What do older people understand by mobility-related difficulties?

Juan Diego Ramos-Pichardo [a], Julio Cabrero-García [a,*], Lorena González-Llopis [b],
María José Cabañero-Martínez [a], Carmen Luz Muñoz-Mendoza [c], Angela Sanjuan-Quiles [a],
Miguel Richart-Martínez [a], Abilio Reig-Ferrer [d]

[a] Department of Nursing, University of Alicante, Alicante, Spain
[b] Department of Health, Alcoy, Alicante, Spain
[c] Department of Nursing, University of Bio Bio, Chillán, Chile
[d] Department of Health Psychology, University of Alicante, Alicante, Spain

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ABSTRACT

Despite the centrality of the difficulty concept in the study of disability, there has been little research on its significance from the point of view of people with functional limitations. The main objective of this study was to describe what older people understand when asked about difficulty in undertaking mobility activities. As a secondary objective, we considered whether there are any differences depending on the type of activities, according to the International Classification of Functioning (ICF) mobility domains.
Methods: Seventeen community-dwelling men and women aged 70 years old or over were interviewed by means of a questionnaire containing 55 items covering the ICF mobility domains. The participants responded to the items while thinking aloud, saying what led them to give a specific answer about their level of difficulty. Inductive content analysis was conducted and categories, subthemes and themes were identified.
Results: Causes of difficulty (pathologies, impairments, symptoms) and accommodations (task modifications and use of aids) were the two themes identified; and their importance (and that of the subthemes included) varied across the types of activity. All the participants said that they had no difficulty in at least one task, despite mentioning changes in the way they performed them.
Conclusions: Older people's opinions were consistent with theoretical models of disability and with the standard practice of measuring functional limitations by asking about the degree of difficulty; however, the design of these measures needs to be improved in order to detect perceptions of no difficulty in the presence of task modification.

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1. Introduction

Difficulty is a central concept in the main disability models, the Disablement Process and International Classification of Functioning, Disability and Health (ICF). The Disablement Process model defines disability as difficulty doing activities in any domain of life (the domains typical for one's age–sex group) due to health or physical functional limitations (Verbrugge & Jette, 1994).

Meanwhile, the ICF reserves the term difficulty for defining activity limitations (the difficulties an individual may have in executing activities), and uses the term problems to refer to restrictions on participation (WHO, 2001). Despite the differences in the terms in the two models, there is a clear parallelism between the concepts which they refer to: functional limitations and activity limitations on the one hand, and disability and participation restrictions on the other (Jette, 2009).

Difficulty is also a critical concept from the perspective of the measurement of disability and functional limitations. In national disability surveys, the respondents are asked directly about their degree of difficulty in performing certain activities: personal care (activities of daily living [ADLs]) and household management tasks (instrumental ADLs [IADLs]), and about difficulties with basic physical, cognitive, and sensory actions (Verbrugge, Mehta, & Wagenfeld-Heintz, 2006). This is, to measure both functional limitations (bending and lifting, descending stairs, walking, etc.)

* Corresponding author at: Department of Nursing, Faculty of Health Sciences, University of Alicante, Apdo. de correos 99, 03080 Alicante, Spain. Tel.: +34 965903400; fax: +34 965 90 35 16.
E-mail addresses: juan.ramos@ua.es (J.D. Ramos-Pichardo), julio.cabrero@ua.es (J. Cabrero-García), lgonzalez866e@gv.gva.es (L. González-Llopis),
mariajose.cabanero@ua.es (M.J. Cabañero-Martínez), calmunoz@ubiobio.cl (C.L. Muñoz-Mendoza), angela.sanjuan@ua.es (A. Sanjuan-Quiles), m.richart@ua.es (M. Richart-Martínez), areig@ua.es (A. Reig-Ferrer).

and disability (difficulty performing basic and instrumental activities of daily living). Moreover, in the context of the measurement of patient-based health outcomes, although some of the most widely used self-reporting measures for assessing physical function (which commonly include items referring to I/ADL and functional limitations) are designed in terms of limitations, such as the Physical Function Questionnaire of the SF-36 (Haley, McHorney, & Ware, 1994), most of the instruments are designed in terms of difficulty (Haley et al., 2002, 2004; Rose, Bjorner, Becker, Fries, & Ware, 2008; Simonsick et al., 2001). However, there are no operational definitions of difficulty as a construct, and these instruments do not give the respondents any instructions on how the different levels of difficulty should be understood.

Despite the theoretical and operational centrality of the difficulty concept in the study of disability and physical function, its significance from the point of view of people with functional limitations or disabilities has been explored to a very limited extent in the literature. Porter (2007) identified six themes which a sample of older women thought about when asked about their difficulties in ADL/IADL, which included thinking that difficulty is not the best word to describe it, difficulty varies from time to time, problems with rating difficulty and wondering what difficulty really is. Other studies have reported difficulty in specific activities as one of the reasons why older people consider themselves disabled (Verbrugge et al., 2006), or as the onset of the search for accommodations to perform a task (Fried, Young, Rubin, Bandeen-Roche & WHAS II Collaborative Research Group, 2001; Lorenz, 2010; Wolinsky, Miller, Andresen, Malmstrom, & Miller, 2005).

Although the surveys and questionnaires for measuring disability and physical function assume that the construct of difficulty has the same meaning for all population groups, this claim has not been proven (Porter, 2007). Different ideas and attitudes about how to define difficulty, or different expectations regarding their own health may influence the perception of difficulty (Cornman et al., 2011; Melzer, Lan, Tom, Deeg, & Guralnik, 2004). It is also assumed that the difficulty construct is similar for any type of activity, and instruments based on difficulty including a wide variety of tasks are used, although there is no literature to support this claim.

The main objective of this study was to describe what older people understand when asked about difficulty when undertaking mobility-related activities. As a secondary objective, we considered whether there are any differences depending on the type of activities, according to the ICF mobility domains (WHO, 2001): walking and moving, changing or maintaining body positions, and carrying, moving and handling objects.

2. Materials and methods

2.1. Design and study sample

The data presented in this article are taken from the initial phase of the creation of a mobility item bank for the older Spanish population. A convenience-consecutive sample of seventeen participants (7 males, 10 females) was selected from individuals aged 70 years old or over who consecutively attended two primary healthcare centers in the Valencian Community (Spain), one of which was in an urban environment (11 participants) and the other in a rural area (6 participants). The exclusion criteria were presentation of cognitive deterioration as assessed by the SPMSQ (Pfeiffer, 1975) or having serious communication problems (e.g. deafness) or blindness.

2.2. Questionnaire

We identified 104 mobility items in the international literature, which were evaluated by a panel of experts as to their relevance and appropriateness to the study population, and their relationship with the indicators and domains of the Mobility section in the Activities and Participation component of the ICF (WHO, 2001). Walking and going up and down stairs were considered separately, while traveling using transportation was not included. As a result of this process, 55 items were selected for the interviews and classified into four domains based on ICF mobility indicators: changing and maintaining body position, carrying, lifting and pushing objects, walking and going up and down stairs. The number of items in each of these domains was: 19 referred to changing or maintaining body positions, 7 to carrying, lifting and pushing, 18 to walking and 11 to going up and down stairs. The core question for all the items was: How much difficulty do you have, without any help from someone or something, in...? This question is similar to that used in other measures of physical function (Haley et al., 2002, 2004).

2.3. Data collection

The data were collected at the primary healthcare centers, but not during the subject's medical appointment. The interviews were face-to-face and followed a semi-structured schedule, with a maximum duration of 60 min. The participants were asked to answer each item with 4 response options (no difficulty, some difficulty, much difficulty and unable to do). Previously, the participants were told to respond to each item thinking aloud, mentioning everything that led them to give a particular response. After the participant had chosen a response option, the interviewer asked open questions for the participant to clarify ideas in order to explore what they meant by difficulty. Because this took place when the participant responded that he/she had no difficulty, we also explored the meanings of no difficulty. This could be interesting, because the literature has identified that some people respond that they have no difficulty despite having made changes to the way they carry out activities (Fried, Herdman, Kuhn, Rubin, & Turano, 1991). The advantage of this type of interview is that all participants are asked the same questions, while they simultaneously allow individual expression and exploration of the issues raised (Adams & Johnson, 1998).

All the participants were given an informed consent form to be returned to the interviewer by their doctor or nurse. All the interviews were audio-recorded.

2.4. Analysis

After verbatim transcription of the interviews, the data were analyzed using qualitative content analysis. Content analysis is a systematic and objective way of describing and quantifying a phenomenon (Elo & Kyngas, 2008). Inductive or conventional thematic content analysis is appropriate when the existing knowledge of a phenomenon is limited (Hsieh & Shannon, 2005).

The analysis was conducted as follows (Graneheim & Lundman, 2004): the interviews were read through several times by two researchers to obtain a sense of the whole. The two researchers then read the interviews separately once again, highlighting the text fragments (words, phrases or sections) that referred to the participants' mobility difficulties. Both the comments on difficulty and comments which mentioned no difficulty were taken into consideration. The text fragments identified by both researchers were deemed to be meaning units, while the discrepancies were resolved in consensus meetings with a third researcher.

The meaning units were then condensed, and the condensed meaning units were abstracted and labeled with a code. The codes were compared according to similarities and differences, and after being discussed and reviewed by the authors, the final grouping of the codes into categories referring to the manifest content of the