Who are the family caregivers? Epidemiologic research

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Context:

Increase in life expectancy;
Technological progress in health;
Improvements in socioeconomic conditions

Increase people with chronic illnesses;
Live longer;
Dependence situation.

Must be developed a full range of services, including home care, not only for the dependent people but also to family caregivers.
Caregiver transition is marked by instrumental care:

- caregivers expend a lot of time on care,
- implications for the health of dependent person and caregivers

We don’t know the dimension of this phenomenon
Objetives:

Characterize families with dependent people: income, household, the attributes of de person with dependence and the attributes of caregiver.

Describe the intensity and regularity of care providing by family caregivers and the perceptions of self-efficacy in role acquisition.
Ethical Issues:

The ethics committees of hospital and a university approved the study.
Methodology:

**Study population and sampling strategy:**

- We used the formula proposed by WHO for epidemiological studies to calculate the sample.

- The selection of family units that comprise the sample is made using the Geographical Database Referencing Information, which allows to know the geographic distribution of households.

- We ranked a city into a 10 strata according to the administrative division and randomly sampled 2351 of 57771 families in this city.

- Geographically stratified random selection of sub-regional accomplished through a system Geographic Information, using Arcgis®.
Sample:

An example

Matosinhos:
Data collection:

- We walked door to door in selected sections in the sample;
- We conduct a home interview using a form;
- Of these 2351 households, 1745 (74.22%) had someone that opened the door in the moment of data collecting;
- We contacted 1745 families, 358 (20.5%) in Senhora da Hora, 330 (18.9%) in Matosinhos, 244 (14%) in S. Mamede de Infesta, 175 (10%) in Leça Balio, 157 (9%) in Custóias, 155 (8.9%) in Leça da Palmeira, 93 (5.3%) in Perafita, 84 (4.8%) in Lavra, 81 (4.6%) in Santa Cruz do Bispo and 68 (3.9%) in Guifões.
- From 1745 families, 143 (8.2%) refused to participated to the survey.
Form:

The form was construct through an extensive literature review, experts consensus among the authors, and on the basis of a previous study.

We investigated several topics in survey, but the main focus for this presentation are:

- Describe family caregivers,
- Frequency and Intensity of care,
- Perceived self-efficacy.
Statistical analyses:

- Data were analyzed using the Statistical Package for Social Sciences - SPSS (version 18.0, SPSS Inc, Chicago, USA);

- For descriptive analysis, for numerical variables were determined measures of central tendency (mean) and dispersion (standard deviation, minimum and maximum). In nominal and ordinal variables frequency tables will be presented with scores and their frequencies.
Results:

- 1602 (families) participants.

- The proportion of families which includes dependents of someone or a device for self-care is 9.5% (n = 152).

- 23% (n=35) refused to participate and point as the main reason: not having time.

- 117 families agreed to take the survey. Should be noted that 4 families have 2 dependents, so the total is 121 dependents and 100 family caregivers.
**Results:**

<table>
<thead>
<tr>
<th>Families</th>
<th>Accommodation</th>
<th>Dependent Person</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 3 elements</td>
<td>• 77.8% (n = 84) not have accessibility for people with reduced mobility</td>
<td>• 74.85 years average</td>
</tr>
<tr>
<td>• 46, 6% classic with 1 core</td>
<td>• 87.6% (n = 99) not have house warming</td>
<td>• 56.7% women</td>
</tr>
<tr>
<td>• 60% family income (Euros per month) 501-1000</td>
<td>• 13.7% (n = 16) no have bath or shower facility</td>
<td>• 52.1% married,</td>
</tr>
<tr>
<td></td>
<td>• 11, 1% (n = 13) no have toilet.</td>
<td>• 52.1% gradual dependency level,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 3.97 years of dependency</td>
</tr>
</tbody>
</table>
Results:

Dependency level

<table>
<thead>
<tr>
<th>Self-care Dependency</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requires assistive person</td>
<td>102</td>
<td>84.3</td>
</tr>
<tr>
<td>Requires assistive device</td>
<td>11</td>
<td>9.1</td>
</tr>
<tr>
<td>Dependent, does not participate</td>
<td>8</td>
<td>6.6</td>
</tr>
</tbody>
</table>
Results:

Family caregivers

- 10% families with dependent people
- 100 family caregivers, 81% women
- Average of 59,51 years
- 41,4% couple and 28,3% are daughters and sons
- 80,4% married
- Low level of education
Results:
Frequency of care provided by family caregivers

Frequência dos cuidados diários prestados pelo PC ao doente
Results:
Frequency of care provided by family caregivers

Frequência dos cuidados semanais prestados pelo PC ao doente
Results:
Frequency of care provided by family caregivers

Frequência dos cuidados mensais prestados pelo PC ao doente

- Aplica maquilhagem: 0
- Arranja as unhas: 2
- Leva a passear/sair de casa, na cadeira de rodas: 7
Percetível self-efficacy

Incompetence

low competence

middle competence

High competence
Conclusion:

- The types of families, as well as their socioeconomic status and type of accommodation are within in country normal range.

- Families are responsible for people who are very dependent, with significant changes in physical condition, who require instrumental care and professional support, including support for nursing.

- We need to focus on the preparation of family caregivers
Thank you

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