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Development of an Instrument for Assessment of Mobility-related Participation Outcomes: the NOMO 1.0

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Abstract

Instruments for assessment of outcomes of mobility device interventions in terms of participation in everyday life and society for persons with walking disability are lacking.

The objective of this article is to describe the development process of the 'Nordic mobility-related participation outcome evaluation of assistive device interventions' (NOMO 1.0).

The instrument is based on the concept of mobility-related participation and was developed in three major steps: 1) Rasch analysis of a mobility-related participation questionnaire based on data from interviews with 111 powered wheelchair or scooter users, demonstrating construct validity but low discriminative ability. 2) Construction of a new self-report instrument, based on the ICF framework in a Nordic context. The development encompassed consultancy with mobility device users (N=41), assistive technology professionals (N=20) and researchers (N=17), and three rounds of pilot testing among mobility device users (N=113). The result was a content valid and feasible

instrument. 3) Reliability testing of the instrument among 147 mobility device users, demonstrating satisfactory test-retest reliability.

The NOMO 1.0 is available free of charge in four Nordic languages. Further psychometric testing of the NOMO 1.0 is being planned.

Introduction

The demand for evidence-based interventions in healthcare is presently high, and also within the field of assistive technology a growing interest is seen. Even though assistive technology outcomes research is increasing, the strength of the evidence of such interventions is weak, partly due to lack of reliable and valid outcome assessment instruments (1-3). The majority of instruments targeting outcomes of assistive technology interventions are used for assessment at the level of body function or activity in a clinical rehabilitation setting (4), while assistive technology mostly aims at enhancing the person's possibilities to participate in everyday life and society. Consequently, there is a need for instruments for assessment at participation level in community settings in real life situations.

Worldwide, preserved or improved participation is increasingly being recognised as the end goal of rehabilitation, especially after the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) (5) was launched (6, 7). In spite of that, only few studies assessing participation outcomes

of rehabilitation have been published (8). According to the ICF, *participation* means 'involvement in a life situation', i.e. what a person actually does in a real life environment, while the related concept *activity* 'is the execution of a task or action by an individual' and describes a person's capacity in a standardised environment. However, given the broad and general character of these definitions, regarding participation there is no consensus in the scientific literature regarding its definition and operationalization (see e.g. (9, 10)). In previous studies, attempts have been made to define specific dimensions of participation (see e.g. (11) Haak et al.).

The ICF uses the term 'assistive products' for assistive technology, categorising it as an environmental factor that may influence participation (5). Mobility, categorised as an activity in the ICF, is in some cases the prerequisite for participation, for example when visiting people, while it is not when for example learning by reading books or using the Internet. Mobility devices such as crutches, rollators, wheelchairs, powered wheelchairs and powered scooters are often used to enable mobility and participation for people with walking impairment [2]. In order to study participation presupposing mobility, we defined the dimension mobility-related participation, a critical

outcome of mobility device interventions (12). Mobility-related participation is a specific dimension of the broad and general participation concept and can therefore be expected to be more responsive to changes (13).

Since mobility is fundamental for participation and a rather high prevalence of mobility impairment prevails, especially among older people (14), mobility devices constitute the group of assistive devices most frequently used (15). In the Nordic countries, i.e. Denmark, Finland, Iceland, Norway, and Sweden, mobility devices are mostly provided free of charge (16) and considerable resources are spent on mobility device provision. In Sweden, for instance, the expenditure on mobility devices was 80 million Euros in 2005 (17). In order to ensure that the resources are used in such a way that mobility-related participation is supported, outcomes research is required.

For outcomes research to be valid, availability of relevant outcome assessment instruments is required. At the time when the development of the 'Nordic mobility-related participation outcome evaluation of assistive device interventions' (NOMO 1.0) was initiated, a literature search did not identify any instrument for assessing mobility-related outcomes of mobility device interventions. Since knowledge

about how an instrument was developed is essential for being able to choose a relevant outcome assessment instrument (18), the objective of this article is to describe the development process of the 'Nordic mobility-related participation outcome evaluation of assistive device interventions' (NOMO 1.0). The process consisted of three major steps: 1) Rasch analysis of a mobility-related participation questionnaire, 2) Construction and pilot testing of new self-report instrument, 3) Reliability testing of the newly developed instrument.

Ethics

All principles in ethical guidelines for human research were followed meticulously in all sub studies. In Iceland formal ethical consent was sought and granted, while this was not required for this type of study in the other countries.

Rasch analysis of a mobility-related participation questionnaire

Methods and materials

The need for an instrument targeting mobility-related participation arose in a cross-sectional interview study on older people's use of powered wheelchairs and powered scooters (19). The first step of the construction of the new instrument was to investigate the concept of mobility-related participation. For this purpose and in order to create a preliminary instrument, a study-specific questionnaire, based on the HAAT model (20) and on surveys of 2,048 older Danes' outdoor mobility activities (21, 22), was developed and used. The questionnaire contained the following items: Shopping; go to day centre, clubs; visit friends and family; go to cafe', restaurant; go to cinema, library; go for a ride; go to church and churchyard; get about in own and others' homes; get about in the garden; go by accessible bus; go by bus, train; other participation aspects.

The construct validity and reliability of the questionnaire were analysed on basis of item response theory (IRT) by means of Rasch analysis (23). Data from the cross-sectional study were utilised for the analysis, consisting of a sample of 111 older

Danish users of powered wheelchairs or powered scooters who had used their device for at least one year. The sample was drawn from municipality files aiming at national representativity. For description of the sample see Table 1. Data were collected by means of face-to-face interviews using the developed questionnaire (19). The analysis encompassed several methods for analysing the fit of item responses to the Rasch model (23), such as conditional likelihood ratio (CLR) tests, item fit statistics, analysis of local dependence, analysis of differential item functioning (DIF), estimation of person parameters, and evaluation of targeting and reliability (24, 25). The Digram software was used for the analysis (26).

[Insert about here Table 1]

Results

The items of the mobility-related participation questionnaire were found to be construct valid and objective. No evidence of DIF was found regarding score group, gender, age or cohabitation (multiple testing: $p=0.044-0.572$), meaning that the result of the

assessment would not depend on any of these factors. As regards the reliability of the instrument in terms of how well the items targeted the investigated sample the results were, however, less encouraging. The instrument had problems discriminating between persons with a high degree of mobility-related participation, i.e., a ceiling effect was demonstrated, and some of the items had the same or very close estimated values, while the intervals between other items were too wide for precise measurement. More detailed results are given elsewhere (23).

Instrument construction and pilot testing

Instrument construction

Given the results from the Rasch analysis showing that the concept of mobility-related participation seemed to be valid, but that more and maybe other items were required, it was decided to construct a new mobility-related participation outcome assessment instrument with similar items. The instrument was constructed by a group of nine assistive technology experts and academics from the five Nordic countries, following the methodology described by Benson & Clark (27). In order to investigate mobility device

users' standpoints concerning the new instrument and its content, user reference groups in the five countries, in all 25 persons, were invited to review the instrument.

The concept at target was mobility-related participation as an outcome of mobility device interventions, i.e. the provision of sticks, crutches, rollators, manual wheelchairs, powered wheelchairs, and powered scooters. Mobility-related participation was defined as participation aspects relevant for the individual, absolutely presupposing mobility. The instrument was to be self-report based, evaluating mobility device interventions at group level in connection with quality development or research. The intended target group was mobility device users of at least 18 years of age and possible to interview.

The theoretical basis for development of the instrument was the ICF framework, and items for the instrument were selected from the ICF list of Activity and Participation (5), selecting participation rather than activity variables whenever it was possible to separate the two concepts (28). Only participation aspects presupposing mobility were selected, for instance reading was not included, while shopping was. Furthermore, variables not included in the ICF list, but suggested by the user reference

groups or found to be valid in the first step were incorporated, e.g. 'going for a walk' and 'going to restaurants and cafés'. As to the ICF variables, they were substantially rephrased to form instrument questions. Subsequently, response scales were developed and some basic descriptive variables, i.e. factors other than mobility devices that may influence mobility-related participation, were included. Not all factors, such as depression, the physical and social environment, or lifestyle were included, and should be investigated by means of separate instruments depending on study purpose and hypothesis. The instrument was developed in Swedish and thereafter translated into the other four languages after each step in the process.

The user reference groups specifically discussed the mobility-related participation items. They were asked to choose the ten most important items and to suggest additional items. Moreover, the user reference groups discussed their general views on the instrument under development and administration issues. Based on the results from the user reference groups, the instrument was revised and subsequently content validated by consultations with new Nordic user reference groups (N=16, Table

1), assistive technology professionals (N=20), and researchers (N=17). Following this, the instrument was once again revised.

Pilot tests

To establish content validity and feasibility (13, 27), the instrument was pilot tested among mobility device users by means of face-to-face interviews and revised in an iterative process until a satisfactory result concerning content validity, response scales, and feasibility was reached. Three pilot tests were carried out encompassing 40, 34, and 39 Nordic study participants, respectively, selected on basis of joint inclusion criteria. (See table 1 for details about the participants). After each interview the participant was asked five questions about the instrument content and feasibility, and the interviewer filled in a questionnaire about her view on the same issues. Subsequently the responses were analysed, and based on the results the project group revised the instrument.

Results

During the different instrument development phases the user reference groups gave valuable and substantial input, ensuring the relevance of the instrument. Overall, the

user reference groups were very positive about the instrument. Still, every input from the user reference groups was not included. For instance, the user groups highlighted user satisfaction as important, but since user satisfaction cannot be considered to be an aspect of the mobility-related participation concept, user satisfaction was not included. Based on the consultations with the user reference groups, the assistive technology professionals, and researchers, and the pilot tests, the instrument was considered content valid and feasible.

This instrument version was called 'The Nordic Assisted Mobility Evaluation' (NAME). It consisted of a baseline questionnaire and a follow-up questionnaire, both comprising two parts, and a manual. Part A encompassed 27 optional background variables, defined for descriptive purposes and to capture differences from baseline to follow-up. Part B was the actual outcomes instrument, consisting of 25 mobility or mobility-related participation items, identical at baseline and follow-up. Part B comprised:

- Four items about dependence in mobility in different environments (indoors at home, getting in/out of home, indoors other places than home, outdoors). The scales were:
 - Dependence in mobility: Whether the person depended on other people in mobility in different environments (yes/no/don't know)
 - Extent of assistance in mobility: To which degree the person depended on other people in mobility in different environments (5-grade ordinal scale: very little – very much assistance)

- 21 items about mobility-related participation aspects, e.g. kitchen work, shopping, attending cultural events, going for walks, and studying/work, applying the following scales:
 - Frequency of mobility-related participation: How often each participation aspect was performed (8-grade ordinal scale: daily – never, and don't know)

- Ease/difficulty during participation: How easy or difficult it was to perform each participation aspect (5-grade ordinal scale: very easy – very difficult, and don't know)
- Mobility-related participation repertoire: The number of participation aspects that the person actually performed (a summed score based on frequency of participation).

For studying changes between pre- and post-mobility device interventions

regarding dependence and assistance in mobility; and frequency of and ease/difficulty in mobility-related participation, we recommend standard non-parametric statistics, since data are ordinal (29). Likewise, effect size should be calculated using non-parametric methods, even though these are not yet well-known (30, 31). Another option would be to calculate odd ratios (29), or the number of users with positive, negative or no changes (32). Mobility-related participation repertoire should be calculated by addition of the aspects that the mobility device user has reported that he/she participated in, resulting in a sumscore. Changes can be analysed by comparing the number of participation

aspects performed before and after the mobility device intervention, using parametric statistics given that data are normally distributed (29).

Reliability test-retest

Methods and materials

With a content valid, acceptable and feasible instrument at hand, further psychometric testing was initiated. The first step was to investigate test-retest reliability and internal consistency (documented in detail elsewhere, see (12)). In all 147 Nordic users of different mobility devices, selected based on defined inclusion criteria, took part in the study. (For description of the participants, see table 1). They were interviewed face-to-face twice by the same trained interviewer with 7 days interval (SD= 4).

Percentage agreement and kappa coefficients were calculated to examine the test-retest reliability of the instrument (13). For categorical data kappa (κ) was computed, and for ordered categorical data, weighted kappa (κ_w) was used. The intraclass correlation coefficient (ICC) with 95% confidence limits was used for continuous data (13, 31). The strength of agreement between the two interviews was

interpreted according to Landis and Koch's guidelines: κ and ICC values <0.00 = poor agreement; $0.00-0.20$ = slight; $0.21-0.40$ = fair; $0.41-0.60$ = moderate; $0.61-0.80$ = substantial; $0.81-1.00$ = almost perfect agreement (33). Internal consistency was analysed by means of Cronbach's alpha. The SAS (for kappa) or SPSS 14.00 software (for all other analyses) were used.

The instrument was subsequently revised due to the test results, e.g. items demonstrating low agreement were deleted and a few new added, and the scales were slightly adapted.

Results

The test-retest agreement of the four scales and the summed score varied from moderate to almost perfect. For the 'Dependence in mobility' and the 'Frequency of mobility-related participation' scales the agreement was substantial, and for the 'Mobility-related participation repertoire' summed score, it was almost perfect. The agreement of the 'Extent of assistance in mobility' scale was moderate, barely exceeding the cut-off to be interpreted as fair. However, after a new 4-grade scale was constructed

based on the 3-graded version in combination with the 'Dependence in mobility' scale, now labelled as 'Extent of dependence' (4-grade ordinal scale: no assistance – much assistance), the agreement turned out substantial. The agreement of the 'Ease/difficulty during participation' scale was moderate. The internal consistency was satisfactory.

Following these findings, the instrument was once again revised and also translated into Danish, Icelandic, Norwegian, and Swedish. The basic structure was kept, but the items were slightly adapted and reduced, ending up with a version comprising 24 items. The two scales on dependence in and extent of assistance in mobility in different environments were replaced with the new 'Extent of dependence' scale. In addition, the manual was revised and translated into the four languages. The test-retest reliability and internal consistency of the final instrument was then considered to be satisfactory.

Finally, in order to reflect the mobility-related participation outcome dimension, the revised instrument was renamed to the "Nordic mobility-related participation outcome evaluation of assistive device interventions", NOMO 1.0.

Discussion and conclusions

This article describes the stepwise development process of the NOMO 1.0, a new Nordic instrument for assessment of mobility-related participation outcomes of mobility device interventions, now available for free in four Nordic languages. The instrument was developed in a process encompassing substantial involvement of mobility device users, both as consultants and respondents, securing instrument relevance. In addition, assistive technology experts and researchers were consulted, and solid content validity and feasibility were established. The concept of mobility-related participation seemed to be construct valid, and further psychometric testing was initiated showing satisfactory test-retest reliability and internal consistency.

The fact that the test-retest agreement of the 'Ease/difficulty during participation' scale was not optimal could be problematic (12), especially because the instrument is aimed at outcome evaluation. The kappa coefficient does, however, exceed 0.50 (12) which is the lower limit for an outcome assessment instrument as recommended by Streiner and Norman (13). Furthermore, when examining other reliability studies where some dimension of participation in real life environments was

investigated, test-retest agreement was similarly found to be relatively low (34, 35). One explanation may be that participation in real life contexts includes a large range of factors that are due to short term changes resulting in inconsistent responses. As pointed out in other studies (36-38), this indicates that the concept of participation is complex.

The concept at target for the instrument is mobility-related participation (12), i.e. one out of several specific dimensions of participation. The concept of participation has recently been given much attention within rehabilitation, and many different understandings and interpretations are being put forward, but there is a lack of consensus on what this multi-dimensional concept actually includes (39, 40). Yet, most literature refers to the ICF definition (5), but this is also being criticised recently, since it represents an outsider's perspective focusing on performance, ignoring the person's insider perspective in terms of preferences, importance, satisfaction and similar aspects that express a person's feelings (41-43). Positioning the NOMO 1.0 in this context, the instrument has an outsider performance perspective in terms of extent of assistance for mobility and frequency of participation, as well as an insider perspective regarding

ease/difficulty in participation. It could be argued, though, that participation preferences are missing from the instrument for it to truly represent an insider's perspective (44).

Since the initiation of the development of the NOMO 1.0, numerous other instruments aiming at measuring aspects of participation outcomes of rehabilitation have been presented. At least three of these target participation outcomes of mobility device interventions: all are based on self-reports, and developed on basis of the the ICF. With the Wheelchair Outcome Measure (WhOM), goal-oriented outcomes of wheelchair interventions can be assessed (45). The outcomes mainly target participation, focusing on importance and satisfaction with a number of self-selected wheelchair-related activities. The WhOM thus essentially differs from the NOMO 1.0 by applying only an insider's perspective, only wheelchairs, and by using self-selected items rather than a list of pre-defined participation aspects. The Facilitators And Barriers Survey of environmental influences on participation among people with lower limb Mobility impairments and limitations (PARTS/M) focuses on various environmental aspects that may influence participation (46). The instrument (a questionnaire) is extensive and consists of six domains, one of which concerns the use of mobility devices as an

environmental factor, while the other domains concern other kinds of environmental factors and accessibility. The PARTS/M is in some respects similar to the NOMO 1.0, but its focus is, however, on all kinds of environmental factors and participation dimensions, while the NOMO 1.0 specifically targets mobility device interventions and mobility-related participation. Even though it is stated that the PARTS/M can be used for outcome assessment it is not clear how this can take place, and the strength of the instrument seems to be examination of what people with mobility impairments perceive to be facilitators and barriers to their participation (46). The third instrument, the Assistive Technology Outcomes Profile for Mobility (ATOP/M) (47), is more similar to the NOMO 1.0. The ATOP/M focuses on difficulty in activity (Physical Performance and Instrumental Activities of Daily Living) and participation (Social Role Performance and Discretionary Social participation) performance with and without the use of a mobility device. The ATOP/M consists of 68 items, but as a computer adaptive testing (CAT) approach is administered, the respondent is only presented to relevant items estimated on basis of the person's ability, reducing the respondent burden substantially. In future development of the NOMO 1.0, merging with the ATOP/M might be considered.

The fact that the instrument is available in Nordic languages is highly relevant because the Nordic countries all are welfare states granting mobility devices for free if they are expected to solve the person's mobility problem. Still, the assistive technology service delivery systems vary among the countries, and using the same instrument for cross-national comparisons may assist in identifying how the most beneficial outcomes of mobility device interventions can be obtained. Presently the instrument is being used in a Danish, Finnish, Norwegian, and Swedish pre-post study on outcomes of powered wheelchair and scooter interventions, as part of a comprehensive battery of questions and other instruments. Data from the study will also be utilized for investigating the instrument's construct validity, sensitivity, and responsiveness, and it will be examined whether the ceiling effect found in the Rasch analysis of the mobility-related questionnaire has been eliminated. So far the first pilot study carried out in Sweden has been published, showing that participation frequency and number of participation aspects did not increase after a powered wheelchair or scooter intervention, while several mobility-related participation aspects were rated as easier (32). This

indicates preliminary good responsiveness concerning participation ease/difficulty, but more studies and specific analyses are required.

For the analysis of the validity of the NOMO 1.0 it may, however, be questioned whether IRT was the most appropriate approach when testing the mobility-related questionnaire. This reservation must be considered for further testing of the NOMO 1.0, and is based on the critique of the use of IRT for testing validity of participation measures, as raised by Dijkers (38). One of the strengths of IRT is its capacity to place items on a linear ratio scale in accordance with items difficulty, transferring dichotomous and ordinal assessments into measurements, i.e. ratio scales (48). In this transformation IRT, however, interprets frequency of items as an expression of difficulty, so that less frequent participation aspects are deemed more difficult than more frequent participation aspects (38). For instance the item 'attend cultural or sports arrangements' will probably be placed as one of the difficult items on the ratio scale, because it is something that people rarely do, while 'visiting friends and family' will be one of the easier items, because people do that more often, even though it actually may be more difficult to visit friends and family (19).

To conclude, this article reports on the development of the NOMO 1.0 instrument, targeting outcomes of mobility device interventions in terms of mobility-related participation. The article documents the stepwise development process, including mobility device user involvement and the establishment of basic psychometric properties in terms of content and construct validity, feasibility, internal consistency, and test-retest reliability. The result of a process involving many experts and users over several years is the NOMO 1.0, which is available in the Danish, Finnish, Norwegian, and Swedish languages and available free of charge. There is a need for further psychometric testing of the NOMO 1.0, applying critically selected methodologies.

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Appendix I: Part B of the instrument*

Extent of assistance in mobility

Items:

1. How much assistance from another person do you need when you move about in your home?
2. How much assistance from another person do you need in order to get out of or into your home?
3. How much assistance from another person do you need in order to move about indoors at other places than in your home?
4. How much assistance from another person do you need in order to get about outdoors? (Regarding getting about walking or similar not using means of transportation.)

Response scales:

No assistance / A little assistance / Some assistance / Much assistance

Frequency of mobility-related participation and ease/difficulty in mobility during participation

Items:

5a. How often do you work in the kitchen (cooking/dishwashing/laying the table etc.)

5b. How easy / difficult is it for you to get about when you work in the kitchen?

These questions are also asked about the following participation aspects:

6. ... wash clothes or garments (clothes, bedding, etc., including drying and ironing)?

7. ... clean the house (light and heavy cleaning ranging from dusting to vacuum)?

8. ... take care of children or other household members in your home?

9. ... attend restaurants, pubs, or cafés?

10. ... go to the hairdressers, chiropodists, etc.?

11. ... do grocery shopping?

12. ... shop in small shops?

13. ... go to the post office or out to post letters?

14. ... go to the bank?

15. ... go out to buy medicine?

16. ... go to the library?

17. ... attend social life in associations, in church, daycenter?

18. ... attend cultural or sports arrangements (e.g. cinema, theatre, football match)?

19. ... engage in hobbies, fitness or sports outside your home?

20. ... bring or fetch children from day-care centre, school, etc.?

21. ... go for a walk (including trips in wheelchair)?

22. ... visit friends and family?

23. ... work or study outside your home?

24. ... do gardening, clear away snow, etc.?

Response scales:

a. Daily / Several times a week / About once a week / Several times a month / About once a month / Several times a year / About once a year / Never

b. (is not answered if the a. response was 'Never') Very easy / Easy / Neither easy nor difficult / Difficult / Very difficult

*The instrument has been translated into English for publication purposes. If, however, the instrument is to be used for outcomes evaluation it must be translated according to standards for instrument translation.

Table 1. Characteristics of mobility device users involved in the development process of the NOMO 1.1

| | Cross-sectional study – Rasch analysis | User reference groups – instrument construction | User reference groups – content validation | Pilot test 1 | Pilot test 2 | Pilot test 3 | Test-retest reliability test |
|------------------|---|--|---|---------------------|---------------------|---------------------|-------------------------------------|
| | N=111 | N=25 | N=16 | N=40 | N=34 | N=39 | N=147 |
| Mobility device | | | | | | | |
| Stick/crutch, n | 0 | 14 | 4 | 4 | 5 | 4 | 40 |
| Walking frame, n | 0 | 0 | 1 | 0 | 0 | 0 | 2 |
| Rollator, n | 0 | 4 | 4 | 15 | 8 | 12 | 31 |

| | | | | | | | |
|--------------------------------|------------|------------|------------|------------|------------|------------|------------|
| Working chair, n | 0 | 0 | 0 | 1 | 2 | 2 | 3 |
| Manual wheelchair, n | 0 | 14 | 8 | 9 | 14 | 10 | 39 |
| Powered wheelchair/scooter, n | 27/84 | 10 | 6 | 11 | 11 | 15 | 15/17 |
| Age, years, mean (range) | 77 (65-92) | 50 (23-85) | 51 (24-93) | 65 (28-93) | 52 (21-85) | 55 (21-88) | 60 (19-93) |
| Gender, men/women | 56/55 | 12/13 | 8/8 | 16/24 | 14/20 | 16/23 | 62/85 |
| Cohabitation, alone/cohabiting | 77/34 | NR | NR | 19/21 | 19/15 | 15/24 | 72/75 |

NR: Not registered