

This is a self-archived version of an original article. This version may differ from the original in pagination and typographic details.

Author(s): Karhula, Maarit; Salminen, Anna-Liisa; Hämäläinen, Päivi I.; Ruutiainen, Juhani; Era, Pertti; Tolvanen, Asko

Title: Psychometric evaluation of the Finnish version of the impact on participation and autonomy questionnaire in persons with multiple sclerosis

Year: 2017

Version: Accepted version (Final draft)

Copyright: © 2017 Informa UK Limited

Rights: In Copyright

Rights url: <http://rightsstatements.org/page/InC/1.0/?language=en>

Please cite the original version:

Karhula, M., Salminen, A.-L., Hämäläinen, P. I., Ruutiainen, J., Era, P., & Tolvanen, A. (2017). Psychometric evaluation of the Finnish version of the impact on participation and autonomy questionnaire in persons with multiple sclerosis. *Scandinavian Journal of Occupational Therapy*, 24(6), 410-420. <https://doi.org/10.1080/11038128.2016.1272630>

Psychometric evaluation of the Finnish version of the Impact on Participation and Autonomy questionnaire in persons with multiple sclerosis

Authors:

Maarit E Karhula^{1,2,3}

Anna-Liisa Salminen⁴

Päivi I Hämäläinen^{5,6}

Juhani Ruutiainen⁶

Pertti Era²

Asko Tolvanen²

¹Mikkeli University of Applied Sciences, Mikkeli, Finland

²University of Jyväskylä, Jyväskylä, Finland

³GeroCenter Foundation for Aging Research & Development, Jyväskylä, Finland

⁴Social Insurance Institution of Finland, Helsinki, Finland

⁵Masku Neurological Rehabilitation Centre, Masku, Finland

⁶Finnish Neuro Society, Masku, Finland

Corresponding author:

Maarit E Karhula, Mikkeli University of Applied Sciences Patteristonkatu 3D, 50100 Mikkeli, Finland. Tel +358 406849441, Fax +358 15 355 6464. Email: maarit.karhula@gmail.com

Psychometric evaluation of the Finnish version of the Impact on Participation and Autonomy questionnaire in persons with multiple sclerosis

Abstract

Objective: The objective of this study was to evaluate the psychometric properties of the Impact on Participation and Autonomy (IPA) questionnaire. The Finnish version of IPA (IPAFin) was translated into Finnish using the protocol for linguistic validation for patient-reported outcomes instruments.

Methods: A total of 194 persons with multiple sclerosis (MS) (mean age 50 years SD 9, 72% female) with moderate to severe disability participated in this study. A confirmatory factor analysis (CFA) was used to confirm the four factor structure of the IPAFin. The Work and Educational Opportunities domain was excluded from analysis, because it was only applicable to 51 persons. Internal consistency was investigated by calculating Cronbach's alpha.

Results: CFA confirmed the construct validity of the IPA (Standardized Root Mean Square Residual = 0.06, Comparative Fit Index = 0.93, Tucker-Lewis Index = 0.93, Root Mean Square Error of Approximation = 0.06), indicating a good fit to the model. There was no difference in the models for females and males. Cronbach's alpha for the four domains ranged between 0.80 and 0.91, indicating good homogeneity.

Conclusion: The construct validity and reliability of the IPAFin is acceptable. IPAFin is a suitable measure of participation in persons with MS.

Keywords:

Assessment, autonomy, confirmatory factor analysis, multiple sclerosis, participation, rehabilitation

Introduction

Multiple Sclerosis (MS) is a degenerative and inflammatory autoimmune disease of the central nervous system with a disabling, progressive and unpredictable course (Compston & Coles 2008b). The estimated global number of persons with MS was 2.3 million in 2013 (Multiple Sclerosis International Federation 2015). Typical body function level impairments due to MS include fatigue, bladder dysfunction, sensory and motor symptoms such as impaired tactile perception, pain, muscle weakness, spasticity and poor walking balance (Holper, Lisa et al. 2010). MS also causes behavioural (Rosti-Otajärvi & Hämäläinen 2013) and cognitive problems (Langdon 2011). The impairments in body functions may impact activities and participation significantly.

Participation has been considered as an important outcome for rehabilitation (Cardol, M. et al. 2002) and especially for occupational therapy (Law, Mary 2002). However there is no consensus on the conceptualization of this complex phenomenon (Dijkers, M. P. 2010). Within the International Classification of Functioning, Disability and Health (ICF) participation restrictions are defined as experienced problems with involvement in life situations (World Health Organization 2001). There are interactions in the ways how the concept of participation is used in the models and theories of occupational therapy and in the ICF. In the Model of Human Occupation (MOHO) the concept occupational participation is contrasted with the concept of participation as defined in the ICF, and the occupational performance is used in the same meaning as activity in the ICF (Kramer, Bowyer & Kielhofner 2008). The key concepts of the Canadian Model of Occupational Performance and Engagement (CMOP-E) are occupational performance and engagement which are closely connected to the ICF participation (Polatajko et al. 2007). In the Person-Environment-Occupation model, occupational performance results from the dynamic relationship between the person, his/her occupations and roles, and the environments in which he/she lives, works and plays (Law, Mary et al. 1996). Participation can be viewed as the lived experience, which is influenced by the person, activity and environment and their mutual interaction (Mallinson & Hammel 2010b). Participation may be affected by environmental factors, and correspondingly, better participation on an individual level may enable individuals contribute to environmental factors that restrict participation. (Piškur 2014). These aspects are common in all the above mentioned occupational therapy models and ICF although there is some variation in how the participation is defined. In this article, participation is understood as an involvement in both activities of daily living (ADL) and social activities not excluding a situation in which a person can be autonomous to some extent or able to control his/her own life, although he/she does not accomplish things independently by him/herself (Perenboom & Chorus 2003a).

The impact of MS on participation is considerable. (Einarsson et al. 2006). The experiences of restrictions in participation are individual and related to all aspects of daily life (Månsson Lexell, Iwarsson & Lexell 2006). The ability to perform satisfactorily with both primary ADL (P-ADL) and instrumental ADL (I-ADL) has been found to be hampered in persons with moderate to severe MS (Månsson & Lexell 2004). Therefore, both P-ADL and I-ADL should be evaluated (Månsson & Lexell 2004). Persons with MS experience that functional limitations have forced them to continuously struggle to maintain engagement and have made it necessary to construct a different life than before (Lexell, Eva Månsson, Lund & Iwarsson 2009). Moreover, the subjective experiences of problems encountered in everyday life vary considerably among persons with MS, for example, from ICF categories “moving around in different locations” or “washing oneself” to “doing housework” or “recreation and leisure” (Karhula et al. 2013). There is an evident need to measure participation with a valid tool to understand the participation restrictions at the individual level and, thus, to better support persons with MS to participate despite these restrictions.

The Impact on Participation and Autonomy (IPA) questionnaire was developed in the Netherlands to measure participation from the individual's point of view (Cardol, M., de Haan, van den Bos, G A, de Jong & de Groot 1999b). The IPA is a generic questionnaire which addresses perceived participation (Cardol, M. et al. 2001). In addition, the questionnaire addresses the concept of autonomy, as the developers found in their literature review that autonomy is a pre-requisite for effective participation, and therefore suggested that autonomy is the ultimate aim of rehabilitation (Cardol, Mieke, Jong & Ward 2002). The original Dutch version of the IPA was developed utilizing the results of the psychometric study as well as experts' and rehabilitation consumers' opinions and it consisted of 31 items (Cardol, M., de Haan, van den Bos, G A, de Jong & de Groot 1999b, Cardol, M. et al. 2001). In the final version of the IPA, the person answers altogether 41 items of which 32 concern the perceived participation and autonomy and nine concern the perceived problems with participation (Sibley et al. 2006b). For older people there is a modified version called IPA-O which includes 22 items (Hammar et al. 2014).

The IPA has been translated into a number of different languages including English, French, Persian and Swedish. Validation studies of the IPA have been conducted with the English (Cardol, M. et al. 2002, Sibley et al. 2006b), Swedish (Lund et al. 2007), French (Poulin & Desrosiers 2010) and Persian versions (Fallahpour et al. 2011). Furthermore, a comparison of the Dutch and English version has been conducted (Kersten et al. 2007). These studies addressed various dimensions of validity and they have been conducted with heterogeneous patient groups. Taken together, the

different versions of the IPA have shown acceptable psychometric properties including construct validity and reliability.

Progressive disease influences how individuals experience restrictions in participation. A constantly changing function requires persons with MS to find and create new ways to participate in everyday life (Lexell, Eva Månsson, Lund & Iwarsson 2009). The progressive nature of the disease may also have an impact on measuring participation.

The psychometric properties of the IPA with persons with MS have been evaluated at least in two studies (Sibley et al. 2006b, Vazirinejad, R., Lilley & Ward 2003). Sixty persons with MS participated in the study of Sibley et al (Sibley et al. 2006b) but their results were not separately reported in terms of validity or reliability. The acceptability of the English version of the IPA was evaluated by 35 persons with MS who considered that from the items of the IPA the Mobility domain was the most relevant and the Education domain least important (Vazirinejad, R., Lilley & Ward 2003). The study did not evaluate the construct validity and reliability of the IPA (Vazirinejad, R., Lilley & Ward 2003).

There is no measure of participation and autonomy in Finnish. Since cultural issues may affect perceptions of participation and autonomy, there is a need to translate and validate IPA into Finnish language and with Persons with MS. The purpose of this study was to evaluate the psychometric properties of IPAFin the perceived participation and autonomy aspect with persons with MS. The perceived problems with participation scale has been found to only be sensitive enough to identify those who experience problems and those who do not (Lund et al. 2007). Therefore, using the perceived problems with participation scale instead of information from individual questions in clinical settings is questionable and it is not appropriate to evaluate the psychometric properties of the problems with participation scale. The study focused on evaluating the construct validity of the IPAFin the perceived participation and autonomy aspect with persons with MS by using a confirmatory factor analysis (CFA) framework and investigating the reliability of the individual IPAFin perceived participation and autonomy domains.

Material and methods

Design and data collection

Persons with MS were included by convenience sampling with pre-defined inclusion and exclusion criteria. The inclusion criteria were as follows: (i) age between 18 and 65 years (inclusive), (ii) a confirmed diagnosis of MS, (iii) ability to fill in

questionnaires independently or with the help of an assistant. Participants were excluded if they were not capable of expressing their own choices or answering questions in the questionnaires. The data for this cross-sectional study was collected in two phases. First data set was collected in 2011 from persons with MS who participated in a two-year multi-professional, group-based out-patient rehabilitation project which was conducted by the Finnish NeuroSociety, the Finnish Social Insurance Institution and the GeroCenter Foundation for Aging Research and Development. Rehabilitation professionals from the Finnish NeuroSociety together with local health care professionals recruited participants from three areas of Finland (Helsinki, Kuopio and Turku) (Salminen et al. 2014). The second data set was collected from persons with MS in 2012–2013 during an in-patient rehabilitation period of 1-3 weeks at Masku Neurological Rehabilitation Center in order to receive a larger sample for the evaluation of validity and reliability of the IPA-Fin. All participants provided written informed, and the study was approved by the Ethics Committees of the Finnish Social Insurance Institution (data set 1) and the Hospital District of Southwest Finland (data set 2).

Assessment methods

The participants' sociodemographic characteristics, including gender, age, living conditions (alone or with others), employment status (disability pension or not) and the duration of the disease were derived from participants using a questionnaire tailored for the purpose. Disease course (relapsing-remitting, primary-progressive, secondary-progressive) was classified by a neurologist from patient records according to Lublin and Reingold (Lublin, F. D. & Reingold 1996). The same neurologist evaluated the severity of MS by using The Expanded Disability Status Scale (EDSS) (Kurtzke 1983). The EDSS score ranges in steps of 0.5 from 0 (no impairment) to 10 (death). In practice, the lower EDSS grades (0–3.5) are defined by the signs in a neurological examination, while grades 4.0 and above are largely dependent on ambulation and the use of the upper extremities (Kurtzke 1983).

The questions in the IPA are organized into nine areas (mobility, self-care, activities in and around the house, looking after one's money, leisure, social life and relationships, helping and supporting other people, paid or voluntary work, education and training) and in the end of the questionnaire there is the conclusive question of chances of living life the way one wants. The perceived participation and autonomy aspect is composed of the domains of Autonomy Indoors (7 items), Family Role (7 items), Autonomy Outdoors (5 items), Social Life and Relationships (7 items) and Work and Education Opportunities (6 items) (24). The nine items on the problems with participation in everyday life constitute the perceived problems with participation aspect and individual items provide important information, for

example, for the rehabilitation goal setting (22). The respondent grades his/her perceived participation and autonomy for each item on a 5-point Likert-scale ranging from 0 (very good) to 4 (very poor) (Cardol, M. et al. 2001). A standardized mean score is calculated for each domain. The respondent also evaluates the problems with participation on nine subscales by rating a 3-point scale from 0 (no problem) to 2 (severe problems). Higher scores indicate lower sense of autonomy and more perceived participation restriction (Cardol, M. et al. 2001).

The IPA was translated into Finnish (IPAFin) using back-translation and expert-group consensus (Kanelisto & Salminen 2011). Permission to translate the IPA into Finnish and to publish it was received from the IPA author Mieke Cardol during 2010 (Kanelisto & Salminen 2011). The Finnish translation is based on the latest (Kersten et al. 2007) version of IPA that includes 32 questions on perceived participation and nine questions on the problems with participation. The protocol for linguistic validation of translated patient-reported outcomes instruments by Acquardo et al. (Acquardo 2004) was adopted and modified for the purposes of this translation process (Figure 1).

[Figure 1 near here]

Both the original Dutch IPA (Cardol, M. et al. 2001) and the English IPA-E (Sibley et al. 2006b, Kersten et al. 2007) were translated into Finnish by a trilingual rehabilitation expert who also compared both versions against each other. Additionally, the English IPA-E was translated into Finnish by an independent professional translator. A third person, who is a rehabilitation expert compared translations and made a proposal for the first Finnish version. This first version was discussed and reviewed in detail in the expert group that included four rehabilitation specialists. To ensure the conceptual equivalence the expert group made some changes that were related to the established Finnish rehabilitation terminology and the concept of autonomy. For example the first translation of the concept "disability" was understood too broadly in this context and therefore the translation was modified. Also the translation of the phrase "with or without aids or assistance" was clarified because in the first translation of the concept "assistance" was understood as "a professional who provides assistance". Therefore the translation of the phrase was modified.

The first version was piloted by a person with a neurological condition. This led to some clarifications in the layout of the questionnaire. Then the first version was used in the assessment of 116 persons with MS. The assessment was implemented as a structured interview that made it possible to collect information on the usability of the questionnaire. This led to minor changes in language and settings. Then, even after interviewing the 116 participants and making minor changes to the second Finnish version was back-translated into English by another professional translator to ensure

the equality of the translation compared to the original English version of the IPA. The back-translation was analysed in the expert group, leading to some semantic changes in the Finnish version. For example the translation of the question "...to what extent does this cause you problems..." was modified. The Finnish language of the questionnaire was then revised by a professional, and finally checked by the expert group. The final third version, IPA-Fin, was accepted by the expert group in 2011.

Participants

Altogether 194 persons with MS (105 in data set 1 and 89 in data set 2) with considerable activity limitations (mean EDSS 6.0, SD 2) participated. Over two thirds of them were female, and the mean age was 50 (SD 9) years (Table 1).

Statistical Analysis

Confirmatory factor analysis (CFA) methods were applied to test the multidimensionality of the theoretical construct of the perceived participation and autonomy aspect of the IPAFin (Byrne 2013). CFA models were estimated and tested by using a statistical modelling program MPLUS 6.0 (Muthén & Muthén 2010). CFA consisted of the process which includes model specification, identification, estimation, testing fit, and re-specification (Kline 2015, Kelloway 2014). In the present study, analysis of the multidimensionality of the IPAFin was conducted in three phases including testing the original four-factor model, the modified model, and models for women and men.

In the first phase of the analysis, CFA was specified as a four-factor model which includes four domains of IPAFin (Autonomy Indoors, Family Role, Autonomy Outdoors and Social Relationships domains) and 26 items. The Work and Educational Opportunities domain (6 items) was excluded from the CFA, because the items were only applicable to 51 persons. After the model specification, the identification of the model was examined. Basically, the model should be over-identified which means that the number of estimable parameters is less than the number of variances and covariances of the observed variables (Byrne 2013). There should be also at least three items for each factor (Kelloway 2014). The identified model was estimated using MPLUS which is designed to solve sets of structural equations (Kelloway 2014). The missing information is expected missing at random (MAR) and the method for estimation was the full information maximum likelihood method (FIML) (Kelloway 2014). Then the fit of the models was tested using several goodness-of-fit indices which produce different information about the model fit, that is, absolute fit, fit adjusting for model parsimony, and fit relative to a null model (Brown, T. A. 2006). Generally, it is recommended that each of these fit indices should be reported and considered, because they provide different information about the model fit (Bollen &

Long 1993). A statistically non-significant ($p > 0.05$) chi-squared statistic means that the model does not significantly differ from the data. The standardized root mean square residual (SRMR) is the average discrepancy between the correlations observed in the input matrix and the correlations predicted by the model (Brown, T. A. 2006), and the good values of SRMR are close to 0.08 or below (Hu & Bentler 1999). The root mean square error of approximation (RMSEA) was used to assess the extent to which a model fits the population reasonably well (Brown, T. A. 2006). The values of RMSEA are good when they are close to 0.06 or below (Hu & Bentler 1999). The comparative fit index (CFI) and Tucker-Lewis index (TLI) values close to 0.95 or above indicate reasonable model fit (Hu & Bentler 1999). In addition, normalized residuals should be normally distributed, and there should not be over 5% of values which exceed the absolute value of over two.

In the second phase, if the original model does not fit to the data, the four-factor model will be re-specified. The model is modified according to the theoretically relevant modification indices of MPLUS 6.12.

Finally, in the third phase of the analysis, even though there were fewer men than women, the equality of the factor loadings and intercepts was tested. A model where the loadings were fixed equal and a model where the loading was estimated freely were compared with chi-square difference testing using the Satorra-Bentler scaled chi-square (Satorra & Bentler 2001). If the loadings were equal, the analysis was continued and compared to the model where intercepts were also constrained equal in and compared to the model in which only factor loadings were fixed equal (Brown, T. A. 2006).

The internal consistency of each five domain of IPAFin was considered good, if the Cronbach's alphas were greater than 0.8 (95% CI 0.7 and 0.9) (Streiner, Norman & Cairney 2014).

Results

Construct validity

The CFA model for perceived participation and autonomy aspect of IPAFin without modification (M1) showed that the theoretical model and the observed data did not fit well (Table 2). All other values of goodness-of-fit indices except the standardized root mean square residual (0.08) were unacceptable. Therefore, the model was modified according to the modification indices of MPLUS 6.12. The structure of the modified IPAFin four factor solution, factor loadings and modifications are presented in Figure 2. The items and standardized factor loadings are presented in Table 3. The

theoretically relevant modifications are presented in Figure 2 and they were as follows: One item of the Family Role domain 3b “minor housework” and one item of the Autonomy Outdoors domain 1c “visiting friends” were loaded by the Autonomy Indoors domain, one item of the Family Role domain 4a “spending income” was loaded by the Autonomy Outdoors domain. Furthermore, 11 residual covariances were added (also presented in Figure 2). Five of the residual covariances were added between items of the Autonomy Indoors domain: 1a “getting around in one’s own house when one wants” and 1b “getting around in one’s house when one wants” (residual correlation 0.39), 1a “getting around in one’s house when one wants” and 2a “getting washed and dressed the way one wishes” (0.19), 1b “getting around in one’s house when one wants” and 2e “eating and drinking when one wants” (-0.43), 2a “getting washed and dressed the way one wishes” and 2b “getting washed and dressed when one wants” (0.67), 2c “getting up and going to bed when one wants” and 2d “going to the toilet when one wishes and needs to” (0.44). In Family Role domain one residual covariance was added between items 3c “getting heavy tasks done around the house” and 3d “getting housework done when one wants them done” (0.49). Also in Autonomy Outdoors domain one residual covariance was added between 1c “visiting relatives and friends when one wants” and 1d “going on the sort of trips and holidays one wants” (0.46). In Social Relationships altogether four residual covariances were added between items: 6a “talking to people close to one on equal terms” and 6b “relationships with people who are close to one” (0.29), 6b “relationships with people who are close to one” and 6c “the respect from people who are close to one” (0.41), 6c “the respect from people who are close to one” and 6e “the respect one receives from acquaintances” (0.25) and in addition, 6d “one’s relationships with acquaintances” and 6e “the respect one receives from acquaintances” (0.49).

[Figure 2 near here]

The indices for the model fit (Table 2) showed that the modified model fitted the data well according to all the other indices (CFI, TLI, RMSEA, SRMR) except chi-square. Moreover, normalized residuals were distributed as expected. The correlations between the factors were quite high, ranging from 0.48 (Autonomy Indoors and Social Relationships) to 0.86 (Autonomy Outdoors and Social Relationships).

The equality of the factor loadings and intercepts of the model between women and men was confirmed (Table 4).

Reliability

All domains had high levels of internal consistency, as determined by a Cronbach's alpha: 0.91 (Autonomy indoors), 0.88 (Family role), 0.88 (Autonomy outdoors) and

0.85 (Social relationships). The Cronbach's alpha for the IPA domain Work and education was 0.80, measured with a smaller sample (n=51).

Discussion

Construct validity and reliability of the IPAFin

The results of this study indicate that the construct of the perceived participation and autonomy aspect of the IPAFin consisting of Autonomy Indoors, Family Role, Autonomy Outdoors and Social Relationship domains is confirmed among persons with MS with moderate to severe disability. The Work and Education Opportunities domain was excluded from the analysis, because only a minority of the participants answered such questions. The results of the modified model support the four factor structure. Only the χ^2 -value shows poor fit; all other fit indices show acceptable fit. However the χ^2 -value considering the complexity of the model (degrees of freedom) is not high. According to Byrne (Byrne 1991) the χ^2 and degrees of freedom ratio values lower than two are considered to represent a minimally potential model fit. In addition, there were fewer than expected normalized residuals with an absolute value over two, and the residuals were distributed normally. Therefore, the model fit could be interpreted as sufficient.

Although the construction of the perceived participation aspect of the IPAFin was confirmed, in the modified model, three items were loaded in addition to the original main factor also to another theoretically relevant factor. Firstly, Item 1c "chances to visit relatives and friends when one wants" was loaded to the original main factor, the Autonomy Outdoors domain (0.55) and, in addition, to the other factor, the Autonomy Indoors domain (0.25). However, that did not disturb the model, because the loading to the main factor Autonomy Outdoors was clearly stronger. Secondly, Item 4a "spending income as wished", which is part of the Family Role domain, loaded more strongly to the Autonomy Outdoor domain (0.59) than to the Family Role domain (-0.01). The relation of Item 4a "the spending income as wished" to the Autonomy Outdoors domain can be interpreted as logical. It could be hypothesized that for most of the participants low income is a factor that affects them; for example, the items of the Autonomy Outdoors domain 1c "their chances to visit relatives and friends", 5a "their use of leisure time the way they desire" and 6g "their chances to see other people as often as they want" are all items that represent this fact. Thirdly, Item 3b "minor housework" loaded more strongly to the Autonomy Indoors domain (0.57) than to the Family Role domain (0.25). This could be explained by the demands of the activity. The demands of the activity Item 3b "chances of getting light tasks done around the house (e.g. making tea or coffee)" is closer to the activities of the Autonomy Indoors domain such as Item 2c "chances of getting up and going to bed" or Item 2e

“chances of eating and drinking” than to the demands of activities of the Family Role domain, for example, Item 3a “chances of contributing to looking after my home”. These two, Item 4a “the spending income as wished” and Item 3b “chances of getting light tasks done around the house”, have also been considered in previous studies.

In the study by Sibley et al (Sibley et al. 2006b), the construction of the IPA was confirmed, although Item 4a “spending income as wished” loaded weakly (-0.12), as did Item 3b “doing minor housework jobs the way one wants” (0.25) to the Family Role domain. They did not show possible crossloadings of those items to any other factor than the main factor. The weak loading of Item 4a “spending income as wished” was explained by the fact that the subjects’ focus varied when they were answering the question; some were considering the physical capacity and others the ability to make decisions (15). In the two recent studies which used the Rasch model, Item 4a “spending income as wished” did not meet the goodness-of-fit criterion (Fallahpour et al. 2011, Lund et al. 2007). Fallahpour et al (Fallahpour et al. 2011) noticed that some respondents did not feel comfortable talking about financial issues with the researcher and that could have made answering unpredictable. Therefore, there is still a need to collect larger samples with a variety of clinical groups before excluding items from IPA or moving one IPA domain to another, especially when there are different kinds of explanations why an item does not load to the main factor. In clinical practice, it is important to consider the loadings of these two items in factors other than the main factor. Thus, if the persons with MS perceives restriction in the Autonomy Outdoors domain, there might also be restrictions in “spending income as wished” and, in the same way, if restrictions are perceived in the Autonomy Indoors domain, restrictions could also be perceived in “minor housework”. These should be considered when discussing the results of the IPA with a person with MS.

Seven correlations between residuals of the items were over 0.40. All of them were between items which loaded to the same factor. For example, in the Social Relations domain, residual correlation of items was high between Item 6b “relations with close people” and Item 6c “respect from close people” (0.41), and between Item 6d “relations with acquaintances” and Item 6e “respect from acquaintances” (0.49). In clinical settings, especially when participation restrictions appear in a certain domain, it is recommended that the answers to single items and the answers to similar items be considered when interpreting the results from different domains.

The ratio of females (72%) to males (28%) in this sample represents relatively well the overall gender distribution in MS (Compston & Coles 2008b). Therefore, a group comparison was conducted although the group of males was smaller than that of

females. The preliminary finding of this study is that the IPAFin can be applied to both genders.

The evaluation of the reliability of the perceived participation and autonomy aspect of IPAFin was conducted with all five domains. Cronbach's alpha showed that the reliability of the IPAFin domains was acceptable.

Methodological considerations

CFA was considered an appropriate method to test the construct of the IPA perceived participation and autonomy aspect which seems to be a multidimensional construct, although the factors strongly correlated with each other. Highly correlated factors indicate that all domains measures the same underlying construct, perceived participation. Former studies (Lund et al. 2007, Kersten et al. 2007, Fallahpour et al. 2011) have used Rasch analysis to study the unidimensionality of the IPA perceived participation and autonomy aspect. In two studies, one conducted using the Swedish version of the IPA (Lund et al. 2007) and the other using both the Dutch and the English version (Kersten et al. 2007) unidimensionality was confirmed. However, the results of the study conducted using the Persian version of the IPA (Fallahpour et al. 2011) support two different constructs: performance-based participation including 19 items of Autonomy Indoors, Family Role and Autonomy Outdoors domains, and social-based participation including 7 items from the Social Relationships domain. Thus, there is evidence from this and former studies (Cardol, M. et al. 2001, Sibley et al. 2006b) that the IPA is a multidimensional construct with correlated factors. At the same time, the perceived participation and autonomy have been found to form a unidimensional construct (Lund et al. 2007, Kersten et al. 2007) or two unidimensional constructs (Fallahpour et al. 2011). However, as Kersten et al (Kersten et al. 2007) have discussed in their study, the scores of the domains instead of the score of the whole perceived participation restriction scale might give appropriate knowledge for clinical practice, as they support, for example, identifying the focus for rehabilitation. Therefore the aim of this study was to confirm the factor structure of IPAFin using CFA. The aim of the further research could be to study the unidimensionality of each domain for example with Rasch analysis. The Autonomy Outdoor domain has even been used separately from the whole IPA in a clinical study (Rantakokko et al. 2016). The systematic translation and cultural adaptation process of the measurement ensures that the results of the study are valid. The translation of the IPA Dutch and English to the Finnish language was conducted carefully according to the protocol for linguistic validation by Acquardo (35).

Limitations of the study

There are some limitations in our study. Firstly, the sample only included persons with moderate to severe disability as measured by EDSS (mean 6.0, SD 2), which limits the generalizability of the results to persons with MS with less limitations. Secondly, the severity of disease may affect how persons experience their participation and can also influence the way they answer the questions. Thirdly, the Work and Educational Opportunities domain was answered by only 51 persons, and the domain was thus excluded from the measure structure of the CFA. On the other hand, in a recent Finnish study on societal costs of MS, half of the persons in working age (aged below 63) in EDSS groups 3.0-4.0, as well as 73% and 84% of persons in EDSS groups 5.0 and 6.0, respectively, had retired prematurely (Ruutiainen et al, 2016). The majority of the participants in our study, like those in many international studies (20, 21, 27, 45), were on disability pension. Finally, although the recommendations for sample size vary (MacCallum et al. 1999), the number of persons with MS in our study was small with respect to the number of parameters estimated. A larger cohort of patients with minor to severe disability and with lower percentage of early retirement would have increased the generalizability of the findings.

Conclusion and clinical implication

In conclusion, the results of this study support the construction of the IPAFin with four perceived participation and autonomy domains. The internal structure of the IPAFin proved to be valid to measure perceived participation and autonomy in persons with MS with moderate to severe disability. IPAFin provides information on which areas of participation and autonomy need more support in the clinical practice of rehabilitation and occupational therapy. In light of these findings it is recommended to consider the individual's perceived participation both at domain and single item levels.

Further research is needed to examine the suitability of the IPAFin for persons with minor disability and other diagnoses. There is also a need to evaluate whether the IPAFin is an appropriate and sensitive enough measure for assessing the change over time or clinically important changes following a rehabilitation intervention.

Conflict of interest statement

The authors declare no conflict of interest.

References

- (1) Compston A, Coles A. Multiple sclerosis. *Lancet* 2008;372:1502-1517.
- (2) Browne P, Chandraratna D, Angood C, et al. Atlas of Multiple Sclerosis 2013: a growing global problem with widespread inequity. *Neurology* 2014;83:1022-1024.

- (3) Holper L, Coenen M, Weise A, Stucki G, Cieza A, Kesselring J. Characterization of functioning in multiple sclerosis using the ICF. *J Neurol* 2010;257:103-113.
- (4) Rosti-Otajärvi E, Hämäläinen P. Behavioural symptoms and impairments in multiple sclerosis: a systematic review and meta-analysis. *Mult Scler* 2013;19:31-45.
- (5) Langdon D. Cognition in multiple sclerosis. *Curr Opin Neurol* 2011;24:244-249.
- (6) Cardol M, Beelen A, van den Bos GA, de Jong BA, de Groot IJ, de Haan RJ. Responsiveness of the Impact on Participation and Autonomy questionnaire. *Arch Phys Med Rehab* 2002;83:1524-1529.
- (7) Law M. Participation in the occupations of everyday life. *Am J Occup Ther* 2002;56:640-649.
- (8) Dijkers M. Issues in the Conceptualization and Measurement of Participation: An Overview. *Arch Phys Med Rehabil* 2010;91:S5-S16.
- (9) World Health Organization. International classification of functioning, disability, and health (ICF). Geneva: World Health Organization; 2001.
- (10) Kramer J, Bowyer P, Kielhofner G. The Model of Human Occupation, the ICF, and the Occupational Therapy Practice Framework: Connections to support best practice around the world. In: Kielhofner G, editor. *Model of Human Occupation, Theory and Application*. fourth ed.: Philadelphia: Lippincott Williams & Wilkins; 2008: 519-528.
- (11) Polatajko HJ, Davis J, Stewart D, Cantin N, Amoroso B, Purdie L, et al. Specifying the domain of concern: Occupation as core. In: Townsend EA, Polatajko HJ, editors. *Enabling occupation II: Advancing an occupational therapy vision for health, well-being, and justice through occupation: CAOT Publications ACE*; 2007: 13-36.
- (12) Law M, Cooper B, Strong S, Stewart D, Rigby P, Letts L. The person-environment-occupation model: A transactive approach to occupational performance. *Can J Occup Ther* 1996;63:9-23.
- (13) Mallinson T, Hammel J. Measurement of participation: intersecting person, task, and environment. *Arch Phys Med Rehabil* 2010;91:S29-S33.
- (14) Piškur B. Social participation: Redesign of education, research, and practice in occupational therapy. *Scand J Occup Ther* 2014;21:S89-S95.
- (15) Perenboom RJM, Chorus AMJ. Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). *Disabil Rehabil* 2003;25:577.
- (16) Einarsson U, Gottberg K, Fredrikson S, von Koch L, Holmqvist LW. Activities of daily living and social activities in people with multiple sclerosis in Stockholm County. *Clin Rehabil* 2006 ;20:543-551.
- (17) Månsson Lexell E, Iwarsson S, Lexell J. The complexity of daily occupations in multiple sclerosis. *Scand J Occup Ther* 2006;13:241-248.
- (18) Månsson E, Lexell J. Performance of activities of daily living in multiple sclerosis. *Disabil Rehabil* 2004;26:576-585.

- (19) Lexell EM, Lund ML, Iwarsson S. Constantly changing lives: experiences of people with multiple sclerosis. *Am J Occup Ther* 2009;63:772-781.
- (20) Karhula ME, Kanelisto KJ, Ruutiainen J, Hämäläinen PI, Salminen A. The activities and participation categories of the ICF Core Sets for multiple sclerosis from the patient perspective. *Disabil Rehabil* 2013;35:492-497.
- (21) Cardol M, de Haan RJ, van den Bos GA, de Jong BA, de Groot IJ. The development of a handicap assessment questionnaire: the Impact on Participation and Autonomy (IPA). *Clin Rehabil* 1999;13:411-419.
- (22) Cardol M, de Haan RJ, de Jong BA, van den Bos GA, de Groot IJ. Psychometric properties of the Impact on Participation and Autonomy Questionnaire. *Arch Phys Med Rehab* 2001;82:210-216.
- (23) Cardol M, Jong BD, Ward CD. On autonomy and participation in rehabilitation. *Disabil Rehabil* 2002;24:970-974.
- (24) Sibley A, Kersten P, Ward CD, White B, Mehta R, George S. Measuring autonomy in disabled people: Validation of a new scale in a UK population. *Clin Rehabil* 2006;20:793-803.
- (25) Hammar IO, Ekelund C, Wilhelmson K, Eklund K. Impact on participation and autonomy: test of validity and reliability for older persons. *Health Psych Res* 2014;2:68-73.
- (26) Lund ML, Fisher AG, Lexell J, Bernspång B. Impact on participation and autonomy questionnaire: internal scale validity of the Swedish version for use in people with spinal cord injury. *J Rehabil Med* 2007;39:156-162.
- (27) Poulin V, Desrosiers J. Validation of the French translation of the Impact on Participation and Autonomy questionnaire (IPAQ). *Can J Occup Ther* 2010 Jun;77:159-166.
- (28) Fallahpour M, Jonsson H, Joghataei MT, Kottorp A. Impact on Participation and Autonomy (IPA): Psychometric evaluation of the Persian version to use for persons with stroke. *Scand J Occup Ther* 2011;18:59-71.
- (29) Kersten P, Cardol M, George S, Ward C, Sibley A, White B. Validity of the impact on participation and autonomy questionnaire: a comparison between two countries. *Disabil Rehabil* 2007;15;29:1502-1509.
- (30) Vazirinejad R, Lilley JM, Ward CD. The 'Impact on Participation and Autonomy': acceptability of the English version in a multiple sclerosis outpatient setting. *Mult Scler* 2003 ;9:612-615.
- (31) Salminen A, Hämäläinen P, Karhula M, Kanelisto K, Ruutiainen J. Group-based multidisciplinary rehabilitation for outpatient clients with MS. Development and evaluation of the rehabilitation model. Helsinki: The Social Insurance Institution of Finland, Studies in social security and health; 2014.
- (32) Lublin FD, Reingold SC. Defining the clinical course of multiple sclerosis: results of an international survey. National Multiple Sclerosis Society (USA) Advisory

Committee on Clinical Trials of New Agents in Multiple Sclerosis. *Neurology* 1996;46:907-911.

(33) Kurtzke JF. Rating neurologic impairment in multiple sclerosis an expanded disability status scale (EDSS). *Neurology* 1983;33:1444.

(34) Kanelisto K, Salminen A. IPA-kyselylomake valinnoista ja osallistumisesta jokapäiväisessä elämässä. Toimintakyvyn itsearviointimenetelmä aikuisille, joilla on fyysisiä toimintarajoitteita. [IPA-questionnaire of choices and participation in everyday life. Self-evaluation measure of functioning for adults with physical limitations] Kelan tutkimusosasto. *Sosiaali- ja terveysturvan selosteita* 76. 2011.

(35) Acquadro C. Linguistic validation manual for patient-reported outcomes (PRO) instruments. : Mapi Research Institute; 2004.

(36) Byrne BM. Structural equation modeling with Mplus: Basic concepts, applications, and programming. : Routledge; 2013: 43-93.

(37) Muthén LK, Muthén BO. Mplus User's Guide: Statistical Analysis with Latent Variables: User's Guide. : Muthén & Muthén; 2010.

(38) Kline RB. Principles and practice of structural equation modeling. : Guilford Publications; 2015: 188-207.

(39) Kelloway EK. Using Mplus for Structural Equation Modeling: A Researcher's Guide: A Researcher's Guide. : SAGE Publications; 2014: 52-93.

(40) Brown TA. Confirmatory Factor Analysis for Applied Research (Methodology In The Social Sciences). 2006: 81-89.

(41) Bollen KA, Long JS. Testing structural equation models. Newbury Park (Calif.): Sage; cop. 1993.

(42) Hu L, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Struct Equ Modeling* 1999;6:1-55.

(43) Satorra A, Bentler P. A scaled difference chi-square test statistic for moment structure analysis. *Psychometrika* 2001;66:507-514.

(44) Streiner DL, Norman GR, Cairney J. Health measurement scales: a practical guide to their development and use. Oxford University Press; 2014.

(45) Byrne BM. The Maslach Burnout Inventory: Validating factorial structure and invariance across intermediate, secondary, and university educators. *Multivar Behav Res* 1991;26:583-605.

(46) Rantakokko M, Portegijs E, Viljanen A, Iwarsson S, Kauppinen M, Rantanen T. Perceived environmental barriers to outdoor mobility and changes in sense of autonomy in participation outdoors among older people: a prospective two-year cohort study. *Aging & mental health* 2016:1-5. Published online 15.3.2016.

(47) MacCallum RC, Widaman KF, Zhang S, Hong S. Sample size in factor analysis. *Psychol Methods* 1999;4:84.

Table 1. Characteristics of the participants (n=194)

Mean /median age years (SD/ min-max)	50/51 (9/26-65)
Mean /median duration of disease years (SD/min-max)	15/14 (8/1-42)
Gender n (%)	
male	55 (28)
female	139 (72)
Living alone n (%)	63 (33)
Disability pension n (%)	161 (83)
Disease severity (EDSS) mean/median (SD / min-max)	6/6 (2/0-9)
mild 0-3.5 n (%)	8 (4)
moderate 4.0-5.5 n (%)	62 (32)
severe 6.0-8.5 n (%)	124 (64)
Disease subtype n (%)	
relapsing-remitting	64 (33)
primary-progressive	40 (20)
secondary-progressive	87 (45)
unknown	3 (2)
Data set 1, collected during out-patient rehabilitation n (%)	105 (54)
Data set 2, collected during short in-patient rehabilitation period n (%)	89 (46)

Table 2. Statistics for CFAs of IPAF in four factors with the original model (M1) and the modified model (M2)

Model	χ^2	df	χ^2/df	p-value	CFI	TLI	RMSEA	SRMR
M1	858.98	293	2.93	< 0.001	0.80	0.79	0.10	0.08
M2	467.28	279	1.67	< 0.001	0.93	0.93	0.06	0.06

M1 = Original four factor model without modifications

M2 = Four factor model with modifications (see modification in the figure 2)

χ^2 = Chi-squared statistic, df = Degrees of freedom, CFI = Comparative fit index, TLI = Tucker-Lewis index, RMSEA = Root mean square error of approximation, SRMR = Standardized root mean square residual

Table 3. Standardized factor loadings of the modified four factor model

Factor	Autonomy Indoors	Family Role	Autonomy Outdoors	Social Relationships
Items of the IPA				
1a getting around in one's house where one wants	.56			
1b getting around in one's house when one wants	.77			
2a getting washed and dressed the way one wishes	.71			
2b getting washed and dressed when one wants	.82			
2c getting up and going to bed when one wants	.79			
2d going to the toilet when one wishes and needs to	.79			
2e eating and drinking when one wants	.88			
3a contributing to looking after one's home		.78		
3b getting light tasks done around the house	.57*	.25		
3c getting heavy tasks done around the house		.74		
3d getting housework done when one wants it done		.78		
3e getting minor repairs and maintenance work done		.71		
3f fulfilling one's role at home as one would like		.82		
4a choosing how one spends one's own money		-.01	.59*	
1c visiting relatives and friends when one wants	.25*		.55	
1d going on the sort of trips and holidays one wants			.66	
5a using leisure time the way one wants			.79	
6g seeing people as often as one wants			.79	
10 living life the way one wants			.81	
6a talking to people close to one on equal terms				.82
6b relationships with people who are close to one				.66
6c the respect from people who are close to one				.66
6d one's relationships with acquaintances				.69
6e the respect one receives from acquaintances				.64
6f having an intimate relationship				.51
7a helping or supporting people in any way				.66

*crossloadings

Table 4. Tests of measurement invariance of the IPAFin in men and women with MS with three different models and the comparisons of the models

Model	χ^2	df	χ^2_{diff}	Δdf	p-value	CFI	TLI	RMSEA	SRMR
M1	912.44	558	-	-	-	0.90	0.88	0.08	0.07
M2	922.40	580	16.17	22	0.807	0.90	0.89	0.08	0.08
M3	951.36	601	28.79	21	0.119	0.90	0.89	0.08	0.08

M1 = Freely estimated factor loadings

M2 = Equal factor loadings

M3 = Equal indicator intercepts

χ^2 = Chi-squared statistic, df = Degrees of freedom, χ^2_{diff} = Chi-squared difference test, Δdf = the difference of degrees of freedom, p-value = p-value of chi-squared difference test, CFI = Comparative fit index, TLI = Tucker-Lewis index, RMSEA = Root mean square error of approximation, SRMR = Standardized root mean square residual

Figure 1. The translation process of the IPA for Finnish language

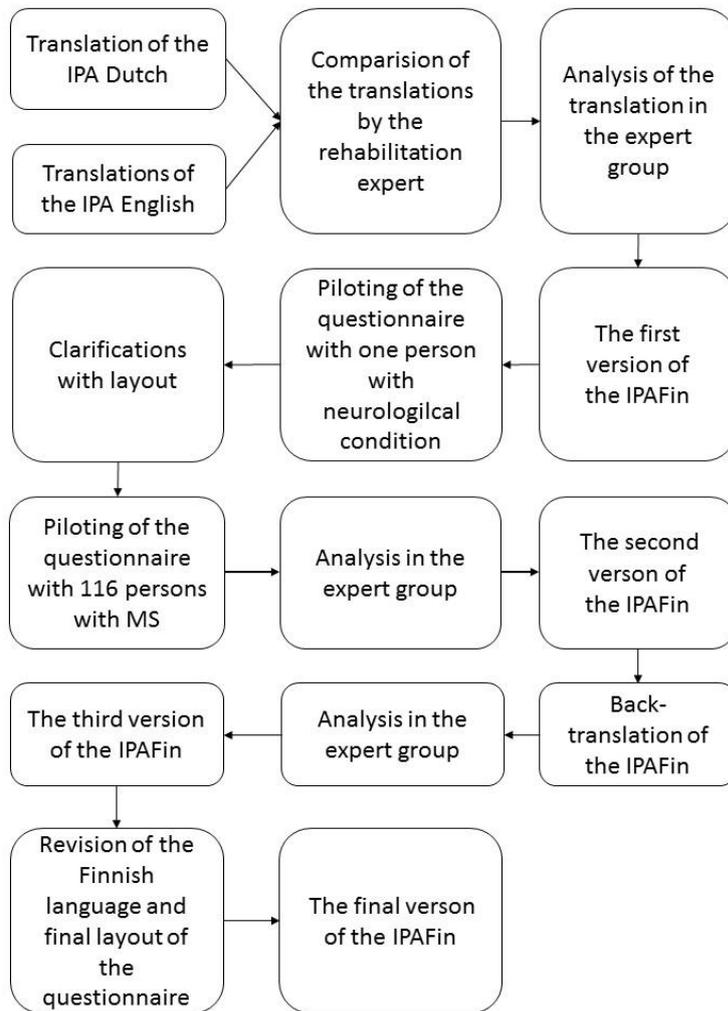


Figure 2. Confirmatory factor model for the modified IPAFin four factor solution.

