UNIVERSIDADE FEDERAL DE MINAS GERAIS
Escola de Educação Física, Fisioterapia e Terapia Ocupacional
Programa de Pós-Graduação em Ciência da Reabilitação

Ana Amélia Moraes Antunes

ANÁLISE DE ASPECTOS EXPERIENCIAIS DA PARTICIPAÇÃO DE ADULTOS COM DEFICIÊNCIA MOTORA NO BRASIL ATRAVÉS DA APLICAÇÃO DO IPA-BR4

Belo Horizonte
2023

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Tese apresentada ao Programa de Pós Graduação em Ciências da Reabilitação da Escola de Educação Física, Fisioterapia e Terapia Ocupacional da Universidade Federal de Minas Gerais, como requisito parcial à obtenção do título de Doutor em Ciências da Reabilitação.

Orientadora: Profª Dra. Daniela Vaz

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A Comissão considerou a tese:

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RESUMO

Introdução: Definições e operacionalizações consistentes sobre participação são essenciais para a avaliação adequada e o desenvolvimento de serviços de reabilitação eficazes. Aspectos subjetivos de participação devem ser mensurados para direcionar as intervenções e pesquisas. Metodos: Esta tese é composta de três estudos: revisão sistemática da literatura para analisar instrumentos que avaliam aspectos experienciais da participação; investigação das propriedades de medida do instrumento definido a partir da revisão, o Impacto na Participação e Autonomia-Br4 (IPA-Br4) para adultos com deficiência motora; e a investigação dos níveis de participação e fatores pessoais e da condição de saúde, em indivíduos acompanhados em um serviço de reabilitação. Resultados: Na revisão foram identificados 10 instrumentos. Foram analisadas as evidências de validade de conteúdo e estrutura interna (validade estrutural e consistência interna), segundo os critérios do Consensus-based Standards for the Selection of Health Measurement Instruments. Apenas três instrumentos, ainda sem versões brasileiras, tiveram boa cobertura de aspectos subjetivos da participação, dos quais um apresentou evidência de alta qualidade de validade estrutural. Entre os dois instrumentos com versões brasileiras, a revisão apontou evidência de alta qualidade de que Escala de Participação não é unidimensional, assim seu escore não pode ser considerado um indicador adequado do nível de participação. A escala Impacto na Participação e Autonomia (IPA) tem boa cobertura de aspectos subjetivos da participação em dois de seus cinco domínios (Vida Social e Relacionamentos, Autonomia ao Ar Livre) enquanto os demais (Autonomia Dentro de Casa, Função Familiar e Função Familiar) se relacionam a atividade. A revisão indicou a necessidade de mais investigações sobre a estrutura interna do IPA. No segundo estudo, foram investigadas a estrutura interna (n =130) e a confiabilidade teste-resteste (n =30) da versão brasileira (IPA-Br4, que não contém o domínio Trabalho e Educação). Foram demonstrados bons índices de confiabilidade, validade estrutural e consistência interna para uma versão digital da escala . No terceiro estudo, foram analisados, (n=160), os níveis de atividade e participação auto reportados, medidos pela IPA, e investigadas, através de um modelo de equações estruturais, as relações entre os escores dos domínios e idade, sexo, comprometimento motor, continência, fadiga, tipo e tempo de lesão. Em geral, os resultados indicaram autonomia razoável a boa para todos os domínios. Fadiga teve efeito negativo em 01 domínio. Conclusões: A versão digital da IPA-Br4 tem confiabilidade teste-reteste e estrutura interna adequada em adultos com deficiência motora. Uma amostra desta população, acompanhada em um serviço de reabilitação, reporta autonomia para participação razoável a boa. Nesta amostra, os fatores da condição de saúde, a idade e o sexo não interferiram na participação.

Palavras chave: Participação; CIF; Autonomia; Deficiência motora.

ABSTRACT

Introduction: Consistent definitions and operationalizations of participation are essential for proper assessment and the development of effective rehabilitation services. Subjective aspects of participation must be measured to guide interventions and research. Methods: This thesis is composed of three studies: a systematic literature review to analyze instruments that assess experiential aspects of participation; investigation of the measurement properties of the instrument defined from the review, Impact of Participation and Autonomy-Br4 (IPA-Br4) for adults with motor disabilities; and the investigation of participation levels and personal factors and health condition, in individuals monitored in a rehabilitation service. Results: In the review, 10 instruments were identified. Evidences of content validity and internal structure (structural validity and internal consistency) were analyzed, according to the criteria of the Consensus-based Standards for the Selection of Health Measurement Instruments. Only three instruments, still without Brazilian versions, had good coverage of subjective aspects of participation, of which one presented high-quality evidence of structural validity. Between the two instruments with Brazilian versions, the review pointed to high-quality evidence that the Participation Scale is not unidimensional, so its score cannot be considered an adequate indicator of the level of participation. The Impact on Participation and Autonomy (IPA) scale has good coverage of subjective aspects of participation in two of its five domains (Social Life and Relationships, Autonomy Outdoors) while the others (Autonomy Indoors, Family Function and Family Function) relate to the activity. The review indicated the need for further investigation into the internal structure of the IPA. In the second study, the internal structure (n =130) and the test-retest reliability (n =30) of the Brazilian version (IPA-Br4, which does not contain the Work and Education domain) were investigated. Good rates of reliability, structural validity and internal consistency were demonstrated for a digital version of the scale. In the third study, self-reported activity and participation levels (n=160), measured by the IPA, were analyzed and the relationships between domain scores and age, sex, impairment motor, continence, fatigue, type and duration of injury. In general, the results indicated reasonable to good autonomy for all domains. Fatigue had a negative effect on 01 domain. Conclusions: The digital version of the IPA-Br4 has test-retest reliability and adequate internal structure in adults with motor disabilities. A sample of this population, monitored in a rehabilitation service, reports autonomy for reasonable to good participation. In this sample, health condition, age and sex factors did not interfere with participation.

Keywords: Participation; ICF; Autonomy; Motor disability.

LISTA DE ABREVIATURAS

CIF	Classificação Internacional de Funcionalidade, Incapacidade e Saúde
OMS	Organização Mundial de Saúde
COSMIN	Consensus-based Stardarts for the selection of health Measurement Instruments
CIM	Community Integration Measure
GRADE	Grading of Recommendations Assessment, Development, and Evaluation
ICF	International Classification of Functioning, Disability, and Health
ICIDH 2	International Classification of Impairments, Disabilities, and Handicap
IPA	Impact on Participation and Autonomy
AFC	Análise Fatorial Confirmatória
KAP	Keele Assessment of Participation
MEAP	Measure of Experiential Aspects of Participation
PS	Participation Scale
PARTS-M	Participation Survey/Mobility
PEM	Participation Enfranchisement Measure
POPS	Participation Objective, Participation Subjective
PRISMA	Preferred Reporting Items for Systematic Review
PROSPERO	Prospective Register of Systematic Reviews
ROPP	Ratting of Perceived Participation
USER-P	Utrecht Scale for Evaluation of Rehabilitation- Participation
ICC	Coeficiente de Correlação Intra-Classe
SPSS	Statistical Package for Social Sciences
SRMS	Standardized Root Mean Square residuals
RMSEA	Root Mean Square Error of Approximation

NIF	Índice de Ajuste Normatizado

SUMÁRIO

PREFÁCIO

A presente tese foi elaborada de acordo com as normas estabelecidas do Programa de Pós-Graduação em Ciências da Reabilitação da Universidade Federal de Minas Gerais (UFMG), sendo estruturada em 5 seções. A primeira seção contém a introdução com a problematização a justificativa do estudo realizado e os objetivos da tese. A segunda seção apresenta o artigo aceito e publicado pela Clinical Rehabilitation que apresenta a etapa do estudo correspondente a Revisão Sistemática da Literatura. A terceira seção apresenta o artigo científico, submetido na Brazilian Journal of Physical Therapy, correspondente a validação da confiabilidade teste-reteste e da estrutura interna do IPA-Br4 para adultos com condições de saúde que cursem com desordens motoras. A quarta seção apresenta o artigo científico submetido na Disability and Rehabilitation correspondente a análise exploratória, através da modelagem de equação estrutural, da relação de fatores pessoais e da condição de saúde com a participação mensurada pela aplicação do IPA-Br4. Na quinta seção estão expostas as considerações finais desta tese. Em seguida, estão indicadas as referências bibliográficas, anexos obrigatórios e no apêndice a versão do IPA-Br4 utilizada nesta pesquisa.

1 INTRODUÇÃO

1.1. Participação – conceito e operacionalização

A Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF) define participação como “o envolvimento em situações de vida”. Neste conceito estão incluídos: situações de vida doméstica, de trabalho, educação, vida social, comunitária, cívica e as relações interpessoais (OMS, 2001; Wong *et al.*, 2017). Na literatura existem variadas terminologias que designam ou se relacionam com participação: inclusão social (Ginis *et al.,* 2017), reintegração social ou comunitária, saúde social, vida independente (Wong *et al.,* 2017), entre outros. A profusão de termos com variados enfoques e significados indica que participação é um constructo complexo e multidimensional (Dijkers, 2006; Hammel *et al.,* 2008). Também indica que apesar dos avanços da CIF em relação ao modelo anterior, a sua definição de participação aparenta ser simplista e incompleta (Vargus-Adams, 2012; Heinemann *et al.,* 2013; Farzad, 2017). Ela vem sendo criticada por pesquisadores e pela comunidade de pessoas com deficiência Ginis *et al.*, 2017; Hammel *et al.,* 2008; Heinemann *et al.,* 2013). Assim, a partir do conceito inicial, ativistas e estudiosos têm buscado aprimorar tanto a definição quanto a operacionalização do conceito de participação.

As críticas à definição se relacionam a vários fatores, sendo o primeiro relativo a ambiguidade conceitual entre atividade e participação. Segundo a CIF atividades são as ações e tarefas executadas por uma pessoa, enquanto participação é definida como o envolvimento em situações da vida (OMS, 2001). A sobreposição conceitual entre atividade e participação torna a sua operacionalização difícil e permite que instrumentos misturem esses conceitos, tornando problemática a interpretação de seus resultados (Ginis *et al*., 2017). Além disso, a CIF propõe um sistema único de classificação para ambas e não fornece uma maneira padronizada para distinguir atividade e participação (Whiteneck; Dijkers, 2009). Atividade e participação estão descritas no manual da CIF em nove capítulos constando dos seguintes domínios (OMS, 2001):

1 – Aprendizagem e aplicação de novos cohecimentos;

2 – Realização de tarefas e exigências gerais;

3 – Comunicação

4 – Mobilidade

5 – Auto-cuidado

6 – Vida doméstica

7 – Interações e relações interpessoais

8 – Principais áreas da vida

9 – Vida comunitária, social e cívica

Não há clara distinção entre quais capítulos se referem a quais constructos. Ao invés disto, a CIF oferece quatro maneiras diferentes pelas quais a distinção pode ser feita, conforme a avaliação do usuário (Whiteneck; Dijkers, 2009).

Outra crítica se relaciona ao quanto as perspectivas de pessoas com deficiência são levadas em conta na CIF, especificamente em relação à definição, operacionalização e mensuração de participação (Hammel *et al*., 2008). A CIF tem sido criticada por falhar em abordar aspectos subjetivos da participação, como seu significado pessoal (Heinemann *et al*., 2013). Consequentemente, a maior parte dos instrumentos de avaliação da participação baseados na CIF não considera valores e percepções individuais (Ginis *et al*., 2017). No entanto, o que constitui participação para uma pessoa é diferente do que constitui para outra, dado que os indivíduos são únicos e tem múltiplos motivos para participar de atividades sociais (Ginis *et al*., 2017). Assim, a avaliação precisa levar em conta a experiência e a perspectiva da pessoa. Mensurar o que é relevante para os pacientes é considerado condição *sine qua non* para avaliação de desfechos de saúde (Prakash; Ganesan, 2021).

Desta forma, a definição e a operacionalização de participação precisam incluir aspectos subjetivos (Heinemann *et al*., 2013), de forma que reflitam e priorizem as perspectivas e experiências das pessoas com deficiência (Hammel *et al*., 2008). Um estudo qualitativo observou que os valores que as pessoas com deficiência atribuem a participação são: engajamento ativo e com significado, escolha e controle, acesso e oportunidade, responsabilidades pessoais e sociais, ter impacto e dar suporte a outras pessoas, estabelecer conexões sociais, estar socialmente incluído e pertencer (Ginis *et al*., 2017; Hammel *et al*., 2008). É necessário acrescentar profundidade ao conceito original de participação e colocar em questão a adequação da avaliação quantitativa de desempenho de tarefas cotidianas como medida de participação.

Nesta perspectiva, novos conceitos mais abrangentes de participação têm sido propostos. Perenboom e Chorus (2003) definem participação como o envolvimento em situações de vida que inclui ser autônomo em alguma extensão ou ser capaz de controlar sua própria vida, mesmo sem a capacidade de fazer as coisas de forma independente. Ware (2007) define a integração social (denominação do autor para participação social) como um processo, através do tempo, no qual com deficiência se desenvolvem e exercitam sua capacidade para conexões (construção e manutenção bem-sucedida de relações interpessoais) e para cidadania (direitos, prerrogativas e responsabilidades). Magasi et al. (2018) definem participação como um conceito centrado na pessoa que pode ser entendido como a habilidade da pessoa em agir na interação com os outros e sua satisfação em fazê-lo. Neste conceito, o senso pessoal de emancipação precisa ser considerado (Heinemann *et al.*, 2013). Senso de emancipação é o conjunto de percepções e valores que dão significado a participação, como o exercício de escolha e controle, a contribuição à comunidade e a sensação de ser valorizado pelos pares (Heinemann *et al.*, 2013). Diversos autores têm buscado, portanto, incorporar os aspectos subjetivos ao conceito de participação.

A tabela abaixo, com diferentes definições de participação e conceitos próximos, como integração social, ilustra o empenho dos pesquisadores em aprimorar a definição de participação incorporando aspectos experienciais ao conceito geral da Organização Mundial de Saúde (OMS):

Autor	**Definição**
OMS, 2001	O envolvimento em situações de vida
Burkov et al., 2002	Participação social ocorre na condução de ações as quais os indivíduos compartilham seus recursos com outros. Existem três tipos de participação social: coletiva, produtiva e política.
Perenboom, R.J., Chorus, A.M., 2003	Participação é o envolvimento em situações de vida as quais incluem ser autônomo em alguma extensão ou ser capaz de controlar sua própria vida, mesmo se não for capaz de fazer coisas de forma independente
Rochette et al., 2006	Realização ótima de atividades diárias e papeis sociais valorizadas pela pessoa ou no ambiente sócio-econômico, que garanta a sobrevivência e o desenvolvimento na sociedade através da vida.
Salzer M.S., 2006	Integração comunitária é a oportunidade de viver em comunidade, e ser valorizado por sua singularidade e habilidades, como qualquer pessoa.
Ware et al., 2007	Integração social é um processo, através do tempo, no qual indivíduos que com deficiência se desenvolvem e exercitam sua capacidade para conexões (construção e manutenção bem-sucedida de relações interpessoais) e para cidadania (direitos, privilégios e responsabilidades).
Lefebvre et al., 2008	Integração social se refere a satisfação vivenciada por um indivíduo em sua situação de vida, seu senso de identidade comunitária e sua autoimagem.
Vargus-Adams J., 2012	Participação é mais do que a frequência, a diversidade e o local onde o indivíduo realiza atividades. Trata-se de um processo subjetivo, interno, que requer satisfação ou realização pessoal.
Ginis et al., 2017	Participação é mais do que quantificar em qual extensão a pessoa desempenha papéis, se relaciona ou realiza um “portfólio de performances”. Aspectos experienciais precisam ser levados em conta. Esses aspectos incluem o senso individual de autonomia, pertencimento, engajamento, desafio, competência e significado.
Magasi et al., 2018	Participação é um conceito centrado na pessoa que pode ser entendido como a habilidade da pessoa em realizar atividades em sua comunidade, sendo importante considerar sua avaliação quando a sua satisfação em participar, bem como suas escolhas e decisões a respeito de sua participação (ou seja, seu engajamento ativo).

Participação é o objetivo final da reabilitação (Farzad, 2017) e foi definida como um direito básico na Convenção Internacional sobre os Direitos das Pessoas com Deficiência ((Ginis *et al*., 2017; ONU, 2006). Definições e operacionalizações consistentes sobre participação são essenciais para a avaliação adequada dos resultados e o desenvolvimento de serviços de reabilitação eficazes e relevantes. Aspectos subjetivos de participação devem ser mensurados na prática clínica por diversas razões. Aspectos objetivos e subjetivos são fracamente correlacionados (Brown *et al*., 2004), sendo que os aspectos experienciais estão mais associados com bem-estar e qualidade de vida (Dijkers, 2006). O uso de medidas exclusivamente objetivas podem gerar interpretações equivocadas e escolhas inadequadas de intervenções uma vez que não se baseiam em valores e metas dos pacientes (Ginis *et al*., 2017; Heinemann *et al*.; 2013). Em suma, o uso de instrumentos que avaliam aspectos subjetivos de participação para indivíduos com deficiência motora é essencial para avaliação de necessidades dos pacientes, da relevância de intervenções de reabilitação e seus resultados (Ginis *et al*., 2017; Whiteneck; Dijkers, 2009; Cardol; Jong; Ward, 2002).

O eixo central deste projeto é explorar aspectos experienciais da participação social de adultos com condição de saúde que cursem com deficiências motoras.

O projeto se dividiu nas seguintes etapas :

1. Realizar uma revisão sistemática da literatura para identificar e analisar os instrumentos que avaliam aspectos subjetivos de participação em adultos com deficiência;

2. Eleger, a partir da revisão sistemática, o instrumento adequado para caracterizar a participação de adultos com deficiência motora no Brasil e realizar os ajustes metodológicos necessários para o uso do mesmo;

3. Realizar análise descritiva e exploratória do nível de participação e da sua relação com fatores pessoais e da condição de saúde.

1.2 Aspectos éticos

Este estudo foi aprovado pelo COEP tendo o número CAAE 32860220.0.0000.0022 (Anexo A). Os participantes ofereceram seu consentimento para participação na pesquisa digitalmente após a leitura do Termo de Consentimento Livre e Esclarecido (Anexo B).

2 ARTIGO 1

Measuring subjective aspects of participation in adults with disabilities: a systematic review of the coverage, content validity and internal structure of standardized instruments

Measuring subjective aspects of participation in adults with disabilities: a systematic review of the coverage, content validity and internal structure of standardized instruments

Abstract

Objective: To systematically review evidence on the coverage, content validity and internal structure of self-report measures capturing subjective aspects of participation for adults with disabilities.

Data sources: EMBASE, MEDLINE, and reference lists were searched until July 10th 2022 for articles on measurement properties of instruments measuring participation as defined in the International Classification of Functioning, Disability and Health, from a subjective perspective.

Method: Each instrument was assessed for its coverage of subjective aspects of participation. The Consensus-based Standards for the Selection of Health Measurement Instruments were used to assess the quality of each study. Content validity and internal structure (structural validity, internal consistency, and cross-cultural validity) were rated against published standards and qualified by the adapted Grading of Recommendations Assessment, Development, and Evaluation.

Results: Thirty-eight studies regarding 10 instruments were analyzed. Most instruments mix activity and participation items. Only the Measure of Experiential Aspects of Participation (with high-quality evidence of sufficient structural validity and generally sufficient internal consistency), the Participation Enfranchisement, and the Community Integration Measure showed adequate coverage. There is high-quality evidence that the Participation Scale is not unidimensional. For all instruments, evidence of content validity is of low- to very low-quality.

Conclusion: In general, the coverage and the evidence for content validity and internal structure of measures capturing experiential aspects of participation is limited. The Measure of Experiential Aspects of Participation has the best level of evidence in support of its use. The score of the Participation Scale cannot be considered an adequate reflection of participation.

Keywords: subjective; experiential; participation; instruments; systematic review

Introduction

Full and effective participation in society is declared a basic right by the United Nations Convention on the Rights of Persons with Disabilities[1]. Maximization of participation has been described as “the ultimate aim of rehabilitation.”[2] According to the International Classification of Functioning, Disability, and Health,[3] participation is defined as “involvement in a life situation.” Participation restriction is defined as “problems an individual may experience in involvement in life situations” and is to be determined “by comparing an individual's participation to that which is expected of an individual without disability in that culture or society” (p. 221).[3] Participation is commonly operationalized as the observable performance of normal social roles, without any account for the subjective experience of the individual.[4] Most of the available participation measures are limited to objective, performance-based quantifiable indicators of participation such as frequency, intensity, length, and variety of activities performed in social contexts.[5–8] Most instruments assume that "more is better", regardless of the value placed by the individual on each activity.[4]

However, people with disabilities argue that they need to be free to define and pursue participation on their own terms rather than meeting societal norms, and that no predetermined set or frequency of activities may be characterized as “full” participation.[9] Participation measures should not penalize their level of participation based on external, norm-based criteria[10] because participation is not a means to an end. Instead, it is an end in itself, it is engaged in for its own sake, it is what gives life its meaning.[11] The personal significance of participation outcomes to patients cannot be reliably inferred from measures of objective aspects because objective and subjective participation aspects are only weakly correlated.[10] More importantly, the subjective aspects, rather than the objective, are more closely associated with general well-being and quality of life.[10,11] With respect to participation, the main question to be answered should not be ”How does this individual’s social activity differ from that of others?” but rather “How does this person experience her social existence?” (p.971).[2]

Generic instruments assessing the subjective aspects of participation for individuals with disabilities are thus essential for the adequate assessment of needs, outcomes, and relevance of rehabilitation interventions.[2,10] A configurative review (conducted to interpret and develop concepts) by Ginis et al. (2017) has identified the subjective perceptions of autonomy, belongingness, challenge, engagement, mastery, and meaning as the key experiential aspects of participation. They recommended that these aspects be considered in conceptualizations and measures of participation.[12]

This systematic review aimed to critically appraise and compare self-report measures capturing subjective aspects of participation for adults with disabilities. A variety of definitions for participation exist in the literature[5,6,11]. This review focused on identifying measures based on the widely adopted International Classification of Functioning, Disability, and Health definition of participation.[3] The measures are evaluated with regard to their coverage of the six key experiential aspects of participation. Because the clinical utility of any standardized instrument depends, minimally, on adequate content validity (having content that adequately reflects the construct to be measured) and sufficient internal structure (having scores that adequately reflect the construct being measured and having all items measuring the same construct)[13,14], a systematic assessment of these measurement properties was conducted with the recently developed Consensus-based Standards for the Selection of Health Measurement Instruments methodology.[13,14] By integrating assessments of methodological quality and results of measurement properties into an evidence synthesis rating system, we provide an evidence-based assessment of instrument properties for clinical and research purposes.

Methods

This review was registered in the Prospective Register of Systematic Reviews (https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020176502) and followed published guidelines for a systematic review of content validity and internal structure.[13–18] It is reported according to the Preferred Reporting Items for Systematic Review.[19]

A comprehensive search for articles published in English, Spanish, or Portuguese was carried out until July 10th 2022 in EMBASE and MEDLINE. The search was limited to articles published after 1997, when the concept of participation first appeared in the International Classification of Functioning and Disability.[20] Search terms, based on a validated search filter[21], were related to participation, standardized instruments, and measurement properties (Appendix 1). As the focus was on instruments operationalizing the construct of participation as defined in the International Classification of Functioning, Disability, and Health[3], rather than on related constructs such as quality of life, all searches included the term “participation”. Secondary searches by the names of the instruments found in the initial search were performed to find additional literature. Systematic reviews of participation instruments and reference lists were also consulted.

We screened the abstracts and included articles based on the following criteria: articles should (1) be peer-reviewed original research; (2) refer to instruments that captured any subjective aspect of participation; (3) report the conceptual development and/or assessments of content validity, structural validity, internal consistency, and/or cross-cultural validity; and (4) have adults with disabilities as the study population. Articles were excluded when (1) the instrument was diagnosis-specific; (2) the instrument measured quality of life, satisfaction with life, or other aspects of well-being rather than participation; (3) only individuals with psychiatric problems were included; (4) the study referred to the creation of the population-specific secondary version of an instrument; (5) the study referred to item banks; (6) a participation instrument was used only to measure outcomes of a clinical intervention. Abstracts and full-text articles were checked for eligibility by two reviewers who worked independently. When the two reviewers could not achieve consensus, a third reviewer adjudicated.

Two reviewers extracted data from included studies independently, using a standard form that included publication information, sample characteristics, instrument characteristics, and assessed measurement properties. Data synthesis was performed by consensus, with disagreements settled through the participation of a third reviewer.

Each instrument’s content was assessed for its coverage of subjective aspects of participation. To avoid confusion between activity (the individual perspective of functioning) and participation (the societal perspective of functioning), participation was operationalized, according to the recommendations of Whiteneck & Dijkers,[11] as referring only to the International Classification of Functioning, Disability, and Health Chapters 7 (“Interpersonal interactions and relationships”), 8

("Major life areas"), 9 ("Community, social, and civic life"), or section d660 ("Assisting others") of Chapter 6 ("Domestic life"). Subjective aspects of participation were classified according to a configurative review by Ginis et al. (2017),[12] which revealed six key experiential aspects of participation: (1) autonomy (i.e., having independence, choice, control); (2) belongingness (i.e., experiencing a sense of belonging, acceptance, inclusion); (3) challenge (i.e., feeling appropriately challenged); (4) engagement (i.e., being engaged in the activity, feeling motivated, focused, involved); (5) mastery (i.e., experiencing achievement, competence, self-efficacy); and (6) meaning (i.e., contributing to a goal, feeling a sense of responsibility). We assessed the content of all instruments (based on items described in the development studies and/or application forms) identifying items that mapped onto the relevant sections of the International Classification of Functioning, Disability, and Health[3], and also onto one or more of the six experiential aspects. Instruments or instruments subscales with 85% or more of the items referring to participation (not activity) from a subjective perspective were considered to have adequate coverage.

The Risk of Bias Checklist[17] was used to assess the methodological quality of the studies. Instrument development studies were assessed with regards to 1) concept elicitation (procedures to identify relevant items for a new instrument according its construct and theoretical basis) and 2) cognitive interviews (to evaluate comprehensiveness and comprehensibility) with patients.[13,14] Content validity studies were assessed with regards to how the relevance, comprehensiveness, and comprehensibility of the measures were investigated.[13,14]

The quality of internal structure (structural validity, internal consistency, and cross-cultural validity/measurement invariance) studies was also assessed with standardized checklists preconized by the Consensus-based Standards for the Selection of Health Measurement Instruments.[17] Adequate investigations of internal structure are essential for instrument selection: structural validity refers the degree to which the scores of the instrument are an adequate reflection of the construct(s) being measured; internal consistency refers to the extent to which items of the instrument or domain are correlated, thus measuring the same concept; and cross-cultural validity/measurement invariance refer to the degree to which the performance of the items on a culturally adapted instrument are an adequate reflection of their performance in the original instrument. For each checklist, the final methodological quality of each study was rated as "very good", "adequate", "doubtful", or "inadequate".[17] Two reviewers independently rated each item in each checklist.

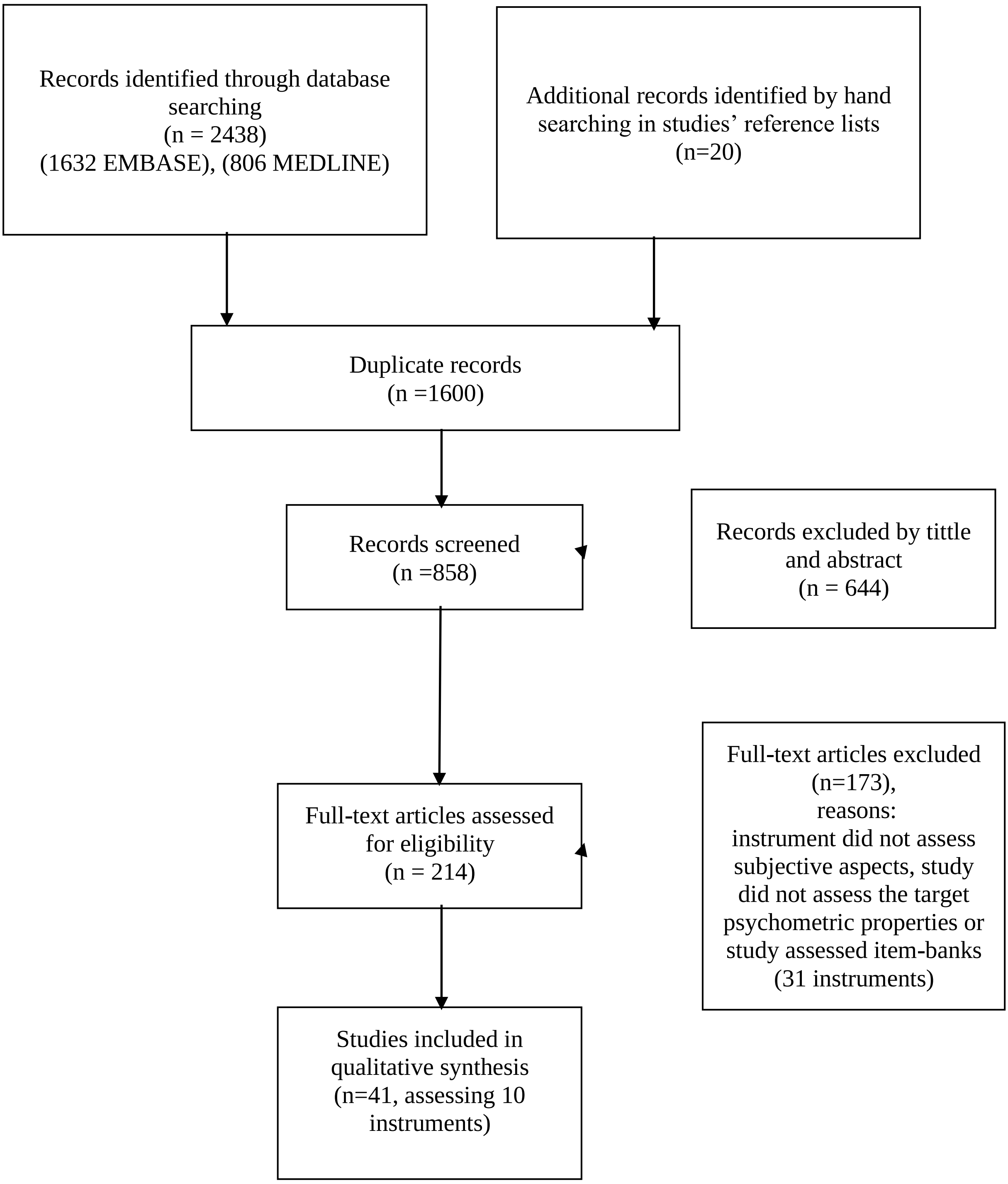
Measurement properties were rated for each instrument or instrument domain. First, with regards to content validity (relevance, comprehensiveness, and comprehensibility), the results of single instrument development studies and content validity studies were rated against pre-defined standards as sufficient (+), insufficient (–), indeterminate (?) or inconsistent[15]. Content validity ratings per instrument were also obtained based on independent judgments by two reviewers, given the operational definitions of participation[11] and experiential aspects[13] (described above). Each structural validity, internal consistency, and cross-cultural validity/measurement invariance result was also rated independently by two reviewers as sufficient, insufficient or indeterminate, per study, against published criteria.[13,14,17]

Finally, the results of all available studies (and reviewers' ratings of content validity) were summarized to determine whether overall, the content validity, structural validity, internal consistency, and cross-cultural validity/measurement invariance were sufficient, insufficient, or inconsistent. The overall ratings were qualified by a grading for the quality of the evidence (defined by consensus between the three reviewers) based on an adaptation of the Grading of Recommendations Assessment, Development, and Evaluation approach.[13] The quality of the evidence for each instrument's measurement property was graded as "high", "moderate", "low", or "very low",[13] Together, the overall results qualified by the final grading of evidence were used to indicate the trustworthiness of the findings. For example, finding high-quality evidence for sufficient structural validity of a given instrument indicates high confidence that this result is true, while finding very low-quality evidence for insufficient internal consistency indicates low confidence in this result, allowing that it could change if new internal consistency studies are performed.

Results

The literature search yielded 2,515 studies. The complete search and selection process detailed in the flow chart diagram (Figure 1). A final number of 38 studies regarding 10 instruments was included in this review.

Figure 1. Prisma flow chart diagram



Instruments

The studies referred to standardized instruments capturing some experiential aspect of participation: the Community Integration Measure[22-27]; Impact on Participation and Autonomy [28-39]; Keele Assessment of Participation[40-41]; Measure of Experiential Aspects of Participation[42]; Participation Survey/Mobility[43]; Participation Objective, Participation Subjective[10]; Participation Enfranchisement Measure[44]; Participation Scale[45-53]; Rating of Perceived Participation[54]; and Utrecht Scale for Evaluation of Rehabilitation-Participation[55-58]. The Impact on Participation and Autonomy and the Participation Scale were the most frequently investigated instruments (12 and 9 studies, respectively). A general description of each instrument is provided in Table 1.

Table 1. General characteristics of reviewed instruments

Instrument name	Target population; available languages	Intended context of use; type; recall period	Scale/Subscales (number of items)	Final scores; interpretation
Community Integration Measure[22]	Various disabilities; English, Chinese	Evaluative; interview or self-administered; recall period not specified	Complete scale (10)	Sum of item scores; higher scores represent more participation
Impact on Participation and Autonomy[28]	Various disabilities; Dutch, English, Persian, Swedish, Danish, Finnish, Italian, Thai	Evaluative; self-administered; recall period not specified	*Perceived Participation:* Autonomy indoors (7) Family Role (7) Autonomy outdoors (6) Social life and relationships (7) Work and education (6) *Problem Experience:* (8)	*Perceived Participation*: Sum or median of item scores for each subscale; higher scores represent worse participation and autonomy *Problem experience*: Items scores are analyzed separately, not summed; higher item scores indicate worse problems.
Keele Assessment of Participation[40]	Various disabilities; English, Dutch	Descriptive and discriminative (population survey); self-administered; recall period: past 4 weeks	Complete scale (11)	Sum of item scores; higher scores represent more participation restrictions
Measure of Experiential Aspects of Participation[42]	Physical disabilities; English	Evaluative; self-administered; recall period not specified	Autonomy (2) Belongingness (2) Challenge (2) Engagement (2) Mastery (2) Meaning (2)	The six subscales can be applied across four life domains (employment, mobility, sport, and exercise) generating a mean score for each subscale-life domain; higher scores represent better experience of participation.
Participation Enfranchisement Measure[44]	Various disabilities; English	Evaluative; interview or self-administered; recall period not specified	Importance of the participation (14) Control over participation (13)	Sums of item scores for each subscale is converted to Rasch measures; higher scores indicate higher attributed importance to participation and control over participation

Participation Objective, Participation Subjective[10]	People with mobility impairments and limitations; English	Evaluative; interview; recall period not specified	Complete scale (26) Domestic Life (8) Interpersonal interactions and Relationships (8) Major Life Areas (3) Transportation (2) Community, Recreational and Civic life (5)	Mean across the multiplication of satisfaction and importance ratings for all items in the complete scale; higher scores represent higher satisfaction with engagement in important areas of life
Participation Scale[45]	Various disabilities; English, Portuguese, Nepalese, Hindi, Bengali, Telugu, Tamil, Nigerian, Twi, French, Kannada, Chinese Indonesian	Evaluative and discriminative; interview or self-administered; recall period not specified	Complete scale (18)	Sum of item scores; higher scores represent worse participation restrictions
Participation Survey/ Mobility[43]	People with mobility impairments and limitations; English	Evaluative; self-administered; recall period: past 4 weeks	Self-care (30) Mobility (26) Domestic life (14) Interpersonal interactions and relationships (15) Major life areas (22) Community, social and civic life (48)	Multiple types of scores defined by an algorithm available in an Excel spreadsheet; interpretation depends on the type of score
Rating of Perceived Participation[54]	Chronic neurological diseases; English	Evaluative; self-administered; recall period not specified	Complete scale (22) Personal maintenance (3) Mobility (4) Exchange information (4) Social relationships (4) Home life (1) Education (1) Work and employment (1) Economic life (2) Civic and Community life (2)	Sum of restriction level scores for each item of the complete scale; higher scores represent worse participation Satisfaction and desire for change for each item are registered as yes/no, and do not generate scores

Utrecht Scale for Evaluation of Rehabilitation-Participation[55]	Various disabilities; English, French, German, Korean	Evaluative; self-administered; recall period not specified	Frequency (11) Restrictions (11) Satisfaction (10)	Sum of item scores that are applicable to the person's situation are converted to 0-100 for each subscale; higher scores indicate higher frequency, less restrictions and higher satisfaction with participation

Coverage of experiential aspects of participation

Table 2 shows each instrument's rationale for including subjective aspects of participation, the percentage of items covering participation content (as defined in this review[11]) from a subjective perspective, and the experiential aspects[12] included in each instrument, with example items. Strengths and limitations of each instrument are also shown. In general, the reasons for assessing subjective aspects included valuing the personal fulfillment of roles rather than capacity for normal role fulfillment[28], giving patients the opportunity to ascribe meaning to their situation[28,42,44] and to describe their perception and experience of participation[22,43,44,54,55] according to their own standards, needs and goals[10,22,40], so that rehabilitation can be directed according to the patient's priorities and desires to change[10,54].

Only the Community Integration Measure, the Measure of Experiential Aspects of Participation and the Participation Enfranchisement Measure have adequate coverage, with more than 85% of items referring to participation from a subjective perspective. The three instruments have the advantage of being rather general in content, not being tied to specific forms or contexts of participation. Three standalone subscales of the Impact on Participation and Autonomy – "autonomy outdoors", "social life and relationships", and "work and education" – also show adequate coverage. All other instruments' main limitation is mixing activity and participation items (see Table 2 for more details).

The Measure of Experiential Aspects of Participation and the Participation Enfranchisement Measure have items covering all six experiential aspects. Most of the remaining measures cover only two or three aspects. Several instruments with satisfaction questions were classified as simultaneously covering two experiential aspects, because individuals may be responding either about mastery (if they experience a sense of accomplishment) or challenge (if the activities are too challenging or they don't have the skills).

Table 2. Coverage of subjective aspects of participation in each instrument

Instrument	Rationale for including subjective aspects	Items pertaining to subjective aspects of participation (%)	Experiential aspects included	Example items	Response options	Strengths and/or limitations
Community Integration Measure[22]	A client-centered measure of community integration intended to reflect how participants themselves describe their perception and experience of participation, making no assumptions about the relative importance of particular activities or relationships.	Complete scale: 90%	Autonomy	I can be independent in this community	Each item: 1- Always disagree 2- Sometimes disagree 3- Neutral 4- Sometimes agree 5- Always agree	**Strengths:** Short, easy to administer. Not tied to specific forms or contexts of participation.
			Belongingness	I feel like part of this community, like I belong here		
			Engagement	There are things that I can do in this community for fun in my free time		
Impact on Participation and Autonomy[28]	A subjective scale of participation whereby people are able to ascribe meaning to their situation. In order to reflect an individual's perception and needs, the instrument conceives of participation as referring more to autonomy and the personal fulfillment of roles than ability or capacity for normal role fulfillment.	*Perceived Participation subscales:* Autonomy indoors: 0% Family Role: 14% Autonomy outdoors: 100% Social life and relationships: 100% Work and education: 100% *Problem experiences subscale:* 0%	Autonomy	My chances of using leisure time the way I want to are...	Perceived Participation Items: 0- Very Good 1- Good 2- Fair 3- Poor 4- Very poor	**Strengths:** Values decisional autonomy above independent performance. **Limitations:** Most items from the Autonomy Indoors and Family Role domains refer to activity rather than participation (but domains are used separately).
			Belongingness	The respect I receive from acquaintances is...		
			Mastery	My chances of achieving or keeping the position that I want, in my paid or voluntary work are...		
			Meaning	My chances of living life the way I want to are...		

Keele Assessment of Participation[40]	A measure of participation restriction in life situations as perceived by people according to their own standards and needs (rather than normative standards), incorporating the influence of environmental factors (e.g., use of devices or help from other people) and personal factors pertinent to the individual.	Complete scale: 54%	Autonomy	During the past 4 weeks, I have met and spoken to other people as and when I have wanted.	Each item: -All of the time -Most of the time -Some of the time -A little of the time -None of the time	**Strengths:** Short, intended for population surveys. **Limitations:** Almost half of the items refer to activity rather than participation.
Measure of Experiential Aspects of Participation[42]	A measure of experiential participation conceptually aligned with the 6 previously identified aspects (autonomy, belongingness, challenge, engagement, mastery, meaning) designed to be relevant to a variety of contexts (employment, mobility, sport, and exercise life domains were tested in the development study).	Autonomy: 100 % Belongingness: 100% Challenge: 100 % Engagement: 100 % Mastery: 100 % Meaning: 100 %		*When engaging in [life domain], I feel...*	Each item: 1- Strongly disagree 2- Disagree 3- Somewhat disagree 4- Neither agree nor disagree 5- Somewhat agree 6- Agree 7- Strongly agree	**Strengths:** Short, easy to administer. Not tied to specific forms or contexts of participation.
			Autonomy	...Free to make my own choices		
			Belongingness	...Accepted by others		
			Challenge	...My skills match the level of difficulty of the activity		
			Engagement	...That time passes very quickly		
			Mastery	...I can achieve my goals		
			Meaning	...A sense of purpose		
Participation Enfranchisement Measure[44]	A measure of enfranchisement, defined as a set of values that give meaning to participation, including active engagement, choice and control, access and	Importance of the participation: 100% Control over participation: 100%	Autonomy	I participate in activities that I choose	Each item: 5- All the time 4- Frequently 3- Sometimes, 2- Seldom,	**Strengths:** Short, easy to administer. Not tied to specific forms or contexts of
			Belongingness	People see my potential		

	opportunity, fulfilling responsibilities, having an impact and supporting others, and social connection. Enfranchisement refers to the individuals' assessment of whether they perceive that the communities in which they want to participate respect their full participation and may also reflect environmental factors and personal characteristics.		Engagement	I am actively involved in my community	1- Almost never	participation.
			Meaning	I contribute to the well-being of my community		
			Mastery/ Challenge	I regularly seek out new challenges		
Participation Objective, Participation Subjective[10]	A measure that taps into the values and goals of the person being assessed, inviting subjective input of service recipients, to better reflect their values. The subjective part of the measure (Participation Subjective) incorporates the preferences of the individual by gauging the individual's satisfaction with his or her level of engagement in each activity, weighted by his or her rating of the activity's importance	*Complete subjective scale:* 76.9% *Subscales:* Domestic Life: 50% Interpersonal interactions and Relationships: 100% Major Life Areas: 100% Transportation: 0% Community Recreational and Civic life: 100%	Meaning/ Mastery/ Challenge	How many times in a typical week/month do you go to places where you might meet new people? (objective question) followed by two subjective questions: Would you like to be doing more or less going to places where you meet new people than you are doing now—or the same? How important to your satisfaction with life is going to places where you might meet new people?	Each item Satisfaction rating: -1 Wanting more -1 Wanting less +1 Same Importance rating: 4- Most 3- Very 2- Moderate 1- Little 0- Not important	**Strengths:** Satisfaction and importance questions can help define intervention goals. **Limitations:** Mixes activity and participation items
Participation Scale[45]	A measure of client-perceived participation restrictions, including those resulting from	Complete scale: 55%	Mastery/ Challenge	Do you work as hard as your peers do (same hours, type of work etc.)?	Each item: 0- Yes/irrelevant, don't want, don't	**Strengths:** Cross-cultural measure developed for the

	perceived stigma, using the peer comparison concept. Contemplates objective (frequency) and subjective (importance) aspects of participation restrictions.			[If sometimes, no or irrelevant] How big a problem is it to you?	need 1- No problem 2- Small problem 3- Medium problem (4-not used) 5- Large problem	context of low and middle-income countries. **Limitations:** Mixes activity and participation items. Mixes objective and subjective aspects (in one single score).
Participation Survey/ Mobility[43]	A survey that includes evaluative aspects of participation (importance, choice, satisfaction) in addition to temporal aspects (frequency, time spent), health-related limitations (illness, pain, fatigue), and environmental support (help from a person and accommodations, adaptations, or special equipment).	Self-care 0% Mobility 10% Domestic life 0% Interpersonal interactions and relationships 40% Major life areas 40% Community, social and civic life 31%	Autonomy	How much choice do you have about participating in community activities compared to others without mobility limitations?	Each item: 3 to 5 categorical options depending on item content E.g.: A lot of choice, Some choice, Little choice, No choice; Very important, Somewhat important, Somewhat unimportant, Not important; Very satisfied, Satisfied, Somewhat satisfied, Dissatisfied	**Strengths:** Comprehensive survey **Limitations**: Long survey. Mixes activity and participation items. Most items do not refer to experiential aspects. The multiple kinds of scores are not easily calculated.
			Meaning	How important is it for you to participate in community activities?		
			Mastery/ Challenge	How satisfied are you with your participation in socializing?		

Rating of Perceived Participation[54]	A measure intended to describe the patient's perceived level of participation and satisfaction and also direct rehabilitation interventions according to the patient's priorities and desire to change particular participation situations.	Personal maintenance: 0% Mobility: 0% Exchange information: 0% Social relationships: 100% Home life: 100% Education: 100% Work and employment: 100% Economic life: 100% Civic and Community life: 100%	Autonomy/ Mastery/ Challenge	'Full participation' is when one is involved in recreational activities in the way and when one wants. Please circle yes or no: I am satisfied with my level of participation I want support to change my level of participation	Satisfaction and desire for change items: - Yes - No	**Strengths:** Gives professionals an opportunity to adapt further assessment based on the patient's desires **Limitations** Mixes activity and participation items. Satisfaction and desire for change ratings do not generate scores.
Utrecht Scale for Evaluation of Rehabilitation-Participation[55]	A measure that covers different aspects of participation with three separate scales: Frequency, Restrictions and Satisfaction with participation	Frequency 0% Restrictions: 0% Satisfaction: 100%	Mastery/ Challenge	How satisfied are you with going out (Such as: eating out, visiting a cafe, the cinema, a concert, alone or with others)?	Satisfaction items: 0- Very dissatisfied 1-Dissatisfied 2-Neutral 3-Satisfied 4-very satisfied	**Strengths:** Short, easy to administer. **Limitations:** 20% of the items refer to activity rather than participation

Quality of studies and evidence synthesis for content validity

Table 3 shows quality ratings for instrument development studies. Most development studies were considered of inadequate quality for lack of cognitive interviews with patients[14]. Two development studies were considered of doubtful quality (Impact on Participation and Autonomy[28] and Participation Survey/Mobility[43]) because of methodological problems in the concept elicitation and cognitive interviews. One development study (Participation Enfranchisement Measure[44]) had indeterminate quality because methods of cognitive testing were not reported. The development study of the Utrecht Scale for Evaluation of Rehabilitation-Participation was not available in English.

Table 3. Quality of instrument development studies

Instrument	Design							Cognitive interview study				Total
	General design requirements					Concept elicitation	Total instrument design	General design requirements	Comprehensibility	Comprehensiveness	Total cognitive interview study	
	Clear construct	Clear origin of construct	Clear target population for which the instrument was developed	Clear context of use	Instrument developed in sample representing the target population			CI study performed in sample representing the target population				
Community Integration Measure[22]	V	V	V	V	D	D	D	I	-	-	I	**I**
Impact on Participation and Autonomy[28]	V	V	V	V	V	D	D	V	D	D	D	**D**
Keele Assessment of Participation[40]	V	V	V	V	A	D	D	A	I	D	I	**I**
Measure of Experiential Aspects of Participation[42]	V	V	V	V	V	D	D	I	-	-	I	**I**
Participation Enfranchisement Measure[44]	V	V	V	V	V	A	A	?	?	D	?	**?**
Participation Objective, Participation Subjective[10]	V	V	V	V	I	-	I	I	-	-	I	**I**
Participation Scale[45]	V	V	V	V	V	D	D	I	-	-	I	**I**
Participation Survey/Mobility[43]	V	V	V	V	V	D	D	V	D	D	D	**D**
Rating of Perceived Participation[54]	V	V	V	V	D	I	D	D	D	D	D	**I**
Utrecht Scale for Evaluation of Rehabilitation	Development study is not available in English, Spanish or Portuguese.											**-**

V: very good, A: adequate, D: doubtful, I: inadequate, -: not assessed due to an 'Inadequate' rating in preceding item, ?: indeterminate because a CI study was performed but methods and results were not reported.

Only one content validity study of doubtful quality assessed the relevance, comprehensiveness, and comprehensibility of the Impact on Participation and Autonomy[38]. No content validity studies for the other instruments were found. The final ratings of content validity results and the associated quality of evidence are available in Table 4. Only the ratings for the Impact on Participation and Autonomy[28] were based on the development study, one content validity study[38], and the reviewer's ratings. For all the other instruments, ratings were based only on development studies (of inadequate or doubtful quality) and the reviewer’s ratings. Thus, evidence quality was only low or very low (except for the Participation Enfranchisement Measure[44], which was graded as indeterminate).

Table 4. Content validity and internal structure ratings with quality of evidence

		Content Validity							
		Relevance		Comprehensiveness		Comprehensibility		Unidimensiona	
Instrument/ Domain		**Rating of results**	**Quality of Evidence**	**Rating of results**	**Quality of Evidence**	**Rating of results**	**Quality of Evidence**	**Rating of results**	**Qua Evi**
Community Integration Measure[22-27]		+	Very low	+	Very low	+	Very low	±	Not du incon
Impact on Participation and Autonomy [28-30,32-37]	Autonomy Indoors*	±	Low	+	Low	+	Low	-	Ver
	Family Role*	±	Low	±	Low	+	Low		
	Autonomy outdoors	+	Low	+	Low	+	Low		
	Social life and relationships	+	Low	+	Low	+	Low		
	Work and Education	+	Low	+	Low	+	Low		
	Problem experience	±	Low	+	Low	+	Low		
Keele Assessment of Participation*†[41]		±	Very low	+	Very low	+	Very low	Not Applicable	I app
Measure of Experiential Aspects of Participation[42]	Autonomy	+	Very low	+	Very low	+	Very low	Not available	I ava
	Belongingness	+	Very low	+	Very low	+	Very low		
	Challenge	+	Very low	+	Very low	+	Very low		
	Engagement	+	Very low	+	Very low	+	Very low		
	Mastery	+	Very low	+	Very low	+	Very low		
	Meaning	+	Very low	+	Very low	+	Very low		
Participation Enfranchisement Measure[44]	Importance	+	?	+	?	+	?	?	Not du indete re
	Control	+	?	+	?	+	?		
Participation Objective Participation Subjective†[10]	PS total*	±	Very low	+	Very low	+	Very low	Not available and not applicable	I ava an app
	Domestic life*	±	Very low	+	Very low	+	Very low		
	Interpersonal interactions and relationships	+	Very low	+	Very low	+	Very low		
	Major life areas	+	Very low	+	Very low	+	Very low		
	Transportation*	±	Very low	+	Very low	+	Very low		
	Community, recreational and civic life	+	Very low	+	Very low	+	Very low		
Participation Scale* [45-52]		±	Very low	+	Very low	+	Very low	–	H
Participation Survey/	Self-care*	±	Low	+	Low	+	Low	Not	I

Mobility [43]	Mobility*	±	Low	+	Low	+	Low	available	ava
	Domestic Life*	±	Low	+	Low	+	Low		
	Interpersonal interactions and relationships*	±	Low	+	Low	+	Low		
	Major life areas*	±	Low	+	Low	+	Low		
	Community social and civic life*	±	Low	+	Low	+	Low		
Rating of Perceived Participation*[54]		±	Very low	+	Very low	±	Very low	Not available	I ava
Utrecht Scale for Evaluation of Rehabilitatio[55-56]	Satisfaction*	±	Very low	+	Very low	+	Very low	–	H

+: Sufficient, -: Insufficient, ?: Indeterminate; ±: Inconsistent

*: Fewer than 85% of the items refer to subjective aspects of participation (more than 15% refer to activity or do not refer to any subjective as

†: Items are not expected to be correlated because the instrument expresses a formative mod

Comprehensibility was sufficient for all instruments except the Rating of Perceived Participation[54] (inconsistent, very low-quality evidence), because reviewers judged that some items were not appropriately worded. Comprehensiveness was sufficient for all instrument domains except the family role domain of the Impact on Participation and Autonomy[28,38] (inconsistent, low-quality evidence) because a content validity study with patients indicated that an extra item, “looking after children”, could be included. The reviewers did not consider comprehensiveness inadequate because in the more recent version of the instrument, the item “My chances of helping or supporting people in any way”, which is arguably more encompassing than “Looking after children”, was added to the “social life and relationships” domain. All the inconsistent ratings for relevance were due to the reviewers' judgment that fewer than 85% of the items were relevant for the construct of interest (subjective aspects of participation) — that is, more than 15% of items either referred to activity rather than participation or did not refer to any subjective content (see Table 2 for specific percentages).

Quality of studies and evidence synthesis for structural validity

Twenty-five studies, most of them of very good (32%) and adequate (20%) quality investigated the structural validity or unidimensionality of 7 instruments (Supplemental table 1). The evidence synthesis for structural validity is available in Table 4.

Supplemental table 1. Characteristics, quality and results of internal structure studies

Instrument	Reference	Language (country)	Patients' characteristics			COSMIN rating of study quality	Ana
			n	Female (%)	Age ± standard deviation; Diagnosis		
Community Integration Measure	McColl et al., (2001)[22]	English (Canada)	92	60	32.1 ± 13.8; brain injury	Doubtful	Princip A (unidi
	Reistetter et al., (2005)[23]	English (USA)	51	27.5	38.8 ± 14.9; brain injury	Adequate	Princip A (unidi
	Liu et al., (2014)[24]	Cantonese (Hong Kong)	62	32.2	60.7 ± 6.3; stroke	Doubtful	Princip A (unidi
	Millis et al., (2014)[27]	English (USA)	279	19.4	44.9 ± 13.6; traumatic brain injury	Very Good	(unidi
Impact on Participation and Autonomy	Cardol et al., (1999)[28]	Dutch (Netherlands)	100	57	47.9± 14.6; several conditions (specific diagnoses not listed) mostly traumatic hand injury (n = 30) and neuromuscular disease (n = 28)	Inadequate	Princip A (struc
	Cardol et al., (2001)[29]	Dutch (Netherlands)	126	62	52.6 ± 13.4; neuromuscular disease, stroke, spinal cord injury, rheumatoid arthritis, and fibromyalgia	Doubtful	Princip A (struc
	Sibley et al., (2006)[30]	English (UK)	213	58	54.0 (SD not reported); multiple sclerosis, rheumatoid arthritis, and spinal cord injury	Doubtful	Confir A (struc
	Kersten et al., (2007)[32]	English (UK)	266	60	Median 50 (range not reported); stroke, neuromuscular disorder, severe hand injury, multiple sclerosis, rheumatoid arthritis, spinal cord injury and minor ailments	Inadequate	(unidin each d com
	Lund et al., (2007)[33]	Swedish (Sweden)	161	37	52 ± 18.2; spinal cord injury	Adequate	(unidi
	Noonan et al., (2010)[34]	English (Canada)	545	33	51.5 ± 16.6; spinal cord injury	Doubtful	Confir A (struc

	Fallahpour et al., (2010)[35]	Persian (Iran)	102	41.2	58.3 ± 11.9; stroke	Adequate	 (unidin eac
	Suttiwong et al., (2013)[36]	Thai (Thailand)	139	20.9	34.2 ± 8.4; spinal cord injury	Inadequate	Princip A (struc
	Karhula et al., (2017)[37]	Finnish (Finland)	194	72	50.0 ± 9.0; multiple sclerosis	Very Good	Confir A (struc
Keele Assessment of Participation	Hermsen et al., (2013)[41]	Dutch (Netherlands) and English (UK)	407	62.4	76.8 ± 6.7; self-reported joint pain	Doubtful	Explo A (unidi
Measure of Experiential Aspects of Participation	Caron et al., (2019)[42]	English (Canada)	228	51.7	49.6 ± 14.7; several conditions (specific diagnoses not listed)	Very Good	Confir A (struc
Participation Enfranchisement Measure	Heineman et al., (2013)[44]	English (USA)	1163	49	53.0 ± 17.0; self-identified disability (specific diagnoses not listed)	Very Good	 (unidin the fin in the i con
Participation Scale	Van Brakel et al., (2006)[45]	Nepali (Nepal), Hindi, Bengali, Telugu and Tamil (India), Portuguese (Brazil)	496	Not reported	Age not reported; leprosy	Inadequate	Explo A (unidi
	Stevelink et al., (2012)[46]	Balngla (Bangladesh), Portuguese (Brazil), Tamil, Bengali Telugu and Hindi (India), Bahasa Indonesia (Indonesia), Nepali (Nepal), Dutch (Netherlands)	5125	40.9	44.1 ± 16.1; several conditions, including leprosy, HIV/ AIDS and various disabilities (specific diagnoses not listed).	Very Good	Explo A and C Fact (unidi
	Stevelink et al., (2013)[47]	Nepali (Nepal)	153	43	38.6 ± 15.3; several conditions (specific diagnoses not listed)	Very Good	Confir A (unidi

	Thammaiah et al., (2017)[52]	Kannada (India)	103	31.1	53.8 ± 19.8; adults with hearing loss	Adequate	Princip A (unidi
	Ibikunle et al., (2016)[48]	Igbo (Nigeria)	40	57.5	Age not reported; leprosy	Inadequate	Princip A (unidi
	Souza et al., (2017)[49]	Portuguese (Brazil)	302	48.0	45.5 ± 14.4 orthopedic or neurological conditions, acutes and chronic (specific diagnoses not listed)	Very Good	(unidi
	Chung et al., (2018)[50]	Chinese (China)	264	56.1	18 to 65 (mean and SD not reported); ankylosing spondylitis, spinal cord injuries, developmental conditions with physical disabilities, brain damage, rheumatoid arthritis, and work-related orthopedic injuries	Adequate	Explo A (unidi
Utrecht Scale for Evaluation of Rehabilitation-Participation	Post et al., (2012)[55]	Dutch (Netherlands)	395	46.6	52.8 (13.5); Musculoskeletal and neurological conditions, heart conditions, brain injury, chronic pain, other	Inadequate	Explo A (unidin ea
	Mader et al., (2016)[56]	German and French (Switzerland)	1,549	28.5	52.4 (14.8) (spinal cord injury)	Very Good	(unidin the Re Satisf

+: sufficient, -: insufficient, ?: indeterminate; ±: inconsistent CFI: Comparative Fit Index, DIF: Differential Item Functioning, R
SRMR: Standardized Root Mean Square residual, TLI: Tucker Lewis Index

ll studies on the Participation Scale [45-,47,49,50,52]) displayed insufficient results (except one with indeterminate results[48]), providing high-quality evidence of insufficient unidimensionality. High-quality evidence of insufficient unidimensionality[55,56] was also found for of the Satisfaction scale of the Utrecht Scale for Evaluation of Rehabilitation – Participation. The score of these scales, therefore, are not an adequate reflection of one single construct, and should not be taken as indicators of what the scales intend to measure.

High-quality evidence[42] was also found for sufficient structural validity of the Measure of Experiential Aspects of Participation. Although the Participation Enfranchisement Measure study was of very good quality[44], information regarding structural validity was incomplete and the results were therefore rated indeterminate.

The results were inconsistent for the structural validity of Impact on Participation and Autonomy, and thus, the level of evidence could not be graded. Two studies[32-33] reported insufficient results. Three studies[30,34,37] reported sufficient results, but with varied (rather than unique) factor structures. The results of one study[35] were indeterminate. Results could not be rated for the three remaining studies[28,29,36] because there are no established criteria to assess structural validity from principal component analysis.

Results were also inconsistent for the unidimensionality of the Community Integration Measure, with no grading of the level of evidence. One study[27] reported sufficient unidimensionality, but two other studies[23,24] reported insufficient unidimensionality.

Quality of studies and evidence synthesis for internal consistency

The internal consistency of the instruments or their subscales was assessed in 30 studies (86% very good, 10% doubtful, 4% inadequate quality). The majority (83%) of the 65 indices reported were above 0.70 (see Supplemental table 2). However, interpretation of internal consistency results requires at least low-quality evidence of sufficient structural validity[13]. Of all instruments, only the Measure of Experiential Aspects of Participation[42] met this requirement. Internal consistency was assessed for each of the six subscales (autonomy, belongingness, challenge, mastery, meaning) across four life domains (employment, mobility, sport, and exercise), totaling 24 assessments. There is high-quality evidence of insufficient internal consistency for the meaning subscale in the mobility, sport, and exercise domains and the engagement subscale in the employment and mobility domains. For all 19 other subscale-life domains, there is high-quality evidence of sufficient internal consistency[42]. No conclusions can be drawn for the internal consistency of the other instruments. Because there is high-quality evidence of the insufficient unidimensionality of the Participation Scale and the Satisfaction scale of the Utrecht Scale for the Evaluation of Participation - Rehabilitation, internal consistency values for these scales should be ignored, and the total score should not be used. See Supplemental table 2 for detailed results.

Supplemental table 2. Characteristics, quality and results of internal consistency studies

Instrument	Reference	Language (country)	Patients' characteristics			COSMIN rating of study quality	Analysis	Results (rating)
			n	**Female (%)**	**Age ± Standard deviation; Diagnosis**			
Community Integration Measure	McColl et al., (2001)[22]	English (Canada)	92	60	32.1 ± 13.8; brain injury	Very Good	Cronbach's alpha	0.87 (0.78 to 0.92) (?)
	Reistetter et al., (2005)[23]	English (USA)	51	27. 5	38.8 ± 14.9; brain injury	Very Good	Cronbach's alpha	0.81 (0.72 to 0.83) (?)
	Griffen et al., (2010)[25]	English (Canada)	279	19.4	44.9 ± 13.6; traumatic brain injury	Very Good	Cronbach's alpha	0.87 (0.85 to 0.90) (?)
	De Wolf et al., (2010)[26]	English (Australia)	58	22	35.3 ± 15.2; spinal cord injury	Very Good	Cronbach's alpha	0.78 (?)
	Liu et al., (2014)[24]	Cantonese (Hong Kong)	62	32.2	60.1 ± 6.2; stroke	Very Good	Cronbach's alpha	0.84 (?)
	Millis et al., (2014)[27]	English (USA)	279	19.4	44.9 ± 13.6; traumatic brain injury	Very Good	Rasch	Person separation: 2.01, reliability: 0.80 (?)
Impact on Participation and Autonomy	Cardol et al., (1999)[28]	Dutch (Netherlands)	100	57	47.9 ± 14.6; several conditions (specific diagnoses not listed)	Very Good	Cronbach's alpha	Autonomy indoors: 0.87 (?) Autonomy outdoors: 0.85 (?) Family role: 0.84 (?), Social life and relationships: 0.86 (?)

	Sibley et al., (2006)[30]	English (UK)	213	58	Mean age not reported; multiple sclerosis, rheumatoid arthritis, and spinal cord injury	Very Good	Cronbach’s alpha	Autonomy Indoors: 0.94 (?) Autonomy Outdoors: 0.91 (?) Family role 0.90: (?) Social life and relationships: 0.86 (?) Work and education: 0.90 (?)
	Lund et al., (2007)[33]	Swedish (Sweden)	161	37	52.0 ± 18.2; spinal cord injury	Very Good	Rasch	Person separation: 4.14, reliability: 0.94 (?) (for the entire set of Perceived Participation items)
	Noonan et al., (2010)[39]	English (Canada)	545	33	51.5± 16.6; spinal cord injury	Very Good	Cronbach’s alpha	Autonomy Indoors: 0.94 (?) Autonomy Outdoors: 0.95 (?) Family role 0.95: (?) Social life and relationships: 0.90 (?) Work and education: 0.96 (?)
	Fallahpour et al., (2010)[35]	Persian (Iran)	102	41.2	58.3 ± 11.9; stroke	Very Good	Rasch	Autonomy Indoors - Person separation: 1.74, reliability: 0.75 (?) Autonomy Outdoors - Person separation: 1.96, reliability: 0.79 (?) Family role - Person separation: 2.51, reliability: 0.86 (?) Social life and relationships - Person separation: 1.57, reliability: 0.71 (?)
	Ghaziani et al., (2012)[31]	Danish (Denmark)	67	56	54 (SD not reported); several conditions (specific diagnoses not listed)	Very Good	Cronbach’s alpha	Autonomy Indoors: 0.81 (?) Autonomy Outdoors: 0.77 (?) Family role: 0.70 (?) Social life and relationships: 0.69 (?) Work and education: 0.72 (?)
	Suttiwong et al., (2013)[36]	Thai (Thailand)	139	20.9	34.2 ± 8.4; spinal cord injury	Very Good	Cronbach’s alpha	Autonomy Indoors: 0.90 (?) Autonomy Outdoors: 0.86 (?) Family role: 0.89 (?) Social life and relationships: 0.88 (?) Work and education: 0.88 (?)
	Karhula et al., (2017)[37]	Finnish (Finland)	194	72	50 ± 9; multiple sclerosis	Very Good	Cronbach’s alpha	Autonomy Indoors: 0.88 (?) Autonomy Outdoors: 0.85 (?) Family role: 0.88 (?) Social life and relationships: 0.85 (?) Work and education: 0.80 (?)

Keele Assessment of Participation	Hermsen et al., (2013)[41]	Dutch (Netherlands) and English (UK)	407	62.4	76.8 ± 6.7; self-reported joint pain	Very Good	Cronbach's alpha	Results are not interpretable because the instrument is based on a formative approach
Measure of Experiential Aspects of Participation	Caron et al., (2019)[42]	English (Canada)	228	51.7	49.6 ± 14.7; several conditions (specific diagnosis not listed)	Very Good	Cronbach's alpha	Engagement in Employment: 0.69 (–) Engagement in Mobility: 0.66 (–) Meaning in Mobility: 0.69 (–) Meaning in Sport: 0.53 (–) Meaning in Exercise: 0.64 (–) All other 19 subscales > 0.70 (+)
Participation Enfranchisement Measure	Heineman et al., (2013)[44]	English (USA)	1163	49	53 ± 17; several conditions (specific diagnosis not listed)	Very Good	Rasch	Person separation: 2.66, reliability not reported (?)
Participation Scale	Van Brakel et al., (2006)[45]	Nepali (Nepal), Hindi, Bengali, Telugu and Tamil (India), Portuguese (Brazil)	496	Not reported	Age not reported; leprosy	Doubtful	Cronbach's alpha	0.92 (result should be ignored)
	Stevelink et al., (2012)[46]	Balngla (Bangladesh), Portuguese (Brazil), Tamil, Bengali Telugu and Hindi (India), Bahasa Indonesia (Indonesia), Nepali (Nepal), Dutch	5125	40.9	44.1 ± 16.1; several conditions (specific diagnosis not listed)	Very Good	Cronbach's alpha	All values above 0.70 (0.85 to 0.94) for the multiple country data sets analyzed (results should be ignored)

		(Netherlands)						
	Zeeuw et al., (2014)[51]	Twi (Ghana) and French (Benin)	386	69.4	Mean age not reported, range: 18 – 43; Buruli ulcer	Very Good	Cronbach's alpha	0.88 (result should be ignored)
	Thammaiah et al., (2017)[52]	Kannada (India)	103	31.1	53.8 ± 19.8 Hearing loss	Doubtful	Cronbach's alpha	0.90 (result should be ignored)
	Ibikunle et al., (2016)[48]	Igbo (Nigeria)	40	57.5	Age not reported; leprosy	Inadequate	Cronbach's alpha	0.91 (result should be ignored)
	Souza et al., (2017)[49]	Portuguese (Brazil)	302	48	45.5 ± 14.4; acute and chronic orthopedic or neurological conditions, (specific diagnoses not listed)	Very Good	Rasch	Person separation index: 1.51, reliability 0.69 (result should be ignored)
	Chung et al., (2018)[50]	Chinese (China)	264	56.1	Age not reported; several conditions (specific diagnosis not listed)	Very Good	Cronbach's alpha	0.93 (result should be ignored)
	Rensen et al., (2010)[53]	Tamil and Bengali (India)	806	50	Age not reported; leprosy	Very Good	Cronbach's alpha	0.93 (result should be ignored)
Participation Survey/Mobility	Gray et al., (2006)[43]	English (USA)	604	57.5	51.5 (SD not reported), several conditions (specific diagnosis not listed)	Doubtful	Cronbach's alpha	Self-care: 0.92 (?) Mobility: 0.72 (?) Domestic life: 0.72 (?) Interpersonal interactions and Relationships: 0.71(?) Major life areas: 0.81 (?) Community, social, and civic life: 0.85 (?)
Utrecht Scale for Evaluation of Rehabilitation-Participation	Post et al, (2012).,[55]	Dutch (Netherlands)	395	46.6	52.8 (13.5); musculoskeletal, brain injury; neurological, heart	Very Good	Cronbach's alpha	Satisfaction: 0.88 (result should be ignored)

					condition, chronic pain			
	Mader et al., (2016)[56]	German and French (Switzerland)	1549	28.5	52.4 (14.8) (traumatic or non-traumatic SCI)	Very Good	Cronbach's alpha	Satisfaction: 0.90 (result should be ignored)
	Lee et al., (2017)[57]	Korean (Korea)	67	31.3	55.3 (13.3); stroke	Very Good	Cronbach's alpha	Satisfaction: 0.67 (result should be ignored)
	Van der Zee et al., (2014)[58]	Dutch (Netherlands)	157	33.8	50.6 (10.5)	Very Good	Cronbach's alpha	Satisfaction: 0.78 (result should be ignored)

+: sufficient, -: insufficient, ?: indeterminate; ±: inconsistent

Quality of studies and evidence synthesis for cross-cultural validity/measurement invariance

Only five studies investigated measurement invariance (Supplemental table 3). Insufficient measurement invariance was demonstrated with high-quality evidence for the Keele Assessment of Participation[41], low-quality evidence for the Participation Scale[49] and the Satisfaction scale of the Utrecht Scale for Evaluation of Rehabilitation - Participation[56], and very low-quality evidence for the Impact on Participation and Autonomy[32,37].

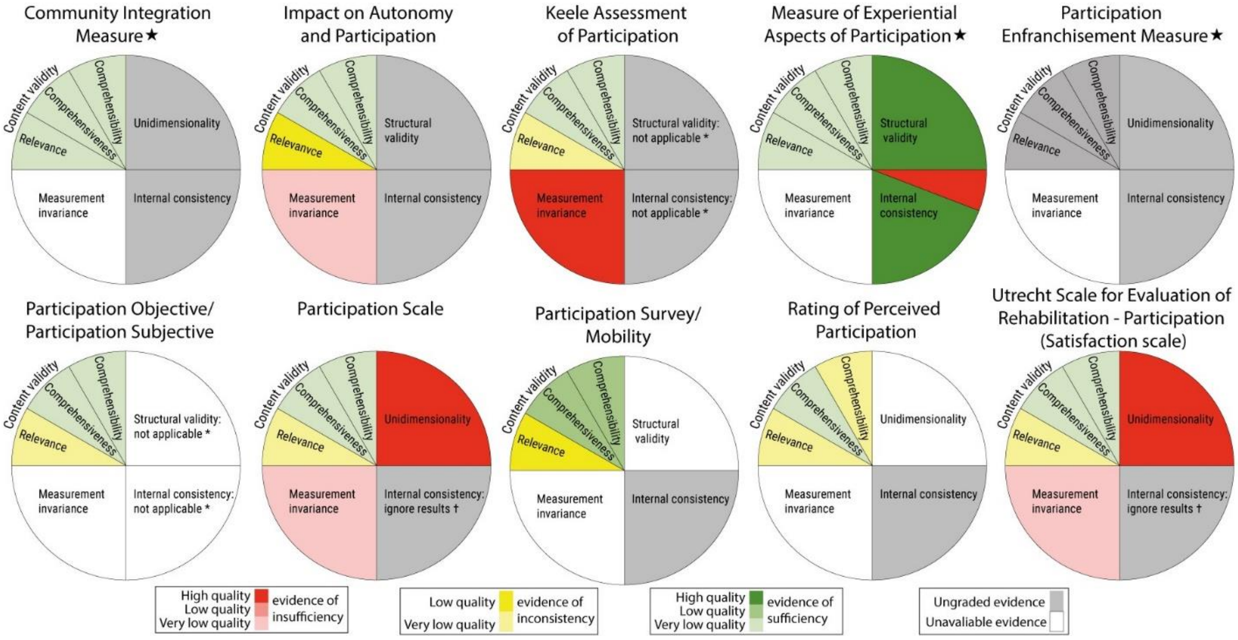
Supplemental table 3. Characteristics, quality and results of cross-cultural validity studies

Instrument	Reference	Language (country)	Patients' characteristics			COSMIN rating of study quality	Analysis Model (type of comparison)	Results (rating)
			n	**Female (%)**	**Age ± SD; Diagnosis**			
Impact on Participation and Autonomy	Karhula et al., (2017)[37]	Finnish (Finland)	194	72	50.0 ± 9.0; multiple sclerosis	Inadequate	Confirmatory Factor Analysis (males vs. females)	Confirmed equality of factor loadings and intercepts between women and men (? due to incompleteness)
	Kersten et al., (2007)[32]	English (UK)	266	60	Median 50 (range not reported); stroke, neuromuscular disorder, severe hand injury, multiple sclerosis, rheumatoid arthritis, spinal cord injury and minor ailments	Inadequate	Rasch (samples from the United Kingdom/the Netherlands)	Item 'self-care achieved the way one chooses' showed uniform DIF by country, item 'getting or keeping a paid or voluntary job' displayed uniform and non-uniform DIF by gender (–)
Keele Assessment of Participation	Hermsen et al., (2013)[41]	Dutch (Netherlands) and English (UK)	407	62.4	76.8 ± 6.7; self-reported joint pain	Very Good	Rasch (samples from the United Kingdom/the Netherlands)	Uniform DIF in item 'interpersonal relations', with Dutch participants having a higher chance to score restrictions on this item (–)
Participation Scale	Souza et al., (2017)[49]	Portuguese (Brazil)	302	48	45.5 ± 14.4; orthopedic or neurological health conditions	Doubtful	Rasch (males vs. females, acute vs. chronic conditions)	DIF between genders in items 'work as hard your peers' and 'household work' and between chronic and acute conditions in items 'take part in casual recreational/social activities' and 'move around inside/outside house/village/neighborhood' (–)
Utrecht Scale for Evaluation of Rehabilitation-Participation	Mader et al., (2016)[56]	French and German (Switzerland)	1549	28.5	52.4 (14.8) (spinal cord injury)	Doubtful	Rash (male/female, paraplegia/tetraplegia, complete/incomplete, age at injury above/below the	DIF in item 'housekeeping' of the complete Satisfaction scale between the German and French versions (–) Other versions of the Satisfaction and Restrictions scales (removing work/education and or partner

				median, time since injury above/below the median, German/French, non-paper form/paper-form)	relationship) also show DIF between male/female, paraplegia/tetraplegia, complete/incomplete and age for several items.

+: sufficient, -: insufficient, ?: indeterminate; ±: inconsistent; DIF: Differential Item Functioning

Figure 2 summarizes all the findings of this review, indicating the final assessments of coverage of subjective aspects of participation and the evidence syntheses for content validity, structural validity, internal consistency and cross-cultural validity/measurement invariance, for each instrument.



Discussion

This review critically appraised and thoroughly assessed the content validity and internal structure of instruments covering subjective aspects of participation. Generic instruments assessing subjective aspects of participation are essential for the adequate assessment of needs, outcomes, and relevance of rehabilitation interventions.[2,11,59] Objective and subjective aspects of participation are conceptually distinct and only weakly correlated[44] and need separate instruments or separate subscales in an instrument.[11,60] The evidence synthesis provided in this review can be used by clinicians and researchers in the selection of adequate instruments.

Three instruments were found to adequately cover subjective aspects of participation: the Community Integration Measure (contemplating autonomy, belongingness and engagement) the Measure of Experiential Aspects of Participation and the Participation Enfranchisement Measure (both contemplating all six aspects). Three subscales of the Impact on Participation and Autonomy also have an adequate proportion of subjective participation items. All the remaining instruments cover some experiential aspect(s) but mix in many activity items as a reflection of the overlap between the participation and activity domains in the International Classification of Functioning, Disability, and Health. Over the years, this overlap has become the most criticized aspect of the Classification because it violates the conceptual distinction that activity occurs at the individual level while participation involves role performance at the societal level.[11] While reducing individual activity limitations has been the traditional focus of rehabilitation, reducing social participation restrictions has been the central focus of people with disabilities and the disability rights movement.[1,2,10,11] Therefore, outcome measures with a clear distinction between activity and participation, such as the ones listed above, are important to properly direct and assess rehabilitation services.

For all instruments, however, the total body of evidence for the content validity was either of low or very low quality (Table 4), indicating that final ratings have low trustworthiness at this point and thus could change with new content validity studies. These results raise concern because content validity is the first measurement property to consider when selecting an instrument.[13–17] If it is unclear what construct(s) the instrument is actually measuring, then the evidence of the remaining measurement properties is of questionable use.[13,14,17] Therefore, the results of this review should stimulate new content validity investigations, ideally based on the recently published standards for a methodological design that is adequate to produce high-quality evidence for the relevance, comprehensiveness, and comprehensibility of an instrument.

In the absence of content validity studies and in the face of many inadequate development studies, ratings for the relevance, comprehensiveness, and comprehensibility of the instruments were very influenced by the judgment of the reviewers. Comprehensiveness and comprehensibility ratings were sufficient for the large majority of cases. Reviewers gave an insufficient rating for relevance (leading to an inconsistent overall rating) for many instruments or instrument domains because more than 15% of the items of referred to activity instead of participation or did not refer to any subjective aspect (Tables 2 and 4), rendering less than 85% of the items relevant for the construct of interest — subjective aspects of participation — as defined in this review.

High-quality (very trustworthy) evidence was found for the sufficient structural validity of the Measure of Experiential Aspects of Participation, with adequate internal consistency across most of its subscales. High-quality evidence was also found for insufficient unidimensionality of the Participation Scale and the Satisfaction scale of the Utrecht Scale for Evaluation of Rehabilitation - Participation, meaning that internal consistency values for these scales should be ignored and the total scale score should not be used.

These results appear consistent with the content of the instruments. The Measure of Experiential Aspects of Participation, like the Participation Enfranchisement Measure, is a generic scale of experiential aspects that can be applied across different life domains or participation situations. Its items, therefore, do not refer to any specific participation situation, but rather to experiential aspects (such as “I do what is desirable for me” or “I can achieve my goals”) applicable to different social performances. The structural validity of the Measure of Experiential Aspects of Participation and Participation Enfranchisement Measure (a recently developed instrument with so far indeterminate results) should be further investigated to produce high-quality, replicable evidence.

In contrast, the Satisfaction scale of the Utrecht Scale for Evaluation of Rehabilitation – Participation, mixes participation and activity items. The Participation scale also lists several participation and some activity items and asks the participant to identify whether there is a participation restriction (objective aspect) and define how big a problem for him/her the restriction in each item is (subjective aspect), transforming all ratings into a single final score. Given the multidimensional nature of participation,[11,12,60,61] the differences between activity and participation and between objective and subjective aspects, the unidimensionality of such instruments would not be expected.

For the other two instruments with pertinent internal structure investigations, the Impact on Participation and Autonomy and the Community Integration Measure, results were inconsistent (therefore with no grading of evidence), meaning that caution is warranted in using their scores. The inconsistencies may be due to the fact that studies use different statistical methods (factor and Rasch analyses), different language versions of the instruments, and populations of different countries. The application of Rasch analyses for participation instruments (which generally leads to insufficient results) is still controversial because it assumes a hierarchical item ordering. Different participation situations, however, may have no clear hierarchical order between them, especially if the importance of each participation situation to an individual is taken into consideration: different individuals may hold different values for the same situation, and an individual may value different situations equally.[62] Additionally, due to the context-sensitive nature of participation, stability in item behavior may not be expected across different cultures. Instead, several context-dependent versions of an instrument may prove more adequate. Indeed, all measurement invariance investigations (for the Keele Assessment of Participation, Participation Scale and the Impact on Participation and Autonomy) produced insufficient results (although future studies with higher quality may produce different results).

If these speculations about the reasons for insufficient internal structure results are pertinent, in the future, other systematic reviews of objective, performance-based participation instruments (not included in this review) may reveal similar problems. To avoid these measurement issues in the assessment of subjective aspects of participation, it may be fruitful to invest in the development and validation of measures that do not rely on particular participation items but instead can be applied across different participation situations, such as the Measure of Experiential Aspects of Participation and Participation Enfranchisement Measure.

The decision to group together different language versions of an instrument may have affected the evidence syntheses. This decision was based on absence of enough studies to allow for a synthesis per version. To allow for more detailed scrutiny, however, the methodological quality and results of each study, specifying language and country, was provided in the Supplemental tables. Another limitation is that results of studies using principal component analysis to assess structural validity could not be rated due to the lack of published rating criteria.

Conclusions

Only the Community Integration Measure, the Measure of Experiential Aspects of Participation and the Participation Enfranchisement Measure cover subjective aspects of participation without mixing in activity items. However, at present, no instrument has high, moderate or even low-quality evidence for sufficient content validity and internal structure, which are necessary for adequate use in clinical and research applications. The level of evidence for adequate content validity of all the instruments measuring subjective aspects of participation is, at present, frail. Therefore, future content validity studies of better quality may produce different findings. The evidence allows for high confidence that the Participation Scale is not unidimensional, rendering the usefulness of its score questionable. The Measure of Experiential Aspects of Participation has sufficient structural validity and generally sufficient internal consistency. Conclusions could not be drawn for the other instruments and their scores should thus be interpreted with care. We recommend further validation of existing instruments, especially the generic experiential measures, and the use of Consensus-based Standards for the selection of Health Measurement Instruments guidelines to help guarantee high-quality investigations.

Clinical Messages

- The Community Integration Measure, the Measure of Experiential Aspects of Participation and the Participation Enfranchisement Measure show adequate cover of subjective aspects of participation
- Evidence for content validity of all 10 instruments is of low- or very low-quality
- There is high-quality evidence of insufficient unidimensionality of the Participation Scale
- There is high-quality evidence of sufficient structural validity of the Measure of Experiential Aspects of Participation

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3 ARTIGO 2

Test-retest reliability and internal structure of the digital version of IPA-Br4 in individuals with motor disabilities

Abstract

Introduction: Participation should be appropriately assessed as an outcome of rehabilitation. Some instruments can capture experiential aspects of participation. The Brazilian version of IPA (IPA-Br4) may better characterize the participation of adults with disabilities. This study aimed to investigate the test-retest reliability and internal structure of the digital version of IPA-Br4 for individuals with diverse health conditions.

Materials and methods: This cross-sectional study with individuals with chronic motor impairments. Thirty individuals participated in the reliability assessment (43.25 ± 10.6 years, 63.3% female) and 130 (47.51 ± 15.73 years, 58.5% male) participated in the structural validity. The assessment of internal structure followed recommendations from the COnsensus-based Standards for the selection of health Measurement INstruments for self-reported outcome measures.

Results: The test-retest reliability following ICC values were observed for each domain: autonomy indoors = 0.84; family role = 0.87; social life and relationships = 0.87; and autonomy outdoors = 0.84. The CFA model for the IPA-Br4 domains (autonomy indoors, family role, social life and relationships, and autonomy outdoors) presented an appropriate fit: $\chi^2(293) = 211.727$, $p = 1.000$, $\chi^2/df = 0.722$, CFI = 1.000, TLI = 1.012, SRMR = 0.089, and RMSEA = 0.057 (90% CI = 0.044 to 0.069). Factor loadings indicated that all items loaded onto their respective factors, with magnitudes > 0.30 ($p < 0.05$). All Cronbach α values (internal consistency) were above 0.82.

Conclusion: According to the results, the digital IPA-Br4 has adequate test-retest reliability and adequate internal structure when used with adults with movement impairments.

Key words: Reability, IPA-Br4, disabilities

Test-retest reliability and internal structure of the digital version of IPA-Br4 in individuals with motor disabilities

Introduction

Participation is the main goal of rehabilitation (1) and a fundamental right according to the Convention on the Rights of Persons with Disabilities (2,3). Thus, it should be appropriately assessed as an outcome of rehabilitation. Also, the International Classification of Functioning, Disability, and Health (ICF) classifies participation as “involvement in life situations”, encompassing domestic life, work, education, social and community involvement, civic activities, and interpersonal relationships (4,5). Although this concept was classified 22 years ago, its assessment with standardized instruments is still challenging (2,6,7) because participation is multidimensional and includes not only objective but also subjective aspects (2,8,9) such as personal meanings, preferences and individual satisfaction with participation (9,10).

Some instruments have therefore been developed to capture experiential aspects of participation. They can help define rehabilitation goals and monitor treatment outcomes according to individual values and preferences (2,10). Adequate instruments are essential for assessing individual needs and rehabilitation outcomes and relevance (2,9,10). Professionals should choose a standardized instrument by considering its purpose, content and measuring properties (11). Data collected using adequate participation instruments allows assessing the effectiveness of rehabilitation and adjusting interventions (9) but is still incipient in Brazil.

A recent systematic review analyzed ten instruments for assessing experiential aspects of participation (12). Three of these had good coverage of experiential aspects (Participation Enfranchisement (9), Community Integration Measure (13) and Measure of Experiential Aspects of Participation (14)) but were not translated and adapted into Brazilian Portuguese (12). Only two instruments were translated and adapted for the Brazilian population: the Participation Scale (P-scale) and Impact on Participation and Autonomy (IPA) questionnaire (12).

The P-scale was developed simultaneously in three countries, including Brazil, to measure social participation in low- and middle-income countries (13) . It is widely used in Brazil (16,17,18,19) and is listed as reference instrument for assessing and monitoring patients with Hansen's disease by the Ministry of Health (20). However, the systematic review showed high-quality evidence that this instrument is not a unidimensional measure (12), with participation and activity mixed in a single scale. Thus, although the P-scale aims to assess participation, its final score does not reflect a single construct and should not be interpreted as an indicator of participation (12).

The Brazilian version of IPA (IPA-Br4) may better characterize the participation of adults with disabilities. The IPA was developed in the Netherlands in the same year as the ICF (2001) and was the first instrument assessing participation from the perspective of personal autonomy (i.e., the opportunity to make choices and exert control over one's own life) (8,21). The IPA is a person-centered instrument as it allows the individual to assess participation based on his or her choices and values, rather than on a normative or “ideal” social standard (22). The systematic review indicated that three IPA subscales (autonomy outdoors, social life and relationships, and work and education) adequately cover experiential aspects of participation, and two (autonomy indoors and family role) are activity-related subscales (12). However, the IPA structural validity (the degree to which the scores of the instrument are an adequate reflection of the constructs being measured) results were inconsistent. Its internal structure (i.e., structural validity and internal consistency) should therefore be further investigated (12).

The IPA was translated and adapted in eight countries: Netherlands (8,21), United Kingdom (23), Sweden (24), Canada (25), Iran (22), Denmark (26), Thailand (27), and Finland (28). It can be used in various clinical populations because it was developed for individuals with movement impairments regardless of their diagnosis (8). However, the IPA-Br4 (printed version) was tested and validated only for individuals with spinal cord injury (29). A reliable digital version of the IPA-Br4 with appropriate internal structure may facilitate assessing participation in varied clinical groups in Brazil. Thus, this study aimed to investigate the test-retest reliability and internal structure of the digital version of IPA-Br4 for Brazilian individuals with diverse health conditions.

Materials and methods

This cross-sectional study was conducted in five units of the SARAH Network of Rehabilitation Hospitals (Belo Horizonte, Brasília-Center, São Luiz, Salvador, and Rio de Janeiro) and approved by the research ethics committee (no. CAAE/32860220.0.0000.0022).

Participants

Individuals with chronic motor impairments who were receiving inpatient or outpatient care in the SARAH Network constituted a convenience sample. Individuals who were illiterate, had difficulty using smartphones or had rapidly progressing diseases were excluded from the study. Thirty individuals participated in the reliability assessment and 130 (a minimum of five individuals for each of the 26 items in the instrument) participated in the structural validity assessment of the IPA to ensure adequate methodological quality (11, 30,31).

Instruments

The IPA-Br4 (29) consists of 26 items assessing perception of participation from an autonomy perspective in four domains: autonomy indoors (7 activity items), family role (7 items, most of activity), social life and relationships (7 participation items), and autonomy outdoors (5 participation items) (8,21). Example items include 'My chances of getting around in my house where I want to:' (autonomy indoors) and 'My chances of using leisure time the way I want to are:' (autonomy outdoors). Response options and scores for each item vary from 'very good (0)' to 'very poor (4)'. Each domain score is calculated as the mean of item scores; high values indicate a worse perception of participation. Also, eight items such as “if your health or your disability affects your chances of getting around where and when you want, to what extent does this cause you problems?” address problems experienced in participation. Responses options range from 'no problems (0)' to 'major problems (2)', with each item assessed individually. The participant must respond to at least 75% of the items in each domain to calculate domain scores (8,21).

Procedures

The digital version of the IPA-Br4 was made available in Google Forms. Professionals of the SARAH Network instructed individuals to access a link to the questionnaire through smartphones. Online meetings with research assistants (physiotherapists) were conducted to standardize the procedures, review the form and instrument items, and address questions. Individuals were instructed to complete the questionnaire in a calm environment with time to read the items. In case of doubts, participants could ask the research assistant for clarification or send a message to the main researcher via WhatsApp. Demographic and health condition data were collected from each individual's electronic medical records. Data for the test-retest reliability analysis (when each participant was asked to answer the questionnaire twice with an interval of at least 7 days) was collected at Belo Horizonte. Data for the internal structure analysis were collected at the five SARAH units.

The assessment of internal structure followed recommendations from the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) for self-reported outcome measures (11,30,31). According to classical test theory, a confirmatory factor analysis (CFA) is recommended to test a premeditated factor structure based on theory or previous analyses (11,30,31,33). CFA tests whether the instrument items are separated, as expected, into different domains (8,21). Also, the sample size should include at least 100 individuals and five times the number of items in the instrument (26 in the IPA-Br4) for adequate methodological quality. Thus, a minimum of 130 individuals were required (11,30,31).

Statistical analysis

Quantitative data were summarized with means and standard deviations. The test-retest reliability for each of the four IPA-Br4 perception of participation domains was assessed with intraclass correlation coefficients (ICC) for single measurements and absolute agreement (32,33); ICC values above 0.75 indicate excellent reliability (34). The Statistical Package for the Social Sciences (version 18.0) was used for all analyses.

CFA with a weighted least squares estimator (35,36) was conducted using the *R* (version 4.2.2) *lavaan* package (37,38) to verify the adjustment of items across the four domains of perception of participation of the IPA-Br4. The following fit indexes were used in this study: χ^2, in which values should be non-significant; χ^2/degrees of freedom (df) ratio, with values ≤ 5 but preferably ≤ 3 considered appropriate; comparative fit index (CFI) and Tucker-Lewis index (TLI), with values ≥ 0.90 but preferably ≥ 0.95 considered adequate; root mean square error of approximation (RMSEA), with values ≤ 0.08 or preferably ≤ 0.06 and confidence interval (CI, upper limit) ≤ 0.10; and standardized root mean square residual (SRMR), with values ≤ 0.08 considered adequate (39,40,41). Next, the internal consistency in each domain was assessed using Cronbach's α coefficient (32,42) with values > 0.70 considered satisfactory.

Results

The test-retest reliability sample consisted of 30 individuals (43.25 ± 10.6 years old, 63.3% female) with the following diagnoses: sequelae of spinal cord injury (17), sequelae of poliomyelitis (3), sequelae of COVID-19 (2), stroke (1) and others (7). The interval between the two applications of the IPA-Br4 ranged between 7 and 20 days (33). The following ICC values were observed for each domain: autonomy indoors = 0.84; family role = 0.87; social life and relationships = 0.87; and autonomy outdoors = 0.84.

The CFA sample consisted of 130 individuals (47.51 ± 15.73 years, 58.5% male). The most prevalent diagnosis was sequelae of spinal cord injury (72), followed by sequelae of stroke (15), COVID-19 (polyneuropathy) (15), poliomyelitis (9), myelomeningocele (8), polyneuropathies (8), ataxias (7), Human T-lymphotropic virus type 1 (4), Parkinson’s disease (4), multiple sclerosis (4), neuromuscular diseases (4), osteoarthritis (3), rheumatologic diseases (3), traumatic brain injury (2), congenital malformations (1), and cerebral palsy (1). Table 1 presents sample characteristics.

The CFA model for the IPA-Br4 domains (autonomy indoors, family role, social life and relationships, and autonomy outdoors) presented an appropriate fit: $\chi^2(293) = 211.727$, p = 1.000, $\chi^2/df = 0.722$, CFI = 1.000, TLI = 1.012, SRMR = 0.089, and RMSEA = 0.057 (90% CI = 0.044 to 0.069). Factor loadings indicated that all items loaded onto their respective factors, with magnitudes > 0.30 ($p < 0.05$). Cronbach α values (internal consistency) were 0.91 (autonomy indoors), 0.90 (autonomy outdoors), 0.90 (family role), and 0.82 (social life and relationships). Figure 1 shows the factorial structure of the IPA-Br4.

Table 1: Sociodemographic characteristics of individuals.

		Reliability (n = 30)	Structural validity and internal consistency (n = 130)
Sex	Male	11(76.0%)	76 (58.5%)
	Female	19 (63.3%)	54 (42.5%)
Age	Young adult (≤ 35years)	13 (43.3%)	29 (22.3%)
	Adult (36 to 60 years)	12 (40.0%)	72 (55.4%)
	Older adult (≥ 61 years)	5(16.7%)	29 (22.3%)
Diagnosis	Sequelae of spinal cord injury	17 (56.6%)	72 (55.4%)
	Sequelae of COVID-19	2 (6.6%)	15 (11.5%)
	Sequelae of stroke	1 (3.3%)	15 (11.5%)
	Sequelae of poliomyelitis	3 (10%)	9 (5.6 %)
	Others	7 (23.3%)	17 (13.1%)
Type of injury	During birth/childhood	7 (23.3%)	26 (20.0%)
	After 18 years old (traumatic)	17 (56.5%)	49 (37.6%)
	After 18 years old (non-traumatic)	6 (20.0%)	55 (42.3%)
Mobility	Non-ambulatory	21 (70.0%)	48 (36.9%)
	Ambulatory	9 (30.0%)	82 (63.1%)

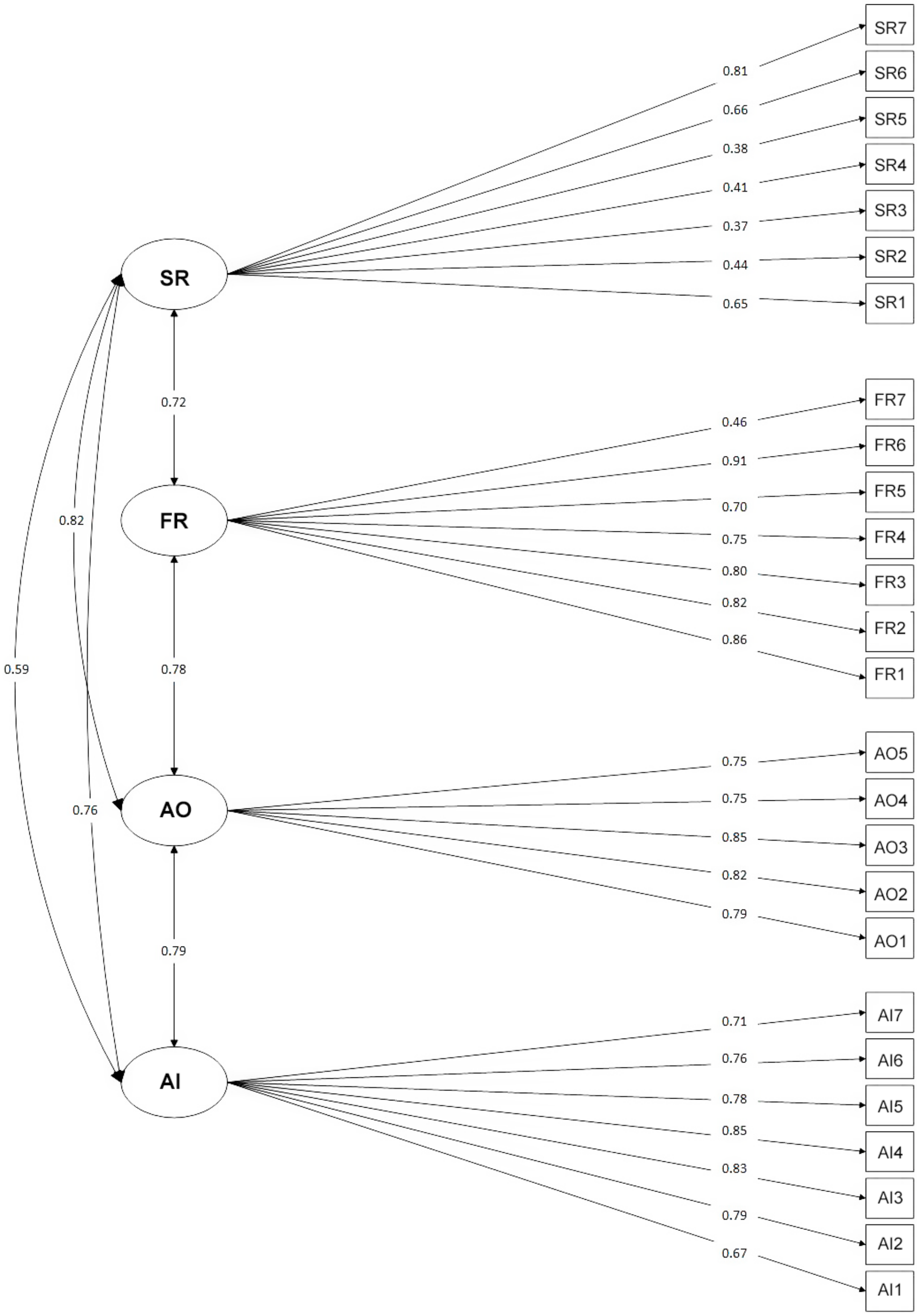

Figure 1. Factor structure of IPA-Br4. SR: Social life and Relationships, FR: Family Role, AO: Autonomy Outdoors, AI: Autonomy Indoors. Values describe the factor loadings of the model.

Discussion

The use of instruments that assess subjective aspects of participation assists in defining outcomes valued by the individual, helping to guide interventions according to their personal interests (2, 7, 9, 10). The data derived from these instruments can point to the need for interventions to enhance support for autonomy (21,29) and promote the individual's social integration, thus contributing to goal setting, the development of intervention protocols, and the allocation of resources in a manner consistent with actual needs (1, 4, 10, 43). It is important, therefore, to define measurement properties of instruments that capture experiential aspects of participation for Brazilian populations.

Measurement properties are not inherent attributes of an instrument. They result from an interaction between the instrument, the tested group and the testing conditions (44). We tested the IPA-Br4 in digital format with a diverse sample of individuals with disabilities and various diagnoses, following COSMIN guidelines for quality assessment (8, 21). This study followed the COSMIN guidelines to ensure adequate methodological quality. Reliability values for the four IPA-Br4 domains were similar to those observed for the original version of the IPA, with ICC values ranging between 0.84 (autonomy indoors and outdoors) and 0.87 (family role and social life and relationships) (8, 21). Other reliability studies for different IPA versions corroborate these results, with ICC values ranging from 0.70 to 0.97 (8, 21, 23, 25, 26, 27). In the factor analysis, results confirmed that the 26 items were divided into the four domains as expected. According to current criteria for assessing structural validity (12, 30, 31), CFI/TLI values > 0.95, RMSEA < 0.06, or SRMR < 0.08 are sufficient. This study obtained a CFI = 1.000, TLI = 1.012, and RMSEA = 0.057, with only the SRMR showing a slight deviation from the cutoff point (0.09). Therefore, the criterion for positive confirmation of structural validity was met.

The present findings contribute to the body of evidence about the IPA. A systematic review (12) revealed inconsistent structural validity results leading to a recommendation of caution in using and interpreting the scores of the instrument (12). In the review, two studies (24, 46) reported negative results, whereas three (23, 25, 28) reported sufficient structural validity (similarly to the present study) but with different factor structures (i.e., different distributions of items among domains). This variation was possibly due to the interaction between different instrument versions (different languages) and target populations of different countries. Since participation is sensitive to context (12), item stability should not be expected among different versions of IPA/ This reinforces the importance of establishing favorable results for the structural validity of the digital version of IPA-Br4, as in the present study

Additionally, once appropriate item distribution was evidenced by the confirmatory factor analysis, results also indicated sufficient internal consistency for all domains. Together, the structural validity and internal consistency results indicate that the digital IPA-Br4 has adequate internal structure, which implies that scores of each domain are appropriate indicators of a subjective sense of autonomy in different activity (autonomy indoors, family role) and participation (autonomy outdoors, social life and relationships) situations.

Limitations and conclusion

In conclusion, according to the results of this study, the digital IPA-Br4 has adequate test-retest reliability and adequate internal structure. (11,30,31) when used with adults with movement impairments. The quality of the reliability methods can be considered "very good", according to COSMIN, as we ensured sample stability between tests, an appropriate interval between measurements, similar test and retest administrations, and description of the type of ICC (adequate for the study). Similarly, the internal consistency testing method can be considered “very good” because Cronbach's α values for each domain were calculated after confirming structural validity. The method for testing structural validity can be considered “adequate” because a sample of five individuals per instrument item was ensured for CFA. The maximum quality score ("very good") would have required a simple of seven individuals per item of the instrument (182 individuals) (8, 21), which was not possible due to recruiting difficulties. To establish high quality evidence of sufficient test-retest reliability and internal structure of the IPA-Br4, other studies with adequate methodological will be required. Additionally, other measurement properties such as content validity, criterion validity, hypothesis testing, measurement error and responsiveness will need to be investigated for the IPA-Br 4.

Conflict of Interest Statement:

The authors declare no conflicts of interest in conducting this study.

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4 ARTIGO 3

Relationship of health condition and personal factors with the participation of adults with physical disabilities: analysis with structural equation modeling

Abstract

Purpose: Participation is an important outcome for rehabilitation services, and has both objective and subjective aspects. The evaluation of subjective aspects is necessary so that rehabilitation strategies are centered on the subject and, therefore, more effective. Understanding the interference of factors related to health conditions and personal factors can increase the focus of rehabilitation approaches on the subject and increase effectiveness.

Material and methods: This cross-sectional study investigated the perception of participation in 160 adults varied motor impairments through the application of the Brazilian version of the Impact on Participation and Autonomy (IPA-Br4) and analyzed the association between personal health condition factors with IPA-Br4 scores with structural equation model with Weighted Least Squares estimator**.**

Results: Perception of participation responses varied, on average, between 1.0 for Autonomy indoors and Social life and relationships to 2.0 for Autonomy outdoors. The structural equation model with obtained a satisfactory fit [$\chi 2(497) = 809.781$, x2/gl = 1.62, $p < 0.001$, CFI = 0.949, TLI = 0.943, SRMR = 0.118, RMSEA = 0.063 (CI90% = 0.055 – 0.071)]. A significant negative influence of fatigue on Autonomy indoors was observed ($\beta = -0.401$, $p = 0.010$).

Conclusion: Adults with disabilities showed participation perception scores varying between good and fair. Except from fatigue, health conditions and and personal factors did not interfere with perception of participation.

Keywords: rehabilitation, participation, adults, disability

Relationship of health condition and personal factors with the participation of adults with physical disabilities: analysis with structural equation modeling

Introduction

Participation, the ultimate goal of rehabilitation (1), is a multifaceted and dynamic concept with varying interpretations across contexts (2). The World Health Organization, through the International Classification of Functioning, Disability, and Health (ICF), defines participation as "involvement in life situations," encompassing domestic life, work, education, social engagement, community involvement, civic activities, and interpersonal relationships (3,4). Notably, there are no universally applicable standards for "ideal" participation; instead, participation must be assessed in alignment with individual values and objectives (2). To enhance the effectiveness of rehabilitation programs, a comprehensive understanding of the mechanisms and influencing factors behind participation is essential.

Participation comprises both objective components, such as the ability to perform daily activities within social contexts and the presence of barriers, facilitators, and assistive technologies, and subjective elements, including a sense of belonging and autonomy (5). Therefore, relying solely on instruments that capture objective aspects, such as measuring individual performance in a predetermined list of social tasks, offers an incomplete perspective on participation, as they fail to consider individual values and preferences (6). This limited understanding can lead to the establishment of inappropriate rehabilitation priorities, not only at the individual level but also in the formulation of public policies (7).

In contrast, assessment tools that incorporate subjective aspects of participation can assist in delineating participation objectives that resonate with individuals, thereby guiding interventions according to their personal interests (6). Data derived from such tools may indicate the necessity for broader-scope interventions, including support for enhancing autonomy and social inclusion, ultimately informing service prioritization (8).

The Impact on Participation and Autonomy Questionnaire (IPA) is one such measurement tool that enables individuals to attribute meaning to their participation experiences. The IPA assesses perceived autonomy levels across various activities and social contexts (9,10). It is applicable to adults with various disabilities, transcending specific diagnoses, and has been translated into multiple languages, facilitating international data comparisons (9,10). The Brazilian version of the IPA, IPA-Br4, has demonstrated sound measurement properties among adults with spinal cord injuries (11, 12), including adequate test-retest reliability and strong internal structure (structural validity and internal consistency) within a sample of adults with diverse disabilities (*in press*). Thus, the IPA can effectively investigate participation in Brazilian populations.

According to the World Health Organization's biopsychosocial model of functioning and disability, participation outcomes are expected to be influenced by health conditions and personal factors (3). For instance, research has demonstrated that health condition factors, such as the timing, type, and severity of injuries, along with personal factors like age and sex, impact participation levels when assessed from an objective perspective (13,14,15,16,17). Qualitative studies have underscored the significance of these factors in shaping the subjective experience of participation (18,19, 20, 21). However, the quantitative impact of factors related to health conditions and personal characteristics on participation, particularly when measured from a subjective perspective, remains to be fully established (1,22).

The exploration of participation among individuals with physical disabilities, from a subjective standpoint, is crucial for defining intervention goals, establishing healthcare protocols, documenting outcomes, and allocating resources in alignment with the genuine needs of individuals (3,23). This study aims to investigate the participation of people with physical disabilities in Brazil and to assess the potential influence of health condition factors and personal characteristics on their participation experiences.

Methods

Participants

Participants were adults who had physical disabilities for at least 6 months due to diverse health conditions and had participated in a rehabilitation program. Such inclusion criteria were chosen so that individuals had already been instructed on using assistive technologies (if prescribed) and encouraged to resume participation in their daily lives. Individuals who had rapidly progressive diseases, were illiterate or reported difficulties using a smartphone were excluded. Participants were selected from outpatient or inpatient care at five units of a network of rehabilitation hospitals, located in four of the five geographic regions of Brazil (SARAH Belo Horizonte, Rio de Janeiro, Salvador, São Luiz and Brasília (Centro)).

Procedures

This study was approved by the ethics committee (CAAE 32860220.0.0000.0022.) Participants provided signed consent from before entering the study. Data collection took place between March 2022 and January 2023. Participants were given instructions to access the research website to fill out the digital version (online form) of the IPA-Br4. An online training session for research assistants on how to approach and assist patients to complete the IPA-Br4 was offered to standardize data collection procedures across the five hospitals of network. Researchers also extracted data on health conditions and personal factors from the medical records of patients participating in the study. The following information was extracted and codified for each patient:

a) Age: Young adult (up to 35 years old), Adult (up to 59 years old) or Elderly (over 60 years old)

b) Sex: Male or Female;

c) Type of injury: non-traumatic occurring from the age of 18, traumatic occurring from the age of 18; occurring at birth or from childhood to the age of 18,

d) Bladder control: absent/partial or present

e) Fatigue: present or absent

f) Mobility impairment: able or unable to walk

Instruments

The IPA, developed in 2001, aims to assess participation and autonomy based on an individual's perception, without focusing on general skills or normative performance of tasks and social roles (9,10). It comprises 32 items related to the "perception of participation," such as "My chances of getting around my house where I want to are". The 32 items are categorized into five domains: Autonomy indoors (7 items), Family role (7 items), Social life and relationships (7 items), Autonomy outdoors (5 items), and Work and education (6 items). The perception items are scored from 0 (very good) to 4 (very poor). The score for each domain is the average of item scores, with higher values indicating a worse perception of participation.

Additionally, there are 8 items documenting "problems experienced in participation," for instance: "With regard to your relationships, to what extent does your illness or disability cause problems?" Problem items are rated from 0 (no problem) to 2 (major problem) and do not generate scores.

The IPA-Br4, adapted for Brazil, includes 26 separate items in the domains of Autonomy Indoors, Family role, Social life and relationships, and Autonomy outdoors (11). Initially validated for individuals with spinal cord injuries (11), the digital version has been adapted for broader use among people with physical disabilities (12). It demonstrated satisfactory test-retest reliability and internal structure through confirmatory factor analysis and internal consistency analysis (12).

4.1.4 Statistical Analysis

Quantitative descriptive data of the participants were summarized using measures of central tendency (mean) and dispersion (standard deviation). Domain scores were obtained by dividing the sum items scores by the number of items in the domain (10, 20, 24, 25, 26). Responses to questions on participation problems were described with frequency counts (10, 20, 24, 25, 26).

The influence of personal factors was investigated through Structural Equation Modeling (SEM) using the Weighted Least Squares estimator, a mixed technique combining factor analysis and regression analysis to explore explanatory relationships between multiple variables, whether latent or observable, simultaneously (27). In the structural model, the following IPA dimensions were considered dependent variables (outcomes): Autonomy indoors, Autonomy outdoors, Family role, and Social life and relationships. The independent (explanatory) variables included categories related to health conditions (type of injury, bladder control, fatigue, and mobility impairment) as well as personal factors (age and sex).

RESULTS

A sample of 160 individuals was utilized to investigate the structural model. The participants' ages ranged from 16 to 78 years (45.9 ± 15.7). The most prevalent diagnosis was sequelae of spinal cord injury (n=74), followed by stroke (n=15), COVID-19 (n=15), poliomyelitis (n=9), myelomeningocele (n=8), ataxia (n=7), neuromuscular diseases (n=7), polyneuropathies (n=7), Parkinson's disease (n=4), multiple sclerosis (n=3), osteoarthritis (n=3), tumor resection (n=2), rheumatic diseases (n=2), traumatic brain injury (n=2), congenital malformations (n=1), and cerebral palsy (n=1). The characteristics of the sample are summarized in Table 1.

Table 1. Sample characteristics (n= 160)

Variables		**n**	**%**
Sex			
	Male	87	54.4
	Female	73	45.6
Age group			
	Young adult	44	27.5
	Adult	83	51.9
	Elderly	33	20.6
Type of Injury			
	Birth/Childhood	39	24.4
	From 18 years old (traumatic)	67	41.9
	From 18 years old (non-traumatic)	54	33.8
Continence			
	Yes	70	43.7
	No	90	56.3
Mobility Impairment			
	Non-walker	68	42.5
	Walker	92	57.5
Fatigue			
	Yes	20	12.5%
	No	140	87.5%

Table 2 displays the descriptive statistics of participants' responses to the IPA-Br4 domains. The participants' average responses varied from 1.0 (Good) for Autonomy indoors and Social life and relationships to 2.0 (Fair) for Autonomy outdoors, all below the midpoint of the response scale.

Table 2. Descriptive statistics of the IPA-Br4 response pattern

Domain	**Standardized sum of scores Median (P25/P75)**	**Perceived participation (%)**		
		very good and good	**Fair**	**Poor and Very Poor**
AI	1.0 (0.3/1.7)	69.2	20.9	8.9
AO	2.0 (1.0/2.6)	45.1	32.8	36.2
FR	1.7 (0.3/1.7)	45.1	26.7	27.9
SR	1.0 (0.3/1.7)	74.5	13.2	12.1

AI: Autonomy indoors, AO: Autonomy outdoors, FR: Family role and SR: Social life and relationships; P25: quartile 1; P75: quartile 3

Descriptive statistics for participants' responses to items on participation problems are provided in Table 3.

Table 3. Participation problems

A/P Domain and IPA-Br4 Item	**No problems (%)**	**Minor problems (%)**	**Severe problems (%)**
Mobility	31 (23.6)	55 (41.9)	45(34.5)
Self-care	49 (37.4)	54 (41.2)	28 (21.3)
Family role	23 (17.5)	57 (43.5)	51 (39)
Finance	32 (24.4)	61 (46.6)	38 (29)
Leisure	32 (24.4)	60 (45.8)	39 (29.7)
Social relationships	34 (25.9)	60 (45.8)	37 (28.2)
Helping and supporting others	32 (24.4)	64 (48.8)	35 (26.7)

The structural equation model with demonstrated a satisfactory fit $\chi2(497)= 809.781$, $\chi2/gl= 1.62$, $p < 0.001$, CFI = 0.949, TLI = 0.943, SRMR = 0.118, RMSEA = 0.063 (90% CI = 0.055 – 0.071). The analysis of direct relationships between explanatory and outcome variables revealed significance only in the negative influence of fatigue on Autonomy indoors ($\beta = -0.401$, $p = 0.010$), as illustrated in Figure 1. The model suggests that the presence of fatigue decreases autonomy indoors by 0.400 standard deviations, or 0.302 real units in the final score of the domain.

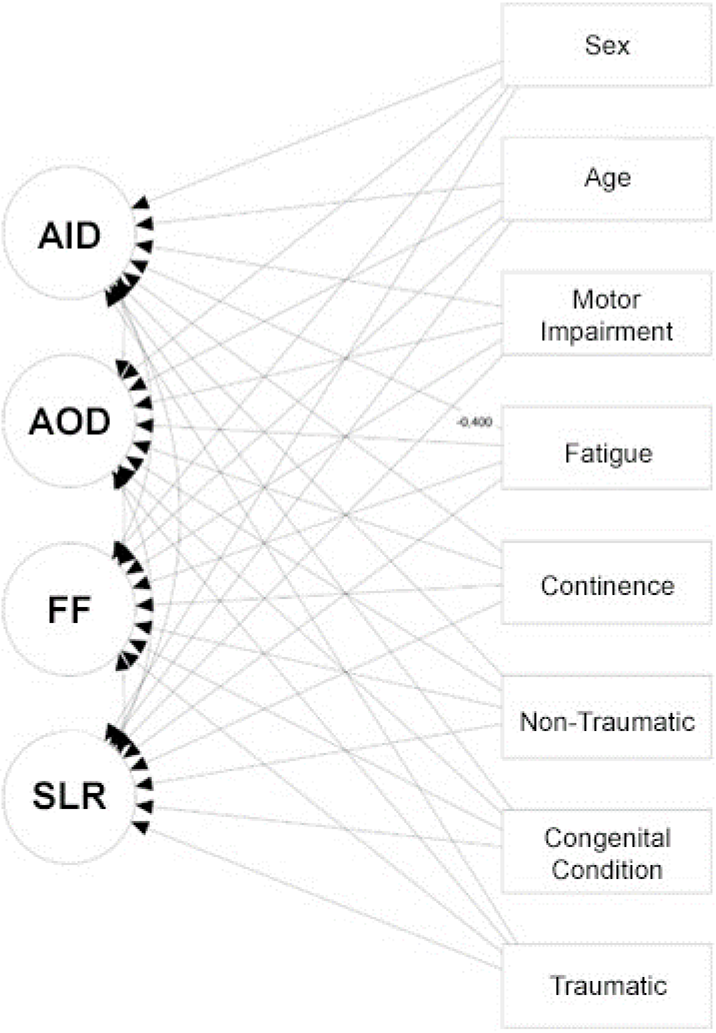

Figure 1. Structural equation model
AI: Autonomy indoors, AO: Autonomy outdoors, FR: Family role and SR: Social life and relationships

DISCUSSION

This study had two main objectives: a) to measure participation using an instrument that captures its subjective aspects in a diverse sample of adults with physical disabilities, and b) to understand the relationships of attributes of the health condition and personal factors to participation. Understanding these relationships allows for adjustments to rehabilitation programs, making them more person-centered, effective, and relevant (5,6,8).

Regarding the scores obtained in the IPA-Br4 domains for perception of participation, the averages ranged from 1 (good) to 2 (fair), values higher than those described in other studies. For instance, Slim et al. reported averages between 1.0 and 1.3 in individuals with Hansen's disease (24). Van de Holst et al. obtained vales between 0.14 and 0.57 for individuals with obstetric brachial palsy sequelae (20). Videler et al. found medians between 0.7 and 1.1 in individuals with type 1A neuropathy (25). In contrast, Lund reported that 96% of respondents with spinal cord injury sequelae reported sufficient (very good to fair) participation (31). In our study, in line with other studies (20, 24, 25, 31). Family roles and Outdoor autonomy had consistently worse perception of participation. These two domains encompass social roles both in domestic and community contexts, adding complexity to participation. In contrast, Autonomy indoors and Social Life and Relationships have a more intimate nature, dependent solely on the individual.

Regarding participation problems, most responses indicated 'Minor problems'. 'Severe problems' was the second most frequent response for all domains except Self-Care. These results indicate greater participation restrictions compared to other studies that reported 'no problems' in most domains (20, 24, 25, 31). The differences in our results compared to the previously reported results could be attributed to our more heterogeneous sample. Additionally, the observed participation restrictions might be influenced by disparities in healthcare access in Brazil, as other studies were conducted in developed countries with more equitable healthcare access (32).

The second objective of this study was to explore the relationship between health condition factors (type of injury, bladder control, fatigue, and mobility impairment) and personal factors (age, gender) with the level of participation indicated by the IPA-Br4 scores. The structural equation model revealed a negative association only between fatigue and

Family role scores. Other variables did not correlate with any IPA-Br4 domain. The Family role domain includes tasks like cleaning and maintaining the house and the garden, activities that might be more challenging for individuals with fatigue due to prolonged postures, physical demands, or difficulties in using mobility aids.

Studies examining the relationship between health condition variables, personal factors, and participation (often measured only by objective aspects) frequently reveal significant relationships. Decreased participation levels might occur with aging (13, 16, 17, 33), in women compared to men (16), in individuals with bladder incontinence (34, 35), and with greater motor impairment (14, 16, 17, 33, 36, 37). Our study investigated whether these influences are apparent when participation is subjectively determined by individuals, and no significant relationships were found. This finding aligns with other studies showing low correlations between these variables and subjective participation assessments (6, 39, 40). Participation assessments that consider subjective aspects, such as autonomy, belonging, challenge, engagement, competence, and personal meaning (8), often do not correlate strongly with the ability to perform specific social tasks (assessed in objective participation instruments). Variables like active engagement, choice and control, access and opportunity, support, and social connection (5, 38, 41) are possibly more relevant in explaining subjective participation scores, as seen in the case of the IPA-Br4.

This study has limitations; the individuals in the sample were undergoing rehabilitation, and this may have potentially influenced their participation levels. Furthermore, participation is a fluid construct, varying over time and being influenced by personal factors and the environment (42, 43). Thus, the lack of relationships between variables like age, sex, time, type of injury, bladder continence, and participation needs further evaluation over time through longitudinal studies.

In conclusion, this study indicates that Brazilian adults with varied diagnoses experiencing physical disabilities and accessing rehabilitation services perceive their participation as ranging between good and fair according to IPA-Br4 scores. Variables like sex, age, type of injury, bladder continence, and impaired mobility did not significantly impact participation levels. However, fatigue negatively influenced Family role domain scores. Rehabilitation services and research should focus on understanding which variables are crucial for promoting the participation of this population.

Declaration of conflicts of interest: There were no conflicts of interest in conducting this study.

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5 CONSIDERAÇÕES FINAIS

O objetivo deste trabalho foi contribuir para a compreensão da participação de brasileiros com deficiências motoras. O retorno à participação em contextos significativos para a pessoa é considerado o desfecho mais importante dos serviços de reabilitação. Participação é um fenômeno complexo e multifatorial. É necessário compreender variáveis que a ela se relacionam e nela interferem ao longo de vida da pessoa. Para que isso seja possível, há um esforço para o desenvolvimento de instrumentos de medida que permitam sua operacionalização clínica.

Estudar participação é uma tarefa árdua. O conceito de participação, na CIF, é relativamente simplista, amplo e vago, e sua codificação conjunta com atividade contribui para a dificuldade em distinguir os limites entre os dois conceitos e encontrar a melhor forma de operacionalizá-los. A confusão entre participação e atividade acaba sobrevalorizando a capacidade de realizar tarefas do dia a dia como indicadora adequada da participação, o que leva a focalizar avaliações e intervenções para o treinamento de habilidades (como a capacidade para a marcha e as transferências, no caso de deficiências físicas que comprometem a mobilidade). Na participação, permanece este foco na capacidade individual observável para o desempenho de papéis sociais. Este foco não permite compreensão de que maneira as pessoas experimentam e interpretam pessoalmente sua participação.

É evidente que habilidades motoras podem facilitar o desempenho de tarefas complexas em ambientes sociais, como se mover pela cidade e frequentar a escola. Entretanto, estas habilidades não são necessárias ou suficientes para determinar os potenciais e limitações para participar. Segundo Vargus-Adams (2012), a participação tem dimensões subjetivas fundamentais. Na prática clínica nos deparamos inúmeras vezes com pacientes, por exemplo, com grande potencial motor, jovens, com poucas complicações secundárias, mas com pobre participação em seu contexto. As dimensões subjetivas da participação precisam ser conhecidas e explorados na mesma profundidade que os fatores objetivos nos programas de reabilitação. A disponibilidade de instrumentos de medida é essencial para isso.

Ginis *et al* (2017) argumentam que a operacionalização da participação em instrumentos de avaliação deve contemplar o senso de pertencimento, significado, desafio, engajamento e competência. Iniciamos esse estudo com uma revisão sistemática, já publicada, para identificar e analisar instrumentos de avaliação que capturassem um ou mais destes aspectos. São ainda poucos os instrumentos disponíveis, e os estudos de validade de conteúdo e estrutura interna tem qualidade limitada. Foram identificados dois instrumentos promissores, o Measure of Experiential Aspects of Participation, e a Parcipation Enfranchisement Measure. Estas medidas ainda precisam passar por processo de adaptação transcultural e validação. No Brasil, foi identificado apenas um instrumento que considera aspectos subjetivos de participação com alguma evidência de validade estrutural. O IPA tem as vantagens de ser um instrumento centrado no indivíduo, sem foco em papeis e habilidades gerais ou padrões normativos, respeitando a inerente subjetividade da participação. Três de seus domínios contemplam adequadamente aspectos subjetivos de participação.

Para o uso do IPA-Br4 em versão digital realizamos inicialmente um estudo de validação na população de interesse. Os 4 domínios do instrumento apresentaram estabilidade com adequados valores confiabilidade teste-reteste, validade estrutural e consistência interna. Com a publicação deste estudo, disponibilizaremos um instrumento de avaliação adequado para diversas condições de saúde no formato digital. Nossa expectativa é facilitar o acesso para pesquisa e nos ambientes de reabilitação.

É importante salientar que durante a aplicação do IPA para os participantes da pesquisa, em um serviço de reabilitação, alguns pacientes expressaram satisfação em refletir sobre sua condição e discutir as razões pelas quais escolhiam as respostas para cada item do instrumento. Alguns reportarem se sentir agradecidos de constatar que mesmo com suas dificuldades motoras conseguiam se perceber atuantes em tarefas que eles julgam importantes, outros ficaram reflexivos ao perceber potenciais situações que limitavam sua participação. O paciente precisa ser protagonista do seu processo de reabilitação, e esta experiência de uso do IPA-Br4 no ambiente de um serviço de reabilitação sugere que o instrumento pode servir como ferramenta para engajar o paciente em sua proposta terapêutica.

Sung *et al*. (2021) descreve que comparado com as pesquisas que envolvem a associação entre aspectos objetivos da participação e as variáveis da condição de saúde e fatores pessoais, as pesquisas desta associação para aspectos subjetivos é limitada. Entender a forma como esses fatores interferem na participação pode nortear os programas de reabilitação. Brown *et al*. (2004) relata que aspectos objetivos e subjetivos da participação são fracamente correlacionados. Portanto, é necessário que investiguemos os fatores que são pertinentes as questões subjetivas para aprofundarmos nosso conhecimento e aprimorarmos os programas de reabilitação, considerando como ponto de partida os componentes subjetivos de participar. A avaliação da participação utilizando instrumentos que avaliam aspectos objetivos em conjunto com instrumentos que captam aspectos experienciais pode nos aproximar da complexidade deste constructo, ao trazerem informações complementares. Poderemos obter esclarecimentos sobre variáveis pertinentes a ambos os aspectos e a forma como as características objetivas e subjetivas interagem e determinam, ao final, a forma e intensidade que o sujeito participa em seus diferentes contextos.

Em síntese, neste estudo buscamos contribuir para a compreensão da participação, especificamente com instrumentos que contemplam aspectos subjetivos. Serviços de reabilitação precisam ser centrados na pessoa, portanto precisamos avançar sobre como a participação é percebida e quais pontos são relevantes para os indivíduos que buscam nossa assistência. Ao pensarmos os programas de reabilitação, as abordagens interdisciplinares buscando engajamento, satisfação e emancipação ao participar são mais promissoras para alcançar resultados relevantes para as pessoas do que abordagens voltadas exclusivamente para a aquisição de habilidades motoras.

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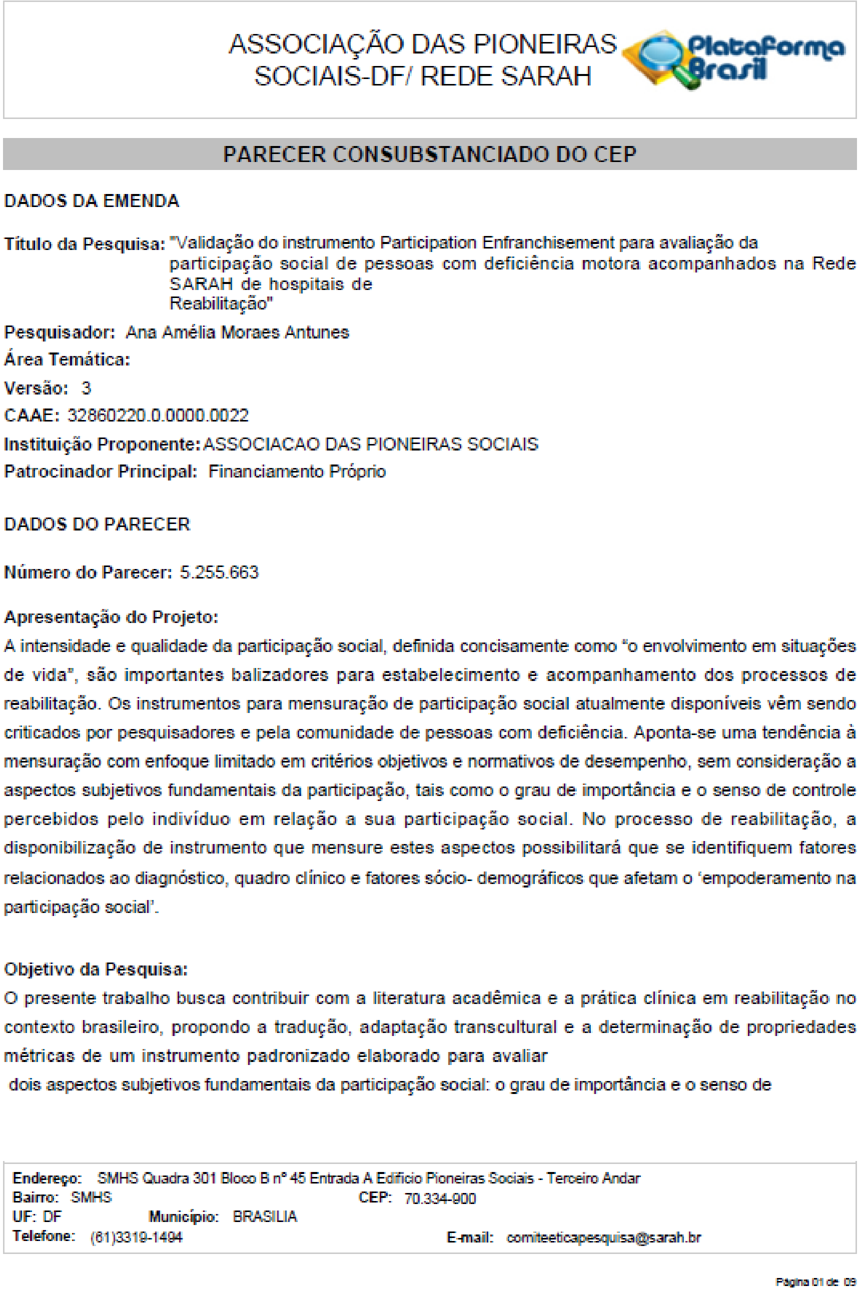
ANEXOS

ANEXO A – PERMISSÃO PARA A PESQUISA



ASSOCIAÇÃO DAS PIONEIRAS
SOCIAIS-DF/ REDE SARAH

PARECER CONSUBSTANCIADO DO CEP

DADOS DA EMENDA

Título da Pesquisa: "Validação do instrumento Participation Enfranchisement para avaliação da participação social de pessoas com deficiência motora acompanhados na Rede SARAH de hospitais de Reabilitação"

Pesquisador: Ana Amélia Moraes Antunes

Área Temática:

Versão: 3

CAAE: 32860220.0.0000.0022

Instituição Proponente: ASSOCIACAO DAS PIONEIRAS SOCIAIS

Patrocinador Principal: Financiamento Próprio

DADOS DO PARECER

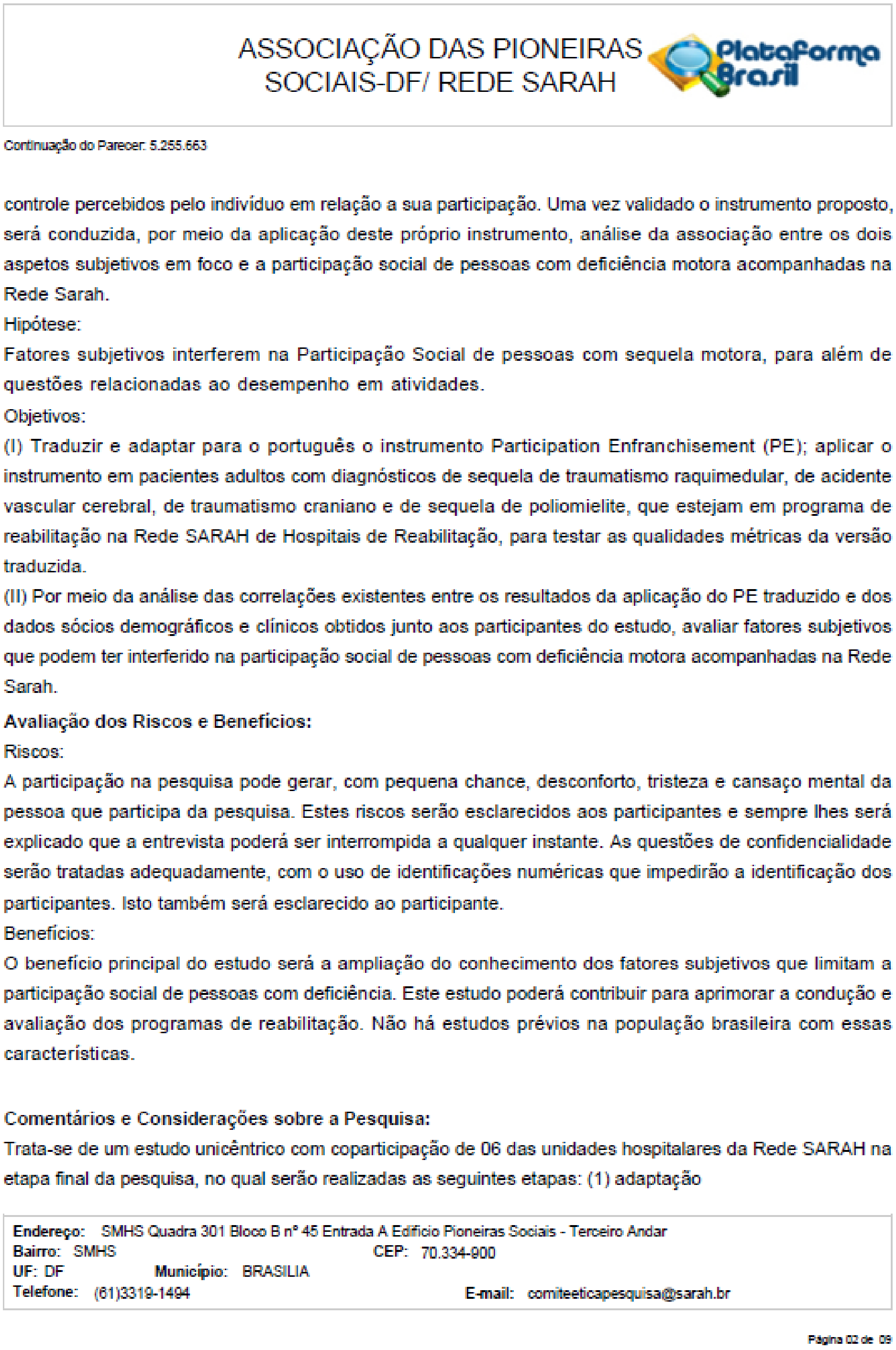
Número do Parecer: 5.255.663

Apresentação do Projeto:

A intensidade e qualidade da participação social, definida concisamente como "o envolvimento em situações de vida", são importantes balizadores para estabelecimento e acompanhamento dos processos de reabilitação. Os instrumentos para mensuração de participação social atualmente disponíveis vêm sendo criticados por pesquisadores e pela comunidade de pessoas com deficiência. Aponta-se uma tendência à mensuração com enfoque limitado em critérios objetivos e normativos de desempenho, sem consideração a aspectos subjetivos fundamentais da participação, tais como o grau de importância e o senso de controle percebidos pelo indivíduo em relação a sua participação social. No processo de reabilitação, a disponibilização de instrumento que mensure estes aspectos possibilitará que se identifiquem fatores relacionados ao diagnóstico, quadro clínico e fatores sócio- demográficos que afetam o 'empoderamento na participação social'.

Objetivo da Pesquisa:

O presente trabalho busca contribuir com a literatura acadêmica e a prática clínica em reabilitação no contexto brasileiro, propondo a tradução, adaptação transcultural e a determinação de propriedades métricas de um instrumento padronizado elaborado para avaliar dois aspectos subjetivos fundamentais da participação social: o grau de importância e o senso de



controle percebidos pelo indivíduo em relação a sua participação. Uma vez validado o instrumento proposto, será conduzida, por meio da aplicação deste próprio instrumento, análise da associação entre os dois aspetos subjetivos em foco e a participação social de pessoas com deficiência motora acompanhadas na Rede Sarah.

Hipótese:

Fatores subjetivos interferem na Participação Social de pessoas com sequela motora, para além de questões relacionadas ao desempenho em atividades.

Objetivos:

(I) Traduzir e adaptar para o português o instrumento Participation Enfranchisement (PE); aplicar o instrumento em pacientes adultos com diagnósticos de sequela de traumatismo raquimedular, de acidente vascular cerebral, de traumatismo craniano e de sequela de poliomielite, que estejam em programa de reabilitação na Rede SARAH de Hospitais de Reabilitação, para testar as qualidades métricas da versão traduzida.

(II) Por meio da análise das correlações existentes entre os resultados da aplicação do PE traduzido e dos dados sócios demográficos e clínicos obtidos junto aos participantes do estudo, avaliar fatores subjetivos que podem ter interferido na participação social de pessoas com deficiência motora acompanhadas na Rede Sarah.

Avaliação dos Riscos e Benefícios:

Riscos:

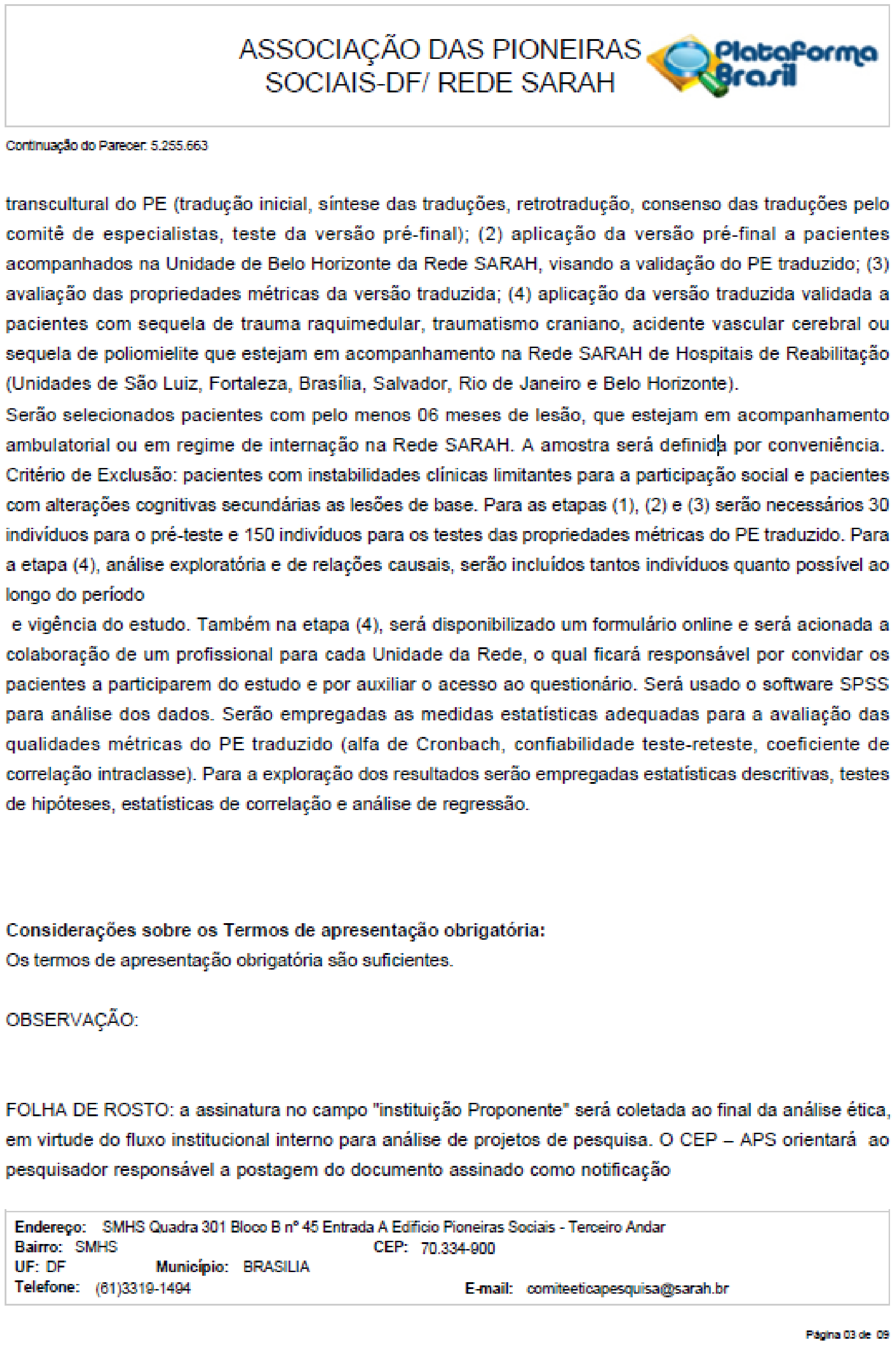
A participação na pesquisa pode gerar, com pequena chance, desconforto, tristeza e cansaço mental da pessoa que participa da pesquisa. Estes riscos serão esclarecidos aos participantes e sempre lhes será explicado que a entrevista poderá ser interrompida a qualquer instante. As questões de confidencialidade serão tratadas adequadamente, com o uso de identificações numéricas que impedirão a identificação dos participantes. Isto também será esclarecido ao participante.

Benefícios:

O benefício principal do estudo será a ampliação do conhecimento dos fatores subjetivos que limitam a participação social de pessoas com deficiência. Este estudo poderá contribuir para aprimorar a condução e avaliação dos programas de reabilitação. Não há estudos prévios na população brasileira com essas características.

Comentários e Considerações sobre a Pesquisa:

Trata-se de um estudo unicêntrico com coparticipação de 06 das unidades hospitalares da Rede SARAH na etapa final da pesquisa, no qual serão realizadas as seguintes etapas: (1) adaptação



transcultural do PE (tradução inicial, síntese das traduções, retrotradução, consenso das traduções pelo comitê de especialistas, teste da versão pré-final); (2) aplicação da versão pré-final a pacientes acompanhados na Unidade de Belo Horizonte da Rede SARAH, visando a validação do PE traduzido; (3) avaliação das propriedades métricas da versão traduzida; (4) aplicação da versão traduzida validada a pacientes com sequela de trauma raquimedular, traumatismo craniano, acidente vascular cerebral ou sequela de poliomielite que estejam em acompanhamento na Rede SARAH de Hospitais de Reabilitação (Unidades de São Luiz, Fortaleza, Brasília, Salvador, Rio de Janeiro e Belo Horizonte).

Serão selecionados pacientes com pelo menos 06 meses de lesão, que estejam em acompanhamento ambulatorial ou em regime de internação na Rede SARAH. A amostra será definida por conveniência.

Critério de Exclusão: pacientes com instabilidades clínicas limitantes para a participação social e pacientes com alterações cognitivas secundárias as lesões de base. Para as etapas (1), (2) e (3) serão necessários 30 indivíduos para o pré-teste e 150 indivíduos para os testes das propriedades métricas do PE traduzido. Para a etapa (4), análise exploratória e de relações causais, serão incluídos tantos indivíduos quanto possível ao longo do período

e vigência do estudo. Também na etapa (4), será disponibilizado um formulário online e será acionada a colaboração de um profissional para cada Unidade da Rede, o qual ficará responsável por convidar os pacientes a participarem do estudo e por auxiliar o acesso ao questionário. Será usado o software SPSS para análise dos dados. Serão empregadas as medidas estatísticas adequadas para a avaliação das qualidades métricas do PE traduzido (alfa de Cronbach, confiabilidade teste-reteste, coeficiente de correlação intraclasse). Para a exploração dos resultados serão empregadas estatísticas descritivas, testes de hipóteses, estatísticas de correlação e análise de regressão.

Considerações sobre os Termos de apresentação obrigatória:
Os termos de apresentação obrigatória são suficientes.

OBSERVAÇÃO:

FOLHA DE ROSTO: a assinatura no campo "instituição Proponente" será coletada ao final da análise ética, em virtude do fluxo institucional interno para análise de projetos de pesquisa. O CEP – APS orientará ao pesquisador responsável a postagem do documento assinado como notificação administrativa. Vide declaração em documento anexo ("decl1").

Recomendações:

Este trabalho está em sua terceira revisão.

Após a realização de 4 rodadas de entrevistas cognitivas e a aplicação de teste reteste para teste da confiabilidade da medida, os resultados encontrados pela pesquisadora foram pobres, demonstrando baixa qualidade da versão traduzida da PE. Realizada avaliação das entrevistas cognitivas e dos itens do instrumento, a pesquisadora observou que as diferenças sócio culturais entre os países de origem do instrumento e do Brasil são relevantes e alguns aspectos mensurados nos itens não têm representação para a cultura brasileira.

Tendo em vista o resultado insatisfatório da tradução, a pesquisadora realizou revisão sistemática da literatura, e selecionou duas escalas, já validadas para brasileiros, a P_Scale (Escala de Participação) (Anexo IV) e a IPA (Impacto na Autonomia e Participação) (Anexo V), com o objetivo de prosseguir o estudo.

Nesta nova submissão, a autora informa este ajuste no curso da pesquisa, e solicita aprovação para prosseguimento.

Conclusões ou Pendências e Lista de Inadequações:

O projeto trata de assunto relevante e atual para a área de reabilitação. Não há restrições éticas, estando aprovado.

ORIENTAÇÕES DO CEP – APS PARA CONDUÇÃO E ACOMPANHAMENTO DA PESQUISA

Tendo em vista a legislação vigente (Resolução CNS 466/12), o CEP-APS recomenda aos Pesquisadores:

1. NOTIFICAR INÍCIO DA PESQUISA por meio de notificação administrativa na Plataforma Brasil;

2. NOTIFICAR INTERRUPÇÃO DO ESTUDO na Plataforma Brasil;

3. NOTIFICAR IMEDIATAMENTE EFEITO ADVERSO relacionados à pesquisa, via notificação na Plataforma Brasil e via documental ao CEP - APS.

4. Comunicar toda e qualquer alteração do projeto e do termo de consentimento via emenda na Plataforma Brasil;

3. Apresentar na forma de notificação relatórios parciais do andamento do projeto a cada 06 (seis) meses e ao término da pesquisa encaminhar a este Comitê um sumário dos resultados do projeto (relatório final), via Plataforma Brasil;

4. Realizar a guarda do material de pesquisa (dados, TCLE, formulário, questionário, entrevistas) por 05 anos após o término da mesma;

5. NOTIFICAR O TÉRMINO DA PESQUISA via notificação administrativa na Plataforma Brasil.

MODELO DE RELATÓRIO FINAL

A) DADOS DO PROJETO

1. CAAE:

2. Pesquisador Responsável:

3. Pesquisadores Assistentes (orientador (a): se houver

4. Título do projeto:

B) DADOS DOS PARTICIPANTES DA PESQUISA

1. Total de sujeitos recrutados em cada local e no total:

2. Total de sujeitos incluídos no estudo em cada local e no total:

3. Total de sujeitos retirados/descontinuados em cada local e no total:

4. Principais razões de retirada/descontinuação:

5. Total de sujeitos que concluíram o estudo em cada local e no total:

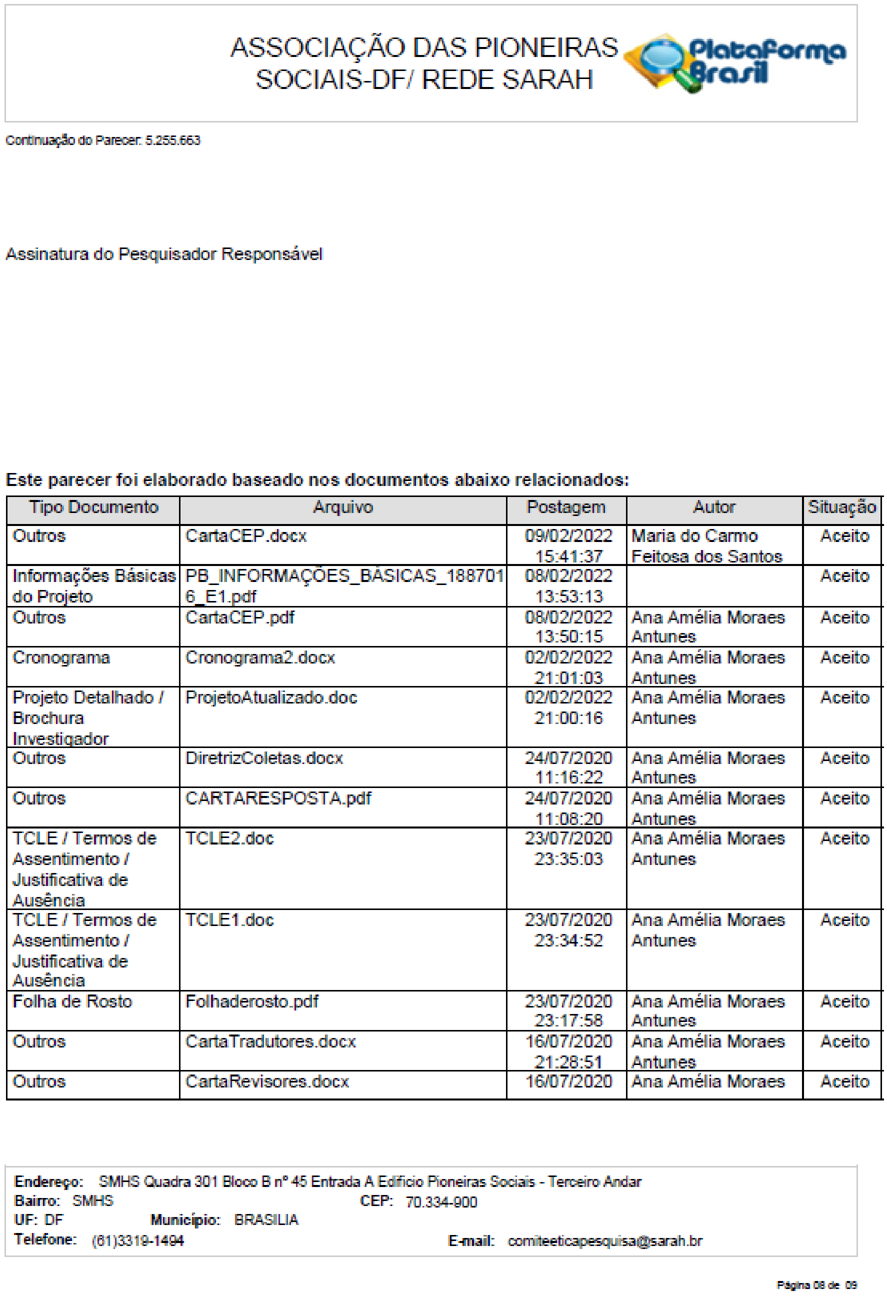
6. Total de eventos sérios ocorridos em cada local e no total:

7. Condutas adotadas em relação aos eventos adversos graves:

8. Houve pedido de indenização por danos causados por este estudo por algum dos participantes?
(Se sim, favor descrever a ocorrência, ressaltando o motivo que a impulsionou e a conduta tomada.)

C) RESULTADOS OBTIDOS

(Descreva resumidamente os resultados e os benefícios resultantes da pesquisa. Se necessário, anexar tabelas, quadros, figuras ou gráficos, para melhor entendimento dos resultados obtidos.)

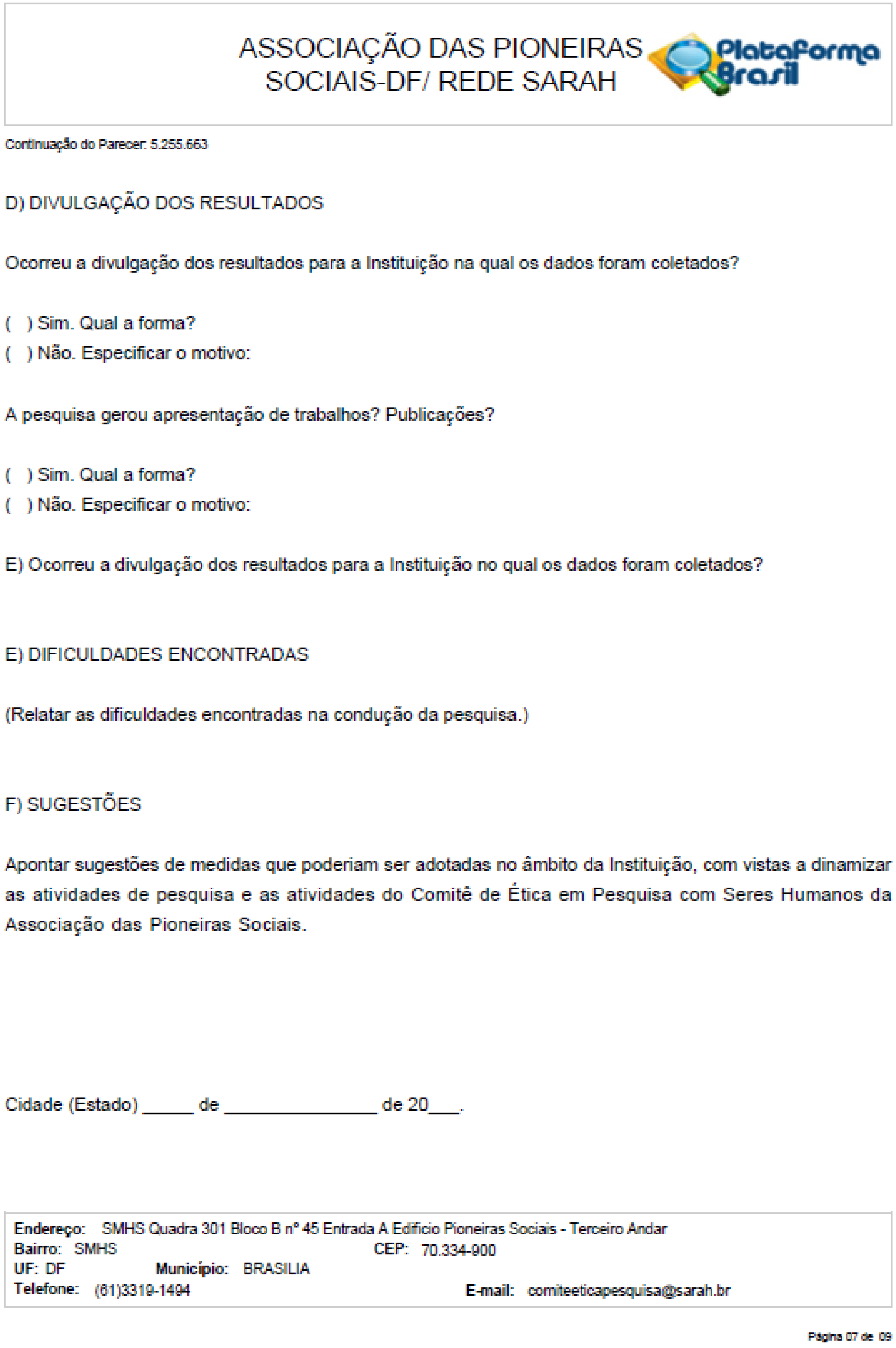


Continuação do Parecer: 5.255.663

Assinatura do Pesquisador Responsável

Este parecer foi elaborado baseado nos documentos abaixo relacionados:

Tipo Documento	Arquivo	Postagem	Autor	Situação
Outros	CartaCEP.docx	09/02/2022 15:41:37	Maria do Carmo Feitosa dos Santos	Aceito
Informações Básicas do Projeto	PB_INFORMAÇÕES_BÁSICAS_1887016_E1.pdf	08/02/2022 13:53:13		Aceito
Outros	CartaCEP.pdf	08/02/2022 13:50:15	Ana Amélia Moraes Antunes	Aceito
Cronograma	Cronograma2.docx	02/02/2022 21:01:03	Ana Amélia Moraes Antunes	Aceito
Projeto Detalhado / Brochura Investigador	ProjetoAtualizado.doc	02/02/2022 21:00:16	Ana Amélia Moraes Antunes	Aceito
Outros	DiretrizColetas.docx	24/07/2020 11:16:22	Ana Amélia Moraes Antunes	Aceito
Outros	CARTARESPOSTA.pdf	24/07/2020 11:08:20	Ana Amélia Moraes Antunes	Aceito
TCLE / Termos de Assentimento / Justificativa de Ausência	TCLE2.doc	23/07/2020 23:35:03	Ana Amélia Moraes Antunes	Aceito
TCLE / Termos de Assentimento / Justificativa de Ausência	TCLE1.doc	23/07/2020 23:34:52	Ana Amélia Moraes Antunes	Aceito
Folha de Rosto	Folhaderosto.pdf	23/07/2020 23:17:58	Ana Amélia Moraes Antunes	Aceito
Outros	CartaTradutores.docx	16/07/2020 21:28:51	Ana Amélia Moraes Antunes	Aceito
Outros	CartaRevisores.docx	16/07/2020	Ana Amélia Moraes	Aceito



ASSOCIAÇÃO DAS PIONEIRAS
SOCIAIS-DF/ REDE SARAH

Continuação do Parecer: 5.255.663

D) DIVULGAÇÃO DOS RESULTADOS

Ocorreu a divulgação dos resultados para a Instituição na qual os dados foram coletados?

( ) Sim. Qual a forma?
( ) Não. Especificar o motivo:

A pesquisa gerou apresentação de trabalhos? Publicações?

( ) Sim. Qual a forma?
( ) Não. Especificar o motivo:

E) Ocorreu a divulgação dos resultados para a Instituição no qual os dados foram coletados?

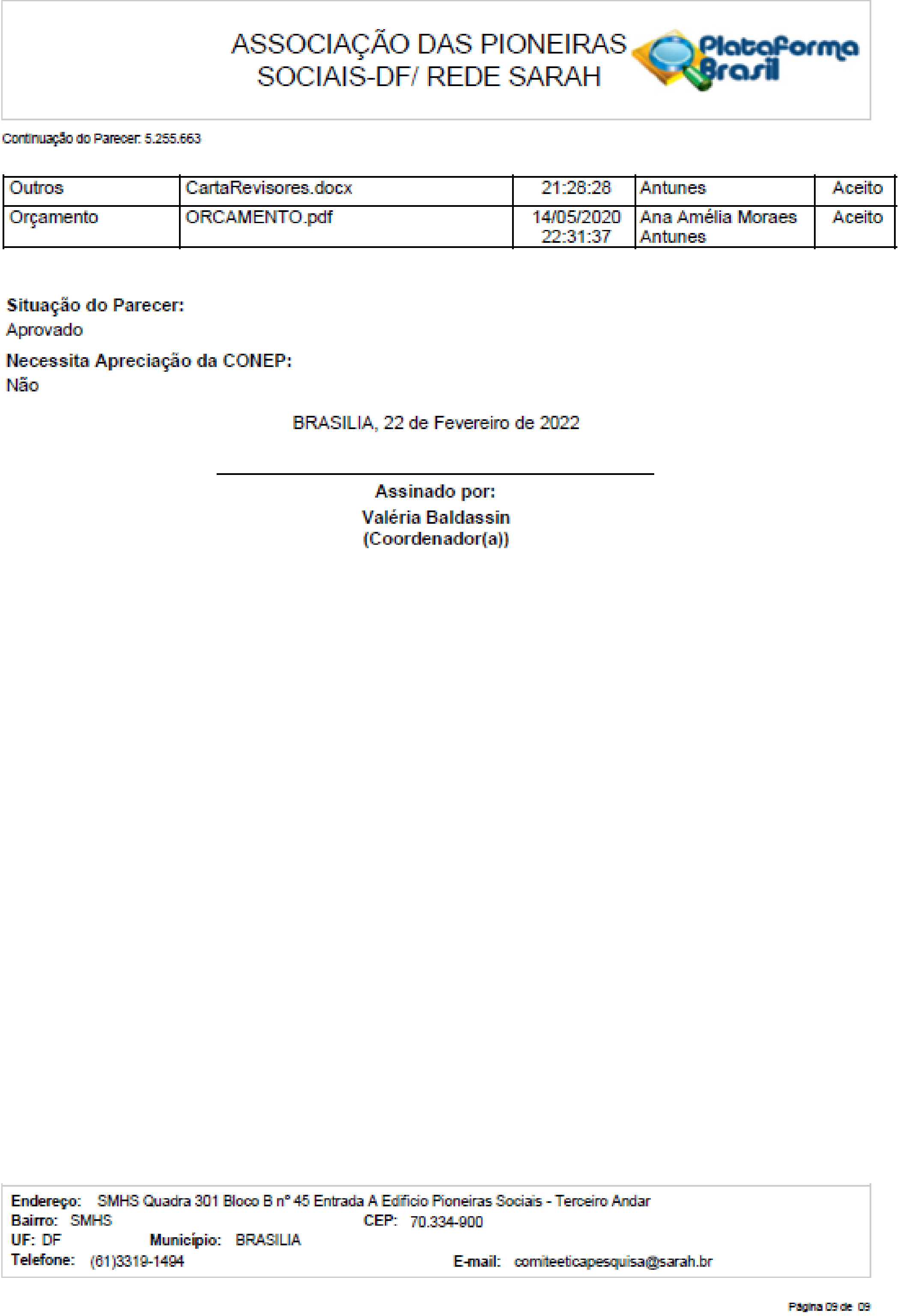
E) DIFICULDADES ENCONTRADAS

(Relatar as dificuldades encontradas na condução da pesquisa.)

F) SUGESTÕES

Apontar sugestões de medidas que poderiam ser adotadas no âmbito da Instituição, com vistas a dinamizar as atividades de pesquisa e as atividades do Comitê de Ética em Pesquisa com Seres Humanos da Associação das Pioneiras Sociais.

Cidade (Estado) _____ de _______________ de 20___.



Continuação do Parecer: 5.255.663

Outros	CartaRevisores.docx	21:28:28	Antunes	Aceito
Orçamento	ORCAMENTO.pdf	14/05/2020 22:31:37	Ana Amélia Moraes Antunes	Aceito

Situação do Parecer:
Aprovado

Necessita Apreciação da CONEP:
Não

BRASILIA, 22 de Fevereiro de 2022

Assinado por:
Valéria Baldassin
(Coordenador(a))

ANEXO B

TERMO DE CONSENTIMENTO LIVRE E ESCLARECIDO

Título da Pesquisa: ASPECTOS EXPERIENCIAIS DE PARTICIPAÇÃO SOCIAL EM ADULTOS COM DEFICIÊNCIA MOTORA

Prezado senhor (a)
____ você está sendo convidado para participar de um projeto de pesquisa que tem como objetivo avaliar as suas respostas das perguntas desse questionário chamado Impacto da Participação e Autonomia. Queremos entender como está acontecendo a participação de pessoas com deficiência física na comunidade. Este projeto será desenvolvido como tese de Doutorado no programa de pós-graduação em Ciências da Reabilitação da Escola de Educação Física, Fisioterapia e Terapia Ocupacional da Universidade Federal de Minas Gerais.

DESCRIÇÃO DOS TESTES A SEREM REALIZADOS: Inicialmente, serão coletadas informações para a sua identificação. Para garantir anonimato, serão utilizados números sequenciais (sem associar o seu nome). Concordando em participar do estudo, você irá preencher o instrumento num computador nas dependências do hospital, sem prejuízo dos seus horários de atendimento. Serão necessários no máximo 20 minutos para o preenchimento do questionário, podendo haver intervalos conforme a sua necessidade.

RISCOS: não há risco físico nesta pesquisa, existindo a possibilidade de desconforto ou frustração durante o preenchimento do instrumento. A aplicação do questionário pode ser interrompida a qualquer momento conforme o seu desejo, sem prejuízo algum para você.

BENEFÍCIOS: Não há benefício direto para você, mas a sua colaboração neste estudo, em conjunto com a colaboração de outros participantes, permitirá a ampliação do conhecimento e a melhoria da abordagem dos serviços de reabilitação

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quanto às estratégias para melhorar a participação comunitária das pessoas com deficiências motoras.

NATUREZA VOLUNTÁRIA DO ESTUDO: A sua participação é voluntária e você tem o direito de se recusar a participar por qualquer razão e a qualquer momento, sem prejuízo algum para sua relação com os profissionais envolvidos ou para o seu tratamento.

GASTOS FINANCEIROS: A aplicação da entrevista e os materiais utilizados na pesquisa não terão nenhum custo para você e você não receberá nenhum pagamento por participar desse estudo.

USO DOS RESULTADOS DA PESQUISA: Os dados obtidos no estudo serão para fins de pesquisa, podendo ser apresentados em congressos e seminários e publicados em artigos científicos, com sua identidade sempre mantida em absoluto sigilo.

DECLARAÇÃO E ASSINATURA

Eu,____ li e entendi toda a informação repassada sobre o estudo, sendo os objetivos e procedimentos satisfatoriamente explicados. Tive tempo, suficiente, para considerar a informação acima e, tive a oportunidade de tirar todas as minhas dúvidas. Estou assinando este termo voluntariamente e, tenho direito, de agora ou mais tarde, discutir qualquer dúvida que venha a ter com relação à pesquisa com: Ana Amélia Moraes Antunes: (0XX31) 99191-7015 (antunesanaamelia@gmail.com).

Assinando este termo de consentimento, eu estou indicando que eu concordo em participar deste estudo.

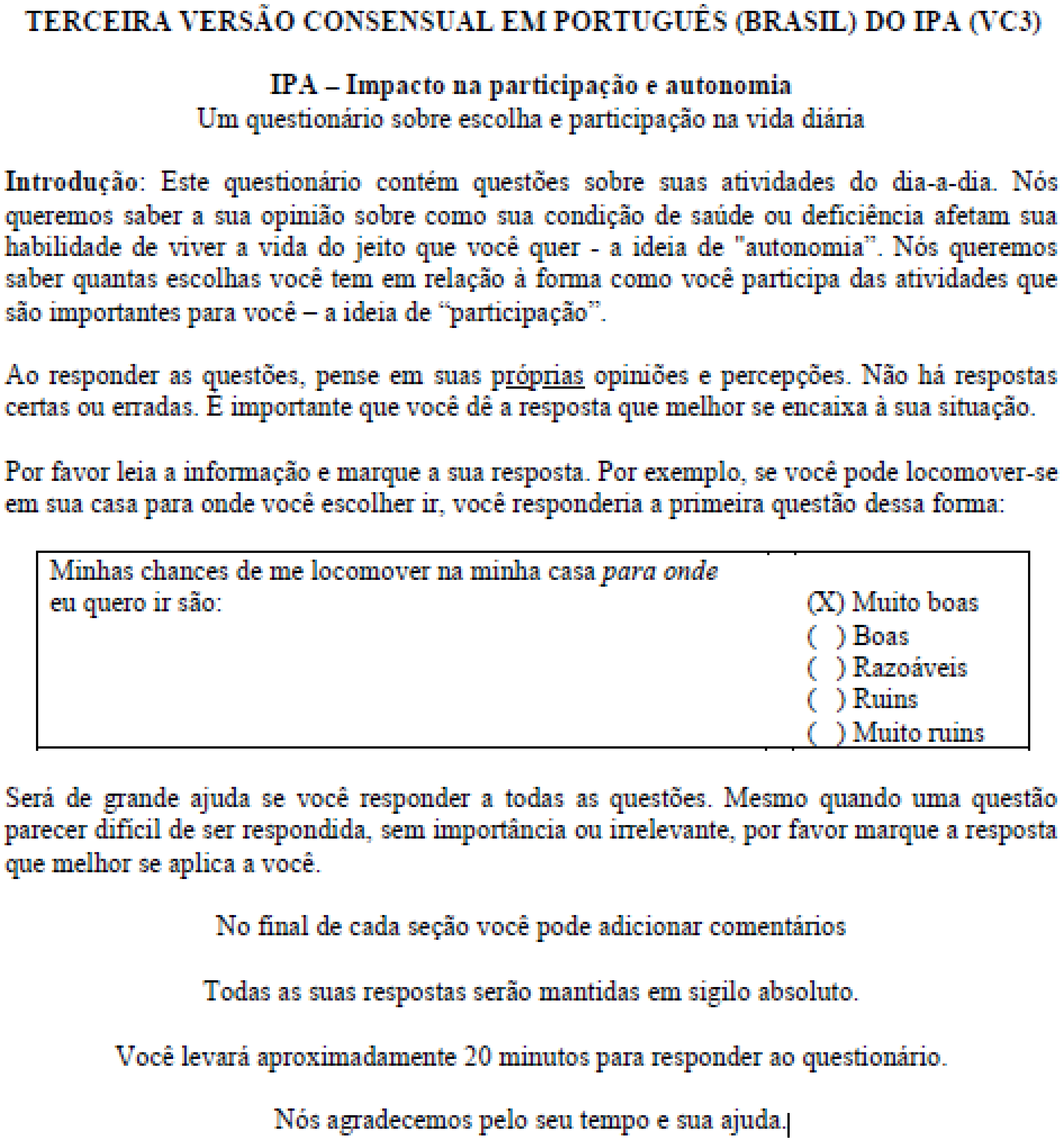
______________________________ ______________
Assinatura do Participante Data

______________________________ ______________
Assinatura do Pesquisador Responsável Data

Este documento será assinado em duas vias, permanecendo uma versão com o participante e a outra com o pesquisador.
O Comitê de Ética em Pesquisa pode ser acionado a qualquer momento para esclarecimento de dúvidas éticas relacionadas a esta pesquisa, pelo telefone: (61) 3319-1494 ou email: comiteeticapesquisa@sarah.br.

APÊNDICE

APÊNDICE A – VERSÃO TRADUZIDA DA IPA - ANDRADE, V.S. Validação para o Brasil do instrumento Impact on Participation and Autonomy para indivíduos com lesão medular. Ribeirão Preto, 2019. p 232; Tese de Doutorado, apresentada à Escola de Enfermagem de Ribeirão Preto/USP.



TERCEIRA VERSÃO CONSENSUAL EM PORTUGUÊS (BRASIL) DO IPA (VC3)

IPA – Impacto na participação e autonomia

Um questionário sobre escolha e participação na vida diária

Introdução: Este questionário contém questões sobre suas atividades do dia-a-dia. Nós queremos saber a sua opinião sobre como sua condição de saúde ou deficiência afetam sua habilidade de viver a vida do jeito que você quer - a ideia de "autonomia". Nós queremos saber quantas escolhas você tem em relação à forma como você participa das atividades que são importantes para você – a ideia de "participação".

Ao responder as questões, pense em suas próprias opiniões e percepções. Não há respostas certas ou erradas. É importante que você dê a resposta que melhor se encaixa à sua situação.

Por favor leia a informação e marque a sua resposta. Por exemplo, se você pode locomover-se em sua casa para onde você escolher ir, você responderia a primeira questão dessa forma:

Minhas chances de me locomover na minha casa *para onde* eu quero ir são:	(X) Muito boas ( ) Boas ( ) Razoáveis ( ) Ruins ( ) Muito ruins

Será de grande ajuda se você responder a todas as questões. Mesmo quando uma questão parecer difícil de ser respondida, sem importância ou irrelevante, por favor marque a resposta que melhor se aplica a você.

No final de cada seção você pode adicionar comentários

Todas as suas respostas serão mantidas em sigilo absoluto.

Você levará aproximadamente 20 minutos para responder ao questionário.

Nós agradecemos pelo seu tempo e sua ajuda.

Impact on participation and autonomy (IPA)

Pontuação:
Espaço reservado para os profissionais responsáveis pela aplicação do questionário

Mobilidade: se movimentar para onde e quando quiser (com ou sem a ajuda de equipamentos ou de pessoas).

Primeiro queremos perguntar algumas questões sobre sua mobilidade: suas chances de se locomover para onde e quando você quiser. Nós estamos interessados em saber se você pode decidir por si próprio para onde e quando você quer ir.

1a. Minhas chances de me locomover em minha casa *para onde* eu quero ir são:

( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

1b. Minhas chances de me locomover em minha casa *quando* eu quero são:

( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

1c. Minhas chances de visitar parentes e amigos *quando* eu quero são:

( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

1d. Minhas chances de viajar e sair de férias conforme eu quero são:

( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

1e. Se sua condição de saúde ou deficiência afetam suas chances de se locomover para onde e quando você quer, o quanto isto causa problemas para você?

( ) Nenhum problema	0
( ) Pequenos problemas	1
( ) Grandes problemas	2

Espaço para comentários sobre sua mobilidade (Opcional):	Pontuação: Espaço reservado para os profissionais responsáveis pela aplicação do questionário

Autocuidado (com ou sem a ajuda de equipamentos ou de pessoas)

As próximas questões são sobre o seu cuidado pessoal. Ao responder essas questões, pense se você pode decidir por si próprio, quando e como você quer que as coisas sejam feitas, mesmo quando você for ajudado por alguém.

2a. Minhas chances de tomar banho ou de ser lavado e de me vestir ou de ser vestido *do jeito* como eu quero são:

( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

2b. Minhas chances de tomar banho ou de ser lavado e de me vestir ou de ser vestido *quando* eu quero são:

( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

2c. Minhas chances de ir para a cama e sair da cama *quando* eu quero são:

( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

2d. Minhas chances de ir ao banheiro *quando* eu quero e preciso são:

( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

2e. Minhas chances de comer e beber *quando* eu quero são:	Pontuação: Espaço reservado para os profissionais responsáveis pela aplicação do questionário
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4
2f. Se sua condição de saúde ou deficiência afetam seu autocuidado, o quanto isto causa problemas para você?	
( ) Nenhum problema	0
( ) Pequenos problemas	1
( ) Grandes problemas	2
Espaço para comentários sobre seu autocuidado (Opcional):	

Atividades na casa (com ou sem a ajuda de equipamentos ou de pessoas).

As próximas questões são sobre as tarefas e responsabilidades que você tem em casa e de que forma sua condição de saúde ou deficiência as influencia. Nós queremos saber se você pode decidir quando e como alguma coisa é feita, mesmo se você não as realiza por si próprio.

3a. Minhas chances de contribuir para cuidar da minha casa *do jeito* como eu quero são:	
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

	Pontuação: Espaço reservado para os profissionais responsáveis pela aplicação do questionário
3b. Minhas chances de ter tarefas leves na casa (exemplo, fazer chá ou café) feitas tanto por mim quanto por outra pessoa, *do jeito* que eu quero, são:	
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4
3c. Minhas chances de ter tarefas pesadas na casa (exemplo, limpeza) feitas tanto por mim quanto por outra pessoa, *do jeito* que eu quero, são:	
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4
3d. Minhas chances de ter o serviço de casa feito, tanto por mim quanto por outra pessoa, *quando* eu quero, são:	
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4
3e. Minhas chances de ter pequenos reparos e trabalhos de manutenção em minha casa e meu jardim feitos, tanto por mim quanto por outra pessoa, *do jeito* que eu quero, são:	
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4
3f. Minhas chances de exercer o meu papel em casa *do jeito como* eu gostaria são:	
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

3g. Se sua condição de saúde ou deficiência afetam suas atividades em casa o quanto isto causa problemas para você?

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os profissionais
responsáveis pela
aplicação do questionário

( ) Nenhum problema	0
( ) Pequenos problemas	1
( ) Grandes problemas	2

Espaço para comentários sobre atividades na casa (Opcional):

Cuidar do seu dinheiro (com ou sem a ajuda de equipamentos ou de pessoas).

As próximas questões são sobre o efeito de sua condição de saúde ou deficiência sobre o controle que você tem com o gasto de seu dinheiro.

4a. Minhas chances de escolher como eu gasto meu próprio dinheiro são:

( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

4b. Se sua condição de saúde ou deficiência afetam suas oportunidades de gastar seu próprio dinheiro, o quanto isto causa problemas para você?

( ) Nenhum problema	0
( ) Pequenos problemas	1
( ) Grandes problemas	2

Espaço para comentários sobre controle da sua situação financeira (Opcional):

Lazer (com ou sem a ajuda de equipamentos ou de pessoas).

As próximas questões são sobre se você pode decidir como usar seu tempo de lazer.

5a. Minhas chances de usar meu tempo para lazer *do jeito* que eu quero são:	Pontuação: Espaço reservado para os profissionais responsáveis pela aplicação do questionário
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

5b. Se sua condição de saúde ou deficiência afetam como você usa seu tempo de lazer, o quanto isto causa problemas para você?

( ) Nenhum problema	0
( ) Pequenos problemas	1
( ) Grandes problemas	2

Espaço para comentários sobre o seu tempo de lazer (Opcional):

Vida social e relacionamentos

As próximas questões são sobre a qualidade e frequência de seus relacionamentos sociais. Nós queremos saber se sua condição de saúde ou deficiência afetam seus relacionamentos.

6a. Minhas chances de conversar com pessoas próximas a mim de igual para igual são:

( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

6b. A qualidade de minhas relações com pessoas próximas a mim é:

( ) Muito boa	0
( ) Boa	1
( ) Razoável	2
( ) Ruim	3
( ) Muito ruim	4

	Pontuação: Espaço reservado para os profissionais responsáveis pela aplicação do questionário
6c. O respeito que eu recebo das pessoas próximas a mim é:	
( ) Muito bom	0
( ) Bom	1
( ) Razoável	2
( ) Ruim	3
( ) Muito ruim	4
6d. Meus relacionamentos com pessoas conhecidas são:	
( ) Muito bons	0
( ) Bons	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4
6e. O respeito que eu recebo das pessoas conhecidas é:	
( ) Muito bom	0
( ) Bom	1
( ) Razoável	2
( ) Ruim	3
( ) Muito ruim	4
6f. Minhas chances de ter um relacionamento intimo são:	
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4
6g. Minhas chances de ver as pessoas com a frequência que eu quero são:	
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

Pontuação: Espaço reservado para os profissionais responsáveis pela aplicação do questionário

6h. Se sua condição de saúde ou deficiência afetam sua vida social e relacionamentos, o quanto isto causa problemas para você?

( ) Nenhum problema	0
( ) Pequenos problemas	1
( ) Grandes problemas	2

Espaço para comentários sobre sua vida social e relacionamentos (Opcional):

Ajudar e apoiar outras pessoas (com ou sem a ajuda de equipamentos ou de pessoas).

As próximas questões são sobre suas oportunidades de ajudar e apoiar outras pessoas da família, vizinhos, amigos ou membros de um grupo.

7a. Minhas chances de ajudar ou apoiar pessoas do jeito que eu quero são:

( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

7b. Se sua condição de saúde ou deficiência afetam suas oportunidades de ajudar outras pessoas, o quanto isso causa problemas para você?

( ) Nenhum problema	0
( ) Pequenos problemas	1
( ) Grandes problemas	2

Espaço para comentários sobre ajudar e apoiar outras pessoas (Opcional):

Trabalho remunerado ou voluntário (com ou sem a ajuda de equipamentos ou de pessoas). As próximas questões são sobre o trabalho remunerado ou voluntário. Nós queremos saber quais são as suas chances de encontrar ou manter um trabalho remunerado ou voluntário, mesmo se isso não for importante para você agora.	Pontuação: Espaço reservado para os profissionais responsáveis pela aplicação do questionário
8a. Minhas chances de conseguir ou manter um trabalho remunerado ou voluntário que eu gostaria são	
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4
Por favor somente responda as 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. Caso contrário, por favor vá para a questão 9.	
8b. Minhas chances de fazer um trabalho remunerado ou voluntário *do jeito* que eu quero são:	
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4
8c. Meus contatos com outras pessoas no meu trabalho remunerado ou voluntário são:	
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4
8d. Minhas chances de conseguir ou manter a posição que eu quero no meu trabalho remunerado ou voluntário são:	
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

	Pontuação: Espaço reservado para os profissionais responsáveis pela aplicação do questionário
8e. Minhas chances de conseguir diferentes trabalhos remunerados ou voluntários são:	
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4
8f. Se sua condição de saúde ou deficiência afetam seu trabalho remunerado ou voluntário, o quanto isto causa problemas para você?	
( ) Nenhum problema	0
( ) Pequenos problemas	1
( ) Grandes problemas	2
Espaço para comentários sobre trabalho remunerado ou voluntário (Opcional):	
Estudar e fazer cursos (com ou sem a ajuda de equipamentos ou de pessoas). As próximas questões são sobre como a sua condição de saúde ou deficiência afetam suas chances de estudar ou fazer cursos que você quer. Se você não quer estudar ou fazer cursos, você pode assinalar a opção 'não se aplica'.	
9a. Minhas chances de estudar ou fazer cursos que eu quero são:	
( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4
( ) Não se aplica	
9b. Se sua condição de saúde ou deficiência afetam suas oportunidades de estudar ou fazer cursos, o quanto isto causa problemas para você?	
( ) Nenhum problema	0
( ) Pequenos problemas	1
( ) Grandes problemas	2

Espaço para comentários sobre suas chances de estudar ou fazer cursos (Opcional):

Pontuação:
Espaço reservado para os profissionais responsáveis pela aplicação do questionário

Concluindo as questões do IPA

Neste questionário você respondeu questões sobre o efeito de sua condição de saúde ou deficiência em sua vida pessoal e social. Considerando isto, você poderia dizer, em geral, se você tem controle suficiente sobre sua própria vida?

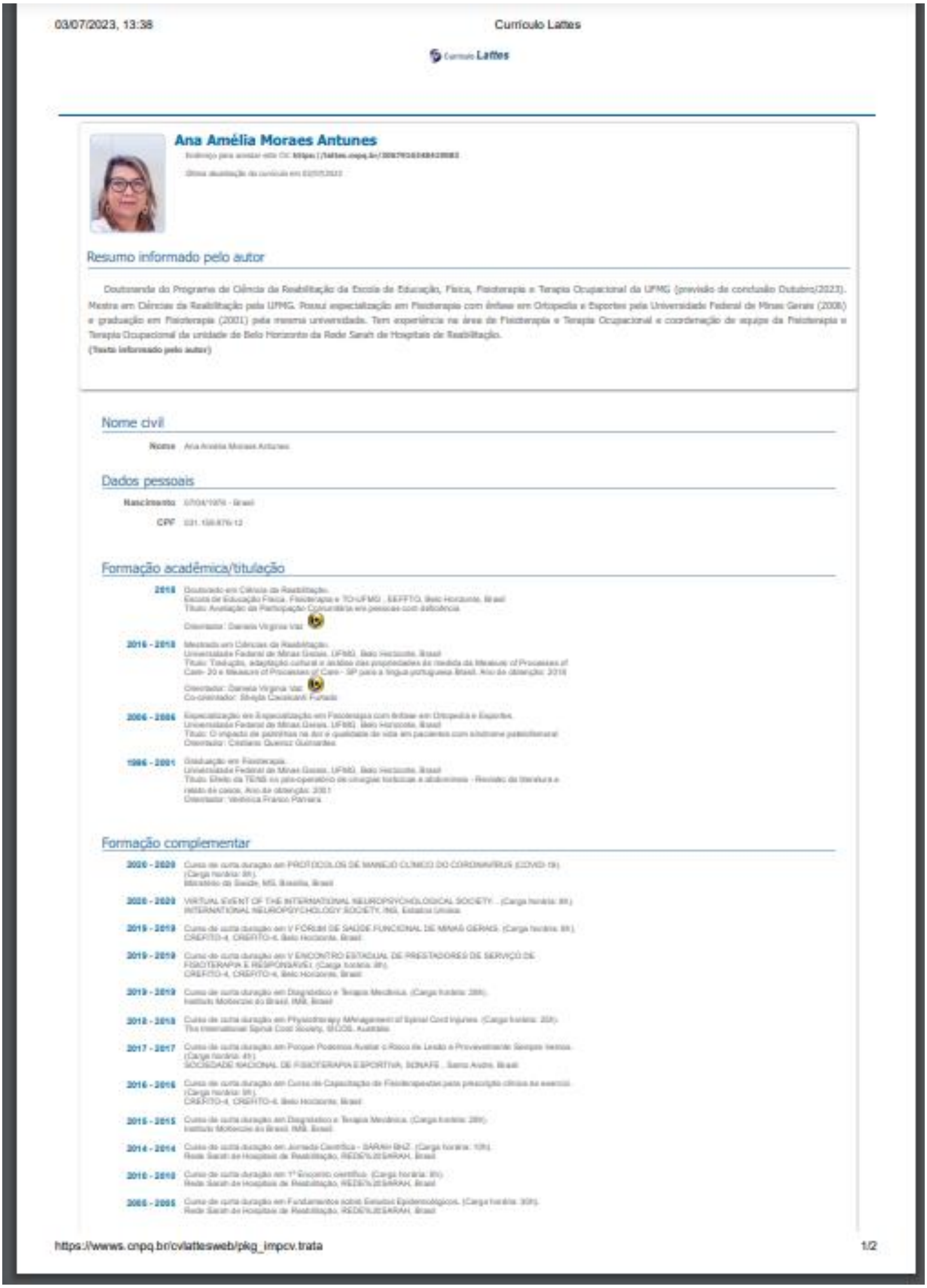
10. Minhas chances de viver a vida do jeito que eu quero são:

( ) Muito boas	0
( ) Boas	1
( ) Razoáveis	2
( ) Ruins	3
( ) Muito ruins	4

Espaço para comentários sobre ter controle sobre sua própria vida (Opcional):

Obrigado pela sua colaboração.

CURRÍCULO



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Currículo Lattes

Ana Amélia Moraes Antunes

Resumo informado pelo autor

Doutoranda do Programa de Ciência da Reabilitação da Escola de Educação, Física, Fisioterapia e Terapia Ocupacional da UFMG (previsão de conclusão Outubro/2023). Mestre em Ciências da Reabilitação pela UFMG. Possui especialização em Fisioterapia com ênfase em Ortopedia e Esportes pela Universidade Federal de Minas Gerais (2006) e graduação em Fisioterapia (2001) pela mesma universidade. Tem experiência na área de Fisioterapia e Terapia Ocupacional e coordenação de equipe da Fisioterapia e Terapia Ocupacional da unidade de Belo Horizonte da Rede Sarah de Hospitais de Reabilitação.

(Texto informado pelo autor)

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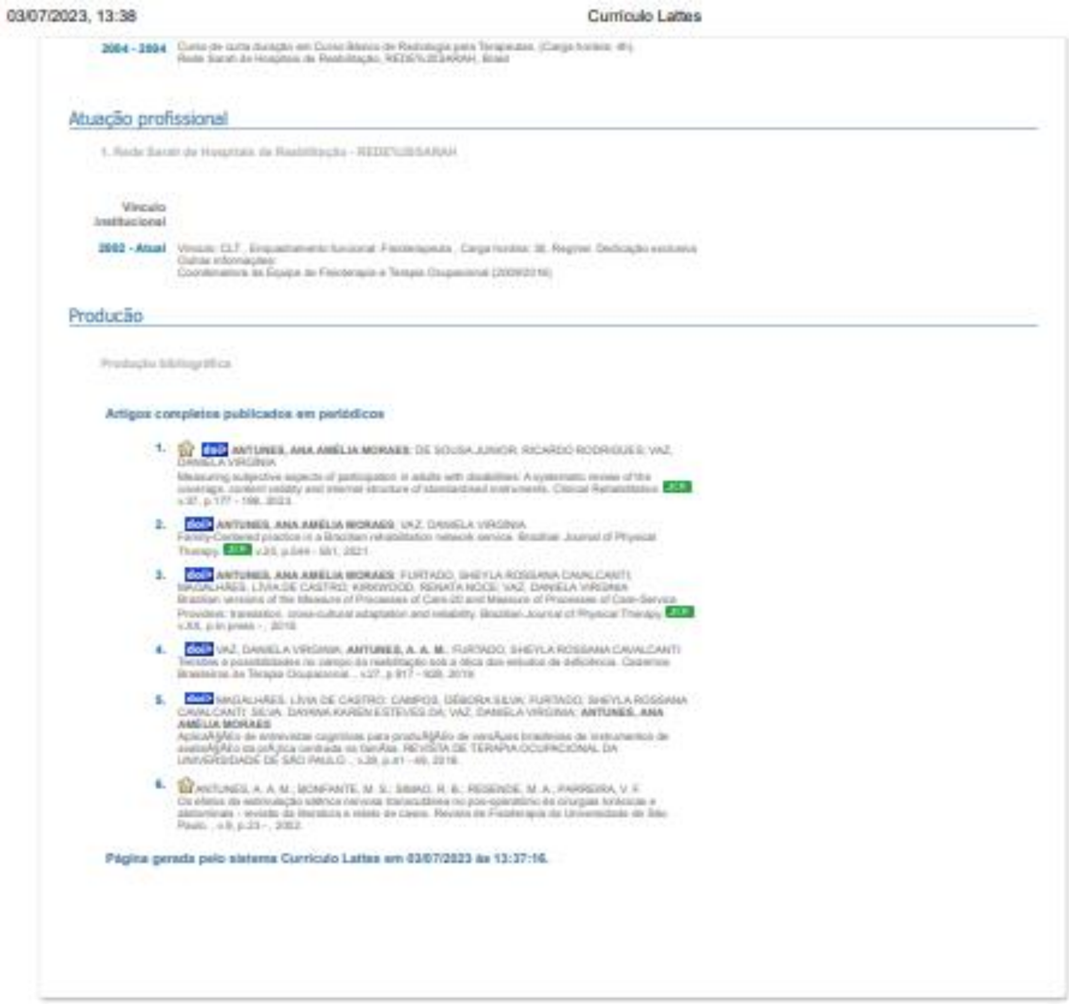

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2004 - 2004 Curso de curta duração em Curso Básico de Radiologia para Terapeutas. (Carga horária: 4h).
Rede Sarah de Hospitais de Reabilitação, REDE%20SARAH, Brasil

Atuação profissional

1. Rede Sarah de Hospitais de Reabilitação - REDE%20SARAH

Vínculo institucional

2002 - Atual Vínculo: CLT , Enquadramento funcional: Fisioterapeuta , Carga horária: 30, Regime: Dedicação exclusiva.
Outras informações:
Coordenadora da Equipe de Fisioterapia e Terapia Ocupacional (2009/2016)

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