

QUALITY OF SEXUAL LIFE AFTER LIMB AMPUTATION

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ABSTRACT

Amputation is an operation used as a last resort when all other treatments have failed to save a limb. It is a traumatic procedure, leading to a change in lifestyle, social status, relationships, and one's body image, all of which affect sex life and sexual satisfaction. The aim of the study was to analyse the available literature regarding the impact of amputation on sex life and sexual satisfaction. The authors considered sexual difficulties faced by amputees, factors associated with their occurrence, and actions that can be taken in order to answer the needs of patients in this clinical group. A literature review confirmed that amputation surgery negatively impacts sex life. Patients' condition after amputation may be characterised by a disturbed perception of their own body, which is a predictor of sexual dysfunction disorders in this group. Patients can benefit from several therapeutic and educational activities, including alternative methods of pain relief and helpful information provided by healthcare representatives and specialised foundations. A review of the available research indicates a lack of concrete systemic and procedural actions to combat the problems described in this paper.

Key words: pain, body image, sexual satisfaction, limb amputation.

INTRODUCTION

Human sexuality is defined as a comprehensive set of behaviours, beliefs, and attitudes related to sexual activity, attractiveness, and identity. It is shaped by various biological, psychological, social, cultural, and environmental factors and is expressed in various forms, such as sexual orientation, gender identity, and sexual behaviour. The World Association for Sexual Health (WAS) defines human sexuality as a central aspect of being human throughout the lifespan; it includes gender, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction [1]. The World Association for Sexual Health also emphasises the significance of considering diverse means of expressing and experiencing sexuality, and the necessity of exhibiting sensitivity and respect in addressing these issues.

Human sexuality is a complex phenomenon, and it is important to distinguish between sexual function and sexual satisfaction. Sexual function includes the physiological functions that enable intercourse (e.g. erection, vaginal lubrication, ejaculation), while sexual satisfaction refers to the subjective feelings associated with the sexual experience. One's sexual

satisfaction depends on factors such as physical and mental well-being, social functioning, relationships, and one's perception of one's sexuality.

Limb amputation is one of many external factors that can affect not only sexual function, but also the way one perceives one's own sexuality [2]. Amputation is a surgical procedure involving the irreversible removal of all or part of a limb or another part of the body (e.g. part of the nose, a damaged organ) [3]. It is usually performed in the event of an injury, disease, or developmental defect of a limb, but can also be caused by many other things, such as cardiovascular diseases, diabetes, cancer, as well as road accidents or accidents at work. The latest official data on the number of amputations in Poland come from 2018 and amount to over 10,000 lower limb amputations per year [4].

The anatomy and physiology of sexual function related to the lower limbs is complex and involves various anatomical areas and physiological functions. For men, erection is related to the blood supply and functioning of the penis, which is controlled by the nervous system. For women, sexual function related to the lower limbs includes sensations from the vagina, clitoris, and pubic area. Lower limb amputation may affect these physiological functions in different

ways, depending on the site of amputation as well as the degree and type of neural damage [5].

Amputation is intended to improve the patient's overall quality of life and prevent medical complications. Nevertheless, it is associated with certain consequences that may worsen quality of life in some areas, thus becoming a daily burden for the patient. This procedure requires reorganising one's life, and sometimes changing profession or giving up professional life completely. People after amputation often become dependent on the help of other people and lose full autonomy. The postoperative period is especially difficult because it requires the amputee to adapt to the new situation and accept their own appearance, which can be difficult. Additionally, limb amputation can cause pain and discomfort, which may affect sexual pleasure. Changes in bodily function caused by limb amputation may also make certain sexual positions or activities more arduous, which in turn may negatively impact sexual satisfaction [5, 6].

MATERIAL AND METHODS

A systematic review of the issue in Polish literature from 2001-2020 and English literature from 1984-2020 was performed. For this purpose, the PubMed and Google Scholar databases were searched.

RESULTS

We identified 94 articles containing the terms "sexual life" and "limb amputation", 29 articles containing the terms "sexuality" and "limb amputation", 121 articles containing both the terms "limb amputation" and "body image", 40 items containing the terms "phantom pain" and "body awareness", and 19 articles containing the terms "phantom pain" and "sexuality". The selected scientific articles were analysed according to specific selection criteria (full-text scientific works that constitute reports from empirical research, descriptions of meta-analyses of issues, or systematic literature reviews). For the purposes of this study, 32 items were identified. The qualitative analysis of the selected items allowed for the identification of 4 basic thematic areas: psychosocial determinants of proper sexual adaptation to limb amputation, the importance of body image after limb amputation, sexual functioning in the context of pain or fear of pain felt due to amputation, and educational and therapeutic needs in the sexual sphere of patients after amputations.

Therefore, in the subsequent parts of this article, the issues most frequently discussed in the literature in the context of caring for the sexual well-being of patients after limb amputation will be discussed. These will include the importance of psychosocial factors related to the sexuality of people after limb

amputation, changes in body image as a result of amputation, and the consequences of chronic pain (and fear of it) after amputation for the sexual sphere. At the end of the article, available systemic interventions aimed at improving the sexual sphere of amputees will be indicated, along with proposals for further solutions. To present the discussed issues more fully, the items identified in the systematic literature review have been supplemented with other literature items, which in the authors' subjective opinion are helpful in understanding the issues discussed.

FINDINGS

Psychosocial determinants of adaptation to limb amputation

The results of the research analysis indicate that assessment of the qualitative aspect of patients' sexual functioning and well-being is no less important than verification of their physiological sexual capabilities after limb amputation. In a study by Verschuren *et al.*, a series of interviews was conducted with adult patients with lower limb amputations, who were participating in rehabilitation treatment [7]. The youngest person examined was 22 years old, and the oldest was 71 years old. Only one participant had noticed temporary problems with sexual function, but many amputees had experienced changes in their sexual well-being. These results confirm that amputees may experience decreased overall sexual well-being, even when there are no clearly defined functional problems. Participation in the study made them aware of the difficulties they were experiencing, and they began to express the need for specialised information and support from specialists to cope with practical problems related to sexual functioning.

Previous research into the impact of lower limb amputation on sexual functioning and satisfaction has analysed various important psychological factors that may moderate the observed relationships. These factors include depression, anxiety, feelings of isolation, and the occurrence of sexual dysfunctions [5]. The results of these studies confirm that people after lower limb amputation experience various difficulties related to sexual functioning, such as achieving or maintaining an erection, experiencing sexual pleasure, and establishing intimate sexual relationships, all of which may worsen their psychoemotional condition.

A group of Turkish scientists conducted a systematic analysis of the impact of lower limb amputation on sexual activity, using tools such as the Hospital Anxiety and Depression Scale, the Beck Depression Inventory – second edition, the Quality of Life and Body Image Inventory, the Self-Awareness of Body Exposure in Intimate Situations Inventory, and the Sexual Satisfaction Inventory [6]. The study aimed to thoroughly

assess the relationship between psychological factors and the ability to function sexually in people who have undergone lower limb amputation. The study involved 65 participants (49 men and 16 women) aged 25 to 87 years. As many as half of the respondents declared they had withdrawn from sexual activity. Of the sexually active study participants, approximately 60% showed clinically significant levels of sexual dysfunction. These results were strongly associated with higher levels of anxiety and depression, and increased body awareness during sexual activity. Specifically, self-rated body image during sexual activities was found to be the best predictor of levels of sexual dysfunction. Negative emotional states experienced after amputation resulting from, among others, changes in body image may affect self-esteem and self-judgment, which in turn may lead to difficulties in establishing intimate sexual relationships.

The impact of amputation on patients' sex lives ultimately depends on many factors, including the level of social and psychological support they receive. It is important to emphasise the importance of individual differences in the development of specific psychological reactions to limb amputation and how sexual experiences are affected by it. Psychosocial aspects of lower limb amputation affect sexual functioning and sexual satisfaction. Personality and social predispositions may contribute to maintaining the ability to fully enjoy sexual life and experience sexual satisfaction despite limb amputation.

Body image and amputation

According to Krueger [8], one's own body image can be understood as a coherent set of internal images organised into a representation of one's own body. The literature also emphasises the multidimensionality of body image by drawing attention to the main dimensions of the body: cognitive, emotional, and behavioural [9]. Chrostowska-Buzun [10] seems to integrate these 2 approaches, defining body image as a cognitive representation of one's own body that has 3 basic aspects: cognitive, affective, and behavioural. This author treats body image as an element of identity. Yet another understanding of the body image construct can be provided by Schier's definition [11], according to which it is a complex process of experiencing oneself in a bodily way, including one's intrapsychic processes as well as interpersonal relationships.

The concept of body image assumes a specific objectification of the body because it states that a given person is an observer of their own body, directs certain feelings towards it, performs certain activities on it, and adopts a given attitude towards it [12]. We should preferably use the concept of body self [13] if we want to go beyond the perceptual image of the

body or the feelings, behaviour, or attitude that an individual has towards their body and describe the way a given person experiences themselves in their body, or how a given person experiences their own physicality and sexuality. The concept of body self combines 2 important aspects: the objective aspect, which concerns the perceptual image of one's own body, i.e. the set of bodily experiences that are revealed in the body image; and the subjective aspect, including experiencing oneself in one's body along with one's own sexuality (the so-called embodied self). Due to the research tradition in the area of the issues discussed, the concepts of body image and bodily self will be used interchangeably. Still, we should go beyond the description of the perceptual image of one's own body and the specificity of an amputee's experience of their own physicality after limb amputation.

The *body self* construct is subject to constant developmental reconstruction, which is especially intensive when significant changes have occurred in the appearance of the body and the ways of experiencing it. As research shows, the state after amputation is certainly a period in which patients must adapt physically, socially, and mentally to changes in the structure, function, and image of the body [13, 14]. At this time, the usually unconscious image of one's own body may become the subject of attention in the sense that attention is consciously directed to it [10]. Mayer *et al.* indicated that changes in the body resulting from amputation and the use of prostheses are reflected in the perceived body schema and body awareness [15]. These types of changes contribute to reformulating the content of cognitive representations of one's own physicality, ultimately also reformulating various emotional reactions, attitudes, and the resulting behaviours of patients. Therefore, these phenomena should be considered in terms of dynamic processes influenced by many factors, such as age, gender, general physical condition, and various social and environmental factors [16].

Limb amputation is generally associated with significant changes in body image. These are often a consequence of the disease process that ultimately led to amputation, entailing psychological trauma experienced because of inevitable changes in appearance. Disturbances in the perception of one's own body after amputation are the result of social valuation of vitality, physical appearance, and physical fitness. Amputation can therefore be seen as a sign of failure. According to research, people often develop symptoms of depression and anxiety in the first 2 years after amputation [17].

Research conducted systematically since the 1980s indicates that limb amputations are often accompanied by changes in body image [18-23]. Anxiety, depression, and lower quality or limitations in physical activity are strongly associated with negative

body image among amputees [24, 25]. For example, research conducted among patients with unilateral tibial amputation showed that these people assessed their body image more negatively than healthy people [26]. Moreover, these people presented fewer appearance-oriented behaviours and attached less importance to taking care of their physical attractiveness.

Different results were obtained in studies conducted by a team from Scandinavia [7], in which only some people reported that the experience of amputation had made them feel unattractive, which could indicate a worse self-image. Such respondents indicated a strongly self-confronting experience of looking at the reflection of their own body in the mirror, even when the amputation had taken place a long time before. However, most respondents indicated that their body image had not changed after amputation. Some respondents reported that amputation had removed the previously experienced pain or the direct cause of their disability, contributing to a sense of relatively high self-satisfaction and, therefore, a more positive self-image after amputation. Among the respondents, there were also those who reported that using a prosthesis instead of a wheelchair had changed their self-image for the better. One study participant clearly indicated that he had a mostly positive attitude towards his self-image, except for when engaging in sexual activities with his partner.

Some amputation researchers are inclined to attribute the observed changes in the perception and experience of an amputee's own body to changes in self-identity. For example, Senra *et al.* [27] point out that changes in identity after lower limb amputation are not the same as the amputee's body image and functioning and may significantly affect their biographical self and awareness of the impairment. Body image disorders that occur in people after limb amputations have further consequences in relation to various areas of patients' functioning. For example, studies have shown that body image may determine the level of physical activity, including sports, in patients after limb amputation [15, 28]. Another study showed that the body image disturbances found in amputees play an important mediating role in the relationship between personal investments and psychosocial outcomes [29]. There are studies indicating that the psychological consequences of lower limb amputation, including (in addition to depressed mood or the development of symptoms of intense anxiety) changes in self-image, influence how amputation is adapted to in the sexual sphere [30, 31].

As many as half of all lower limb amputees participating in the study by Woods *et al.* [32] were not sexually active. Approximately 60% of the sexually active participants of that study presented various sexual dysfunctions, which were accompanied by higher levels of anxiety and depression. Patients after ampu-

tation who were diagnosed with sexual dysfunction were more self-aware of their own body exposure during sexual activities. Self-awareness of body image during sexual activities was also the strongest predictor of sexual dysfunctions in the group of people after lower limb amputations.

Qualitative research in a group of women after this type of amputation [33] highlighted 3 dominant themes in their narratives, which the authors of the study defined in turn: "I don't like the way I am", indicating a changed relationship between the subjects and their bodily selves; "I am spoiled/unwanted", indicating changes experienced by respondents in romantic relationships; and "I am the same but different", referring to changes in women's social roles. These patients' accounts highlighted experiences of reduced sexual well-being as well as disrupted body image, stigmatisation, and reduced resilience.

Stump pain and phantom pain

The literature review shows that pain is one of the most troublesome ailments for many people after amputation. Chronic pain lasting several months after surgery does not serve a warning or protective function but becomes a disease. In such a case, it causes a deterioration of the quality of life in the emotional, physical, social, and sexual spheres. After amputation, pain can be divided into 2 categories: stump pain, which occurs within the amputation wound or scar, and phantom pain.

Stump pain is usually reminiscent of the receptor pain that occurs after surgery. The most common causes of stump pain are osteomyelitis, thromboembolism, inflammation, and pressure ulcers. The pain may be caused by dressings that are too tight or a poorly fitting prosthesis. It is a constant pain that is dull, drilling or pulling, or sometimes burning. Sometimes it occurs in a paroxysmal form [34].

Phantom pain occurs in 60-80% of patients immediately after surgery [34, 35]. As time passes, the pain becomes less bothersome and occurs less frequently. After the complete healing of the wound, pain persists in 2-4% of patients approximately 2 years after surgery. It then constitutes a huge therapeutic challenge as the pain or discomfort is felt despite the absence of the limb. Several mechanisms for this phenomenon have been described, but no single reason has been clearly identified. It is believed that this is most likely a multifactorial process influenced by somatic, psychological, and social factors [35]. The strongest sensations concern the distal parts of the limbs (e.g. hands, feet, fingers) because they have a larger representation in the sensory cortex. Due to the memory of pain in the limb, pain is more intense in people who had limb pain before surgery. Phantom pain is usually permanent and may intensify or be triggered

by touching the stump, fatigue, drowsiness, anxiety, nervousness, and thoughts about amputation [34, 36]. Intensification is also observed in the evening or at night [34].

As research reports indicate, pain significantly affects physical well-being, has a negative impact on one's psychophysical condition, and perception of pain is greater in clinical groups with higher levels of depression. Additionally, the presence of chronic pain makes it difficult to diagnose and treat depression. In general, all the factors mentioned above are interconnected and influence each other, which leads to a deterioration in the quality of an amputee's sexual life [37].

A study that assessed the relationship between overall pain (without distinguishing between phantom pain and stump pain) showed that pain after amputation was accompanied by deterioration of sexual function. Overall lower International Index of Erectile Function (IIEF) scores have been observed in people suffering from amputation pain. One study indicated that amputation is associated with decreased sexual function in male patients, while lower scores were found for erectile function, sexual desire, and overall satisfaction [5]. The extent of pain during intercourse may affect sexual positions, which in turn may limit the ability to achieve sexual satisfaction [5].

The literature review allowed us to conclude that an important problem faced by patients after amputation that significantly affects their well-being in the sexual sphere is the fear of pain during intercourse. This problem also affects patients' partners, who are often afraid that they may cause stump pain [38].

It is important to emphasise that the pharmacotherapy that is used to treat phantom pain may also constitute an obstacle to sexual activity after amputation. In the treatment of phantom pain, antidepressants, beta-blockers, and antiepileptic drugs are used, among others [39]. All the above-mentioned groups of drugs may cause low libido as a side effect and have a negative impact on sexual life. Patients using these drugs to treat phantom pain after limb amputation report less willingness to return to sexual activity [40, 41].

Sexual education and therapeutic activities for amputees.

Sexual education for amputees still seems to be a neglected aspect in the therapeutic process of patients. There is a great need in this group for educational and therapeutic activities in the field of sexuality and returning to sexual activity. Although amputees show interest in receiving education and support in this area, they rarely have the opportunity to talk about it with health care representatives [42]. In one study of health care workers caring for ampu-

tees, only 20% of them had been asked questions by their patients about sexual matters [43]. Considering the size of the problem and the frequency of difficulties with sexual functioning among amputees, it can be concluded that they feel shame and are afraid to discuss such topics. In this study, specialists themselves did not feel competent to conduct this type of conversation with patients. An effective solution to this problem may be to create protocols and algorithms that identify who should be responsible for raising these issues with patients, as well as more frequent and more detailed training of staff in the field of sexual education [43].

Reports from patients who have undergone lower limb amputations indicate the potential importance of a compassionate approach in therapeutic interventions [33]. Another conclusion from the research of Ward Khan *et al.* states the need for health care professionals to involve the partners of patients after limb amputation in conversations regarding sexual rehabilitation, as well as the need to encourage patients to build a mutual support network.

Some publications indicate the effectiveness of cognitive-behavioural psychotherapy in improving the process of adaptation to changes in body image as it can significantly improve patients' everyday functioning, also in relation to the sexual sphere [44]. The authors of this study propose the use of various forms of psychoeducation and psychotherapy, taking into account psychotherapeutic influences implemented in the form of individual psychotherapy, couples' psychotherapy, and group psychotherapy. It should be emphasised that this psychotherapeutic trend has a developed methodology for working with patients experiencing pain resulting from amputation [45] as well as experiencing losses in their own body [46], not to mention the many positive outcomes of working with patients experiencing changes in their own body and their consequences [47].

A review of the literature on pain after limb amputation shows that it is very important to focus on the treatment of stump pain and phantom pain by selecting appropriate drugs or other treatment methods, such as physiotherapy, biofeedback, or acupuncture. It also seems important to educate patients and their partners about the side effects of medications that affect sexual life, e.g. low libido.

Treating chronic phantom pain with methods other than pharmaceuticals may be an additional therapeutic option for patients who experience side effects such as decreased libido. These include elements of physical therapy, such as transcutaneous electrical nerve stimulation (TENS), acupuncture, thermotherapy, and the use of ultrasound [8]. Another important aspect is early mobilisation of the affected limb and the fitting of appropriate prostheses as soon as possible [44]. For people after amputation,

appropriate prostheses significantly affect their self-esteem and perception of their own body. However, research conducted among students of orthotics and prosthetics shows that they do not feel prepared to discuss sexual issues with their future patients [48].

Mirror therapy is another effective method of combating phantom pain. It involves exercising the healthy limb every day while observing it in the mirror, creating the illusion that there are 2 healthy limbs. This allows the correct image of the limb to be recreated in the cerebral cortex, which results in a reduction of pain or phantom sensations [49].

Social campaigns organised by foundations supporting disabled people are of great help in supporting the sexuality of amputees. Normalising the image of an amputee as active and sexually satisfied is very necessary not only for patients or their partners, but also for society. Through conferences, educational films, scientific research, and enabling contact with specialists, these organisations try to dispel stereotypes related to the sexual life of people with disabilities. Within this process, the exchange of experiences between patients is also very important [50].

CONCLUSIONS

The conducted review of research on the sexuality of people after limb amputation indicates several difficulties in the area of sexuality that people from this clinical group may face, including both psychoemotional and psychosocial factors, as well as purely physical or even physiological factors. In essence, the importance of medical staff providing basic information on sexuality after amputations should be emphasised [7] because it may help identify potential difficulties amputees will face when it comes to sexual intercourse. Using various forms of supporting amputees in coping with difficulties and sometimes providing them with appropriate psychological, psychotherapeutic, and medical care can improve the quality of their sexual life, but it can also be preventive in nature, protecting against further negative mental health consequences.

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