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Multimedia material about velopharynx and primary palatoplasty for orientation of caregivers of children with cleft lip and palate

Material multimídia para orientação dos cuidadores de bebês com fissura labiopalatina sobre velofaringe e palatoplastia primária

ABSTRACT

Purpose: The objective of this study was to describe the process of elaboration and evaluation of multimedia material for caregivers about velopharynx, speech, and primary palatoplasty in babies with cleft lip and palate. **Methods:** The elaboration of the material involved an interdisciplinary relationship between the fields of Speech Language Pathology and Audiology, Dentistry and Arts. The definition and execution of the following activities were based on the principles of art education involving the following: characterization of audience, characterization of content, identification and elaboration of illustrations, characterization of educational approach, elaboration of text and narratives, definition of audiovisual sequence, and video preparation. The material was evaluated with the participation of 41 caregivers of patients with cleft lip and palate involving the comparison between acquired knowledge using an evaluation script applied before and after presenting the material. **Results:** An increase was observed in correct responses regarding the role of velopharynx and the importance of primary palatoplasty for speech. **Conclusions:** The multimedia was effective in optimizing the knowledge of caregivers, suggesting the importance of such material during orientation.

RESUMO

Objetivo: O objetivo deste trabalho é apresentar e discutir a elaboração e a avaliação de material multimídia, destinado à orientação dos cuidadores de bebês com fissura labiopalatina, mais especificamente orientação sobre a velofaringe, palatoplastia primária e fala com relação às fissuras labiopalatinas. Métodos: A elaboração do material envolveu interdisciplinarmente as áreas de Fonoaudiologia, Odontologia e Arte. Permeado por princípios da arte-educação, houve definição e execução dos seguintes aspectos: caracterização do público alvo, caracterização do conteúdo, identificação e elaboração de ilustrações didáticas, caracterização da abordagem educacional, elaboração do texto/narração, definição da sequência audiovisual e conversão em vídeo. A avaliação do material foi conduzida com a participação de 41 cuidadores de pacientes com fissura labiopalatina e envolveu a comparação dos conhecimentos dos participantes por meio de um roteiro avaliativo, aplicado antes e depois da apresentação do material. Resultados: Ocorreu aumento para as respostas corretas referentes ao papel da velofaringe e a importância da palatoplastia primária na fala. Conclusão: O material multimídia mostrou-se efetivo na otimização dos conhecimentos dos cuidadores, sugerindo a relevância de seu papel em momentos de orientação.

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INTRODUCTION

Cleft lip and palate (CLP) is one of the most common anomalies that is present in 1 out of 650 births in Brazil⁽¹⁾, generating aesthetic and functional impairment of the affected areas. This anomaly involves openings in the lip and/or palate, treated with a complex and long process of rehabilitation that can last more than 20 years. This treatment requires interdisciplinary follow-up involving doctors, dentists, speech-language pathologists, psychologists, nutritionists, and nurses, among other health professionals. Currently, in Brazil, according to the Ministry of Health⁽²⁾, there are 26 registered centers that provide some type of outpatient care and/or surgical treatment for people with CLP. These centers are distributed as follows: 1 in the North, 3 in the Midwest region, 4 in the Northeast, 7 in the South, and 11 in the Southeast, of which 8 are in the state of São Paulo. However, not all centers provide services for every stage of the treatment. These data present us with a scenario regarding the inequalities found in the supply of qualified care in the country. The training of health professionals focused on craniofacial anomalies is a responsibility of the institution where this study was conducted, thus contributing to the decentralization and optimization of services in this field. To optimize services, there are actions guided towards increasing the knowledge of patients and caregivers regarding the cleft and its implications assuring families the fulfillment of their rights to information while fostering their understanding of the rehabilitation process.

The primary surgeries to correct the lip and palate generally occur during the first year of life, with the primary palatoplasty guided to promote the reconstruction of the palate and the velopharynx. The velopharynx is the area of the vocal tract that controls communication between the oral and the nasal cavities for functions such as speech and feeding⁽³⁾. During speech, the soft palate and the pharyngeal walls interact by opening and closing the velopharynx, in order to separate or to communicate the oral and nasal cavities according to the characteristic of the sound to be produced. Velopharyngeal dysfunction or inadequacy can compromise the quality of the sound produced. Therefore, it is important to promote prevention initiatives to guide caregivers (parents, family members, or other individuals who care for children with CLP) regarding the role of primary surgeries to correct cleft palate and regarding the importance of having these surgeries in the period proposed by the rehabilitation team. A surgery performed too late can cause complications that affect the operation of the velopharynx, therefore interfering with the processes of feeding, hearing, and speech development, which can become unintelligible. In the mid and long terms, it can affect the quality of life of these individuals. If the surgery is performed on the indicated schedule, under appropriate clinical conditions, it can foster the process of rehabilitation and reduce the burden of the treatment as a whole for the individual and their caregivers, considering all of the psychosocial aspects involved.

It is common for caregivers to be unaware of laboratorial and clinical conditions for surgery when they enter the rehabilitation institution. They do not know about the general health status of the child, making it impossible for the surgery to take place on time. Some authors^(4,5) suggest it is important that the professionals involved in handling the CLP provide clear information about the treatment protocol as an opportunity to promote adherence. Other authors⁽⁵⁾ consider the essence of a careful look at the health education process, as the health professional training model in Brazil results in a model of care that is very little resolute and impersonal, interfering with the receptiveness and opportunities of adherence to treatment.

Recent studies have shown that the use of multimedia can effectively contribute with the learning process in the health field⁽⁶⁻⁸⁾. In this analysis, the multimedia material adopts different formats of information (images, videos, sounds, animations, etc.), while stimulating different perceptions and sensations, as well as varied ways of acquiring knowledge⁽⁹⁾. The term knowledge is used herein referring to the ability to remember or recognize information, as suggested in the original Bloom's Taxonomy(10). The quality of multimedia materials can directly affect the level of interpretation and understanding of the message⁽⁹⁾. Thus, on the one hand, wel-1-designed multimedia materials can help with acceptance, receptiveness, and understanding of the content presented. On the other hand, poor materials can discourage or even mislead the user⁽⁹⁾. However, there are only a few studies describing the development of multimedia materials specifically related to the CLP, as well as further evaluations. This suggests that the materials used to provide guidance to caregivers of people with CLP have not been considered as research objects, thus reducing the chances of identifying their effectiveness in achieving the goals. Multimedia materials about the velopharynx and the role of palatoplasty in children with CLP, in particular, were not found.

This work came up as a result of the need to subsidize the relationship between health professionals and caregivers of people with CLP, in order to optimize the moments of present and/ or distant orientation, increasing the receptivity of caregivers. The lack of materials on this subject (CLP, velopharynx, and palatoplasty), designed specifically for this audience, with accessible verbal and visual language, is a known fact. The objective of this study is to present and discuss the development and the evaluation of multimedia materials that can guide caregivers of babies with CLP, more specifically on velopharynx, primary palatoplasty, and speech. The hypothesis in this study is that the materials prepared with resources and didactic illustrations created specifically for this purpose result in major improvement of participants' knowledge, thus reflecting the emergency of the strategies and materials used for an effective orientation of caregivers dealing with people with CLP.

METHODS

This study was approved by the Ethics Committee of the institution where it was conducted, and included 41 caregivers of children with CLP. The work involved the development and the evaluation of multimedia materials by comparing the knowledge observed before and after the material was presented to the caregivers.

The preparation of the material included principles of art education for the elaboration of images, animations, three-dimensional items, and teaching strategies, considering some aspects of the audience. The steps for creating the material were adapted from a similar study⁽⁷⁾ involving the definition and/or execution of the following: a) target audience, b) content, c) didactic illustrations, d) educational script, e) text and narration, f) audiovisual sequence, and g) video conversion. The material was prepared to overcome the limitations between socioeconomic and cultural backgrounds of caregivers and health professionals, as an initiative addressed to preventing development sequelae.

The evaluation analyzed the impact of the material on the knowledge of caregivers of children with CLP. The population of interest in this study comprised literate caregivers who awaited corrective surgeries on CLP of the patients. Caregivers with hearing disorders and/or those who were illiterate were not included in this study, as the material has not been adapted to this audience yet.

In the course of 4 months, 41 caregivers of children with CLP were addressed individually, while awaiting the surgery of their patients. One caregiver did not complete the information regarding personal characteristics. Of the 40 participants who reported all investigated data, 26 were female (65%) and 14 were male (35%); their ages ranged between 18 and 54 years, with an average of 30.5 years; 23 (57.5%) participants were mothers of patients, 12 (30%) were fathers, 2 were grandparents (5%), 2 were uncles (5%), and 1 was an aunt (2.5%). Two (5%) caregivers reported not having access to DVD players in their households, 13 (32.5%) mentioned not having access to the internet, whereas 39 (95%) considered that watching the material once was enough for their understanding. Finally, two (5%) participants wanted to revise the presentation. Participants came from the five Brazilian regions and nine states (AM, ES, GO, MA, MG, MS, PR, RJ, and SP). As for social stratification, participants were distributed in the lower upper class (57%), lower-lower class (28%) and mid-lower class (15%), confirming the social stratification data from the institution where the study took place⁽¹¹⁾. It is worth noting that the lower-lower group, which relates to the population that is mostly in need, is not the group with the highest percentage of attendance to the institution, suggesting a point to be investigated. This intensifies the proposal to prepare guidance materials, which can be provided from a distance. Therefore, this part of the population can be reached, thus increasing the percentage of attendance in this group.

After obtaining the informed consent to participate in the study, participants received an evaluation form to answer the questions concerning the content of the material before watching it, in order to show prior knowledge on the subjects covered. Then, the 10-minute multimedia material was presented, and each participant could watch it as many times as necessary. Afterwards, each participant answered the same evaluation once again to emphasize the possible changes regarding their knowledge on the matters in question.

The preparation of the evaluation observed the skills, defined as objectives to be achieved with the multimedia material, and incorporated images and colloquial vocabulary used in the presentation. The script comprised 20 items divided into 9 questions that accompanied the progression of the content in the multimedia material. The immediate impact of the material on the knowledge of caregivers was assessed by comparing the percentage of correct answers before the caregivers had watched the multimedia material with the percentage of correct answers after the caregivers had watched the multimedia material.

RESULTS

Elaboration

The elaboration process resulted in a 10-minute long multimedia material called "Keep an Eye on Speech". The material was prepared in PowerPoint, and the content was inserted in an increasing order of complexity, defined according to the skills to be achieved: 1) ability to recognize clinical terms; 2) ability to identify the inside images of mouth (oral cavity), nose (nasal cavity), throat (pharynx), and velopharynx; 3) ability to recognize the parts and the operation of the palate; 4) ability to recognize the role of velopharynx in the production of oral and nasal sounds; 5) ability to identify the role and the importance of primary palatoplasty for the reconstruction of velopharynx; and 6) ability to identify actions that can be used by the caregiver to facilitate the conduction of palatoplasty on the schedule prescribed by the rehabilitation team.

The interpretation of images is a cultural process in which a person produces and decodes the image recognized, or the image he or she was taught to decode(12,13). Then, it is important to remember that our vision is limited, so we look at the world but we only see what we understand and the things we can find meaning in⁽¹⁴⁾. Just after undergoing an initial stage of decoding, the reader can deduce interpretations and assimilate the information represented in the image. Some authors⁽¹⁵⁾ also emphasize that images play a key role in the creation and conceptualization of scientific ideas. Therefore, we conclude that in order to establish a useful dialogue with caregivers, it is essential to try and understand the context and, therefore, the thoughts of this heterogeneous audience. It is important to find common points in their cultural references that can serve as base for the production of orientation materials, then maximizing the chances of reaching the desired behavior changes. The didactic illustrations selected for the multimedia material have been prepared specifically to guide caregivers, and were inserted into a set of manuals(16) available in the institution where this study was conducted. These illustrations have been prepared in an interdisciplinary process (Art Education, Speech Language Pathology and Audiology and Dentistry). They were demonstrated to many patients and caregivers in meetings of Rede Profis - a network that brings together associations of parents and people with CLP in the country, aiming at technical and scientific exchange of knowledge and the strengthening of actions that defend the interests and rights of people with disabilities(17-19). Suggestions and opinions on the illustrations were registered during informal dialogues with the caregivers. Thus, the graphics have undergone some changes by incorporating the thoughts of the users before they were finalized. The changes were based on criteria established through the interactions with patients and caregivers⁽²⁰⁾.

In addition to the didactic illustrations, photographic images exemplifying the CLP were used, comparing it to the oral cavity without fissure. Images of a three-dimensional anatomical model were also used. This three-dimensional anatomical model was also made in an interdisciplinary process with the purpose of advising caregivers of individuals with CLP⁽²⁰⁾. The development of a set of skills was structured with the goal of optimizing time, relationship, and dialogue between caregivers and health professionals in present or distance interventions.

The text was drafted and the images were defined simultaneously (as well as specific graphic effects for each frame). The educational script (appropriate approach to each situation presented on screen) was also created at the same time. A tool (printed material) for synchronizing the graphics (images) was created, with the text (narrative) and the proposed skills, allowing the conference between the proposed objectives and the strategies used. A simple vocabulary was mixed with the introduction of clinical terms, when associated with the use of significant images and analogies. Also, significant text messages were inserted with short sentences, easy to interpret and with a strong meaning⁽⁶⁾. The voice tone used in the narration was similar to that of a real dialogue, thus generating a sense of approximation and establishing a relationship of trust and empathy.

The presentation of "Keep an Eye on Speech" consists of a sequence of 74 slides, composed of images and an explanatory script. Throughout the presentation, images, narration, and texts complement each other, to facilitate the audience understanding. The slides were organized according to the sequence of the skills addressed, as they have been proposed based on an order of complexity favoring the expected learning process. The material was converted into a demonstration video and copied in DVD to assess its impact on the knowledge of caregivers.

Assessment

The assessment of the impact of the material on the knowledge of caregivers showed that, after the presentation, the minimum number of correct answers increased from 20% to 46%, whereas the maximum number of correct answers increased from 85% to 98%, resulting in improvements regarding the overall average: from 61% to 86%, as shown in Figure 1. The Chi-squared test (χ^2 -test) showed statistically significant differences in the answers about the contents addressed: the ability to recognize the parts and the operation of the palate (p<0.001); the ability to recognize the role of the velopharynx in the production of oral and nasal sounds (p<0.001); and the ability to recognize that palatoplasty rebuilds the hard and soft palate in order to create the velopharynx (p<0.001).

DISCUSSION

The primary surgical correction of CLP is usually performed during the first year of life, and it is important that the surgery schedule be maintained as proposed by the teams. At the

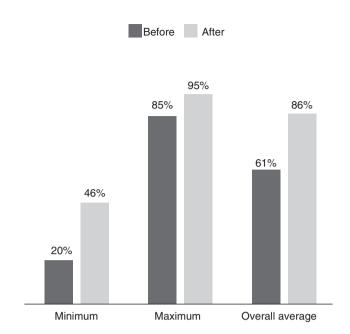


Figure 1. Comparison between correct answers before and after the presentation of the multimedia material "Keep an Eye on Speech"

institution where this research was carried out, about 20% of the highly complex procedures are postponed, partly because of the clinical and laboratorial conditions of the children, who do not have basic health conditions⁽²¹⁾: fever, anemia, lice, scabies, itch or mycosis, worms, skin sores or injuries with pus, bronchitis, asthma, wheezing chest, cough, the flu or catarrh, infected throat or ear, tooth decay, vomiting or diarrhea, infectious diseases, low weight, etc. The proposed treatment, which offers highly complex services, includes the orientation addressed to caregivers regarding the importance of primary care to promote clinical and laboratorial conditions that are suitable for performing surgeries on schedule. Yet, there is delay in procedures for babies with chronic conditions that could have been prevented if they had been treated in family health programs in their cities of origin. This reality suggests (along with other social aspect issues) difficulties regarding the adherence of caregivers, or even miscommunication. This affects the understanding of the treatment offered by teams in highly complex health services and the importance of integrating these services to health primary care in the cities of origin, thus benefitting the users.

First of all, the fact that it is a right of the patients that their caregivers have access to orientation⁽²²⁾, which is often overlooked or performed improperly, was the main motivation for the development and evaluation of the multimedia material presented here. The orientation of caregivers also provides other significant benefits for all of the parties involved, such as better understanding of aspects related to the health conditions of patients and their circumstances, as well as the stages of care, higher ability to handle crises, and emotional well-being^(23,24). One cannot disregard other psychosocial factors and make a direct association between guidance and adherence, especially when it comes to material that will be submitted to different

contexts of use, which can belong to a dialogic process of guidance and also be offered vertically⁽²⁵⁾. At the same time, one cannot neglect the duty of health professionals to provide clear information and make a contribution that favors more adherence to treatment, especially when associated with other factors and initiatives.

The pedagogical reflection that guided the preparation of the material "Keep an Eye on Speech" was the point of intersection between the fields of Arts, Health, and Education, and was very beneficial for this work. The progress came in identifying that reading an artistic image is substantiated by the role of subjectivity (as it comprises the action in which almost everything is allowed, since it is based on the reader's thoughts, feelings, and emotions). When a scientific image is interpreted, apparently the opposite occurs. The subjectivity is replaced by the need for objective and clear understanding of the content to be addressed. In both cases, to effectively achieve the interlocutor, mediation is necessary in image reading to promote knowledge. Such reflection emphasized how a properly chosen image may favor, instead of complicate, the dialogue between the teacher (in this case, health professionals) and the student (in this case, caregivers). If images must be selected for orientation, the same is true for multimedia materials, which are dynamic images along with narration and graphics. In practice, the proposal aimed at raising awareness for basic health care, making the individual more participatory and more autonomous in building his or her knowledge, as well as more observer and with greater ability to act critically and assertively in terms of caring for his or her child.

In general, during the preparation of the material, it was observed that the transposition of Art Education to Health Education context was essential and was the base for the decisions of the authors, who:

- Used images as the starting point for the construction of concepts;
- Used images that were previously developed for the purpose of orientation, facilitating its reading;
- Presented the content gradually and increasingly, presenting information from the perspective of parents and caregivers, intercalating the moment to appreciate and to contextualize;
- Put the interlocutor in observation and reflection, helping to recognize, in himself or herself, some autonomy in building his or her knowledge;
- Contributed to the familiarization of the layperson using images containing visual information on the functional anatomy of the child with CLP;
- Proposed a clear and objective health promotion action that can be easily implemented by parents and caregivers.

Seeking to optimize the learning process with visual information that can empower the understanding of the content and the development of the proposed skills, most of the work was dedicated to the analysis, selection, and imaging. In this sense, the participation of researchers in academic and clinical activities, and the follow-up of patients, opened up opportunities for reflection and analysis of the visual material used so far by professionals in some sectors of the institution. This helped to

identify the elements that had a negative effect on decoding images and information as a whole (and that should be prevented in the preparation of multimedia materials), compromising knowledge acquisition.

Some initiatives of multimedia material assessment involve public opinion research on the content or the format of the presentation(26-28). This culture of adopting public opinion in a rehabilitation hospital, however, may raise some issues. In a society in which health is covered by many professionals with a paternalistic view, the expectation is to find more passive and "always satisfied" users at all services. Therefore, even when there is the option of anonymity in responses, the attitude of unconditional gratitude for the service received is common in people who have grown up in a system in which treatment and adequate information are not considered to be a right of the citizens. These individuals are in fragile situations and have become vulnerable, as they are in an unequal power relationship⁽²⁹⁾. It was also observed that, in opinion polls, it is not possible to control the differences between the socioeconomic and the cultural context of the participants and the one represented by the institution where the study was conducted. Usually, the waiting room of the institution provides more comfort and well-being than the household of the respondents, leading to a biased view that everything offered is positive in that environment. The material evaluation protocol, therefore, involved an evaluation script to identify changes in the skills of the users. The implementation of the script before showing the material assumes that participants have different levels of knowledge. In addition, it establishes the basis to compare the knowledge after showing the material in order to identify its real immediate impact on the awareness of caregivers after being exposed to the content. Further analyses are necessary to investigate the use of multimedia material and its relationship with long-term memory.

Numerical results show that before exposure to the content, the minimum number of correct responses was 20%. It is important to mention that this study occurred during the waiting time for surgeries of CLP in children, some of whom were 3 months old (minimum age). We met a minimum of 20% (4 hits of 20 questions), which leads us to question: during those 3 months or more, how did the caregivers have access to information regarding CLP? What is the quality of the information they found in different media, or even when receiving them from others? When a minimum of 20% of hits before is compared the minimum number of hits after watching the material, there is an increase to 46%. This is valuable when we consider how the material was presented (while waiting for the children's surgery) and when we observe that the participants only watched the multimedia material once, without repetition (despite being allowed). It is important to analyze that the multimedia material presents content with different levels of complexity, and it was prepared to be watched several times, accompanied by the orientation of a professional engaged in rehabilitation, which did not occur in this study.

Before the access to the material, the maximum number of correct answers was 85%, increasing to 95% after watching it. This increasing percentage reinforces the idea that even the

group with more previous knowledge had no awareness of some specific issues regarding the speech development of children with CLP. There was a statistically significant difference between the condition before and after the access to the material regarding the ability to recognize the parts and the operation of the palate; the ability to recognize the role of velopharynx in the production of oral and nasal sounds; and the ability to recognize that, with the palatoplasty, the surgeon rebuilds the hard and soft palate, creating the velopharynx. In other words, these data indicate that before watching the multimedia material caregivers were unaware of an important goal of the surgery. The set of skills that presented statistical difference corresponds to more complex contents, representing a strong theoretical goal. In this case, the numbers allow us to infer that the core objective of the multimedia material has been reached, thus indicating its relevance.

The careful orientation of caregivers and the verification of acquisition or expansion of knowledge are important in a country with just a few qualified professionals who can provide highly complex services to patients with craniofacial anomalies. Therefore, the material developed can facilitate actions, supporting initiatives that propose larger processes for raising more awareness, in person or via telehealth, tele-education, and telecare, increasing the supply of long-distance health services⁽³⁰⁾.

The actions conducted and described here, which converged into the creation of the multimedia material, aim at optimizing the long and complex process of managing craniofacial anomalies, favoring the guidance of caregivers both in person and at a distance. It also supports the reflection and behavioral changes of the staff involved in the orientation processes, as well as the training programs addressed to students and other professionals involved in the management of CLP.

The set of actions described here has led to dialogues between health professionals, patients, and caregivers, since it offers subsidies to intermediate the orientation process. In addition, it reduces a wide relational gap between the professional (with academic graduation, using specific vocabulary and complex concepts to be transmitted) and the caregivers (who have access to little information allied to the momentary vulnerability caused by health conditions). The process benefits caregivers by allowing them access to clearer information, and it also contributes to train more qualified professionals, providing greater reflection about the urgent need to improve the procedures of health education. By contributing to humanizing the relations in moments of guidance, the set of actions leads to better quality of life, favoring adherence, making the treatment faster and minimizing comorbidities related to craniofacial anomalies. The social impact of the materials and strategies described herein, however, has the potential to be expanded, as it favors the treatment on schedule and minimizes sequelae (and the pain associated with them). Consequently, it may reduce the time and the use of health resources for the management of CLP. In proposing more effective guidance models, the work aims at contributing with long-term changes regarding the results of adherence. Nowadays, around 20% of the surgeries scheduled at the institution where the study took place are cancelled because patients without adequate clinical and laboratorial

conditions arrive for surgery⁽²¹⁾. It is estimated, for example, that it is possible to help reduce the number of cancellations by changing the behavior of caregivers regarding basic health care during the preoperative period. With more adequate orientation programs, a reduction is expected on the cost of cancellation procedures for the hospital, for SUS (Brazil's Public Health System) and for patients and their families. An expansion is expected with respect to possibilities and initiatives addressed to the public that is often unattended. For the patient, in particular, it is estimated that in addition to reducing travel costs, absence from work and from school, the implementation of a permanent and more effective process of health education also has a wide impact on the prevention of comorbidities related to the rehabilitation process.

CONCLUSION

The material was prepared and evaluated in a process that suggests the benefits of the interdisciplinary fields of Speech Language Pathology and Audiology, Dentistry and Art Education. The results confirmed the hypothesis, as the exposure to multimedia material – prepared with resources and didactic illustrations created specifically for this purpose – resulted in a significant increase of knowledge among participants. This shows the emergency nature of care that must be offered with the strategies and materials used in moments of guidance addressed to caregivers of people with CLP, so it can be effective and contribute to improve the quality of life of people with CLP and their caregivers.

*All authors participated in the drafting of the guidance material used in this work, and reviewed the text. TLC and JCRD participated in the evaluation of the guidance material, and drafting of the text.

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