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IMPACT OF REHABILITATION WITH MAXILLOFACIAL PROSTHESES ON PATIENTS' QUALITY OF LIFE

IMPACTO DA REABILITAÇÃO COM PRÓTESES BUCOMAXILOFACIAIS NA QUALIDADE DE VIDA DOS PACIENTES

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Abstract
Objectives: To characterize the positive impacts and difficulties in the rehabilitation process with prostheses, clinical, social and psychological relevance of the work of the dental surgeon and the importance of the topic in the academic environment. **Methods:** A Qualitative Basic Research was carried out, with data collection by individual interview, online, by video calls. The population studied consisted of people of both sexes, over 18 years of age, who underwent or are in the process of oral and maxillofacial prosthetic rehabilitation, including oral and extraoral prostheses. **Results:** From the reports, it was possible to know the changes in the general health of the patient. The population studied consisted of 4 women and 2 men, in addition to the report of the mother of one of the interviewed patients. The reports of this study showed that the use of prostheses and rehabilitation had a positive impact on all cases heard. The prostheses contributed to the general health of each patient, according to their look, their history and their unique vision. **Conclusion:** In addition to partially restoring the function of the lost or mutilated organ, oral and maxillofacial prostheses made it possible to preserve and protect part of post-surgical structures, also improving the natural esthetics of the organ or tissue.

Keywords: Dentistry; Cleft Palate; Eye, Artificial; Maxillofacial Prothesis; Rehabilitation.

Resumo
Objetivos: Caracterizar os impactos positivos e dificuldades no processo de reabilitação com próteses, relevâncias clínicas, sociais e psicológicas do trabalho do cirurgião dentista e a importância do tema no meio acadêmico. **Metodologia:** Realizou-se uma Pesquisa Básica Qualitativa, com coleta de dados por entrevista individual, de forma online, por videochamadas. A população estudada constituiu-se de pessoas de ambos os sexos, maiores de 18 anos, que realizaram ou estão em processo de reabilitação protética bucomaxilofacial, incluindo próteses orais e extraorais. **Resultados:** A partir dos relatos, foi possível conhecer as mudanças na saúde geral do paciente. A população estudada constituiu-se de 4 mulheres e 2 homens, além do depoimento da mãe de um dos pacientes entrevistados. Os relatos deste estudo demonstraram que o uso das próteses e a reabilitação impactaram positivamente em todos os casos ouvidos. As próteses colaboraram para a saúde geral de cada paciente, de acordo com seu olhar, sua história e sua visão única. **Conclusão:** Além de restabelecerem parcialmente a função do órgão

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perdido ou mutilado, as próteses bucomaxilofaciais possibilitaram a preservação e proteção de parte de estruturas pós cirúrgicas, melhorando também a estética natural do órgão ou tecido.

Palavras-chave: Odontologia; Fissura Palatina; Prótese Ocular; Prótese Maxilofacial; Reabilitação.

INTRODUCTION

The face attracts attention in human relationships, allowing the expression of feelings, emotions, and communication with the world[1]. However, for some individuals, walking the streets under unfamiliar gazes and simultaneously having a satisfactory social life is not as straightforward.

Facial mutilations hinder the establishment of emotional bonds and directly or indirectly impact various aspects of daily life[2]. Individuals with congenital anomalies, those who have experienced accidents and physical traumas, or those who have undergone facial amputations due to oncological treatments, may experience compromised physical, emotional, psychological, and social well-being. These individuals are often subjected to curious glances and may grapple with feelings of inferiority, anxiety, helplessness, shyness, and the insecurity of being treated derogatorily due to their appearance or rejected by their social environment[1,3].

In light of this, it is essential to reflect on the broad perception of the concept of health, as highlighted in the Constitution of the Federative Republic of Brazil, Article 196, promulgated on October 5, 1988. Health is now understood not only as the absence of diseases but as a result of living conditions, exposure to risk factors, or determinants of holistic health, such as access to food, transportation, work, leisure, income, sanitation, and essential services. Therefore, supported by the current Constitutional text and Law number 8.080, dated September 19, 1990, it can be asserted that patients should receive humane and comprehensive care that respects their values, history, and reality in all dimensions[4,5].

The dental specialty of maxillofacial prosthesis, still relatively unknown to the general population, fits into this context of restoring health in a comprehensive manner. This includes harmonizing patients' facial features through intra and extraoral prostheses, supporting them in reintegrating into social life, professional

activities, and family, and aiding in the restoration of their dignity[1]. These prostheses are produced through the acquisition of images, modeling, and 3D printing, involving the reconstruction of elements of the human head and neck. This encompasses the oral cavity, and palate, and the reconstruction of extraoral components, performing corrections or reconstructions of auricular, ocular, or nasal elements, seeking the restructuring of the lost member through removable artificial prostheses or other non-removable prostheses for mutilated patients[6]. Specialists in this field seek materials that not only reconstruct the amputated member but also resemble human skin and serve as quality restorative material[7], protecting the structures and tissues still present in the face.

After a meticulous review of qualitative scientific studies related to the social discussion on the subject, it was observed that there is a lack of comprehensive and indispensable research on this topic. This gap in the current literature highlights how limited the number of individuals, not only in the general population but also in the academic community, who have access to information about this dental specialty is, despite its significant impact on improving the quality of life for these patients. Thus, it emphasizes the urgent importance of promoting the dissemination of this knowledge in the academic environment to train a larger number of professionals to meet this specific demand and thereby contribute effectively to improving the living conditions of the involved patients.

Therefore, the study aims to analyze patients' perceptions of the maxillofacial prosthesis rehabilitation process and its impacts on the quality of life. Additionally, it aims to explore the difficulties in the prosthetic rehabilitation process, elucidating the clinical, social, and psychological relevance of the dentist's work.

METHODOLOGY

A qualitative basic research approach was employed, utilizing data collection through individual online interviews conducted via video calls. This study involved the participation of 6 patients, all over 18 years of age, of both genders, who underwent maxillofacial prosthetic rehabilitation, including oral and extraoral prostheses.

The determination of the number of interviewees followed the saturation method, with the inclusion of new participants limited by redundancy or repetition of information that did not add additional value to the research by not presenting novel data beyond what had already been obtained[8].

Due to various challenges in recruiting patients, volunteers for the study were selected through social media. The identification of these participants occurred through groups or individuals engaged in virtual activities to raise awareness among the population, seeking to provide support, voice, and visibility to these patients.

Therefore, for inclusion in the study, volunteers from the Federative Units of Brazil who had undergone maxillofacial prosthetic rehabilitation or family members who accompanied the rehabilitation process were selected. No exclusion criteria were established.

Data collection took place between July and September 2021. Semi-structured interviews were conducted with a guiding script of questions. The study questions were related to their life history and how prosthetic rehabilitation did or did not modify their reality. Participants were asked about their expectations regarding the rehabilitation process, including technical care, reactions from family and society, considering pre and post-rehabilitation realities. Additionally, participants also reported impacts on their mental health after mutilation and changes in this dimension post-treatment; economic aspects related to treatment, and modifications in professional life during this entire period. The interview questions were designed to guide the interview, providing a better understanding of the participants' experience from injury to rehabilitation, from the patient's perspective and their interpretation of events.

After expressing their agreement to participate in this research by signing the Informed Consent Form (ICF), the patients' testimonials were collected, lasting between forty minutes and two hours, without interruption due to elapsed time. Participants had complete freedom to think and formulate their responses. Efforts were made to respect the emotional impact generated by the interview, making it longer when necessary.

Following the transcription of the interviews, reading, and interpretation of the material constructed during the interviews, the data were analyzed using the discourse method and organized to enable the analysis of patterns and concepts in the study.

The investigations were conducted in accordance with the principles contained in the Declaration of Helsinki. The study was approved by the Research Ethics Committee of the Roberto Santos General Hospital. Approval number: 4,852,922.

RESULTS AND DISCUSSION

From the narratives, it became possible to understand some of the changes in the overall health of the patients. Accounts of traumatic experiences that impacted the quality of life led to behavioral changes, both related to initial isolation and fear, as well as the rehabilitation process, adaptation, and acceptance. The recurring mention of the need to disseminate the topic, still relatively unknown and rarely discussed in academic circles, highlighted the importance of incorporating knowledge about intra and extraoral prostheses into the education of dentists during their university years. Emphasis was also placed on the significance of humanized diagnosis and follow-up.

The studied population consisted of 5 women and 2 men residing in the Central West (Goiás), Northeast (Bahia), Southeast (São Paulo and Minas Gerais), and South (Paraná and Rio Grande do Sul) regions, all over 18 years old, who underwent or are in the process of maxillofacial prosthetic rehabilitation. Notably, one of the interviewed patients' mothers participated in the study. Video calls facilitated the interviewing of patients from various regions of the country, providing the research with the opportunity to address different cultures and realities in light of each patient's experiences (Figure 1).

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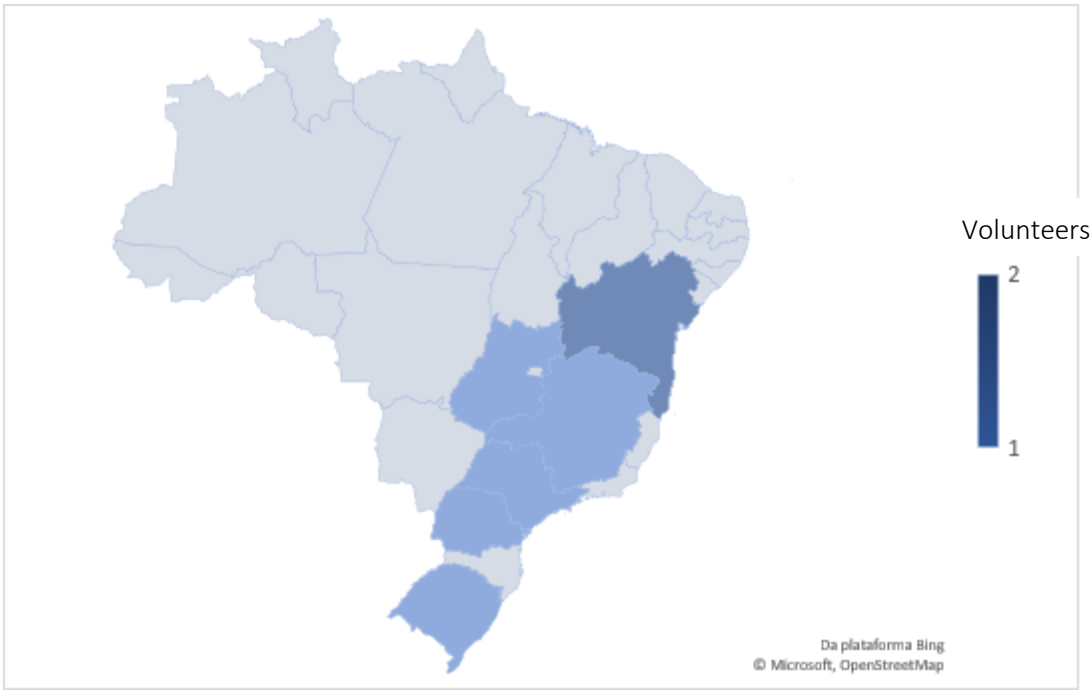

Figure 1. Number of Interviewed Volunteers by State.

- Isolation and Fear vs. Rehabilitation and Quality of Life

The loss of part of the face is a traumatic factor for the patient as it causes a change in appearance, facial asymmetry, and alters the individual's self-image, resulting in the impairment of many other aspects of their life. Individuals who experience facial alterations or amputations, especially with compromised speech functions, often tend to isolate themselves, compromising physical, emotional, and psychological health[9,3].

> "I developed a trauma from hearing my mother saying that I would be a disgrace to the family, that I wouldn't achieve anything in life, that no one would want me (...) my schoolmates used to talk to me like this: 'Oh! Is so-and-so dating you? Until the day I want to, because I am perfect and you're not...' I heard that several times." (Interview 3).

This interviewee's account exemplifies the traumatic and humiliating experiences endured by numerous patients with facial amputations before rehabilitation. These approaches often occur more subtly, but that doesn't mean they are any less cruel. By restoring the face and reestablishing the aesthetics of the missing or malformed part, maxillofacial prosthesis directly impact the restoration of patients' self-esteem and their quality of life[10].

> "Suddenly, you look at yourself in the mirror and say: 'oh, but it's still not perfect...', but I say, it helps you immensely... I went to college after I got it, so I entered college, there were people who didn't even know about my process... I completed college, in four years, some people didn't even know... I always talk about the importance of the prosthesis for you to feel secure, and for you to be able to talk about it... Not to hurt you, but to start understanding that the problem is not yours, it's not you who's defective: it's the other person's view. And if the other person doesn't treat you well, great! It's that relationship that's not worth having, you know?" (Interview 2).

The process of acceptance and adaptation to the new condition varies depending on each individual's peculiarities. However, the use of prostheses contributes to the restoration of self-esteem, aiding in overcoming trauma and improving the quality of life. Professional support, along with the support of close relationships, is closely linked to each person's reactions to this reality and can provide serenity and support to the patient in the challenges faced. Family social and cultural values may indicate the establishment of the most effective strategies to help the patient go through the illness process[11].

> "If anyone has any doubts, don't hesitate because this is a gem that money can't buy... Because for me, it's a trophy that I won after I started using the prosthesis... It's a dream, as long as I'm alive, I intend to keep it... It's something that changes our lives. It changed mine. I use it and intend to use it for as long as I'm here on earth" (Interview 3).

> "I think the cleft lip contributed so much to the construction of my personality that I feel proud of it" (Interview 5).

- Acceptance and Adaptation Process

During the recruitment of volunteers, strong hindering factors were observed in reaching patients who use other prostheses. In this experience, there is a variety of feelings, a process that ranges from denial to self-acceptance and adaptation to the new reality[12]. Cases of isolation or the acceptance process of the moment lived by each person with mutilation were evident during this study. Prejudice from people, limited representation in major media outlets, lack of knowledge, and unpreparedness of many healthcare professionals and the general population were

reported in the interviews. All these facts, along with the scarcity of current scientific articles for research, affirm the assumptions that initiated this study and confirm the need for more research in the universe addressed by this article.

> ".. speaking publicly is a big challenge. But it used to be much worse, you know? I was very ashamed, I couldn't... I always walked with my head down, I didn't talk, and I had difficulty making friends." (Interview 5)

> "So, we like to leave those people intrigued, to know a little about our story. And accept! Accept... We see that you're here alive... And it's accepting, you know? It's thanking God for being here. Having gone through all the surgeries. It's not a disability, it's not one side of your face that is more twisted, that will make your life horrible... You can very well find strength in other people, in people like you (researcher), who are doing everything for us..." (Interview 4)

Sometimes, even after the patient has overcome the challenge, there are still difficulties on the part of the family.

> "I still have people in MY family who still have a little difficulty accepting. For example, I like a lot of photos without the prosthesis, and sometimes I get it from my own family, like: 'Oh, but I look at this and it still hurts me.' And I say: 'I don't see it as pain, I see it as overcoming, right? Look here... let's go, let's change, reframe this.'" (Interview 2)

By reconstructing these lost structures alloplastically, the professional also takes on a social responsibility. Faced with this reality, the various hardships faced by people who have undergone trauma resulting in amputations, and plastic surgery could not resolve, make prosthetic repair the most viable treatment. Such patients need professionals, and dentists, who work towards providing excellent care. Terms like "acceptance," "process," and "experience" were mentioned several times during the interviews, as depicted in the word cloud (Figure 2).

Therefore, it is indispensable that professionals contribute to rescuing the possibility of living with more dignity and promoting this knowledge in academic circles.

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Figure 2. Word Cloud of Most Frequently Mentioned Words by Rehabilitated Volunteers woth Maxillofacial prothesis.

- University Education: Importance of Knowledge about Intra and Extraoral Prostheses in the Training of Dentists, in Humanized Diagnosis and Follow-up.

The lack of preparedness among healthcare professionals regarding this issue and the way they communicate the diagnosis, to the family and the patient, can be crucial in how they will deal with the situation they are experiencing. The reactions provoked by the diagnosis can influence the family's bond with the patient or the image he has of himself[13].

> "They were not professionals who simply graduated in dentistry but specialized in this problem. So, they already had a different vision, another approach to this. And since it was a multidisciplinary team, they talk to each other all the time. Nothing is done alone. So the final result is better." (Interview 6)

Such care falls to the healthcare professional through humanizing care, studying during undergraduate education, and continuously throughout the professional practice, to ensure confidence and discernment when delivering the diagnosis and throughout the entire treatment.

> "I find it so important... to make it truly scientific, to bring it into the University... it is through knowledge that we will be able to go further, make it accessible to the population..." (Interview 2).

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In addition to the importance of scientific knowledge, it is also evident in the interviewee's subsequent statement that the prejudice experienced by individuals with facial losses and aesthetic, functional, or psychic alterations is a factor that distances them from social interaction, experienced in its entirety[14].

> "...I had a friend from the community, she had cancer and lost part of her face. Unfortunately, she died and did not have this opportunity... and today I look at some works done, right, some prostheses that include the cheek, nose... I remember her... how difficult it was for her... she was ashamed to go out on the street to receive visitors, and I imagine how much this affects not only women because I sometimes talk to some men, and they have a lot of difficulty in this matter of relationships, and I say: 'Wow, it could have been an incredible help for her!'" (Interview 2)

In other cases, there is even a lack of knowledge among some Dentists about the proper treatment, which can delay and hinder the entire rehabilitation process, as indicated in the interviewee's account.

> "And dentists... I don't feel a preparation. When I go to a dentist and say, 'Look, I have a cleft lip and palate, my dental load is different...' The person doesn't know... asks what it is... So I don't think there is preparation, you know? I think there is a lack of a subject for you to understand. It's not just a characteristic, it's not just a detail... When a person comes and says: 'I want to fix my smile,' give importance because she will be carrying that scar... So, in terms of aesthetics, surgery, scar... the doctor is 100% perfect... In orthodontics, I don't think there is so much preparation." (Interview 4)

Maxillofacial prosthesis offers a new perspective for society towards the patient and consequently their social reintegration[15]. When there is no knowledge of cases and their treatments, the trust between patient and professional becomes increasingly fragile. Dialogue, education, and knowledge are essential for satisfactory interaction between the doctor and the patient and for a relationship of mutual care and trust[16].

> "When I put it on... the first day of the prosthesis after... 3 months after my accident, right, it was total joy. Oh, it's very exciting! Self-esteem, right? It improves self-esteem a lot, right? It changes everything, changes everything." (Interview 1)

Thus, awakening the undergraduate, still in university, to the field of maxillofacial prosthesis will result in new research, clinical experience, increased knowledge, and professional confidence, which is essential for more effective treatment. The establishment of the bond can be achieved through humanizing care,

through the dentist's knowledge and approach to the reality lived by the patient, fostering successful rehabilitation.

> "Formerly there was no doctor in our region, there was only the doctor from the union, and he used to say it was cataract. So it just got worse, just got worse... then one day my eye wouldn't open anymore... just turned into pus. It was the time he sent me to BH, I even had surgery at the “Hospital das Clínicas” (Clinical Hospital), in São Francisco. The doctors there said that if they had sent me a couple of days earlier, I wouldn't have lost my eye. They had to remove the eye because the worm was already moving to the other cornea. Then I could lose both corneas if he didn't kill one cornea... After 3 months that I had entered the waiting list, I already found a cornea. So when I went to do all the procedures, all the exams, my cornea was dead... So I went after the doctor who operated on me in BH, and he explained to me. It was the mistake of the doctor who attended in my city because if he had sent me 2 days earlier, he would have saved my sight." (Interview 3)

The role of the dentist, as a healthcare professional, must go beyond the treatment of tooth-related pathologies and technical procedures[19]. It is essential that medical professionals can perceive the human being in an integral, complex way, in its various dimensions, seeking, through their work, ways to restore the quality of life of each patient, reducing their anxiety and discomfort in the pre-treatment and post-professional intervention period[17]. Therefore, they can provide the patient with effective technical attention and the possibility of being welcomed with respect so that the psychological traumas generated by mutilation do not worsen due to professional neglect and insensitivity.

Patient rehabilitation includes early diagnosis and intervention. For rehabilitation, continuous attention and the professional's guidance to the concepts of broad health and social inclusion are necessary[18]. Thus, it is fundamental, in the training of dentists, to seek the interface between learning and service to the community, also working in conjunction with other professionals and providing the patient with a multidisciplinary, integral, and humanitarian approach. Thus, the professional/patient relationship should be seen beyond the treatment of pathologies, but by building a relationship of trust and collaboration[19],[17], is much desired in these rehabilitations, which are largely of high complexity.

The methodological approach used revealed some limitations regarding data collection. The memory bias is one of these limitations, as volunteers may not remember certain situations completely. This can be attributed to the time elapsed

since the events or possible traumas related to the issues under analysis. Additionally, as it is a sensitive topic, there was reluctance to address certain issues related to the theme.

Another limiting factor of the work was the pandemic period in which this was carried out. Support groups were sought; however, with the restrictions of the period in question, it was not possible to have face-to-face access to these groups and reference centers for maxillofacial prosthesis rehabilitation. Therefore, it was necessary to recruit volunteers online, which was a significant factor that directly influenced the number of people interviewed, consequently reducing the sample size.

CONCLUSIONS

The accounts in this study demonstrated that the use of prostheses and rehabilitation had a positive impact on all cases heard.

The prostheses contributed to the overall health of each patient, according to their perspective, history and personal unique vision. In addition to partially restoring the function of the lost or mutilated organ, maxillofacial prosthesis allowed for the preservation and protection of post-surgical structures, also improving the natural aesthetics of the organ or tissue.

The importance of disseminating the knowledge built in the possibility of contributing to the scientific community was evident. The creation of foundations for improving the quality of life of this population was confirmed throughout the entire work. The dissemination of these studies will act in promoting the quality of life and health of patients in an expanded way, and the knowledge acquired by each professional will contribute to the possibility of inclusion or re-inclusion of each person in social and community life.

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