

# Morbidity in the Dependent Elderly Cared by Home-Teams of the National Network of Continued Integrated Care in the Lisbon and Tagus Valley: Cross-Sectional Study



## Morbilidade em Idosos Dependentes ao Cuidado das Equipas Domiciliárias da Rede Nacional de Cuidados Continuados Integrados na Região de Lisboa e Vale do Tejo: Estudo Transversal Observacional

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### ABSTRACT

**Introduction:** In Portugal, the National Network of Continuing Integrated Care's mission is to take care of new health and social needs. The aim of the study was to know the disease burden and disability of the elderly (75 and over) cared by the integrated continuing care teams.

**Material and Methods:** A cross-sectional study carried out in a sample of 230 participants, from 25 teams randomly selected in the region of Lisbon and Tagus Valley. Data were collected at the patient's home through caregiver's interviewing. The variables studied were: socio-demographic; disability determinants; degree (Barthel's scale) and duration of disability; morbidity (diagnoses, number and Charlson index).

**Results:** The study population had: on average 84 years; low or no scholar degree level (88.7%); on average 9.5 problems per person and a Charlson index of 8.48; disability over 42 months (severe in 65.2%). The most frequent disability-determinants were: dementia, stroke and femur fracture. The most frequent diagnoses were: osteoarthritis, hypertension and dementia.

**Discussion:** The results revealed a high disease burden (Charlson of 8.48) and disability. Although the diagnoses were those expected and comparable with the literature, their coexistence was universal, averaging 9.5 per person, affecting different organs/systems. Multimorbidity, coupled with severe disability, leads to clinical and organizational-care challenges, as well as the need for other population base studies.

**Conclusion:** The population cared by the integrated continuing care teams is at risk: elderly, with low scholar degree level, with a high disease-burden and disability.

**Keywords:** Aged, 80 and over; Frail Elderly; Homes for the Aged; Long-Term Care; Portugal

### RESUMO

**Introdução:** Em Portugal, a Rede Nacional de Cuidados Continuados Integrados tem como missão dar resposta às novas necessidades de saúde e sociais. Definiu-se como objetivo do estudo conhecer a carga de doença e de dependência dos idosos (75 e mais anos) ao cuidado das equipas de cuidados continuados integrados.

**Material e Métodos:** Estudo descritivo transversal, numa amostra de 230 participantes, distribuídos por 25 equipas na região de Lisboa e Vale do Tejo, aleatoriamente selecionadas. A colheita de dados decorreu no domicílio dos doentes por entrevista ao cuidador. As variáveis estudadas foram: sociodemográficas; determinantes de incapacidade; grau (escala de Barthel) e duração de dependência; morbilidade (diagnósticos, número e índice de Charlson).

**Resultados:** A população em estudo tinha: em média, 84 anos; baixa escolaridade (88,7%); dependência durante 42 meses, grave em 65,2%; em média, 9,5 diagnósticos por pessoa e um índice de Charlson de 8,48. Os determinantes de incapacidade mais frequentes foram: demência, acidente vascular cerebral e fratura do fémur. Os diagnósticos mais frequentes foram: osteoartrose, hipertensão e demência.

**Discussão:** Os resultados revelaram uma elevada carga de doença (Charlson de 8,48) e de dependência. Apesar dos diagnósticos serem os esperados e comparáveis com os dados da literatura, a coexistência de dois ou mais foi universal, em média 9,5 por pessoa, afetando diferentes aparelhos/sistemas. A multimorbilidade, a par duma elevada dependência, acarreta desafios clínicos e organizacionais, bem como a necessidade de estudos populacionais.

**Conclusão:** A população ao cuidado das equipas de cuidados continuados integrados é de risco: idosa, com baixa escolaridade, com elevada carga de doença e de dependência.

**Palavras-chave:** Assistência de Longa Duração; Avaliação Geriátrica; Comorbidade; Idoso Fragilizado; Idosos, 80 anos ou mais; Instituição de Longa Permanência para Idosos; Portugal

### INTRODUCTION

Global and European population is ageing and more people – especially women – live longer and beyond the age of 80. Since 2004, there are more people aged 65 and over than under the age of 15 in Europe.<sup>1</sup> Life expectancy and longevity in Portugal have been increasing, in line with the overall demographic ageing trend.<sup>2,3</sup>

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Older adults overall present with different chronic health conditions and none should be separately assessed or approached. Comorbidity and multimorbidity both correspond to the presence of 'any co-occurrence of more than one health condition within a patient' (Table 1). Supporters of the concept of multimorbidity tend to focus on primary healthcare practice in which the identification of one index disease may not always be obvious or even useful.<sup>4,5</sup> The concept of comorbidity has been used to give the awareness of disease burden, defined by the total burden of physiological dysfunction or by total illness burden with an impact on the individual.<sup>4</sup> According with the variability in the number and severity of comorbidities among elderly patients, age is inadequately used as a proxy for morbidity burden.<sup>6</sup> Charlson Comorbidity Index (CCI) is one of the most widespread instruments to measure disease burden, using morbidities with different impact on total morbidity burden (e.g. solid metastatic cancer = 6, diabetes with complications = 2) based on the relative risk of mortality.<sup>7</sup> CCI allows for the measurement of comorbidity (e.g. severe comorbidity = 3) and estimate mortality (e.g. 85% three-year mortality rate is estimated by a score  $\geq 5$ ).<sup>7</sup> However, multimorbidity, disease burden and patient complexity have not yet been clearly defined.<sup>4</sup>

Apart from morbidity, older patients suffer from a progressive decline in physical strength, walking speed, manual dexterity, memory and cognitive ability, even with no evident pathology (frailty).<sup>6</sup> Multimorbidity and frailty are overlapping concepts in elderly people, even though they are not interchangeable.<sup>8</sup> Frailty is 'a state of vulnerability' defined as a progressive loss of reserve and adaptive capacity associated with a general decline in health leading to disability, loss of independence, hospitalisation, excessive use of healthcare resources, admission to long-term care and death (Table 1).<sup>6,8,9</sup> These are complex patients frequently presenting with physical and mental morbidity, polypharmacy and social vulnerability in demand for a multidisciplinary primary healthcare (PHC) approach.<sup>8</sup> Despite the widespread use of the term 'frailty', there is no agreement on its definition nor on any specific instrument for an easy identification.<sup>9</sup> Frailty has been considered in one study as the loss of independence as measured by Barthel index and the presence of frailty was defined by a Barthel index score below 90 (mildly dependent).<sup>9</sup>

Data on elderly dependency rate are scarce and multiple measurement tools have been used, either measuring the dependency in the activities of daily living (i.e. feeding, dressing, walking) such as Barthel index<sup>10</sup> or including instrumental activities (i.e. cooking, using the phone, self-

management), such as the Lawton-Brody scale.<sup>11</sup> The prevalence and causes of dependency have been analysed in a population-based cross-sectional Japanese study using Barthel index<sup>12</sup> and a 20.1% dependency rate has been found, doubled with every 5-year increment in age (e.g. 4.9% between the age of 65 and 69 years, 9.7% between 70 and 74, up to 62.3% in the 85 plus age group) and was higher in women.<sup>12</sup>

Portugal has adapted to social and demographic changes as well as to social and healthcare needs with the development in 2006 and the maintenance from then onwards of the National Network of Long-term Integrated Care [*Rede Nacional de Cuidados Continuados Integrados* (RNCCI)] under the Ministry of Health and the Ministry of Labour and Social Solidarity.<sup>13-15</sup> This is a structure of inter-sectoral linkages between healthcare and social support, characterised by its decentralisation within different healthcare regions.<sup>13-17</sup> Healthcare and social support are ensured by different healthcare typologies including long-term integrated care multidisciplinary teams [*equipas de cuidados continuados integrados* (ECCI)];<sup>16</sup> it is assumed that patients in long-term care do not present with any criteria for being admitted to the hospital and have an adequate family and social support.<sup>15,16</sup>

After ten years of service of the RNCCI, the knowledge on disease burden of the patients in long-term care with the ECCI seems crucial. This study aimed at the identification of morbidities, determinants of disability, levels and duration of dependency of patients aged 75 and over in performing basic activities of daily living (Barthel index).

## MATERIAL AND METHODS

This was a cross-sectional, descriptive, analytical study involving interviews with caregivers. Due to feasibility reasons, the study focused on the region of Lisbon and the Tagus Valley and caregivers of patients looked after the ECCI were interviewed. The study population (n = 324,878) corresponded to patients aged 75 and over living in the area.<sup>18</sup> The sample size (n = 229) was based on this population and on the prevalence of multimorbidity (92%)<sup>19</sup> in this age group and the alpha level was set to 0.05. Due to the fact that participants could not be randomly selected as patients looked after the ECCI correspond to a dynamic population group, a two-stage sampling has been carried out in order to obtain a representative sample. Simple randomisation within the different ECCIs was carried out in the first stage, aimed at ensuring an adequate sample size. A total of 25 out of the 56 different operational ECCI were randomised, corresponding to 829 patients (long-term

Table 1 – Concept summary

<b>Multimorbidity</b>	Co-occurrence of more than one health condition within a patient
<b>Comorbidity</b>	Co-occurrence of more than one health condition within a patient, in which one is defined as the index disease
<b>Frailty</b>	State of vulnerability defined as a progressive loss of reserve and adaptive capacity associated with a general decline in health leading to disability

care capacity), considering the losses associated with ECCI bed occupancy rate (according with an estimated 60% occupancy rate) and compliance to the eligibility criteria. The second stage of sampling involved the inclusion of all eligible patients in long-term care with each team having accepted to participate in the study over the period of time planned for data collection.

The following eligibility criteria were defined:

- Inclusion:
  - Patients in long-term care with an ECCI;
  - Patients aged 75 and over;
  - Patients receiving care from unpaid caregivers
  - Patients accepting to participate in the study.
- Exclusion:
  - Patients who were institutionalised at the time of the interview;
  - Patients aged under 75; or
  - Whenever patient and caregiver were both illiterate.

Anyone with a personal (e.g. friends of neighbours) or family relationship and providing unpaid care to a patient was defined as an informal caregiver.

Caregivers were interviewed, in order not to restrict the identification of any morbidity to the patient’s physical illness.

Sociodemographic (age, gender, education level) and different variables related to the aims of the study were analysed, including (i) the determinants of disability (those that were associated with patient’s disability – dependency and need of support from a third person, identified by the caregiver), (ii) disability onset (from the moment when

disability has been identified), (iii) level of dependency (dependency in activities of daily living – Barthel index),<sup>10</sup> (iv) morbidity (Charlson Comorbidity Index)<sup>20,21</sup> and (v) each of the dichotomised problems, in addition to (vi) the most frequent health problems in the elderly<sup>22</sup> and the diagnoses that were described by caregivers in response to the item ‘others’.

The questionnaire was based on the abovementioned variables and a two-stage test of eligibility, comprehensibility and applicability has been carried out (12 participants in total, aged 47 to 79 with an education level between ‘illiteracy’ and ‘graduation’).

Data were collected at patient’s home, based on an interview carried out by the researcher with the patient’s caregiver during the ECCI visit or during a planned visit. Data collection was standardized through the application by the researcher of the same instrument to all the participants. Initially, an open-ended question addressed patient’s general health status and other diagnoses and both were subsequently coded according with the International Classification of Primary Care – 2<sup>nd</sup> version (ICPC-2)<sup>23</sup> in view of the context in which the study was carried out. Both the response to open-ended questions and clinical data on patient’s morbidities were confirmed through the analysis of patient’s therapy and from any available medical information (e.g. discharge summary of any other medical report).

Data were recorded on a Word file during the interview, then exported to an Excel spreadsheet and subsequently to SPSS, version 23 software.

Frequencies were analysed for nominal variables and

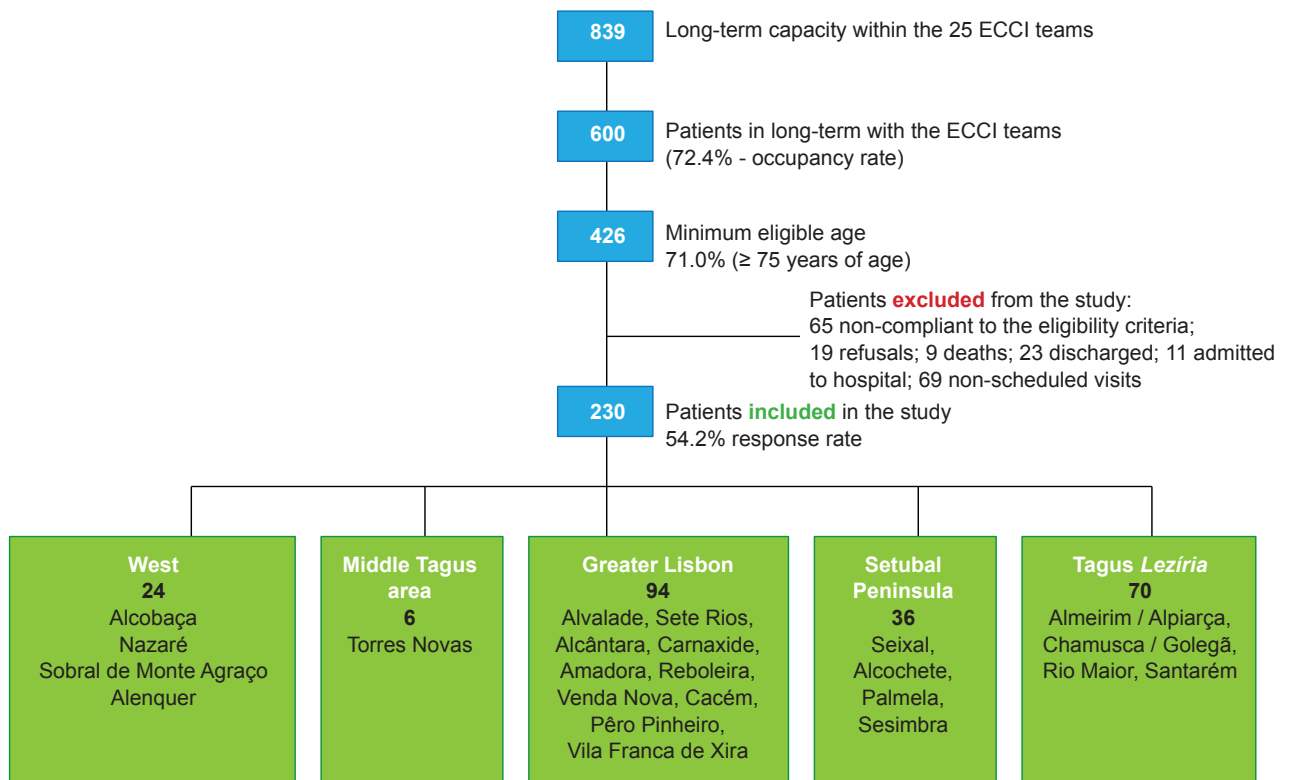


Figure 1 – Flowchart of patient compliance to eligibility criteria and patient distribution by regions

**Table 2** – Sociodemographic characteristics of the group of patients

Age	Mean
	83.59 years
Gender	Female (124) Male (106)
Education level	Frequency n (%)
Illiterate	56 (24.3)
Knows how to read and write	37 (16.1)
Primary	111 (48.3)
Lower and higher secondary	9 (3.9)
High school	12 (5.2)
Graduation	5 (2.2)

means with confidence intervals for numerical variables. The presence of any association between variables has been analysed by using Spearman's correlation coefficient, chi-square and Pearson's correlation coefficient.

The study was approved by the Ethics Committee of the ARSLVT and by the *Comissão Nacional de Proteção de Dados* (the Portuguese Data Protection Authority).

## RESULTS

Patient's compliance to the eligibility criteria is shown in Fig. 1, including the distribution of the 230 elderly patients in our group by regions (NUTS III).

Patient's sociodemographic characteristics are shown in Table 2. Minimum eligible age (75 and over) was met by 71% of the patients, in whom a mean age of 83.58 years was found, with female and low education level (basic education found in 48.3% and illiteracy in 40.4% of the patients) predominance. Thirty four elderly patients (14.8%) lived alone.

Caregivers were asked about the patient's chronic health condition that they identified as the cause for patient's disability (dependency and need for support from a third person) and about patient's disability onset. The

determinants of disability and their onset were identified (Table 3); stroke, femur fracture and dementia were the most frequently found and ten determinants of disability corresponded to more than two thirds (74.3%) of all the reasons for dependency described by caregivers. The determinant '*deixou de andar*' ('lost the ability to walk') (12.2%) was described by caregivers as the cause for disability, even though it was not included into any nosological entity.

Total dependency in non-instrumental activities of daily living was found in 53.9% of the participants (as per Barthel index) and severe to total dependency in 65.2% (Table 4). Mean dependency duration of 42.0 months [95% CI: 33.6 – 50.4] has been found, with a significant association ( $p < 0.05$ ) between duration and level of dependency. Mean score of 32.4 [95% CI: 27.9 – 36.9] has been found when using Barthel index, with a significant gender difference ( $p < 0.05$ ) regarding total dependency, which was higher in men. A significant association has been found between total dependency and patient's age ( $p < 0.05$ ). Significant differences regarding dependency were found between the different regions ( $p < 0.05$ ) and dependency was higher in Greater Lisbon and in the *Lezíria* (OR = 1.1) and lower in the Setubal Peninsula and in the West (OR 0.9 and 0.7, respectively).

Osteoarthritis and high blood pressure were the most frequently found health conditions, as shown in Table 5. Gender differences were found and higher frequency of osteoarthritis, osteoporosis and chronic skin ulcer was found in women. High blood pressure, cerebrovascular disease, non-metastatic cancer and chronic obstructive pulmonary disease (COPD) were more frequently found in men. A significant gender difference has been found ( $p < 0.05$ ) regarding cerebrovascular disease, osteoporosis, COPD, chronic skin ulcer and non-metastatic cancer. Circulatory, psychological, musculoskeletal, endocrine, metabolic & nutritional and neurological were the most frequently systems affected [K;P;L;T;N]. The neurological

**Table 3** – Most frequent determinants of disability, per gender

Determinants of disability <sup>a</sup>	ICPC2	F	%	M	%	Total	%
Stroke	K90	19	15.3	27	25.5	46	20.0
Femur fracture	L75	23	18.5	7	6.6	30	13.0
Other musculoskeletal disorders (lost the ability to walk)		18	14.5	10	9.4	28	12.2
Dementia	P70	14	11.3	13	12.3	27	11.7
Chronic skin ulcer	S97	8	6.5	7	6.6	15	6.5
Cancer		4	3.2	6	5.7	10	4.3
Limb amputation	L98	4	3.2	4	3.8	8	3.5
Traumatic brain injury	N80	5	4.0	1	0.9	6	2.6
Parkinsonism	N87	2	1.6	4	3.8	6	2.6
Heart failure	K77	2	1.6	3	2.8	5	2.2
Other fractures	L76	2	1.6	2	1.9	4	1.7
Knee osteoarthritis	L90	2	1.6	1	0.9	3	1.3

<sup>a</sup> In total, 39 determinants of disability were described

Table 4 – Frequency of dependency in activities of daily living per gender and age group

Barthel index (score)	Gender		Total (%)	Age group				
	F	M		75 - 79	80 - 84	85 - 89	90 - 94	95 - 99
Total dependency (0 - 25)	75 (60.5)	49 (46.2)	124 (53.9)	30 (44.8)	34 (50.7)	32 (58.2)	18 (64.3)	10 (76.9)
Severe dependency (26 - 50)	9 (7.3)	17 (16.0)	26 (11.3)	8 (11.9)	8 (11.9)	7 (12.7)	2 (7.1)	1 (7.7)
Moderate dependency (51 - 75)	19 (15.3)	22 (20.8)	41 (17.8)	17 (25.4)	13 (19.4)	6 (10.9)	5 (17.9)	0 (0.0)
Mild dependency (76 - 99)	19 (15.3)	17 (16.0)	36 (15.7)	11 (16.4)	11 (16.4)	9 (16.4)	3 (10.7)	2 (15.4)
Autonomy (100)	2 (1.6)	1 (0.9)	3 (1.3)	1 (1.5)	1 (1.5)	1 (1.8)	0 (0.0)	0 (0.0)
Total	124 (100)	106 (100)	230 (100)	67 (100)	67 (100)	55 (100)	28 (100)	13 (100)

Table 5 – The 20 leading health conditions coded according with the ICPC2 list

	Female (%)	Male (%)	Total (%)
Osteoarthritis (L89 to L91)	99 (79.8)	76 (71.7)	175 (76.1)
High blood pressure (K86 to 87)	83 (66.9)	83 (78.3)	166 (72.2)
Dementia (P70)	82 (66.1)	62 (62.3)	148 (64.3)
Stroke (K91)	52 (41.9)	62 (58.5)	114 (49.6)
Sleep disorder (P06)	62 (50.0)	42 (39.6)	106 (45.2)
Peripheral vascular disease (K92)	51 (41.1)	49 (46.2)	100 (43.5)
Depressive disorder (P76)	42 (33.9)	48 (45.3)	90 (39.1)
Osteoporosis (L95)	64 (51.6)	25 (23.6)	89 (38.7)
Heart failure (K77)	42 (33.9)	37 (34.9)	79 (34.3)
Anxiety disorder (P74)	45 (36.3)	32 (30.2)	77 (33.5)
Diabetes (T89 and 90)	39 (31.5)	36 (34.0)	75 (32.6)
Chronic skin ulcer (S97)	36 (29.0)	18 (17.0)	54 (23.5)
Lipid disorder (T93)	24 (19.4)	22 (20.8)	46 (20.0)
Obesity (T82)	24 (19.4)	21 (19.8)	45 (19.6)
Peptic ulcer (D85 and 86)	17 (13.7)	24 (22.6)	41 (17.8)
Non-metastatic cancer	14 (11.3)	25 (23.6)	39 (17.0)
Chronic obstructive pulmonary disease (R95)	7 (5.6)	27 (25.5)	34 (14.8)
Cardiac arrhythmia (K80)	13 (10.5)	16 (15.1)	29 (12.6)
Pain general / multiple sites (A01)	12 (9.7)	9 (8.5)	21 (9.1)
Atrial fibrillation / flutter (K78)	10 (8.1)	10 (9.4)	20 (8.7)

system should be mentioned, as none of the neurological diseases has been on the 20 best ranked diagnoses and the presence of hemiplegia, epilepsy and parkinsonism were the most frequently described.

Multimorbidity was present in all the patients (Fig. 2) with a 9.5 average number of chronic health conditions per patient [95% CI: 9.1 – 9.9], nine in women and 10 in men, with a confirmed correlation with patient's gender ( $p < 0.05$ ). An 8.48 average CCI score has been found [95% CI: 8.14 – 8.83; 7.96 in female [95% CI: 7.5 – 8.42] and 9.09 in male patients [95% CI: 8.59 – 9.6], showing a significant difference as explained by the confidence intervals per gender.

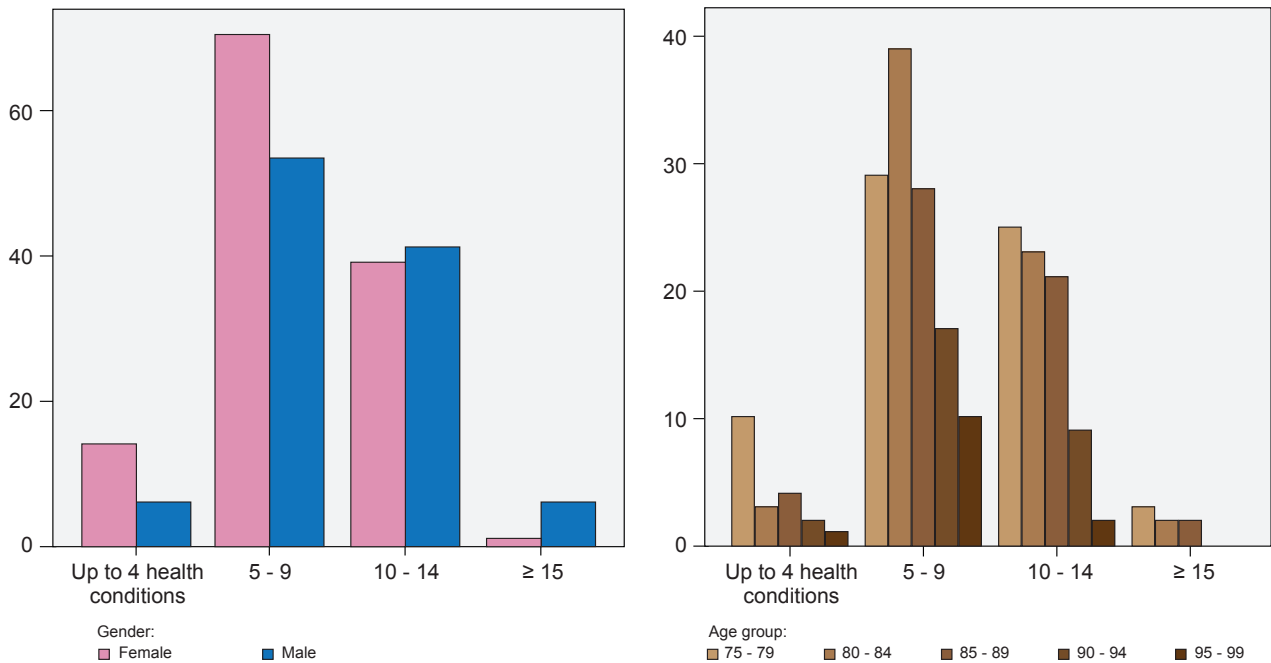
No significant association has been found between patient's age (Fig. 2) and the number of chronic health

conditions, with a lower number of health conditions found in the oldest age groups [9.46 (75-79); 9.75 (80-84); 9.96 (85-89); 8.71 (90-94); 7.92 (95-99)].

## DISCUSSION

The different ECCI within the RNCCI look after a very aged population, shown by a 71% percentage of participants meeting the minimum eligible age (patients aged 75 and over) (Fig. 1), with a female predominance, in line with what has been found in Europe.<sup>24,25</sup> Mean age of the participants was 83.59 years, 88.7% had a low education level (40.4 % were illiterate and 48.3% had basic education) and around 15% of the patients lived alone. The education level is considered as an economic indicator,<sup>26</sup> even though this group predominantly included female and elderly patients





**Figure 2** – Multimorbidity per gender and age group

Mean of 9,5 chronic health conditions was found [95% CI: 9.1 – 9.9] per patient, higher in men and showing a significant gender correlation ( $p < 0.05$ ). A non-significant correlation between multimorbidity and patient's age was found.

Mean CCI score of 8.48 [95% CI: 8.14 – 8.83] was found; 7.96 CCI score [95% CI: 7.50 – 8.42] was found in female, lower to what was found in male patients: 9.09 [95% CI: 8.59 – 9.60].

and therefore, due to social and cultural reasons, it cannot be considered at the lowest social stratum. In our group, 53.9% of the participants were total-dependency and 65.2% were severe to total-dependency patients (Table 3). These results are in line with the European data showing that increased life expectancy did not necessarily led to an increase in the number of healthy life years, rather leading to a remaining lifetime with functional impairment or disability.<sup>25</sup> The percentage of dependent patients in our study is higher when compared to the population-based Japanese study (20.1%),<sup>12</sup> which can be explained by the inclusion criteria adopted for our study (patients aged 75 or over, with their own caregiver and in long-term care provided by an ECCI team. Significant associations ( $p < 0.05$ ) were found between patient's gender, age and severity of dependency, assigning a high degree of internal validity to the results.

The fact that the 'lost the ability to walk' item has been described by caregivers as a determinant for disability explaining for the dependency and the need for the support from third persons was surprising. However, when considering the frailty phenotype of the elderly patients (weight loss, tiredness, weakness, low physical activity and mobility disability)<sup>6,27,28</sup> and considering the presence of non-cognitive signs and symptoms of dementia (gait and balance abnormalities),<sup>29,30</sup> the results seem to show the coexistence of a decline in patient's motor function and ageing and / or dementia (age-related cognitive decline).<sup>31</sup> Walking was considered as an automatic motor task, even though the emergent evidence suggests that it is a complex activity requiring physical (e.g. musculoskeletal, vascular, endocrine), memory and motor abilities including body

balance and coordination.<sup>29,31,32</sup> The complexity of motor changes in the elderly can be measured: step frequency, gait speed or multitasking (e.g. walking while talking).<sup>33</sup> Age-related changes, including decreased muscular strength, sarcopenia and sensorial changes (e.g. proprioception, vision and hearing) have an impact on patient's postural control.<sup>32</sup> The presence of gait abnormalities can help the identification of the risk for mobility decline, falls and progression to dementia. The reverse is also true: changes in mobility can be delayed and the risk of fall can be reduced in patients with cognitive impairment with specific training of the attention and executive function.<sup>31,32</sup> If the 'lost the ability to walk' item is considered as a non-cognitive manifestation of dementia, the signs and symptoms of dementia can be assumed as the most frequent cause for disability, as recognized by caregivers (24.9%).

Fractures are becoming one of the most prevalent health problems in ageing population.<sup>34</sup> Fractures have been considered as a public health issue due to the negative impact on patient's physical and mental health and to the contribution for morbidity burden, mortality and the need for healthcare.<sup>34</sup> Osteoporosis is a well-known risk factor potentially increasing vulnerability to fractures when associated with the frailty syndrome in elderly patients. In a systematic revision, despite involving different heterogeneous studies, patients classified as frail were found to have an increased risk of fracture when compared to non-frail patients.<sup>34</sup> However, the precise mechanisms underlying the association between frailty and an increased risk of fracture are not well known and this association is usually considered as complex and multifactorial.<sup>34</sup> Femur

fracture (13%) and traumatic brain injury (2.6%) were identified in the study as determinants of disability, reflecting the risk of fall, in addition to gait abnormalities.

The results regarding the causes for disability [dementia (23.9%), stroke (20%) and fractures (13%)] are in line with those found in the Japanese study (23.5%, 24.7% and 12.9%, respectively).<sup>12</sup>

The most frequent chronic health conditions are shown in Table 5 and were in line with other studies carried out under different contexts (community or hospital-based),<sup>22,35,36</sup> regardless of the patient's age.<sup>37,38</sup> Within each body system, the most frequent problems found in our group of patients were in line with those found by another community-based study on disease burden carried out in the UK and involving elderly patients.<sup>39</sup> Data from the EUROSTAT have confirmed high blood pressure, osteoarthritis and diabetes as the most frequent problems in outpatient settings.<sup>40</sup> Our results were also in line with the European data: high blood pressure, stroke, dementia, osteoarthritis, osteoporosis, diabetes, epilepsy and parkinsonism.<sup>40</sup>

Chronic skin ulcer is among the five leading causes for dependency and is among the 12 most frequent diagnoses (23.5%) found in our group, in line with the results found in a prevalence study carried out in a long-term care unit.<sup>35,41</sup> COPD is also among the 20 most frequent problems and a significant association has been found with male gender, in line with literature.<sup>42</sup>

The frequency of dementia (64.3%) and depression (39.1%) found in our group of patients should be mentioned with the analysis of Table 5. Considering that data collection has been supplemented with therapy, a potential over-record may have existed due to the maintenance of the antidepressant therapy. When compared to literature, depression is confirmed as being frequent in dementia in all stages (20 to 30%)<sup>43</sup> and higher in vascular dementia (42.9%).<sup>43</sup>

A high disease burden has been found in this study, shown by a mean number of 9.5 chronic health conditions per patient [95% CI: 9.1 – 9.9] and by an 8.48 CCI score [95% CI: 8.14 – 8.83]. As shown in Fig. 2, an association between disease burden (number of chronic health conditions) and male gender has been found, unlike what was found in literature.<sup>44,45</sup>

A difference between age groups has been found in population-based studies, showing higher multimorbidity in the elderly patients.<sup>45</sup> As only elderly patients were involved in our study, no difference has been found between age groups and multimorbidity seemed to be lower in the group of the oldest patients (aged 90 or above). These data reinforce the need to question patient's age as a proxy of disease burden in the population.<sup>6</sup>

In our study, the patients living longer seemed to show lower multimorbidity (number of chronic health conditions), even though these were more dependent. A Swedish study involving a population aged 60 and over was aimed at the assessment of age-related differences in physical performance and at the identification of differences related

to multimorbidity. Multimorbidity was associated with poorer physical performance, particularly in younger men and explained for only part of age-related differences.<sup>46</sup> The apparently lower multimorbidity in the oldest patients, in addition to higher age-related dependency should deserve a relevant reflection and further studies should be carried out to clarify the borderline between multimorbidity and frailty and /or dependency in the oldest patients.

The results of the study showed its internal coherence, one example being the association between severity and duration of patient dependency, between age and severity of patient dependency and its external coherence was shown by the abovementioned similarities with literature. The following limitations should be mentioned:

- Sample size and its representativeness, particularly as regards the oldest patients aged over 90;
- Identification of patient health conditions (based on caregiver's description, even though supplemented with therapeutic and medical information);
- The use of Barthel index, not including any instrumental activity.

Some distinctive aspects of the study should be mentioned:

- The results corresponded to outpatient data obtained from long-term home care teams within the RNCCI;
- Elderly patients were included in the study (aged 75 and over), excluded from the Health National Survey (*Inquérito Nacional de Saúde*) based on a medical examination<sup>37</sup> and included in literature into the group of patients aged 65 or over, or into non-disaggregated data of patients over the age of 85;
- Disease burden has been characterised in an outpatient setting by using CCI and the concept of multimorbidity.

The oldest patients aged 90 or over were found to have lower number of chronic health conditions, which will claim for further studies. Disease burden and multimorbidity are in need for research.<sup>47</sup> The knowledge on disease burden and dependency in the elderly population in long-term care with the ECCI will be useful for a reflection on the adequate healthcare organisation model and subsequent resource allocation.

A further population-based study would be very relevant for the assessment of morbidity and dependency of the Portuguese elderly patients. This elderly population, with high multimorbidity and dependency, with no criteria for admission to the hospital, is challenging both clinically (e.g. individual applicability of the available evidence) and for the organisation (e.g. home-based long-term care services).

## CONCLUSION

The study population in long-term care with the ECCI mostly involved elderly patients (mean age of 83.59), showing high disease burden (mean number of 9.5 chronic health conditions per patient and an 8.48 Charlson Comorbidity Index score) and dependency (65.2% severe to total-dependency patients). Stroke, femur fracture and dementia were the most frequent determinants of disability. The most frequent pathologies reflected the leading (osteoarthritis

and high blood pressure) and age-related (dementia) pathologies in the population. Multimorbidity, related to the high level of dependency and affecting different systems, is challenging both clinically (e.g. applicability of the evidence) and for the organisation (e.g. home-based long-term care services).

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## HUMAN AND ANIMAL PROTECTION

The authors declare that the followed procedures were according to regulations established by the Ethics and Clinical Research Committee and according to the Helsinki Declaration of the World Medical Association.

## DATA CONFIDENTIALITY

The authors declare that they have followed the protocols of their work centre on the publication of patient data.

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The authors declare that there were no conflicts of interest in writing this manuscript.

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