children through their caregivers or parents responsible, and adolescents; which could be a problem because of the age differences. However, it was considered that the pamphlet was sufficiently simple with clear information for the age group to which it was

intended. In addition, the organization of the pamphlet was able to arouse curiosity and thus made it readable and informative.

Another point addressed in this phase was the suggestion to place the figures in the background and the text in the foreground. This suggestion was not incorporated because the association between what you read and what should be done, as demonstrated by the figure, could be lost. The suggestion of adopting colored figures was carried out in the third stage.

In the next stage, the participants evaluated the pamphlet positively concerning the content and they only had suggestions about the organization: the introduction of "colored pictures" and "something that catches attention on the cover". Considering the results of the second and third stage, the graphic design was remade by a visual programmer. Also at this stage, comments that "language was easy" and the "length of the pamphlet was appropriate" were made; moreover, these comments coincided with the assessments made in the second stage by professionals.

The fourth stage revealed the lack of dental guidance for CKD patients and their caregivers, since most had never been informed about the need of dental care. Gonçalves et al. (2009) assessed the educational dimension of a nephrology team (physicians, nurses, and nursing assistants) in relation to oral health of CKD patients. Most professionals were aware that CKD can affect oral health in some way, however less than half of them advise their patients about it. Regarding oral hygiene habits, 51.1% of professionals guide their patients about some oral health care and 66.6% of professionals reported having patients needing dental care. Of these, only 35% forward them to dental services. In addition, many patients reported that they did not go to the dentist, a fact that was justified by the routine of dialysis. Although patients with CKD have more contact with the medical staff, they have less time to visit the dentist, so other resources are needed to guide oral care. This reinforces the importance of pamphlets to inform and stimulate self-care, preventing the onset of oral problems.

At the Clinic for Kidney Diseases where the fourth stage of testing was conducted, there were 6 children and adolescents on dialysis, and all were interviewed. Despite being a qualitative analysis study, with a small sample, the assessment of the pamphlet was not impaired since everyone interviewed in this phase evaluated the brochure as "very good/interesting" and the reviews were similar. The most relevant concern was the fact that buccal problems could interfere in transplant surgery. There were further questions by the parents/caregivers about oral health care as well as questions about the delay in tooth eruption and pigmentation of the teeth, which showed that this population was interested to receive more information about their health status. Thus, it seems that there is a demand to prepare a new pamphlet covering more aspects concerning the relationship between CKD and dentistry.

5. Conclusion

The validation process was important, since it helped to improve the technical content; it verified whether the communication and language were adequate and accessible to the age group to which it was intended; and it incorporated essential suggestions. This pamphlet is intended to stimulate self-care in children and adolescents with CKD and encourage them to provide for their own oral health.

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