

Development process of an assessment instrument on the level of difficulty perceived by caregivers for the elderly

Proceso de desarrollo de una evaluación de la evaluación en el nivel de dificultad percibido por los caregivers para los ancianos

Processo de desenvolvimento de um instrumento de avaliação sobre o nível de dificuldade percebido pelos cuidadores para os idosos

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ABSTRACT: The objective of this study was to build an instrument to assess the level of difficulties perceived by caregivers for the elderly. Methods: cross-sectional study, semi-structured interview carried out with informal caregivers for the elderly. In the first phase of this study, a semi-structured interview was conducted with the first sample of informal caregivers. From these results, an assessment instrument of level of difficulty felt by the informal caregiver while performing the care was built. In the second phase, the instrument was used with the second sample of informal caregivers to assess its internal consistency through Cronbach's Alpha coefficient. Results: the instrument was constituted by eleven domains and forty-eight items. Each item was to be ranked from 1 to 5, representing the best and the worst score, respectively. Internal Consistency analysis of the instrument was performed using Cronbach's alpha coefficient.

The Cronbach's alpha values revealed a good internal consistency to the eleven domains of the instrument, with the coefficient ranging from .74 to 1.00. These values are considered good or even excellent. The total Cronbach's Alpha coefficient value of this instrument is .98. **Conclusion:** the analysis of the Cronbach's alpha values showed good internal consistency for the eleven domains of the instrument, i.e., the answers on the instrument are coherent with its questions. The assessment instrument reached its goal in assessing the difficulty informal caregivers feel when caring for the elderly. It is recommended that the instrument is reproduced in a target population representative for external validity.

Keywords: Family Caregivers; Elderly; Data Collection; Activities of Daily Living.

RESUMEN: *El objetivo de este estudio fue construir un instrumento para evaluar el nivel de dificultad percibido por los cuidadores para los ancianos. Métodos: estudio transversal, entrevista semiestructurada llevada a cabo con cuidadores informales para personas mayores. En la primera fase de este estudio, se realizó una entrevista semiestructurada con la primera muestra de cuidadores informales. A partir de estos resultados, se construyó un instrumento de evaluación del nivel de dificultad que sintió el cuidador informal al realizar la atención. En la segunda fase, el instrumento se utilizó con la segunda muestra de cuidadores informales para evaluar su consistencia interna a través del coeficiente alfa de Cronbach. Resultados: el instrumento estuvo constituido por once dominios y cuarenta y ocho ítems. Cada ítem debía clasificarse de 1 a 5, lo que representa el puntaje mejor y el peor, respectivamente. El análisis de consistencia interna del instrumento se realizó utilizando el coeficiente alfa de Cronbach. Los valores alfa de Cronbach revelaron una buena consistencia interna en los once dominios del instrumento, con un coeficiente que oscila entre .74 y 1.00. Estos valores se consideran buenos o incluso excelentes. El valor total del coeficiente alfa de Cronbach de este instrumento es .98. Conclusión: el análisis de los valores alfa de Cronbach mostró una buena consistencia interna para los once dominios del instrumento, es decir, las respuestas en el instrumento son coherentes con sus preguntas. El instrumento de evaluación llegó a su fin para evaluar la dificultad que sienten los cuidadores informales al cuidar a los ancianos. Se recomienda que el instrumento se reproduzca en un representante de población objetivo para la validez externa.*

Palabras clave: *Cuidadores familiares; Mayor; Recopilación de datos; Actividades de la vida diaria.*

RESUMO: *O objetivo deste estudo foi construir um instrumento para avaliar o nível de dificuldade percebido pelos cuidadores para com os idosos. Como métodos, estudo transversal, entrevista semiestruturada realizada com cuidadores informais de idosos. Na primeira fase deste estudo, foi realizada uma entrevista semiestruturada com a primeira amostra de cuidadores informais. A partir desses resultados, foi construído um instrumento de avaliação do nível de dificuldade sentido pelo cuidador informal durante a realização do cuidado. Na segunda fase, o instrumento foi utilizado com a segunda amostra de cuidadores informais, para avaliar sua consistência interna, por meio do coeficiente Alfa de Cronbach. Como resultados, o instrumento foi constituído por onze domínios e quarenta e oito itens. Cada item deveria ser classificado de 1 a 5, representando a melhor e a pior pontuação, respectivamente. A análise da Consistência Interna do Instrumento foi realizada por meio do coeficiente Alfa de Cronbach. Os valores do Alfa de Cronbach revelaram uma boa consistência interna para os onze domínios do instrumento, com o coeficiente variando de 0,74 a 1,00. Esses valores são considerados bons ou até excelentes. O valor do coeficiente Alfa de Cronbach total deste instrumento é de 0,98. Concluindo, a análise dos valores do alfa de Cronbach mostrou boa consistência interna para os onze domínios do instrumento, ou seja, as respostas no instrumento são coerentes com suas questões. O instrumento de avaliação chegou a avaliar a dificuldade que os cuidadores informais sentem quando cuidam dos idosos. Recomenda-se que o instrumento seja reproduzido em uma população-alvo representativa de validade externa.*

Palavras-chave: *Cuidadores Familiares; Idoso; Coleção de dados; Atividades do dia a dia.*

Introduction

According to demographic data, the elderly population in Brazil has grown considerably (IBGE, 2009). This scenario contributes to an increase in the indicators of morbidity and mortality from chronic diseases that compromise the independence and hence the autonomy of the elderly people requiring permanent care (Nascimento, Moraes, Silva, Veloso, and Vale, 2008).

Generally, the family takes the responsibility at the time when the life conditions of one of its members change.

Family members are the first ones to recognize these needs and to provide essential care to the elderly who becomes dependent (Braz, & Ciosak, 2009)

A study by Perracini (1994) with informal caregivers showed that personal care were the most onerous tasks considered by respondents and that, generally, these tasks were administered without support.

Pavarini, and Neri (2000) emphasize some difficulties inherent to the task of caring. Among these, the authors highlight the lack of sufficient information to carry out the care, lack of social resources and skilled people to support the caregiver.

The daily activities for the elderly are multiple and from diverse domains, continuous and related to meeting the health needs of the elderly. Thus, the daily care brings difficulties to emotional, physical, economic and social aspects for the caregiver. Therefore, the assistance and the support of health professionals for the family becomes necessary (Vieira, Fialho, Freitas, & Jorge, 2011).

Considering the above, the activities and tasks performed by informal caregivers directly affect the quality of life of dependent elderly and that, there are no instruments that measure the difficulties of the caregiver, the need to build an instrument for assessing the level of difficulty of informal caregivers to perform care is observed.

Objective

The aim of this study was to develop a data collection instrument that measures the level of difficulty of informal caregivers to assist in basic tasks and activities of daily living related to caring for the elderly.

Materials and Methods

The following methodological approach was chosen for the construction of instruments after a systematic literature review on the area:

Interview with informal caregivers

In order to acknowledge the reality of Brazilian care, informal caregivers of elderly people were invited to participate in a semi-structured interview about the tasks and daily life related to the act of caring.

The sample for the interviews were recruited from the Family Health Strategy (FHS) members in the neighborhood Jardim Adamantina, in the city of Adamantina, SP and Jardim Teruel in Marília, SP, Brazil.

The instruments for assessing functional capacity by Lawton and Brody (1969), and Katz Index (1963) guided the topics to develop the semi-structured interview scripts related to caregivers' aid in activities of daily living for the dependent elderly.

FHS's community health agents from Jardim Teruel and Jardim Adamantina invited caregivers in the community to answer the interviews.

The criteria for answering the interviews included:

- the elderly person cared by the caregiver needed assistance for at least one basic activity of daily living;
- the participant had to be the primary caregiver;
- the caregiver had to be informal, i.e., not engaged in paid care work.

Each group counted with the participation of three (n=03) caregivers. They were all female, mean age 50.3 ± 12.1 years, all reported to be "housewives", did not perform paid activities, and have performed the care on average for 88.2 ± 107.5 months.

The six (n=06) elderly attended by the participant caregivers were, on average, 75.2 ± 7.0 years, and four (n=04) were female and two (n=02) were male. About their marital status, five (n=05) were widower and one (n=01) married.

The study was submitted and approved by Faculdade de Medicina de Marília Research Ethics Committee - number 638/11.

Elaboration of the construct

The questions were formulated, considering the analysis of the content on the discussions and obtained literature.

The elaboration of the construct was composed by domains. Once the aspects of each domain were defined, the items were prepared by capturing the nuances that permeate every area.

All items that focused on the theme of this study, i.e., related to elderly care were listed in the construct.

At this stage, the goal was to develop an instrument to collect data Likert type (1932/1993), with closed questions and multiple choice.

Submission to judges

After the development of the instrument "Assessment on the Level of Difficulty perceived by Caregivers for the Elderly", in order to follow a conceptual and methodological rigor of research, we submitted for analysis by three judges.

Thus, after the trial, the analysis of the material was performed in order to conclude whether the instrument showed the expected degree of representativeness.

Pretest

The application of the instrument, highlighting the applicability of items in the target population. This application was conducted with informal caregivers assisted by the family health strategy Jardim Teruel and Jardim Adamantina.

At this phase, the degree of understanding of each question and the instrument in its entirety were assessed. The researchers asked a small sample of caregivers to record their impressions whether feeling any difficulty in understanding the items that make up the instrument. After the analysis of the level of understanding and design of the sample, one last interference in the construct was performed, thus obtaining the latest version of the instrument.

To conduct the pretest, the informal caregivers who agreed to participate voluntarily in the study were invited and signed an informed consent.

The data collections were carried out at the caregivers' homes through interviews conducted by the head investigator.

The final version of the instrument was applied to a sample of eleven (n=11) informal caregivers for statistical analysis. Similarly to the group interview, all caregivers were female, mean age 55.5 ± 12.5 years. None of the participants worked outside at the time of the interview, and seven (n=07) reported being "housewives" and four (n=04) were retired. The participants performed the care of the elderly, on average 70.9 ± 92.8 months.

The eleven (n=11) dependent seniors, cared by the participant caregivers were, on average, 72.6 ± 9.3 years of age, five (n=05) were female and two (n=02) were male. Concerning marital status, seven (n=07) were married and four (n=04) were widowed. The clinical diagnosis of major occurrence in the sample was stroke sequel.

Statistical Analysis

The credibility of a measuring instrument shall be estimated by correlation coefficients.

Cronbach's Alpha coefficient measures the degree of covariance among the items, thereby serving as an indicator of internal consistency of the test (Streiner, 1993).

Cronbach's formula shows that if all items vary individually, Alpha equals to 1, i.e. the items are homogeneous and will produce exactly the same variance.

Whereas this occurrence is rare, Alpha demonstrates consistency among the items in the instrument. The coefficient can range from 0 to 1, while internal consistency above .70 are accepted (Streiner, 1993).

Results

The instrument is composed of eleven domains and 48 assessment items; each item presented one to five indicators representing the worst and best scores, respectively, as shown below (Figure 1):

The analysis of the Cronbach's Alpha values showed good internal consistency for the eleven domains of the instrument, with the Alpha coefficient ranging between .74 and 1 (Table 1).

Figure 1. Assessment on the Level of Difficulty perceived by Caregivers for the Elderly

Assessment on the Level of Difficulty perceived by Caregivers for the Elderly

Preliminary instructions for the caregivers

We are conducting a survey to assess how we could take better care of the elderly. From your experience, we believe you could help us greatly. We worked out a few questions to study how to better care for the elderly. Could you help us by answering these questions?

Identification

Caregiver's name:		
Age:	Gender:	Time/care:
Marital status:	Occupation:	Kin:

Assistance to care

In general, how do you feel when caring for the elderly:

I have no difficulties in performing the care	I have little difficulties in performing the care	I have difficulty in performing the care	I have great difficulty in performing the care	I cannot perform the care
1	2	3	4	5

The questions of the following items must be answered only if you reported difficulty in performing the care, i.e., whether the scores were 2, 3, 4 or 5.

Level of difficulty in helping the Daily Living Activities

The chart below shows the Daily Living Activities.

Initially, answer: "I perform this activity without difficulty", "I perform this activity with difficulties" or "It's so difficult that I cannot perform this activity."

If the answer is: "I perform this activity with difficulties", mark the level of difficulty: "it is a little difficult", "it is difficult" or "It's very difficult."

If the activity is not routinely performed by the caregiver, or if the elderly performs it by himself, the interviewer shall score one.

	I perform this activity without difficulties	I perform this activity with difficulties			It's so difficult that I cannot perform this activity
		It is a little difficult	It's difficult	It is very difficult	
In relation to food	1	2	3	4	5
In relation to changing clothes	1	2	3	4	5
In relation to bath	1	2	3	4	5
In relation to personal hygiene	1	2	3	4	5
In relation to medication	1	2	3	4	5
In relation to mobility	1	2	3	4	5
In relation to lifting	1	2	3	4	5
In relation to the position in bed	1	2	3	4	5
In relation to evacuation and urination	1	2	3	4	5

Identification of difficulties per task

The charts below show the daily tasks of care.

Initially, answer: "I perform this task without difficulty", "I perform this task with difficulties" or "It's so difficult that I cannot perform this task."

If the answer is: "I perform this task with difficulties", mark the level of difficulty: "it is a little difficult", "it is difficult" or "It's very difficult."

If the task is not routinely performed by the caregiver, or if the elderly performs it by himself, the interviewer shall score one.

FEED	I perform this activity without difficulties	I perform this activity with difficulties			It's so difficult that I cannot perform this activity
		It is a little difficult	It's difficult	It is very difficult	
On the knowledge of proper food for the elderly	1	2	3	4	5
To acquire necessary food for the elderly	1	2	3	4	5
For preparing food	1	2	3	4	5
To prepare food in the correct texture	1	2	3	4	5
To assist to eat	1	2	3	4	5
To assist to ingest liquids	1	2	3	4	5

DRESSING	I perform this activity without difficulties	I perform this activity with difficulties			It's so difficult that I cannot perform this activity
		It is a little difficult	It's difficult	It is very difficult	
Helping the elderly to get dressed and undressed	1	2	3	4	5

BATH	I perform this activity without difficulties	I perform this activity with difficulties			It's so difficult that I cannot perform this activity
		It is a little difficult	It's difficult	It is very difficult	
Acquiring devices such as special chairs, parallel bars and other adaptations	1	2	3	4	5
Preparing the bath	1	2	3	4	5
Washing the elderly's hair	1	2	3	4	5
Lathering the elderly	1	2	3	4	5
Helping the elderly with intimate hygiene	1	2	3	4	5
Drying the elderly after bath	1	2	3	4	5

PERSONAL HYGIENE	I perform this activity without difficulties	I perform this activity with difficulties			It's so difficult that I cannot perform this activity
		It is a little difficult	It's difficult	It is very difficult	
Assisting the elderly to brush teeth, mouth and/or false teeth	1	2	3	4	5
Assisting the elderly to brush and/or comb hair	1	2	3	4	5
Cutting the elderly's hair	1	2	3	4	5
Trimming the elderly's nails	1	2	3	4	5
Blowing and/or	1	2	3	4	5

cleaning the elderly's nose					
Cleaning the elderly after urinating and/or evacuating	1	2	3	4	5
Making bandages	1	2	3	4	5
Changing the elderly's diaper	1	2	3	4	5

MEDICATION	I perform this activity without difficulties	I perform this activity with difficulties			It's so difficult that I cannot perform this activity
		It is a little difficult	It's difficult	It is very difficult	
Knowledge about the effect of each drug	1	2	3	4	5
Controlling schedules	1	2	3	4	5
Organizing the medicine	1	2	3	4	5
About the collaboration of the elderly	1	2	3	4	5

MOBILITY	I perform this activity without difficulties	I perform this activity with difficulties			It's so difficult that I cannot perform this activity
		It is a little difficult	It's difficult	It is very difficult	
Assisting in using walkers, canes, crutches or wheelchair	1	2	3	4	5
Assisting the elderly to get around indoors	1	2	3	4	5
Assisting the elderly to get around outdoors	1	2	3	4	5
Assisting the elderly to go up and down stairs	1	2	3	4	5

TRANSFERS	I perform this activity without difficulties	I perform this activity with difficulties			It's so difficult that I cannot perform this activity
		It is a little difficult	It's difficult	It is very difficult	
Assisting the elderly to move from wheelchair to toilet	1	2	3	4	5
Assisting the elderly to move from wheelchair to a vehicle	1	2	3	4	5
Assisting the elderly to move from wheelchair to bed	1	2	3	4	5

POSITIONING IN BED	I perform this activity without difficulties	I perform this activity with difficulties			It's so difficult that I cannot perform this activity
		It is a little difficult	It's difficult	It is very difficult	

About the knowledge of correct positions when lying in bed	1	2	3	4	5
About the use of pillows, special mattresses, foam wedges and/or other utensils	1	2	3	4	5
Assisting the elderly to change position in bed	1	2	3	4	5
Assisting the elderly to change position in chair	1	2	3	4	5

EVACUATE AND URINATE	I perform this activity without difficulties	I perform this activity with difficulties			It's so difficult that I cannot perform this activity
		It is a little difficult	It's difficult	It is very difficult	
Realizing when the elderly needs to urinate	1	2	3	4	5
Realizing when the elderly needs to evacuate	1	2	3	4	5

Interviewer's name:
Date:

Table 1. Statistical analysis of the instrument internal consistency using Cronbach's Alpha

Domains of the instrument	Cronbach's alpha
Assistance to care	.981
Level of difficulty in helping the Daily Living Activities	.931
<i>Identification of difficulties per task</i>	
Feed	.877
Dressing	.981
Bath	.904
Personal Hygiene	.890
Medication	.812
Mobility	.916
Transfers	.890
Positioning in Bed	.746
Evacuate and Urinate	1
Total	.981

Discussion

Perracini (1994) describes that caring for a dependent related elderly generates disturbances to the caregiver and other family members once several factors may influence the context of care.

Among these factors, the tasks involving the care and judgment on them provide significant data on planning interventions based on real needs, derived from the analysis of information from the caregiver's point of view.

According to Almeida, Rodrigues, and Escola (2013), the construction of assessment instruments carry the possibility to deepen the study on an essential aspect of health care, which is the relationship between vulnerability and caring.

As for Parasuraman (1991), there is no standard methodology for the construction of assessment instruments, but recommendations of several authors (Gil, 2008; Reichenheim, & Moraes, 2002; Pasquali, 1998).

Thus, the design of this instrument was based from the material obtained through the literature review that involves the area and the information obtained in group interviews.

Chou, K.R., Jiann-Chyun, & Chu, H. (2002) emphasized that assessment instruments should be built on the same cultural context where they will be used. However, certain phenomena are common in many places. Thus, it was justified to collect primarily national material for the design of this work.

For Corrente (2009), a measuring instrument is only valid when it measures what it was designed to in a reliable way and with an acceptable degree of accuracy. Therefore, there are several techniques for its measurement.

The items comprising this instrument showed Alpha coefficients ranging between .74 and 1 and the total Alpha coefficient was .98, which demonstrated satisfactory index of representativeness and consistency of this instrument.

The contents of semi-structured interviews with informal caregivers, along with the literature review, supplied the necessary information for the construction of the items of the instrument.

The study achieved the proposed objectives as the instrument was constructed with optimal internal consistency and succeeded in assessing the level of difficulty informal caregivers feel when caring.

We suggest this study should be continued, as the instrument shall establish the highest and lowest scores for difficulty and shall be reproduced in a target population which is representative for external validity.

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