

Ajustamento psicossocial de pessoas com amputação: ponto de vista

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ABSTRACT: Every year in Brazil, thousands of people undergo an amputation procedure. In this scenario, institutions that provide care – from surgery to rehabilitation – need to plan and evaluate their care programs based on evidence published in national and international specialized literature. Therefore, aiming to discuss this issue and generate reflections for interventions of the rehabilitation team, this study discusses clinical, sociodemographic and psychosocial factors associated with the process of adjustment to the prosthesis. This study suggests that, in the Brazilian scenario, future investigations should focus on variables of a psychosocial nature, such as the most recent international studies.

Keywords: Amputation; Psychosocial adjustment; Rehabilitation.

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RESUMO: Anualmente, no Brasil, milhares de pessoas são submetidas a procedimento de amputação. Nesse cenário, as instituições que prestam cuidados – desde a etapa cirúrgica ao processo de reabilitação – necessitam planejar e avaliar seus programas assistenciais tendo por base evidências divulgadas pela literatura especializada nacional e internacional. Visando, portanto, propiciar a problematização da temática e gerar reflexões para a intervenção da equipe de reabilitação, este artigo discute fatores clínicos, sociodemográficos e psicossociais associados ao processo de ajustamento à prótese. Sugere-se que, no cenário brasileiro, futuras investigações focalizem variáveis de natureza psicossocial, a exemplo dos estudos internacionais mais recentes.

Descritores: Amputação; Ajustamento psicossocial; Reabilitação.

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INTRODUCTION

Amputation is a surgical procedure in which a limb is partially or totally removed due to physical trauma, tumors or vascular diseases. Amputation is performed aiming to promote the patient's survival and functional improvements, and reduce painful symptoms. In this sense, health care professionals should consider it as a reconstructive intervention^{1,2}.

As the term "amputee" involves the idea of a physical loss, a contemporary critical trend advocates it should be replaced with "person with amputation." In fact, concerns about psychological, social, and behavioral factors have increased, including the creation – by a UK workgroup – of the term *psychoprosthetics* (psychology in prosthetic use) to designate the specific field of studies about the use of prostheses based on conceptions of the rehabilitation process^{3,4}.

As a consequence of wars and conflicts, health demands from amputations have reached global proportions. Estimates suggest between 300,000 and 400,000 survivors of landmine explosions, and 10,000 to 15,000 new cases of amputation every year⁵. Recent data show that around 1.7 million people in the United States have lost one limb due to vascular problems (54%), trauma (45%), and cancer (2%)^{6,7}. Estimates suggest 3.6 million amputees⁸ by 2050.

In Brazil, the lack of appropriate epidemiological measures prevents recognition of regional differences and understanding of national historical evolution. According to indicators provided by the Ministry of Health in 2013, about 40,000 people had an amputation in 2011⁹, indicating the importance of the work for adjustment and well-being of this population.

When evaluating a health condition, health states and contextual factors interact mutually, so that different elements, such as cognition and independence, can positively or negatively impact the way a subject perceives himself. This constant dynamic between personal and environmental factors reinforces the participatory character of the subject and the integration nature of rehabilitation. Then, the concept of adjustment involves the relationship between the subject and the needs resulting from the context of illness or amputation. Particularly regarding amputation and prosthetic use, deeper theoretical and practical knowledge about this theme is required¹⁰.

In 1977, *Prosthetics and Orthotics International Journal* criticized the emphasis on studies addressing the patient's physical condition, rather than the psychosocial perspective. In 2002 this idea was reinforced¹¹. In 2004, *Disability and Rehabilitation* journal dedicated its issues

14 & 15 of volume 26 to issues related to phantom pain and psychosocial aspects (for instance, sexuality), considering that it is not about minimizing the biomedical dimension of the clinical condition, but ensuring improved care¹¹.

In this scenario, institutions that provide care – from surgery to rehabilitation – lack to consistent information to plan and evaluate their care programs. Therefore, it is essential to gather evidence published in the scientific literature to support coherent and effective actions.

Considering these clinical and investigative interests, this study addresses factors related to the experience of amputation, such as clinical, sociodemographic and psychosocial aspects associated with the process of adjustment to the prosthesis aiming to present contributions from the literature and promote reflections about this theme.

The literature on amputation shows that until the 1980s, emphasis was placed on functionality, which was assessed considering the length of time the prosthesis was used (number of hours) and activities performed at home or in community settings. In the 1990s, the focus was on the level of independence achieved by patients in daily activities and continuity after participating in a rehabilitation program¹². Starting in the 2000s, efforts were directed to understanding psychosocial factors and their influence on the rehabilitation process. Thematic axes related to this theme are discussed below.

Clinical and sociodemographic characteristics and psychosocial factors

Characteristics of the clinical condition – such as etiology and level of amputation, time after the surgical procedure, pain intensity perceived by the patient, and use of prostheses – affect the patient's perception of the impact of amputation on his daily life¹¹.

Oncologic cases, in which amputation is performed to preserve life, tend to present a better adjustment than the cases of accidents leading to a lost limb. It may happen due to the presence of other significant factors, such as the need to continue oncological treatment for healing, which could consider amputation as a secondary factor to survival. Then, the adjustment process could be favored by considering amputation as a recovery tool or a useful process, encouraging the participation and engagement of the subject¹¹.

Excisions at circumscribed body extremities, less intense pain and longer excision are also associated with better adjustment. However, the sensation of phantom limb interferes negatively in the patient's adjustment and quality of life^{11,13}.

For young patients, accepting an amputation may be more difficult as they are in a development stage where autonomy and independence are strongly wanted¹¹. In this sense, significant and long-term relationships, years of schooling, and higher socioeconomic level favor well-being and satisfaction with life¹³. Regarding gender, there is evidence that women with amputation deal with more challenges and prioritize the reestablishment of feminine traits, while men tend to value functional recovery¹⁴. However, it is important to take into account the fundamental principles of the person-environment interaction, the social context, and the patient engagement to this process.

Regarding the clinical experience of specialized health teams – just like other conditions of chronic illness – the literature emphasizes that amputation causes multiple changes for patients and their support network due to threats to survival and numerous psychological, environmental, financial and social challenges. Consequently, adjustment to disability corresponds to a multidimensional and subjective process that affects different areas of human existence^{3,15}.

In other words, unlike past perspectives, a consensus observed in the literature analyzed for this study is that the physical aspects of disability are less important in this process¹⁶. Therefore, the surgical and pharmacological progress is no longer the focus, which is now on the psychosocial needs of the patient. Then, particularly in relation to those individuals who refuse to wear a prosthesis or who wear it for short periods, the authors suggest that factors of this nature influence their non-adhesion to the therapy³.

Regarding the social dimension, it is important to reinforce that there is a noxious synergy between stigma and isolation that increases the damages experienced with amputation and intensifies the clinical and sociodemographic elements¹⁶.

Regarding the psychological aspects, feelings of vulnerability, self-perception of dependence, and situations of stress can be added to more serious symptoms, including psychiatric disorders. However, studies on depression among amputees reported results between 28.7% and 51.4%^{17,18}. In addition, when comparing these studies, instrumental and methodological heterogeneity is observed, which limits the support for clinical management from rehabilitation professionals. Several studies have shown significant levels of anxiety and depression between the post-amputation period and the rehabilitation start. Then, even if the psychic suffering lasts two years following the loss of a limb, it is not permanently destructive, progressively reducing until it equals the general population¹⁹.

To understand the psychological impact of

amputation in adults using a prosthesis, it is crucial to assess how patients and their caregivers cope with that situation. Among the strategies adopted, the literature shows that the social support perceived and received – in its informational, instrumental and emotional forms – supports the adaptation of those involved in this experience²⁰.

A meaning attributed to prosthesis

The terms ‘adjustment to amputation’ and ‘adjustment to prosthesis’ are often used interchangeably. However, these conditions are different, since amputation is not always followed by the introduction of a prosthesis³.

The possibility of wearing a prosthesis can contribute to the ideal physical and social appearance established by the environment where the patient lives. However, in some circumstances the use of a prosthesis may be concealed by the patient for the purpose of rebuilding a sense of normality and self-esteem. Then, while for some the prosthesis is part of a secret identity, for others it is experienced as a valuable artifact and extension of one’s self. For these patients, showing the prosthesis would correspond to a specific social identity and the ‘right to difference and efficiency.’ In general, most patients basically want autonomy and freedom over time^{14,20}.

In this point of view, the meaning initially attributed and the meaning developed with the participation of other amputees and their social support network (family members, friends, and health care professionals) will promote differentiated perceptions that will mediate various actions of adjustment. Fitting a prosthesis can assume a singular character and provide an additional characteristic of self-integration and enhancement of skills and abilities. On the other hand, a prosthesis can enhance pre-amputation personal limitations and interrupt development in the different domains of life. In summary, even though the learning process with the prosthesis is described as painful and arduous, most amputees give it a functional or aesthetic value that encourages them to overcome their challenges^{20,21}.

Body image

Body image is a polysemic concept that includes perceptual, cognitive, behavioral, and affective experiences of an individual in relation to his own body. Body image is dynamically and continuously influenced by internal factors (such as feelings of comfort or discomfort) and external factors (such as sociocultural norms)²².

The individual who experiences physical mutilation is confronted with different body images, such as the initial

perception of a non-mutilated body, developed before the limb loss; the perception of a traumatized body resulting from an accident or surgery injury; the idea of a healed body, developed after care; and finally, the perception of a body that is 'extended or complemented' by the prosthesis¹⁶. One of the challenges of psychosocial adjustment is to conciliate these conflicting images¹³.

The reaction to an amputated body, initially disturbing, needs to be reworked. As displaying amputated limbs become more usual, amputation and prosthesis can become progressively naturalized. According to reports of patients, non-acceptance of their modified bodies means living in the past and in eternal mourning²¹. As expected, an inverse correlation between a satisfactory body image and the symptoms of anxiety and depression²³ is identified. In addition, this study shows that poor body image has a correlation with negative perception of well-being and quality of life²³.

Rehabilitation process: particularities in cases of amputation

Due to an increase in contemporary society, the cases of lower limb amputation are a growing concern of health professionals and require complex multidisciplinary follow-up^{3,24}.

The rehabilitation process involves typical stages: a) pre-amputation; b) surgery; c) post-amputation; d) rehabilitation with the prosthesis; and e) maintenance. All these stages should be adjusted to the goals defined by the health team members and the patient, which could mean not trying to adapt to the prosthesis or choosing to walk without this kind of help. Depending on the etiology, the duration of each stage may be different. Traumatic amputations

can generate a more concise process compared to cases of vascular alterations^{24,17}.

The literature recommends the patient's psychological preparation should start in the pre-amputation stage. In this period, the patient should receive information, guidance, and specialized support. Thus, psychoeducational interventions focused on the needs of the patients and their family caregivers aim to clarify: a) factors for the therapeutic decision; b) surgical procedures; c) expected results; d) sensation of phantom pain, sexual and social readjustment; e) adaptation and use of prosthesis; and f) home return and follow-up^{3,20,25}.

In the post-amputation stage, patients deal with their uncertainties with professional help, and activities shared with other amputees provide support and are encouraged by the health team, as they are sources of information based on personal experience that support the necessary changes⁹⁻¹¹. Immediate prosthetic adaptation and development of rehabilitation program are proper measures for overall patient adjustment. Such practice is suggested for the first three months after amputation to promote acceptance of prosthesis and avoid excessive attention to the physical deficiency and pain sensations. It should be noted that these cases present better results in gait tests, neuropsychological evaluation, and daily activities with the prosthesis²⁰. In the maintenance stage, the follow-up is guided by the relationships previously built between the patient, the family members, and the interdisciplinary rehabilitation team.

In summary, it is a consensus in the literature that specialized teams and researchers should prioritize the psychosocial factors. Further qualitative studies addressing the impact of amputation on the patient are required, considering the diversified and dynamic nature of the variables involved in the rehabilitation process.

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