

The Family Dynamics of Elder Elderly in the Context of Porto, Portugal¹

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Descriptive study aiming to understand the family dynamics of elderly people aged 80 years or older, receiving family care at home. Caregivers and elderly, registered at the family health unit of Greater Porto, comprised a sample of 107 pairs. Data were collected between 09/2009 and 03/2010. The following instruments were applied: family APGAR, quality of life and lifestyle scale. The results that stand out are: increase in male partners serving as caregivers for dependent partners; substantial inclusion in the list of family caregivers: grandchildren, nieces, nephews, siblings. The caregiver lifestyle was considered regular, as well as the caregiver and elderly's quality of life, although the family dynamics showed to work well. Limitations prevent further generalizations, but offer relevant support for the development of the family health and family nursing program.

Descriptors: Family; Aged, 80 and over; Family Health Program; Family Nursing.

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A dinâmica da família de idosos mais idosos no contexto de Porto, Portugal

Este é um estudo descritivo que objetivou conhecer a dinâmica de família de idosos com 80 anos ou mais, sob cuidados do familiar cuidador, em domicílio. Cuidadores e idosos, registrados na unidade de saúde familiar da grande região do Porto, compuseram amostra de 107 unidades. Dados colhidos entre 9/2009 e 3/2010, por instrumentos de dinâmica familiar, qualidade de vida e de estilo de vida, resultaram em: aumento de cuidador masculino e de cônjuge idoso de seu par dependente e inclusão substancial no elenco de familiares cuidadores: netas(os), sobrinhas(os) e irmãs(os). Estilo de vida do cuidador revelou-se regular como também a qualidade de vida de ambos: cuidador e idoso, apesar de a dinâmica de família se mostrar de boa funcionalidade. Limitações impedem a generalização dos resultados, porém, fornece subsídios relevantes para o desenvolvimento do programa de saúde familiar e de enfermagem de família.

Descritores: Família; Idoso de 80 Anos ou mais; Programa Saúde da Família; Enfermagem de Família.

La dinámica de la familia de ancianos con edad avanzada en el contexto de la ciudad de Porto, Portugal

Se trata de un estudio descriptivo, que tuvo por objetivo conocer la dinámica de familia de ancianos con 80 años o más, bajo cuidados de familiar, en su domicilio. El cuidador y el anciano, que estaban registrados en la unidad de salud familiar de la grande región de la ciudad de Porto, en Portugal, compusieron la muestra de 107 sujetos pareados. Los datos fueron recolectados entre 09/2009 y 03/2010 por medio del APGAR familiar, de calidad de vida y de estilo de vida; los resultados mostraron: aumento de cuidador masculino; conyugue anciano dependiente de su par; e, inclusión substancial de familiares en el elenco de cuidadores (nietas(os), sobrinos(os), hermanas(os)). A pesar de la dinámica de la familia mostrarse de buena funcionalidad, el estilo de vida del cuidador y la calidad de vida de ambos (cuidador y anciano) se mostraron regulares. Las limitaciones del estudio impiden la generalización de los resultados; sin embargo ofrece subsidios relevantes para el desarrollo del programa de salud familiar y de enfermería de familia.

Descritores: Familia; Anciano de 80 o Más años; Programa de Salud Familiar; Enfermería de la Familia.

Introduction

All over the world but mainly in developed countries, especially in the European Union, issues resulting from population aging and people's increased longevity have raises a wide range of discussions, notably regarding public policies for healthcare and prolonged and continuous care delivery to the aging population⁽¹⁾. Since the end of the 1990's, Portugal has been demonstrating demographic structure changes, with increasing numbers of elderly people (aged 65 years and older) in relative as well as absolute terms. The 2001⁽²⁾ census reveals that

Portugal has a population of 10.356 million inhabitants, 16.4% of whom are elderly (1.693 million), almost half of whom are elder elderly (690,125), indicating simultaneous aging inside the range. The elderly population's distribution is not homogeneous though: socioeconomic asymmetry coincides with geographical asymmetry between the cost and the interior, the latter with its older and poorer population. Mainly associated with unfavorable socioeconomic conditions, longevity negatively affects elderly people's functionality,

weakening them. Poverty mainly affects the elderly⁽²⁾, as the current risk rate of poverty in the elderly (24%) is higher than the general rate (15%). Many elderly may stay active and fully independent until the end of their days, despite concrete threats of prevalent chronic-degenerative illnesses⁽³⁾. The prevalence of Chronicity and longevity have contributed to increase the number of elderly with functional impairments, implying constant care by health services and, mainly, by families⁽³⁻⁴⁾. This care is generally delivered at home, with one family member notably assuming the responsibility as the main caregiver. Other family members can help in complementary activities, which is why they are called secondary caregivers⁽⁵⁻⁶⁾. Home is seen today as a space where dependent people, whether elderly or not, can remain stable and preserve their quality of life. The home care experience has become increasingly frequent in daily family life⁽⁶⁻⁷⁾. In line with this trend, elderly care policies defend that the home is the best place for the elderly to get old, with possibilities of guaranteeing autonomy and preserving their identity and dignity. Taking care of dependent elderly affected by chronic or acute conditions constitutes a frequent condition in families.

Across history, in most countries, women have delivered care to the elderly, mainly wives, daughters and granddaughters, which is explained by women's traditional essentially domestic and family functions. Women's progressive participation in the job market, among other factors, however, has modified this reality. Nevertheless, they have been playing the role of caregivers, accumulating their care and domestic activities, besides going out to work. This burden has contributed to negligence of other people and has compromised their own health⁽⁵⁻⁷⁾. Although current literature signals the multiple characteristics and needs of families who take care of dependent elderly, contextualized knowledge is lacking, considering that these elderly have become older, more or less fragilized depending on the circumstances, indicating new upcoming demands. Thus, this study aimed to get to know the dynamics of family functioning in the context of day/night care relations between the caregiving family and the elderly (80 years and older) relative who is dependent for care.

Family dynamics – a conceptual framework

When examining family dynamics, it is important to explore its relations, which reveal harmony or disharmony in the functioning of the care unit, like in the

present case, in which one family member is dependent, the elderly who is weak due to advanced age, demanding protection, care, solidarity, affection and love from the family. The idealization of the family as a context of protection and care, however, can take the form of a place of violence and oppression⁽⁷⁻⁸⁾. In view of that possibility, assessment is essential for health intervention purposes. The APGAR⁽⁸⁻⁹⁾, an efficient family functioning screening test, assesses the following dimensions through five questions: adaptation, partnership, growth, affection and resolve. The family function refers to the way family members see the family when attending to this commitment and permits identifying individual perceptions of family values as a psychosocial or social support resource. The way people perceive the efficacy and quality of this resource will significantly influence their health status. Healthy families demonstrate the integrity of these components as they represent the support and care unit. Higher APGAR scores demonstrate the family's greater capacity to adapt to the new situation and possible and probable role changes, while a low score can represent a stressful environment, marked by low adaptability to the new situation, thus demanding fast and appropriate interventions.

Method

In this exploratory, diagnostic assessment study, participants were pairs of main family caregivers and elderly dependent for healthcare and activities of daily living. Porto, located on the North coast of Portugal, was the study context. Greater Porto^(2,10) concentrates a population of 263,131 inhabitants. According to demographic projections, its rate corresponds to 19.4%, higher than the country's mean rate (16.4%) and 51.047 in absolute figures, 32,517 (63.7%) of whom are women and 18,530 (36.3%) men. The age group of 85 years and older is equivalent to 3,947 (1.5%).

The Ministry of Health is working to set up Family Health Units across the Portuguese territory⁽¹¹⁻¹²⁾ and that is where elderly living in the family context are registered. Family health team nurses have been essential, participating in the families' linking around health promotion and care actions in the community and domestic sphere. Family Health Units in Porto have increased, currently corresponding to 64 out of 119 existing unit across the North of the country⁽¹¹⁻¹²⁾. The target population in this study comprised families of elderly care dependents at the age of 80 and older, living in the domestic-family context and whose

family members are responsible for controlling their life and health. A convenience sample was obtained, locating the pairs at the Family Health Units with higher concentrations of elderly people and with easier access for the research team. The following inclusion criteria were defined to select the participants: families registered at the Family Health Unit and for whose elderly members home visits were indicated because they were care-dependent; both members of the pair able to answer the researcher's questions and, at the same time, voluntarily accepting to participate in the study; also, at the time of data collection, the elderly should not be hospitalized. Data were collected between 09/2009 and 03/2010. The selected pairs were invited and, after their acceptance, they signed the Informed Consent Term and the instruments were applied. The QPFC – Caregiving Family Profile Questionnaire⁽¹³⁾ was applied to the family caregiver to answer identification questions regarding sociodemographic variables, health status and care situations of both the family caregiver and dependent elderly. To the elderly, the abovementioned Family APGAR⁽⁸⁻⁹⁾ was applied, with five simple questions on intra-family adaptation, contact and communication, growth and development, family affection and dedication, with the following response alternatives: always, almost always, sometimes, rarely and never, corresponding to four, three, two points, one point and zero, respectively. Assessment is based on the total score, classifying the family in three types: highly functional, functional, moderately functional and severely dysfunctional. Validity and credibility studies for this test guarantee the safety of its application⁽⁹⁾. To complement the family dynamics results, individual perceptions of correlated aspects like quality of life and lifestyle were also assessed. Thus, the WHOQOL⁽¹⁴⁻¹⁶⁾, the quality of life assessment instrument developed by WHO, was applied to the family members and elderly. The WHOQOL-Bref version, with 26 questions, covering four domains and preserving the twenty-four facets of the original WHOQOL-100, was applied to the relatives. Each question is accompanied by five Likert-style alternative answers, ranging from 1 to 5. For the elderly, besides the WHOQOL – Bref, the 24-question WHOQOL – Old was applied, which includes specific aspects like: Sensory functioning; Autonomy; Past, present and future activities; Death and dying; and Intimacy. All WHOQOL versions were tested, with good validity and reliability scores⁽¹⁵⁻¹⁶⁾. Moreover, to family members, the Scale of Wellbeing was applied⁽¹⁷⁾, which assesses the lifestyle through behaviors that

affect health. This scale assesses five habitual actions: nutrition, physical activities, preventive behaviors for health, social relations and stress control, reflecting people's attitudes, values and opportunities. Each action contains three items, totaling 15 questions. Answer scores can range from zero to 3 for each item. The maximum total score is 45, corresponding to an excellent lifestyle, and the minimum zero, which represents and inadequate lifestyle. Tests revealed acceptable validity and reliability⁽¹⁷⁾. With a view to replication in different centers, this project was submitted to the Institutional Review Board at UFSC (where the project coordination was located), in compliance with Resolution 196/96 by the Brazilian Ministry of Health National Health Council. Approval was registered under No 051/08.

Results

Sample characteristics

The sample includes 107 elder elderly and their respective main family caregivers, as shown in Tables 1 and 2.

Table 1 – Characteristics of elder elderly receiving family care at home, Greater Porto, Portugal, 2010

Sample characteristics – Elderly (n=107)	n	%
Age per range		
Up to 84	59	55.1
85 to 89	42	39.2
90 or more	6	5.6
Gender		
Male	29	27.1
Female	78	72.9
Education		
Illiterate	30	28.1
Pre-school until 4 years	53	49.6
Unfinished/finished first year elementary school	10	9.2
Unfinished/finished first year elementary school	14	13.1
Marital status		
Married	34	31.8
Divorced/separated/single	19	17.7
Widowed	54	50.5
Age of elderly's spouse		
Mean in years /SD	84/4.5	
Professed religion (Catholic)		
Yes	103	97.0
Parenthood with family caregiver		
Son/Daughter	50	46.7
Nephew/Niece	19	17.8
Partner	18	16.8
Sister	11	10.3
Others (brother, daughter-in-law, son-in-law, friend and granddaughter)	9	8.9

(continue...)

Table 1 – (continuation)

Sample characteristics – Elderly (n=107)	n	%
House where the elderly lives		
Owned/usufruct	15	14.0
Rented	66	61.7
Of caregiver/other relative	26	24.3
Diseases suffered		
Arterial Hypertension	60	56.1
Sequela of CVA	24	22.4
Heart disease	20	18.7
Diabetes mellitus	22	20.6
Cancer (colon, breast, lung, bladder, skin and stomach)	16	14.9
Parkinson's Disease	7	6.5
Mean Quality of Life scores (WHOQOL-Bref 0-100)		
Mean scores/SF	62.0/11.9	
Mean Quality of Life scores (WHOQOL-Old 0-100)		
Mean scores/SF	67.0/13.1	
Family Dynamics Apgar		
Good Functionality (Scores 13-20)	72	67.3
Moderate dysfunctionality (Scores 9-12)	20	14.0
Severe dysfunctionality (Scores 0-8)	15	18.7

Most participants in the sample are women and widowed. On the other hand, 31.8% of the sample were still married, even at the age of 80 years and older, half of whom receive care from their spouse.

Table 2 – Characteristics of main family caregivers for elderly aged 80 years and older, dependent on care, Greater Porto, Portugal, 2010

Sample characteristics – Caregiver for the elderly (n: 107)	n	%
Age		
Mean in years/SD	58/15.4	
Gender		
Male	43	40.2
Female	64	59.8
Marital Status		
Married	76	71.0
Divorced/separated/single	27	25.2
Widowed	4	3.7
Education		
Illiterate	3	2.8
Pre-school until 4 years	22	20.5
Unfinished/finished first year elementary school	49	45.8
Unfinished/finished first year elementary school or unfinished higher education	33	30.8
Occupation/Work		
Yes	40	38.0
Takes care of other dependents		
Yes	27	25.0
Lives with the elderly receiving care		
Yes	80	75.0

(continue...)

Table 2 – (continuation)

Sample characteristics – Caregiver for the elderly (n: 107)	n	%
Self-appreciated health		
Excellent / good	38	35.5
Regular	61	57.0
Bad / very bad	8	7.5
Quality of Life -WHOQOL/Bref, 0-100		
Mean score/SD	73.0/12.3	
Lifestyle-Nahas scale, 0-45		
Mean score/SD	26.2/4.4	

Caregivers' mean age is 58 years, ranging between 30 and 89 years. Most of them are married, many still go out to work and take care of other dependents in the family. When asked about how they perceive their own health, the regular health response prevailed. This perception is equivalent to quality of life and lifestyle assessment, which also obtained regular scores.

Quality of life of the elderly and family caregiver

Quality of life⁽¹⁴⁻¹⁶⁾ represents the individual perception of one's position in life in the context of the culture and value system one is inserted in and related to objectives and expectations, standards and concerns. This perception has an important subjective value, as it directly influences one's state of wellbeing, health and the feeling of greater or lesser competency to administer one's own life under any circumstance. The elderly people's responses to the WHOQOL-Bref scored low in the physical and social relations domain: relatives, on the other hand, self-assessed themselves with lower scores in the environment and psychological domains, as observed in Table 3.

Table 3 – Mean scores and standard deviations on WHOQOL-Bref domains (range 0-100) for elderly and caregivers, Greater Porto, Portugal, 2010

WHOQOL-Bref domain	Mean		Standard deviation	
	Elderly	Caregiver	Elderly	Caregiver
Physical	48.4	76.5	20.8	15.9
Psychological	53.0	65.7	15.3	14.8
Social Relations	50.9	71.5	14.7	14.3
Environment	58.7	64.1	12.3	12.4

Table 4 shows the mean scores per age range on the WHOQOL Old. The general mean score was influenced by higher scores on Sensory functioning, Social participation and Death and dying.

Table 4 – Mean and standard deviation of WHOQOL-Old (range 0-100) domain scores for the elderly per age range, Greater Porto, Portugal, 2010

WHOQOL-Old domain	Age Range					
	Up to 84		85 to 89		90 or more	
	Mean	SD	Mean	SD	Mean	SD
Sensory functioning	76.2	20.9	62.6	27.4	40.6	33.2
Autonomy	53.1	20.9	62.1	19.2	60.1	30.3
Past, present and future activities	56.2	14.8	59.2	15.7	53.1	9.5
Social participation	47.1	20.7	54.5	17.8	36.5	21.4
Death and dying	46.2	33.6	47.6	37.3	58.3	46.5
Intimacy	69.5	21.7	76.6	22.1	81.2	22.1

The analysis of the association between the WHOQOL-Bref and WHOQOL-Old scores, tested using Spearman's correlation coefficient, resulted in $r = 0.63013$, with statistical significance $p < 0.000001$. This coefficient was adopted because data did not show normal distribution. A moderate positive relation is evidenced between both instrument scores.

Family functionality

The assessment of family dynamics from the perspective of the elderly, through the application of the Family APGAR, demonstrates that most elderly in this study see their family as a care relations unit, which good or moderate functionality (Tabela 1).

Caregivers' Health-related Lifestyle

Lifestyle was assessed through the Scale of Wellbeing⁽¹⁷⁾, with a total mean score of 26.2, within a possible range from zero to 45. Caregivers' lifestyle was considered regular, equivalent to the regular results for quality of life too.

Discussion

The predominance of elderly women in the sample confirms the trend of the already known feminization of old age^(2,10). The low education level found was also predictable, in view of the preceding reality of people aged 80 years or older today. The prevalence of chronic-degenerative illnesses constitutes a common epidemiological parameter in aging populations⁽³⁻⁴⁾. The irremediable fact of prolonged contact with chronicity due to increased longevity can make people lose quality of life if the public policy of a continued and integrated care network⁽¹⁸⁾ for the life and health of elderly people is not put in practice. It is important to grant priority coverage to poorer families (86% in this study), which divides the sole resource of elderly people's retirement

benefit. In the study, caregivers are still mostly women, including daughters, nieces, granddaughters and sisters, as identified in other studies^(5-6,19-20), although a new fact is emerging: the growth in male caregivers. In comparison with an earlier study⁽⁵⁾, performed four years ago in the same context, this percentage has doubled. This growth, however, was already appointed in 1999, in a Ministry of Health report on the support program for the elderly⁽¹¹⁾, estimating that the share of men as informal caregivers figured around 28 to 37%, although little is known about male informal caregivers, even in the international context⁽²¹⁻²²⁾, with extremely scarce literature. In our midst⁽²³⁾, a qualitative study involving male elderly caregivers for their sick spouses spent considerable time and energy, against traditional gender stereotypes of attributing family care to women. The reasons for them being caregivers were: duty and obligation, marital commitment, reciprocity and gratitude for longlasting marital life. As for feelings, they experienced a wide and often ambiguous range: satisfaction and pride, but also sadness, frustration and revolt. A similar study⁽²³⁻²⁴⁾ attempted to question the elderly caregivers' decision to take care of their spouses with dementia conditions. Among the results, the following stood out: love, reciprocal obligations, redemption. According to the author, what makes elderly men decide to take care is probably the crucial element in this experience and probably the main difference between male and female care. Further knowledge on male and particularly elderly caregivers is essential. Nevertheless, any available data entail direct implications for family care practice. Professionals, especially nurses, need to reconsider the stereotype of care always being linked to women. Men need and can be encouraged for this family task, following the example of men who decided to take care of their wives, courageously going against social and cultural values and assuming the care task, classified as eminently female.

The caregivers studied here live in the same house as the elderly receiving care in 75% of cases, often motivated by the facility of care, but mainly by families' impoverishment. This data supports some study results^(5,7,19-22), particularly highlighting the proportion of 17% of caregiving partners found here, as confirmed by some studies that mark the increase in elderly caregivers, male and female partners, taking charge of care for their partners. These caregivers also suffer because of feelings of solitude and social isolation, as observed here in quality of life assessments, with lower scores in the psychological and environment domains. Therefore, in practice, local social support networks need to be articulated, based on Health Services, with a view to maintaining families' social inclusion.

Many of the caregivers in this research (64.5%) answered that their health was regular or bad, and also showed a lifestyle with a regular total mean score, possibly due to the stress and burden the care task entails, with little time left to take care of themselves and the elderly, besides the exhaustion of their own aging, as demonstrated in many foreign studies and confirmed in some Brazilian ones^(5-7,23-24).

From the perspective of the elderly dependent on their relatives' care, the assessment of family dynamics through the application of the Family APGAR demonstrated adequate family functionality in 67.3%. In principle, this more dynamic positive result does not exempt the alert for family care interventions in the new conditions the family experiences regarding the need and expectation of home care for the elderly. It is the place for anticipated intervention to prevent possible family crises^(12,19). The study also reveals 32.7% of elderly living in families with severe and moderate family dysfunction, which should not cause estrangement, as care delivery to an elderly person with chronic illnesses and other problems can develop some form of stress in the family, such as the lack of adaptability to changes in family members' roles, to new intra-family relationship styles and to the care relations themselves. This result remits to family care interventions by professionals, mainly nurses, who are involved in the administration of family difficulties to deal with dependent elderly people's problems that need care or are receiving care. When elderly patients report on a family crisis, in general, family resources are inappropriate to respond to the needs and/or signal the existence of weakened or vulnerable areas in the family context, which may be interfering in family members' ability to find strategies and resources to develop their role as caregivers^(10,12,19).

Family members' personal perceptions of certain variables, however, such as quality of life and healthy lifestyle or not, can influence the family dynamics, turning it more or less adaptative, more or less functional, in view of a situation that represents a new fact to cope with: an elderly member who gets ill and becomes more fragile and care-dependent by the day, influencing intrafamily relations.

Both WHOQOL versions equivalently assessed quality of life, as a positive association was found, tested using Spearman's correlation. This confirms the advantages of the WHOQOL - Old, as it permits assessing the particularities of elderly people's more positive or negative perceptions of aspects in the quality of life domains. Both assessments of the elderly fell in the median or regular quality of life classification. On the WHOQOL-Bref, the low mean score in the physical domain, related to health, contributed to a regular total score. On the WHOQOL-Old, the low mean score regarding social participation in the quality of life domains revealed a regular general quality of life level. Assessment according to this version, however, revealed considerable differences among the six aspects and, when their scores were distributed across the age ranges (80-84, 85-89, 90 and +), it was verified that variations are not necessarily regular as age advances, indicating the manifestation of elderly people's particularities, even at more advanced ages.

Final considerations

Despite the study limitations, whose data were extracted from a convenience sample, which impedes their generalization, results represent useful support for professional practice, mainly for Family nurses. In summary, noteworthy results regarding family caregivers for the elderly tend to change what is found in the literature: increase in male caregivers; increase in elderly caregiving partners; more substantial inclusion of family caregivers, like nieces and nephews, grandchildren, siblings.

Families in this study seem to have a vocation for elderly care, given their favorable assessment of the family dynamics. Caregiver and elderly quality of life, on the other hand, display similar regular assessments. The caregiver's lifestyle revealed regular results, like quality of life. The caregiver's lack of external social opportunities and the elderly's affected health status and wellbeing seem to converge towards a regular or median result.

Implications for practice entail the need to understand caregiving families not only as partners in care, but also as clientes/users of social and health services.

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