Cadernos Brasileiros de
Terapia Ocupacional
Brazilian Journal of Occupational Therapy

ISSN 2526-8910

Original Article

Cross-cultural adaptation of the Impact on Participation and Autonomy questionnaire for Brazil for people with spinal cord injury

Adaptação transcultural do questionário Impact on Participation and Autonomy para o Brasil para pessoas com lesão medular

Valéria Sousa de Andrade[a], Maíra Ferreira do Amaral[a], Roberta Alvarenga Reis[b], Fabiana Faleiros Castro[c], Claudia Benedita dos Santos[c]

[a]Universidade Federal do Triângulo Mineiro – UFTM, Uberaba, MG, Brasil.
[b]Universidade Federal do Rio Grande do Sul – UFRGS, Porto Alegre, RS, Brasil.
[c]Universidade de São Paulo – USP, Ribeirão Preto, SP, Brasil.

How to cite: Andrade, V. S., Amaral, M. F., Reis, R. A., Castro, F. F., & Santos, C. B. (2024). Cross-cultural adaptation of the Impact on Participation and Autonomy questionnaire for Brazil for people with spinal cord injury. Cadernos Brasileiros de Terapia Ocupacional, 32, e3714. https://doi.org/10.1590/2526-8910.ctoAO285737142

Abstract

Introduction: People with chronic conditions and/or disabilities can have an impact on their autonomy and participation, impairing their performance in daily activities. The measurement of these constructs should consider the biopsychosocial model. **Objective:** To cross-culturally adapt the Impact on Participation and Autonomy questionnaire for people with spinal cord injury for use in the Brazilian context. **Method:** Methodological study carried out in a rehabilitation center of a Brazilian public hospital involving people with spinal cord injury aged 18 and over. Internationally standardized procedures were followed for the translation-backtranslation process and evaluation of the semantic aspects of the questionnaire. **Results:** The questionnaire was translated by two independent professionals, followed by a synthesis of the translations. The semantic, cultural, idiomatic and conceptual equivalences were then verified by the Expert Committee, followed by back-translation, which was sent to the author of the questionnaire. Eighteen people with spinal cord injury took part in the cognitive debriefing, with an average age of 38.8 years (SD = 13.1). Participants pointed out that the final version was good or very good (n=17), the questions were easy to understand (n=11), with items that are very important for the state of health/illness (n=14) and that there were no difficulties using the response categories (n=11). **Conclusion:** The Brazilian version of the Impact on Participation and Autonomy questionnaire was easily understood, accepted and considered relevant by the participants. After validation, the questionnaire could

Received on Dec. 16, 2023; 1st Revision on Feb. 2, 2024; Accepted on Apr. 8, 2024.

be included in the clinical practice of rehabilitating people with spinal cord injury considering biopsychosocial aspects.

Keywords: Translating; Surveys and Questionnaires; Social Participation; Personal Autonomy; Rehabilitation.

Resumo

Introdução: Pessoas com condições crônicas e/ou deficiências podem apresentar impacto no exercício de sua autonomia e participação, com prejuízo para o desempenho em atividades diárias. A mensuração desses construtos deve considerar o modelo biopsicossocial. **Objetivo:** Adaptar transculturalmente o questionário Impact on Participation and Autonomy para pessoas com lesão medular para uso no contexto brasileiro. **Método:** Estudo metodológico desenvolvido em centro de reabilitação de um hospital público brasileiro envolvendo pessoas com lesão medular maiores de 18 anos. Foram seguidos procedimentos padronizados internacionalmente para o processo de tradução-retrotradução e avaliação dos aspectos semânticos do questionário. **Resultados:** Foi realizada a tradução do questionário por dois profissionais independentes, seguida da síntese das traduções. Posteriormente, foram averiguadas as equivalências semântica, cultural, idiomática e conceitual pelo Comitê de Especialistas, sucedida pela retrotradução e envio ao autor do questionário. Participaram da avaliação semântica 18 pessoas com lesão medular com idade média de 38,8 anos (DP = 13,1). Os participantes apontaram que a versão final estava boa ou muito boa (n=17), sendo as questões de fácil compreensão (n=11), com itens muito importantes para o estado de saúde/doença (n=14) e que não havia dificuldades para utilizar as categorias de resposta (n=11). **Conclusão:** A versão adaptada do questionário Impact on Participation and Autonomy para o Brasil foi facilmente compreendida, aceita e considerada relevante pelos participantes. Após a validação, o questionário poderá ser incluído na prática clínica de reabilitação de pessoas com lesão medular, considerando os aspectos biopsicossociais.

Palavras-chave: Tradução; Inquéritos e Questionários; Participação Social; Autonomia Pessoal; Reabilitação.

Introduction

The term participation has several connotations relating to therapeutic decisions, community, citizenship, politics and management, finance, and self-government, also having a social meaning (Santos, 2016). Although there is no consensus on its conceptualization, the American Occupational Therapy Association (AOTA) defines participation as something that occurs naturally when the individual actively engages in performing occupations or activities of daily living that are important and meaningful to them. Likewise, it emphasizes that participation corresponds to the individual's commitment to occupations that are personally satisfying and pertinent to their culture (American Occupational Therapy Association, 2020; Sibley et al., 2006). According to the International Classification of Functioning, Disability and Health (ICF), participation is used as a neutral lexicon to describe social health and functioning. It corresponds to the individual's involvement in a real-life situation considering their physiological functions, anatomical structures, execution of tasks, and physical, social and attitudinal environments in which they live and conduct their life (Silva et al., 2017; Organização Mundial de Saúde, 2020).

Effective participation is given by autonomy, which is defined as the individual's ability to decide for themselves and to exercise some control over themselves in relation to how, when, where and in what way something should be done (Organização Mundial de Saúde, 2020). Considering personal perception, participation connects with autonomy by adding a personal perspective so that the individual is willing to participate (Cardol et al., 2002a). This relationship is also verified when it is conceived that the autonomy constitutes as a prerequisite for the participation and a key factor in guaranteeing the same (Cardol et al., 2002a; Cardol et al., 2001).

When considering the autonomy of individuals with chronic diseases and/or disabilities, it is noted that its loss can generally impact participation, consequently hindering performance in daily situations and social roles. In a literature review, it was observed that participation is evaluated by several instruments, such as the Impact on Participation and Autonomy (IPA) (Cardol et al., 1999), the Participation Measure for Post-Acute Care (PM-PAC) (Gandek et al., 2007), the Participation Objective, Participation Subjective (POPS) (Brown et al., 2004), the Participation and Activity Measurement System (PAMS) (Harris et al., 2010), the Maastricht Social Participation Profile (MSPP) (Mars et al., 2009), the Reintegration to Normal Living Index (RNL) (Wood-Dauphinee et al., 1988), the Craig Handicap Assessment and Reporting Technique (CHART) (Hall et al., 1998), the Sickness Impact Profile (SIP) (Bergner et al., 1981), the London Handicap Scale, Participation Survey/Mobility (PARTS/M) (Harwood et al., 1994), the Participation Scale (P-Scale) (Van Brakel et al., 2006), and the Assessment of Life Habits (LIFE-H) (Noreau et al., 2002). Among them, the LIFE-H and the P-Scale are validated for Brazil (Dutra et al., 2022; Assumpção et al., 2016).

The autonomy is evaluated by the IPA, the Maastricht Personal Autonomy Questionnaire (MPAQ) (Mars et al., 2014), and the Independent Living Skills Survey (ILSS) (Menditto et al., 1999), being this one validated for Brazil (Bandeira et al., 2002).

The IPA questionnaire is the only instrument that measures the evaluation of autonomy simultaneously to the participation of people with chronic diseases. Based on the principles of the Beta ICIDH-2 version, which is a precursor model of the ICF, the IPA was originally developed in Dutch (Cardol et al., 1999) and translated later into English (Sibley et al., 2006). From this version, it was validated for Finnish (Karhula et al., 2017), Italian (Franchignoni et al., 2007), Danish (Ghaziani et al., 2013), Farsi (Fallahpour et al., 2011), French (Poulin & Desrosiers, 2010), Polish (Opara et al., 2008), Portuguese (Portugal) (Pedro & Pais-Ribeiro, 2008), Thai (Suttiwong et al., 2013) and Swedish (Lund et al., 2007).

The IPA was validated for chronic health conditions, including neuromuscular conditions, acquired immunodeficiency syndrome, diabetes mellitus, amyotrophic lateral sclerosis, hereditary motor sensory neuropathy (Cardol et al., 1999), limb girdle dystrophy, hereditary motor and sensory neuropathy, fibromyalgia (Cardol et al., 2002b), hand injury, Parkinson's disease (Franchignoni et al., 2007), heart diseases (Mordouei et al., 2019), amputation (Byra & Duda, 2019), cancer (Kaya et al., 2023), post-polio disease, traumatic brain injury, cerebral vascular accident, multiple sclerosis, rheumatoid arthritis and spinal cord injury (SCI) (Ghaziani et al., 2013). SCI consists of damage to the spinal cord due to traumatic or non-traumatic causes that causes temporary or permanent changes in its function leading to physical, psychological, and financial burden for the patients and their families (Hu et al., 2023). According to health professionals and caregivers' observations, there are barriers to the optimal participation for people with SCI, such as overprotection, judgment or inferiorization for not being able to socially participate (Andrade et al., 2019).

Thus, by assuming the importance of measuring participation and autonomy and aiming to provide support for their approach in clinical practice, the purpose of this study was to cross-culturally adapt the IPA questionnaire to Brazil for people with SCI. It is believed that the availability of this instrument to Brazil can support decision-making in clinical practice with a view to propose actions that cooperate for the biopsychosocial reinsertion of this population.

Method

This methodological study was developed at the rehabilitation center of a Brazilian public tertiary care hospital after being approved by the Ethics Committee of the College of Nursing of the University of São Paulo (USP) with the Research Protocol CAAE 57330716.2.1001.5393/2016. The participants, who consisted of adults and older people with SCI, were informed about the details of the study and their rights. Then, they signed two copies of the informed consent form, one of which was kept by them and the other by the researchers.

Prior to initiating the research, the author of the IPA authorized its use, and the researchers obtained a copy of it from the website of the Netherlands Institute for Health Services Research (Kersten, 2007a).

The Questionnaire Impact on Participation and Autonomy (IPA)

The IPA enables verifying the degree of participation perceived by the individual in various life situations, as well as their experience of problems related to the participation. In this way, it is possible to quantify restrictions in participation and limitations in autonomy. Most of the items are aimed at assessing such components that people with chronic disabilities and/or incapacities can experience when involved in life situations and social roles in their community environment, such as performing tasks at home as desired, helping and supporting others, spending leisure time just the way it is intended, performing small repairs on the house or in the garden in the manner intended, and so on (Cardol et al., 1999).

The original version of the IPA was developed based on the results of psychometric studies, as well as incorporating the opinions of experts and rehabilitation professionals. The questionnaire can be self-completed by the participants, without the need for explanation from the researchers, or by the researchers, or it can be used as a postal questionnaire (Kersten et al., 2007b).

The most current version of the IPA in English consists of 32 items that are grouped into five subscales: autonomy in the home, family role, autonomy outside the home, social life and relationships, and work and education. Each item has identical response categories grouped into a Likert scale ranging from 0 (very good) to 4 (very poor) (Kersten et al., 2007b).

In addition to examining the limitations on participation and autonomy per se, the IPA also examines how problematic such limitations are viewed by the individual. These limitations are assessed through nine issues related to mobility, self-care, in-home and out-of-home activities, money management, leisure, social life and relationships, help and support to others, paid or voluntary work, and education and training. The response options between the questions are identical and grouped on a Likert scale ranging from 0 (no problem) to 2 (many problems) (Kersten et al., 2007b). It is observed that these questions are not presented in the format of subscales, but rather as limitations in participation and autonomy. This is due to the need to organize the questionnaire in a logical order for the individual. As a result, the nine questions that examine the extent to which constraints are conceived as problematic by the individual do not directly refer to the five subscales that analyze the degree of participation and autonomy. The nine questions are useful for clinical decision-making (Kersten et al., 2007b).

The score of each subscale is calculated by dividing the sum of the items answered by the number of items in each subscale. At least 75% of the items in each subscale must be answered in order to arrive at a reliable score for the subscale. If no more than 25% of the items in each subscale are answered, there is no way to calculate the score of the subscale. On the other hand, the items relating to how the individual analyzes the limitations are evaluated individually. The higher the score, the more limitations the individual will have in relation to participation and autonomy, or the more problematic are such limitations. An average score of zero with respect to the subscales will indicate an absence of obstacles in participation and autonomy. The zero score in relation to perception of the problems by the individual implies the non-experience of problems for the area in question (Cardol, 2005; Kersten et al., 2007b).

This study aimed to cross-culturally adapt the IPA. To do so, international guidelines for translation and adaptation of health questionnaires were followed (Beaton et al., 2000; Ferrer et al., 1996; European DISABKIDS Group, 2006).

Cross-cultural Translation of the IPA

For this stage, the original English version of the IPA (OV) was independently translated into Portuguese (Brazil) by two bilingual translators who were familiar with the subject of this study. After producing independent translations, two versions of the IPA were created in Portuguese (Brazil). The translations were then compared and discussed by the research group and one of the translators, resulting in the consensual version called the first consensual version of the IPA in Portuguese (Brazil) (CV1). After this, an expert committee analyzed the semantic, idiomatic, experiential and conceptual equivalence of the CVI, which resulted in the second consensual IPA version in Portuguese (Brazil) (CV2). It was considered valid items with a concordance of 80% or more (Pasquali, 1988).

The CV2 was back-translated into English by a qualified translator whose native language was English and was not involved in the previous stages nor aware of the concepts explored or the objectives of the study (BTV). This version was sent to the author of the IPA who proposed modifications (CA). This version was analyzed by the authors of this study and the expert committee, resulting in the third consensual IPA version in Portuguese (Brazil) (CV3), which was submitted to the cognitive debriefing process.

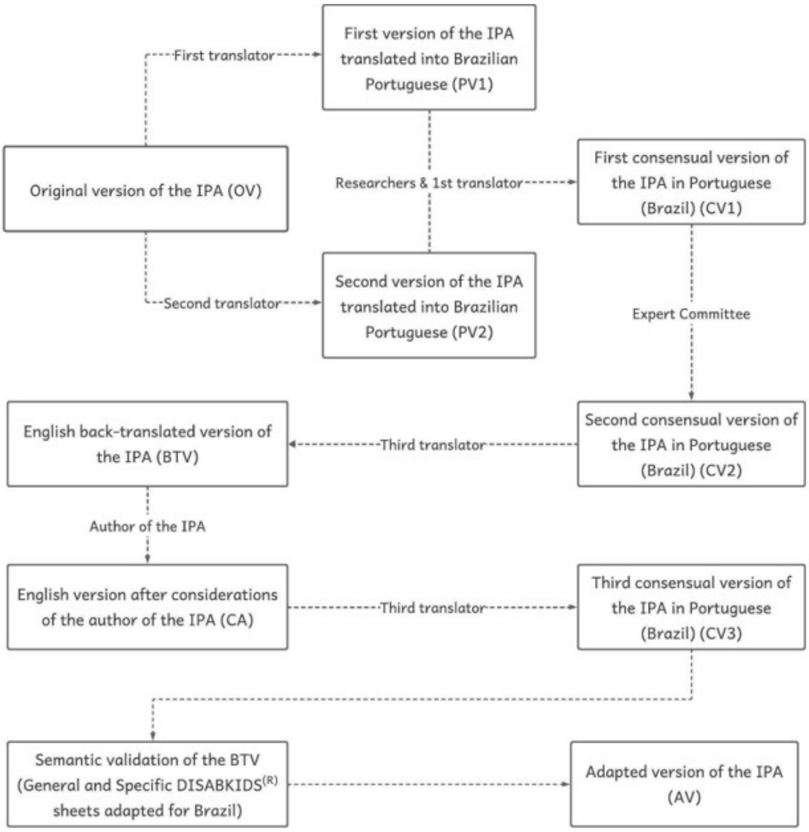
Cognitive Debriefing of the IPA CV3

To identify possible problems with understanding the subscales and items of the CV3, a pencil-and-paper format of this version was conducted to a cognitive debriefing process. This study phase comprised adult patients aged 18 or over with a diagnosis of SCI who attended a rehabilitation center of a Brazilian tertiary level public hospital. This hospital is located in a medium-sized city in the interior of the state of São Paulo and offers a reference care for people with different health conditions, being the largest hospital in the region accredited to the Brazilian Unified Health System. The following exclusion criteria were adopted: brain damage, cognitive deficit, or other comorbidities associated with SCI that prevented them from understanding the researcher's instructions. These criteria were identified according to the researcher's observation.

The researchers collected the participants' sociodemographic and clinical status through their electronic records, after the participants themselves had filled out the CV3. The participants' impression of the CV3 was investigated by a general and specific sheet originally developed by the European DISABKIDS Group® (European DISABKIDS Group, 2006) adapted for Brazil by the Research Group on Health Measures (GPEMSA-CNPq). The following questions were asked: “What do you think about our questionnaire in general?”, “Are the questions understandable?”, “Did you have any difficulties in using the answer categories?”, “Are the questions relevant for your health condition/disease?”, and “Would you like to change/add something in the questionnaire?”.

In relation to implementing the specific instrument, the participants were not able to go through all of the questionnaire and check each question because of time exposure and burden. Therefore, only a subset of items was applied to each group of participants. The cognitive debriefing was performed per facets by dividing the participants into a subset and permuting these subsets, so that the first tested participant got subset A, the second participant subset B, and so on. Each subset of questions was answered by participants with different levels of education in order to check that the translation of the questions was fully understood by people with various levels of education. Therefore, subset A was composed of questions 1a to 2f, B of questions 3a to 4b, C of questions 5a to 6h, and D of questions 7a to 10. The participants of each subset answered the following questions: “Is this specific question important for your situation?”, “Are the answer choices clear and consistent according to the question?” and “Can you tell me in your own words what this question means to you?”

Regarding illiterate participants, the researchers read the CV3 and they answered it, while for the tetraplegics who were unable to write the patients themselves read the version and the researchers wrote their answers. Graphic 1 describes the cross-cultural adaptation process used in this study.



Graphic 1. Flowchart of the cross-cultural adaptation process adopted in the study.

Results

Cross-cultural adaptation of IPA

The original English IPA version (OV) was translated into Portuguese (Brazil) by two health professionals, one of them being an Occupational Therapist and the other a Psychologist. The expert committee was composed of two nurses, two Occupational Therapists, and a Psychologist, all of them different from the ones who translated the IPA into Portuguese (Brazil).

The IPA CV1 revision by the expert committee lasted an average duration of 180 minutes, where the following changes emerged and were followed: “lesão medular” (in the sentence “Se sua lesão medular afeta (...),o quanto isto causa problemas para você?”) was substituted for “condição de saúde ou deficiência”, since it envisions future validations of the IPA Brazilian version for other types of populations. The end of the phrase “levantar e ir para a cama” (in the sentence “Minhas chances de levantar e ir para a cama quando eu quero são:”) was changed to “ir para a cama e sair da cama” for better understanding by the target population. The end of the phrase “membros de um clube” (in the original “The next questions are about your opportunities to help and support other people such as family, neighbours, friends or members of a club”) was changed to “membros de um grupo”, since the lexicon in English "club" does not have the sense of a group of people as advocated by the idea of the original sentence. Changes were also made in “O questionário leva mais ou menos 20 minutos para ser respondido” to “Você levará aproximadamente 20 minutos para responder o questionário”.

After these modifications, the backward version of the IPA was sent to the author, who then listed the following considerations: a) review the last two translated options of the five Likert-type answers (i.e., “bad/very bad”) as proposed in the OV (i.e., “poor/very poor”) since they seem more severe than such version; b) analyze the last two translated options of the three Likert-type answers (i.e., “a few problems/many problems”), which are related to the quantity of problems and not to the weight of the problems, as proposed in the OV (i.e., “minor problems/major problems”); c) on questions 2a e 2b, consider not only “taking a bath” and “dressing” according the translation, but also “being washed” and “being dressed”; and d) on question 3b check the translation “simple household tasks", which is related to the difficulty and not to the energy that it is needed, as proposed in the OV (i.e., “light household tasks”).

The author’s recommendations were reviewed by the researchers and the expert committee who decided to: a) maintain the last two answers of the five Likert-type options (i.e., “bad/very bad”) since, in Likert scales, the options must keep an antonym idea between them (e.g., "very good/very bad" or "totally disagree/totally agree"). Besides, the change proposed by the author (i.e., "poor/very poor") does not denote an idea or something that is not good, as in Portuguese (Brazil); b) change the last two options of the three Likert-type answers into “minor problems” and “major problems”, as recommended by the author; c) add “being washed” and “being dressed” on questions 2a and 2b, as suggested by the author; and d) adopt “light household task" instead of “simple household task" on question 3b, as proposed by the author. After being sent to the author, and agreed by him, the modifications were translated into Portuguese by the researchers, corresponding to CV3 (Table 1).

Table 1. Decision-making process the options according to the author's questioning in the IPA adaptation - Ribeirão Preto/SP, Brazil.

OV	CV2	BTV	CA	CV3
( ) Very good	( ) *Muito bom* (or *muito bons* or *muito boa* or *muito boas*)	( ) Very good	( ) Very good	( ) *Muito bom* (or *muito bons* or *muito boa* or *muito boas*)
( ) Good	( ) *Bom* (or *bons or boa* or *boas*)	( ) Good	( ) Good	( ) *Bom* (or *bons or boa* or *boas*)
( ) Fair	( ) *Moderada*	( ) Reasonable	( ) Fair	( ) *Razoável*
( ) Poor	( ) *Ruim* (or *ruins*)	( ) Bad	( ) Poor	( ) *Ruim* (or *ruins*)
( ) Very poor	( ) *Muito ruim* (or *muito ruins*)	( ) Very bad	( ) Very poor	( ) *Muito ruim* (or *muito ruins*)
( ) No problems	( ) *Nenhum problema*	( ) No problems	( ) No problems	( ) *Nenhum problema*
( ) Minor problems	( ) *Poucos problemas*	( ) A few problems	( ) Minor problems	( ) *Pequenos problemas*
( ) Major problems	( ) *Muitos problemas*	( ) Many problems	( ) Major problems	( ) *Grandes problemas*
Question 2a. My chances of getting washed and dressed the way I wish are:	*Questão 2a. Minhas chances de tomar banho e ser vestido da forma que eu desejo são:*	Question 2a. My chances of taking a bath and dressing the way I want are:	Question 2a. My chances of taking a bath or receiving a bath and dressing or being dressed the way I want are:	*2a. Minhas chances de tomar banho ou ser banhado, e de me vestir ou ser vestido do jeito que eu quero são:*
Question 2b. My chances of getting washed and dressed when I want are:	*Questão 2b. Minhas chances de tomar banho e ser vestido quando eu desejo são:*	Question 2b. My chances of taking a bath and dressing when I want are:	Question 2b. My chances of taking a bath or receiving a bath and dressing or being dressed when I want are:	*Questão 2b. Minhas chances de tomar banho ou de ser lavado e de me vestir ou de ser vestido quando eu quero são:*

Table 1. Continued…

OV	CV2	BTV	CA	CV3
Question 3b. My chances of getting light tasks done around the house (e.g., , making tea or coffee), either by myself or by others, the way I want them done are:	*3b. Minhas chances de fazer tarefas simples na casa (exemplo, fazer chá ou café), tanto por mim quanto pelos outros, da forma que eu quero que elas sejam feitas são:*	Question 3b. My chances of having simple tasks done around the house (for example, making tea or coffee) done either by me or by another person, the way I want are:	3b. My chances of getting light tasks done around the house (e.g., , making tea or coffee), either by myself or by others, the way I want them done are:	*Questão 3b. Minhas chances de ter tarefas leves na casa (por exemplo, fazer chá ou café) feitas tanto por mim quanto por outra pessoa do jeito que eu quero são:*

OV: Original Version of the IPA; CV2: Second consensual version of the IPA in Portuguese (Brazil); BTV: Back-translated version of the IPA into English; CA: English version of the IPA after considerations of its author; CV3: Third consensual version of the IPA in Portuguese (Brazil).

Cognitive Debriefing of the IPA CV3

Sample description

Eighteen individuals with SCI took part in this study, the majority of whom (16/88.8%) were male. The age of the participants ranged from 20 to 67 years ($\bar{x}$=38.8/SD=13.1). Almost all of them were injured by car accidents (12/66.7%) and retired due to disability (9/50%). The sociodemographic and clinical characteristics of the participants are described in Table 2.

Table 2. Sociodemographic and clinical variables of the participants (n = 18) - Ribeirão Preto/SP, Brazil.

Variables	Answers	n(%)
Age	20 to 30	6(33.3)
	31 to 40	4(22.2)
	41 to 50	4(22.2)
	51 to 60	3(16.7)
	61+	1(5.6)
Education Level	Elementary (incomplete or complete)	11(61.1)
	High School (incomplete or complete)	5(27.8)
	Secondary (incomplete or complete)	2(11.1)
Marital status	Single	7(38.9)
	Married	7(38.9)
	Living with someone	2(11.1)
	Widowed	1(5.6)
	Divorced	1(5.6)
Number of people the participant lives with	0-2	11(61.1)
	3-4	7(38.9)
Professional situation	Retired due to disability	9(50.0)
	Laid off with benefits	7(38.9)
	Inactive without benefits	1(5.6)
	Active (receiving a monthly salary)	1(5.6)
Monthly income	1 to 3 minimum salaries	16(89,9)
	10 or more minimum salaries	1(5.6)
	Waiting for unemployment insurance	1(5.6)

Table 2. Continued…

Variables	Answers	n(%)
Cause of the SCI	Car accident	10(55.6)
	Firearm accident	2(11.1)
	Bicycle accident	2(11.1)
	Trampling	1(5.6)
	Diving into shallow water	1(5.6)
	Falling	1(5.6)
	No information on the cause of injury	1(5.6)
Level of SCI	According to the neurological level	
	C5-C7	7(38.9)
	T1-T9	10(55.6)
	L1	1(5.6)
	According to the impairment level (AIS)	
	A	11(66.1)
	B	2(11.1)
	C	3(16.7)
	D	2(11.1)

SCI: Spinal cord injury; AIS: American Spinal Injury Association Impairment Scale

The time spent by the participants to complete the CV3 ranged from 9-25 minutes ($\bar{x}$=19.2/DP=4.9).

When analyzing the participants' general impression of the CV3, it was observed that the version was generally well accepted and easily understood. Most participants considered the IPA to be very good or good (17/94.4%), with easy-to-understand questions (11/66.1%), no difficulty in answering category choices (11/66.1%), and very important to their health condition (14/77.8%) (Table 3).

Table 3. Participants' general impression of the IPA CV3 (n=18) – Ribeirão Preto/SP, Brazil.

Items of the General Validation sheet	Answers	n (%)
What was your impression of our questionnaire?	Very good	5 (27.8)
	Good	12 (66.6)
	Not good	1 (5.6)
Are the questions understandable?	Easy to understand	11 (66.1)
	Sometimes difficulty	7 (38.9)
What about the response categories? Did you have any difficulties using them?	No difficulties	11 (66.1)
	Some difficulties	6 (33.3)
	A lot of difficulties	1 (5.6)
Are the questions important to your health condition?	Very important	14 (77.8)
	Sometimes relevant	4 (22.2)

Regarding the answers to the specific validation sheet, despite good understanding of the CV3 with the majority of participants responding to the fact that there were no suggestions for changing the CV3, two participants demonstrated confusion regarding questions 1a ("Minhas chances de me locomover em minha casa para onde eu quero ir são:”) and 1b (“Minhas chances de me locomover em minha casa quando eu quero são:”), as well as 2a (“Minhas chances de tomar banho (ou de ser banhado) e me de vestir (ou de ser vestido) do jeito como eu quero são:”) and 2b (“Minhas chances de tomar banho (ou de ser banhado) e de me vestir (ou de ser vestido) quando eu quero são:”). In addition, when starting the questionnaire and reading question 1a ("My chances of getting from my house to where I want to go are:"), one participant suggested giving examples to it, as he didn't understand it. He commented that the questionnaire became easier to understand once he had understood this question.

Furthermore, two other participants pointed out the need to include the term “acessibilidade” in the questionnaire because in question 2d (“Minhas chances de ir ao banheiro quando que eu quero e preciso são:”) presented a meaning of non-accessibility for them, and not the capacity (or inability) to be able to do something. In longer sentences such as “Minhas chances de ter pequenos reparos e trabalhos de manutenção em minha casa e no meu jardim, feitos tanto por mim quanto por outra pessoa do jeito que eu quero, são:” and “Por favor somente responda às questões 8b a 8f se você tem alguma forma de trabalho remunerado ou voluntário, mesmo se você não estiver trabalhando no momento devido à sua condição de saúde ou deficiência.”, it was also observed that some participants needed the researchers to explain the meaning for better understanding and a consequent response.

The questions involving the lexis "when" (e.g., "My chances of visiting relatives and friends when I want to are:") and "where to" (e.g., "My chances of getting around my house to where I want to go are:") caused confusion among the participants. The researchers considered that, as well as underlining these lexical terms to differentiate the questions they are in, the proposal would also be to highlight them in bold. In order to standardize the IPA and avoid similar confusions, the same suggestion was decided in respect to the other similar questions. The lexicon "when", present in several questions, has been changed to "at the moment that", as it conveys a broader idea of temporality than "when", which denotes a specific time. These modifications were defined by the first, second and fifth authors of the research and should be forwarded to the IPA author with the appropriate explanations.

The suggestion regarding accessibility proposed by two participants was not accepted since the objective of the IPA is not regarding an evaluation of "accessibility", but on restrictions of participation and autonomy. In relation to the long sentences, there was no change since it is necessary to preserve the original IPA structure.

Discussion

With a focus on evaluating participation associated with autonomy, this study aimed to cross-culturally adapt the IPA to Brazil for people with SCI.

Due to possible inequalities between definitions as well as values and behaviors observed in different cultural contexts, it is necessary that the use of an elaborated instrument and validated in other scenarios be preceded by systematic and reliable cultural translation and adaptation, so that it maintains the theoretical assumption used in the original one to be used in other cultures (Oku et al., 2006). In this study, the translation process led to the questionnaire being suitable for the Portuguese language (Brazil) as a result of using well-established criteria based on international guidelines for translation and adaptation of health questionnaires (Beaton et al., 2000; Cruz et al., 2019; Ferrer et al., 1996; European DISABKIDS Group, 2006; Romeiro et al., 2020).

Aiming at the ideal cross-cultural adaptation of terms whose meanings do not correspond to those used in the Brazilian sociocultural reality or of phrases that did not indicate clarity for the reader's full understanding, the researchers used strategies to ensure that words and/or expressions and/or phrases remained true to each situation specified by the original. Thus, procedures such as additions, substitutions and modifications of terms were performed, but with all changes made with the consent of the questionnaire's author (Coster & Mancini, 2015). For example, the term "club" observed in the phrase "The next questions are about your opportunities to help and support other people such as family, neighbors, friends or members of a club", denoting the idea of a group of people, was modified to "grupo" in order to ensure the idea of the question's content, and therefore the ideal understanding of the reader.

Compared to the OV, some adaptations of the BTV were checked by the author of the IPA, who suggested modifications. Almost all of them were accepted and adjusted by the researchers, as proposed by the author of the IPA. Some of them, however, were not. The words "bad" and "very bad" were not replaced by "poor" and "very poor", as suggested by the author. This is due to the fact that, while checking the meaning of the words "poor" and "very poor", the researchers found out that they referred to the idea of "not having quality or having a lower standard". In the Portuguese version of the IPA, those options should have the idea of "not being adequate or ideal". Furthermore, considering that the Likert scale options should be direct opposite of each other (Willits et al., 2016), the researchers considered it appropriate to keep the term "very bad" (and not "poor"), as opposed to "very good", and "bad" (and not "very poor"), as opposed to "good".

At the cross-cultural adaptation, the IPA CV3 was easily answered and well-accepted by most participants, as well as considered important for the current health condition. However, it was observed that participants who reported difficulty in understanding the IPA pointed out common items, especially those with lexicons "quando" and "para onde". In these cases, the professional using this version of the IPA should take care to help the respondent, thus ensuring full understanding of questions involving these lexicons in order to avoid bias and therefore ensuring reliable answers.

In relation to the long items, this aspect was portrayed by the IPA validation study for the Danish, in which an allusion was made to the need for future validation studies for linguistic improvement in the problematic items observed in Denmark's version (Fallahpour et al., 2011). The difficulty of understanding such sentences may also have been due to the low educational level of the majority of participants, which is consistent with findings from studies for validation instruments in which participants with greater difficulty in understanding the issues were those with less schooling time (Furtado et al., 2014; Deon et al., 2011). This may also explain the great variability observed in the time to answer this questionnaire (9 to 25 minutes). Therefore, the authors of this study recommend that this aspect be considered at the time of applying the IPA as a low educational level population might be observed as a reality of Brazilian public health services.

Regarding the inclusion of the term accessibility suggested by some participants, the researchers felt that it was not applicable, since the IPA is a questionnaire, whose purpose is to assess autonomy and participation, not accessibility. It should also be noted that although accessibility is considered an environmental factor according to the ICF (Organização Mundial de Saúde, 2020), and it is also related to autonomy and participation, there are other factors that should also be considered, such as body and function structures and personal factors. Thus, including the term accessibility in the IPA would favour one of these factors (i.e., environmental factor), which is just as important for autonomy and participation as the others.

Although this study has the use of only one outpatient clinic for recruiting people with SCI and there was little variability in participants' aspects, such as age, level of education and neurological and impairment levels of SCI, these limitations did not jeopardize the achievement of the objective of this study, i.e. to carry out the cross-cultural adaptation of the English version of the IPA to Brazil. The researchers considered that there was a satisfactory number of participants to carry out the qualitative phase of this study, but clarify that the translated version of the IPA needs to be validated by testing its psychometric properties.

Conclusion

In this study information exchange among professionals from different areas of scientific knowledge, the author of the original IPA version questionnaire and the participants enabled better understanding of the impact of SCI on the participation and autonomy of people with such health condition, which is a relevant aspect in comprehensive health care considering the individual as the central focus of treatment.

In having an adapted version of the IPA for Brazilian people with SCI, the continuity of this study in order to validate the instrument with this population is proposed. Thus, the use of internationally standardized methods will allow a comparison of results from applying the IPA in research conducted between different regions of Brazil and/or between Brazil and other countries in which it is validated.

After completion of the validation process, the IPA can be included in clinical practice aiming at rehabilitating individuals with a focus on biopsychosocial aspects, aiding in intervention processes.

References

American Occupational Therapy Association – AOTA. (2020). Occupational therapy practice framework: Domain and process (4th ed.). *American Journal of Occupational Therapy, 74*(suppl 2), 7412410010p1-7412410010p87.

Andrade, V. S., Faleiros, F., Balestrero, L. M., Romeiro, V., & Santos, C. B. (2019). Participação social e autonomia pessoal de indivíduos com lesão medular. *Revista Brasileira de Enfermagem*, *72*(1), 241-247.

Assumpção, F. S. N., Faria-Fortini, I., Basílio, M. L., Magalhães, L. C., Carvalho, A. C., & Teixeira-Salmela, L. F. (2016). Adaptação transcultural do LIFE-H 3.1: um instrumento de avaliação da participação social. *Cadernos de Saude Publica*, *32*(6), 1-12.

Bandeira, M., Abelha, L., & Gonçalves, S. (2002). Independent Living Skills Survey of Psychiatric Patients (ILSS-BR). *Archives of Clinical Psychiatry*, *30*(4), 121-125.

Beaton, D. E., Bombardier, C., Guillemin, F., & Ferraz, M. B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine*, *25*(4), 3186-3191.

Bergner, M., Bobbitt, R. A., Carter, W. B., & Gilson, B. S. (1981). The Sickness Impact Profile: development and final revision of a health status measure. *Medical Care*, *19*(8), 787-805.

Brown, M., Dijkers, M. P. J. M., Gordon, W. A., Ashman, T., Charatz, H., & Cheng, Z. (2004). Participation objective, participation subjective - a measure of participation combining outsider and insider perspectives. *The Journal of Head Trauma Rehabilitation*, *19*(6), 459-481.

Byra, S., & Duda, M. (2019). Impact on Participation and Autonomy Questionnaire (IPA) – Impact on Participation and Autonomy Questionnaire (IPA) – sprawdzenie w3aœciwoœci psychometrycznych polskiej wersji narzêdzia. *Dyskursy pedagogiki specjalnej, 35*, 103-126.

Cardol, M. (2005). *Vragenlijst 'Impact op Participatie en Autonomie' (IPA): handleiding.* Retrieved in 2024, March 30, from https://www.nivel.nl/sites/default/files/bestanden/INT-handleiding_vragenlijstIPA.pdf

Cardol, M., de Haan, R. J., de Jong, B. A., Van den Bos, G. A., & de Groot, I. J. M. (2001). Psychometric properties of the Impact on Participation and Autonomy Questionnaire. *Archives of Physical Medicine and Rehabilitation*, *82*(2), 210-216.

Cardol, M., de Haan, R. J., Van den Bos, G. A., Jong, B. A., & Groot, I. J. M. (1999). The development of a handicap assessment questionnaire: the Impact on Participation and Autonomy (IPA). *Clinical Rehabilitation*, *13*(5), 411-419.

Cardol, M., de Jong, B. A., & Ward, C. D. (2002a). On autonomy and participation. *Disability and Rehabilitation*, *24*(18), 970-974.

Cardol, M., de Jong, B. A., Van den Bos, G. A., Beelen, A., de Groot, I. J. M., & de Haan, R. J. (2002b). Beyond disability: perceived participation in people with a chronic disabling condition. *Clinical Rehabilitation*, *16*(1), 27-35.

Coster, W. J., & Mancini, M. C. (2015). Recomendações para a tradução e adaptação transcultural de instrumentos para a pesquisa e a prática em Terapia Ocupacional. *Revista de Terapia Ocupacional da Universidade de São Paulo*, *26*(1), 50-57.

Cruz, C. M. C., Parkinson, S., Rodrigues, D. S., Carrijo, D. C. M., Costa, J. D., Fachin-Martins, E., & Pfeiffer, L. I. (2019). Cross-cultural adaptation, face validity and reliability of the Model of Human Occupation Screening Tool to Brazilian Portuguese. *Cadernos Brasileiros de Terapia Ocupacional*, *27*(4), 691-702.

Deon, K. C., Santos, D. M. S. S., Reis, R. A., Fegadoli, C., Bullinger, M., & Santos, C. B. (2011). Tradução e adaptação cultural para o Brasil do DISABKIDS® Atopic Dermatitis Module (ADM). *Revista da Escola de Enfermagem da Universidade de São Paulo*, *45*(2), 450-457.

Dutra, F. C. M. S., Alves, A. C., Aramaki, A. L., Amaral, M. F., & Cavalcanti, A. (2022). Confiabilidade interavaliadores e teste-reteste da escala de participação (P-Scale) em pacientes após acidente vascular cerebral. *Acta fisiátrica, 29*(1), 42-49.

European DISABKIDS Group. (2006). *The DISABKIDS Questionnaire. Quality of Life questionnaire for children with chronic conditions. Handbook.* Lengerich: Pabst Science Publishers.

Fallahpour, M., Jonsson, H., Joghataei, M. T., & Kottorp, A. (2011). Impact on Participation and Autonomy (IPA): psychometric evaluation of the Persian version to use for persons with stroke. *Scandinavian Journal of Occupational Therapy*, *18*(1), 59-71.

Ferrer, M., Alonso, J., Prieto, L., Plaza, V., Monsó, E., Marrades, R., Aguar, M. C., Khalaf, A., & Antó, J. M. (1996). Validity and reliability of the St George's Respiratory Questionnaire after adaptation to a different language and culture: the Spanish example. *The European Respiratory Journal*, *9*(6), 1160-1166.

Franchignoni, F., Ferriero, G., Giordano, A., Guglielmi, V., & Picco, D. (2007). Rasch psychometric validation of the Impact on Participation and Autonomy questionnaire in people with Parkinson's disease. *Europa Medicophysica*, *43*(4), 451-461.

Furtado, S. R. C., Sampaio, R. F., Vaz, D. V., Pinho, B. A. S., Nascimento, I. O., & Mancini, M. C. (2014). Brazilian version of the instrument of environmental assessment Craig Hospital Inventory of Environmental Factors (CHIEF): translation, cross-cultural adaptation, and reliability. *Brazilian Journal of Physical Therapy*, *18*(3), 259-267.

Gandek, B., Sinclair, S. J., Jette, A. M., & Ware Junior, J. E. (2007). Development and initial psychometric evaluation of the participation measure for post-acute care (PM-PAC). *American Journal of Physical Medicine & Rehabilitation*, *86*(1), 57-71.

Ghaziani, E., Krogh, A. G., & Lund, H. (2013). Developing a Danish version of the "Impact on Participation and Autonomy Questionnaire". *Scandinavian Journal of Occupational Therapy*, *20*(3), 190-200.

Hall, K., Dijjers, M., Whiteneck, G., Brooks, C. A., & Krause, J. S. (1998). The Craig Handicap Assessment and Reporting Technique (CHART): Metric Properties and Scoring. *Topics in Spinal Cord Injury Rehabilitation*, *4*(1), 16-30.

Harris, F., Sprigle, S., Sonenblum, S. E., & Maurer, C. L. (2010). The participation and activity measurement system: an example application among people who use wheeled mobility devices. *Disability and Rehabilitation. Assistive Technology*, *5*(48), 48-57.

Harwood, R. H., Robers, A., Dickinson, E., & Ebrahim, S. (1994). Measuring handicap: the London Handicap Scale, a new outcome measure for chronic disease. *Quality in Health Care*, *3*(1), 11-16.

Hu, X., Xu, W., Ren, Y., Wang, Z., He, X., Huang, R., Ma, B., Zhao, J., Zhu, R., & Cheng, L. (2023). Spinal cord injury: molecular mechanisms and therapeutic interventions. *Signal Transduction and Targeted Therapy*, *8*(1), 245. PMid:37357239. http://doi.org/10.1038/s41392-023-01477-6

Karhula, M. E., Salminen, A. L., Hämäläinen, P., Ruuthiainen, J., Era, P., & Tolvanen, A. (2017). Psychometric evaluation of the Finnish version of the impact on participation and autonomy questionnaire in persons with multiple sclerosis. *Scandinavian Journal of Occupational Therapy*, *24*(6), 410-420.

Kaya, C., Chan, F., Iwanaga, K., Wu, J. R., & Bezyak, J. (2023). A Psychometric validation of the impact on participation and autonomy questionnaire in a sample of turkish cancer survivors. *Rehabilitation Counseling Bulletin*, 00343552221146160.

Kersten, P. (2007a). *'Impact on Participation and Autonomy' (IPA). Manual to the English version: IPA.* Retrieved in 2024, March 30, from https://www.nivel.nl/sites/default/files/bestanden/INT-IPA-Manual.pdf

Kersten, P., Cardol, M., George, S., Ward, C., Sibley, A., & White, B. (2007b). Validity of the impact on participation and autonomy questionnaire: a comparison between two countries. *Disability and Rehabilitation*, *29*(19), 1502-1509.

Lund, M. L., Fisher, A. G., Lexell, J., & Bernspång, B. (2007). Impact on participation and autonomy questionnaire: internal scale validity of the Swedish version for use in people with spinal cord injury. *Journal of Rehabilitation Medicine*, *39*(2), 156-162.

Mars, G. M. J., Van Eijk, J. T. M., Post, M. W. M., Proot, I. M., Mesters, I., & Kemper, G. I. J. M. (2014). Development and psychometric properties of the Maastricht Personal Autonomy Questionnaire (MPAQ) in older adults with a chronic physical illness. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *23*(6), 1777-1787.

Mars, G. M., Kempen, G. I. J. M., Post, M. W. M., Proot, I. M., Mesters, I., & Van Eijk, J. T. M. (2009). The Maastricht social participation profile: development and clinimetric properties in older adults with a chronic physical illness. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *18*(9), 1207-1218.

Menditto, A. A., Wallace, C. J., Liberman, R. P., Wall, V., Jones, J., Tuomi, N., & Stuve, P. (1999). Functional assessment of Independent Living Skills. *Psychiatric Rehabilitation Skills*, *3*(2), 200-219.

Mordouei, Z., Fathollahi, M. S., Rezaeian, M., Mirzaei, M., Safarian, M., & Vazirinejad, R. (2019). A study of participation and autonomy in cardiovascular patients with positive angiography results in the city of Rafsanjan in 2017. *Journal of Community Health*, *13*(1), 74-83.

Noreau, L., Fougeyrollas, P., & Vincent, C. (2002). The LIFE-H: assessment of the quality of social participation. *Technology and Disability*, *14*(3), 113-118.

Oku, E. C., Andrade, A. A. P., Stadiniky, S. P., Carrera, E. F., & Tellini, G. (2006). Tradução e Adaptação Cultural do Modifed-University of California at Los Angeles Shoulder Rating Scale para a Língua Portuguesa. *Revista Brasileira de Reumatologia*, *46*(4), 246-252. http://doi.org/10.1590/S0482-50042006000400003.

Opara, J. A., Mehlich, K., & Bielecki, A. (2008). Kwestionariusz wpływu na uczestnictwo i Autonomię–Impact on Participation and Autonomy (IPA). *Wiadomoœci Lekarskie*, *61*(1-3), 58-61.

Organização Mundial de Saúde – OMS. (2020). *CIF. Classificação Internacional de Funcionalidade, Incapacidade e Saúde*. São Paulo: Edusp - Editora da Universidade de São Paulo.

Pasquali, L. (1988). Princípios de elaboração de escalas psicológicas. *Revista de Psiquiatría Clínica (Santiago)*, *25*(5), 206-213.

Pedro, L., & Pais-Ribeiro, J. (2008). Análise psicométrica da escala de impacto na autonomia e participação, em pessoas com esclerose múltipla. *Psicologia, Saúde & Doenças*, *9*(2), 271-281.

Poulin, V., & Desrosiers, J. (2010). Validation française de questionnaires de participation sociale auprès d'aînés en situation d'incapacités. *Canadian Journal of Occupational Therapy*, *77*(3), 159-166.

Romeiro, V., Bullinger, M., Marziale, M. H. P., Fegadolli, C., Reis, R. A., Silveira, R. C. C. P., Costa-Júnior, M. L., Sousa, F. A. E. F., Andrade, V. S., Conacci, B. J., Nascimento, F. K., & Santos, C. B. (2020). DISABKIDS® no Brasil: avanços e perspectivas futuras na produção do conhecimento científico. *Revista Latino-Americana de Enfermagem*, *28*, 1-14.

Santos, W. (2016). Deficiência como restrição de participação social: desafios para avaliação a partir da Lei Brasileira de Inclusão. *Ciencia & Saude Coletiva*, *21*(10), 3007-3015.

Sibley, A., Kersten, P., Ward, C. D., White, B., Mehta, R., & George, S. (2006). Measuring autonomy in disabled people: validation of a new scale in a UK population. *Clinical Rehabilitation*, *20*(9), 793-803.

Silva, S. M., Corrêa, J. C. F., & Pereira, G. S. (2017). Social participation following a stroke: an assessment in accordance with the international classification of functioning, disability and health. *Disability and Rehabilitation*, *41*(8), 879-886.

Suttiwong, J., Vongsirinavarat, M., Vachalathiti, R., & Chaiyawat, P. (2013). Impact on participation and autonomy questionnaire: psychometric properties of the Thai version. *Journal of Physical Therapy Science*, *25*(7), 769-774.

Van Brakel, W. H., Anderson, A. M., Mutatkar, R. K., Bakirtzief, Z., Nicholls, P. G., Raju, M. S., & Das-Pattanayak, R. K. (2006). The Participation Scale: measuring a key concept in public health. *Disability and Rehabilitation*, *28*(4), 193-203.

Willits, F. K., Theodori, G. L., & Luloff, A. E. (2016). Another look at Likert scales. *Journal of Rural Social Sciences*, *31*(3), 126-139.

Wood-Dauphinee, S. L., Opzoomer, M. A., Williams, J. I., Marchand, B., & Spitzer, W. O. (1988). Assessment of global function: the Reintegration to Normal Living Index. *Archives of Physical Medicine and Rehabilitation*, *69*(8), 583-590.

Authors' Contributions

Valéria Sousa de Andrade carried out the study's planning, data collection and analysis, and wrote the manuscript; Maíra Ferreira do Amaral wrote the manuscript; Roberta Alvarenga Reis and Fabiana Faleiros Castro revised the manuscript; Claudia Benedita dos Santos guided the study, data collection and analysis and revised the manuscript. All authors approved the final version of the text.

Corresponding author

Valéria Sousa de Andrade
e-mail: valeria.andrade@uftm.edu.br

Section editor

Prof. Dr. Daniel Marinho Cezar da Cruz