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Amendola, Fernanda; Martins Alvarenga, Márcia Regina; Correia Gaspar, Jaqueline; Hitomi Yamashita, Cintia; de Campos Oliveira, Maria Amélia

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Face validity of an index of family vulnerability to disability and dependence*

VALIDADE APARENTE DE UM ÍNDICE DE VULNERABILIDADE DAS FAMÍLIAS A INCAPACIDADE E DEPENDÊNCIA

VALIDAD APARENTE DE UN ÍNDICE DE VULNERABILIDAD DE LAS FAMILIAS A DISCAPACIDAD Y DEPENDENCIA

Fernanda Amendola¹, Márcia Regina Martins Alvarenga², Jaqueline Correia Gaspar³, Cintia Hitomi Yamashita⁴, Maria Amélia de Campos Oliveira⁵

ABSTRACT

This study aimed to propose and validate an index to identify families in a vulnerable situation to disability and dependency. It was adapted from the Index of Family Development (IFD), by adding indicators associated with the emergence of disability and dependency. *Delphi* technique was used to validation and five experts were consulted in the matter. The adopted level of agreement between judges was 80%. After two rounds of evaluations, adjustments were made related to the form and content of the instrument. Items were transferred from one component to another, some were added, others, deleted. The resulting Index is composed of eight domains, 38 components and 103 questions. The resulting Index is composed of eight domains, 38 components and 103 questions. The multidisciplinary contribution to the construction of an index that aims to capture the physical and social vulnerability of the families to disability and dependence provided the first step for the development of a tool for diagnosis and intervention that can be used by health professionals enrolled in primary care.

DESCRIPTORS

Disabled persons
Family
Primary Health Care
Validation studies
Indexes

RESUMO

Este estudo teve como objetivo propor e validar um índice para identificar famílias em situação de vulnerabilidade a incapacidades e dependência. Adaptou-se o Índice de Desenvolvimento da Família, acrescentando indicadores associados ao surgimento de incapacidade e dependência. Para validação aparente, utilizou-se a técnica *Delphi* e foram consultados cinco *experts* no assunto. Foi adotado nível de concordância de 80% entre os juízes. Após duas rodadas de avaliação, foram realizados ajustes quanto à forma e ao conteúdo do instrumento. Itens foram transferidos de componente, outros acrescentados e alguns, excluídos. O Índice resultante é composto por oito domínios, 38 componentes e 103 questões. A contribuição multiprofissional para a construção de um índice que se propõe a captar a vulnerabilidade física e social das famílias resultou na primeira etapa para o desenvolvimento de uma ferramenta de diagnóstico e intervenção para profissionais de saúde que prestam assistência às famílias na Atenção Básica.

DESCRIPTORES

Pessoas com deficiência
Família
Atenção Primária à Saúde
Estudos de validação
Índices

RESUMEN

El estudio objetivó proponer y validar un índice para identificar familias en situación de vulnerabilidad a incapacidades y dependencia. Se adaptó el Índice de Desarrollo Familiar, adicionándosele indicadores asociados al surgimiento de incapacidad y dependencia. Para la validación aparente se utilizó la técnica *Delphi* y se consultaron cinco *expertos* en el tema. Se adoptó un nivel de concordancia de 80% entre los especialistas. Luego de dos rondas de evaluación, se realizaron ajustes respecto a forma y contenido del instrumento. Se agregaron algunos ítems y se excluyeron otros. El índice resultante está compuesto por ocho dominios, 38 componentes y 103 preguntas. La aportación multidisciplinaria a la construcción de un índice que tiene como objetivo captar la vulnerabilidad física y social de las familias a la discapacidad y dependencia resultó en la primera etapa para el desarrollo de una herramienta para diagnóstico y intervención de profesionales que prestan servicios sanitarios de asistencia a familias en la atención primaria.

DESCRIPTORES

Personas con discapacidad
Familia
Atención Primaria de Salud
Estudios de validación
Índices

* Extracted from the Research Group "Avaliação de Necessidades de Saúde", School of Nursing, University of São Paulo, 2011. ¹RN. Master in Nursing. Doctoral student of the Nursing Graduate Program, School of Nursing, University of São Paulo. São Paulo, SP, Brazil. fernanda_amendola@yahoo.com ²RN. Ph.D. in Nursing of the School of Nursing, University of São Paulo. Teacher at the Faculty of Nursing, State University of Mato Grosso do Sul. marciaregina@uems.br ³RN. Master in Nursing. Doctoral student of the Interunits Graduate Program, School of Nursing and Ribeirão Preto College of Nursing, University of São Paulo. São Paulo, SP, Brazil. jcgaspar@usp.br ⁴RN. Master student of the Nursing Graduate Program, School of Nursing, University of São Paulo. São Paulo, SP, Brazil. cintia.hitomi.yamashita@usp.br ⁵RN. Full Professor of the Collective Health Nursing Department, School of Nursing, University of São Paulo. São Paulo, SP, Brazil. macampos@usp.br

INTRODUCTION

The demographic transition that peaked the 20th century due to the progress of science and technology and the improvement of the population's life conditions has had a great impact on the collective human epidemiological profile, and in the control and treatment of disease. Non-infectious chronic diseases, neoplasms and external causes were shown as the main causes of morbimortality, surpassing infectious diseases as the leading cause of death in both developed and developing countries⁽¹⁾. This scenario increases aging of the population and the number of people presenting with functional losses and dependency. In order to provide services to meet the growing demand, health public policies and actions are necessary.

One of the main challenges in health care has been qualifying Family Health Strategy teams (FHS) in identifying, planning, implementing and evaluating intervention strategies under the enhanced perspective of social determination and the various conditioning factors of the health-illness process, especially regarding the more vulnerable families under their care.

In Brazil, there are many senior citizens who, due to family or social reasons, live alone or live within poor families who have restricted assets and resources. Under the holistic health care point of view, these conditions are propitious for the onset of incapability and dependency, resulting in families with a higher risk for vulnerability.

The concept of vulnerability overcomes the individual and multifactorial risks. It is connected to the theory-methodology of Collective Health and the social determination of the health-illness process, as it encompasses the singular, particular and structural dimensions of reality in analyzing the determining factors of the health-illness process of different social groups⁽²⁾.

Based on the concept of vulnerability and on the theory-methodology referential of Collective Health, this present study has the objective to propose an index to assess vulnerable families to incapability and dependency. The existing instrument known as Family Development Index (IDF in Brazilian acronyms)⁽³⁾ was used as a base. The new instrument will be used to identify the most vulnerable families and to assist them through in intervention plan for monitoring the determining factors of their life and health conditions, identifying the most appropriate interventions for their health needs. It may also serve as a diagnosis and intervention instrument both in management and in the care of these families within the FHS scope.

OBJECTIVE

Propose a Family Vulnerability Index to identify people at risk for incapability and dependency and verify its face validity

METHOD

Stage 1 – Adjustment of the Family Development Index

The Family Development Index (IDF), a *synthetic indicator* to measure the development degree of families, was adjusted allowing to assess the vulnerability degree⁽³⁾. Generally, in a synthetic indicator, the incorporated dimensions assume positive and neutral weight, differentiated or not.

The IDF was elaborated to use the available information in the basic questionnaire of the National Research per Domicile Sample (PNAD in Brazilian acronyms). It comprises six dimensions, 26 components and 48 indicators. The six evaluated dimensions of life conditions are:

Lack of vulnerability: situations in which the volume of resources a family has increased to satisfy its needs, such as food and health care;

Access to knowledge: means used by the families to satisfy their needs, assessed by educational level, professional qualification and level of literacy;

Access to work: the opportunities a person has to use his/her productive capacity;

Resources availability: *per capita* family income, a fundamental resource for acquiring assets and services to satisfy its needs;

Child development: a social target to ensure children have what they need to meet their full developmental potential; and

Housing conditions: related to life conditions.

These indicators permit to estimate life and work conditions of families. However, since capturing the families' vulnerability regarding incapability and dependency is intended, two other domains were added, following a broadly-used criterion in other studies after a literature review:

Social relations: families' social support and network, which may influence the functional capacity, dependency and autonomy of people.

Health conditions: a compound of conditions that can be related to incapability and dependency. Components

The concept of vulnerability overcomes the individual and multifactorial risks. It is connected to the theory-methodology of Collective Health and the social determination of the health-illness process ...

of these domains are: chronic diseases, compliance with treatment, medications, hospital admissions, falls, subjective health evaluation, access to health services, physical capabilities, functional capacity and presence of mental disorders.

Therefore, a new instrument comprising eight domains, 38 components and 95 indicators was created and forwarded to a selection of judges for comments and evaluation.

Stage 2 – Evaluation of the selection of judges

Throughout January to July of 2011, the new instrument was presented to a selection of judges composed of researchers and health professionals, who were experts in the conditions intended to be measured by the Index. These judges analyzed the Index regarding its *face validity*. This validation technique permits to evaluate whether or not the instrument can measure what it is intended to⁽⁴⁾. Although it is considered a less sophisticated test, apparent validation is fundamental in the construction of an instrument, so that other validation tests can be employed sequentially.

When consulting the judges, the *Delphi* technique was used in order to obtain a consensus. In the *Delphi* method,

a group of specialists is surveyed through a questionnaire, which is recalled many times until a convergence of answers is obtained - a consensus, representing the consolidation of the intuitive judgment of the group⁽⁵⁾.

Following these stages, the instrument was modified, both in its structure and in its contents.

The level of agreement found among the judges was 80%. Three rounds were performed so that the agreement level adopted could be reached. In each round, the judges' comments were tabulated and exclusion, inclusion and items adjustments needs were verified, allowing each judge to revise his/her position in the face and consideration of the others' arguments.

RESULTS AND DISCUSSION

Eight judges were invited to participate in the research; however, one refused the opportunity, alleging lack of time. Two signed the Free and Informed Consent Form; however, they had personal issues that prevented them from participating in the research. Therefore, five judges in total participated in the study; two nurses and researchers in the specialty of gerontology, a nurse and a sanitation physician who work in case management connected to a Primary Health home care service and a social worker and gerontologist, who works as a researcher.

Judges Evaluation – DELPHI Technique

After two rounds of the judges' evaluations, five items were transferred from the component 'educational level'

to a new component named *education level of the head of the household*. Five questions were added to *access to durable assets*, four to the *social network* component and three to the *social support* component. Four other items were excluded from the *functional capacity* component. As observed in table 1, after the index was subjected to the expert committee, nine additions to the instrument were performed (one component and eight questions); therefore, the new Index is now composed of eight domains, 38 components and 103 questions. Many suggestions made by the judges in the first round were agreed to by all of them in the second and the final round.

Table 1 - Number distribution of the instrument general composition, according to domains, components and questions, in the 1st and 2nd rounds - São Paulo, 2011

Index composition	1 ^a round	2 ^a round
	N	N
Total domains	8	8
Total components	37	38
Total questions	95	103
Total items in the instrument	140	149

The items that presented less than an 80% agreement level among the judges are presented as follows.

1st ROUND

Justification to *exclude* (E) or *maintain with adjustments* (A) the items in the instrument were classified regarding structure and content. In total, 92 suggestions were made, 49 (53.3%) regarding the content and 43(46.7%) regarding the structure. From all 140 items evaluated, including domains, components and questions, only 17 items (12.1%) presented an agreement level lower than 80%, four (23.5%) regarding structure and 13(76.5%) regarding content.

Items inciting disagreement regarding structure related to the *early work*, *medication*, *subjective health evaluation* and *mental disorders* components. These components presented an agreement level of 60%.

Regarding question 35 (*In this house, are there any working children under 16?*), each judge pointed out a different key aspect. One of them suggested a question about working children between the ages of 14 and 16, since the previous question already asked about working children aged 14 or less. Most judges also pointed out the repetitive nature of questions in the following components: *existence of children*, *adolescents and young adults*, *senior citizens*, *income*, *access to school* and *chronic diseases*. It was clarified that, as in the IDF, *repetitive* items are included on purpose (cascade), as an alternative to attributing different weight to certain components. Hence, every item has the same weight, facilitating score calculations and allowing some items to indicate greater vulnerability by scoring higher than the items that indicate less vulnerability.

In this same question, another suggestion regarding income was to add the term *paid*, so that it would clarify that the question regards work with payment.

Polypharmacy is defined as the simultaneous use of five or more medications, a common practice within the senior citizen population. It is associated with an increased risk and severity of adverse reactions to medication, precipitating confusion, incontinence and urinary dysfunction and falls⁽⁶⁾, resulting in incapability and dependency. This aspect was approached in question 72 (*Is there a member of the family using five or more medications?*). The judges also observed that there was a lack of information in capturing the concept of polypharmacy and they suggested the addition of the terms *continuous use* and *simultaneously*.

In question 76, which subjectively evaluated family health, there was poor construction of the question and judges suggested altering it to read: *is there someone in the family who considers his/her own health as poor or very poor?*

Question 92 reads: *in this house, is there someone with a psychiatric mental disorder? (major depressive disorder, suicide, anxiety disorder, obsessive-compulsive disorder, schizophrenia, psychosis, bipolar disorder)?* One of

the judges suggested including the examples in the question, eliminating the brackets. Another judge required the substitution of the term *suicide* for *suicide attempt*. As the influence of some social and health characteristics on the functional capacity of senior citizens was investigated⁽⁷⁾, there were findings that validated that mental health was associated with moderate or severe dependency.

Major disagreements among the judges referred mainly to the content of the questions (Table 2). Regarding the social network component (Q58 and Q59), one of the judges suggested the inclusion of definitions for the terms *family members*, *friends* and *living close*. Therefore, the instrument added an enhanced concept of family, comprising *people considered as family, with or without blood ties*⁽⁸⁾. *Friends* were defined as *people who maintain a friendship relationship* and *living close* was defined as *within walking distance*, because the objective of the question was to evaluate the social network that can easily be activated in case of need.

Also within this component, two more categories were suggested, to be included in the frequency in which family members and friends visited: *at least once a month* and *at least once a year*. This inclusion was performed since the social network primarily refers to the quantitative aspects

Table 2 - Distribution of instrument items with an agreement percentage lower than 80% among judges, related to content, in the 1st round - São Paulo, 2011

ITEM	JUDGES										Agreement level (%)
	1		2		3		4		5		
	E	A	E	A	E	A	E	A	E	A	
In this house:											
Q58 - Are there relatives living nearby?	X		X								60
Q59 – Are there friends living nearby?	X		X								60
Q61 - Does the family receive visits from relatives at least once/week?	X		X								60
Q62 - Does the family receive friends/neighbors visits at least once/week?	X		X								60
Q63 - Is there someone who has no one to count on, in case of need?	X		X					X			40
Q64 - Is there someone who has no help if he/she finds himself/herself in bed permanently or is dependent on others for performing daily tasks?	X		X		X		X		X		20
Q65 - Is there someone who does not have anyone to take him/her to appointments or health services, in case of need?	X		X		X		X		X		20
Q76 – Is there someone with poor or very poor health?	X							X			60
Q79 - Is there someone who needs transportation to get to the health services location?	X		X								60
Q85 - Is there someone who has difficulty in feeding, personal hygiene, getting dressed, controlling bowel or bladder function, mobilizing and/or transferring (Basic Activities of Daily Living- BADL)?			X				X				60
Q86 - Is there someone with severe difficulties in feeding, personal hygiene, getting dressed, controlling bowel or bladder function, mobilizing and/or transferring (Basic Activities of Daily Living- BADL)?			X				X				60
Q89 - Is there someone in the house who has some difficulty with activities such as housecleaning, laundry, cooking, using appliances, shopping, using private and public transportation, controlling their own medications and finances? (Instrumental Activities of Daily Living – IADL)?			X				X				60
Q90 - Is there someone in the house who has severe difficulty with activities such as housecleaning, laundry, cooking, using appliances, shopping, using private and public transportation, controlling their own medications and finances? (IADL)?			X				X				60

E – Exclude A- Adjust

of the group of people with which the individual maintains contact or any type of social bond⁽⁹⁾.

One of the most polarizing components, with a low agreement level among the judges, was *social support*. Some of the questions were considered quite subjective; for example, regarding the question *Is there someone in this house who cannot count on anyone else in case of need*, one of the judges argued that it is only possible to know who we can count on when we actually need help. However, the question was maintained, since the Index looks at the vulnerability of families in regards to incapability and dependency, and this question permits to identify the most evident cases of lack of support. On the other hand, since the questions were quite generic, the decision to separate them into the types of support that are more closely related to incapability and dependency was made, resulting in a distinction between emotional, instrumental or material, affective and positive interaction as forms of support⁽¹⁰⁻¹²⁾.

In a study regarding the investigation of social support and the network of family caregivers for dependent people, caregivers who were observed to have some type of informal support presented a higher average score of quality of life than those who did not have such support. Although it does not necessarily represent actual 'help', the number of people living in the same house was observed to be correlated with a better support network, since more people who could provide help were close⁽¹³⁾.

The subjective health evaluation component received corrections regarding structure and content. One of the judges questioned the truth of the answers regarding the influence of emotional conditions. Many studies have demonstrated that health self-evaluation is an important determining factor for worsening health conditions, including dependency. An investigation⁽¹⁴⁾ of factors associated with functional incapacity among senior citizens in the Metropolitan Region of Belo Horizonte, Minas Gerais, found the prevalence of incapacity to be 16% (8% mild and 8% severe). Among the characteristics in this study, age and negative health status presented significant and independent associations with both levels of incapacity.

Regarding access to health services, question 79 was criticized by the judges. They expressed that needing transportation to reach the services does not necessarily mean there is difficulty in accessing it. The intent of the question was to verify if there were health services near the family's residence. Therefore, ceding the judge's wishes, the question was modified to: *In this house, is there someone who cannot walk to a health services location?* In a study of senior citizens in a Family Health Unit, 48.4% of the subjects had difficulties in accessing the service, mostly due to structural barriers (13.3%)⁽¹⁵⁾.

Functional capacity was evaluated by the questions that verified if someone in the house had any difficulty in performing BADLs and IADLs without help (Q85 and Q86; Q89 and Q90). Judges questioned how to evaluate if the difficulties were severe without using a specific instrument of measure. One of them suggested that these questions should be removed and replaced with only one

question: *In this house, is there a person who, without help, cannot perform the following activities...* This option was chosen, since the instrument is not striving to deeply look at the individuals within families, but to identify situations of vulnerability within the entire family.

A domicile inquiry performed in the elderly population of Joaçaba, Santa Catarina, between the years 2003 and 2004, found a prevalence rate of 37.1% of senior citizens with diminished functional capacity, associated with age (70 years or more), female gender and a negative self-perception of their economic situation⁽¹⁶⁾. Another study that related health conditions, functional capacity and social status verified that within the two years of the study, individuals with the lowest income presented with the worst health and physical conditions, both for the 20 to 64 year age bracket and for the >65 years age brackets⁽¹⁷⁾.

2nd ROUND

In the 2nd round, judges made 26 suggestions, seven (26.9%) related to content and 19 related to structure (73.1%). Of the 149 evaluated items, only four (2.7%) presented an agreement level lower than 80%, three related to content and one related to structure.

The construction of items using a cascade structure was not yet clear for some judges, who, once again, suggested modifications to questions 34 and 35, so that ages mentioned would not be repeated. Therefore, once again, it was clarified that this construction was intentional.

Once more the question regarding polypharmacy was not agreed upon among the judges, and adding the term *different medication* to the term *continuous use* was suggested. Therefore, the concept of polypharmacy was fully approached in the question (*In this house, is there anyone who continuously uses 5 or more different medications at the same time?*).

The question regarding the *access to health services* component, modified in the prior round, was not agreed upon among the judges in the second round. The way in which the question was elaborated was observed to produce answers that would indicate possible functional incapacity of a family member regarding their ability to walk to the health services location. However, verifying the distance from the domicile was considered a difficult factor to assess and, in any account, had already been asked in the previous item (*Health services frequently used by the family are distant from the residence, not within walking distance?*). One of the judges suggested adding a question to approach another aspect of accessibility, regarding the impossibility of using public transportation to go to the health services location, an item accepted by the others and by final agreement. Accessibility is an important element of access that can be limited as a result of accessibility issues, making it impossible for people to reach health service locations⁽¹⁸⁾.

Items that did not reach an 80% agreement level in the second round were modified and once again sent to the judges for a final round, in which all agreed to the corrections. Therefore, all items reached an agreement level above 80%.

CONCLUSION

Suggestions made by the judges that had not reached an 80% agreement level were not discussed in this paper, although they were considered in the re-elaboration of the questions. Surveying the group of judges enables the improvement and legitimization of the new measuring instrument that is being proposed. This is the first stage for the construction and validation of the Index, which will go through other validation tests after being applied to families served by the Primary Health Services.

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