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Portraying the amputation of lower limbs: an approach using ICF

Retratando a amputação de membros inferiores: uma abordagem por meio da CIF

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Abstract

Introduction: Amputation is a trauma that involves important functional, psychological and social sequelae. The International Classification of Functioning, Disability and Health (ICF) is based on the biopsychosocial model and enables understanding functioning and disability through the interaction of its components. **Objective:** This study's aim was to depict functioning and disability using the ICF conceptual interaction model from the perspective of individuals who suffered a lower limb amputation. **Methods:** The qualitative approach was used and included a semi-structured interview held with six participants. **Results:** All the participants used assistive devices such as crutches, wheelchairs or walkers: three used prostheses and the other three emphasized their difficulty in acquiring prostheses from the Social Security Service or Public Health System. Social support, especially that provided by family and friends, is a major facilitator. The importance of acquiring and adapting prostheses to enable the rehabilitation of amputees became clear; however, rehabilitation is not restricted to the acquisition of prostheses. A rehabilitation program directed to restoring functionality is needed. **Conclusion:** The multidirectional approach using the ICF's conceptual interaction model enabled important insights concerning public health issues, such as obstacles related to the access to rehabilitation services and a lack of preparedness on the part of health professionals in relation to care provided to amputees.

Keywords: Amputation. International Classification of Functioning, Disability and Health (ICF). Rehabilitation.

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Resumo

Introdução: *A amputação é um trauma que envolve sequelas funcionais, psicológicas e sociais importantes. A Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF) baseia-se no modelo biopsicossocial e permite a compreensão dos processos de funcionalidade e incapacidade através da interação dos seus componentes.* ***Objetivo:*** *O objetivo deste estudo foi retratar o processo de funcionalidade e de incapacidade por meio do Modelo de Interação Conceitual da CIF a partir da percepção de pessoas que sofreram amputação de membro inferior.* ***Métodos:*** *Utilizou-se abordagem qualitativa com realização de uma entrevista semiestruturada, aplicadas em seis sujeitos.* ***Resultados:*** *Todos os entrevistados faziam uso de dispositivos auxiliares de marcha como muletas, cadeira de rodas, andadores sendo que três deles possuíam prótese, e os outros três destacaram dificuldades de aquisição da mesma por meio do SUS ou Previdência Social. O suporte social, sobretudo aquele oferecido pelos familiares e amigos, é importante facilitador. Ficou evidenciada a importância da aquisição e adaptação à prótese para reabilitação da pessoa amputada, porém reabilitar não é somente adquirir a prótese, pois é preciso da reabilitação para a funcionalidade.* ***Conclusão:*** *A abordagem multidirecional, por meio modelo de interação conceitual da CIF, permitiu refletir questões importantes da saúde pública, como os obstáculos relacionados ao acesso aos serviços de reabilitação e o despreparo dos profissionais de saúde no cuidado à pessoa amputada.*

Palavras-chave: *Amputação. Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF). Reabilitação.*

Introduction

The amputation of lower limbs is a trauma that involves important functional, psychological and social sequelae that interfere in the individual's quality of life (1, 2). It is a public health problem faced around the globe. Amputations of lower limbs are estimated to account for 85% of all amputations, though there is no precise information concerning this epidemiology in Brazil (3).

Looking at the amputee from the perspective of functionality broadens horizons and contextualizes the individual, family, and community from a social perspective, giving priority to aspects related to social inclusion, the performance of activities and the participation of the individual in his/her family, community and society (3, 4).

The Amputee National Guidelines (3) recommend that the International Classification of Functioning, Disability and Health (ICF) be used in research, surveillance and reports, and also by workers from the public health system to monitor the functional status of amputees (5, 6). The use of the ICF among individuals who experienced amputations ensures their right to move through different functional conditions, clarifying, for instance, the benefits accruing from the use of prostheses provided by the Brazilian Public Health System (SUS) during daily living activities. Rehabilitation actions stand out and provide a feasible alternative for the government, together with social support mechanisms, to qualitatively assess the process in which individuals with disabilities recover their autonomy and quality of life (3).

In addition to a universal coding scheme, the ICF proposes a model to think of functioning and disability based on the junction of two dichotomous models: interest in disability (biomedical model) and social interest (social model) (7). The biomedical model considers disability a problem of the person directly caused by a disease, trauma or any other health condition that requires medical care under the form of individual treatment provided by healthcare workers (8). The social model considers disability to be primarily a problem created by society, in which disability is not an attribute of the individual, rather a complex set of conditions, many of which are created by the social environment itself. Hence, the solution for the health problem, in that understanding, requires social action and is the responsibility of society to make the necessary environmental changes (4).

The ICF also enables assessing the impact of the presence or absence of facilitators and barriers that positively or negatively influence an amputee's functional performance. Environmental barriers, such as inaccessible physical environment, lack of appropriate assistive technology, negative attitudes of people toward disability, as well as deficient services, systems, and inappropriate or nonexistent policies, can hinder the routine of amputees. Facilitators, as opposed to barriers, are elements that facilitate functioning and reduce the impairment of an individual (9).

The onset of a disability brings with it numerous barriers with the potential to harm an individual's physical, social and economic wellbeing, aside from potentially having an adverse impact on education, employment, income and unequal access to health services, political and social participation (10, 11, 12).

The identification of barriers to the access of health public services can help explain why people who have experienced amputation wait so long to obtain prostheses and usually are able to access rehabilitation services provided by the SUS only late in the process (13).

Few studies explore the perceptions of individuals concerning their functioning and also take into account the individuals' cognitive, emotional, and motivational states and how contextual factors interact in the social environment to produce disability (14). Based on the understanding that the context that emerges when a disability is involved essentially individual and depends on the environment, this study's objective was to portray the functioning and disability spectrum through the Conceptual Interaction Model provided by the ICF based on the perceptions of people who had their lower limbs amputated.

Methods

This is a descriptive, exploratory study with a qualitative approach. Qualitative studies focus on the individual as a whole and on the context of the world s/he experiences, trusting subjective reports and experiences, enabling a greater range of meanings and unexpected connections. Additionally, they focus on the individual so s/he is able to express personal feelings and experiences, "giving him/her a voice" (15, 16).

Six individuals, both sexes, with amputated lower limbs, older than 18 years old, and with cognitive capacity were selected. Amputations included unilateral or bilateral transfemoral, knee disarticulation and transtibial amputations, with either trauma caused by traffic accidents or vascular problems. These individuals also received care provided by the Extension Project: Amputee Multidisciplinary Rehabilitation, Santa Catarina State University (UDESC). This project has existed for four years and focuses on the physical therapy, pre- and post-prosthetization, of people who had limbs amputated and are covered by the public health system. These individuals were intentionally selected, since in a qualitative approach, the composition of the investigation group seeks to include the main social actors experiencing the phenomenon under study.

The study was approved by the Institutional Review Board at UDESC (No. 902.159) in accordance to Resolution No. 196/9613. All the participants were informed of the study's objectives and data collection procedures and voluntarily signed free and informed consent forms and agreed with being recorded so that all ethical precepts concerning confidentiality, anonymity and freedom to withdraw from the study at any time were complied with.

Data were collected in two stages: a questionnaire addressing personal information and history of amputation was completed and then a semi-structured interview was conducted.

The interviewer was a physical therapist with six years of experience in the field of collective health and two years caring for patients with amputated lower limbs. A pilot test was initially conducted with interviews held with three individuals in order to be familiarized with the instrument and the dialogical approach with the population under study.

Immediately after the pilot test, the interviews were individually conducted in a private room. Interviews were audio recorded and guided by a script addressing the study's questions in order to capture the perceptions and opinions of the participants concerning the main barriers and facilitators involved in the process of therapeutic choices: access to health services, including Primary Health Care (PHC), and average and high complexity services; access to assistive devices and prostheses; and access to rehabilitation, in order to portray functioning and disability as experienced after an amputation.

As part of the methodological process, the authors transcribed the audio-recorded interviews and checked the transcriptions. At this point, data analysis was initiated through pre-analysis, exploration of material, treatment and interpretation of data. In this process, the raw material was organized into categorized thematic units based on the ICF components. The thematic units can be seen as units of meaning that naturally emerge from a text (17). To adapt the narratives so that they correspond to the standardized ICF language, transcription and coding of data was based on the model provided by Cieza et al. (18). The transcription is a resource, through which the researcher makes the context more accessible to readers, re-elaborating the text and giving emphasis to each interview's vital tone and the most expressive categories (19).

Data were organized into frames representing the Conceptual Model of Interaction of ICF components (4). The diagram shows that disability and functioning are seen as the result of interactions between health

conditions (diseases, disorders, injuries) and contextual factors. Contextual factors include external factors (e.g., social attitudes, architectural characteristics, legal and social structures, as well as climate, terrain, and so on), while internal factors include gender, age, lifestyle, social status, education, occupation, past and present experiences, general behavior, character, and other factors that influence the way disability is experienced by individuals.

The participants' individual diagrams enable depicting and interpreting the interaction among the biopsychosocial ICF model's components involved in the disability of each amputee. To facilitate the presentation of data, we created two diagrams unifying data provided by the three interviewees with prostheses and the three without prostheses. Data were presented according to the important role prostheses play in one's health condition, to facilitate both the physical and psychological rehabilitation of individuals (20).

The theoretical framework was based on the International Classification of Functioning, Disease and Health (4) from the WHO Collaborative Center for the Classification of Diseases in Portuguese, University of São Paulo, and published in Brazil by EDUSP in 2003.

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Results

The interviews generated 288 minutes of recording and lasted 48 minutes, on average. Six individuals who experienced the amputation of a lower limb participated. All the participants reported their perceptions concerning the main barriers and facilitators involved in rehabilitation. Of the interviewees, two were women and four were men, aged from 35 to 61 years old, with an average age of 47 years (SD ± 9.91). In regard to their marital statuses, 3 (three) were married, 2 (two) were single and 1 (one) was separated. Regarding the amputation, 5 (five) had a transfemoral amputation and only 1 (one) had a transtibial amputation; three presented traumatic etiology (ICD T13-6) caused by traffic accidents and three presented a vascular etiology (ICD I73-9). Time since amputation ranged from 1 to 9 years (± 4.16); three individuals used prostheses and three did not.

The participants' occupations prior to amputation were: one dressmaker, one security guard, one administrative assistant, one truck driver, one cement mason assistant, and one fisherman. Currently, most participants are either off work or retired due to the amputation (five participants).

The transcription and coding of primary data were grouped according to the script's questions and are presented in Table 1.

The first diagram (Figure 1) depicts the functioning and disability of amputees who did not have prostheses. The health condition generated by the amputation impacted the interviewees' body structures and functions, as reported by the participants and transcribed in accordance with standardized ICF language: decreased muscle tone and decreased movement amplitude; changes in tactile function (itching and change in stump sensitivity); and change in emotional functions (moments of discouragement).

Table 1 - Description of ICF categories based on the Interview Script

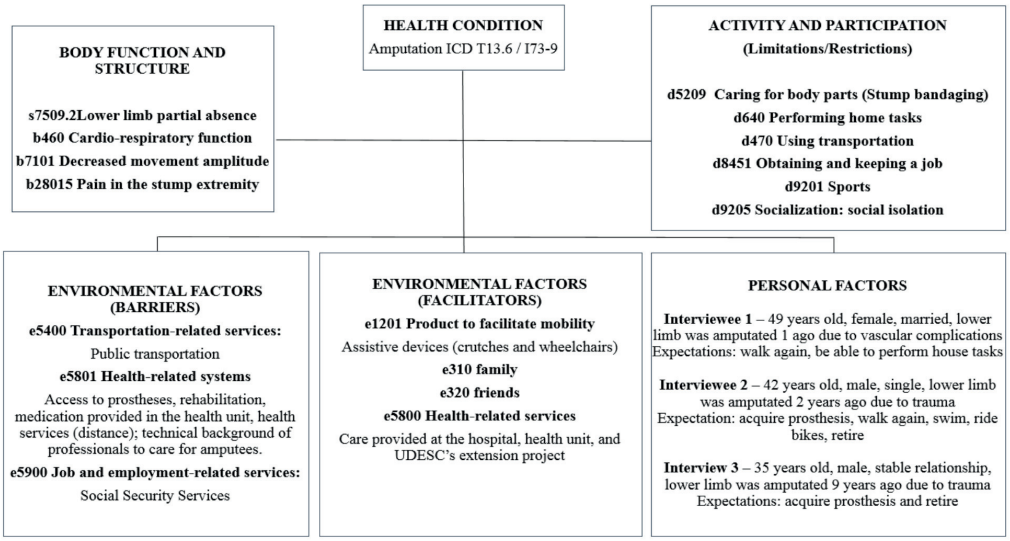
(To be continued)

Item	ICF category	Additional Information
Which health services have you been through since your amputation? What do you think of the access to these places?	e5801 Health-related systems d470 Using transportation e5400 Transportation-related systems	Difficult access to rehabilitation services - Difficulty in using public transportation services
Have you ever been to the Health unit after the amputation? How do you see your health unit?	e5801 Health-related systems d5209 Caring for body parts	Care provided to amputees, professionals' technical background, distance from the health unit Guidance on stump bandaging
Have you ever consulted with experts, such as orthopedists, physiatrists, vascular, physical therapists, occupational therapists, psychologists or nutritionists?	e5801 Health-related systems d4602 Mobility outside home	Participation in UDESC' extension project and professionals' technical background -

(Conclusion)

Do you use or have you used crutches, canes, wheelchairs, or walkers? What difficulties have you faced or what factors have facilitated for you getting these devices?	e1201 Product to facilitate mobility e310 Family e320 Friends	Use of crutches, wheelchairs, and walkers - -
Do you use or have you used prosthesis? What difficulties have you faced getting the prosthesis? What were the factors that facilitated you getting the prosthesis?	e1151 Support products for daily personal use d450 Take care of home objects e310 Family e320 Friends e5900 Job and employment-related systems	Prostheses How to use prosthesis - - Access to Social Security Services

Note: Interviews with the participants and coding based on the Model adapted by Cieza (2005).



Note: Structured Interview Script organized according to the ICF Conceptual Model (World Health Organization, 2003).

Figure 1 - ICF Conceptual Interaction Model – Amputees who do not use prostheses.

The study's participants report various limitations, especially those related to self-care, home tasks, specific difficulties regarding stump bandaging, and exercising. Limitations regarding mobility, such as difficulties moving within and outside the home, even with the help of assistive devices to facilitate gait, difficulty using transportation (driving a motor vehicle or using public transportation). Additionally, the reports indicated individuals are significantly restricted in their participation in their social milieu, which is evidenced by abandonment of leisure activities and sports, loosing their jobs, and social isolation.

In terms of environmental factors, most reports present the following facilitators: the physical therapy provided in the extension Project: Amputees Multidisciplinary Rehabilitation (UDESC), family and friends support, the quality of health care provided in the hospital setting and in health units. Assistive devices such as wheelchairs, walkers and crutches were other environmental factors considered to facilitate functioning.

The interviewees who did not use prostheses also reported barriers in the health system, obstacles that are faced accessing specialized services expected within a rehabilitation program (e.g., physical and psychological therapy) and in access to prostheses. Other barriers involve a lack of preparedness of healthcare workers to provide care to amputees, such as not providing guidance on stump bandaging. Difficult access to health units, given geographical distance, as well as difficulty obtaining medication in these places also stood out.

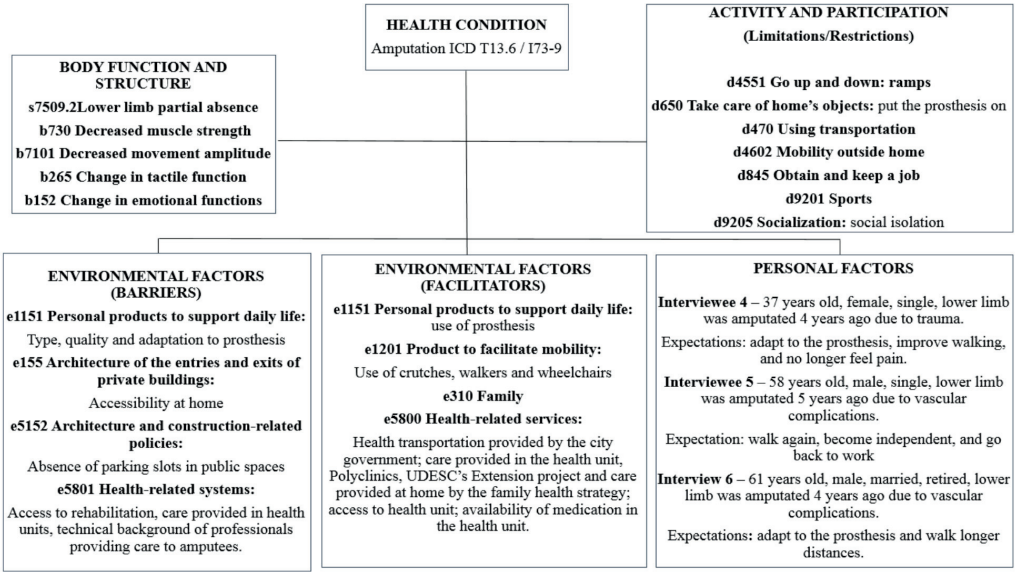
The reports include barriers concerning jobs and employment, difficulty accessing Social Security and Professional Rehabilitation services, in addition to a

lack of welfare benefits. The interviewees who do not use prostheses noted that the public transportation is an environmental barrier that mainly impedes participation in social situations.

When we analyze personal factors, expectations concerning rehabilitation stand out, especially the acquisition of prostheses, and, therefore, the possibility of walking again, of being able to perform household chores and leisure activities. Another expectation frequently mentioned by the participants was related to the possibility of retiring.

The second diagram (Figure 2) represents the functioning and disability spectrum of amputees using prostheses. Also, the amputation continues to have an impact on the interviewees' body structures and functions such as: partial absence of lower limb; cardiorespiratory function; pain in the stump; and decreased movement amplitude.

The participants who use prostheses pointed out limitations regarding mobility for short and long distances, or even leaving home, emphasizing difficulties going down ramps using prosthesis, using public transportation and driving a motor vehicle. Limitations in putting the prosthesis on and participating in sports were also reported. In regard to restricted participation, similar to the first diagram, the participants reported losing their jobs and social isolation caused by the disability.



Note: Structured Interview Script organized according to the ICF Conceptual Model (World Health Organization, 2003)

Figure 2 - ICF Conceptual Interaction Model – Amputees who use prostheses.

In regard to the environmental factors, the participants reported that a prosthesis is an important facilitator of the rehabilitation process, as well as the care provided by the Extension Project: Amputee Multidisciplinary Rehabilitation (UDESC). They also reported the care provided at home by the family health teams after amputation, in addition to access to healthcare and medication provided by the health units. Transportation provided by the city government or their own means of transportation stood out as important facilitators of an individual's mobility.

Barriers faced in health services, access to rehabilitation and physical therapy treatment, a lack of preparedness on the part of healthcare workers, and lack of guidance stood out. In regard to personal products provided to support daily life, barriers included the quality of prostheses provided by the SUS and lack of guidance on how to use these devices, which hinder adaptation to equipment in daily life.

In regard to support networks, barriers include a lack of family support regarding frustration that is experienced due to the need to depend on others to perform various daily living activities. One issue raised by the participants referred to the architecture of their homes, circulation areas, which are obstacles to accessibility. Similarly, they questioned policies related to

architecture and construction due to a lack of parking spaces and accessible areas for disabled individuals arriving at specialized outpatient services.

Personal factors of those using prostheses included expectations for the rehabilitation process and adaptation to the prosthesis, the possibility of walking longer distances, and becoming independent. Additionally, one interviewee highlighted his desire to be rehired and have a paid job.

Discussion

Two specific diagrams were developed (Figures 2 and 3) and portray the functioning and disability of amputees using the ICF Conceptual Interaction Model. The hypothesis was that individuals who used prostheses would face fewer personal and environmental barriers and fewer difficulties performing activities and engaging in social participation. The functional portraits, however, show various inter-relationships among the functioning components proposed by the ICF, with many causes and effects experienced by both those using prostheses and those who did not. All the amputees experienced limitations in activities and restrictions on social participation, suggesting that the process faced after an amputation includes many functional losses (21, 6).

In general, the participants who used prostheses presented similar characteristics, even given a health condition that impacts body structures and functions, while aspects such as pain, changed sensitivity, decreased strength and movement amplitude, become a common aspect seen as components that restrict an individual's activities. This shows the negative effect of amputation on one's body structures and functions that result in difficulties faced in the individuals' performance of daily living activities and in their mobility, as observed by other studies (12, 22). These limitations, in turn, influence the participation of the individuals in the community, as they induce a process of becoming socially isolated, both for those using prostheses and those who do not. These negative responses may interfere in one's recovery and self-care, as well as possibly leading to a feeling of discouragement and hopelessness regarding the recovery process (23). Additionally, shame and social stigma and a feeling of suffering discrimination due to one's physical condition can result in aversion to one's own body. For that, social support networks are extremely important in the coping process and in encouraging social reinsertion (6, 19, 24).

Family support is an important facilitator of the regaining the ability to function because it enables social participation and encourages self-care. Pedrinelli (1) states that support, especially that provided by the family, is one of the most important aspects on a patient's recovery, because the family is one of the human being's main groups of reference. This fact was also evidenced in other studies in which individuals receiving greater social support present better health conditions, and better physical and psychological performance, in addition to greater treatment adherence (11, 14). A study conducted with patients who had lower limbs amputated (6) reports a high correlation between ICF qualifiers and the results of a quality of life scale (SF-36), especially in the social function domain.

In regard to products intended to facilitate mobility, the interviewees reported that assistive devices such crutches, walkers, and wheelchairs provided by the SUS are accessible. Access to prostheses, however, as well as their quality, requires attention. While those who did not have prosthesis reported a long wait to acquire them, those who already had prostheses reported various barriers related to the type and quality of these devices, and a lack of appropriate training that hindered adaptation to the equipment, and both of which caused pain and premature tiredness when walking. Therefore, these devices end up interfering in daily activities and limiting the participation of individuals in society (21). Despite the technological advancements achieved in prosthetic components that enable tailored fitting systems according to the profile of each patient, the devices provided by the SUS are still traditional devices with little technology in terms of precision, quality, comfort or use. The material used does not always follow scientific technical criteria and, when meeting resistance criteria, they present problems related to excess weight that causes significant inconvenience to users and added costs to the SUS (25).

According to Salawu et al. (26), the manufacturing of prostheses requires specific knowledge, especially in regard to fitting a prosthesis, otherwise the individual may experience wounds on the stump caused by a poor fit, eventually requiring the interruption of its use, restricting the individual's activities, and even preventing him/her from working. Tonon da Luz (27) concluded that wounds and weariness related to a stump cause functional limitations directly affecting amputees' quality of life.

Prostheses play an important role in rehabilitation because they compensate for functional loss and

improve mobility. Their quality influences adaptation so that the heavier the prosthesis, the greater one's energetic expenditure and the poorer is mobility, which impairs quality of life and decreases satisfaction (28, 29). Additionally, aspects such as prosthesis alignment and symmetry contribute to better adaptation and functionality, enabling the individual to more rapidly resume work and social life (30).

Nonetheless, the rehabilitation of an amputee does not necessarily include prostheses; as shown in this portrayal of the ICF, having a prosthesis is not synonymous of independence. There is a need for a rehabilitation process focused on functionality to enable individuals to perform daily living activities within their social environments, regardless the use of prostheses (21, 31).

These individuals experience many barriers in the health system and services, which negatively affect their activities and participation, hindering access to the specialized care necessary for those with an amputation and to their rehabilitation (multidisciplinary treatment). The reports indicate a lack of preparedness on the part of healthcare workers when providing care to amputees, not providing appropriate guidance regarding stump care and bandaging. This situation harms the delivery of integral care and effective rehabilitation (32).

In contrast, access to the Extension Project: Amputee Multidisciplinary Rehabilitation (UDESC) appears as a facilitating environmental factor for functioning. The university extension project makes an effort to provide care to amputees in an attempt to compensate for barriers faced when accessing rehabilitation services within the Brazilian health system. The Amputee National Guidelines, a document sanctioned by the Ministry of Health, reinforces the importance of the early implementation of rehabilitation actions and of preventing disabilities through an integrated rehabilitation services network; in practice, however, there are many gaps caused by a lack of resources and effective implementation of policies directed to disabled people, in which care delivery, when available, is disconnected and disorganized (3, 33).

Additionally, many disabled individuals cannot leave their homes due to architectural problems both in their own abodes and in public areas, due to mobility problems and transportation, among others (10, 34). Studies identified that cost, geographical distance, and lack of transportation/difficult access to services, along with the fact these individuals no longer feel useful or do not feel satisfied with themselves (4).

There are also difficulties regarding the possibility of going back to work related to professional rehabilitation. In the ICF Activity and Participation component, only one of the interviewees continues to work after amputation. The others reported being off work or retired. Considering that the average age of the participants was 47 years, thus considered to be in a productive age bracket, professional rehabilitation has not been effective. This aspect may be related to barriers found in the Social Security Service due to failures in the professional rehabilitation model provided by the state. The service does not comply with what is provided in the Social Security Law regarding professional habilitation and rehabilitation in order to professionally and socially (re)insert individuals, victims of some injury or sequelae, and his/her dependents (35, 36).

Guarino (37) observed this situation when he analyzed the rate of return to work among 78 individuals with lower limb amputations. He verified that 54 of these individuals were retired and only 8 resumed work, while the remaining had some continued benefit or were seeking a job.

Despite considerable spending on disability compensation and early retirement, which could often be avoided, there is a lack of specific and well-planned actions, the implementation of which depends on political-administrative will and a paradigm shift regarding an increased focus on the etiology of all these health conditions (38).

The way the ICF was structured, with its dimensions that comprise various health conditions, healthcare workers are able to see the patient individually and to identify situations that are not normally identified in routine assessments, but which end up interfering in the lives of these individuals and in their social participation. The importance of using the ICF across disciplines becomes clear and this study facilitates its use in various settings, such as clinical practice, teaching and research.

Conclusion

This study clarified the following interactions among ICF components: the amputation of a lower limb changes one's body structure and functions, as it decreases muscle tone and movement amplitude, in addition to changes directly related to the stump, such as decreased local sensitivity. These changes directly affect participation in activities, especially those regarding mobility, leading to social isolation. Various environmental barriers were

reported regarding difficult access to health services or lack of preparedness on the part of healthcare workers in regard to the care provided to amputees. A family and friends support network can ease the social reinsertion of individuals who expect to be able to resume independent daily living activities and work.

The multidirectional approach, through the use of the ICF conceptual interaction model, enabled reflection upon important issues from the public health sphere, such as obstacles related to access to specialized services necessary when there is a condition of amputation. The relevance of having access to prostheses for the rehabilitation of amputees became clear; however, rehabilitation does not necessarily mean acquiring prostheses. There is a need to implement a rehabilitation process directed to the individual's functioning.

We suggest that future studies include instruments or scales that enable assessing functioning and disability through ICF coding and qualifiers to measure and compare data among health services, countries and at different points of the rehabilitation process. We also verified the need for studies addressing and comparing perceptions of amputees who use prostheses and those who do not.

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