# Living older in the family context: dependency in self-care\*

VIVER COM MAIS IDADE EM CONTEXTO FAMILIAR: DEPENDÊNCIA NO AUTO CUIDADO

VIVIR CON MÁS EDAD EN CONTEXTO FAMILIAR: DEPENDENCIA EN EL AUTOCUIDADO

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#### **ABSTRACT**

The purpose of this study is to help improve nursing care to dependent people and their families. The study objectives were: to describe the degree of dependency of the elderly in the family context; to identify the sociodemographic characteristics of the dependent elderly in the family context: to describe the main cause of dependency in the aged at home. This is a exploratory, descriptive study with a quantitative approach. In the period comprised between October 2007 and June 2008, 108 families from a northern region of Portugal were selected, with an elderly dependent. It was a convenience sample. For the collection of information, we used a questionnaire with the Barthel Index. Results showed that older people are predominantly women, widows, in average 81 years old, with severe level of dependence, and the leading cause of dependence was circulatory system diseases.

## **DESCRIPTORS**

Aged Frail elderly Family Caregivers Activities of daily living Geriatric nursing

#### **RESUMO**

A finalidade deste estudo é contribuir para a melhoria da assistência de enfermagem à pessoa dependente e sua família. O traba-Iho teve como objetivos: descrever o grau de dependência de idosos em contexto familiar; identificar características sociodemográficas dos idosos dependentes em contexto familiar: descrever a principal causa que originou a dependência nos idosos que se encontram no domicílio. A opção metodológica foi uma abordagem quantitativa de natureza exploratória descritiva. No período de outubro 2007 a junho de 2008 foram seleccionadas 108 famílias, de uma região norte de Portugal, com um idoso dependente. Foi uma amostra de conveniência. Para a colheita de informação recorremos a um inquérito onde incluímos o índice de Barthel. Os resultados mostraram que os idosos são predominantemente mulheres, viúvas, com média de idade de 81 anos, com nível grave de dependência, cuja principal causa foram as doenças do sistema circulatório.

## **DESCRITORES**

Idoso Idoso fragilizado Família Cuidadores Atividades cotidianas Enfermagem geriátrica

#### RESUMEN

Este estudio objetiva contribuir con la mejoría de la atención de enfermería a personas dependientes y sus familias. El trabajo tuvo como metas: describir grado de dependencia de ancianos dependientes en contexto familiar; describir la causa principal del origen de dependencia en ancianos que se encuentran en domicilio. La opción metodológica fue un abordaje cuantitativo de naturaleza exploratorio-descriptiva. En el período de octubre 2007 a junio 2008 fueron seleccionadas 108 familias del norte de Portugal, con un anciano dependiente. Fue una muestra de conveniencia. Para recoger la información recurrimos a un cuestionario donde incluimos el índice de Barthel. Los resultados mostraron que los ancianos son predominantemente mujeres, viudas, con media de edad de 81 años, con nivel grave de dependencia, la principal causa de dependencia fueron enfermedades del sistema circulatorio.

## **DESCRIPTORES**

Anciano Anciano frágil Família Cuidadores Actividades cotidianas Enfermería geriátrica

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## INTRODUCTION

Health promotion, which includes Health Education, has facilitated significant transformations and improved public health. Coupled with the more recent technological advancements in preventive and curative medicine, it has led to increased life expectancy and a reduced rate of mortality. Concomitantly with the decline in mortality, there has been a decline in fertility, which accentuates the population's aging process.

Aging consists of a complex process in the biological evolution of live organisms and a psychological and social process of human beings' development. It can be analyzed from various perspectives, being a normal, universal, gradual and irreversible process in which endogenous deterioration of the body's functional capacities occurs. It has long been perceived as a pathological phenomenon, though being an elderly individual is not synonymous with being sick. The body's biological decline, called aging process, causes the aging of structures and in the general aspect of the human body, as well as a decline in its organic functions, which causes individuals to be dependent on others for performing self-care(1-3).

The term dependency is linked to fragility in geriatric practice and is seen as a vulnerability the person presents in the face of challenges inherent to the environment. This condition is generally observed in individuals with a combination of diseases or functional limitations, which reduces their capacity to adapt to the stress caused by acute or chron- development of chronic constant help to perform both IADLs and ic diseases<sup>(4)</sup>. Hence, dependence is a state in which people, due to reasons linked to a lack or loss of physical, psychological or intellectual autonomy, need assistance or help from other people to perform daily living tasks.

To deal with life people develop Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). The scientific community considers the first to be: bathing, dressing and feeding oneself, toilet use, controlling the sphincters, while the second refers to: cleaning, cooking, going shopping, using means of transportation, dealing with money, taking medication, using the telephone, among others. The loss of the ability to perform IADLs may occur before ADLs because the first are more complex(5).

There is a semantic distinction in the terms Independency/Dependency and these should not be confounded with autonomy. Hence, the concept of dependency should not be linked to the concept of autonomy<sup>(6)</sup>. The first is functional, implies dependence on something or someone, is limited and related to a health disorder that translates into a difficulty or impossibility to perform basic and instrumental activities in daily life. Autonomy comes from autos (myself) and nomoi (law) and designates capacity, freedom

and the right to establish one's own rules and ability to selfrule. Autonomy refers to an individual's ability to decide about his/her own life. Thus, an elderly individual may be dependent and yet enjoy full autonomy(7-10).

Evaluating one's degree of dependence helps to determine the type of care required. Evaluation is composed of indicators for a more precise diagnosis of care based on the functional response of the individual and then is translated into degrees of dependence.

Dependence may occur at any age, though its prevalence increases as individuals age given the onset and development of chronic diseases that may lead to different types and levels of dependence(11).

Considering a human being as an open system, we may reinforce the idea that physical, psychological, economic and social dependencies exist and each of them inter-relate and thus is the human being constituted as a whole. The most usual view is to classify dependence in terms of different degrees: total, severe, moderate, mild and independent.

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Some authors(2) consider an individual with mild dependence to need only daily supervision or monitoring since this individual has some independence and is able to perform certain daily living activities. An individual with moderate dependence needs supervision and support from another to perform some specific activities. Finally, an individual with severe dependence needs ADLs; these are generally bedridden individuals with severe mobility restrictions.

Dependence is not a new phenomenon. Dependent individuals have always existed, only now dependence is a problem with social, psychological, economic, political and financial implications for not only the dependent individual but also for those who dedicate their time to care for and help the dependent person.

The convergence of different factors such as demographic aging, increased life expectancy, and alterations in the structure of families require this phenomenon to be urgently and appropriately addressed in order to deal with political, technological, social, economic, psychological and family issues(4,12).

The family is undoubtedly a key pillar of support in our society. It is the first social unit where a person is inserted and also the first institution that contributes to one's development and socialization; it is a reality at the human being's arrival, in their lives and at their departure(11). The family is usually seen as a significant institution that provides support and effective realization of an individual or ensures the solidarity required by family members through the course of aging(11,13-14).



Among the different health problems affecting elderly individuals, dependence has a strong impact on the family and the society in which they live, which justifies the study of this problem in a city in the north of Portugal. This study is part of a larger doctoral project in Nursing Sciences *Taking care of the family with a dependent elderly individual: Education in Nursing*. It addresses only the degree of dependence of elderly individuals as well as the main pathology that generated the dependence.

#### **OBJECTIVES**

This study identifies and acknowledges the profile of dependent elderly individuals in the family context to contribute to improved care provided by nurses of dependent individuals and their families. Hence the following objectives were defined:

- Describe the degree of dependence of elderly individuals in the family context:
- Identify the socio-demographic characteristics of dependent elderly individuals in the family context;
- Identify the main cause of dependence in elderly individuals in the family context;
- Validate internal consistency and reliability of the Barthel scale.

## **METHOD**

This is an exploratory descriptive study of a quantitative nature. Elderly individuals living in the family context in a city in the north of Portugal were selected for this study. The ethics committee of the General Board of Primary Health Care where the elderly individuals were registered (Health Units or Family Health Units) approved the project. The elderly individuals and/or their families voluntarily participated in the study and signed free and informed consent forms.

## **Population and Sample**

The target population included dependent elderly individuals residing in this city during the period in which data were collected (October 2007 to June 2008). The nursing teams from the Health Units and Family Health Units contributed to minimize difficulties in identifying, selecting and accessing families.

The following inclusion criteria were used:

- Being an elderly individual (65 years old or older);
- Living at home;
- Being dependent in the performance of at least one self-care action;
- Having assistance at home from the health unit or family health unit.

A total of 108 families were selected. The sampling process did not take into account the percentage of the sample in relation to the total population because we did not access current epidemiological studies addressing the population in this specific city. The access of the individuals was considered, thus this is a convenience sample calculated in relation to the data collection instruments used.

## Data collection instruments

The instrument used to collect data was organized into different parts to address socio-demographic data and clinical variables. The Barthel scale was used and allowed evaluating ADLs. This scale measures the functional independence and mobility of individuals with chronic pathologies indicating whether the individual requires care or not, and is designed to evaluate whether the individual is able to perform certain tasks independently. The scale is composed of 10 items: feeding, bathing, grooming, dressing, bladder and bowel control, movement, chair/bed transference, mobility and climbing stairs. Its total score ranges from 0 to 100, while a score between 0-20 indicates total dependence; 21-6 severe dependence; 61-90 indicates moderate dependence; 91-99 mild dependence and a score of 100 indicates the individual is independent. This scale was applied through direct observation and interviews with the elderly individuals or their families. To characterize the elderly individuals, identifying items were included: gender, marital status, and medical diagnosis from which dependence originated.

All the deontological premises recommended by ethics applied to research with human subjects were complied with during the methodological process (Process nº 003616/2007Mar02). The involved institutions authorized the study and the participants signed free and informed consent forms. Each questionnaire was coded with a number in order to ensure confidentiality. Data were analyzed through descriptive statistics by the SPSS program, version 15.

# **RESULTS**

Most of the 108 dependent elderly individuals in the family context were women (62%). Almost all individuals were either widowed (52%), married or were in stable relationships (44%); only about 4% were single and none were divorced or separated, as observed in Table 1.

**Table 1 -** Marital status of elderly individuals – City in the north of Portugal - 2008

Marital Status	N	%
Married/Stable union	48	44.4
Single	4	3.7
Divorced/separated	0	0.0
Widowed	56	51.9
Total	108	100.0



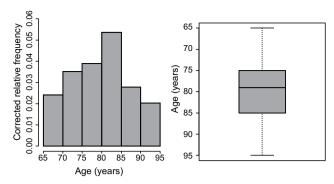


Figure 1 - Representation of elderly individuals' age - City in the north of Portugal - 2008

The age distribution presented in Figure 1 is slightly negatively asymmetric, which means there is a predominance of younger individuals (between 65 and 85 years old). The ages are distributed in an interval between 65 and 95 years old (inclusion criterion) but there are few individuals older than 85 years of age. The most frequent age range is between 80 and 85 years old and the number of individuals beyond this age range strongly decreases. This idea is demonstrated in Table 2 by the average age (about 80 years old) or median (81 years old), which means that half of the individuals were up to 81 years old. The first quartile includes

individuals aged between 65 and 75 years old, revealing there is some concentration of low ages.

**Table 2** - Characterization of elderly individuals' ages - City in the north of Portugal - 2008

Coefficients	Value
Minimum	65.00
Maximum	95.00
Average	80.16
1° Quartile	75.00
Median	81.00
3º Quartile	85.00
Standard deviation	7.66
Coefficient of variation	9.6%

The level of dependence of these individuals was measured using the Barthel scale. Dependence was evaluated in each category of the scale. Table 3 presents the distribution of elderly individuals according to levels of dependence. The highest level of dependence predominates in all self-care actions and reaches more than three quarters of the elderly individuals. There are very few individuals with a high level of independence or even with a moderate level of dependence.

Table 3 - Evaluation of elderly individuals' dependence - City in the north of Portugal - 2008

		Level of Dependence								
Self-care		1		2		3		4	5	5
	N	%	N	%	N	%	N	%	N	%
Grooming	73	67.6	17	15.7	9	8.3	4	3.7	5	4.6
Bathing	78	72.2	12	11.1	10	9.3	5	4.6	3	2.8
Feeding	62	57.4	15	13.9	10	9.3	12	11.1	9	8.3
Γoilet use	78	72.2	10	9.3	12	11.1	1	0.9	7	6.5
Climbing stairs	83	76.9	10	9.3	8	7.4	3	2.8	4	3.7
Dressing	71	65.7	21	19.4	5	4.6	6	5.6	5	4.6
Bowel functions	69	63.9	15	13.9	9	8.3	4	3.7	11	10.2
Bladder functions	73	67.6	4	3.7	4	3.7	11	10.2	16	14.8
Transfers (bed to chair and back)	71	65.7	19	17.6	5	4.6	5	4.6	8	7.4
Mobility	70	64.8	13	12.0	10	9.3	5	4.6	10	9.3

After this exploratory analysis, an analysis of the conceptual structure of the scale evaluating dependence was performed through a factorial analysis given the identification of factors underlying the responses. Such factors permit identifying similarities in the responses and detect dimensions that describe them, that is, they allow understanding the characteristics behind patterns found in the data. It was possible to validate the scale, measuring its validity for the intended objective.

In order to verify whether data are appropriate to perform a factorial analysis, we undertook calculating the Kaiser-Meyer-Olkin coefficient, which measures sampling adequacy, the value of which was 0.922, which is very high. Hence, it was appropriate to perform a factorial analysis with the data.

A factorial analysis was performed with the extraction of factors using the method of principal components in which it is necessary to first determine the number of factors to retain. All the rules normally used to select the number of factors to retain in the analysis lead to a solution with a single factor. One of these rules consists of selecting the factors whose own associated values are above 1 (the first factor is the only one meeting such a criterion, with a value of 8.399); the second rule consists of restoring 80% of the total variance, which leads to the same solution (the first factor explains 83.99% of total variance); the third rule commonly used is based on a scree plot, where the number of factors is chosen so that there is a larger break of the percentage of explained variance. Using this procedure, only one factor is chosen again (since the percentage of the explained variance through the second factor is only



5.38%). Therefore, a factorial solution with a single factor is obtained. The results of the factorial analysis presented in Table 4 indicate the factorial loads of the questions in a single factor. Then, the analysis to verify the scale's validity was performed to determine the questionnaire's internal consistency and reliability. Cronbach's alpha coefficient was used and its value was 0.98, which is extremely high and reveals the scale has very strong internal consistency.

**Table 4** - Factorial structure of evaluation of the level of dependence - city in the north of Portugal - 2008

Question	Factor 1
Grooming	0.908
Bathing	0.889
Feeding	0.920
Toilet use	0.927
Climbing stairs	0.871
Dressing	0.942
Bowel function	0.940
Bladder function	0.886
Transferências da cadeira e cama	0.930
Mobility	0.949

This study aimed to identify the primary cause that led to dependence. We consulted the Groups of International Classification of Homogenous Diagnoses (ICD10), which has been in effect in Portugal since 2002, to develop the class intervals. We verified that the main causes of dependence were diseases of the circulatory system, accounting for a little more than half (55.6%) of the answers; nervous system diseases accounted for 15.7% of the cases, mental and behavioral disorders accounted for 11.1%, diseases of the digestive tract and osteomuscular diseases accounted for 9.3%, lesions, poisoning and other consequences of external causes accounted for 6.5%, tumors accounted for 5.6% and finally, endocrine diseases accounted for 3.7%. Hence, there were many reasons leading to the dependence of elderly individuals living in the family context.

## DISCUSSION

The increased growth of the population of elderly individuals is a current trend. Even though individuals are living longer, they present a combination of chronic pathologies. Empirical evidence shows that the aging process usually brings with it disease and incapacity and chronic diseases are directly related to functional incapacity.

This study's results indicate that dependent elderly individuals living in the family context in a city in the north of Portugal are predominantly widowed or married women, aged 80 years old on average. These individuals were classified with a very high level of dependence; they were predominantly bedridden individuals with severe mobility restrictions. Therefore, they require total help in all self-care actions. This finding acknowledges that old age leads to a diminished functional capacity. Results of a recent study reveal that even though women live longer, the chances of living without incapacity are lower when compared to those of

men. These differences between genders are a consequence of the higher rate of mortality observed among men. The average life expectancy increased about 11 years for men and 13 years for women between 1960 and 2001<sup>(14,17)</sup>.

The main cause of dependence originated from diseases in the circulatory system. (Stroke is included.) These results are in accordance with Portuguese and international studies that indicate a growing prevalence of these pathologies<sup>(14,18-20)</sup>. Usually sequelae and limitations have severe personal, family and social implications<sup>(1,3-4,15,17,21)</sup>.

It is a well-known fact that families assume responsibility for the care delivered to dependent elderly individuals<sup>(11,13-14,17)</sup>, even when there is an abundant supply of formal support services. The family continues to play the main role in support provided to dependent individuals in the family context even with limited physical, financial and human resources.

Even though nursing professionals already deliver care to family groups, the challenge posed to the nursing field is to include the family as a unit of care, as a system, or the family as a care context. This change in paradigm requires a personalized evaluation so that interventions appropriate to the specificity of each family are implemented<sup>(21)</sup>.

The data collection instrument was useful given its efficacy in the evaluation process and facility with which it can be applied. The factorial analysis points to one factor. It is understandable that such a solution was reached because it became clear in the exploratory analysis that the great majority of individuals are totally dependent in all the scale's items. Consequently, this very high level of dependence is the only characteristic relevant in the evaluation of the level of dependence of elderly individuals. The factorial loads evidence that all items are very well represented in a single factor, which means that the elderly individuals are in general very dependent. This scale has been applied in different contexts and is considered an appropriate instrument to evaluate the level of dependence to perform daily living activities of elderly individuals in the family context. Review studies of instruments that evaluate the functional state of elderly individuals confirm that the Barthel scale presents consistent reliability and validity results(14,18-20). Hence, this study addressing 108 families with dependent elderly individuals allowed us to better characterize the functional capacity of dependent elderly individuals living in the family context in a city in the north of Portugal.

## CONCLUSION

The 21st century is the aging century. This phenomenon poses new challenges and requires one to reflect on issues with increasing relevance such as living longer in the family context, means of subsistence, family health, intergeneration solidarity, among others. From this social phenomenon emerges the need to create new economic activities and professions, especially in care delivered to



the community and solidarity networks. In other words, there is a need for specific services taking into account the specific needs of elderly individuals and their families.

The current context, in which there is higher life expectancy and chronic diseases, contributes to the prevalence of functional limitations in elderly individuals, which implies the need for continuous, long-duration, increasingly complex and frequent care. The family generally provides such care with or without support.

Considering the limitations of this study concerning the level of dependence of elderly individuals in the family context and the main pathology that led to dependence, we conclude that Portuguese families take care of elderly individuals with a high level of dependence. These data are significant in the current context of demographic transformations and family structures and point to the evident need for high level policy to support families in addition to the implementation of an urgent intervention with them.

### **REFERENCES**

- 1. Papaléo Neto M, Ponte J. Envelhecimento: desafio na transição do século. In: Papaléo Neto, M, editor. Gerontologia: a velhice e o envelhecimento em visão globalizada. São Paulo: Atheneu; 2000. p. 3-12.
- Paúl MC, Fonseca AF. Envelhecer em Portugal. Lisboa: Climepsi; 2005.
- 3. Figueiredo D. Cuidados familiares ao idoso dependente. Lisboa: Climepsi; 2007.
- Caldas CP. Envelhecimento com dependência: responsabilidades e demandas da família. Cad Saúde Publica. 2003;19(3):773-81.
- Cantera IR. "Escalas de Valoración en Contextos Geriátricos".
  In: Fernándéz-Ballesteros R., Gerontología social. Madrid: Ediciones Pirámide; 2000. p. 65-78.
- 6. Rodríguez P. El problema de la dependencia en las personas mayores. Document Soc. 1998; 112(1):33-63.
- 7. Orem D. Modelo de Orem: conceptos de enfermería en la prática. Barcelona: Masson; 1993.
- 8. Andrch R, Porqueddu B. Educazione: all'autonomia. Lisboa: Minerva Medica; 1990.
- 9. Preto LSR. O desenvolvimento da autonomia como factor de adaptação ao ensino superior. Rev Referência (Coimbra). 2003;10(1):63-71.
- 10. Meneses MTPC. Autonomia do enfermeiro: realidade ou utopia?. Pensar Enferm. 2004; 8(2):38-41.
- Martins MM. Uma crise acidental na família. Coimbra: Formasau; 2002.

A special interest on the part of health professionals, especially nurses, to recognize the needs and difficulties faced by families who care for dependent elderly individuals is highlighted. Family Health Units are been currently implemented in Portugal and these results may be of interest in decision-making concerning care delivered not only to dependent elderly individuals but also to the families, which are currently the main caregivers in society. Social and health services need to intensify preventive care and support the binomial elderly individual-family as a more appropriate strategy.

A family with a dependent member requires a family evaluation by health professionals so that the impact this individual causes on the family system is known. Such knowledge helps to determine the support required to meet this individual's needs, and to identify the strengths and fragilities of particular families. The disease usually affects all the members in the family group. Therefore, professionals need to visualize this context and provide humanized and holistic care to elderly individuals and their families.

- 12. Gómez SC, Ferrer GJ, Rigla FR, López VS. La sobrecarga de las cuidadoras de personas dependientes: Análisis y propuestas de intervenção psicossocial. Valencia: Tirant lo Blanch; 2006.
- 13. Hanson SM. Enfermagem de cuidados de saúde à família: teoria, prática e investigação. Loures: Lusodidacta; 2005.
- 14. Lobo A, Pereira A. Idoso institucionalizado: funcionalidade e aptidão física. Rev Referência (Coimbra). 2007;2(4):61-8.
- 15. Portugal. Insituto Nacional de Estatística (INE). Censos 2001: resultados preliminares: XIV recenseamento geral da população: IV recenseamento geral da habitação. Lisboa: INE; 2001.
- Rikli R, Jones C. Functional fitness normative scores for community-residing older adults, ages 60-94. J Aging Phys Act. 1999;7(2):162-81.
- 17. Araújo IM, Paul C, Martins M. Cuidar das Famílias com um idoso dependente por AVC: Do hospital à Comunidade: um desafio. Rev Referência (Coimbra). 2008;2(7):43-53.
- 18. Araújo F, Ribeiro JLP, Oliveira A, Pinto C. Validação do Índice de Barthel numa amostra de idosos não institucionalizados. Rev Portuguesa Saúde Pública. 2007;25(2):59-66.
- Nardi EFR, Oliveira MLF. Significado de cuidar de idosos dependentes na perspectiva do cuidador familiar. Ciênc Cuidado Saúde. 2009;8(3):428-35.
- Sequeira C. Cuidar de idosos dependentes. Quarteto: Coimbra; 2007.
- Figueiredo MHJS, Martins MMFPS. From practice contexts towards the (co)construction of family nursing care models. Rev Esc Enferm USP [Internet]. 2009 [cited 2010 Jul 20];43(3):615-21. Available from: http://www.scielo.br/pdf/reeusp/v43n3/en\_a17v43n3.pdf