



National School of Public Health

NOVA UNIVERSITY LISBON

The National Network for Long-Term Care in Portugal

Assessing the characteristics and the outcomes of the nursing homes and home and community based-services' beneficiaries

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Assessing the characteristics and the outcomes of the nursing homes and home and community based-services' beneficiaries

This thesis is presented as part of the requirements for the Degree of Doctor of Public Health, under supervision of Prof. Céu Mateus and Prof. João Pereira

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In honour of Margarida Bentes (1956-2009)

There are people whose wisdom, experience and eloquence, or just the sympathy and affection they transmit to those around them, can fill an entire room. Such a person was Margarida Bentes, to whom I dedicate this work. It was an honour and a privilege daily to work and learn with her, who had the gift of making each one of us the best we could be. Her early disappearance has undoubtedly left an unfillable gap in the Portuguese Healthcare sector.

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Abstract

Background: The Portuguese National Network for Long-term Care (RNCCI) was formally created in 2006. The main goals of this work are to assess the reform of the RNCCI and to compare the long-term care (LTC) delivered through Home and Community-Based Services (HCBS) with care provided in the three Nursing Homes (NH) units, by identifying their main characteristics, the outcomes after treatment and the main predictors of length of care (LOC).

Data Source: Extracted from the LTC monitoring system, the dataset contained the records of 20,984 people aged ≥ 60 years, admitted and discharged in 2015 in mainland Portugal.

Methods: Firstly, we assessed the evolution of the main features of LTC reform in Portugal, identified its strengths, weaknesses and the main challenges ahead. Then, in order to identify the main risk factors on the likelihood of a person receiving care in each care setting, we used odds ratios and marginal effect. Thirdly, we used the Cox Proportional Hazards Model and ordinal logistic regressions to assess, respectively, mortality and patients' outcomes after treatment. Finally, the General Linear Model was performed to assess the influence of patients' dependence levels on their LOC.

Results: Despite regional asymmetries in the provision of care, the creation of the RNCCI filled a gap in the National Health Service. Secondly, after adjusting for several variables, there are differences in the numbers of people correctly referred to each care setting. Then, most people present no changes in their cognitive and physical status after treatment. Finally, LOC is mostly influenced by the to which setting patients are admitted.

Conclusions: Although the full implementation of the RNCCI was planned to be concluded over a 10-year period, public spending financial constraints have slowed its development since 2011. Thus, given the scarcity of resources, it is vital to adopt a robust, comprehensive assessment tool to ensure that the provision of care is tailored to each person's needs.

Keywords: Portuguese; Nursing Homes; Home and Community-Based Services; Dependency levels; Outcomes; Length of Care.

Resumo

Contexto: A Rede Nacional de Cuidados Continuados (RNCCI) foi formalmente criada em 2006. Os principais objetivos deste trabalho são avaliar a reforma da RNCCI e comparar os cuidados continuados (LTC) prestados através de Cuidados Domiciliários (HCBS) com cuidados prestados em três unidades de internamento (NH), através da identificação das suas principais características, *outcomes* após os cuidados e os principais preditores da duração de cuidados (LOC).

Fonte de dados: Utilizando o sistema de monitorização dos LTC, a base de dados contém registos de 20,984 indivíduos com idade ≥ 60 anos, admitidos e com alta em 2015 em Portugal continental.

Métodos: Primeiro, avaliámos a evolução das principais características da reforma dos LTC em Portugal, identificámos os seus pontos fortes, fracos e principais desafios. Posteriormente, para identificar os principais fatores de risco na probabilidade de um indivíduo receber cuidados em cada tipologia de cuidados, foram calculados os *odds ratios* e efeitos marginais. Terceiro, utilizámos o modelo *Cox Proportional Hazards* e Regressões Ordinais para avaliar, respetivamente, a mortalidade e *outcomes* dos doentes após tratamento. Finalmente, o *General Linear Model* foi utilizado para avaliar a influência dos níveis de dependência dos doentes na sua LOC.

Resultados: Apesar das assimetrias regionais na prestação de cuidados, a criação da RNCCI preencheu uma lacuna no Serviço Nacional de Saúde. Segundo, após o ajustamento de diversas variáveis, existem diferenças no número de indivíduos corretamente referenciados para cada tipologia de cuidados. Posteriormente, a maioria dos indivíduos não apresenta alterações no seu estado cognitivo e físico após o tratamento. Finalmente, a LOC é principalmente influenciada pela tipologia onde os pacientes são admitidos.

Conclusões: Embora a implementação total da RNCCI tenha sido planeada para ser concluída num período de 10 anos, as restrições financeiras sobre os gastos públicos em vigor desde 2011 contribuíram para diminuir o seu desenvolvimento. Assim, dada a escassez de recursos, é vital adotar uma ferramenta de avaliação robusta e completa para garantir que a prestação de cuidados seja adaptada às necessidades de cada pessoa.

Palavras-chave: Portugal; Cuidados institucionalizados; Cuidados domiciliários; Níveis de dependência; *Outcomes*; Duração dos cuidados.

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List of abbreviations

ACES - Primary Care Trusts

ACSS - Central Administration of the Healthcare System

ADL – Activities of daily living

ARS - Regional Health Administrations

ECCI – Integrated Continuous Care Teams

ECL – Local Coordination Teams

ECR – Regional Coordination Teams

EGA – Discharge Management Teams

HCBS – Home and Community-Based Services

IADL – Instrumental activities of daily living

IPSS – Private Institutions of Social Solidarity

LOC – Length of care

LTC – Long-term care

MAB – Bio-psychosocial Assessment Instrument

MMSE – Mini-Mental State Examination

NH – Nursing Homes

NHS – National Health Service

NUTS – Nomenclature of Territorial Units for Statistics

OECD – Organisation for Economic Co-operation and Development

PRO – Patient-Reported Outcomes

PROM – Patient-Reported Outcome Measures

RNCCI – National Network for Long-term Care

UC – Convalescence Units

UCP – Palliative Care Units

ULDM – Long-Term and Maintenance Units

UMCCI – Mission Unit of Integrated Continuous Care

UMDR – Medium-Term and Rehabilitation Units

WHO – World Health Organisation

1. INTRODUCTION

In the years to come, the age structure in most advanced industrial societies will be unlike anything that has been witnessed in the history of mankind (1,2). According to the World Health Organisation (WHO), it is predicted that by 2050 there will be 2 billion people over 60 years old, meaning that this group's proportion of world population will have increased from 12% to 22% between in 2015 and 2050 (3).

Portugal, and the EU-28, are no exceptions. Based on projections made by Eurostat (2018), it is estimated that between 2010 and 2060 the number of people aged 65 and over will increase by 73% in Portugal and 75% in the EU-28, reaching in both cases 30% of the total population (4). The number of people aged 85 or over is likely to increase by 4 times (from 0.20 million in 2010 to 0.76 million in 2060) in Portugal and by 3.5 times (from 10.36 million in 2010 to 36.85 million in 2060) in EU-28, in the same period. In addition, the old-age dependency index for Portugal, and for the EU-28 countries, is projected to show annual increases of 6.1% and 4.4%, respectively, rising, in each case, to 0.7 and 0.5 elderly people per working-age person (4).

Until recently, 65 years was the point when it was assumed one entered old age, i.e., passed from work to retirement. But our perception of what it means to be "old" has now changed (5). We now have three categories: there are the "young-old" who, despite having reached the official retirement age of 65, continue to live a vigorous and productive life; the "old-old" who, although they have begun to slow down, still have a relatively healthy and active life; and, finally, we are beginning to talk about of the "oldest", those aged 85+, who tend to be partially or totally dependent on others.

These new labels and terms are related less to chronological age *per se* than to a person's physical and mental condition. Thus, the main defining feature of our time seems to be that we are older for a longer period, and more vigorous in old age, than was once possible. At the same time, though, we are more likely to suffer prolonged periods of disability and dependency.

Consequently, these demographic changes and the concomitant increase in chronic diseases and new patterns of growing morbidity and functional restrictions (1,2), will necessitate policies that encourage the coordination of the healthcare, social support and *continuum* care sectors as a whole.

1.1. Defining Long-Term Care

Since the term 'Long-Term Care' (LTC) refers to a myriad of services designed to provide assistance over prolonged periods (6,7), its definition, and the way in which services are categorised, vary between international entities such as the WHO, the Organisation for Economic Cooperation and Development (OECD) and the European Commission.

For the WHO (2002), LTC includes activities intended for people unable to care for themselves fully in the long term, and is provided by informal caregivers (e.g. family and friends), formal professional providers or volunteers (8). These services include personal care (e.g., bathing and personal hygiene), home chores (e.g., preparing meals or housekeeping), management of daily life tasks (e.g., shopping, taking medication or transportation), assistive devices (e.g., wheelchairs), or home improvements (e.g., ramps or handrails). More recently, the WHO report on ageing and health (2015), defines the term LTC as "the activities undertaken by others to ensure that people with or at risk of a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity" (3).

The OECD, on the other hand, defines LTC as a cross-cutting sector which includes a wide range of services to people who are help dependent for a long period, in the ability to perform Activity(ies) of Daily Living (ADL) and/or Instrumental Activity(ies) of Daily Living (IADL) (9). These activities include rehabilitation, basic medical services and social care, or other services such as transportation, meal preparation, occupational and education, either for the beneficiaries or their relatives. In 2011, the OECD offered another definition, describing this sector as a set of services required by people with reduced functional, physical or cognitive capacity, who consequently become dependent on help in performing ADL for long periods of time (10). These personal care services are often provided by a combination of several basic services, such as medical, nursing, rehabilitation and palliative care.

For the European Commission, the term LTC covers various health and social services usually provided to people with some kind of physical or mental disability, to elderly who are in a fragile situation and specific groups that need help in their ADLs (11).

Given these slight differences, there is no consensus at the international level on the definition of LTC, types of support, organisational models, policies relating to access and key factors needed to ensure its sustainability (6). Moreover, the differences between the health and social support policies adopted by each country make it difficult to establish parameters by which international comparisons can be made, whether in terms

of concepts, organisational or financing models, but especially the assessment of the quality of care.

Nevertheless, it is common to all the definitions that LTC includes hands-on, direct care and general supervisory assistance to a frail population. Moreover, the type, frequency, and intensity of services may vary according to people's needs, with some needing assistance a few times a week, others full-time support.

1.2. Care settings

Often, the provision of LTC services is associated with two main settings (6,7): institutional, known as Nursing Homes (NH), and non-institutional, known as Home and Community-Based Services (HCBS).

The NH are institutional facilities offering 24-hour room and board, supervision and more intensive nursing care. Usually, services include some or all of personal care, support in performing daily living, nursing, medical and medication management, physical rehabilitation (either as a short-term service followed by a hospital discharge or as maintenance rehabilitation), social activities and transportation. In the HCBS, although care is usually provided in the person's home, it may also be in community settings such as adult day care or adult day health centres. Even though the services provided may be similar to those in NH, they also include home-delivered meals, home reconfiguration or home renovation.

According to the authors of the Portuguese National Health Plan, "it is important to recognise that in Portugal there is little evaluation of the quality of care and its variability. Even in major reforms, there is no culture of assessing their impact. Important changes such as [...] Long-term Care Units have hardly been evaluated, or if it happened, it has been very inadequate" (12). As success in any organisation goes hand in hand with transparency, measuring it and sharing results, are both essential. For most commercial companies, success can be measured by the revenues received over the years. In the healthcare sector, one major measure of "success" is patients' outcomes. However, given the difficulty of defining and distinguishing between outcomes accurately, using this measure of success becomes more a challenging and complex task.

True, there is broad agreement among stakeholders involved in the care delivery process (e.g. policy makers, staff, patients, caregivers and society) on the importance of defining the dimensions and metrics of assessment. But there has for some years been, according to Porter and Teisberg (2006), too much attention paid to measuring and

controlling health care expenditures, and not enough to measuring the main concerns of this sector: the adequacy of care and its impact on patients' quality of life (13).

1.3. Thesis structure

The present work, therefore, aims to address some of these issues and to contribute to a better understanding of this new and increasingly important field. In order to do so, it fills some important gaps in the literature regarding the provision of LTC in Portugal. Thus, it assesses for the first time the reforms undertaken since 2006 by identifying the main achievements and the challenges ahead; it investigates, using the entire LTC national database, the extent to which the populations of each care setting differ from each other; it assesses patients' outcomes after treatment; and, it assesses the influence of people' dependency levels at admission on their length of care.

This thesis has nine chapters:

- **Chapter I: Introduction**, identifies some of the main definitions of LTC by different international entities and characterises the main LTC care settings;
- **Chapter II: Background**, offers a comprehensive analysis of the main characteristics of the National Network for Long-Term Care reform in Portugal, and identifies the main risk factors for LTC admission and the expected outcomes mentioned in the literature for institutional and non-institutional populations;
- **Chapter III: Objectives**, describes the primary and secondary goals of the thesis;
- **Chapter IV: Data Source**, describes the database, the care settings and the numbers of patients included in the empirical analyses;
- **Chapter V: Results**, presents the papers produced during this thesis;
- **Chapter VI: Conclusions**, summarises the key findings of each paper and identifies some of the pathways of change;
- **Chapter VII: Further investigation**, identifies some topics of investigation that will be useful in the further development of long-term care in Portugal.

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2. BACKGROUND

Until recently, elderly people with chronic illness and/or in situations of physical/cognitive dependency often ended up being hospitalised for a long period, receiving care they did not need and taking up acute beds that could be used by those who really needed this type of care.

The philosophy behind the 'continuum of care' is that after the acute problems have been treated, those in need of rehabilitation, readjustment and/or reintegration, should be referred to specific units that provide continuous care more efficiently in resource terms and, at the same time, more effectively in terms of patient outcomes.

To meet these new challenges, it is essential to develop a new organisational model. Thus, the Integrated Continuous Care (in Portuguese, *cuidados continuados integrados*) model is becoming a fundamental tool in all developed countries for improving efficiency in healthcare organisations and ensuring the link between the Healthcare and the Social Support sectors. Thus, based on this premise, the LTC system was created.

In this context, the next part of this chapter aims to provide an overview of the Portuguese National Network for Long-term Care (*Rede Nacional de Cuidados Continuados Integrados*, RNCCI) reform since its inception in 2006, taking into account a number of core dimensions: background, target population, coordination, ownership, organisational structure, financing system, placement process and treatment places.

2.1. The Portuguese National Network for Long-Term Care

In Portugal, LTC is understood to be "the series of health and/or social support interventions which, due to joint evaluation, focus on global recovery understood as the process of therapeutic and social support, active and ongoing, which aims to promote autonomy, improving the functioning of the person in a situation of dependency, through rehabilitation, readaptation and reintegration into the family and social life" (16).

The provision of care defined by the RNCCI has a multidimensional design encompassing prevention, rehabilitation, re-adaptation and social reintegration services. Its main goals are preventing, reducing and delaying disability in order to promote the inclusion of people with functional dependency in the community and providing support in prevention measures and health education (16).

2.1.1. Context

As with other substantial reforms of healthcare systems, the Portuguese LTC system experienced advances and retreats during the evolution of the model we know today. Following the adoption of the new policies required for the reconfiguration of the system of health and social care necessitated by these new challenges, several historical milestones were passed and partnerships formed, culminating in the formal creation of the current RNCCI.

A mandatory social insurance health system for workers - the *Caixa de Previdência* - was initiated in 1946 and the NHS was created in 1979 with the aim of ensuring universal coverage and free access to healthcare (17,18).

In 1983, the new statutes of the private non-profit institutions called Private Institutions of Social Solidarity (*Instituições Particulares de Solidariedade Social*, IPSS) were approved (19), with the *Misericórdias* (religious non-profit-making institutions with a charitable background) being the main providers. Since then, several cooperation and financial agreements with the state have been established through the Ministry of Labour and Social Solidarity, which is considered a strategic partner in the provision of social care services (20). The main services provided by the IPSS include institutional care, day centres and the Domiciliary Support Service which provides hygiene, nursing, transportation, meals and laundry services to people at home (17,21).

Due to the increasing number of dependent people, and based on the work developed from 1983 with the IPSS, the RNCCI was launched in 2006 as a partnership between the Ministry of Health and the Ministry of Labour and Social Solidarity (16), largely using the existing institutions.

The full implementation of the RNCCI was planned to occur over a period of 10 years. During this period, three stages were defined, leading to the required coverage ratio of number of beds per 1,000 inhabitants aged ≥ 65 years (**Table 1**) (22):

- Stage I (2006-2008): expand the pilot schemes and consolidate the planning, management and assessment features of the RNCCI. Goal: reach 30% of national coverage;
- Stage II (2009-2012): develop the information systems to enable the collection and comparison of results between Units. Goal: reach 60% of national coverage;
- Stage III (2013-2016): consolidate and stabilise the care model. Goal: reach 100% coverage of the total mainland population.

Table 1: Coverage ratios defined for each stage

	Stage I (2006 - 2008)		Stage II (2009 - 2012)		Stage III (2013 - 2016)	
Care setting ¹	Total beds	Beds per 1,000 inhab. aged ≥65 years	Total beds	Beds per 1,000 inhab. aged ≥65 years	Total beds	Beds per 1,000 inhab. aged ≥65 years
Nursing Homes						
UC	977	0.6	1,954	1.2	2,931	1.8
UMDR	1,139	0.7	2,117	1.3	3,257	2.0
ULDM	2,720	1.67	5,374	3.3	8,143	5.0
UCP	326	0.2	651	0.4	977	0.6
HCBS (number of teams)	363	1 in each primary care centre	363	1 in each primary care centre	363	1 in each primary care centre

Legend: UC: Convalescence Units; UMDR: Medium Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units; UCP: Palliative Care Units; HCBS: Home and Community-Based Services.

Source: Monitoring report of the RNCCI pilot schemes (22)

2.1.2. Beneficiaries

According to national law, the RNCCI aims "to provide integrated continuous care to people, regardless of age, who are in a situation of dependency" (16). Despite the target population being the elderly, everyone suffering the loss of physical or cognitive autonomy, or requiring continuous health monitoring and social support, is entitled to receive LTC in Portugal. Thus, according to the Portuguese law, the main target groups include (16):

- People with functional dependency;
- People with progressive chronic diseases and severe functional dependency due to a physical or mental illness;
- People suffering from a terminal illness.

2.1.3. Coordination

Three levels of government are responsible for the coordination of RNCCI care (16,23,24):

- At Central level, the Ministry of Health develops national health policy and monitors its implementation. The national coordination of the RNCCI was the responsibility of the Mission Unit of Integrated Continuous Care (*Unidade de Missão dos Cuidados Continuados Integrados*, UMCCI) between June 2006 and December of 2012. Subsequently, the Central Administration of the Healthcare

¹ For more information regarding the care settings, please consult: 2.1.5. Organisational structure

System (*Administração Central do Sistema de Saúde, ACSS*) as assumed its coordination.

- At Regional level, with the aim of flexibility and decentralisation, the guidelines set by the central authority are implemented by the five Regional Coordination Teams (*Equipas de Coordenação Regional, ECR*)², one in each Regional Health Administrations (*Administrações Regionais de Saúde, ARS*). These teams comprise professionals in a number of disciplines, who are responsible for the planning, management, monitoring and assessment of the RNCCI, ensuring access, quality and appropriateness of services.
- At Local level, the Local Coordination Teams (*Equipas de Coordenação Local, ECL*)³, located in the Primary Care Trusts (*Agrupamentos de Centro de Saúde, ACES*), ensure the development and coordination of resources and activities with the various referring entities, namely hospitals and primary care.

The basic working, and networking design of this new level of care, which operates across the two sectors, health and social support, demands that responses of various types are shared between hospitals - through the Discharge Management Teams (*Equipas de Gestão de Altas, EGA*) - and primary care - through the Integrated Continuous Care Teams (*Equipas de Cuidados Continuados Integrados, ECCI*)⁴ (25,26). These two entities are responsible for the referral process, one located in the acute hospitals (namely the EGA) and the other located in the primary care health centres (namely the ECCI).

Based on information provided by the various LTC national reports, hospitals continue to be the leading referral entity in Portugal (**Table 2**).

Table 2: Percentage of patients referred by referral entity

	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
Primary care (%)	n.a.	28%	31%	30%	34%	34%	33%	35%	37%	34%
Hospitals (%)	n.a.	72%	69%	70%	66%	66%	67%	65%	63%	66%

Legend: n.a.: not available

Source: Author's extrapolation based on the RNCCI national reports (27–31)

2.1.4. Ownership

Due to cultural, demographic and epidemiological changes, the traditional reliance on informal caregivers as the first line of social care has been decreasing (18). Thus, the

² For further information, please see Appendix 1 – Care coordination levels, main responsibilities

³ Idem.

⁴ Idem.

formal provision of LTC is mostly made by the IPSS, with the *Misericórdias* being the main providers of these services. Nevertheless, besides the IPSS, several public institutions belonging to the NHS and a growing number of for-profit-institutions with protocols with the State have emerged to provide this care, which co-finances the costs per person treated (**Table 3**).

Table 3: Number of protocols assigned by ownership

Ownership	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
NHS	10	18	23	27	32	29	28	26	15	15
IPSS										
<i>Misericórdias</i>	71	89	100	116	131	134	157	169	177	181
Others	20	26	29	35	41	55	60	69	84	98
For-profit-institutions	5	16	37	40	52	49	51	52	60	66
TOTAL	106	149	189	218	256	267	296	316	336	360

Legend: NHS: National Health Service; IPSS: Private Institutions of Social Solidarity.

Source: Author's extrapolation based on the RNCCI national reports (27–31)

Based on **Table 4**, the IPSS continues to have the highest percentage of beds by type of ownership, with the *Misericórdias* being responsible for almost 50% of the total number.

Table 4: Number of beds by ownership

Ownership	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
NHS	193	307	378	425	529	480	477	443	299	299
IPSS										
<i>Misericórdias</i>	1,224	1,628	1,919	2,241	2,569	2,795	3,322	3,596	3,799	3,990
Others	325	482	597	823	1074	1247	1360	1598	2046	2,341
For-profit-institutions	160	453	1,044	1,136	1,423	1,389	1,483	1,523	1,615	1,770
TOTAL	1,902	2,870	3,938	4,625	5,595	5,911	6,642	7,160	7,759	8,400

Legend: NHS: National Health Service; IPSS: Private Institutions of Social Solidarity.

Source: Author's extrapolation based on the RNCCI national reports (27–31)

2.1.5. Organisational structure

In order to ensure the provision of services, and their coordination between health care and social support sectors, LTC in Portugal is organised in two main care settings (16,32): Nursing Homes (NH) and Home and Community-Based Services (HCBS).

In the NH, although services like personal hygiene, drugs prescription and administration, psychological and social support are provided to all patients (32,33), the expected length of stay, the intensity of nursing, medical and physiotherapy care differs between the particular care Units:

- Convalescence Units (*Unidades de Convalescença*, UC): the goal here is to guarantee the clinical and functional stabilisation of each person, providing rehabilitation care to those who have a temporary loss of, but potentially recoverable, autonomy, but do not require acute hospital care. It is mostly intended for people discharged from hospital services such as internal medicine, oncology, general surgery, orthopaedics/traumatology and neurology. Nursing, medical and physiotherapy care are provided intensively, on a daily basis, in order to ensure a rapid recovery of the lost autonomy. In this units, the expected length of stay is less than 30 consecutive days;
- Medium Term and Rehabilitation Units (*Unidades de Média Duração e Reabilitação*, UMDR): the goal here is to contribute to the better management of the UC beds, by providing less intensive and technologically differentiated care. Its beneficiaries are people from other LTC care settings, social security and solidarity institutions, other health facilities than hospitals, as well as from home. Although nursing care is provided on a daily basis, the medical and the rehabilitation care is provided on two days per week. The defined length of stay for these units is between 31 and 90 consecutive days;
- Long-Term and Maintenance Units (*Unidades de Longa Duração e Manutenção*, ULDM): the goal here is to contribute to the better bed management of the previous units and is intended for people with difficulties of community inclusion due to lack of family and social resources, as well as for caregivers' respite care. In this case, while the nursing care is provided daily, the medical and rehabilitation care are provided once a week. The expected length of stay is more than 90 consecutive days;
- Palliative Care Units (*Unidades de Cuidados Paliativos*, UCP): aimed to offer late-stage and end-of-life care to patients with a terminal illness. In 2015, these Units were included in the National Network of Palliative Care (*Rede Nacional de Cuidados Paliativos*) (34). There is no expected length of stay.

In the HCBS care setting, the care is provided at home between 8 am and 8 pm by a multidisciplinary team under the responsibility of the primary care centres, to people in a situation of functional dependency, who are convalescing. Typically they cannot leave their home but do not require hospitalisation (24). Here, The main services provided include personal hygiene, medical, nursing, and rehabilitation care, occupational therapy, education and psychosocial support involving both patients and their caregivers

(32,33). Individuals without a caregiver, in need of 24 h care or only social care are not entitling to receive these care.

2.1.6. Needs assessment instrument

Care recipients' degree of need for LTC, and the prioritisation of types of care, are assessed by reference to the seriousness of their disease, their dependency level and the availability of social and family involvement. The information on Portuguese LTC beneficiaries is collected by a Central organisation, the ACSS, through a management and monitoring platform known as "GestCare CCI". This platform gathers various types of information such as:

- Adverse drug reactions;
- Clinical information: admission diagnosis coded according to International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM);
- Consumables (bandages, diapers, drugs);
- Dependency levels;
- Diabetes risk/assessment;
- Medical assessment;
- Nursing assessment;
- Pain assessment;
- Palliative care assessment;
- Patient administrative information;
- Patient and episode identification;
- Region of care;
- Registration of infections;
- Risk of fall;
- Care setting;
- Social assessment;
- Ulcers risk/assessment.

The tool used to codify each person's dependency level is called the Bio-psychosocial Assessment Instrument⁵ (*Método de Avaliação Biopsicossocial*, MAB). The MAB is common to all regions across the country and collects information in three main areas (35) (**Table 5**):

⁵ For further information, please see Appendix 2 – Bio-psychosocial Assessment Instrument

Table 5: *The Portuguese Bio-psychosocial Assessment Instrument*

<p>BIOLOGICAL</p> <ul style="list-style-type: none"> • Activities of Daily Living (36) (toileting, dressing, bathing, transferring/bed, transferring/chair, continence/urination, continence/defecation and feeding); • Age; • Falls; • Gender; • Health complaints; • Instrumental Activities of Daily Living (37); • Locomotion (ability to walk at home, walk in the street, climb stairs and vision/hearing); • State of nutrition; 	<p>PSYCHOLOGICAL</p> <ul style="list-style-type: none"> • Cognitive status (38) (temporal - year, month, day, season and day of the week - and spatial - country, province, city/town, home and floor - orientation); • Emotional complaints; <p>SOCIAL</p> <ul style="list-style-type: none"> • Habits; • Social status;
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The responsibility for the assessment of the three core dimensions (cognitive, physical and locomotion) lies with hospitals for people who are hospitalised and with primary care if they are currently living in the community.

The process used to assess the person's overall dependency level in each dimension occurs in three stages (39,40):

- First, the ability to perform each activity is evaluated using a four system score, namely:
 - Score 0 (bad/ incapable), when a person cannot do without regular caregivers and/or means of support for functional replacement and does not cooperate;
 - Score 1 (unsatisfactory/ dependent), when s/he cannot do without regular caregivers and/or means of support for functional replacement but cooperates;
 - Score 2 (satisfactory/ autonomous), whether a person can or cannot do without regular means of support (other than caregivers) for functional replacement, and cooperates;
 - Score 3 (good/ independent), when a person does not need caregivers and/or other means of support for functional replacement.
- Next, while the patient's overall ADL/locomotion status is determined by considering the lowest score obtained in the eight ADL activities and four Locomotion activities assessed, his/her cognitive status is determined by the average score of the ten activities analysed.
- Finally, based on the previous scores for each dimension, people may be classified into two major groups: dependent and independent. In the first case, they can be further subdivided as either incapable or dependent, while the second can be classified into autonomous or independent (39).

Although there is no global score that takes into account the level of dependency in each area, the result obtained, transcribed sequentially, allows an overall comprehensive evaluation, called the “Bio-psychosocial Profile” under the following headings: Gender, Age, Health Claims, Nutrition, Locomotion, Falls, ADL, IADL, Emotional, Cognitive Status, Social Status and Habits; it is presented as a sequence of 12 digits between 0 and 3, for example: 01 013 323 23 23 (40).

2.1.7. Placement process

After determining the person’s care needs, providers should refer them to the best care setting, taking into account his/her dependency level, expected length of care need (in case of institutional care) and, whenever possible, proximity to their residence. If s/he is hospitalised, the identification of these cases is under the responsibility of the respective hospital EGA, preferably within 48 hours after inpatient admission. If the person is currently living in the community, these cases are identified by the primary care centres.

After each referral entity has checked that the admission requirements have been fulfilled (e.g., the assessment of dependency level, social support, medical conditions and the identification of the person’s care needs), the admission proposal is sent to the person’s nearest ECL, which is responsible for validating each proposal and identifying the best care setting for each case. According to the national guidelines, this process should take between 48 and 72 hours⁶ (16,25).

Subsequently, the ECL evaluates the process by checking whether (or not) the referral criteria have been met. If not, the proposal is sent back to the referral entity. If yes, the ECL checks whether or not the care setting is, in fact, the most appropriate for each case. Then, if the proposed setting is accepted by the person and their family members, the admission requirements are stated, and then both the informed consent (IC) and agreement to the terms of acceptance (TA) must be obtained from either the recipient of care or their representative.

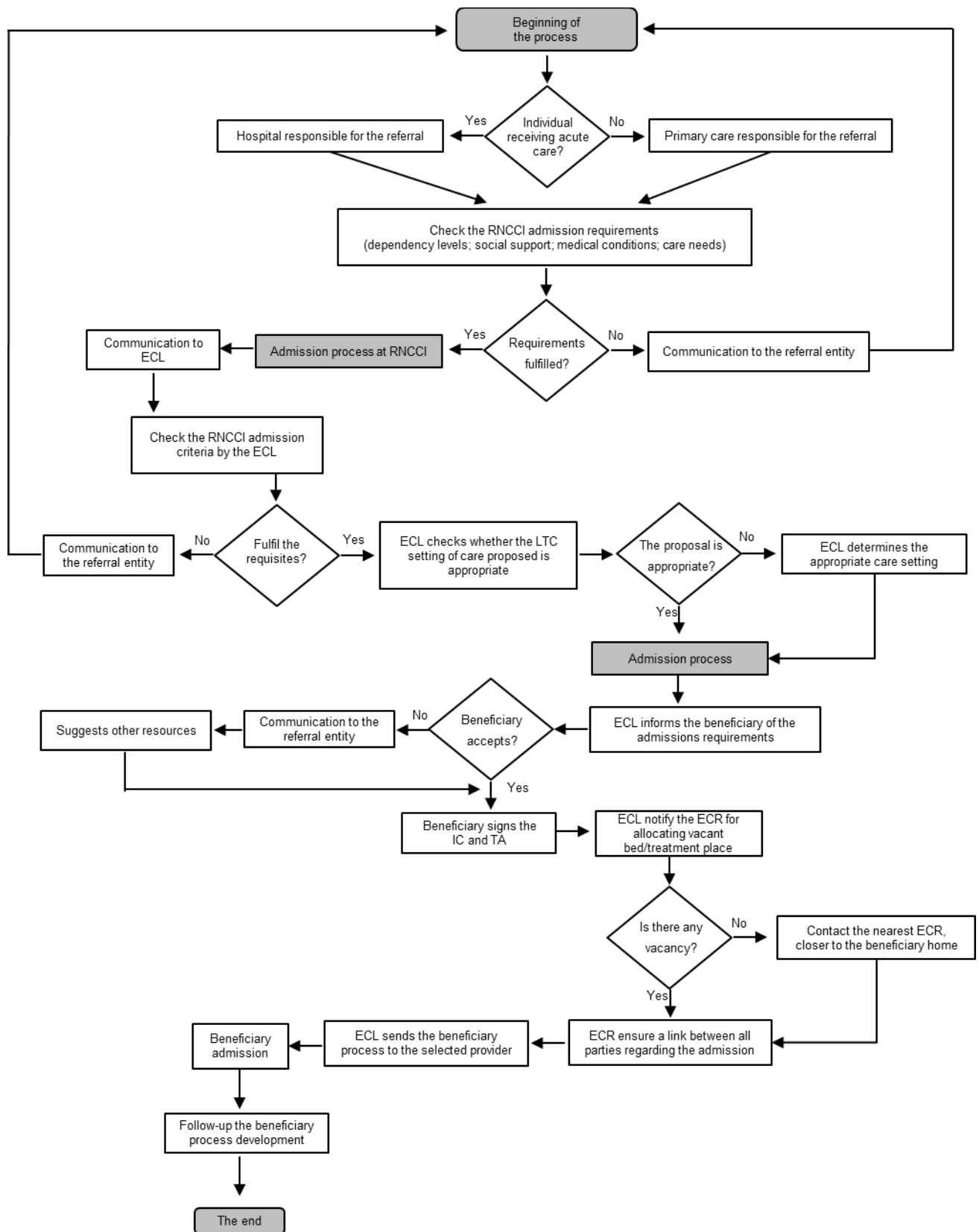
The next phase of this process is the contact with the respective ECR, which has the responsibility of allocating the care provider, taking into account the care setting determined (in the case of NH). If there are no treatment places available in the person’s home region, the ECR should contact the nearest region.

⁶ According to national data, despite the expected referral time be 48-72 hours, this expected time is only met in around 40% of the cases (90). One of the possible reason for these differences pointed out by this report, is the fact that ECL have other functions in addition to those regarding the RNCCI placement, both in health care and in social security sector, which may contribute to the lack of response within the stipulated time.

Finally, the ECR should ensure coordination between all the players (ECL, care recipient, referral entity and the care provider) and monitor the recovery process of each person (e.g., mobility, discharge plan, updating/revision the social security services, among others).

Figure 1 schematizes the several stages of the admission process at the RNCCI.

Figure 1: National Network for Long-term Care (RNCCI) placement process



Source: Adapted from legislative framework and referral placement process model (24,41)

2.1.8. Financing system

The model adopted by the RNCCI encompasses several sources that complement each other (42,43): (1) public funding ensured by the State Budget and shared between the health and social sectors; (2) profits from social gambling and betting (e.g., national lottery) allocated to the Ministry of Health and to the Ministry of Labour and Social Solidarity; and, (3) means-tested co-payments.

The price paid by the Ministry of Health and the Ministry of Labour and Social Solidarity to each LTC Unit depends on the care setting (**Table 6**). When the care is provided at HCBS, UC and UCP, the cost is entirely covered by the Ministry of Health. When the care is provided at UMDR or ULDM, the payment is shared between both Ministries. Whereas the Ministry of Health pays, respectively, 70% and 20%, the Ministry of Labour and Social Solidarity pays the remainder (44). In these last two NH Units, payment by care users is means-tested based on the percentage of the annual average per capita wealth held and income received by all household members (including wages, bank deposits, financial assets, pensions, public housing allowances and social benefits but excluding dependency disability allowances) for the part covered by the Ministry of Labour and Social Solidarity (45,46).

Table 6: National tariff, by source of financing per care setting (€ per person/day)

Care settings	Ministry of Health	Ministry of Labour and Social Solidarity	Total (people/day)
Nursing Homes			
UC	105.46	-	105.46
UCP	105.46	-	105.46
UMDR	67.75	19.81	87.56
ULDM	29.85	30.34	60.19
Home Care (HCBS)	9.58	-	9.58

Legend: UC: Convalescence Units; UCP: Palliative Care Units; UMDR: Medium Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units; HCBS: Home and Community-Based Services.

Source: Author's extrapolation based on Ordinance 184/2015 (44)

Concerning the Portuguese LTC expenditures, they increased as a percentage both of Gross Domestic Product and of current healthcare budget over the years (47) (**Table 7**).

Table 7: Long-term care expenditures in Portugal

	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
Long-term care expenditures (Euro, Millions, current prices)										
Ministry of Health	14.79	23.34	60.19	113.49	112.22	138.05	120.31	120.94	116.69	136.06
Ministry of Labour and Social Solidarity	2.24	9.70	14.85	19.57	25.21	26.46	27.70	31.76	34.86	36.37
TOTAL	17.03	33.03	75.04	133.05	137.43	164.50	148.00	152.71	151.55	172.44
As a share of GDP (%) (**)	0.69	0.74	0.78	0.78	0.79	0.86	0.89	0.94	0.96	n.a.
As a share of current healthcare expenditure (%) (**)	7.6	7.9	7.9	7.9	8.3	9.2	9.9	10.4	10.7	n.a.

Legend: n.a.: not available; GDP: Gross Domestic Product; (**) includes the expenditures of both long-term care public health and social components (47)

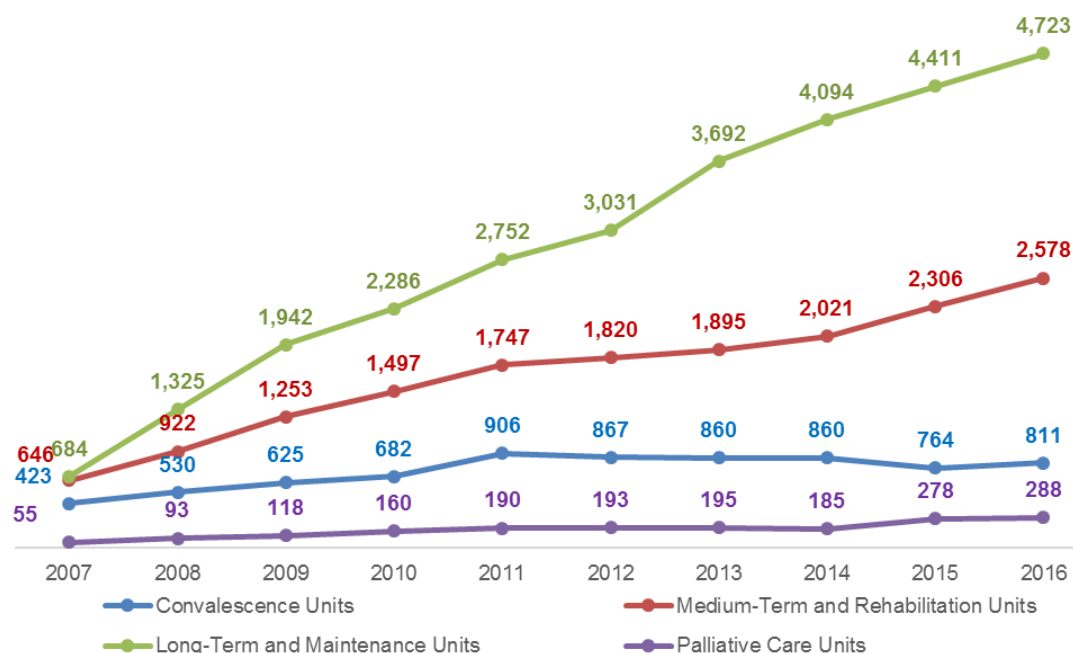
Source: Author's extrapolation based on national reports (27–31)

2.1.9. Main features

2.1.9.1. Treatment places

The number of NH beds increased from 1,808 to 8,400 between 2007 and 2016 (**Graph 1**). On average, 56% of the total number of NH beds are the concern of the ULDM, followed by the UMDR (31%), UC (10%) and the UCP (3%).

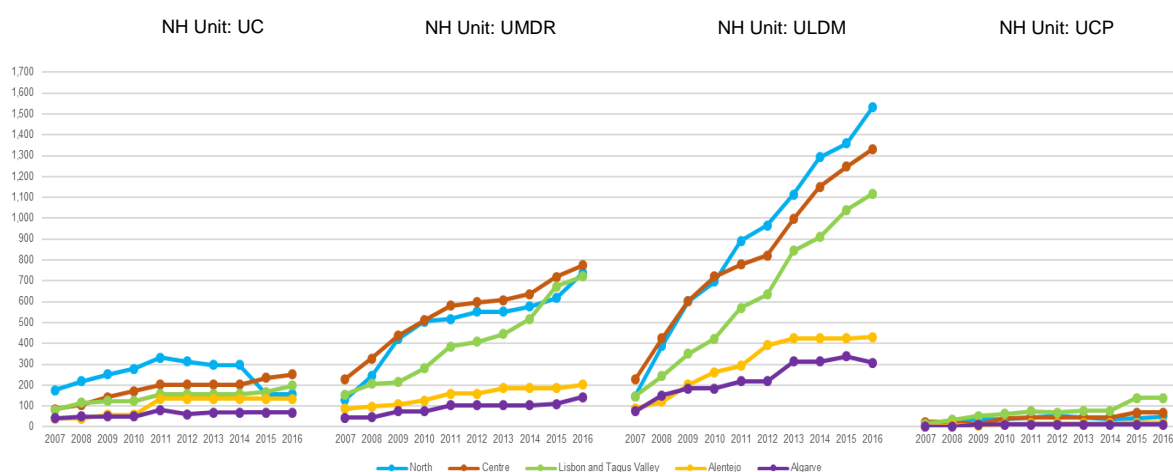
Graph 1: Nursing Home Care Units: evolution of the number of beds



Source: Author's extrapolation based on RNCCI national reports (27–31)

The number of NH beds has increased over the years in all regions, regardless of the Unit of care⁷ (**Graph 2**). In UC in particular, the region with the highest number of beds in 2016 is the Centre (251 beds), followed by Lisbon and Tagus Valley (199 beds), the North (157 beds), Alentejo (135 beds) and the Algarve (69 beds). Regarding the UMDR, although the Centre (775 beds) is the region with the highest number of beds in 2016, the region with the strongest growth between 2015 and 2016 was the Algarve (+31%). The North is the region with the highest number of ULDM beds (1,534), followed by the Centre (1,332) and Lisbon and Tagus Valley (1,119). These three regions are responsible for 84% of the total ULDM supply in Portugal. Finally, the number of UCP beds is considerably lower than the previous three Units of care.

Graph 2: Nursing Home Units of care by NUTS II: number of beds



Legend: NH: Nursing Home; UC: Convalescence Units; UCP: Palliative Care Units; UMDR: Medium Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units.

Source: Author's extrapolation based on RNCCI national reports (27–31)

Concerning the non-institutionalised care, the number of teams within primary care responsible for providing HCBS increased from 72 in 2008 to 286 in 2015 (**Table 8**) and then decreased slightly, to 279, in 2016.

⁷ For further information, please see Appendix 3 – Treatment places

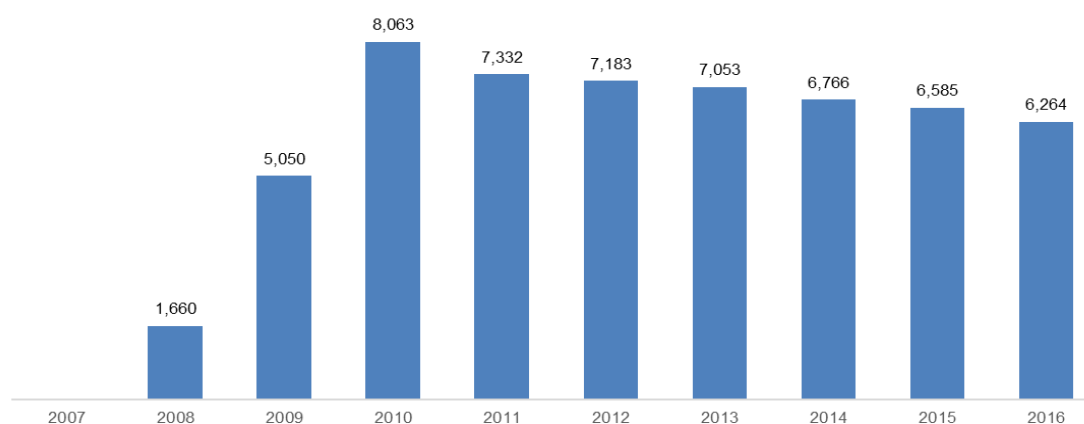
Table 8: Home and Community Based-Services – Number of teams

	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
North	n.a.	0	9	71	86	84	85	84	82	84
Centre	n.a.	39	43	42	45	40	54	61	72	66
Lisbon and Tagus Valley	n.a.	6	6	58	58	54	60	60	63	60
Alentejo	n.a.	9	10	15	35	35	36	37	37	37
Algarve	n.a.	18	28	28	29	30	32	32	32	32
Total	n.a.	72	96	214	253	243	267	274	286	279

Legend: n.a.: not available

Source: Author's extrapolation based on the RNCCI national reports (27–31)

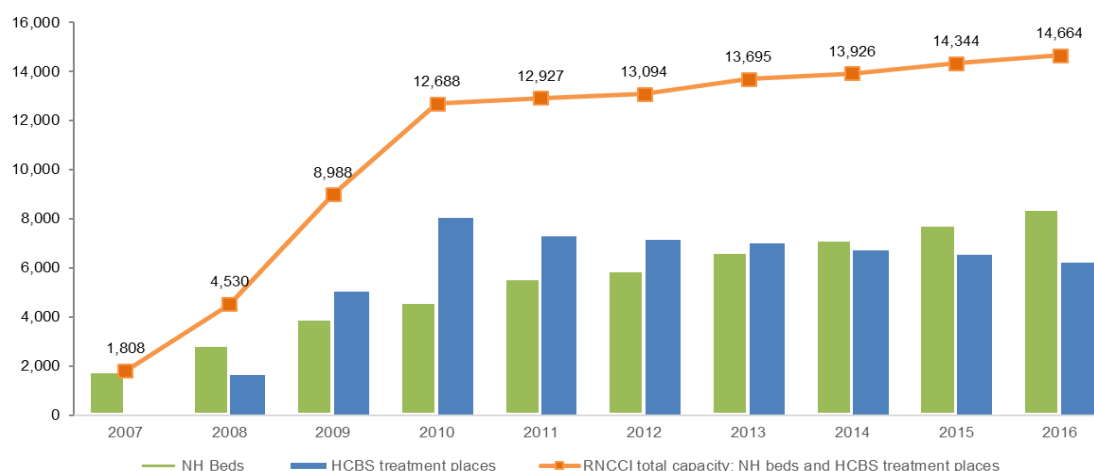
Due to the growing number of home care teams available, the overall HCBS treatment places increased from 1,660 to 8,063 between 2008 and 2010 (**Graph 3**) but has since then decreased continuously, reaching in 2016 the lowest number since 2009.

Graph 3: Home and Community Based-Services: evolution of the number of treatment places

Source: Author's extrapolation based on RNCCI national reports (27–31)

In summary, based on the previous data, the total number of RNCCI treatment places (including NH beds and HCBS places) has grown over the years from 4,530 in 2008 to 14,664 in 2016 (**Graph 4**).

Graph 4: RNCCI total supply: NH beds and HCBS treatment places



Legend: NH: Nursing Homes; HCBS: Home and Community-Based Services.

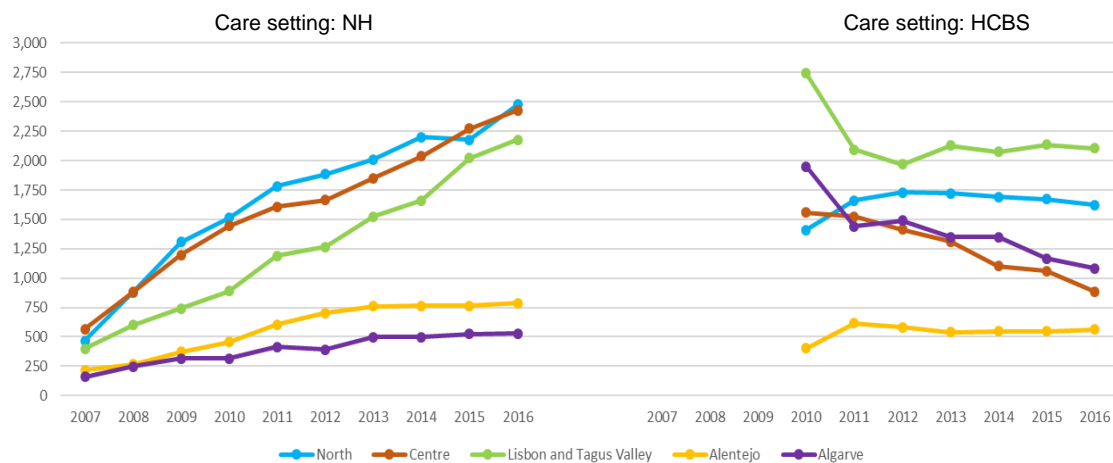
Source: Author's extrapolation based on RNCCI national reports (27–31)

Concerning the five regions of Portugal mainland, several conclusions can be highlighted⁸ (**Graph 5**). Regarding the NH Units of care, there has been a widespread and continuously growing number of NH beds in all regions. Between 2008 and 2016, the region of Lisbon and Tagus Valley saw the fastest growth in the number of beds (5.5-fold increase), followed by the North (5.3-fold), the Centre (4.3), the Alentejo (3.6) and finally the Algarve (3.3). In 2007, the Centre held 31% of the total number of beds, followed by the North (26%), Lisbon and Tagus Valley (22%), Alentejo (12%) and Algarve (9%). In 2016, the North and Centre held about the same percentage of NH beds (30% each), followed by Lisbon and Tagus Valley (26%), the Alentejo (9%) and the Algarve (6%).

There are no data on the HCBS treatment places from NUTS II in 2008 and 2009. Nevertheless, according to national data from 2010 and 2016, only Alentejo and the North increased the number of places (+40% and +15%, respectively). In the other regions, the number decreased during this period (Algarve: -44%, Centre: -43% and Lisbon and Tagus Valley: -23%).

⁸ For further information, please see Appendix 3 – Treatment places

Graph 5: RNCCI total supply by NUTS II: NH beds and HCBS treatment places

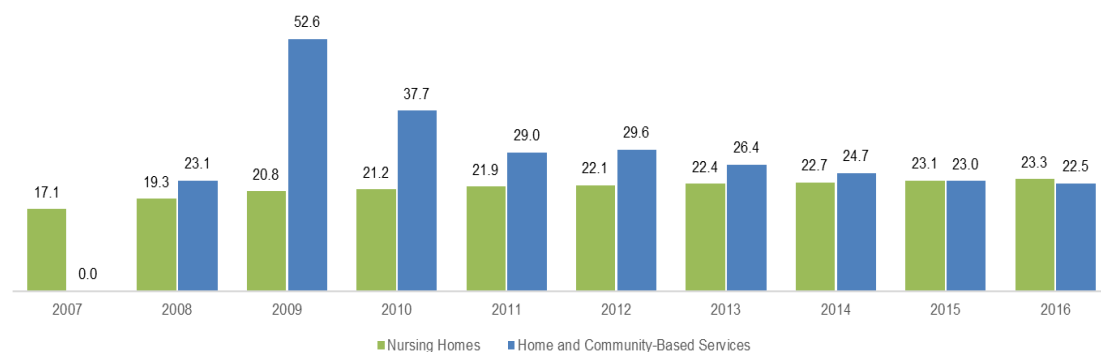


Legend: NH: Nursing Homes; HCBS: Home and Community-Based Services.

Source: Author's extrapolation based on the RNCCI national reports (27–31)

Finally, the **Graph 6** shows that whereas the average number of people treated by NH bed is increasing over the years, the ratio in HCBS shows opposite results.

Graph 6: Average number of people treated by treatment place (NH beds and HCBS places)



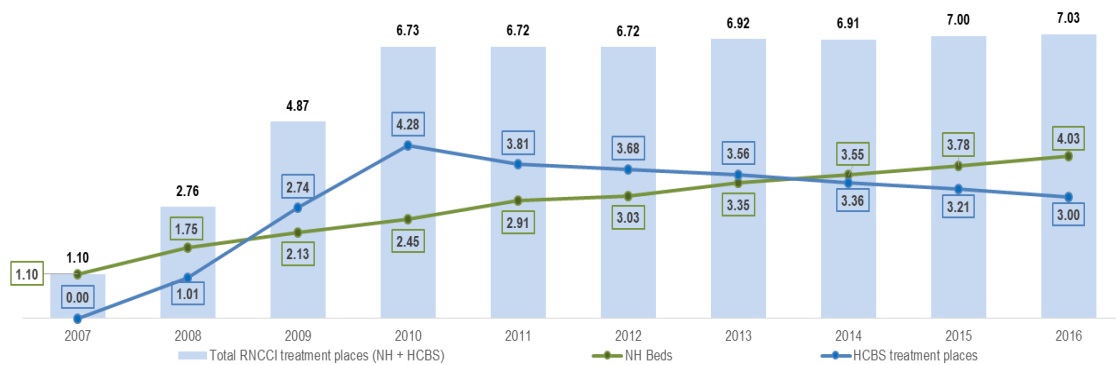
Legend: NH: Nursing Homes; HCBS: Home and Community-Based Services.

Source: Author's extrapolation based on the RNCCI national reports (27–31)

2.1.9.2. Treatment places per 1,000 inhabitants ≥ 65 years old

Regarding the total RNCCI supply per 1,000 inhabitants aged 65 or over, the NH/HCBS ratios increased from 1.75/1.01 in 2008 to 4.03/3.00 in 2016 (**Graph 7**). The biggest difference between the two care settings was in 2010 (with a higher ratio in HCBS), but thereafter the gap narrowed, and then after 2014, the NH/HCBS had a greater proportion.

Graph 7: RNCCI total treatment places (NH + HCBS) per 1,000 inhabitants ≥ 65 years old

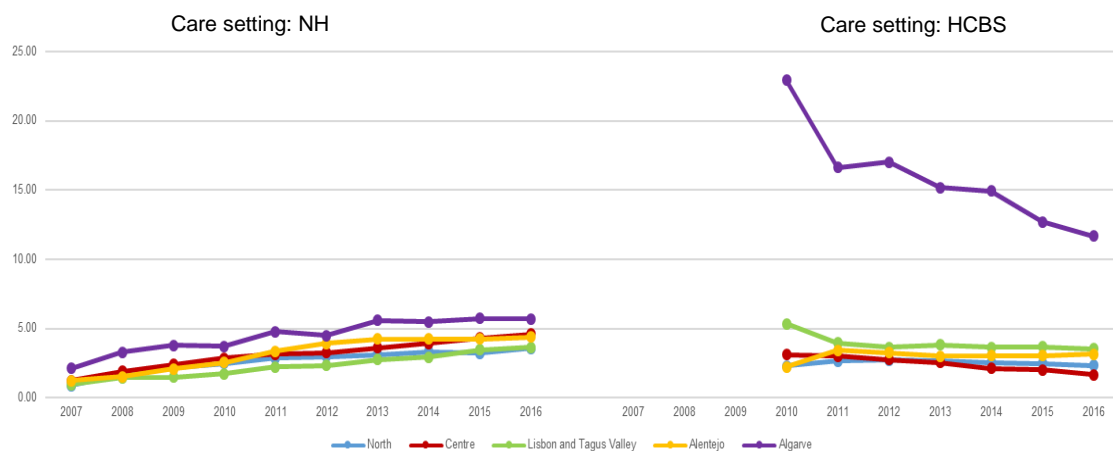


Legend: NH: Nursing Homes; HCBS: Home and Community-Based Services.

Source: Author's extrapolation based on the RNCCI national reports (27–31)

The Algarve continues to have the highest ratio of both NH beds and HCBS treatment places per 1,000 inhabitants ≥ 65 years old⁹ (**Graph 8**). The results are similar regardless of the NH Unit of care (**Graph 9**)¹⁰.

Graph 8: RNCCI total treatment places (NH + HCBS) by NUTS II per 1,000 inhabitants ≥ 65 years old



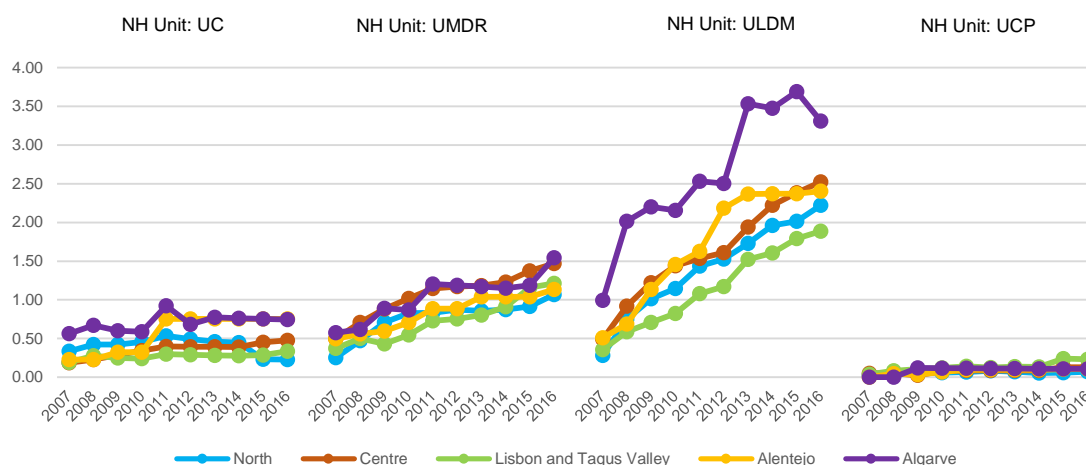
Legend: NH: Nursing Homes; HCBS: Home and Community-Based Services.

Source: Author's extrapolation based on the RNCCI national reports (27–31) and Portuguese demographic statistics (48)

⁹ For further information, please see Appendix 3 – Treatment places

¹⁰ Idem.

Graph 9: Nursing Home Units of care by NUTS II: number of beds per 1,000 inhabitants ≥ 65 years old



Legend: NH: Nursing Homes; UC: Convalence Units; UCP: Palliative Care Units; UMDR: Medium Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units.

Source: Author's extrapolation based on the RNCCI national reports (27–31) and Portuguese demographic statistics (48)

2.1.9.3. Treatment places: comparing the “actual numbers” with the forecasts

As mentioned before, it was planned that the full implementation of the RNCCI would happen gradually over a period of 10 years, in three stages. The data showed, however, that at each stage the total numbers of treatment places (**Table 9**) and the ratio per 1,000 inhabitants aged ≥ 65 years (**Table 10**), was below those forecast for each care setting.

At the last stage (2013-2016), the UC (-72%) and the UCP (-71%) were the NH Units of care with the greatest proportionate difference between the forecast and the actual numbers per 1,000 inhabitants aged ≥ 65 years, followed by the ULDM (-42%) and the UMDR (-21%). The number of HCBS teams was 23% below forecast.

Table 9: Differences between forecast and actual numbers of beds at the end of each stage

	Stage I (2006 - 2008)		Stage II (2009 - 2012)		Stage III (2013 - 2016)	
	Forecast	Actual *	Forecast	Actual **	Forecast	Actual ***
NH Units of care						
UC	977	530	1,954	867	2,931	811
UMDR	1,139	922	2,117	1,820	3,257	2,578
ULDM	2,720	1,325	5,374	3,031	8,143	4,723
UCP	326	93	651	193	977	278
HCBS (number of teams)	363	72	363	243	363	279

* values of 2008; ** values of 2012; *** values of 2016

Legend: NH: Nursing Homes; UC: Convalescence Units; UCP: Palliative Care Units; UMDR: Medium Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units; HCBS: Home and Community-Based Services.

Source: Author's extrapolation based on the RNCCI national reports (22,27,29,31)

Table 10: Differences between forecast and actual numbers of treatment places per 1,000 inhabitants aged ≥65 years at the end of each stage

	Stage I (2006 - 2008)		Stage II (2009 - 2012)		Stage III (2013 - 2016)	
	Forecast	Actual *	Forecast	Actual **	Forecast	Actual ***
NH Units of care						
UC	0.6	0.32	1.2	0.44	1.8	0.39
UMDR	0.7	0.56	1.3	0.93	2.0	1.24
ULDM	1.67	0.81	3.3	1.55	5.0	2.27
UCP	0.2	0.06	0.4	0.10	0.6	0.14

* values of 2008; ** values of 2012; *** values of 2016

Legend: NH: Nursing Homes; UC: Convalescence Units; UCP: Palliative Care Units; UMDR: Medium Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units.

Source: Author's extrapolation based on the RNCCI national reports (22,27,29,31) and Portuguese demographic statistics (48)

2.2. Risk factors for long-term care admission

As the population becomes older (1) and (multi)morbidity patterns change (2), the demand for LTC services is expected to increase. Although people needing care prefer to remain in their homes for as long as possible in order to maintain their social networks and stay in their familiar environment (49–53), when the level of care requires extensive care, admission to an institutional facility may become necessary (51). Given this new reality, much research has been devoted to identifying the risk profiles of each population in order to anticipate future demand for LTC services, and for developing and targeting programmes to delay or prevent admissions to institutional settings (7,54,55).

Based on the behavioural model for health care services use, one of the most frequently used frameworks for research on LTC utilisation, the probability of receiving care in each setting is a function of three sets of factors: predisposition (to use services), ease or difficulty of access and health care system factors.

Thus, in order to contribute to the ongoing research regarding the planning of LTC services based on the peoples' needs, the aim of this section of the work is to identify the main risk factors that influence the probability of receiving care in each care setting (institutional and non-institutional). The section is organised in three broad sub-sections: socio-demographic characteristics, dependency levels and other dimensions.

2.2.1. Socio-demographic characteristics

Age

The association between age and the use of LTC services is well established (7,53–55). Because advanced age is normally associated with general frailty, which could cause dependency in various daily activities, several studies have shown that older people are more likely to receive care in an institutional setting than in an HCBS (49,51,64,65,56–63).

For example, one study found that men of 85+ were 19 times more likely than 65-74 year-olds to be admitted to an institution, and women 15 times (56). Another study found that the older group were four times more likely to be admitted to a NH than those aged 60-74 years old (57). There is a range of different findings, however, on the exact effects of ageing on the numbers. Whereas one study concluded that for each additional month of age the probability of being admitted to a NH increased by about 1% (60), in a recent study from Canada this increase in probability was found to be 3% for each additional year (64). A German study, moreover, found that the significant effects on NH

admissions resulted from the combination of age with other factors (49). In this case, whereas those aged 75-81, single and both physically and cognitively impaired were more likely to be admitted to a NH, having 81 or more years old and being physical/cognitive impairment no longer made a significant difference.

More recently, Lee et al. (2014) studied people with dementia with LTC insurance in South Korea and also found statistical differences between age groups (62). In this case, people in institutional care settings were older than those exclusively receiving HCBS care and then those receiving combined care (institutional and community care).

Finally, several studies (66–70) have found no statistically significant differences between the mean ages of the populations of both care settings, in absolute numbers. Others concluded that, although in absolute numbers those receiving home care were more likely to be younger than those in a NH, after using the Propensity-Score Matching method to control the differences between the populations, there were no significant differences in age between them (71–73).

Gender

The results in the literature on the influence of gender appear to be mixed (7,54,55). Some studies found that NH have a higher proportion of men than HCBS care settings (57,67,74,75) but others have concluded the opposite (51,58,61,71,72); and still others found no statistically significant differences between the care settings (49,59,66,68,69).

Regarding the mix findings in the literature, while in Wieland et al. (2010) study the proportion of men was 37% in NH and 25% in HCBS (75), two other studies found that only 40% of NH admissions were women (57,74). Conversely, several studies have found that the proportions of women ranged from 57% to 82% (51,58,61,71,72).

Social support

The two aspects of social support that seem to influence the risk of admission in each care setting are marital status and the availability (or not) of support from family and other caregivers.

On marital status, four studies from the USA (57,60,68,75), one from South Korea (58), one from Germany (49) and two from Canada (51,64) concluded that non-married people were more likely to receive care at a NH than in a HCBS. For example, two studies concluded that the probability of unmarried people being admitted to a NH was 56% and 76% higher than for married people (57,60). More recently, in Canada, one study found that married people were more likely to receive home care (37.5%) than to be admitted

to a NH facility (29.5%) (51) and were also more likely to enter the LTC sector through home care rather than institutional care (64).

The higher the involvement of family and other caregivers in supporting the old person, the more likely s/he will remain in the community (56,60,62,65,66,76). Tomiak et al. (2000) found that for men, the more people there were in the household, the better were their chances of avoiding admittance to an NH facility, whereas for women the association was not statistically significant (56). Another study found that all people receiving home care were cared for by at least one family member, unlike those in a NH, which indicates that there was more family involvement in caregiving for people in the first care setting (66). A study that examined how the commitment of states to HCBS affects the risk of NH admission found that the risk of being admitted to a NH was reduced for those who had greater family resources such as being married, had a younger spouse or lived with children or close to them (60). More recently, whereas one study involving people with dementia concluded that those receiving only HCBS care were more likely to have some family/caregivers support than those receiving only NH or combined care (62), Wu et al. (2014) found that, not only people in institutions were likely to have fewer family members than those receiving HCBS, when predisposing, enabling, and need factors were considered simultaneously, these individuals had a higher use of LTC (76).

Finally, although Penning et al. (2016) concluded that living arrangements were not significantly associated with HCBS care (64), Lee and Cho (2016) found that whereas in absolute numbers people in HCBS care were more likely to have some family/caregivers support than those in a NH, after controlling several characteristics there were no significant differences between them (72).

Level of education

Similarly with the previous variables, the association between the level of education and the LTC services is not well proven (7,54,55). In Tomiak et al. (2000) study, when compared with those in the lowest quartile of education, women with a higher level of education have a 60% chance not to be admitted in a NH (56). However, this association was not statistically significant for men.

Sloane et al. (2005) found statistically significant differences in absolute numbers according to level of education, with a lower percentage of people with schooling to eighth-grade in the HCBS population than in NH, and a higher percentage with schooling beyond twelfth-grade (68). On the other hand, whereas two studies found no significant differences in the level of education between these populations (49,75), Muramatsu et

al. (2007) concluded that having been in education for a longer period increases the risk of NH admission by about 3% than those with only a few years of education (60).

More recently, Wu et al. (2014) study found not only that the proportion of illiterate people in NH was higher than in HCBS, but also that a higher level of education achieved was also associated with greater LTC use when predisposing and enabling factors were considered together (76). In this case, those with 7 or more years of education were 25% more likely than illiterate people to receive some LTC service.

2.2.2. Dependency levels

Because a person's dependency level cannot be measured simply by the diagnosis of diseases, it is essential to conduct a more detailed assessment of each person. The assessment usually aims to identify his/her physical and cognitive impairment, and contribute to the definition of the actions needed for the maintenance and/or recovery, total or partial, of their lost capacities (77).

Physical function - Comparing the baseline levels

Note: here, and subsequently, 'baseline' refers to 'at the time of admission' to one or another care system.

A number of authors have found, after assessing the abilities of people in NH and HCBS to perform daily activities using the Barthel Index, statistically significant differences between the populations and concluded that, whereas the proportion of people in NH classified as "highly dependent" ranged from 27% to 34%, in HCBS it was 1% to 17% (69,74,78). Frytak et al. (2001) studied the physical function by assessing the ability to perform five ADL (continence, feeding, toileting, transferring, and dressing) using a scale ranging from 0 (no functional limitations) to 100 points (complete dependency) (79). In this case, whereas the population in NH had a global score of 57, those in HCBS had a score of 17, meaning a higher dependency level among the former group. Xie et al. (2002) had similar findings: after assessing four ADL (feeding, urine incontinence, faecal incontinence and mobility), the percentage of people classified as functionally dependent in NH was approximately three times higher than those in HCBS (67).

Borrayo et al. (2002) found that the number of ADL that a person could not do at all, or needed some help or supervision, was higher among those in NH (3.9 activities) than those in HCBS (2.2 activities) (57). Moreover, these authors also found that the percentage of people considered independent in performing each of the six activities assessed ranged from 4% to 34% in the first group and from 27% to 71% in the second

group. A similar trend was found in four studies (59,60,68,80). For example, in Gruber-Baldini et al. (2007) study, whereas 39% of people with dementia receiving community care had no physical limitations and only 11% were totally dependent in performing all six ADL assessed, these percentages among those in NH were 5% and 51%, respectively (59).

In Germany, two studies concluded that not only the association between older age and physical impairment that was significantly associated with NH admission (49), but also that the proportion of those classified in the very severe level was higher in NH than in HCBS (81).

In two studies from South Korea, the authors, one using 13 (70) and the other using 23 items of physical assessment (62) in people with dementia, found significantly higher scores among those in NH, indicating lower independency levels than among those receiving HCBS care. A study from Taiwan had similar findings: the percentage of people in NH with 4-6 items of ADL disability was higher than those receiving HCBS care (75% and 55%, respectively), indicating a higher physical dependency level (76).

On whether or not the 'Ageing in place policy' (community-based living before institutionalization) delays NH admission, a study from the USA concluded that the average level of physical dependency of newly admitted NH patients increased between 2007 and 2012 and around 80% required limited to extensive assistance in performing all ADL tasks except eating, which required only supervision (63). According to the authors, the help needed with activities such as dressing, transferring and eating increased significantly over the years.

More recently, although several studies concluded that the population receiving home care were more physically dependent at the time of admission than those receiving NH (51,65,71,73), after using the Propensity-Score Matching method to control the baseline differences between populations, two studies found no statistical differences (71,73) . Finally, other authors, after using the same method in people with stroke, concluded that although the motor disturbances were not significantly different between the home care and the NH groups, the first ones were significantly less dependent in performing ADL than the second group (72).

Physical function - Influence on the risk of being admitted in each care setting

Besides the differences between the two populations at the time of admission, several authors studied the predictive power of functional dependency in the risk of being admitted to each care setting.

Using the proportional hazard regression model, a study from Canada found that men and women considered functionally disabled have a probability of being admitted to a NH 3.2 and 1.6 times higher, respectively, than those considered not disabled (56). More recently, another study from Canada used the ADL Self-Performance Hierarchy Scale and concluded that people with physical dependency were 37% less likely to receive care at home than in an institution (64).

In Borrayo et al. (2002) study, after using a multinomial logistic regression to analyse the probability of receiving LTC in NH versus HCBS care settings, the authors found that not only people who were less functionally dependent were more likely to be admitted to a HCBS, but also that for each additional 'dependant ADL' the probability of being admitted to a NH increased by about 93% (57). Other authors also found - albeit not statistically significantly - that for each additional ADL limitation the probability of being admitted to a NH increased by about 4% (60). In addition to the influence of the ADL, the ability to perform more complex activities such as IADL was found to have a statistically significant influence: for each additional limitation in performing some IADL, the probability of being admitted to a NH increased by about 27%.

Finally, in a recent study seeking to identify the determinants of LTC services among the elderly, people with 4-6 items of ADL disability were 21.5 times more likely to use some LTC services than those without a disability when predisposing, enabling and need factors were considered together (76).

Cognitive function - Comparing the baseline levels

Similarly with the previous case, there also differences in cognitive status between NH and HCBS populations both in numbers at the time of admission and on the risk of being admitted to each care setting.

After using the Mini Mental State Examination (MMSE) scale, two studies from the UK (74,78), one from Taiwan (69) and another from South Korea (70) concluded that people admitted to NH were more cognitively impaired upon admission than those receiving HCBS care. In the first study, in which the scores ranged from 0 (high dependency) to 20 (low dependency) points, while the median cognitive score among those in NH was

12 points, it was 16 points among those receiving home care (78). In the second study, whereas 23% of people in HCBS were classified as “more impaired” (score 0-9 points), this percentage among those in NH was 45% (74). In Kuo et al. (2010) study, the percentage of the NH population considered fully dependent upon admission (47%) was almost four times higher than those in HCBS (12%) (69). Finally, after using the Korean version of the MMSE scale (K-MMSE), which ranged from 0 (total impaired) to 11 (independent) points, the authors calculated an average score 7.5 points for those at home care and 6.1 for those in NH (70).

In a study conducted in Florida, USA, the authors assessed people’s cognitive status by classifying them into one of four levels of dependency, ranging from 0 (independent) to 3 (severe impairment) (57). Although no statistical significance was shown, the average score upon admission ranged from 1.42 (NH) to 1.72 (HCBS), indicating a worse status among those at the second group. Contrary to these findings, two studies from the USA (68,80) and one from Canada (51) found statistically significant differences between the populations, in which the HCBS people exhibited less severe cognitive impairment than the people in the NH. In this case, while the first paper used the Minimum Data Set Cognition Scale (68), the other two used the cognitive performance scale to assess cognitive status (51,80). In Lee et al. (2014) study, the authors used ten items to assess cognitive function, adopting a scale ranging from 0 (independence) to 10 (impaired) points (62), in order to compare people with dementia according to the LTC services they were receiving. In this case, those receiving exclusively institutional care (7.7 points) had statistically significant worse status on admission than those receiving solely HCBS (7.4 points) or those receiving combined care (7.5 points).

Finally, although in two studies the people receiving home care were more likely to have poorer cognitive function than those receiving NH upon admission (71,73), after using the Propensity-Score Matching method to control the baseline differences between the populations, the differences were not statistically significant.

Cognitive function - Influence on the risk of being admitted to each care setting

In Rothera et al. (2003) study, cognitive status was one of the most significant factors associated with the type of care provided (74). In this case, those with greater cognitive impairment (score 0-9 points) had a lower probability (around 63%) of receiving home care services than those less impaired (score 10-30 points).

Based on a multinomial logistic regression, a study from Florida concluded that people with a diagnosis of Alzheimer’s disease or high levels of cognitive impairment were more likely to be admitted to a NH than to be in HCBS (57). This was also reflected in two

other studies (60,64), where the authors used the MMSE and concluded that those cognitively impaired had a higher probability (around 27%) of being admitted to a NH than to a HCBS (60), and in the second study, from Canada, the Cognitive Performance Scale was used and a similar probability was found (around 32%) (64).

According to some of these studies, the fact that the HCBS population was less likely to have been diagnosed with a mental disease, or found to be cognitively impaired, may be explained by the fact that people receiving home care are less likely to have access to a neurological evaluation that can lead to a more specific diagnosis.

2.2.3. Medical conditions

Because LTC beneficiaries are usually elderly people with chronic diseases which often influence their physical and cognitive ability, accurate information about medical diagnoses is essential for planning care, monitoring and predicting the rehabilitation outcomes.

In this area, too, there are conflicting conclusions in the literature. After considering the average number of comorbidities, whereas several authors have concluded that the NH population had a higher burden of diseases (64,68,72), others have concluded the opposite (57,81). For that matter, after considering several medical conditions, Sloane et al. (2005) found that the average number of chronic diseases was higher among people in NH (4.4) than among those in HCBS (3.6) (68). Lee and Cho (2016) assessed older adults with a stroke and found a higher percentage of people with four or more chronic diseases among those receiving care in NH (9%) than among those in HCBS (7%) (72). Finally, concerning the influence of medical conditions on the risk of being admitted to each LTC care setting, Penning et al. (2016) in Canada concluded that for each additional chronic disease the probability of being admitted to NH care increased by 10.3% (64).

On the opposite side, after considering sixteen medical conditions, Borrayo et al. (2002) concluded that, on admission to care, the average numbers of chronic diseases among those in HCBS and NH were 3.3 and 2.5 respectively (57). Nevertheless, although the existence of more chronic diseases decreases the probability of being admitted to a NH facility by about 12%, this association was not statistically significant. More recently, using the Charlson Comorbidity Index to account for all inpatient and outpatient diagnoses documented for each person, a study from Germany found a slightly higher index among the community population upon admission, independently of the required level of care by which each person was classified (81).

In addition to the simple numbers of chronic diseases, several studies have found differences regarding the prevalence of specific medical conditions between both populations (49,51,56,59,63,71,72,75,76,78).

On this question, whereas some authors have concluded that people with a diagnosis of dementia were more likely to be in a NH (59,78), Tomiak et al. (2000) found that the presence of specific medical conditions not only increases the risk of NH admission but also that their influences on men were different from that on women (56). In this study, diagnosis of dementia and the presence of Alzheimer's disease increased the risk of NH admission by 20.2 times for men and 10.0 times for women, musculoskeletal disorders by 2.8 times and stroke by 2.3 times for men, and other mental disorders by 2.7 for men and by 1.8 times for women.

In Wieland et al. (2010) study, statistically significant differences were found in the prevalence of several medical conditions between NH and HCBS patients (75). In particular, whereas the prevalence of congestive heart failure (13.5% vs. 27.1%), diabetes (29.5% vs. 39.2%) and stroke (23.5% vs. 24.7%) was lower among the first group, fewer of those receiving home care had heart diseases (12.5% vs. 13.0%), anaemia (11.4% vs. 15.2%), cancer (7.5% vs. 8.5%), renal failure (6.5% vs. 7.0%) and diagnosis of dementia (18.0% vs. 50.2%) than in the institutional population.

In two studies comparing people with dementia receiving care at home with those in residential facilities, the authors reached opposite conclusions. In Germany, Luppá et al. (2012) found no significant differences between the two care settings in the numbers of people with coronary heart disease, myocardial infarct, Parkinson disease or stroke (49), but in a Canadian study, medical conditions such as Parkinson's disease, heart disease, diabetes and renal disease were more prevalent among institutional patients (51).

Regarding the use of LTC services, a study from Taiwan concluded that although people with hypertension, stroke or dementia were more likely to use some LTC services than those without these chronic diseases (1.60, 2.08 and 2.32 times more, respectively), there were no statistically significant differences in the number of people with some of these diseases between NH and HCBS care settings (76).

On the question of whether the 'Ageing in place' policy delays NH admission, Young et al. (2015) analysed LTC admissions from 2007 to 2012 and concluded that the most prevalent health characteristics that were increasing among people being admitted to institutional care were hypertension (73% to 80%), bowel incontinence (51% to 56%) and dementia (34% to 42%) (63). The prevalence of heart failure, on the other hand, declined by approximately 3%.

More recently, in the study by Lee et al. (2015), although there is a higher prevalence of dementia and musculoskeletal diseases among NH (45% and 64%) people than among those in HCBS (40% and 43%), this latter population were more likely to have stroke, hypertension, diabetes or pressure ulcers (49%, 47% 23% and 15%, respectively) than the first group (36%, 45% 17% and 11%, respectively) (71). Nevertheless, after adjusting for several baseline characteristics, the differences were not statistically significant. Similarly with the previous study, even after adjusting to several baseline characteristics there were no significant differences between the two populations, whereas the people in NH were more likely to have dementia (47% vs 27%), osteoporosis (9% and 8%) or fractures (12% vs 11%), the people in HCBS were more likely to have hypertension (65% vs 63%), diabetes (28% vs 23%) or back pain (13% vs 12%) (72).

2.2.4. Other dimensions

Several others dimensions were analysed by several authors to identify the main characteristics that differentiate the population of the two care settings, namely the region of care, behavioural problems, anxiety and depression and length of care.

Region of care

Although there were no statistically significant differences among men, women living in urban areas had a 60% higher risk of being admitted to a NH than those living in a rural area (56). A study conducted in Florida, in which the region of the state was a factor considered in examining variables that affect LTC supply, concluded that people living in regions where the availability of NH beds was above the state median, and the alternative LTC programmes were limited, were less likely to receive HCBS care (57). In Wu et al. (2014) study, when predisposing, enabling and need factors were considered simultaneously, people in urban areas were significantly more likely (by around 68%) to be in LTC care than those living in non-urban areas (76).

More recently, a Canadian study that looked at people admitted into the public LTC system over a four-year period, 2008 to 2011, concluded that, although it was not statistically significant, people living in an urban region had a lower probability of receiving community care than those in non-urban areas (64).

As mentioned by Muramatsu et al. (2007), in addition to people's dependency levels, a further influence on which care setting people end up in may be the combination of their living arrangements and the characteristics of the region in which they live (60). In this case, the authors found that, although living in a State with higher HCBS expenditures

was associated with lower risk of NH admission among childless older people, this association was not statistically significant among those with living children.

Conversely, two studies from South Korea compared those receiving care in three geographical regions (metropolitan, small city and rural area) and found that, while there was a significantly higher percentage of people receiving home care in a metropolitan area, the reverse was true for those living in a rural area (71,72).

Behavioural problems

Aggressive behaviour, physical or verbal towards other LTC users, nursing staff or others care workers is not uncommon in LTC care settings. Thus, in order to better prepare and alert staff for this type of care user, several studies have been conducted, using a range of methods, to identify the main features of behavioural problems, and their severity.

Again, in this area, the literature offers a contradictory picture: whereas some authors found no statistically significant differences between NH and HCBS populations (68,74), others concluded that the former group had a higher percentage of people with behavioural problems (64,67,71,75) and others reached to an opposite conclusion (62).

Rothera et al. (2003) used the Neuropsychiatric Inventory scale to assess non-cognitive psychiatric features (e.g., elation/ euphoria, apathy/ indifference, disinhibition, irritability/lability, motor disturbance, night-time behaviours, appetite/eating) and concluded that 92% and 83% of the NH and HCBS populations, respectively, had at least one disturbed behavioural problem (74). There was, however, no statistically significant difference in terms of the total number of behavioural problems or the severity of disturbance between the populations. Another study resulted in a similar conclusion: the authors used a short version of the Cohen-Mansfield Agitation Inventory scale with a cohort of people with a diagnosis of dementia (mild, moderate or severe), and also found no statistically significant differences in the prevalence of behaviour problems between both populations (68).

Four other studies, however, reached different conclusions. In Xie et al. (2002), not only was the percentage of people with behavioural problems on admission, such as verbal or physical aggression or danger of self-harm, higher among those in NH (53% vs 30%), but also the presence of such problems was strongly associated with requiring a high level of institutional care (67). Wieland et al. (2010), using features such as wandering, verbal abuse, physical abuse and socially inappropriate behaviour, also found a significantly higher prevalence of all these symptoms among people in NH, when compared with those receiving community care (75). Lee et al. (2015), after assessing 14 behavioural problems, found statistically significant differences between the average

numbers of problems of the two populations (71). In this case, while those receiving institutional care had on average 3.6 behavioural problems those receiving HCBS had on average 2.4. Finally, Penning et al. (2016) in Canada assessed problematic behaviour by examining data on wandering, verbal abuse, physical abuse, disruptive behaviour and resisting care, using a score ranging from 0 to 5, with higher scores indicating more behavioural problems (64). They found that fewer behaviour problems decreased the risk of being admitted to a NH by 23%.

More recently, Lee et al. (2014) reached an opposite conclusion. After assessing behavioural symptoms by using the presence or absence of 16 items, the authors concluded that people who received care only in NH had fewer behavioural problems (an average of 4.5) than those receiving only home care (average of 4.6 problems) or combined care (average of 5.2 problems) (62).

Depression

Similarly to the previous case, symptoms of depression are also experienced by those receiving LTC, so accurate information on this needs to be gathered by nursing staff in order to minimise its effects on people's recovery.

Researching this area, Rothera et al. (2003) adopted the Geriatric Depression Scale, using a score ranging from 0 to 20, with higher scores indicating more depression levels (74). They found that, although the median depression score was higher among those in NH (7 points, ranging from 0-18 points) than for those in HCBS (5 points, ranging from 0-19 points), clinical depression was not associated with the type of care provided. Similar to the previous case, Gruber-Baldini et al. (2007) also found - though without statistical significance - a higher prevalence of depression among those in NH (around 47%), than with those receiving community care (around 30%) (59).

Contradictorily, after using the Cornell Scale for Depression in Dementia to record the depressive symptoms, Sloane et al. (2005) found statistically significant differences between the two populations, with those receiving care at home (4.5 points) having more depression symptoms than those in NH (3.6 points) (68).

More recently, two studies from Canada used the Depression Rating Scale, with the scores ranging from 0 to 14 points, with the higher values indicating more numerous or frequent symptoms (51,64). In Bartfay et al. (2016), not only were these symptoms more prevalent among the people in the institutions, they were also positively associated with late diagnosis of dementia (51). Penning et al. (2016) assessed LTC trajectories over a 4-year period and found no significant depression symptoms related to any specific population (64).

Psychological Well-Being

Frytak et al. (2001) adopted the SF-36 Short-Form Health Survey using a score ranging from 0 to 100 points, with a high score indicating high psychological well-being (79). In this case, although people in HCBS presented a higher score on admission than those in NH, after controlling for other health and social variables no significant differences were found between them. Nevertheless, other variables included in the psychological well-being model such as the perceptions of staff, pain interference in performing ADL, general health status and involvement in solo activities, were significantly related to the initial status.

Pain and Discomfort

In Oregon, USA, Frytak et al. (2001) measured the frequency of occurrence of seven items, namely: aches and pains in joints or muscles, chest pain, shortness of breath, dizziness, itching and burning, headaches and coughing (79). Although the authors found no significance differences between both populations, being female, having a diagnosis of congestive heart failure, with poorer general health and more physical disabilities were more likely to report higher levels of pain and discomfort on admission. Finally, in another study from Canada, Bartfay et al. (2016) found not only a higher prevalence of daily pain symptoms among people receiving home care but also that the presence of pain was negatively associated with late diagnosis of dementia (51).

Length of care

On the differences between the length of care in each care setting, two studies from the USA reached different findings (59,68). Gruber-Baldini et al. (2007) found that the length of stay of those in NH (896 days) was longer than those in HCBS (740 days), but de Sloane et al. (2005) concluded the opposite (329 vs. 336 days).

Young et al. (2015) examined whether 'Ageing in place' delays NH admission among New York State home care beneficiaries and concluded that between 2007 and 2012, the average length of care at home before NH admission increased from 8 to 17 months, enhancing the importance of the 'Ageing in place' policy (63).

Table 11: Comparing characteristics of Nursing Homes and Home and Community-Based Services populations

Ref	Year	Age	Gender	Social support	Level of education	Physical function	Cognitive function	Medical conditions	Other dimensions
(Challis et al., 2000) (78)	2000					NH: more dependent;	NH: more impaired;	NH: more people with dementia;	
(Tomiak et al., 2000) (56)	2000	NH: older;	NH: higher percentage of male;	NH: less social support;	NH: more people with higher education;			NH: higher burden of comorbidities	Region of care: urban area associated with NH admission;
(Chiu, Shyu and Liu, 2001) (66)	2001	No differences;	No differences;	NH: less social support;		No differences;			
(Frytak et al., 2001) (79)	2001					NH: more dependent;			Psychological well-being: no differences; Pain and discomfort: no differences;
(Borrayo et al., 2002) (57)	2002	NH: older;	NH: higher percentage of male;	NH: more likely to be widowed /never married/ divorced;		NH: more dependent;	No differences;	NH: lower burden of comorbidities;	Region of care: urban area associated with NH admission;
(Xie et al., 2002) (67)	2002	No differences;	NH: higher percentage of male;	NH: less social support;		NH: more dependent;			Behavioural problems: higher percentage in NH;
(Rothera et al., 2003) (74)	2003		NH: higher percentage of male;			NH: more dependent;	NH: more impaired;		Behavioural problems: no differences; Depression: higher percentage in NH;
(Kim and Yang, 2005) (58)	2005	NH: older;	NH: higher percentage of females;	NH: more likely to be widowed /never married/ divorced;					
(Sloane et al., 2005) (68)	2005	No differences;	No differences;	NH: more likely to be widowed /never married/ divorced;	NH: fewer people with higher education;	NH: more dependent;	NH: more impaired;	NH: higher burden of comorbidities;	Behavioural problems: no differences; Depression: higher percentage in HCBS; Length of care: longer in NH;

Ref	Year	Age	Gender	Social support	Level of education	Physical function	Cognitive function	Medical conditions	Other dimensions
(Gruber-Baldini et al., 2007) (59)	2007	NH: older;	No differences;			NH: more dependent;		NH: more people with dementia;	Depression: higher percentage in NH; Length of care: longer in HCBS;
(Muramatsu et al., 2007) (60)	2007	NH: older;		NH: more likely to be widowed /never married/ divorced; NH: less social support;	NH: more people with higher education;	NH: more dependent;	NH: more impaired;		
(Kuo et al., 2010) (69)	2010	No differences;	No differences;	No differences between the settings;		NH: more dependent;	NH: more impaired;		
(Wieland et al., 2010) (75)	2010	No differences;	NH: higher percentage of males;	NH: more likely to be widowed /never married/ divorced;	No differences;			NH: more people with heart diseases, anaemia, cancer, renal failure and dementia;	Behavioural problems: higher percentage in NH;
(Häcker and Hackmann, 2012) (61)	2012	NH: older;	NH: higher percentage of females;						
(Luppa et al., 2012) (49)	2012	NH: older;	No differences;	NH: more likely to be widowed /never married/ divorced;	No differences;	NH: more dependent;	NH: more dependent;	No differences;	
(Kane et al., 2013) (80)	2013					NH: more dependent;	NH: more dependent;		
(Kim, Kwon and Shin, 2013) (70)	2013	No differences;	NH: higher percentage of females;			NH: more dependent;	NH: more impaired;	NH: lower burden of comorbidities;	
(Schwarzkopf et al., 2013) (81)	2013	NH: older;	NH: higher percentage of females;			NH: more dependent;			

Ref	Year	Age	Gender	Social support	Level of education	Physical function	Cognitive function	Medical conditions	Other dimensions
(Lee et al., 2014) (62)	2014	NH: older;	NH: higher percentage of females;	NH: less social support;		NH: more dependent;	NH: more impaired;		Behavioural problems: higher percentage in HCBS;
(Wu et al., 2014) (76)	2014			NH: less social support;	NH: fewer people with higher education;	NH: more dependent;			Region of care: urban area associated with NH admission;
(Lee et al., 2015) (71)	2015	NH: older;	NH: higher percentage of females;			NH: less dependent;	NH: more impaired;		Region of care: urban area associated with HCBS care; Behavioural problems: higher percentage in NH;
(Wübker et al., 2015) (65)	2015	NH: older;		NH: less social support;		NH: more dependent;			
(Young et al., 2015) (63)	2015	NH: older;	NH: higher percentage of females;					NH: more people with hypertension, bowel incontinence and dementia;	
(Bartfay, Bartfay and Gorey, 2016) (51)	2016	NH: older;	NH: higher percentage of females;	NH: more likely to be widowed /never married/ divorced;		NH: more dependent;	NH: more dependent;	NH: more people with Parkinson's disease, Diabetes mellitus and renal disease;	Pain scale: more symptoms in HCBS people; Depression: higher percentage in NH;
(Lee and Cho, 2016) (72)	2016	NH: older;	NH: higher percentage of females;	NH: less social support;				NH: higher burden of comorbidities;	Region of care: urban area associated with HCBS care;
(Newcomer et al., 2016) (73)	2016	NH: older;	NH: higher percentage of females;	NH: fewer people living alone;		NH: more dependent;			
(Penning et al., 2016) (64)	2016	NH: older;	NH: higher percentage of females;	NH: more likely to be widowed /never married/ divorced; No differences in social support;		NH: more dependent;		NH: higher burden of comorbidities;	Behavioural problems: higher percentage in NH; Depression: no differences;

Legend: NH: Nursing Homes; HCBS: Home and Community-Based Services

2.3. Outcomes in long-term care

The outcomes in the LTC sector result from a complex interplay among different characteristics of the services' recipients, the care environment and the services provided. Although NH and HCBS seem to offer similar services, they differ in terms of frequency, intensity and supervision (6,7). Consequently, the expected outcomes may also be different between the settings.

Even though most studies included in this present review analyse the differences between NH and HCBS populations, only few have compared their outcomes (7). For this work, the term *outcome* is defined by the difference between scores in at least two moments in time, regardless of the area analysed, and/or the destination after discharge. An *outcome*, then, can be seen as positive (dependency level at a point later than admission lower than it was on admission), negative (dependency level at a point later than admission higher than it was on admission) or null (dependency level at a point later than admission the same as it was on admission).

In order to identify the main differences between NH and HCBS patients' outcomes, three main groups of analyses were defined: dependency levels, mortality and other dimensions.

2.3.1. Dependency levels

Physical functions

On the outcomes of physical functions in both care settings, the literature - again - offers differing findings (82,83). While some studies found no significant differences in the deterioration of ADL functions between NH and HCBS populations (66,68,79), others found better outcomes in HCBS people (62,71,72,74,80) and one study found that only the NH population showed some ADL improvements (58).

No differences between both populations

In order to compare the cost-effectiveness between people with severe stroke at four care settings (hospital chronic care, NH, home care and family care), Chiu et al. (2001) assessed people's physical status at four moments in time, using the Katz Index (66). Based on this analysis, the authors found no significant improvement in ADL scores at the end of the third month, for either in NH or home care. In a study from the USA, Frytak et al. (2001) studied the differences in outcomes trajectories for ADL between both care settings and found that, although the type of setting was strongly related to functional

ability on admission, it was not significantly associated with functional improvement (79). Finally, after adjusting for baseline age, gender, race, education, marital status, length of time since admission, cognitive status and comorbidities, Sloane et al. (2005) found no statistically significant differences in the mean rate of decline in ADL between the care settings, for either the mild dementia cohort or the moderate-to-severe dementia cohort (68).

Better outcomes in the HCBS population

In a cohort of older people admitted for long-term nursing and home care in the UK, Rothera et al. (2003) compared the differences between the admission and the follow-up scores on the daily activity “continence” using the Barthel Index (74). In this case, 70% of the HCBS people considered as “high needs” on admission improved their function ability, the equivalent figure was 22% among those in NH.

Kane et al. (2013) assessed the impact of increased investment in HCBS care in seven states in the USA, and concluded that after three months there had been a higher proportionate increase of people with no ADL dependencies in the HCBS program than in the NH (80).

After assessing two cohorts of LTC people with dementia, one observing people over one year (2008 and 2009) and the second over a period of two years (2008-2010), Lee et al. (2014) offered a number of conclusions on the performance of basic (i.e., ADL) or more complex (i.e., IADL) activities (62). In the first cohort, while around 42% of all patients improved their ability to perform ADL (45% of those who had only home care, 41% of those receiving only institutional care and 36% of those receiving combined care), only 27% improved the ability to perform IADL (30% of those receiving only home care, 26% of those receiving only institutional and 27% of those receiving combined care). Regarding the second cohort, 45% of all patients improved their ability to perform ADL (49% of those receiving only home care, 44% of those receiving only institutional and 39% of those receiving combined care). And 29% of all people improved their ability to perform IADL (32% of those receiving only home care, 28% of those receiving only institutional and 27% of those receiving combined care). Finally, after controlling for several covariates, the people in home care had a significantly lower average ADL/IADL scores than those in NH at the second cohort, indicating a better physical status.

Moreover, in a study comparing the outcomes of older adults in NH and home care settings, Lee et al. (2015) concluded that dependency in performing daily activities after one year was significantly lower in the home care group, that is, this group was less deteriorated than those in NH (71). A similar finding by Lee and Cho (2016) in Japan

(72). After looking at changes in rehabilitation needs after one year, the authors found significantly greater improvements in older adults with stroke who received care at home, than in those in NH. The data on their dependency levels (with level 1 being the most dependent and level 3 being the least dependent) showed that whereas 47% of those receiving home care remained at level 2, 42% improved to level 3 or higher and 11% worsened to level 1, these percentages at the NH group stood at 63%, 21% and 16%, respectively.

Better outcomes in NH population

In order to assess the cost-effectiveness of treating people with stroke in NH and HCBS, Kim and Yang (2005) used an ADL index constructed from self-performance scores in four ADL domains (bed mobility, toileting, transferring and eating) (58). In this case, not only those in NH presented a better physical function both on admission and after three months, comparing both scores, only functional improvement was statistically significant among these people.

Cognitive status

Although less frequently than the physical functions, some studies have also assessed changes in cognitive status between two moments in time. Similarly to the previous case, the results are not consistent.

No differences between both populations

After adjusting for several characteristics (age, gender, race, education, marital status, length of time spent in care, cognitive status, and number of comorbid conditions), Sloane et al. (2005) found no statistically significant differences in the mean rate of cognitive decline after one year between the two care settings, for either the mild dementia cohort or the moderate-to-severe dementia cohort (68). A similar finding in Kim and Yang (2005) study (58). After using the Cognitive Performance Scale to assess the cognitive status of people with stroke who were receiving NH or HCBS care, the authors concluded that both populations presented similar scores between the baseline level and after three months

Better outcomes in HCBS population

Conversely, other studies have found better cognitive outcomes among those receiving HCBS, than among those in NH. In this case, after using the Mini Mental State Examination, Rothera et al. (2003) found that whereas 66% of the people in HCBS considered as “high needs” on admission improved their cognitive function “orientation”,

this percentage stood at 11% among those in NH (74). More recently, after assessing two cohorts of people in LTC the authors reached several conclusions regarding cognitive status (62). While 36% of the people of the first cohort (2008 and 2009) had some cognitive improvement, 38% did so from the longer cohort (2008-2010). Similarly to the case with physical improvement, in both cohorts the number of people with cognitive improvement was higher among those receiving only home care (around 38%) than for those receiving only institutional (around 36%) or combined care (around 34%).

2.3.2. Mortality

Since the number of deaths in the LTC sector is inevitably high, it is important to estimate the expected length of survival after a person's admission and identify the main mortality predictors so that policy-makers can optimise the planning of services provision. On this topic, three studies have found no significant differences in mortality rates between NH and HCBS populations, either after adjusting for baseline variables (68), when comparing patients receiving care exclusively in NH, HCBS or combined care (62) or after one year of follow-up (52). Others have found a higher mortality among those in NH (59,61,75), and another one studied the patterns and determinants of LTC trajectories (64).

In the first study, although the crude mortality rate of people in NH was higher than that of those receiving HCBS care, for both mild and moderate-to-severe dementia subgroups, after controlling for several baseline characteristics (age, gender, race, education, race, education, marital status, length of stay, cognition, and comorbidity) the authors found no significant differences between the care settings in the death rate per 100 people per quarter (68). As in Lee et al. (2014) study, after using a cohort of people with dementia with at least one contact with any LTC service between 2008-2010, the authors found no statistically significant differences in the mortality rates between those receiving only home care (20%), only institutional care (19%) or combined care (21%) (62). Finally, after comparing several outcomes between both care settings, Blackburn et al. (2016) in the USA also found no statistically significant differences between the mortality rates of people in institutions (24%) and out of institutions (22%) after one year of follow-up (52).

In the second case, two studies found not only that the annual mortality rates were higher in the NH setting than in the community (59,61), but also that the mortality risk at admission was significantly higher among those admitted to NH (75). In this last case, after stratifying the cohort by risk level, the proportion of people in NH with moderate-to-high mortality risk people in NH (72%) was also greater than for those in HCBS (59%).

More recently, after studying the patterns and determinants of LTC trajectories in a Canada health region using estimated latent transition probabilities by year (2008-2010), Penning et al. (2016) concluded that the risk of mortality was higher among those admitted to NH (ranged 16% to 23%), than for those receiving home care (range 7% to 17%) (64). On the other hand, older age, male gender and having more chronic conditions were some factors associated which increased the likelihood of mortality in both settings.

However, in spite of the wide range of magnitudes between the studies, several authors have concluded that the most important mortality risk factors are usually older age, male gender, the absence of a social support network, the presence of certain medical conditions (e.g., neoplasms, musculoskeletal or respiratory diseases) and high levels of cognitive and physical dependency (84–87).

2.3.3. Other dimensions

In order to compare the differences between the outcomes of the two care settings, several others dimensions have been analysed such as pain and discomfort, psychological well-being, rates of withdrawals, depression and behavioural problems (62,68,79).

On pain and discomfort, even though the people included in the Oregon study of Frytak et al. (2001) experienced an increasing rate after six months and one year of their LTC enrolment, the type of care setting did not influence these changes (79). According to the authors, with the exception of patients with a diagnosis of stroke, none of the variables in the pain and discomfort model were a good predictor of the acceleration rate. Similarly to the previous case, these authors also concluded that the care setting had no significant influence on the changes of psychological well-being status.

On changes in withdrawal rate, Sloane et al. (2005), after looking at depressive symptoms and behaviour problems over one year after LTC enrolment, found no significant differences between people in the home care and NH settings, either for the mild dementia cohort or the moderate-to-severe dementia cohort, after adjusting for baseline characteristics (age, gender, race, education, marital status, length of stay, cognitive status and comorbidities) (68). More recently, after assessing people enrolled in LTC from 2008 to 2010, Lee et al. (2014) found significant differences in the percentages of people with improvements in their behaviour problems over this period of time (62). In this case, the number of people with a better score in 2010 than at

baseline was lower among those receiving only NH (62%), than for those receiving only home care (63%) or combined care (66%).

Table 12: Comparing the outcomes between Nursing Homes and Home and Community-Based Services populations

Ref	Year	Physical improvement	Cognitive improvement	Mortality	Other dimensions
(Chiu, Shyu and Liu, 2001) (66)	2001	No differences;			
(Frytak et al., 2001) (79)	2001	No differences;			Pain and discomfort: no differences; Psychological well-being: no differences;
(Rothera et al., 2003) (74)	2003	HCBS: better outcomes;	HCBS: better outcomes;		
(Kim and Yang, 2005) (58)	2005	NH: better outcomes;	No differences;		
(Sloane et al., 2005) (68)	2005	No differences;	No differences;	No differences;	Withdrawal rate: no differences; Depressive symptoms: no differences; Behaviour problems: no differences;
(Gruber-Baldini et al., 2007) (59)	2007			NH: higher mortality;	
(Wieland et al., 2010) (75)	2010			NH: higher mortality;	
(Häcker and Hackmann, 2012) (61)	2012			NH: higher mortality;	
(Kane et al., 2013) (80)	2013	HCBS: better outcomes;	HCBS: better outcomes		
(Lee et al., 2014) (62)	2014	HCBS: better outcomes;	HCBS: better outcomes;	No differences;	Behaviour problems: better outcomes in HCBS;
(Lee et al., 2015) (71)	2015	HCBS: better outcomes;			
(Blackburn, Locher and Kilgore, 2016) (52)	2016			No differences;	
(Lee and Cho, 2016) (72)	2016	HCBS: better outcomes;			
(Penning et al., 2016) (64)	2016			NH: higher mortality;	

Legend: NH: Nursing Homes; HCBS: Home and Community-Based Services

3. OBJECTIVES

The main goals of this thesis are to assess the RNCCI reform since 2006 considering several core dimensions, to identify the main characteristics of the NH/HCBS' beneficiaries, to assess their outcomes after treatment and to identify the main predictors of people's length of care (LOC). For these purposes, the thesis was developed along four main chapters, each one corresponding to a specific paper (**Figure 2**).

The first chapter assesses the LTC reform in Portugal since its inception, taking into account several core dimensions and, whenever possible, compares them with other European countries. Then, it analyses the evolution of its main features over the last decade and critically assesses the strengths and weaknesses of the RNCCI as a flagship of health policy achievement for Portugal. Finally, it identifies some of the main challenges ahead.

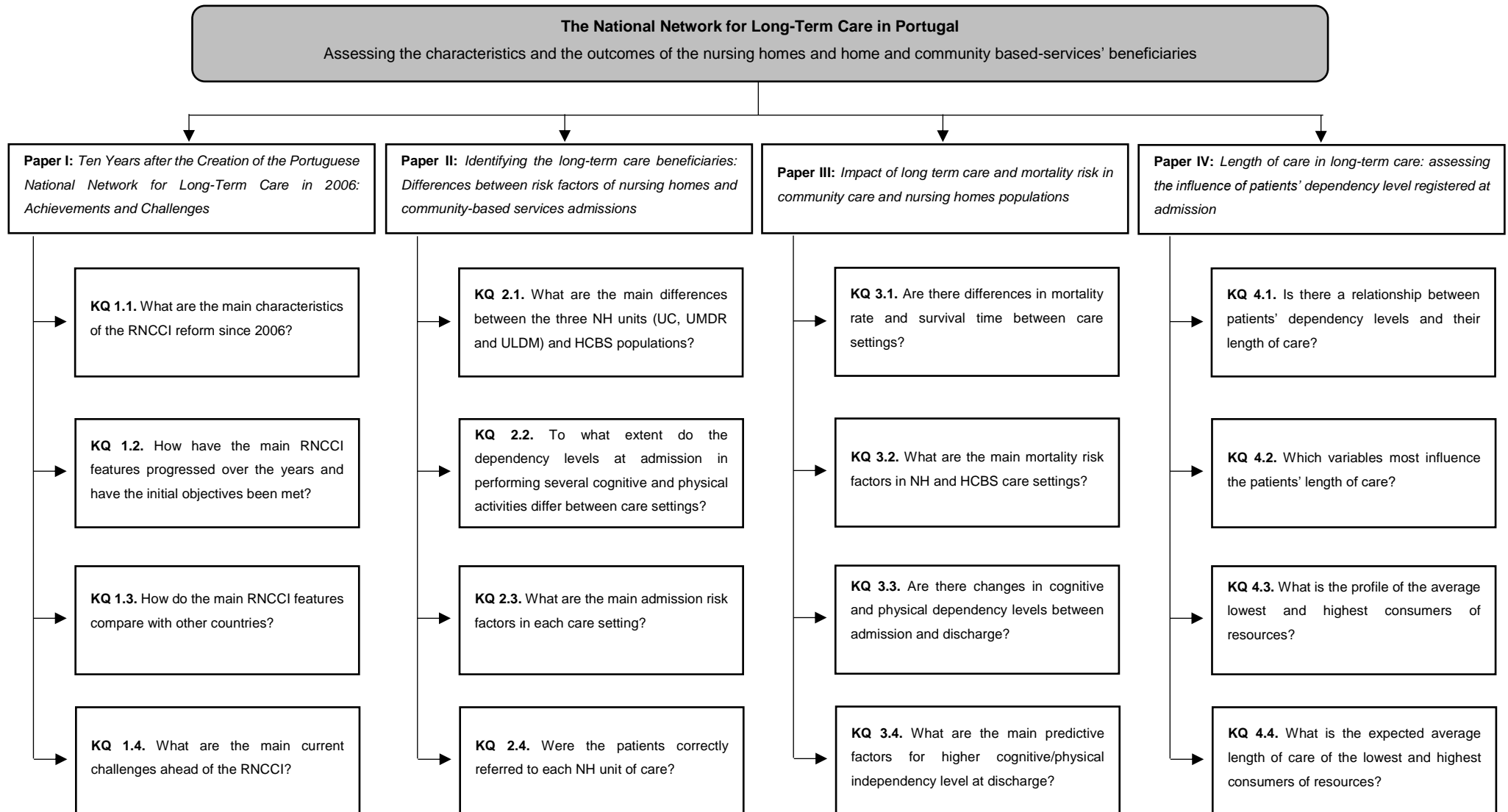
As for the following three chapters, we used the LTC national database.

The second chapter analyses the extent to which the populations of the LTC care settings differ from each other, in order to investigate the adequacy of the referral placement, considering the person's needs. Comparisons are made between the dependency levels - by reference to performance in several cognitive and physical activities - of those receiving home care and those receiving institutional care. Lastly, the chapter identifies some of the main admission risk factors for each care setting, and the numbers of patients correctly referred to each NH type of care unit after considering a number of characteristics of adjustment.

The third chapter studies two areas in the LTC sector that may help policy-makers and staff to improve the way care is provided to such a fragile population: mortality and patients' outcomes after treatment. Differences between NH and HCBS in mortality rate and survival time are assessed, and the main mortality risk factors in the two settings identified. The chapter then compared cognitive and physical dependency levels between admission and discharge in order to assess the outcomes in functionality after treatment, and identified the main predictive factors to be classified in a higher cognitive/physical independency level at discharge.

Finally, the last chapter assesses the influence of people' dependency levels as registered at admission on their LOC, in order to identify the main profiles of the lowest and highest consumers of resources, and to estimate the average LOC for both cases.

Figure 2 Key-Questions (KQ) defined in each paper



4. METHODOLOGY SUMMARY

In spite of each of the papers included in chapter 5 has a section on methodology, in this chapter a summary of the most important features concerning data source, criteria for inclusion and exclusion of participants and care settings, variables of interest and statistical analysis is presented.

This thesis fulfils all regulations of data protection and the findings of others authors are properly cited and the source identified.

There are no conflicts of interests to declare.

4.1. Data source

The database used in this thesis was created considering the information gathered on the national monitoring platform, called “GestCare CCI”, which is responsible for the management and monitoring of the RNCCI placement circuit, for the characterization of patients’ demographic, social and dependency levels, as well as for the management of NH beds and HCBS treatment places. As mentioned before¹¹, although this platform currently gathers various types of information for each individual admitted in a LTC setting - in order to identify the level of dependency of each one and, thus, define a specific care plan -, some were not available at the time of this work (e.g. adverse drug reactions, infections or consumables) and others lacked high-quality information (e.g. instrumental activities of daily living, risk of falls or diabetes assessment).

Thus, in order to construct our database, we included two types of data (Table 13):

- a) General information, which includes patients’ identification numbers, admission/discharge dates, placement process dates, region of care, care setting and referral entity;
- b) Bio-psychosocial Assessment Instrument¹² (*Método de Avaliação Biopsicossocial, MAB*) is a structured and standardized instrument of screening for biopsychosocial classification. Regarding its creation, this instrument was developed as part of a PhD thesis and applied by a single investigator in a convenience sample of 152 people aged 65 or over, followed in a primary care centre in Lisbon (39). Subsequently, was used in a sample of 2,516 people aged 55 years and older, representative of the population of Mainland Portugal, with the participation of a dozen inquirers, a team of researchers and a team of study

¹¹ For further information, please see 2.1.6. Needs assessment instrument

¹² For further information, please see Appendix 2 – Bio-psychosocial Assessment Instrument

coordinators (88). The main goal of this epidemiological study was to identify the profile of ageing and the prevalence of dependencies of the Portuguese population. Finally, since 2007, MAB has been used as the instrument to identify the dependency levels of patients receiving care at RNCCI (89).

For the purpose of this thesis we included two set of variables collected by the MAB:

- Sociodemographic features for each patient: age, gender, marital status, level of education, availability of family/neighbour support and medical conditions; and
- Information regarding their overall status in the three dimensions assessed by this Instrument (cognitive, activities of daily living and locomotion), as well as the dependency level in performing each of its activities. With the exception of those who deceased, we identified these dependency levels on both admission and discharge.

The data used was provided by the Portuguese Central Administration of Health System (ACSS), entity responsible for managing the Portuguese long-term care system. Before sharing the data, all patients' identifiers, such as patients' identification in each setting of care and patient record were anonymized. Variables like name, social security number, phone number or address were not shared with researchers.

4.1.1. Limitations

Despite the existence of a standard instrument across the country that allows LTC staff to assess patients' physical and cognitive dependency levels, several limitations may be point out:

- i. It is not possible to combine all the information captured into a single index in order to identify the overall status for each patient. Thus, not only the use of this instrument for benchmarking analyses between institutions becomes limited, it is not possible to use it for reimbursement purposes to differentiate the financing of each LTC unit of care based on patients' casemix.
- ii. The difference on how the overall status is determined in each dimension¹³ - where the physical status is determined by considering the lowest score obtained in the activities assessed, and the cognitive status is determined by the average score of the ten activities analysed -, can bias the determination of the overall dependency level of each patient.

¹³ For further information, please see 2.1.6. Needs assessment instrument

- iii. Given the scarce information regarding all medical conditions for each patient, besides the admission diagnosis, it is not possible to identify and differentiate patients' comorbidity burden in each setting of care.
- iv. Finally, additional variables that may influence the overall results - such as the ability to perform more complex activities (e.g. instrumental activities of daily living), transitions between settings of care, or other risk factors (like smoking, obesity, alcohol and drugs) - were not analysed due to their poor quality or lack of availability.

Table 13: GestCare CCI database – General information

Dimension	Variable	Items	Type of variable	Score	Obs.
General					
	ID Episode		String	-	Anonymized
	ID Patient		String	-	Anonymized
	Admission date		Date	-	-
	Discharge date		Date	-	-
	Length of care		Scale	-	Days of care
	Placement process: ECL to ECR		Scale	-	Days between phases
	Placement process: ECL to Admission		Scale	-	Days between phases
	Placement process: ECR to Admission		Scale	-	Days between phases
	Region of care	North Centre Lisbon and Tagus Valley Alentejo Algarve	Nominal	-	-
	Death	Yes No	Nominal	-	-
	Care setting	Convalescence Unit Medium Term and Rehabilitation Unit Long-Term and Maintenance Unit Home and Community-Based Services	Nominal	-	-
	Referral entity	Hospital: General Surgery Hospital: Internal Medicine Hospital: Neurology Hospital: Orthopaedics Other entities	Nominal	-	-
MAB: Biological					
	Gender	Male Female	Nominal	-	-
	Age		Scale	-	Years
	Medical condition	ICD-9-MC codes	Nominal	-	-
	Activities of daily Living status *		Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed: admission / discharge
		Activity: Transferring (bed)	Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed: admission / discharge
		Activity: Transferring (chair)	Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed: admission / discharge
		Activity: Dressing	Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed: admission / discharge
		Activity: Feeding	Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed: admission / discharge
		Activity: Toileting	Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed: admission / discharge
		Activity Living: Bathing	Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed: admission / discharge
		Activity: Continence (defecation)	Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed: admission / discharge

Dimension	Variable	Items	Type of variable	Score	Obs.
	Activity: Continence (urination)		Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed: admission / discharge
	Locomotion status *		Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed: admission / discharge
	Activity: Walking at home		Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed: admission / discharge
	Activity: Walking in the street		Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed: admission / discharge
	Activity: Climbing stairs		Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed: admission / discharge
MAB: Psychological					
	Cognitive status **		Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed: admission / discharge
	Temporal orientation: Year		Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed: admission / discharge
	Temporal orientation: Month		Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed: admission / discharge
	Temporal orientation: Day		Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed: admission / discharge
	Temporal orientation: Season		Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed: admission / discharge
	Temporal orientation: Day of the week		Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed: admission / discharge
	Spatial orientation: Country		Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed: admission / discharge
	Spatial orientation: Province		Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed: admission / discharge
	Spatial orientation: City/town		Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed: admission / discharge
	Spatial orientation: Home		Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed: admission / discharge
	Spatial orientation: Floor		Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed: admission / discharge
MAB: Social					
	Level of education	Illiterate 1-6 7-12 13+ years	Nominal	-	-
	Marital status	Married Widow Single Divorced	Nominal	-	-
	Family/neighbour support	With Support Without Support	Nominal	-	-

* Status determined by considering the lowest score obtained in each activity assessed; ** Status determined by the average score of the ten activities assessed.

Table 14: GestCare CCI database – Bio-psychosocial Assessment Instrument

Dimension	Variable	Items	Type of variable	Score	Obs.
Biological					
	Gender	Male Female	Nominal	-	-
	Age		Scale	-	Years
	Medical condition	ICD-9-MC codes	Nominal	-	-
	Activities of daily Living		Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed at admission and discharge
		Activity: Transferring (bed)	Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed at admission and discharge
		Activity: Transferring (chair)	Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed at admission and discharge
		Activity: Dressing	Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed at admission and discharge
		Activity: Feeding	Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed at admission and discharge
		Activity: Toileting	Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed at admission and discharge
		Activity Living: Bathing	Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed at admission and discharge
		Activity: Continence (defecation)	Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed at admission and discharge
		Activity: Continence (urination)	Ordinal	0= Incapable; 1= Dependent; 2= Autonomous; 3= Independent	Assessed at admission and discharge

Dimension	Variable	Items	Type of variable	Score	Obs.
Psychological					
	Cognitive status		Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed at admission and discharge
		Time orientation: Year	Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed at admission and discharge
		Time orientation: Month	Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed at admission and discharge
		Time orientation: Day	Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed at admission and discharge
		Time orientation: Season	Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed at admission and discharge
		Time orientation: Day of the week	Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed at admission and discharge
		Spatial orientation: Country	Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed at admission and discharge
		Spatial orientation: Province	Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed at admission and discharge
		Spatial orientation: City/town	Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed at admission and discharge
		Spatial orientation: Home	Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed at admission and discharge
		Spatial orientation: Floor	Ordinal	0= Bad; 1= Unsatisfactory; 2= Satisfactory; 3= Good	Assessed at admission and discharge
Social					
	Level of education	Illiterate 1-6 7-12 13+ years	Nominal	-	-
	Marital status	Married Widow Single Divorced	Nominal	-	-
	Family/neighbour support	With Support Without Support	Nominal	-	-

Legend: ICD-9-CM: International Classification Of Diseases, Ninth Revision, Clinical Modification

4.2. Participants and Care settings

Although the dataset had information on 27,832 patients, we excluded individuals receiving palliative care, those without information concerning their gender, marital status or family/neighbour support, cognitive and physical status at admission, as well as those aged up to 59 years old (Figure 3). Thus, the final population included in the cross-sectional studies consists of 20,984 individuals aged 60 or more, admitted and discharged in 2015, from all over the country.

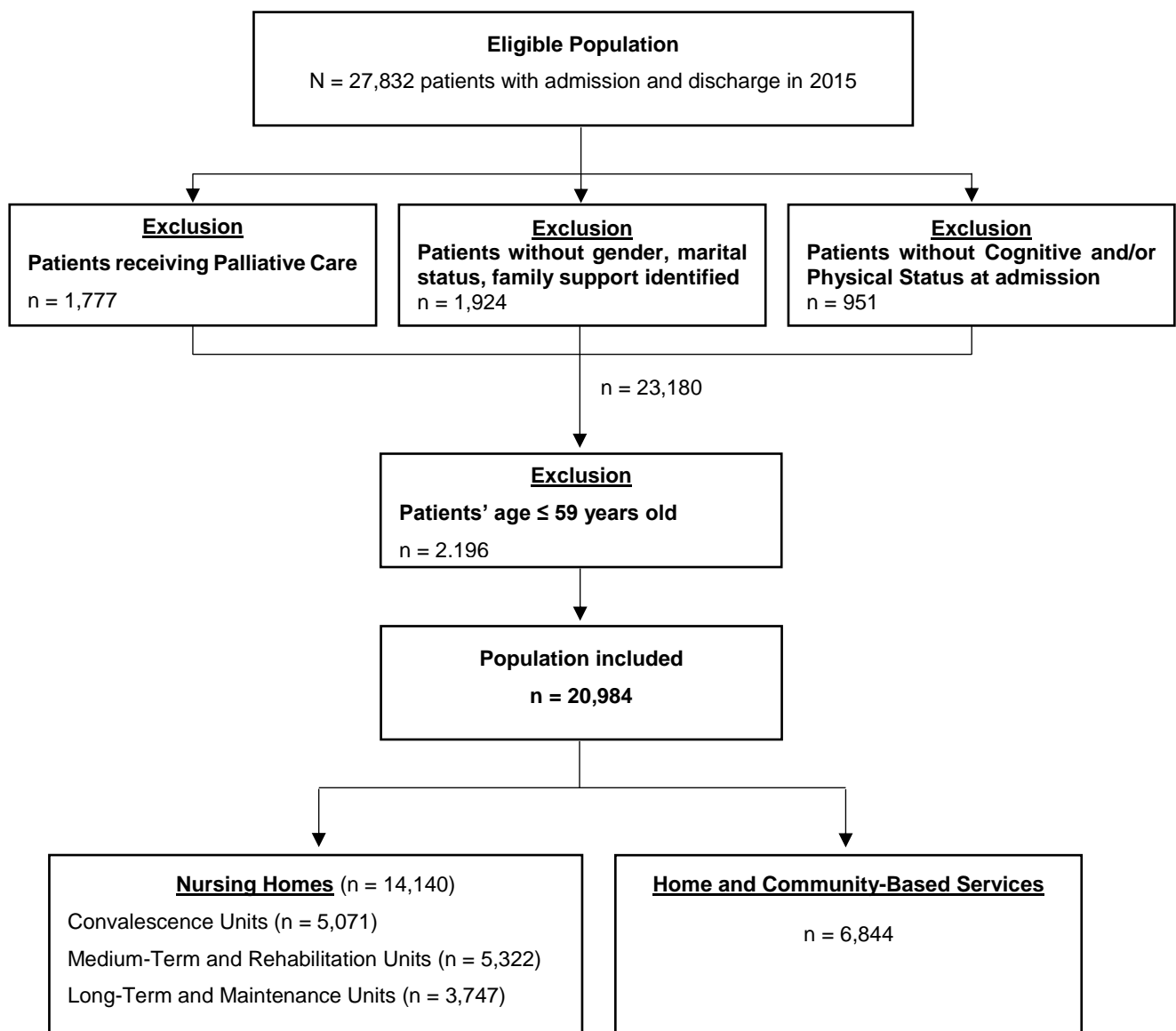


Figure 3: Study population and eligibility criteria

4.3. METHODOLOGY

The methodology adopted was defined according to the aim of each study.

4.3.1. Ten Years after the Creation of the Portuguese National Network for Long-Term Care in 2006: Achievements and Challenges

The goal of this work is to offer an assessment of the policies implemented in the last decade regarding the formal creation of the RNCCI in 2006, and aiming at vertically integrate primary care, hospital care and long term care under the umbrella of the NHS.

In order to achieve the previous goal, this paper's methodology can be described in the following four main stages:

- I. First, we reviewed several information regarding the RNCCI since its inception published in the literature, national reports and data publicly available;
- II. Based on the previous background, we were able to identify the main actors involved, the partnerships between them and the legislative framework in order to achieve the RNCCI goals. Thus, this second stage culminated with the definition of the main pillars of the RNCCI;
- III. Then, at the same time that we assessed the RNCCI achievements and failures in each pillar, we seek to, whenever possible, compare it to what's in place in other countries;
- IV. Finally, based on the differences between the forecasted goals and the real achievements, we identified some of the current challenges and the ongoing developments, as well as the main strengths and weaknesses associated to the RNCCI.

As mentioned in this manuscript, the information presented had not been collated previously or made available to an international audience.

4.3.2. Who are the long-term care beneficiaries? Differences between nursing homes and community-based services populations

In order to explore, for the first time in Portugal, to what extent the three NH units (UC, UMDR and ULDM) and the HCBS populations differ from each other, this study aimed to investigate the placement adequacy in each setting of care, considering the individual's needs. For this matter, three main analyses were performed:

- We used the One-Way ANOVA to identify and compare the mean dependency scores at admission between settings of care, in each cognitive/physical activity.
- Then, in order to identify the main risk factors on the likelihood that an individual receives care at NH/HCBS setting, a logistic regression was performed, using these settings of care as the dependent variables.
- Finally, since the three NH units of care follow an intrinsic order as the individuals' dependency level increases, the ordered logistic regression model was used to estimate the probability of a patient with certain characteristics to be placed in one of the units. Thus, since the Unit with the highest predicted probability ('NH Unit Expected') it is assumed to be the most appropriate for the patient, we compared the Unit where he/she was admitted ('NH Unit Observed') and the expected Unit given by the model ('NH Unit Expected').

In the two final analyses, three main sets of explanatory variables were included: sociodemographic characteristics such as age, gender, marital status, family/neighbour support, and educational level; medical conditions; and dependency levels such as cognitive and physical status at admission.

4.3.3. Impact of long term care and mortality risk in community care and nursing homes populations

This study aimed to identify the survival time, the mortality risk factors and the individuals' characteristics associated with cognitive and physical status at discharge, among the Portuguese LTC population.

Concerning the mortality assessment, the Kaplan-Meier survival analysis was conducted to determine the median survival time in the two main settings of care and within the three NH units of care. Then, a Cox Proportional Hazards Model was used to identify the predictive power of several variables (socio-demographic characteristics, medical conditions, cognitive and physical dependency level at admission, referral entity) for mortality risk in NH and HCBS settings of care.

As for the outcomes assessment, the Wilcoxon signed-rank test was used to measure changes in cognitive and physical dependency level between admission and discharge, both for all population and for only those alive at discharge. Then, two cumulative odds ordinal logistic regressions were run to determine the effect of several variables on the ability to predict the cognitive and physical status, using the dependency level at discharge as dependent variable. In this last analysis, only individuals alive at discharge were included.

4.3.4. Length of care in long-term care: assessing the influence of patients' dependency level registered at admission

This study aimed to analyse the influence of patients' physical and cognitive dependency levels at admission on their Lengths of Care (LOC), in each care setting. After a descriptive analysis on the LOC variable, some atypical behaviour was found in around 25% of our population, especially for patients receiving institutionalized care. In this case, the fact that there is a higher percentage of discharges at 30 and 90 days at UC and UMDR, respectively, may be related to the maximum expected LOC defined for each care setting, and not directly explained by patients' characteristics. Thus, after removing this atypical data, the cohort of this study consists of 15,752 patients.

For the regression modelling, we considered, for each care setting, the LOC (in days) as the dependent variable. Using the scores obtained by each patient after assessing their dependency status in each functional/cognitive activities, we included as explanatory variables the number of activities in which they were considered "dependent" (classification at admission with scores 0 or 1) in locomotion, activities of daily living and cognitive status. As covariates variables, we included patients' age (in years), gender, social network (availability or not of family/neighbour support) and the number of beds/treatment places per 1,000 inhabitants aged 65 or over.

Thus, the analysis on how the dependent variable LOC varies with the covariates was performed for each care setting using a Generalized Linear Model (GLM) with Gamma distribution, in order to account for the skewness of the density function of the LOC random variable, using an identity link function.

5. RESULTS

Until recently, the public sector was not involved in the provision of LTC: it was mainly provided by *Misericórdias* (non-profit-making institutions with a religious background). In June 2006, because of the increasing proportion of elderly persons in the population and the need to diversify the provision of services, the RNCCI was formally created.

Since then, there have been virtually no studies published on the evolution of the RNCCI since its inception, either comparisons of the forecast goals with outcomes or research on the beneficiaries of care.

This chapter, therefore, presents the results related to each of the four main objectives of this thesis.

5.1. Ten Years after the Creation of the Portuguese National Network for Long-Term Care in 2006: Achievements and Challenges

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Health Reform Monitor

Ten Years after the Creation of the Portuguese National Network for Long-Term Care in 2006: Achievements and Challenges[☆]

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ABSTRACT

The Portuguese National Network for Long-term Integrated Care (*Rede Nacional de Cuidados Continuados*, RNCCI) was created in 2006 as a partnership between the Ministry of Health and the Ministry of Labour and Social Solidarity. The formal provision of care within the RNCCI is made up of non-profit and non-public institutions called Private Institutions of Social Solidarity, public institutions belonging to the National Health Service and for-profit-institutions. These institutions are organized by type of care in two main settings: (i) Home and Community-Based Services and (ii) four types of Nursing Homes to account for different care needs. This is the first study that assesses the RNCCI reform in Portugal since 2006 and takes into account several core dimensions: coordination, ownership, organizational structure, financing system and main features, as well as the challenges ahead. Evidence suggests that despite providing universal access, Portuguese policy-makers face the following challenges: multiple sources of financing, the existence of several care settings and the sustained increase of admissions at the RNCCI, the dominance of institutionalization, the existence of waiting lists, regional asymmetries, the absence of a financing model based on dependence levels, or the difficulty to use the instrument of needs assessment for international comparison.

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1. Policy background

The current demographic and epidemiological transition is posing more challenges in developed countries, namely due to the increasing percentage of elderly and changes in patients' morbidity (e.g. increase of chronic diseases with longer treatment times) [1]. With a rapidly ageing population, Portugal is not an exception. This situation has worsened due to the effects of the economic crisis, which resulted in the emigration of fertile and active citizens [2].

Conscious that the adoption of new policies to (re)configure the health and social care is essential to face these new challenges, several historical milestones and partnerships between the Ministry of Health (MoH) and the Ministry of Labour and Social Solidarity (MLSS) culminated in the formal creation of the current National Network for Long-term Integrated Care (*Rede Nacional de Cuidados Continuados Integrados*, RNCCI).

Based on already existing institutions, the RNCCI has, as its backbone, the non-profit and non-public institutions known as Private Institutions of Social Solidarity (*Instituições Particulares de Solidariedade Social*, IPSS) [3], with the *Misericórdias* (religious non-profit-making institutions with a charitable background) being the main providers [4,5]. Based on the work developed with the IPSS, and in line with the redefinition of long-term care (LTC) services in many European countries due to the increasing number of dependents (Table 1) [6–9], the RNCCI was launched in 2006 [10]. Since then, besides the IPSS and public institutions, a growing number of for-profit-institutions with protocols with the MoH have emerged to provide LTC.

This is the first time that information about the RNCCI has been collated and made available to an international audience, as well as analysed to provide a thorough assessment of its achievement while providing some guidance to policy-makers on potential improvements and future challenges.

2. Main features of the Portuguese LTC system

The RNCCI embraces all forms of continuous, rehabilitation, palliative and nursing care for people with mental and physical lim-

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Table 1
Main characteristics of the long-term care system in selected countries.

Countries	Beneficiaries	Coordination	Organizational structure	Needs assessment instrument	Financing system ⁺	Beds per 1000 inhab. ≥ 65 years	Individuals treated per 1000 inhab. ≥ 65 years (NH/HCBS) ⁺⁺
France	Dependent persons (mainly individuals aged ≥60 years)	Central government (National Solidarity Fund for Autonomy) and departments (<i>les Conseils généraux</i>).	Personalized allowance for autonomy (<i>Allocation personnalisée d'autonomie</i> , APA), households (<i>établissements d'hébergement pour personnes âgées</i>) and long term inpatient units (<i>unités de soins de longue durée</i>).	<ul style="list-style-type: none"> • Dimensions assessed: ability to perform ADL. • Instruments used: <ol style="list-style-type: none"> a) Individuals aged up to 60 years: <i>Guide d'évaluation des besoins de compensation des personnes handi-capées</i> (GEVA) (no dependence levels); b) Individuals aged over 60 years: <i>Autonomie, Gérontologie, Groupe Isso Ressource</i> (AGGIR) (4 dependence levels). 	<ul style="list-style-type: none"> • Public spending on LTC as% of GDP: 1.89% (20% via cash benefits, 80% in-kind). • LTC as a share of current healthcare expenditure: 17.1%. 	53.1	n.a./n.a.
Germany	All insured persons depending on the extent of LTC needs, regardless the age	Central Association of Health Insurance Funds (<i>Spitzenverband</i>), Federal Association of LTC Insurance Funds (<i>Spitzenverband Bund der Pflegekassen</i>) and the Confederation of Municipal Authorities' Associations (<i>Bundesvereinigung der kommunalen Spitzenverbände</i>)	Home care (in-cash and in-kind), in day- or night-care institutions and nursing homes.	<ul style="list-style-type: none"> • Dimensions assessed: ability to perform ADL and IADL. • 4 dependence levels (I, II, III and hardship cases). 	<ul style="list-style-type: none"> • Public spending on LTC as% of GDP: 1.91% (31% via cash benefits, 69% in-kind). • LTC as a share of current healthcare expenditure: 17.1%. 	54.4	48.0/121.0
Italy	Dependent persons (mainly elderly)	Central government (<i>Istituto Nazionale Previdenza Sociale</i>), local health units (<i>aziende sanitarie locali</i>) and municipalities.	Community care, residential care and cash benefits.	The instrument used differs according to each region. Nevertheless, the multidimensional assessment is based on validated international standards.	<ul style="list-style-type: none"> • Public spending on LTC as% of GDP: 0.91% (42% via cash benefits, 58% in-kind). • LTC as a share of current healthcare expenditure: 10.1%. 	18.5	34.4/68.2
Netherlands	Dependent persons (mainly elderly)	Exceptional Medical Expenses Act (<i>Algemene Wet Bijzondere Ziektekosten</i>), regional care offices (<i>zorgkantoren</i>) and municipalities.	Home care, nursing homes and cash benefits.	<ul style="list-style-type: none"> • Under responsibility of the Centre for Care Assessment (<i>Centrum Indicatiestelling Zorg</i>). • Dimensions assessed: somatic, psycho-geriatric, physical, sensory or intellectual handicap, psycho-social problems. • There are no levels of dependence. 	<ul style="list-style-type: none"> • Public spending on LTC as% of GDP: 3.96%. • LTC as a share of current healthcare expenditure: 37.4%. 	73.9	84.2/183.7

Table 1 (Continued)

Countries	Beneficiaries	Coordination	Organizational structure	Needs assessment instrument	Financing system [*]	Beds per 1000 inhab. ≥ 65 years ^{**}	Individuals treated per 1000 inhab. ≥ 65 years (NH/HCBS) ^{**}
Portugal	Dependent persons (mainly elderly)	Central government (MoH and the MLSS), regional (<i>Administrações Regionais de Saúde</i>) and local (<i>Agrupamentos de Centro de Saúde</i>).	Nursing Homes (Convalescence Units, Medium Term and Rehabilitation Units and Long-Term and Maintenance Units), palliative care (National Network of Palliative Care) and home care.	<ul style="list-style-type: none"> • Dimensions assessed: biological, psychological and social. • Instrument used: Integrated Bio-psychosocial Assessment Instrument. • 4 dependence levels (incapable, dependent, autonomous and independent). 	<ul style="list-style-type: none"> • Public spending on LTC as% of GDP: 0.96% (1% via cash benefits, 99% in-kind). • LTC as a share of current healthcare expenditure: 10.7%. 	4.03	15.1/9.1
Spain	Dependent persons (mainly elderly)	Central government, regional (<i>Comunidades Autónomas</i>) and local entities.	Tele-care, home care, personal care help, residential care and day/night residential services.	The instrument used differs according to each region. Nevertheless, the multidimensional assessment is based on validated international standards.	<ul style="list-style-type: none"> • Public spending on LTC as% of GDP: 0.90% (33% via cash benefits, 67% in-kind). • LTC as a share of current healthcare expenditure: 9.8%. 	44.4	24.3/93.9
Sweden	Dependent persons (mainly elderly)	Regional authorities (<i>Skåne</i> and <i>Västra Götaland</i>), municipalities, county councils.	Home care, nursing homes, day activities, home nursing care, meal services, personal safety alarms and home adaptation.	The instrument used differs according to each region. Nevertheless, the multidimensional assessment is based on validated international standards.	<ul style="list-style-type: none"> • Public spending on LTC as% of GDP: 3.46% (4% via cash benefits, 96% in-kind). • LTC as a share of current healthcare expenditure: 31.5%. 	65.5	60.8/175.7

Source: France [6,23], Germany [6,23], Italy [6,7,23], Netherlands [8,23], Portugal [7,23], Spain [6,7,23], Sweden [6,23].

Note: The comparative countries were selected based on its geographical and cultural proximity (Spain, France and Italy), as well as for the more experience and diversity of services provided (Germany, Sweden and the Netherlands).

ADL: Activities of daily living; IADL: Instrumental activities of daily living; n.a.: not available; MoH: Ministry of Health; MLSS: Ministry of Labour and Social Solidarity.

^{*} Long-term care public expenditures, including both health and social components, in 2015 [29].

^{**} includes both public and private beds except for Portugal where only beds paid by the NHS are considered, data from 2015 [29].

itations, who are unable to take care of themselves without some support [10]. The following section identifies the main pillars of the LTC in Portugal and, whenever possible, compare them to other countries.

2.1. Beneficiaries

Similar to several European LTC systems (Table 1), the RNCCI offers universal coverage for those in a situation of physical or cognitive impairment, or requiring continuous health monitoring and social support [10]. Despite all inhabitants being eligible for LTC, the existence of regional asymmetries in care coverage still poses an important barrier to access to LTC. According to recent estimates, 93% of the Portuguese population had poor access to institutionalized care in 2014, given the lack of beds available [11].

2.2. Coordination

As in several European countries (Table 1), the Portuguese LTC system is decentralized and hierarchized, being managed at three governmental levels [2,5,7]: i) Central, where the MoH develops the national health policy and monitors its implementation; ii) Regional, where the five Regional Health Administrations implement the national health policies goals and coordinate all levels of health care; and iii) Local, where the Primary Care Trusts are responsible for providing home care and refer patients to LTC.

2.3. Organizational structure

As for care provision, given the cultural proximity between countries and the large experience in the provision of LTC, the Portuguese public system of LTC is based on the Catalan model (*CatSalut*) [12,13]. It is organized in two main settings of care: Home and Community-Based Services (HCBS) and Nursing Homes (NH) [10]. Human resources are not allocated according to patients' needs as in other European countries [6,7,9], but by the number of weekly hours of care a patient is entitled to receive from each professional category [14].

Regarding HCBS, the nursing, medical and rehabilitation care is provided at home between 8am to 8pm to people with functional dependence by teams working in primary care centres [15]. Individuals without a caregiver, in need of 24 h care or only social care are excluded. Initially there were four types of NH [10], i) Convalescence Units (*Unidades de Convalescença*, UC) provide medical, nursing and rehabilitation care on a daily basis to individuals with an expected maximum length of stay of 30 consecutive days; ii) Medium Term and Rehabilitation Units (*Unidades de Média Duração e Reabilitação*, UMDR) offer less intensive nursing and rehabilitation care, with an expected length of stay between 31 and 90 consecutive days; iii) Long-Term and Maintenance Units (*Unidades de Longa Duração e Manutenção*, ULDM) aimed at individuals with difficulties of community inclusion and caregivers' respite care, with an expected length of stay of 90 or more consecutive days; iv) Palliative Care Units (*Unidades de Cuidados Paliativos*, UCP) aimed to offer late stage and end-of-life care to patients with terminal illness. In 2015, these Units were included in the National Network of Palliative Care (*Rede Nacional de Cuidados Paliativos*) [16].

2.4. Needs assessment

The assessment of the burden of diseases, dependence level or social enrolment are typically used to rank the recipients of care and to ascertain the level of LTC needs. Thus, several countries have adopted different assessment methods [6], which may vary across regions (Table 1), with some using them for financial

reimbursement purposes or to identify the complexity level of the individuals treated like Spain (Catalonia) [13] or Italy (Tuscany) [17]. In Portugal, there is only one tool to identify the dependence level of each individual: the Integrated Bio-psychosocial Assessment Instrument. It collects information in three domains [18]:

- Biological: age, gender, clinical conditions and physical status using the Katz Index of Independence in activities of daily living [19] (toileting, dressing, bathing, transferring/bed, transferring/chair, continence/urination, continence/defecation and feeding);
- Psychological: cognitive status using the Mini-Mental State Examination [20] (including the ability to answer questions about temporal and spatial orientation);
- Social: level of education, marital status and availability of informal support.

The responsibility for this assessment lies with hospitals if the individuals are hospitalized or primary care providers if they are living in the community. Then, based on the physical and cognitive scale used, patients are classified into one of four dependence levels [21]: i) incapable, when individual does not cooperate and needs indispensable and regular caregivers and/or means of support; ii) dependent, when individual cooperates but needs indispensable and regular caregivers and/or means of support; iii) autonomous, when individual cooperates but needs regular means (but not caregivers) of support; iv) independent when individual does not need caregivers and/or means of support. After determining the care needs, providers should refer them to the best setting of care after taking into account his/her dependence level, expected length of care need (in case of institutionalization care) and, whenever possible, proximity to their residence.

2.5. Financing system

The model adopted by the RNCCI encompasses several sources that complement each other [7,22]: i) public funding ensured by the State Budget and shared between the health and social sectors; ii) profits from social gambling and betting (e.g., national lottery) allocated to the MoH (16.6%) and to the MLSS (13.4%); and, iii) means tested co-payments. Although 80% and 20% of the LTC services among countries in the EU are in-kind and cash-benefits, in Portugal they reached 99.3% and 0.7%, respectively [23]. This difference is explained by the scarce resources for cash-benefits, especially during the economic crisis period which resulted in a cut of benefits for some allowances for dependent adults [24], but still ensured the provision of public LTC through in-kind services.

The price paid by the MoH and the MLSS depends on where the care is provided [10]. If it is at HCBS (9.58€ user/day), UC (105.46€ user/day) or UCP (105.46€ user/day), the payment is entirely supported by the MoH. If it is at UMDR (87.56€ user/day) or ULDM (60.19€ user/day), the payment is shared between the MoH (70% and 20%, respectively) and the MLSS (30% and 80%, respectively) [25]. In these last two types of NH, payment by care users is means tested based on a percentage of the annual average per capita wealth of all household members (including wages, bank deposits, financial assets, pensions, public housing allowances and social benefits but, excluding dependence disability allowances) for the part covered by the MLSS [26–28]. Although the amount supported by each individual is reviewed whenever there are changes in the household arrangement, it cannot exceed the price published for each Unit [27].

Table 2
The evolution of the main features of the RNCCI.

	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
Nursing Home public beds										
Convalescence Units	423	530	625	682	906	867	860	860	764	811
Medium Term and Rehabilitation Units	646	922	1,253	1,497	1,747	1,820	1,895	2,021	2,306	2,578
Long-Term and Maintenance Units	684	1,325	1,942	2,286	2,752	3,031	3,692	4,094	4,411	4,723
Palliative Care Units	55	93	118	160	190	193	195	185	278	288
Total number of beds	1,808	2,870	3,938	4,625	5,595	5,911	6,642	7,160	7,759	8,400
Average number of beds per institution	17.4	19.3	20.8	21.2	21.9	22.1	22.4	22.7	23.1	23.3
Average number of patients treated per bed	3.3	4.7	5.3	5.6	5.8	4.5	4.3	4.4	4.0	3.9
Home and Community-Based Services										
Number of teams	37	72	96	214	253	243	267	274	286	279
Number of treatment places	n.a.	1,660	5,050	8,063	7,332	7,183	7,053	6,766	6,585	6,264
Number of treatment places per team	n.a.	23.1	52.6	37.7	29.0	29.6	26.4	24.7	23.0	22.5
Beds and treatment places per 1000 inhab. ≥ 65 years										
Nursing Homes	1.10	1.58	2.13	2.45	2.91	3.03	3.35	3.55	3.78	4.03
Home and Community-Based Services	n.a.	0.92	2.74	4.28	3.81	3.68	3.56	3.36	3.21	3.00
TOTAL		2.50	4.87	6.73	6.72	6.72	6.92	6.91	7.00	7.03
Number of individuals treated*										
Nursing Homes	5,934	13,457	20,692	25,990	32,713	26,831	28,721	31,191	31,307	32,545
Home and Community-Based Services	n.a.	1,660	2,608	5,278	9,139	11,578	13,804	14,577	15,221	15,582
TOTAL	5,934	15,117	23,300	31,268	41,852	38,409	42,525	45,768	46,528	48,127
Number of individuals treated/1000 inhab. ≥ 65 years										
Nursing Homes	3.6	7.4	11.2	13.8	17.0	13.8	14.5	15.5	15.3	15.6
Home and Community-Based Services	n.a.	0.9	1.4	2.8	4.8	5.9	7.0	7.2	7.4	7.5
TOTAL	3.6	8.3	12.6	16.6	21.8	19.7	21.5	22.7	22.7	23.1
Long-term care expenditures (Euro, Millions, current prices)										
Ministry of Health	14.79	23.34	60.19	113.49	112.22	138.05	120.31	120.94	116.69	136.06
Ministry of Labour and Social Solidarity	2.24	9.70	14.85	19.57	25.21	26.46	27.70	31.76	34.86	36.37
TOTAL	17.03	33.03	75.04	133.05	137.43	164.50	148.00	152.71	151.55	172.44
As a share of gross domestic product (%)**	0.69	0.74	0.78	0.78	0.79	0.86	0.89	0.94	0.96	n.a.
As a share of current healthcare expenditure (%)**	7.6	7.9	7.9	7.9	8.3	9.2	9.9	10.4	10.7	n.a.

Source: Authors elaboration based on the national reports [30,32–35].

Legend: n.a.: not available.

* Includes individuals admitted in previous years who received some type of care in each year.

** Includes the expenditures of both long-term care public health and social components [29].

3. Development of the RNCCI since 2006

Despite the existence of regional asymmetries in LTC provision, the number of NH beds increased steadily over the years. The ULDM was the setting with the highest proportion of beds in 2016 (56%), followed by the UMDR (31%), UC (10%) and the UCP (3%) (Table 2). Considering both ratios of public beds/treatment places and individuals treated per 1000 inhabitants aged ≥ 65 years old, Portugal has also been showing a consistent growth over the years. However, despite the last indicator being lower than several European countries (Table 1), based on the latest national data available, the number of individuals waiting to be admitted at RNCCI has increased from 1,400 in 2016 [30] to 2,450 in 2017 (September) [31]. This shows an increase in referrals but also a lack of capacity to deal with current demand. Concerning the share of LTC public expenditures on GDP and health care expenditure, Portugal (Table 2) presents higher ratios than Spain or Italy (Table 1), even when undergoing a difficult financial and economic crisis.

Although the fully RNCCI implementation was planned to be concluded over a 10-year period, culminating in 2016, the results obtained for each phase fell short of those forecasted (Table 3). The financial restraints policies implemented between 2011 and 2014 due to the intervention by the Troika [36,37] was one of the reasons that contributed to limited RNCCI growth. Nevertheless, the expenditures in the RNCCI increased both as a share of the GDP and as a share of current health care expenditures (Table 2). Other rea-

sons for limited RNCCI growth are related to insufficient revenue from social gambling to finance the RNCCI [38] and a lack of public resources to fund signed-protocols between the state and third sector entities.

4. Current challenges and ongoing developments

The universal access, the multiple sources of financing, the existence of several NH to account for different care needs or the sustained increase of admissions in both settings of LTC, are considered to be some of the RNCCI achievements (Box 1). On the opposite side, the predominance of institutionalization, the existence of waiting lists, regional asymmetries, the absence of a financing model based on the dependence levels, or the difficulty to use the instrument of needs assessment for international comparison, are some of the aspects to be improved in the future.

Several measures have been implemented which target the main challenges for LTC. First, there is an ongoing joint project between the MoH and the MLSS called Programme of Integrated Support to the Elderly (*Programa de Apoio Integrado a Idosos*), which has enabled the development of initiatives in both health and social areas oriented for home care and informal caregivers as part of a job creation policy [40]. However, given the scarcity of formal HCBS responses, it remains essential to reinforce primary care providers with human and material resources to target risk groups living in the community and develop initiatives aimed at maintaining the

Table 3

Difference between the number of “forecasted” and “real” beds in each stage.

NH Units	Stage I (2006–2008)		Stage II (2009–20012)		Stage III (2013–20016)	
	Forecasted (Real [*])		Forecasted (Real ^{**})		Forecasted (Real ^{***})	
	Number beds	Beds/1000 inhab. aged ≥ 65 years	Number beds	Beds/1000 inhab. aged ≥ 65 years	Number beds	Beds/1000 inhab. aged ≥ 65 years
UC	977 (530)	0.60 (0.32)	1,954 (867)	1.20 (0.44)	2,931 (811)	1.80 (0.39)
UMDR	1,139 (922)	0.70 (0.56)	2,117 (1820)	1.30 (0.93)	3,257 (2578)	2.00 (1.24)
ULDM	2,720 (1325)	1.67 (0.81)	5,374 (3031)	3.30 (1.55)	8,143 (4723)	5.00 (2.27)
UCP	326 (93)	0.20 (0.06)	651 (193)	0.40 (0.10)	977 (288)	0.60 (0.14)
HCBS (number of teams)	363 (72)	–	363 (243)	–	363 (279)	–

Source: Authors elaboration based on the national reports [30,32,34,39].

^{*} Values of 2008.^{**} Values of 2012.^{***} Values of 2016; UC: Convalescence Units; UCP: Palliative Care Units; UMDR: Medium Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units; HCBS: Home and Community-Based Services.**Box 1: Strengths and weaknesses associated to the RNCCI.****Strengths**

- Filled a gap in the National Health Service;
- Universal coverage to long-term care;
- Multiple sources of financing;
- Different nursing homes types to account for different care needs;
- Sustained increase of referrals and admissions to the RNCCI;
- The existence of an autonomous National Network of Palliative Care;
- Free beds in the hospital setting.

Weaknesses

- Predominance of institutionalization over home care;
- Regional asymmetries in the provision of care;
- Financing model based on the number days of care provided;
- No consequences for non-compliance with the expected length of care defined for each type of nursing home, what contributes to increase costs and waiting lists;
- The instrument used to assess the dependence level does not allow a complete evaluation of each individual, limiting any benchmarking analysis between settings of care.

autonomy of the elderly in their usual living environment. Besides, other approaches such as the initiative by the recent report of the European Forum for Primary Care, could be consider, which entails the creation of multidisciplinary teams (physicians, nurses, pharmacists and social workers), responsible for the implementation of a proactive geriatric assessment of individual medical, functional and social needs [41].

Secondly, given the importance to collect accurate information for each patient, an Ordinance was recently published [42] which demands a more complete patient assessment before referral to the RNCCI. The identification of all comorbidities, a detailed medical, nursing and social evaluations, as well as the assessment of the function degree using the International Classification of Functioning, Disability and Health is required [43]. Nevertheless, it is key to underline the importance of collecting relevant data to inform the design of a patient's care plan. Furthermore, adopting international validated metrics for monitoring the quality of the care provided and for benchmarking between similar LTC settings is of paramount importance.

Third, given the role of informal care [2], in 2016 the MoH published a Dispatch creating the National Programme for Health,

Literacy and Self-care (*Programa Nacional para a Saúde, Literacia e Autocuidados*) with the purpose of creating a structured network of informal caregivers [44]. Thus, projects developed under this Programme should aim at the reinforcement of the citizens' role in the NHS through partnerships between several players, to prevent social exclusion and develop and share techniques for promoting health literacy in both NH and HCBS settings, for both caregivers and dependent individuals.

Finally, a change in the financing model included patients' dependence levels and risk adjustment models and removed existing incentives to unnecessary care and bed occupancy of people who no longer need care. This change might not only improve the bed/treatment places turnover, but could also help to tackle existing waiting lists. Although there are no plans or deadlines for implementing these measures, some policy-makers from the MoH have publicly stated that policies to tackle this area are vital to ensure the efficiency and growth of LTC in Portugal in the future [45].

5. Conclusions

In 2006, driven by policies to vertically integrate the provision of all types of care within the NHS, the RNCCI was set up to take advantage of already existence resources (largely non-profit-making institutions). Its main sources of funding was shared by the MoH and the MLSS. This is the first study that collects monitoring data on the evolution of the LTC in Portugal since its inception, making it available to an international audience by providing an assessment of the current state of the RNCCI and guidance on existing challenges and gaps for Portuguese policy-makers.

Based on the organisation of the LTC model of Catalonia, the RNCCI is coordinated by central, regional and local entities, similar to other EU countries such as Spain, Italy and Sweden. The RNCCI provision of in-kind services is much higher than the EU average, while the provision of cash-benefits is minimal. Co-payments are means tested and update yearly. The financial constraints over public spending in place since 2011 have also contributed to a slower development of the national network. Despite public LTC expenditures as a share of the GDP increasing in the same period, further efforts should focus on improving the efficiency and accessibility of the LTC system in Portugal.

Conflict of interest statement

Nothing to declare.

References

- [1] Eurostat. Population Demography Statistics; 2017. <http://ec.europa.eu/eurostat/data/database> (Accessed February 5, 2017).
- [2] Simões J, Augusto G, Fronteira I, Hernández-Quevedo C. Portugal health system review. *Health Systems in Transition* 2017;19:1–184.
- [3] D.R. Decree-Law no. 119/83, 25th of February – IPSS statutes (in Portuguese) 1983. <http://www.amu.org.pt/pdfs/Estatuto%20das%20IPSS.pdf> (Accessed May 29, 2017).
- [4] Santana S, Dias A, Souza E, Rocha N. The Domiciliary Support Service in Portugal and the change of paradigm in care provision. *International Journal of Integrated Care* 2007;7:1–8. [http://dx.doi.org/10.1016/S1096-4959\(03\)00375-0](http://dx.doi.org/10.1016/S1096-4959(03)00375-0).
- [5] Santana S, Szczygiel N, Redondo P. Integration of care systems in Portugal: anatomy of recent reforms. *International Journal of Integrated Care* 2014;14:1–10. <http://dx.doi.org/10.5334/ijic.989>.
- [6] Le Bihan B, Martin C. A comparative case study of care systems for frail elderly people: Germany, Spain, France, Italy, United Kingdom and Sweden. *Social Policy & Administration* 2006;40:26–46. <http://dx.doi.org/10.1111/j.1467-9515.2006.00475.x>.
- [7] Costa-Font J, Gori C, Santana S. Financing long-term care in Southwest Europe: Italy, Portugal and Spain. *Financing Long-Term Care in Southwest Europe* 2012:170–86. http://dx.doi.org/10.1057/9780230349193_10. London: Palgrave Macmillan UK.
- [8] Maarse JAMH, Jeurissen PPP. The policy and politics of the 2015 long-term care reform in the Netherlands. *Health Policy (New York)* 2016;120:241–5. <http://dx.doi.org/10.1016/j.healthpol.2016.01.014>.
- [9] Peña-Longobardo LM, Oliva-Moreno J, García-Armesto S, Hernández-Quevedo C. The Spanish long-term care system in transition: ten years since the 2006 dependency act. *Health Policy (New York)* 2016;120:1177–82. <http://dx.doi.org/10.1016/j.healthpol.2016.08.012>.
- [10] D.R. Decree-Law 101/2006. D.R. I Série A, 6th of July – Creation of the Portuguese National Network for Long-term Integrated Care (Rede Nacional de Cuidados Continuados Integrados) (in Portuguese) 2006:3856–65. <http://www.acss.min-saude.pt/wp-content/uploads/2016/10/Decreto-Lei.101.2006-1.pdf>.
- [11] ERS (in Portuguese) Porto Access quality and competition in long-term and palliative care; 2015.
- [12] García Ameijeiras MC, Abenozo Guardiola M. Consideraciones para el análisis coste-beneficio en la red sociosanitaria. *Rehabilitación* 2004;38:362–7. [http://dx.doi.org/10.1016/S0048-7120\(04\)73493-3](http://dx.doi.org/10.1016/S0048-7120(04)73493-3).
- [13] Salvà A, Roqué M, Vallès E, Bustins M, Rodó M, Sanchez P. Description of the clinical complexity of patients admitted to long term care hospitals in Catalonia during 2003–2009. *Revista Española de Geriatria y Gerontología* 2014;49:59–64. <http://dx.doi.org/10.1016/j.regg.2013.07.006> (in Spanish).
- [14] D.R. Ordinance no. 174/2010, 10th of September, which updates the operational conditions of the nursing homes and home care settings of care (in Portuguese) 2014:4865–82. <http://www.sg.min-saude.pt/NR/rdonlyres/F1071041-A28D-4B06-8CB5-D640D1D60D80/41897/Portaria174.2014.pdf> (Accessed June 1, 2017).
- [15] ARSN. Procedures manual to implement and develop the HCBS; 2014 (in Portuguese) Porto.
- [16] D.R. Decree-Law no. 136/2015, 28th of July – Creation of the National Palliative Care Network (Rede Nacional de Cuidados Paliativos – RNCP) (in Portuguese) 2015:1–11. <http://www.acss.min-saude.pt/wp-content/uploads/2016/10/Decreto-Lei.136.2015.pdf> (Accessed June 19, 2017).
- [17] Francesconi P, Cantini E, Bavazzano E, Lauretani F, Bandinelli S, Buiatti E, et al. Classification of residents in nursing homes in Tuscany (Italy) using resource utilization groups version III (RUG-III). *Aging Clinical and Experimental Research* 2006;18:133–40.
- [18] Abreu Nogueira J, Girão M, Guerreiro I. Post acute and long term care: instrument for evaluating outcomes national network for integrated continuous care Portugal. Lisbon: UMCCI; 2010.
- [19] Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW, Katz S, et al. Studies of illness in the aged: the index of ADL, a standardized measure of biological and psychosocial function. *JAMA* 1963;185:914. <http://dx.doi.org/10.1001/jama.1963.03060120024016>.
- [20] Folstein MF, Folstein SE, McHugh PR. Mini-mental. A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research* 1975;12:189–98.
- [21] Abreu Nogueira J, Girão M, Guerreiro I. Outcomes of physical autonomy in Post Acute and Long Term Care National Network for Integrated Continuous Care Portugal. Lisbon: UMCCI; 2010.
- [22] D.R. Decree-Law 106/2011, 21st of October – Distribution of net results of social games (in Portuguese) 2011. http://www.pgdlisboa.pt/leis/lei_mostra_articulado.php?nid=2580&tabela=leis&so_miolo= (Accessed February 5, 2017).
- [23] European-Commission. Joint report on health care and long-term care systems & fiscal sustainability volume 2 country documents, vol. 8014; 2016. <http://dx.doi.org/10.2765/86203>. Brussels.
- [24] Wall K, Leitão M, Correia S, Ramos V. Family policies in 2014 and 2015 – key developments; 2014 (in Portuguese) Lisbon.
- [25] D.R. Ordinance no. 184/2015, 23th of June – Price definition of health care and social support provided in the inpatient and outpatient units of the Portuguese National Network for Long-term Integrated Care (in Portuguese) 2015. <https://dre.pt/application/conteudo/67541740> (Accessed February 5, 2017).
- [26] Joël M-E, Dufour-Kippelen S, Samitca S. The long-term care system for the elderly in Portugal; 2010. Brussels.
- [27] D.R. Normative Dispatch no. 34/2007 – Definition of the social support co-payments at the Medium Term and Rehabilitation Units and the Long-Term and Maintenance Units (in Portuguese) 2007:27412–4. <http://www.acss.min-saude.pt/wp-content/uploads/2016/10/Despacho-normativo.34.2007.pdf> (Accessed June 3, 2017).
- [28] D.R. Ordinance no. 1087-A/2007, 5th of September- Price definition of health care and social support provided in the inpatient and outpatient units of the Portuguese National Network for Long-term Integrated Care (in Portuguese) 2007. <http://www.acss.min-saude.pt/wp-content/uploads/2016/10/Portaria.1087A.2007.pdf> (Accessed June 16, 2017).
- [29] OECD. OECD statistics: long-term care resources and utilisation; 2017. <http://stats.oecd.org/> (Accessed September 2, 2017).
- [30] ACSS. Monitoring the Portuguese National Network for Long-term Integrated Care – 2016; 2017 (in Portuguese) Lisbon.
- [31] NHS. Transparency portal: users awaiting for admission at RNCCI; 2017. <https://transparencia.sns.gov.pt/explore/dataset/rncci-episodios/?sort=data> (Accessed September 4, 2017) (in Portuguese).
- [32] UMCCI. Monitoring the Portuguese National Network for long-term integrated care – 2008; 2009 (in Portuguese) Lisbon.
- [33] UMCCI. Monitoring the Portuguese National Network for long-term integrated care – 2010; 2011 (in Portuguese) Lisbon.
- [34] UMCCI. Monitoring the Portuguese National Network for long-term integrated care in 2012 – final report; 2013 (in Portuguese) Lisbon.
- [35] ACSS. Monitoring the Portuguese National Network for long-term integrated care – 2014; 2015 (in Portuguese) Lisbon.
- [36] MFAP. Programme of stability and growth: 2011–2014; 2011 (in Portuguese) Lisbon.
- [37] MoU. Portugal – memorandum of understanding on specific economic policy conditionality; 2011.
- [38] Costa JL, Mourão V. The risk perspective in Portugal's National Network for Integrated Continuous Care (RNCCI): an evaluation by health experts and decision-makers. *Saúde e Sociedade* 2015;24:501–14. <http://dx.doi.org/10.1590/S0104-12902015000200009> (in Portuguese).
- [39] UMCCI. Monitoring report on the implementation of the pilot experiences of the Portuguese National Network for long-term integrated care; 2007 (in Portuguese) Lisbon.
- [40] D.R. Joint Dispatch no. 259/97, 21st of August – Creation of the Programme of Integrated Support to the Elderly (PAII) (in Portuguese) 1997. <http://www.seg-social.pt/documents/10152/87923/DESP.CONJ.259.1997/4a846364-eab5-489f-aa6f-9b771ffe71a5> (Accessed September 5, 2017).
- [41] Boeckxstaens P, De Graaf P. Primary care and care for older persons: position paper of the European Forum for Primary Care. *Quality in Primary Care* 2011;19:369–89.
- [42] D.R. Ordinance no. 50/2017, 2nd of February – Streamlining the referral process by assessing the degree of functionality using the International Classification of Functioning, Disability and Health (ICF) (in Portuguese) 2017:608–29. <https://dre.pt/application/file/a/106390686> (Accessed September 5, 2017).
- [43] WHO. International Classification of Functioning, Disability and Health (ICF); 2001. Geneva.
- [44] D.R. Dispatch No. 3618-A/2016, 10th of March 2016 – Creation of the National Programme for Health, Literacy and Self-care (in Portuguese) 2016. <https://dre.pt/application/file/a/73833787> (Accessed September 5, 2017).
- [45] Mestre R. Where do we go? Long-term care network as a national structure: evolution, present, future and financial sustainability of the network (in Portuguese). In: União das Misericórdias Portuguesas, editor. II Conf. long-term Integr. care, Fátima: 2016.

5.2. Identifying the long-term care beneficiaries: Differences between risk factors of nursing homes and community-based services admissions

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ABSTRACT

Background: The Portuguese long-term care sector is organized in Home and Community-Based Services (HCBS) and three nursing home (NH) care units: Convalescence, Medium-Term and Rehabilitation, and Long-Term and Maintenance. The primary goal of this study is to identify the main risk factors of admission in each setting of care.

Methods: The study included 14,140 patients from NH and 6,844 from HCBS from all over the country. A logistic regression was estimated to determine the risk of being admitted into an NH setting of care, using sociodemographic characteristics, medical conditions and dependence levels at admission as independent variables, and region of care, referral entity, the placement process and the length of care as control variables. Then, ordered logistic regression was used to identify the contribution of the above risk factors in each specific NH unit.

Results: Being female, not being married, not having family/neighbour support, being literate, having a mental illness, or being cognitively or physically impaired are the main predictors of NH risk of admission. Within the NH setting of care, older age, having family/neighbour support, having neoplasms or a mental illness, or being cognitively/physically impaired increases the probability of being referred to a longer care unit. Only 74%, 57% and 47% of the individuals were accurately referred to each NH type of care units, respectively.

Conclusions: It is necessary to take into account variations in needs for individual assistance, avoiding situations whereby patients with the same needs receive different levels of care.

Keywords: Portuguese long-term care, Nursing Homes, Home and Community-Based Services, Dependence levels, Types of care units

BACKGROUND

The widespread increase in life expectancy is perhaps one of the greatest achievements of humankind. Consequently, changes in demographic features - characterized by an elderly population, an increase of chronic diseases and new patterns of growing morbidity and functional restrictions (Barnett et al. 2012; Rechel et al. 2013) - are already a reality in most developed countries.

Thus, the evolution and (re)configuration of the health system should be influenced by the adoption of adequate health policies in order to encourage the coordination of the healthcare, social support and long-term care (LTC) sectors as a whole. As for the LTC sector, it embraces all forms of continuous, personal, rehabilitation and nursing care, designed to provide assistance over prolonged periods to people with mental and physical impairment and unable to look after themselves without some degree of external support (Kaye and Harrington 2015; Wysocki et al. 2015). Often, this care provision is associated with two main settings: (1) institutional, known as Nursing Homes (NH); and (2) non-institutional, known as Home and Community-Based Services (HCBS).

Although these settings of care seem to offer similar services, they differ in terms of frequency, intensity and degree of supervision (Kaye and Harrington 2015; Wysocki et al. 2015). Thus, several differences between the two settings have been reported in the literature, either related to expenditures (Kuo et al. 2010; Schwarzkopf et al. 2013; Wübker et al. 2015; Newcomer et al. 2016), functional changes (Forster et al. 2010; Kane et al. 2013; Crocker et al. 2013; Lee et al. 2015; O'Caoimh et al. 2015; Lee and Cho 2016), mortality (Schwarzkopf et al. 2013; Blackburn et al. 2016), quality of life (Kuo et al. 2010; Toot et al. 2017) or frequency of acute care visits (Schwarzkopf et al. 2013; O'Caoimh et al. 2015; Blackburn et al. 2016). Nevertheless, as mentioned in two literature reviews (Wysocki et al. 2015; O'Caoimh et al. 2015), given the differences in data collection, selection of populations and methodological strategies, there are very few studies from which to draw conclusions about the differences in effectiveness between HCBS and NH care in several of these outcomes.

It has been widely mentioned in the literature that patients prefer to stay in their homes for as long as possible in order to keep their social networks and to maintain their family environment (Luppa et al. 2012; Hajek et al. 2015; Bartfay et al. 2016; Blackburn et al. 2016; Toot et al. 2017); nevertheless, when care needs are extensive, admission to an institution may be inevitable and necessary (Bartfay et al. 2016). For that matter, in order to (re)define new policies to determine the proper setting of care for each person, much attention has been devoted to identifying the main risk factors leading to

institutionalization (Gaugler et al. 2007; Luppá et al. 2010; Wysocki et al. 2015). Usually, they include patients' (1) socio-demographic characteristics, (2) medical conditions, and especially (3) the physical and cognitive dependence levels.

Regarding the first group of risk factors, the association between education level and the use of LTC services is not well proven (Muramatsu et al. 2007; Gaugler et al. 2007; Wieland et al. 2010; Luppá et al. 2010), while characteristics such as older age (Gruber-Baldini et al. 2007; Muramatsu et al. 2007; Gaugler et al. 2007; Luppá et al. 2010, 2012; Häcker and Hackmann 2012; Schwarzkopf et al. 2013; Helvik et al. 2014; Lee et al. 2015; Wübker et al. 2015; Bartfay et al. 2016; Lee and Cho 2016; Penning et al. 2016), female gender (Gaugler et al. 2007; Häcker and Hackmann 2012; Kim et al. 2013; Schwarzkopf et al. 2013; Helvik et al. 2014; Lee et al. 2015; Bartfay et al. 2016; Newcomer et al. 2016; Lee and Cho 2016; Penning et al. 2016) and being widowed or single (Muramatsu et al. 2007; Gaugler et al. 2007; Wieland et al. 2010; Luppá et al. 2012; Hajek et al. 2015; Bartfay et al. 2016; Penning et al. 2016) are usually known to be risk factors associated with institutionalized care. As for the social network, the higher the family/caregiver involvement, the more likely that an individual remains in the community (HCBS) (Muramatsu et al. 2007; Luppá et al. 2010, 2012; Lee et al. 2015; O'Caoimh et al. 2015; Wübker et al. 2015; Newcomer et al. 2016; Lee and Cho 2016).

Concerning the influence of chronic medical conditions, the findings are inconsistent. A literature review found low evidence of significant differences in several conditions (e.g. stroke, hypertension, respiratory diseases, incontinence or depression) as a predictor of NH admission (Luppá et al. 2010); a study from Germany concluded that individuals receiving HCBS care had a higher burden of diseases (Schwarzkopf et al. 2013); and other authors found a higher prevalence dementia, Parkinson's disease, diabetes, renal disease or cancer within the NH population, when compared with those receiving home care (Gaugler et al. 2007; Wieland et al. 2010; Bartfay et al. 2016; Lee and Cho 2016; Penning et al. 2016).

As a person's dependence level cannot be measured based on the clinical diagnosis, it is essential to conduct a more detailed assessment aimed at identifying their physical and cognitive limitations. Such evaluation contributes to the definition of each care plan either for maintaining or delaying the total or partial loss of capacities. Based on several studies from the US (Gruber-Baldini et al. 2007; Muramatsu et al. 2007; Gaugler et al. 2007; Wieland et al. 2010; Kane et al. 2013; Newcomer et al. 2016), Canada (Bartfay et al. 2016; Penning et al. 2016), Taiwan (Kuo et al. 2010), South Korea (Kim et al. 2013), Germany (Luppá et al. 2010, 2012; Schwarzkopf et al. 2013; Hajek et al. 2015), the Netherlands (Helvik et al. 2014) and a study including eight European countries (Wübker

et al. 2015), the conclusions were very similar: those receiving care at NHs are usually cognitively and physically more dependent than those receiving HCBS.

Finally, although other risk factors may be associated to NH/HCBS placement, such as region where the care is provided (Muramatsu et al. 2007; Helvik et al. 2014; Lee and Cho 2016; Penning et al. 2016; Toot et al. 2017), length of care (Gruber-Baldini et al. 2007; Häcker and Hackmann 2012; Newcomer et al. 2016; Blackburn et al. 2016; Lee and Cho 2016), referral entity and placement process (Helvik et al. 2014), their influence is not yet well proven.

The Portuguese long-term care system

In Portugal, the National Network for Long-term Integrated Care (*Rede Nacional de Cuidados Continuados Integrados*, RNCCI) was created in 2006 as a partnership between the Ministry of Health and the Ministry of Employment and Social Solidarity (D.R. 2006), taking advantage of the already existing resources (largely non-profit-making institutions) (Lopes et al. 2018). The type of care provided is organized into the two main settings of care mentioned earlier, namely HCBS and NH, with this last being provided through three types of care units (D.R. 2006):

- Convalescence Units (*Unidades de Convalescença*, UC): intended for individuals discharged from hospital services in need of convalescence care; nursing, medical and physiotherapy care are provided on a daily basis; the expected length of care is up to 30 consecutive days;
- Medium-Term and Rehabilitation Units (*Unidades de Média Duração e Reabilitação*, UMDR): intended to provide less intensive support; while the nursing care is provided on a daily basis, the medical and rehabilitation care is provided twice a week; the expected length of care is between 31 and 90 consecutive days;
- Long-Term and Maintenance Units (*Unidades de Longa Duração e Manutenção*, ULDM): intended for individuals with difficulties of community inclusion and for caregivers' respite care; whereas the nursing care is provided daily, the medical and rehabilitation care is provided once a week; the expected length of care is 90 or more consecutive days.

The goal of the HCBS is to provide nursing and rehabilitation care at home, through multidisciplinary teams working in primary care centres, to people in a functional dependency situation, with a terminal illness or a convalescence process, in a situation that does not require hospitalization and without the possibility of moving from home (D.R. 2006). Services such as personal hygiene, educational support for both patients

and caregivers, as well as nursing, rehabilitation and medical care are provided daily, including weekends, between 8am and 8pm (D.R. 2014; Instituto da Segurança Social 2017). Individuals with care needs during the night period, in need for only social support or without informal caregivers, are excluded.

Regarding the RNCCI placement process, after individuals are referred from a hospital or primary care unit, the care request goes to the Local Coordination Teams (*Equipas de Coordenação Local*, ECL), and then, if the applicant fulfils the requirements, the request is sent to the Regional Coordination Teams (*Equipas de Coordenação Regional*, ECR). To streamline the coordination between the referring entity and the individual admission in any setting of care, the national guideline recommends that potential LTC beneficiaries should be flagged for the RNCCI in the first 72 hours after this type of care need is identified, especially after hospitalization.

OBJECTIVES

The main goals of this work are to assess whether referrals to the different care settings take into account patients' needs, and to explore, for the first time in Portugal, to what extent the populations referred to NH (UC, UMDR and ULDM) and HCBS differ from each other. Currently, very little is known about the LTC in Portugal, its organization, settings of care and beneficiaries' characteristics. NH residents with low dependence levels are usually seen as prime candidates to be initially served by HCBS or to be relocated back as soon as possible into the community (Kane et al. 2013). Nevertheless, the lack of formal responses to populations' needs and the existence of regional asymmetries of LTC resources (Lee et al. 2015) may result in inadequate referrals for each setting of care.

METHODS

Data source

We used data from the so-called Integrated Assessment Instrument (*Instrumento de Avaliação Integrado*) (Abreu Nogueira et al. 2010), the Portuguese LTC monitoring system run by the RNCCI staff to evaluate all patients. Besides general data concerning the setting of care, region of care, referral entity, placement process and length of care, this instrument collects data in three main areas (Botelho 1999): (1) Biological: age, gender, medical conditions at admission, and the ability to perform eight activities of daily living (ADL), based on the Katz' ADL index (toileting, dressing, bathing, transferring/bed, transferring/chair, continence/urination, continence/defecation and feeding) (Katz et al. 1963); (2) Psychological: assessment of the cognitive status through the ability to answer ten questions about temporal and spatial orientation (year, month, day, season and day

of the week; and country, province, city/town, home and floor, respectively); the evaluation is performed using the Mini-Mental State Examination (Folstein et al. 1975); and finally (3) Social: level of education, marital status and the availability of family/neighbour support.

The procedure of assessment of the overall cognitive and physical dependence levels of a patient is performed as follows. First, each individual is assigned a score according to the ability to answer each orientation question and to perform each ADL mentioned above (Botelho 1999; Abreu Nogueira et al. 2010). The scores levels are (a) bad/incapable (score 0), when the individual is not able to cooperate and needs indispensable and regular caregivers and/or means of support; (b) unsatisfactory/dependent (score 1), when the individual can cooperate but needs indispensable and regular caregivers and/or means of support; (c) satisfactory/autonomous (score 2), when the individual cooperates but needs regular means (but not caregivers) of support; and (d) good/independent (score 3), when the individual does not need caregivers and/or means of support. In a second stage, the ADL overall status is determined by considering the lowest score obtained in the eight assessed activities, while the cognitive status is determined by the average score in the ten orientation questions. Based on these two scores, each individual's overall physical and cognitive status is then classified into one of four dependence groups, from bad/incapable to good/independent.

Statistical analysis

The population of this descriptive cross-sectional study consists of 20,984 individuals, aged 60 years old or more, with admission and discharge in a LTC setting of care in 2015, from all over the country.

Concerning the descriptive analysis, several variables were taken into account to identify the main differences between the populations in each setting of care (Table 1). Given the importance of ensuring the shortest time in the placement process, three phases were analysed: (1) time taken to notify the request for care between the ECL and the ECR; (2) time between the arrival of the request at ECR and the individual's admission; and (3) total time elapsed between the arrival of the request at ECL and the individuals' admission in each setting of care.

The physical and cognitive dependence profile in each activity, at admission, is identified and compared across settings of care through One-Way ANOVA (Fig.1).

Finally, in order to identify the main risk factors on the likelihood that an individual receives care in each setting of care, two methods were used. Firstly, a logistic

regression with Forward-LR method was performed, using the two main settings of care as the dependent variable (HCBS=0, NH=1) (Table 2). Secondly, since the three NH units of care follow an intrinsic order as the individuals' dependence level increases, the ordered logistic regression model was used (Table 3) and the marginal effects were calculated (Table 4). In this case, we used the three NH units (UC=1, UMDR=2, ULDM=3) as dependent variable.

Explanatory variables

In the two final analyses, three main sets of explanatory variables were included: sociodemographic characteristics such as age, gender, marital status, family/neighbour support, and educational level; medical conditions; and dependence levels such as cognitive and physical status at admission. The choice of variables is based on the factors mentioned in the literature to be significantly associated with the risk of being admitted to a NH.

Covariates

As for covariates, we used the referral entity, region of care, duration of placement process (days between ECL to Admission) and length of care (days).

All analyses were run with SPSS Statistics software (v.20, IBM SPSS, Chicago, IL) and with STATA statistical software (release 13), with a significance level of 0.05.

RESULTS

Descriptive analysis

There are substantial differences between the numbers of individuals treated in each Portuguese geographic region, with three of them (North, Centre and Lisbon and Tagus Valley) encompassing 80% of the analysed patients (Table 1). When compared to the HCBS population, the NH individuals present, on average, a similar age (80 years old), a higher percentage of females but a lower percentage of married people, family/neighbour support and illiterate individuals. The diseases of the circulatory system, injury and poisoning, neoplasms and diseases of the musculoskeletal system are responsible for 70% of the total population medical conditions (64% and 72% for HCBS and NH population, respectively). As for the cognitive and physical status at admission, the percentage of individuals classified into the two lowest levels is higher at NH (54.5% and 71.2%) than in HCBS (45.9% and 69.0%) setting of care. Regarding the referral entities, although overall 64% of individuals were referred from hospitals, most people referred to HCBS (56%) came from other entities, especially from the primary care centres, while this happens only in 27% of the cases for NH. Regarding the hospital

services, the internal medicine (18%/32%) and orthopaedic services (15%/21%) are the ones with the highest percentage of referral to the HCBS/NH setting of care (data not shown, available upon request). Finally, regarding the placement process and the length of care, whereas the first is longer for NH admissions, the individuals at HCBS receive care for a longer period.

Comparing the three NH units of care, the population at UC is slightly younger, has a higher percentage of females, fewer married people and a lower percentage of illiterate individuals than the other two units. As for the medical conditions, while the two main groups of individuals at UC and UMDR suffer from diseases of the circulatory system and injury and poisoning, almost 16% of the ULDM population presents mental disorders as their main admission diagnosis (the second largest group). Concerning the cognitive/physical status at admission, the dependence levels increase as we go from the UC to the ULDM. Finally, the percentage of individuals referred from hospitals to the UC is higher; the placement process is faster; and the length of care is lower when compared to both the UMDR and to the ULDM.

Table 1: Population characteristics in each setting of care

	All samples	HCBS	NH	Nursing Homes Units		
				UC	UMDR	ULDM
Population	20,984	6,844	14140	5,071	5,322	3,747
Region of care: %						
North	34.3	39.6	60.4	18.9	24.7	16.8
Centre	21.9	10.5	89.5	27.9	31.5	30.1
Lisbon and Tagus Valley	24.4	40.5	59.5	20.3	26.1	13.1
Alentejo	8.8	27.4	72.6	34.6	21.8	16.2
Algarve	10.7	41.8	58.2	33.8	16.1	8.3
Age (years)						
Median / Mean	80.0 / 79.2	80.0 / 79.9	80.0 / 78.9	79.0 / 77.7	79.0 / 78.4	82.0 / 81.2
Gender (%)						
Female / Male	57.7 / 42.3	55.7 / 44.3	58.7 / 41.3	60.9 / 39.1	57.3 / 42.7	57.9 / 42.1
Marital Status (%)						
Married	45.5	49.9	43.3	42.4	43.3	44.5
Widow	37.0	34.2	38.3	37.9	37.9	39.4
Single	10.5	9.3	11.1	11.4	11.4	10.1
Divorced	7.1	6.6	7.4	8.3	7.4	6.0
Family or neighbour support (%)						
Without support	53.2	38.3	60.4	57.1	67.4	54.8
With support	46.8	61.7	39.6	42.9	32.6	45.2
Educational level (%)						
0 years of education (illiterate)	50.5	55.7	48.1	46.1	48.8	49.7
1 to 6 years of education	44.2	39.0	46.7	47.5	46.4	45.9
7 to 12 years of education	2.8	2.6	3.0	3.5	2.8	2.5
13 or more years of education	2.4	2.8	2.3	2.8	2.1	1.9
Medical conditions (%)						
Diseases of the circulatory system	31.8	22.3	36.2	31.1	40.9	36.4
Injury and poisoning	23.8	21.5	24.9	34.6	26.2	9.7
Neoplasms	7.2	12.3	4.9	3.6	3.8	8.1
Diseases of the musculoskeletal system	6.8	7.5	6.5	12.5	3.3	2.9
Diseases of the respiratory system	5.8	7.3	5.1	4.6	4.4	6.8
Diseases of the nervous system	5.6	5.3	5.6	4.2	4.7	8.9
Diseases of the skin and subcutaneous tissue	5.6	9.7	3.6	1.6	6.5	2.3
Mental illness	5.4	4.6	5.8	1.2	3.3	15.7
Others	8.1	9.6	7.4	6.6	6.9	9.3
Cognitive status admission (%)						
Bad	41.0	37.0	42.9	27.3	45.7	60.2
Unsatisfactory	10.8	8.9	11.6	11.4	13.4	9.4
Satisfactory	10.1	8.4	10.9	13.4	10.9	7.5
Good	38.1	45.7	34.5	47.8	30.0	22.9
Physical status admission (%)						
Incapable	17.7	18.3	17.4	7.4	18.7	29.3
Dependent	52.8	50.7	53.8	51.8	60.1	47.6
Autonomous	14.0	13.5	14.2	18.2	11.4	12.8
Independent	15.5	17.5	14.5	22.6	9.8	10.3
Referral entity (%)						
Hospital	63.5	44.4	72.8	88.5	78.3	43.6
Others	36.5	55.6	27.2	11.5	21.7	56.4
Placement process (days)						
ECL to ECR: Median / Mean	3.0 / 6.3	2.0 / 3.7	5.0 / 7.5	2.0 / 3.7	7.0 / 9.2	6.0 / 10.4
ECR to Admission: Median / Mean	8.0 / 17.7	2.0 / 8.5	13.0 / 22.2	9.0 / 12.3	25.0 / 30.1	9.0 / 24.5
ECL to Admission: Median / Mean	14.0 / 24.1	5.0 / 12.3	21.0 / 29.9	13.0 / 16.0	35.0 / 39.3	20.0 / 35.2
Length of care (days)						
Median / Mean	42.0 / 57.9	49.0 / 64.2	38.0 / 54.9	30.0 / 35.4	79.0 / 68.6	38.0 / 60.5

Legend: HCBS: Home and Community-Based Services; NH: Nursing Homes; UC: Convalescence Units; UMDR: Medium-Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units; ECL: Local Coordination Teams; ECR: Regional Coordination Teams. All differences significant at the 1% level.

Dependence levels at admission

Although the population at NH presents a higher dependence level in all assessed cognitive and physical activities when compared to HCBS population (data not shown, available upon request), there are significant differences between all settings of care (Fig.1). Within the three NH units of care, the cognitive impairment at admission in each activity increases as we go from the UC to the ULDM. In this case, while the first group was globally assessed as “satisfactory” (score 2), the second was assessed as “unsatisfactory” (score 1). On the other hand, the individuals receiving home care (HCBS) present a cognitive status slightly lower than the UC individuals but higher than the two remaining units.

Regarding the ability to perform several basic daily activities, the results are similar to the previous case. Once again, the UC population is considered more physically independent; the ULDM individuals are the most impaired; and the HCBS population presents a dependence level similar to the UC population but higher than the two other units.

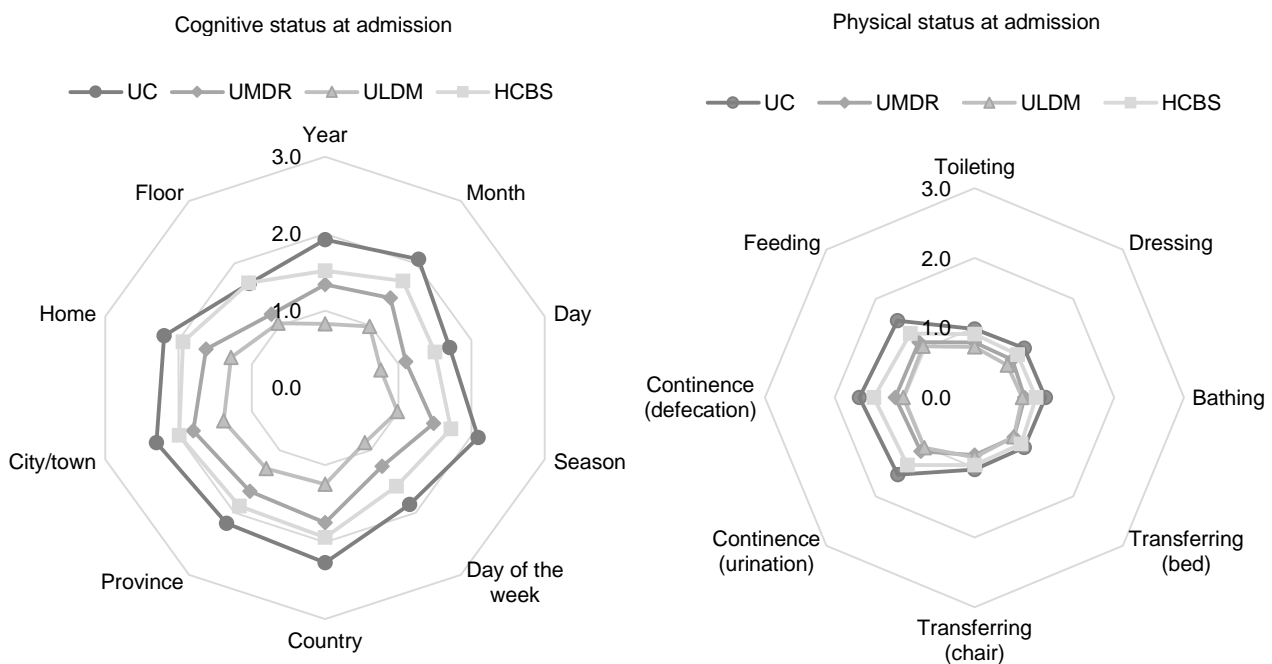


Fig. 1: One-Way ANOVA comparing the cognitive and physical dependence levels at admission in each activity, between settings of care

Legend: HCBS: Home and Community-Based Services; NH: Nursing Homes; UC: Convalescence Units; UMDR: Medium-Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units; Dependency levels identified by scores, where score 0: bad/incapable; score 1: unsatisfactory/dependent; score 2: satisfactory/autonomous; score 3: good/independent.

All difference between settings of care are significant with $p < 0.001$.

Determining the risk of being admitted into an NH or HCBS setting of care

Table 2 shows the main predictors of NH admission. Results show that, when compared to those receiving HCBS care, being female ($p=0.005$), not being married (widow or single/divorced, $p<0.001$) or being literate ($p<0.001$) increases the probability of an individual receiving care in an NH setting. On the contrary, older age ($p<0.001$) and having family/neighbour support ($p<0.001$) increases the chances of receiving home care (HCBS).

Regarding the medical conditions, the risk of being admitted into an NH setting of care increases with mental illness ($p<0.001$), diseases of the circulatory ($p<0.001$), nervous ($p<0.001$) or musculoskeletal ($p=0.022$) systems; on the other hand, conditions such as neoplasms ($p<0.001$), diseases of the skin and subcutaneous tissue ($p<0.001$) and diseases of the respiratory system ($p=0.007$) have the opposite effect.

Considering the influence of the dependence levels at admission, being classified at a higher level of cognitive ($p<0.001$) and physical ($p=0.027$) independence - when compared to the individuals with the worst level of impairment - decreases the chance of being admitted into an NH setting of care.

Table 2: Logistic regression predicting the probability of receiving care at an NH setting of care

Variables	OR	95% C.I.	
		Lower	Lower
Age	0.987 **	0,982	0,992
Gender			
Male	Reference		
Female	1.120 *	1,035	1,212
Marital Status			
Married	Reference		
Widow	1.275 **	1,168	1,391
Single/divorced	1.309 **	1,178	1,455
Family/neighbour support			
Without support	Reference		
With support	0.401 **	0,372	0,432
Educational level			
Illiterate	Reference		
literate	1.397 **	1,297	1,505
Medical conditions			
Other	Reference		
Neoplasms	0.520 **	0,435	0,621
Mental illness	2.046 **	1,663	2,517
Diseases of the nervous system	1.625 **	1,338	1,975
Diseases of the circulatory system	1.880 **	1,634	2,163
Diseases of the respiratory system	0.774 *	0,643	0,932
Diseases of the skin and subcutaneous tissue	0.571 **	0,470	0,695
Disease of musculoskeletal system	1.240 *	1,032	1,489
Injury and poisoning	1.248 *	1,081	1,441
Cognitive status at admission			
Bad	Reference		
Unsatisfactory	0.839 *	0,735	0,958
Satisfactory	0.869 *	0,757	0,998
Good	0.629 **	0,572	0,691
Physical status at admission			
Incapable	Reference		
Dependent	1.322 **	1,215	1,437
Autonomous	1.049	0,844	1,305
Independent	0.767 *	0,606	0,971
Referral entity			
Other	Reference		
Hospital	4.084 **	3,768	4,427
Region of care			
North	Reference		
Centre	8.684 **	7,670	9,833
Lisbon and Tagus Valley	0.732 **	0,666	0,804
Alentejo	2.422 **	2,099	2,794
Algarve	1.368 **	1,213	1,542
ECL to Admission (days)	1.039 **	1,037	1,041
Length of care (days)	0.992 **	0,992	0,993
Constant	1.247		

Legend: NH: nursing homes; ECL: Local Coordination Teams;

* significant at $p < 0.05$; ** significant at $p < 0.001$;

Determining the risk of being admitted into each NH unit

Considering the sociodemographic and the main medical conditions, results in Table 3 show that the following factors increase the probability of being referred to a longer (ULDM) institutionalized unit of care: older age (+0.4 percentage points, p.p.), having family/neighbour support (+1.7 p.p.) and having neoplasms (+12.0 p.p.) or mental illness (+19.2 p.p.). On the opposite side, being female (+1.1 p.p.), being single/divorced (+1.6%), being literate (+2.3 p.p.), having diseases of the skin/subcutaneous tissue (+16.6 p.p.) or diseases of the musculoskeletal system (+23.9 p.p.) increase the chance of being referred to a short stay (UC) unit of care.

Of the several individuals' characteristics included in this analysis, the cognitive and physical status at admission are those that play a greater influence in determining the admission in each NH unit of care. Compared to those with a heavier cognitive impairment, the individuals considered cognitively independent have a higher probability (+15.7 p.p.) of being referenced to the UC, whereas the probability of going to the UMDR or to the ULDM decreases in 3.5 p.p. and 12.2 p.p., respectively. Similarly, the more independent an individual is considered at admission, the less likely that individual is to be referred to a care unit with a longer expected length of care, compared to those with higher physical dependence (UC: +11.0 p.p., UMDR: -2.7 p.p. and ULDM: -8.3 p.p.).

Table 3: Marginal effects of the Ordered Logistic Regression for each Nursing Home unit of care

Variables		UC (Marginal effects)	UMDR (Marginal effects)	ULDM (Marginal effects)
Age		-0,0046 ***	0,0009 ***	0,0037 ***
Gender	Male	Reference	Reference	Reference
	Female	0,0112 *	-0,0023 *	-0,0090 *
Marital Status				
	Married	Reference	Reference	Reference
	Widow	0,0068	-0,0014	-0,0054
	Single/divorced	0,0156 *	-0,0032 *	-0,0123 *
Family or neighbour support				
	Without support	Reference	Reference	Reference
	With support	-0,0212 ***	0,0043 ***	0,0169 ***
Education level				
	Illiterate	Reference	Reference	Reference
	literate	0,0228 ***	-0,0046 ***	-0,0182 ***
Medical conditions				
	Other	Reference	Reference	Reference
	Neoplasms	-0,1085 ***	-0,011 **	0,1197 ***
	Mental illness	-0,1567 ***	-0,036 ***	0,1923 ***
	Diseases of the nervous system	-0,0221	0,001	0,0208
	Diseases of the circulatory system	0,0370 **	-0,005 ***	-0,0319 **
	Diseases of the respiratory system	-0,0101	0,001	0,0093
	Diseases of the skin and subcutaneous tissue	0,1663 ***	-0,046 ***	-0,1206 ***
	Disease of musculoskeletal system	0,2390 ***	-0,080 ***	-0,1587 ***
	Injury and poisoning	0,1415 ***	-0,036 ***	-0,1059 ***
Cognitive status at admission				
	Bad	Reference	Reference	Reference
	Unsatisfactory	0,0972 ***	-0,0157 ***	-0,0815 ***
	Satisfactory	0,1071 ***	-0,0185 ***	-0,0887 ***
	Good	0,1567 ***	-0,0349 ***	-0,1218 ***
Physical status at admission				
	Incapable	Reference	Reference	Reference
	Dependent	0,0799 ***	-0,0172 ***	-0,0627 ***
	Autonomous	0,1093 ***	-0,0266 ***	-0,0827 ***
	Independent	0,1095 ***	-0,0266 **	-0,0829 ***
Referral entity				
	Other	Reference	Reference	Reference
	Hospital	0,2853 ***	-0,0579 ***	-0,2275 ***
Region of care				
	North	Reference	Reference	Reference
	Centre	0,0622 ***	-0,0071 ***	-0,0551 ***
	Lisbon and Tagus Valley	0,0911 ***	-0,0135 ***	-0,0776 ***
	Alentejo	0,2155 ***	-0,0576 ***	-0,1579 ***
	Algarve	0,2123 ***	-0,0562 ***	-0,1562 ***
ECL to Admission (days)		-0,0027 ***	0,0005 ***	0,0021 ***
Length of care (days)		-0,0020 ***	0,0004 ***	0,0016 ***

Legend: NH: Nursing Homes; UC: Convalescence Units; UMDR: Medium-Term and Rehabilitation Units; ULDM:

Long-Term and Maintenance Units; ECL: Local Coordination Teams;

* significant at $p < 0.1$; ** significant at $p < 0.05$; *** significant at $p < 0.001$

After adjusting for all the variables of the previous analysis (Table 3), Table 4 identifies the differences between the number of individuals actually referred to each unit (“Unit: admission”) and the expected unit (“Unit: predicted”). Results show that 73.7%, 56.5% and 47.1% of the individuals were correctly referred to the UC, UMDR and to the ULDM, respectively (shaded cells).

Table 4: Match cases between the admission and the predicted Unit

Unit: admission	Unit: predicted			Total
	UC	UMDR	ULDM	
UC	73.7%	25.1%	1.2%	5,071
UMDR	23.6%	56.5%	19.9%	5,322
ULDM	9.3%	43.6%	47.1%	3,747

Legend: UC: Convalescence Units; UMDR: Medium-Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units

DISCUSSION

This study found that the main risk factors significantly associated with NH admission were the following: being female, having low social support (being widowed/single/divorced and having a low family/neighbour support), being literate, presenting some specific medical conditions (mental illness, diseases of the nervous, the circulatory and the musculoskeletal system) and being physically/cognitively dependent.

Regarding the influence of male gender and low social support, this study reaches conclusions similar to those of previous researchers (Muramatsu et al. 2007; Gaugler et al. 2007; Luppá et al. 2010, 2012; Häcker and Hackmann 2012; Schwarzkopf et al. 2013; Kim et al. 2013; Helvik et al. 2014; Wübker et al. 2015; Hajek et al. 2015; Bartfay et al. 2016; Penning et al. 2016). The fact that women have a higher life expectancy, and at the same time higher prevalence of physical and mental health comorbidity (Barnett et al. 2012), implies that the absence or the death of a spouse could aggravate the level of dependence and the inability to take care of themselves, and consequently increase the chances to receive institutionalized care (Luppá et al. 2012). Thus, not only is essential to define joint policies between the social and healthcare sectors in order to identify these risk groups, but also to create appropriate responses which enables them to stay in the community as long as possible with quality of life. Moreover, despite being created to provide longstanding care, the RNCCI additionally allows stays for a maximum of 90 days per year intended to relieve the burden of those caring for such dependent individuals. Thus, the fact that the probability of being admitted in a longer-care unit (ULMD) increases for patients with family/neighbour support, may be due to caregivers' respite care. Further research to understand this result is required.

For what concerns the effects of age, the evidence of this study is opposite to that of several previous works (Gruber-Baldini et al. 2007; Muramatsu et al. 2007; Gaugler et

al. 2007; Luppá et al. 2010, 2012; Schwarzkopf et al. 2013; Helvik et al. 2014; Lee et al. 2015; Wübker et al. 2015; Bartfay et al. 2016; Newcomer et al. 2016; Lee and Cho 2016; Penning et al. 2016), having found that older age has a small but positive influence on the chance of receiving HCBS care. Since older age is not a referral criterion for LTC admission in Portugal, it might be that these individuals have more family/caregiver support, which may contribute to delaying the admission into an NH facility. On the other hand, the fact that older age decreases the risk of being admitted into short care units (UC) may be explained by the fact that these units were created for individuals with a greater potential for autonomy recovery. Even though the evidence points to physical rehabilitation being associated with ADL function improvement in LTC facilities (Forster et al. 2010; Crocker et al. 2013) and even considering that in general younger individuals may be better able to regain some of the lost autonomy, still larger scale investigations are needed to confirm the effectiveness of care, including follow-up studies.

As for medical conditions, the findings are inconsistent. Although there is evidence that NH residents have usually a higher burden of diseases (Gaugler et al. 2007; Wieland et al. 2010; Bartfay et al. 2016; Penning et al. 2016), and also that chronic diseases such as depression, incontinence or diabetes are significant risk factors of NH admission (Luppá et al. 2010), recent studies concluded that no statistically significant differences are present between institutionalized and non-institutionalized individuals, after adjusting for the individuals' baseline characteristics (Lee et al. 2015; Blackburn et al. 2016; Lee and Cho 2016). Unfortunately, it is not possible to identify the burden of diseases of the Portuguese LTC individuals, due to the lack of information besides the main diagnosis at admission. Nevertheless, the finding that some medical conditions are a significant risk factor of NH admission can help the policy makers define specific care plans to account for the different needs.

The individuals' dependence levels are often recognized as highly relevant to determine the intensity of care services and consequently the best setting of care. In line with several studies (Gruber-Baldini et al. 2007; Kuo et al. 2010; Kim et al. 2013; Helvik et al. 2014; Wübker et al. 2015; Bartfay et al. 2016; Penning et al. 2016), we found that being classified in a higher cognitive and physical dependence level increases the risk of NH admission. Considering these findings, two reflections are necessary: first, it is essential that policy makers pay attention to staffing mix in order to tailor each setting of care with the proper resources to meet the individuals' needs; additionally, there is a need to change the financing model, by including patients' dependence levels and risk adjustment models, in order to avoid adverse selection of patients based on their case-mix by each setting of care.

Finally, a striking result is the low proportion of correct matches between the “admission” versus the “predicted” NH unit of care; in fact, only 74%, 57% and 47% of the individuals were correctly referred to the UC, UMDR and ULDM, respectively, after adjusting for several variables. Although recent studies have found differences in results after controlling for baseline characteristics (Lee et al. 2015; Newcomer et al. 2016; Blackburn et al. 2016; Lee and Cho 2016), our findings may be a consequence of both the lack of NH units of care and the regional asymmetries in the provision of care in Portugal. Besides the fact that 93% of the Portuguese population had poor access to institutionalized care, given the lack of beds available (ERS 2015), the results of this study also suggest an inadequate referral of individuals, the existence of a waste of resources, as well as the care provision not being appropriate for the real needs.

Despite the many important findings of this study, several limitations should be pointed out. Firstly, differences in data collection, selection of populations and methodological strategies across studies make it difficult to compare results, as highlighted in several literature reviews (Luppa et al. 2010; Crocker et al. 2013; Wysocki et al. 2015; O’Caoimh et al. 2015; Toot et al. 2017). Secondly, these results are difficult to compare to other national studies, given that the Portuguese LTC database is still underexplored, and that there are virtually no studies in the literature since the creation of the RNCCI. Thirdly, given the scarce information regarding medical conditions, it was not possible to identify and assess the comorbidity burden of the individuals in each setting of care. Finally, additional variables that may influence the overall results - such as the ability to perform more complex activities (e.g. instrumental activities of daily living), transitions between settings of care, or other risk factors (like smoking, obesity, alcohol and drugs) - were not analysed due to their poor quality. Further research to understand the influence of these variables is required.

CONCLUSIONS

Since the effect of certain risk factors for LTC admission may be influenced by each country’s culture, policies and living conditions, these factors need to be studied and contextualized in each specific culture and setting. Based on this study, several conclusions arise.

To the best of the authors’ knowledge, in comparison to other studies published, the approximately 21,000 patients included here represent the largest dataset analysed for a period of 1 year. Having said this, the results here presented are robust for the Portuguese LTC context.

Secondly, it is important to take into account variations in needs for individual assistance, avoiding similar situations as in this study, whereby patients with the same dependence level are referred to different settings of care and end up receiving different levels of care. Thus, the existence of a multidisciplinary case management team may be a key factor to balance both demand and supply needs, in order to guarantee an appropriate use of resources. Thirdly, the existence of regional asymmetries in care provision, and the predominance of institutionalized care over home care in Portugal, may negatively influence the referral process. Therefore, there is a need to implement an auditing process to ensure continuous improvement in the referral process. Moreover, it is essential to reverse the situation observed in the last years of loss of home care treatment places, by investing in primary care staff and to create new care teams. Finally, although formal care may be the most visible part of LTC systems, there is an important share that remains “hidden”, usually provided by family and friends. When informal care is provided by working individuals, they may be challenged in combining paid work with caring duties, compromising their future employability and career opportunities. Therefore, not only it is of paramount importance to enhance the provision of home care, but it is also vital to define policies that protect informal caregivers by allowing flexible work schedule, paid care leave or stimulate the respite care to alleviate caregiving burden and stress, for instance.

This study contributes to the literature by shedding light on the differences between the NH and the HCBS populations and by identifying the main predictors of admission in each type of care. Furthermore, results are analysed separately for three types of NH units, responsible for providing care to individuals with different dependence levels. Last, but not least, it contributes for a better understanding of the organization of the Portuguese LTC and provides leads to what can be improved.

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REFERENCES

- Abreu Nogueira J, Girão M, Guerreiro I (2010) Post Acute and Long Term Care: instrument for evaluating outcomes National Network for Integrated Continuous Care Portugal. UMCCI, Lisbon
- Barnett K, Mercer SW, Norbury M, et al (2012) Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet* 380:37–43. doi: 10.1016/S0140-6736(12)60240-2
- Bartfay E, Bartfay WJ, Gorey KM (2016) Dementia care in Ontario, Canada: evidence of more timely diagnosis among persons with dementia receiving care at home compared with residential facilities. *Public Health* 130:6–12. doi: 10.1016/j.puhe.2015.10.002
- Blackburn J, Locher JL, Kilgore ML (2016) Comparison of Long-term Care in Nursing Homes Versus Home Health: Costs and Outcomes in Alabama. *Gerontologist* 56:215–21. doi: 10.1093/geront/gnu021
- Botelho MA (1999) Autonomia Funcional em Idosos: Caracterização multidimensional em idosos utentes de um centro de saúde urbano (Functional Autonomy in Elders: Multidimensional characterization in elderly users of an urban primary care centre). Faculdade de Ciências Médicas da Universidade Nova de Lisboa
- Crocker T, Young J, Forster A, et al (2013) The effect of physical rehabilitation on activities of daily living in older residents of long-term care facilities: systematic review with meta-analysis. *Age Ageing* 42:682–8. doi: 10.1093/ageing/afp133
- D.R. (2006) Decree-Law 101/2006. D.R. I Serie A, 6th of July - Creation of the Portuguese National Network for Long-term Care [in Portuguese]. http://www.acss.min-saude.pt/wp-content/uploads/2016/10/Decreto-Lei_101_2006-1.pdf
- D.R. (2014) Ordinance no. 174/2010, 10th of September, which updates the operational conditions of the nursing homes and home care settings of care [in Portuguese]. http://www.sg.min-saude.pt/NR/rdonlyres/F1071041-A28D-4B06-8CB5-D640D1D60D80/41897/Portaria174_2014.pdf. Accessed 1 Jun 2017
- ERS (2015) Access, quality and competition in long-term and palliative care [in Portuguese]. Porto
- Folstein MF, Folstein SE, McHugh PR (1975) Mini-mental. A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 12:189–98
- Forster A, Lambley R, Young JB (2010) Is physical rehabilitation for older people in long-term care effective? Findings from a systematic review. *Age Ageing* 39:169–175. doi: 10.1093/ageing/afp247
- Gaugler JE, Duval S, Anderson KA, Kane RL (2007) Predicting nursing home admission in the U.S: a meta-analysis. *BMC Geriatr* 7:13. doi: 10.1186/1471-2318-7-13
- Gruber-Baldini AL, Stuart B, Zuckerman IH, et al (2007) Treatment of dementia in community-dwelling and institutionalized medicare beneficiaries. *J Am Geriatr Soc* 55:1508–1516. doi: 10.1111/j.1532-5415.2007.01387.x
- Häcker J, Hackmann T (2012) Los(t) in long-term care: empirical evidence from German data 2000-2009. *Health Econ* 21:1427–1443. doi: 10.1002/hecl.1805
- Hajek A, Brettschneider C, Lange C, et al (2015) Longitudinal Predictors of Institutionalization in Old Age. *PLoS One* 10:e0144203. doi: 10.1371/journal.pone.0144203
- Helvik AS, Skancke RH, Selbæk G, Engedal K (2014) Nursing home admission during the first year after hospitalization - The contribution of cognitive impairment. *PLoS One* 9:. doi: 10.1371/journal.pone.0086116

- Instituto da Segurança Social (2017) Practical guide - National Network for Long-term Care [in Portuguese]. Lisbon
- Kane RL, Lum TY, Kane RA, et al (2013) Does Home-and Community-Based Care Affect Nursing Home Use? *J Aging Soc Policy* 25:146–160. doi: 10.1080/08959420.2013.766069
- Katz S, Ford AB, Moskowitz RW, et al (1963) Studies of illness in the aged: the index of ADL, a standardized measure of biological and psychosocial function. *JAMA* 185:914. doi: 10.1001/jama.1963.03060120024016
- Kaye HS, Harrington C (2015) Long-term services and supports in the community: Toward a research agenda. *Disabil Health J* 8:3–8. doi: 10.1016/j.dhjo.2014.09.003
- Kim YH, Kwon CH, Shin HI (2013) Validity of motor impairment scale in long-term care insurance system of Korea. *Ann Rehabil Med* 37:403–412. doi: 10.5535/arm.2013.37.3.403
- Kuo Y-C, Lan C-F, Chen L-K, Lan VM (2010) Dementia care costs and the patient's quality of life (QoL) in Taiwan: home versus institutional care services. *Arch Gerontol Geriatr* 51:159–63. doi: 10.1016/j.archger.2009.10.001
- Lee K, Cho E (2016) Activities of daily living and rehabilitation needs for older adults with a stroke: A comparison of home care and nursing home care. *Japan J Nurs Sci* 14:103–111. doi: 10.1111/jjns.12139
- Lee TW, Cho E, Yim ES, et al (2015) Activities of Daily Living in Nursing Home and Home Care Settings: A Retrospective 1-Year Cohort Study. *J Am Med Dir Assoc* 16:114–119. doi: 10.1016/j.jamda.2014.07.013
- Lopes H, Mateus C, Hernández-Quevedo C (2018) Ten Years since the 2006 Creation of the Portuguese National Network for Long-Term Care: Achievements and Challenges. *Health Policy (New York)* 122:210–216. doi: 10.1016/J.HEALTHPOL.2018.01.001
- Luppa M, Luck T, Weyerer S, et al (2010) Prediction of institutionalization in the elderly. A systematic review. *Age Ageing* 39:31–38. doi: 10.1093/ageing/afp202
- Luppa M, Riedel-Heller SG, Luck T, et al (2012) Age-related predictors of institutionalization: results of the German study on ageing, cognition and dementia in primary care patients (AgeCoDe). *Soc Psychiatry Psychiatr Epidemiol* 47:263–270. doi: 10.1007/s00127-010-0333-9
- Muramatsu N, Yin H, Campbell RT, et al (2007) Risk of nursing home admission among older americans: does states' spending on home- and community-based services matter? *J Gerontol B Psychol Sci Soc Sci* 62:S169-78
- Newcomer RJ, Ko M, Kang T, et al (2016) Health Care Expenditures After Initiating Long-term Services and Supports in the Community Versus in a Nursing Facility. *Med Care* 54:221–8. doi: 10.1097/MLR.0000000000000491
- O'Caoimh R, Cornally N, Weathers E, et al (2015) Risk prediction in the community: A systematic review of case-finding instruments that predict adverse healthcare outcomes in community-dwelling older adults. *Maturitas* 82:3–21. doi: 10.1016/j.maturitas.2015.03.009
- Penning MJ, Cloutier DS, Nuernberger K, et al (2016) Long-term Care Trajectories in Canadian Context: Patterns and Predictors of Publicly Funded Care. *J Gerontol B Psychol Sci Soc Sci* gbw104. doi: 10.1093/geronb/gbw104
- Rechel B, Grundy E, Robine J-M, et al (2013) Ageing in the European Union. *Lancet* 381:1312–1322. doi: 10.1016/S0140-6736(12)62087-X
- Schwarzkopf L, Menn P, Leidl R, et al (2013) Are community-living and institutionalized dementia patients cared for differently? Evidence on service utilization and costs of care

from German insurance claims data. *BMC Health Serv Res* 13:2. doi: 10.1186/1472-6963-13-2

Toot S, Swinson T, Devine M, et al (2017) Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis. *Int Psychogeriatrics* 29:195–208. doi: 10.1017/S1041610216001654

Wieland D, Boland R, Baskins J, Kinoshian B (2010) Five-year survival in a program of all-inclusive care for elderly compared with alternative institutional and home-and community-based care. *Journals Gerontol - Ser A Biol Sci Med Sci* 65 A:721–726. doi: 10.1093/gerona/glq040

Wübker A, Zwakhalen SMG, Challis D, et al (2015) Costs of care for people with dementia just before and after nursing home placement: primary data from eight European countries. *Eur J Heal Econ* 16:689–707. doi: 10.1007/s10198-014-0620-6

Wysocki A, Butler M, Kane RL, et al (2015) Long-Term Services and Supports for Older Adults: A Review of Home and Community-Based Services Versus Institutional Care. *J Aging Soc Policy* 27:255–79. doi: 10.1080/08959420.2015.1024545

5.3. Impact of long term care and mortality risk in community care and nursing homes populations

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ABSTRACT

Objectives: To identify the survival time, the mortality risk factors and the individuals' characteristics associated with cognitive and physical status at discharge, among the Portuguese long-term care (LTC) populations.

Settings: Home-and-Community-Based Services (HCBS) and three types of Nursing Homes (NH).

Participants: 20,984 individuals admitted and discharged in 2015.

Measurements: The Kaplan-Meier survival analysis and the Cox Proportional Hazards Models were used to study the mortality risk; the Wilcoxon signed-rank test to identify the number of individuals with cognitive and physical changes between admission and discharge; two cumulative odds ordinal logistic regressions to predict the cognitive and physical dependence levels at discharge

Results: The mortality rate at HCBS was 30%, and 17% at the NH, with a median survival time of 173 and 200 days, respectively. The main factors associated with higher mortality were older age, male gender, family/neighbour support, neoplasms and cognitive/physical dependence at admission. In NH/HCBS, 26%/18% of individuals improve their cognitive status, while in physical status the proportion was 38%/27%, respectively. Finally, older age, being illiterate and being classified at the lowest cognitive and physical status at admission decrease the likelihood of achieving a higher level of cognitive and physical independence at discharge.

Conclusions: The adoption of a robust and complete assessment tool, the definition of guidelines to enable a periodical assessment of individuals' autonomy and the adoption of benchmark metrics allowing the comparison of results between similar units are some of the main goals to be taken into account for future developments of this care in Portugal.

1. Background

Needs assessments nowadays play a fundamental role in the planning process of healthcare and social services and are even considered a means in the clinical context to reach a specific diagnosis (Iezzoni, 2004). Being the main premise of the long-term care (LTC) sector “care over cure”, it is important to define metrics of needs assessment in several areas to help healthcare providers to (re)design patient care, develop clinical pathways and predict with higher accuracy their rehabilitation outcome at discharge.

Although several studies analysed the differences between Nursing Homes (NH) and Home and Community-Based Services (HCBS) populations in order to identify factors determining admissions into each setting of care, it is not easy or consensual to define the best areas for outcome assessment. Usually, outcome measures are related either to mortality or to changes of cognitive and physical dependence levels.

Thus, to assess these outcomes, it is important to incorporate different individual-mix factors, including socio-demographic characteristics, medical conditions as well as the physical and cognitive status (Iezzoni, 2004; Gindin et al., 2007; Fusco et al., 2009; Seematter-Bagnoud et al., 2013).

Regarding the mortality assessment, because the number of deaths in LTC is usually high, it is important to estimate the expected length of survival after an individual's admission and identify the main mortality predictors so that policy makers can optimize the planning of services provision. For that matter, in spite of different magnitudes between studies, several authors concluded that the most relevant mortality risk factors include older age, male gender, the absence of a social support network, the presence of certain medical conditions (e.g., neoplasms, musculoskeletal or respiratory diseases) and high levels of cognitive and physical dependence (Carlson et al., 2001; Jakobsson & Hallberg, 2006; Lee, Chau, Hui, Chan, & Woo, 2009; Hjaltadóttir, Hallberg,

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Ekwall, & Nyberg, 2011; Luo & Waite, 2014; Sung, 2014; Vetrano et al., 2018). After assessing the mortality rate, some authors found no differences between NH and HCBS, either after adjusting for baseline variables (age, gender, race, education, race, education, marital status, length of stay, cognition, and comorbidity) (Sloane et al., 2005) or when comparing patients receiving care at NH, HCBS or combined care (Lee, Yim, Cho, & Chung, 2014). Others found a higher mortality among those at NH (Jakobsson and Hallberg, 2006; Gruber-Baldini, Stuart, Zuckerman, Simoni-Wastila, & Miller, 2007; Wieland, Boland, Baskins, & Kinoshian, 2010; Häcker & Hackmann, 2012).

Concerning the physical outcomes, whereas some authors found no significant differences in the deterioration in performing activities of daily living (ADL) between the two settings of care (Chiu, Shyu, & Liu, 2001; Frytak, Kane, Finch, Kane, & Maude-Griffin, 2001; Sloane et al., 2005; Marioni, Chatfield, Brayne, & Matthews, 2011), others found better outcomes among HCBS individuals (Rothera, Jones, Harwood, Avery, & Waite, 2003; Lee et al., 2014; Lee et al., 2015; Lee & Cho, 2016) and others concluded that only the NH population showed some ADL improvements (Kim & Yang, 2005). As for changes in cognitive status, although some authors found no statistical differences between the two settings of care (Kim & Yang, 2005; Sloane et al., 2005), others found better outcomes among those at HCBS (Rothera et al., 2003; Lee et al., 2014).

Besides the overall differences in outcomes between these two populations, several findings can be highlighted concerning the influence of different variables as predictors of physical and cognitive changes. Older age seems to be related to a higher cognitive impairment (Anderson, Sachdev, Brodaty, Trollor, & Andrews, 2007; Moraes, Pinto, Lopes, Litvoc, & Bottino, 2010); moreover, some studies concluded that younger age positively influences the physical improvement (Frytak et al., 2001; Gindin et al., 2007; Häcker & Hackmann, 2012; Kim, Kwon, & Shin, 2013; Seematter-Bagnoud et al., 2013) but others found no significant effect (Bagg, Pombo, & Hopman, 2002; Perrig-Chiello, Perrig, Uebelbacher, & Stähelin, 2006; Jerez-Roig, de Brito Macedo Ferreira, de Araújo, & Costa Lima, 2017; Phillips, Leary, Blankenship, & Zimmerman, 2017). In most health facilities with similar rehabilitation programmes, men and women are expected to achieve similar progress and outcomes. Despite gender being an independent risk factor for cognitive function (Anderson et al., 2007; Moraes et al., 2010), some authors found no statistically significant association between gender and changes in cognitive (Marioni et al., 2011) and physical status (Cameron, Schaafsma, Wilson, Baker, & Buckley, 2012; Kim et al., 2013; Jerez-Roig et al., 2017; Phillips et al., 2017). Others concluded that women were twice as likely to show physical improvements compared to men (Gindin et al., 2007). Within HCBS individuals, one study concluded that women were more likely to achieve functional recovery (Seematter-Bagnoud et al., 2013), while others concluded the opposite (Perrig-Chiello et al., 2006; Häcker & Hackmann, 2012).

Since LTC patients are usually elderly people with chronic diseases, what often influences their dependence levels, accurate information regarding medical diagnoses is essential for care planning and monitoring for predicting their rehabilitation outcomes. As concluded by several studies, individuals with fewer chronic diseases are more likely to achieve better outcomes (Gindin et al., 2007; Cameron, Schaafsma, Wilson, Baker, & Buckley, 2012; Seematter-Bagnoud et al., 2013). Finally, whereas global limitations in motor functions at admission combined with cognitive impairment can influence the overall levels of disability at discharge (Gindin et al., 2007; Vogt, Wieland, Bach, Himmelreich, & Banzer, 2008; Fusco et al., 2009; Cameron et al., 2012; Häcker & Hackmann, 2012; Kim et al., 2013; Seematter-Bagnoud et al., 2013; Jerez-Roig et al., 2017) limitations in the ability to perform single ADL at admission like the use of a wheelchair (Singh, Hunter, Philip, & Todd, 2006), walking (Suzuki et al., 2006) or transfers (to the toilet and/or to the bed/chair) (Gialanella, Santoro, & Ferlucci, 2012), can also be seen as important outcome predictors.

1.1. The long-term care in Portugal

In Portugal, the National Network for Long-term Integrated Care (*Rede Nacional de Cuidados Continuados Integrados*, RNCCI) was created in 2006 as a partnership between the Ministry of Health and the Ministry of Employment and Social Solidarity (Decree-Law 101/2006). As defined by the Portuguese legislation, the RNCCI is organized into two main settings of care (Decree-Law 101/2006): HCBS and NH.

As for the HCBS, the care is provided between 8am and 8pm at home under the responsibility of the primary care centre teams, to people with functional dependence but who do not require acute care. Of the several services provided, stands out the personal hygiene, medical, nursing and rehabilitation care, occupational therapy, education and psychosocial support involving both patients and their caregivers (Ordinance no. 174/2010; ISS, 2017). Individuals with care needs during the night, in need for only social support or without informal caregivers, are excluded.

In order to respond to different needs, the NH in Portugal are organized into three types of care units (Decree-Law 101/2006). Although services like personal hygiene, drugs prescription and administration, psychological and social support are provided to all patients (Ordinance no. 174/2010; ISS, 2017), the intensity of nursing, medical and physiotherapy care differs according to the type of care units, namely (Decree-Law 101/2006; Ordinance no. 174/2010): (i) Convalescence Units (*Unidades de Convalescença*, UC), which provide nursing, medical and physiotherapy care on a daily basis for individuals discharged from hospitals in need of convalescence care up to 30 consecutive days; (ii) the Medium-Term and Rehabilitation Units (*Unidades de Média Duração e Reabilitação*, UMDR), which provide less intensive and differentiated care (while the nursing care is provided daily, the medical and rehabilitation care is provided two days per week) for individuals with an expected length of care between 31 and 90 consecutive days; and (iii) the Long-Term and Maintenance Units (*Unidades de Longa Duração e Manutenção*, ULDM), which provide daily nursing care (medical and rehabilitation care only once a week) for individuals with difficulties with community inclusion as well as for caregivers' respite care, with a length of care higher than 90 consecutive days.

2. Objectives

The main goal of this research is to contribute to a better understanding of two areas in the LTC sector that may help policy makers and staff to improve the way care is provided to such a fragile population: mortality and patients' outcomes. Regarding the first one, we aim to identify the median survival time within NH and HCBS settings of care and identify the predictive power of several variables on the mortality risk in each setting. Then, we aim to quantify the impact of care provided by looking at the number of individuals who showed changes in their physical and cognitive dependence level between admission and discharge as well as to identify the individuals' characteristics associated with each status at discharge.

3. Data and methods

3.1. Data source

The dataset contains records of 20,984 individuals aged ≥ 60 years, admitted and discharged in 2015 in Portugal mainland, of which 14,140 were from NH and 6844 from HCBS.

Besides the identification of the length of care, referral entity, region and setting of care, this study includes results from the Portuguese screening tool used by LTC healthcare professionals to assess patients' dependence levels, called Integrated Bio-psychosocial Assessment Instrument (Abreu Nogueira, Girão, & Guerreiro, 2010). The information collected by this tool and used in this study is divided in three areas

(Botelho, 1999): (i) Biological: age, gender, medical conditions at admission and the ability to perform eight ADL using the Katz' ADL index (Katz et al., 1963) (toileting, dressing, bathing, transferring/bed, transferring/chair, continence/urination, continence/defecation and feeding) in two moments (admission and discharge); (ii) Psychological: assessment of the cognitive status through the ability to answer questions about temporal (year, month, day, season and day of the week) and spatial (country, province, city/town, home and floor) orientation using the Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975) in two moments (admission and discharge); and (iii) Social: level of education, marital status and the availability of family/neighbour support.

Regarding the assessment of the cognitive/physical status of each individual, this tool does it in three stages (Botelho, 1999; Abreu Nogueira et al., 2010). First, it assesses the ability to perform each activity using a four system score: score 0 (bad/incapable); score 1 (unsatisfactory/dependent); score 2 (satisfactory/autonomous); and score 3 (good/independent). Then, while the overall physical status is determined by considering the lowest score obtained in the eight activities assessed, the cognitive status is determined by the average score

of the ten activities analysed. Finally, based on the previous cognitive/physical scores, each individual is further classified into one of the four dependence groups.

3.2. Methodology and model adopted

The Kaplan-Meier survival analysis (log-rank test) was conducted to determine the median survival time in the two main settings of care and within the three NH units of care. Then, a Cox Proportional Hazards Model was used to identify the predictive power of several variables (socio-demographic characteristics, medical conditions, cognitive and physical dependence level at admission, referral entity) for mortality risk in NH and HCBS settings of care. Third, the Wilcoxon signed-rank test was used to measure changes in cognitive and physical dependence level between admission and discharge, both for all population and for only those alive at discharge. Finally, two cumulative odds ordinal logistic regressions were run to determine the effect of several variables on the ability to predict the cognitive (Model 1) and physical (Model 2) status, using the dependence level at discharge as dependent variable. From the several aspects mentioned in the literature, which may

Table 1
Population' characteristics in each setting of care.

	All	HCBS	NH	NH units of care		
				UC	UMDR	ULDM
Population	20,984	6,844	14,140	5,071	5,332	3,747
Age						
Mean (SD)	79.2 (8.3)	79.9 (8.5)	78.9 (8.3)	77.7 (8.3)	78.4 (8.0)	81.2 (8.1)
Gender (%)						
Female/Male	57.7/42.3	55.7/44.3	58.7/41.3	60.9/39.1	57.3/42.7	57.9/42.1
Marital Status (%)						
Married	45.5	49.9	43.3	42.4	43.3	44.5
Widow	37.0	34.2	38.3	37.9	37.9	39.4
Single/Divorced	17.6	15.9	18.4	19.7	18.8	16.1
Family/neighbour support (% yes)	44.4	58.2	38.7	42.5	31.4	43.8
Education level (%)						
Illiterate	50.5	55.7	48.1	46.1	48.8	49.7
Literate	49.5	44.3	51.9	53.9	51.2	50.3
Medical conditions (%)						
Circulatory system	31.8	22.3	36.2	31.1	40.9	36.4
Injury and poisoning	23.8	21.5	24.9	34.6	26.2	9.7
Neoplasms	7.2	12.3	4.9	3.6	3.8	8.1
Musculoskeletal system	6.8	7.5	6.5	12.5	3.3	2.9
Respiratory system	5.8	7.3	5.1	4.6	4.4	6.8
Nervous system	5.6	5.3	5.6	4.2	4.7	8.9
Skin and subcutaneous tissue	5.6	9.7	3.6	1.6	6.5	2.3
Mental illness	5.4	4.6	5.8	1.2	3.3	15.7
Cognitive status admission (%)						
Bad	41.0	37.0	42.9	27.3	45.7	60.2
Unsatisfactory	10.8	8.9	11.6	11.4	13.4	9.4
Satisfactory	10.1	8.4	10.9	13.4	10.9	7.5
Good	38.1	45.7	34.5	47.8	30.0	22.9
Physical status admission (%)						
Incapable	17.7	18.3	17.4	7.4	18.7	29.3
Dependent	52.8	50.7	53.8	51.8	60.1	47.6
Autonomous	14.0	13.5	14.2	18.2	11.4	12.8
Independent	15.5	17.5	14.5	22.6	9.8	10.3
Referral entity (%)						
Hospital: General Surgery	6.4	5.7	6.7	8.9	7.2	3.2
Hospital: Internal Medicine	27.5	18.4	31.9	30.3	36.7	27.2
Hospital: Neurology	4.5	1.4	6.0	5.9	7.8	3.6
Hospital: Orthopaedics	18.9	14.6	21.0	35.3	18.8	4.7
Other entities	42.7	59.8	34.4	19.6	29.6	61.2
Length of care (days)						
Mean (SD)	57.9 (47.3)	64.2 (56.9)	54.9 (41.4)	35.4 (18.3)	68.9 (40.4)	60.5 (53.3)

Legend: HCBS: Home and Community-Based Services; NH: Nursing Homes; UC: Convalescence Units; UMDR: Medium-Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units; SD: Standard Deviation.

Table 2
Mortality rate and survival time in each setting of care.

Settings of care	Mortality rate	Estimate median survival time (days)	95% C.I.		p-value
			Lower	Lower	
All	21.1%	197.0	186.6	207.4	$\chi^2 = 173.3^*$
Home and Community-Based Services	29.5%	173.0	159.5	186.5	
Nursing Homes	17.0%	200.0	189.2	210.8	
UC	6.0%	288.0	75.5	500.5	$\chi^2 = 412.3^*$
UMDR	18.0%	202.0	183.0	221.0	
ULDM	30.5%	158.0	141.7	174.3	

Legend: C.I.: confidence interval; UC: Convalescence Units; UMDR: Medium-Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units.

χ^2 : Log Rank test (Mantel-Cox).

* significant at $p < 0.001$.

influence the status at discharge, we selected as explanatory variables the socio-demographic characteristics, medical conditions, cognitive/physical dependence levels at admission and settings of care. Even though the direct association of other factors like the referral entity and length of care is not yet well proven (Frytak et al., 2001; Gindin et al., 2007; Cameron et al., 2012; Häcker & Hackmann, 2012), they were used as control variables. In this last analysis, only individuals alive at discharge were included.

All analyses were made with SPSS Statistics software (v.20, IBM SPSS, Chicago, IL), using a significance level of 0.05.

3.3. Population characteristics

Comparing the two main settings of care, the NH population is slightly younger, has a higher percentage of females, lower percentage of married people and fewer individuals with family/neighbour support than the HCBS population (Table 1). The main group of medical conditions registered at admission are diseases of circulatory system, injury and poisoning and neoplasms, and the percentage of individuals classified into the two lowest levels of cognitive and physical independence

Table 3
Cox Proportional Hazard models predicting the time to death in individuals upon admission in NH and HCBS settings of care.

	Model 1: HCBS (N = 6,571)				Model 2: NH (N = 14,020)			
		OR	Hazard Ratios (95% C.I.)			OR	Hazard Ratios (95% C.I.)	
			Lower	Lower			Lower	Lower
Age	1.019	***	1.013	1.025	1.030	***	1.025	1.036
Gender								
Male	1.237	***	1.124	1.362	1.446	***	1.329	1.573
Female	Reference				Reference			
Family or neighbour support								
Without support	0.695	***	0.630	0.767	0.759	***	0.699	0.825
With support	Reference				Reference			
Education level								
Illiterate	–		–	–	1.088	**	1.002	1.182
Literate	Reference				Reference			
Medical conditions								
Neoplasms	3.666	***	3.043	4.417	2.389	***	1.997	2.858
Mental illness	1.012		0.786	1.304	0.657	***	0.525	0.823
Diseases of the nervous system	0.776	*	0.593	1.017	0.803	*	0.644	1.001
Diseases of the circulatory system	0.796	**	0.656	0.967	0.669	***	0.575	0.779
Diseases of the respiratory system	1.122		0.898	1.402	1.383	**	1.150	1.663
Diseases of the skin and subcutaneous tissue	1.304	**	1.065	1.597	1.523	***	1.258	1.843
Disease of musculoskeletal system	0.416	***	0.278	0.622	0.413	***	0.277	0.616
Injury and poisoning	0.491	***	0.376	0.640	0.675	***	0.550	0.828
Other	Reference				Reference			
Cognitive status at admission								
Bad	1.779	***	1.568	2.019	1.789	***	1.587	2.018
Unsatisfactory	1.358	**	1.128	1.634	1.261	**	1.073	1.482
Satisfactory	1.113		0.920	1.348	1.136		0.946	1.365
Good	Reference				Reference			
Physical status at admission								
Incapable	1.453	**	1.051	2.010	1.398	*	0.956	2.045
Dependent	1.130		0.823	1.552	0.961		0.659	1.401
Autonomous	0.983		0.659	1.467	1.119		0.695	1.802
Independent	Reference				Reference			
Referral entity								
Hospital: General Surgery	0.576	***	0.454	0.730	0.993	***	0.838	1.176
Hospital: Internal Medicine	1.250	***	1.108	1.411	1.219	***	1.101	1.349
Hospital: Neurology	0.643	*	0.391	1.057	0.837	*	0.682	1.027
Hospital: Orthopaedics	0.622	**	0.455	0.850	0.546	***	0.441	0.676
Other entities	Reference				Reference			

Legend: C.I.: Confidence Interval; HCBS: Home and Community-Based Services; NH: Nursing Homes; UC: Convalescence Units; UMDR: Medium-Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units.

* Significant at $p < 0.1$.

** Significant at $p < 0.05$.

*** Significant at $p < 0.001$.

is higher at NH (54.5% and 71.2%) than in HCBS (45.9% and 69.0%) setting of care. Regarding the referral entity, while most NH individuals are referred from hospital services, like internal medicine and orthopaedic, the majority of the HCBS individuals are referred by other entities, such as the primary care providers.

4. Results

4.1. Outcomes assessment: mortality risk

The overall mortality rate is 21.1%, with a median survival time of 197 days (Table 2). Comparing the two main settings of care, the HCBS population presents a higher mortality rate and a lower survival time when compared to the institutionalized population ($p < 0.001$). Within the three NH units, the mortality rate increases as we go from a shorter (UC) to a longer (ULDM) care unit, and consequently, the median survival time has the opposite behaviour ($p < 0.001$).

Table 3 identifies the variables with statistical significance for the mortality risk in each setting of care. Regarding the socio-demographic factors, older age and male gender increase the risk of mortality in both settings of care ($p < 0.001$). On the other hand, the absence of family/neighbour support ($p < 0.001$) decreases the mortality risk in both models, being illiterate ($p = 0.045$) has the opposite effect but only at NH. Concerning the medical conditions, while having a diagnosis of neoplasms ($p < 0.001$) or diseases of the skin and subcutaneous tissue (HCBS: $p = 0.010$; NH: $p < 0.001$) increases the risk of mortality in both settings of care, individuals with diseases of the musculoskeletal ($p < 0.001$) or circulatory system (HCBS: $p = 0.021$; NH: $p < 0.001$) present the opposite result. Looking at dependence levels, compared to

those classified as cognitively or physically independent at admission, being classified in the highest level of impairment increases the risk of mortality in both settings of care. Finally, regarding the referral entity, while individuals referred by internal medicine services have a higher probability to die ($p < 0.001$), those referred by the orthopaedics services have the opposite chance (HCBS: $p = 0.003$; NH: $p < 0.001$).

4.2. Outcomes assessment: changes in the dependence level

Comparing the percentage of individuals with cognitive and physical changes between all population and only those alive at discharge, several differences can be highlighted (Fig. 1). Regarding the cognitive status, the percentage of individuals who maintained or improved their status was higher among those alive at discharge (61% and 24%) when compared to the whole population (48% and 19%). Despite a similar trend between HCBS and NH settings of care, the percentage of individuals with cognitive improvement was higher within the second group for both populations. Comparing the three NH units of care, although the percentage of individuals with some improvements decreases as we go from the UC to the ULDM, the majority maintained their cognitive status between admission and discharge. Concerning the physical status, despite a similar trend towards the cognitive status, the UC is the only setting of care where the percentage of individuals who improved is higher than those who worsened or maintained their function abilities, both in the whole population (44%) and in only those alive at discharge (45%).

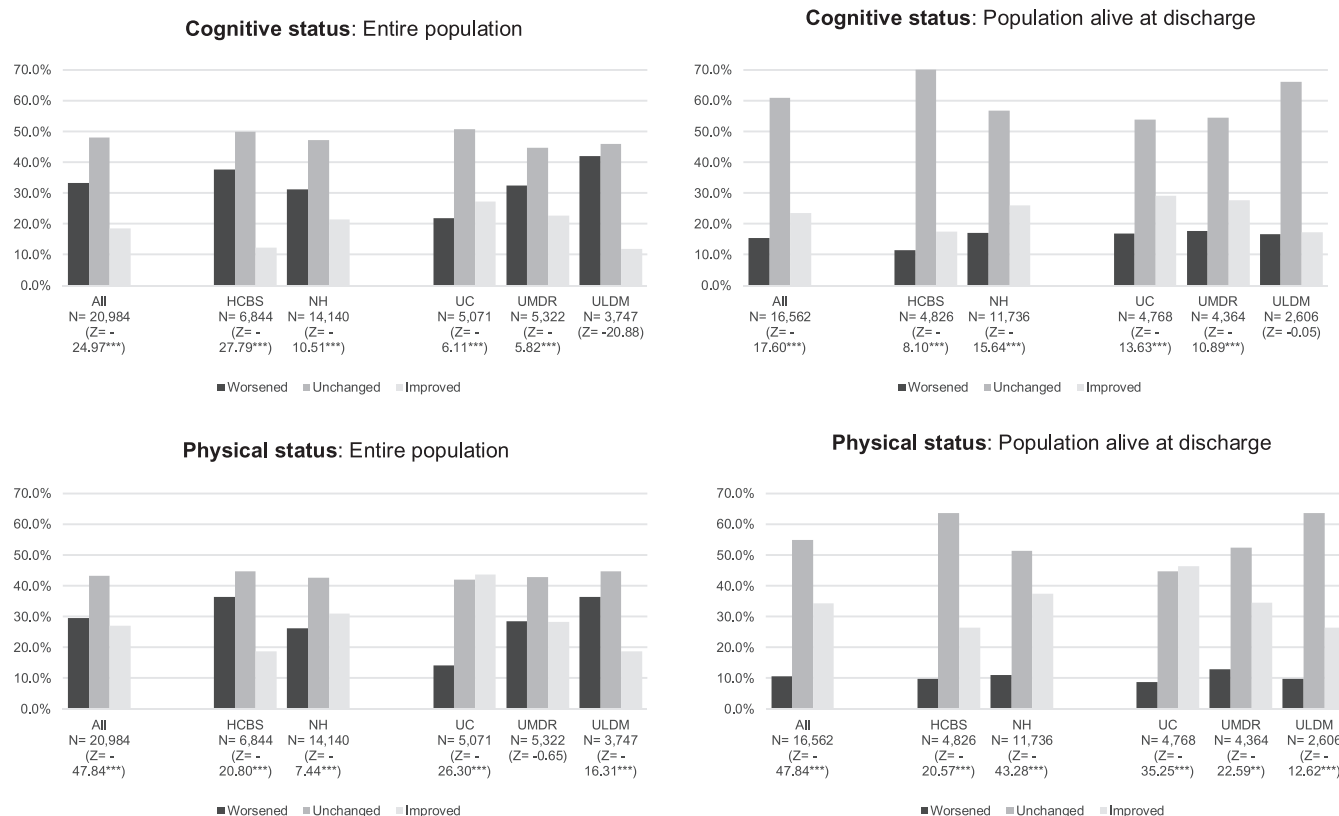


Fig. 1. Percentage of individuals who had changes in their cognitive and physical dependence level between admission and discharge.

Legend: HCBS: Home and Community-Based Services; NH: Nursing Homes; UC: Convalescence Units; UMDR: Medium-Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units.

Wilcoxon signed-rank test, based on negative ranks. Difference in dependence level between admission and discharge: * significant at $p < 0.1$; ** significant at $p < 0.05$; *** significant at $p < 0.001$

4.3. Outcomes assessment: predicting the dependence level at discharge

Table 4 identifies the predictive power of each variable on the cognitive (Model 1) and physical status (Model 2) at discharge. Only family/neighbour support was excluded from both models, due to a lack of statistical significance.

The socio-demographic characteristics that most contribute to decreasing the odds of being classified at a higher cognitive and physical independence status at discharge are older age ($p < 0.001$), being married (Model 1: $p = 0.026$; Model 2: $p = 0.006$) or being a widow(er) (Model 1: $p = 0.052$, Model 2: $p = 0.085$) when compared to single/divorced people and being illiterate (Model 1: $p = 0.013$; Model 2: $p = 0.006$). While male gender seems to have a negative influence on

the physical status at discharge (Model 2: $p = 0.057$), it has the opposite effect on the cognitive status at discharge (Model 1: $p = 0.074$).

Compared to other medical conditions at admission, while having mental illness ($p < 0.001$) decreases the probability of being classified at a higher level of cognitive independence at discharge, having musculoskeletal diseases ($p < 0.001$) has the opposite effect. With respect to the physical status, while having diseases of the skin and subcutaneous tissue ($p < 0.001$) or the circulatory ($p < 0.001$) or respiratory ($p = 0.038$) system decreases the probability of being classified at a higher independence level at discharge, having musculoskeletal diseases or mental illness ($p < 0.001$) has the opposite effect.

Compared to those classified at a higher independence level at

Table 4
Ordinal regressions predicting the cognitive and physical dependence levels at discharge.

	Model 1 Cognitive status at discharge				Model 2 Physical status at discharge			
	OR		95% C.I.		OR		95% C.I.	
			Lower	Lower			Lower	Lower
Age	0.957	***	0.953	0.962	0.967	***	0.963	0.971
Gender								
Male	1.069	*	0.994	1.150	0.937	*	0.877	1.002
Female	Reference				Reference			
Marital Status								
Married	0.897	**	0.816	0.987	0.888	**	0.815	0.967
Widow	0.907	*	0.821	1.001	0.924	*	0.845	1.011
Single/divorced	Reference				Reference			
Education level								
Illiterate	0.917	**	0.857	0.982	0.918	**	0.863	0.976
literate	Reference				Reference			
Medical conditions								
Neoplasms	1.462	***	1.194	1.790	0.956		0.798	1.144
Mental illness	0.374	***	0.307	0.456	2.496	***	2.098	2.971
Diseases of the nervous system	0.894		0.749	1.068	0.980		0.829	1.158
Diseases of the circulatory system	0.913		0.800	1.043	0.710	***	0.627	0.804
Diseases of the respiratory system	1.019		0.842	1.234	0.825	**	0.689	0.989
Diseases of the skin and subcutaneous tissue	0.860		0.703	1.052	0.457	***	0.375	0.556
Disease of musculoskeletal system	2.381	***	1.945	2.916	2.004	***	1.705	2.356
Injury and poisoning	1.172	**	1.007	1.363	1.079		0.940	1.240
Other	Reference				Reference			
Cognitive status at admission								
Bad	0.088	***	0.081	0.096	0.359	***	0.332	0.390
Unsatisfactory	0.253	***	0.228	0.282	0.454	***	0.408	0.505
Satisfactory	0.540	***	0.483	0.604	0.814	***	0.735	0.902
Good	Reference				Reference			
Physical status at admission								
Incapable	0.433	***	0.334	0.560	0.018	***	0.014	0.022
Dependent	0.687	**	0.533	0.886	0.061	***	0.049	0.075
Autonomous	1.211		0.868	1.690	0.233	***	0.178	0.304
Independent	Reference				Reference			
Settings of care								
UC	1.044		0.946	1.152	2.031	***	1.866	2.210
UMDR	0.712	***	0.649	0.781	1.094	**	1.004	1.192
ULDM	0.516	***	0.463	0.575	0.894	**	0.807	0.989
HCBS	Reference				Reference			
Referral entity								
Hospital: General Surgery	1.449	***	1.250	1.678	1.105		0.969	1.261
Hospital: Internal Medicine	1.202	***	1.094	1.320	1.200	***	1.098	1.311
Hospital: Neurology	1.260	**	1.074	1.479	1.122		0.962	1.310
Hospital: Orthopaedics	1.430	***	1.268	1.613	1.198	**	1.081	1.329
Other entities	Reference				Reference			
Length of care (days)	1.001	**	1.000	1.002	—		—	—

Legend: CI: Confidence Interval; HCBS: Home and Community-Based Services; NH: Nursing Homes; UC: Convalescence Units; UMDR: Medium-Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units;

* Significant at $p < 0.1$.

** Significant at $p < 0.05$.

*** Significant at $p < 0.001$.

admission, being considered cognitively or physically impaired at admission decreases the probability of achieving a higher status at discharge ($p < 0.001$). Regarding the NH units, compared to HCBS, while being admitted at UC increases the probability of achieving a better cognitive (Model 1: although not statistically significant) or physical (Model 2: $p < 0.001$) status at discharge, being admitted at ULDM (Model 1: $p < 0.001$; Model 2: $p = 0.030$) has the opposite effect.

5. Discussion

5.1. Outcomes assessment: mortality risk

Because the mortality rate in the LTC sector is usually high and the predictive intensity of several variables may vary according to the setting of care, its assessment is clinically useful and valuable, not only for health care professionals but also for managers and policy makers. Contrary to the findings of several authors (Jakobsson and Hallberg, 2006; Gruber-Baldini et al., 2007; Wieland et al., 2010; Häcker & Hackmann, 2012; Shah, Carey, Harris, DeWilde, & Cook, 2013), in this study, the higher mortality rate among HCBS than in the NH population may be explained by the existence of different institutionalized units of care. Although the ULDM have a mortality rate five times higher and approximately half of the estimated time of survival than UC, reflecting the higher severity of the first population, both results are very similar to the results of those who received home care (HCBS). Because these two settings of care were designed to respond to different care needs, these results may indicate possible problems regarding the referral process that are worth to be explored.

Based on the Cox regression analysis, several factors have been found to predict the mortality risk in each setting of care. Concerning the socio-demographic characteristics, whereas older age and male gender increase the risk of mortality in both settings of care, not having family/neighbour support has the opposite effect. Although some authors concluded that the effect of these characteristics were not statistically significant (Carlson et al., 2001), this finding is similar to several studies (Jakobsson and Hallberg, 2006; Lee et al., 2009; Hjaltadóttir et al., 2011; Shah et al., 2013; Luo & Waite, 2014; Sung, 2014). Previous studies have concluded that individuals with minimal family/neighbour support and low social engagement levels present higher mortality risks (Jakobsson and Hallberg, 2006; Hjaltadóttir et al., 2011; Luo & Waite, 2014; Vetrano et al., 2018), therefore finding the opposite effect in our study is rather surprising. Further research to understand this result is required.

Although some authors left out the comorbidities in their mortality risk model, arguing that those have been well captured by the scopes of cognitive and physical status given by the scales used respectively (Lee et al., 2009), others found that some medical conditions (such as neoplasms, respiratory or cardiovascular diseases) are important risk factors of mortality (Jakobsson and Hallberg, 2006; Shah et al., 2013; Sung, 2014). The fact that, in this study, individuals with neoplasms or diseases of the skin and subcutaneous tissue have a higher mortality risk is something to be considered by policy makers, referral entities and staff in order to adopt special care plan for these individuals, before and after their admission into each setting of care. Finally, as concluded by previous research, as well as by this study, being classified at a higher physical (Carlson et al., 2001; Jakobsson and Hallberg, 2006; Lee et al., 2009; Hjaltadóttir et al., 2011; Sung, 2014) and cognitive (Jakobsson and Hallberg, 2006; Lee et al., 2009; Sung, 2014) dependence level at admission increases the risk of mortality in all settings of care. Thus, policy makers have to realize that the accurate assessment of a person's status plays an important role in the referral process and should be taken into consideration when selecting the best setting of care for each individual.

5.2. Outcomes assessment: changes in the dependence level

In this study, while 34% of those alive at discharge had improved their physical status (38% at NH; 27% at HCBS), the percentage of individuals who maintained the same status stood at 55% (51% at NH; 64% at HCBS). Looking to the literature, although a study among 600 community-dwelling elderly had reached a similar finding (improved: 33%; unchanged: 62%) (Fusco et al., 2009), in a study with 2,754 patients aged ≥ 65 years admitted into a post-acute rehabilitation facility over a four-year period, 85% of the individuals improved their functional status (unchanged: 10%) (Seematter-Bagnoud et al., 2013). On the other hand, whereas a study comparing two cohorts of patients with dementia concluded that 45% of the individuals improved (44% at NH; 48% at HCBS) or 20% maintained their physical status (similar percentage at NH and HCBS) (Lee et al., 2014), in a recent study at NH these percentages reached to 14% and 34% (Jerez-Roig et al., 2017), respectively. Concerning the cognitive status, while the percentage of individuals with some improvement in this study stood at 24% (26% at NH; 18% at HCBS), 61% maintained the same status (57% at NH; 71% at HCBS). For that matter, after collecting data two months apart, a study on a subset of 2,275 older patients in England and Wales concluded that the percentage of individuals with cognitive improvement ranged between 14%–21%, and 58%–78% maintained their status (Marioni et al., 2011). In another study performed with a group of patients with dementia, the authors concluded that 38% showed some improvement (37% at NH and 39% at HCBS), and 36% maintained their status (36% at NH and 34% at HCBS) (Lee et al., 2014).

Given the overall results, an higher number of individuals improving their physical status compared to the cognitive improvement is in line with several studies (Vogt et al., 2008; Gialanella, Santoro, & Ferlucci, 2012; Lee et al., 2014), and may be explained by the greater tendency of the RNCCI to focus on the total or partial recovery of lost physical autonomy. Nevertheless, since the LTC sector focuses on elderly frail persons with a high level of dependence, it is deemed necessary that staff and policy makers work towards the implementation of standard control measures to insure that each setting offers a care programme tailored to individuals' needs. On the other hand, it is also vital to assess the ability of the Integrated Bio-psychosocial Assessment Instrument to accurately capture dependency levels and its performance when used in repeated measurements for the same individual (admission and discharge, for instance).

5.3. Outcomes assessment: predicting the dependence level at discharge

In this study, the main features that contribute to decrease the probability of being classified as a higher cognitive and physical independence status at discharge are older age, low social support and low levels of cognitive and physical independence at admission. These findings are important for empowering the policy makers to (re)adapt, if necessary, the provision of care whenever they encounter individuals with these characteristics in need of some kind of LTC services.

With respect to age, although several studies suggest similar findings, either among institutionalized (Frytak et al., 2001; Gindin et al., 2007; Kim et al., 2013) or non-institutionalized (Seematter-Bagnoud et al., 2013) individuals, others found no significant influence on physical outcomes, either at NH (Bagg et al., 2002; Cameron et al., 2012; Jerez-Roig et al., 2017; Phillips et al., 2017) or at HCBS settings of care (Perrig-Chiello et al., 2006; Kim et al., 2013). Concerning the social support features, there is no consensus about their influence. In some studies, those living alone remained at increased probability of physical recovery (Fusco et al., 2009; Seematter-Bagnoud et al., 2013); others concluded the opposite (Kim et al., 2013); and others found no relationship (Frytak et al., 2001). In our study, although the availability (or lack) of family/neighbour support was not statistically significant for cognitive or physical improvement, being married decreases the chance of being classified at a higher independence level at discharge.

Although this seems contradictory, one possible explanation is that, instead of trying to perform certain tasks on their own, the fact that these individuals have some kind of help from third parties may limit the recovery of their lost functions.

Regarding the influence of the baseline dependence levels as predictors of the final status, this study has reached similar conclusions as previous research published: (i) being cognitively independent at admission has a positive influence on physical improvement, both among NH (Gindin et al., 2007; Cameron et al., 2012; Gialanella, Santoro, & Ferlucci, 2012; Kim et al., 2013; Jerez-Roig et al., 2017) and HCBS (Vogt et al., 2008; Fusco et al., 2009; Kim et al., 2013; Seematter-Bagnoud et al., 2013) populations; (ii) physical status at admission is also a good predictor of both physical and cognitive status at discharge. In this case, some studies at NH concluded that a higher independence level at admission not only increases the chances of being classified at a higher cognitive independence level at discharge (Marioni et al., 2011; Cameron et al., 2012), but it also has positive influences on the physical level at discharge, within both NH (Cameron et al., 2012; Gialanella, Santoro, & Ferlucci, 2012; Kim et al., 2013; Jerez-Roig et al., 2017) and HCBS (Perrig-Chiello et al., 2006; Fusco et al., 2009; Kim et al., 2013; Seematter-Bagnoud et al., 2013) populations. Based on these results, it becomes evident the importance of providing health professionals with reliable tools that allow an accurate assessment of the dependence levels of this population in order to predict with more certainty their outcomes.

As for medical conditions, although it was not possible to identify the burden of disease for each individual, one main conclusion stood out: those with musculoskeletal diseases have a higher probability of achieving both cognitive and physical improvements than those without these diseases. For that matter, after assessing the outcomes of patients admitted into post-acute care facilities, Gindin et al. (2007) found that, while those who had a stroke were less likely to show physical improvement than those who hadn't had a stroke, individuals with a hip fracture had more than double the probability of achieving improvement than those without a hip fracture (Gindin et al., 2007). On the other hand, in a cohort of 560 older people from Australia, although disability on admission was higher in individuals with a stroke and a hip fracture and lower for those with joint replacement, after six months, the group had a better chance of achieving physical and cognitive scores (Cameron et al., 2012). More recently, in a study conducted over a four-year period, whereas individuals with musculoskeletal diseases were more likely to achieve some functional recovery, those who did not recover more often presented some cerebrovascular diseases (Seematter-Bagnoud et al., 2013). Thus, despite appearing to be contradictory, given the emphasis on the physical recovery of this population, the progressive improvement in their functionality during their length of care also has a consequently positive effect on their cognitive recovery. Therefore, it is vital that managers and staff of each setting of care become aware of the importance of having a more detailed record of all medical conditions of each individual in order to adapt the care plan to each situation to maximize the benefits of the care provided.

As for the length of care, even though several studies have found it positively associated with the chances of being classified into a more independent physical status at discharge in both settings of care (Gindin et al., 2007; Cameron et al., 2012; Häcker & Hackmann, 2012), in our study, there seems to be a smaller but positive influence only regarding the cognitive improvement. Policy makers and staff should reflect upon such a conclusion in order to assess whether (or not) the length of stay is actually used to restore the lost autonomy, or if the intensity and frequency of the care provided is, in fact, adapted to the care needs. Thus, only when it is possible to combine the care needs, the intensity and the frequency of care, as well as the length of stay, will it be possible to leverage the existing resources in favour of these individuals.

Regarding the limitations, this study only considers individuals already admitted into an LTC setting, thus the results hold in identical

settings. Second, because the mortality analysis only takes into account observations for a one-year period, it is not possible to verify whether these findings are (or have been) consistent over the years. Third, since only the admission diagnosis is available for each individual, it is not possible to identify the morbidity burden and assess its influence as a risk factor. Finally, although in this work we mainly used individuals' characteristics, other circumstances such as transfers to other care settings, number of hospital admissions, number of medications being taken, staff skill mix or the intensity of care received may play a role in cognitive/functional recovery but were not taken into account as information was not available.

6. Conclusions

This is the first work that uses the entire national database, providing a valid description of the LTC situation in Portugal and its main outcomes. Although it is difficult to draw definitive conclusions regarding the power of different predictors in forecasting the outcomes of LTC services, the knowledge about the mortality risk factors and the impact of care provision on dependence levels are critical to policy makers and staff to help them to shape a more suitable care plan for future patients.

From this work, two main conclusions have arisen. First, those receiving home care have a higher mortality rate than the ones staying in NH and NH treating more severe patients also present higher mortality rates, as could be anticipated. Second, most individuals present no changes in their cognitive and physical status from admission to discharge, especially those receiving home care. This is an important finding for policy makers and deserves further research as it puts at stake the current goals of the Portuguese LTC system.

Although the RNCCI has defined a set of indicators for quality monitoring and some are already publicly available (NHS, 2017), there are several challenges ahead for policy makers: (i) critically assess the reliability of the current screening tool in identifying individuals' dependence levels; (ii) implement a patient-reported outcomes measures to support improvement in the quality and safety of healthcare delivery, similar to what is currently in place in other countries (Fischer et al., 2018; Kearns, Cornally, & Molloy, 2017; Wiering, de Boer, & Delnoij, 2017); (iii) use risk adjustment methods for measuring quality of care rather than interpreting raw incidence or prevalence rates; and (iv) rethink the funding system as currently it is based on a per diem, which presents well known perverse incentives for the payer.

Conflict of interest statement

Nothing to declare.

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References

- Abreu Nogueira, J., Girão, M., & Guerreiro, I. (2010). *Outcomes of physical autonomy in post acute and long term care national network for integrated continuous care Portugal*. Lisbon: UMCCI.
- Anderson, T. M., Sachdev, P. S., Brodaty, H., Trollor, J. N., & Andrews, G. (2007). Effects of sociodemographic and health variables on mini-mental state exam scores in older Australians. *American Journal of Geriatric Psychiatry*, 15, 467–476. <http://dx.doi.org/10.1097/JGP.0b013e3180547053>.
- Bagg, S., Pombo, A. P., & Hopman, W. (2002). Effect of age on functional outcomes after stroke rehabilitation. *Stroke*, 33, 179–185. <http://dx.doi.org/10.1161/hs0102.101224>.
- Botelho, M. A. (1999). *Autonomia Funcional em Idosos: Caracterização multidimensional em*

- idosos utentes de um centro de saúde urbano (Functional Autonomy in Elders: Multidimensional characterization in elderly users of an urban primary care centre). Faculdade de Ciências Médicas da Universidade Nova de Lisboa.
- Cameron, I. D., Schaafsma, F. G., Wilson, S., Baker, W., & Buckley, S. (2012). Outcomes of rehabilitation in older people-functioning and cognition are the most important predictors: An inception cohort study. *Journal of Rehabilitation Medicine*, 44(1), 24–30. <http://dx.doi.org/10.2340/16501977-09011>.
- Carlson, M. C., Brandt, J., Steele, C., Baker, A., Stern, Y., & Lyketsos, C. G. (2001). Predictor index of mortality in dementia patients upon entry into long-term care. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 56, M567–M570.
- Chiu, L., Shyu, W. C., & Liu, Y. H. (2001). Comparisons of the cost-effectiveness among hospital chronic care, nursing home placement, home nursing care and family care for severe stroke patients. *Journal of Advanced Nursing*, 33, 380–386. <http://dx.doi.org/10.1046/j.1365-2648.2001.01703.x>.
- Decreto-Law 101/2006 (2006). D.R. I serie A, 6th of July, Creation of the portuguese national network for long-term care. 3856–3865. [in Portuguese] http://www.acss.min-saude.pt/wp-content/uploads/2016/10/Decreto-Lei_101_2006-1.pdf.
- Fischer, F., Gibbons, C., Coste, J., Valderas, J. M., Rose, M., & Leplège, A. (2018). Measurement invariance and general population reference values of the PROMIS Profile 29 in the UK, France, and Germany. *Quality of Life Research*. <http://dx.doi.org/10.1007/s11136-018-1785-8>.
- Folstein, M. F., Folstein, S. E., & McHugh Mini-mental, P. R. (1975). A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189–198.
- Frytak, J. R., Kane, R. A., Finch, M. D., Kane, R. L., & Maude-Griffin, R. (2001). Outcome trajectories for assisted living and nursing facility residents in Oregon. *Health Services Research*, 36, 91–111.
- Fusco, D., Boichicchio, G. B., Onder, G., Barillaro, C., Bernabei, R., & Landi, F. (2009). Predictors of rehabilitation outcome among frail elderly patients living in the community. *Journal of the American Medical Directors Association*, 10, 335–341. <http://dx.doi.org/10.1016/j.jamda.2009.02.004>.
- Gialanella, B., Santoro, R., & Ferlucci, C. (2012). Predicting outcome after stroke: the role of basic activities of daily living. *European Journal of Physical and Rehabilitation Medicine*, 48, 1–9.
- Gindin, J., Walter-Ginzburg, A., Geitzen, M., Epstein, S., Levi, S., Landi, F., et al. (2007). Predictors of rehabilitation outcomes: A comparison of israeli and italian geriatric Post-Acute Care (PAC) facilities using the minimum data set (MDS). *Journal of the American Medical Directors Association*, 8, 233–242. <http://dx.doi.org/10.1016/j.jamda.2006.12.032>.
- Gruber-Baldini, A. L., Stuart, B., Zuckerman, I. H., Simoni-Wastila, L., & Miller, R. (2007). Treatment of dementia in community-dwelling and institutionalized medicare beneficiaries. *Journal of the American Geriatrics Society*, 55, 1508–1516. <http://dx.doi.org/10.1111/j.1532-5415.2007.01387.x>.
- Häcker, J., & Hackmann, T. (2012). Los(t) in long-term care: Empirical evidence from German data 2000–2009. *Health Economics*, 21, 1427–1443. <http://dx.doi.org/10.1002/hec.1805>.
- Hjaltadóttir, I., Hallberg, I. R., Ekwall, A. K., & Nyberg, P. (2011). Predicting mortality of residents at admission to nursing home: A longitudinal cohort study. *BMC Health Services Research*, 11, 86. <http://dx.doi.org/10.1186/1472-6963-11-86>.
- ISS (2017). Instituto da Segurança Social, Practical guide. National Network for Long-term Care [in Portuguese] Lisbon.
- Iezzoni, L. I. (2004). Risk adjusting rehabilitation outcomes: An overview of methodologic issues. *American Journal of Physical Medicine and Rehabilitation*, 83, 316–326.
- Jakobsson, U., & Hallberg, I. R. (2006). Mortality among elderly receiving long-term care: A longitudinal cohort study. *Aging Clinical and Experimental Research*, 18, 503–511. <http://dx.doi.org/10.1007/BF03324851>.
- Jerez-Roig, J., de Brito Macedo Ferreira, L. M., de Araújo, J. R. Torres, & Costa Lima, K. (2017). Functional decline in nursing home residents: A prognostic study. *PLoS One*, 12, e0177353. <http://dx.doi.org/10.1371/journal.pone.0177353>.
- Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., Jaffe, M. W., Katz, S., et al. (1963). Studies of illness in the aged: The index of ADL, a standardized measure of biological and psychosocial function. *JAMA*, 185, 914. <http://dx.doi.org/10.1001/jama.1963.03060120024016>.
- Kearns, T., Connolly, N., & Molloy, W. (2017). Patient reported outcome measures of quality of end-of-life care: A systematic review. *Maturitas*, 96, 16–25. <http://dx.doi.org/10.1016/j.maturitas.2016.11.004>.
- Kim, E.-Y., & Yang, B.-M. (2005). Cost-effectiveness of long-term care services in South Korea. *Archives of Gerontology and Geriatrics*, 40, 73–83. <http://dx.doi.org/10.1016/j.archger.2004.05.007>.
- Kim, Y. H., Kwon, C. H., & Shin, H. I. (2013). Validity of motor impairment scale in long-term care insurance system of Korea. *Annals of Physical and Rehabilitation Medicine*, 37, 403–413. <http://dx.doi.org/10.5535/arm.2013.37.3.403>.
- Lee, K., & Cho, E. (2016). Activities of daily living and rehabilitation needs for older adults with a stroke: A comparison of home care and nursing home care. *Japan Journal of Nursing Science*, 14(2), 103–111. <http://dx.doi.org/10.1111/jjns.12139>.
- Lee, J. S. W., Chau, P. P. H., Hui, E., Chan, F., & Woo, J. (2009). Survival prediction in nursing home residents using the minimum data set subscales: ADL self-performance hierarchy, cognitive performance and the changes in health, end-stage disease and symptoms and signs scales. *European Journal of Public Health*, 19, 308–312. <http://dx.doi.org/10.1093/eurpub/ckp006>.
- Lee, T. W., Yim, E., Cho, E., & Chung, J. (2014). Cognitive function, behavioral problems, and physical function in long-term care insurance beneficiaries with dementia in South Korea: Comparison of home care and institutional care services. *Journal of the American Geriatrics Society*, 62, 1467–1475. <http://dx.doi.org/10.1111/jgs.12944>.
- Lee, T. W., Cho, E., Yim, E. S., Lee, H. S., Ko, Y. K., Kim, B. N., et al. (2015). Activities of daily living in nursing home and home care settings: A retrospective 1-year cohort study. *Journal of the American Medical Directors Association*, 16, 114–119. <http://dx.doi.org/10.1016/j.jamda.2014.07.013>.
- Luo, Y., & Waite, L. J. (2014). Loneliness and mortality among older adults in China. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 69, 633–645. <http://dx.doi.org/10.1093/geronb/gbu007>.
- Marioni, R. E., Chatfield, M., Brayne, C., & Matthews, F. E. (2011). The reliability of assigning individuals to cognitive states using the mini mental-state examination: A population-based prospective cohort study. *BMC Medical Research Methodology*, 11, 127. <http://dx.doi.org/10.1186/1471-2288-11-127>.
- Moraes, C., Pinto, J. A., Lopes, M. A., Litvoc, J., & Bottino, C. M. C. (2010). Impact of sociodemographic and health variables on mini-mental state examination in a community-based sample of older people. *European Archives of Psychiatry and Clinical Neuroscience*, 260, 535–542. <http://dx.doi.org/10.1007/s00406-010-0104-3>.
- NHS (2017). Transparency portal national network for long-term integrated care indicators. [in portuguese] <https://transparencia.sns.gov.pt/explore/?sort=title&q=mncci>. (Accessed August 18 2017).
- Ordinance no. 174/2010 (2014). D.R. I serie, no 174, 10th of September, which updates the operational conditions of the nursing homes and home care settings of care. 4865–4882 [in Portuguese] http://www.sg.min-saude.pt/NR/rdonlyres/F1071041-A28D-4B06-8CB5-D640D1D60D80/41897/Portaria174_2014.pdf3mncci. (Accessed June 1 2017).
- Perrig-Chiello, P., Perrig, W. J., Uebelbacher, A., & Stähelin, H. B. (2006). Impact of physical and psychological resources on functional autonomy in old age. *Psychology, Health & Medicine*, 11, 470–482. <http://dx.doi.org/10.1080/13548500600726633>.
- Phillips, L. J., Leary, E., Blankenship, J., & Zimmerman, S. (2017). Physical function, relocation, and mortality outcomes in residential care and assisted living residents. *Journal of Aging and Health*. <http://dx.doi.org/10.1177/0898264317740047> [898264317740047].
- Rothera, I., Jones, R., Harwood, R., Avery, A., & Waite, J. (2003). Health status and assessed need for a cohort of older people admitted to nursing and residential homes. *Age and Ageing*, 32, 303–309. <http://dx.doi.org/10.1093/ageing/32.3.303>.
- Seematter-Bagnoud, L., Lécureux, E., Rochat, S., Monod, S., Lenoble-Hoskovec, C., & Büla, C. J. (2013). Predictors of functional recovery in patients admitted to geriatric postacute rehabilitation. *Archives of Physical Medicine and Rehabilitation*, 94, 2373–2380. <http://dx.doi.org/10.1016/j.apmr.2013.06.024>.
- Shah, S. M., Carey, I. M., Harris, T., DeWilde, S., & Cook, D. G. (2013). Mortality in older care home residents in England and Wales. *Age and Ageing*, 42, 209–215. <http://dx.doi.org/10.1093/ageing/afsl74>.
- Singh, R., Hunter, J., Philip, A., & Todd, I. (2006). Predicting those who will walk after rehabilitation in a specialist stroke unit. *Clinical Rehabilitation*, 20, 149–152.
- Sloane, P. D., Zimmerman, S., Gruber-Baldini, A. L., Hebel, J. R., Magaziner, J., & Konrad, T. R. (2005). Health and functional outcomes and health care utilization of persons with dementia in residential care and assisted living facilities: Comparison with nursing homes. *Gerontologist*, 45 [Spec No 124–132].
- Sung, K. (2014). Predictive factors associated with death of elderly in nursing homes. *Asian Nursing Research (Korean Soc Nurs Sci)*, 8, 143–149. <http://dx.doi.org/10.1016/j.anr.2014.05.004>.
- Suzuki, M., Omori, M., Hatakeyama, M., Yamada, S., Matsushita, K., & Iijima, S. (2006). Predicting recovery of upper-body dressing ability after stroke. *Archives of Physical Medicine and Rehabilitation*, 87, 1496–1502. <http://dx.doi.org/10.1016/j.apmr.2006.07.026>.
- Vetrano, D. L., Collamati, A., Magnavita, N., Sowa, A., Topinkova, E., Finne-Soveri, H., et al. (2018). Health determinants and survival in nursing home residents in Europe: Results from the SHELTER study. *Maturitas*, 107, 19–25. <http://dx.doi.org/10.1016/j.maturitas.2017.09.014>.
- Vogt, L., Wieland, K., Bach, M., Himmelreich, H., & Banzer, W. (2008). Cognitive status and ambulatory rehabilitation outcome in geriatric patients. *Journal of Rehabilitation Medicine*, 40, 876–878. <http://dx.doi.org/10.2340/16501977-0260>.
- Wieland, D., Boland, R., Baskins, J., & Kinoshian, B. (2010). Five-year survival in a program of all-inclusive care for elderly compared with alternative institutional and home-and community-based care. *The Journals of Gerontology Series B, Psychological Sciences and Social Science*, 65, 721–726. <http://dx.doi.org/10.1093/gerona/gllq040>.
- Wiering, B., de Boer, D., & Delnoij, D. (2017). Patient involvement in the development of patient-reported outcome measures: A scoping review. *Health Expectations*, 20(1), 11–23. <http://dx.doi.org/10.1111/hex.12442>.

5.4. Length of care in long-term care: assessing the influence of patients' dependency level registered at admission

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ABSTRACT

Background: The Portuguese National Network for Long-term Integrated Care was created in 2006.

Goal: To analyse the influence of patients' physical and cognitive dependency levels at admission on their Lengths of Care (LOC) in each care setting.

Design: Retrospective cohort study.

Setting: Home and Community-Based Services (HCBS) and three Nursing Home (NH) Units: Short, Medium and Long Stay Care.

Methods: Four Generalised Linear Models (GLM) were adjusted to each care setting. Explanatory variables such as age, gender, number of beds/treatment places per 1,000 inhabitants over age 65, family/neighbour support and dependency levels (locomotion, cognitive and activities of daily living) were used to model the random variable LOC. GLM with Gamma distribution and identity link function were performed in the four models. Levels of dependency were considered as the number of the two lowest scores in patients' admission.

Results: Although the variables with the greatest influence on LOC are older age, male gender, the number of beds/treatment places and having support from family and/or neighbours, only patients' functional dependency levels at admission were statistically significant. No relationship was found between cognitive status and LOC.

Conclusions: In order to assess the performance of care providers and to adapt the LOC to individuals' needs, it is essential to implement a quality control system to identify their dependency levels, define a Minimum Data Set common to all settings of care and adopt a classification system for patients receiving long-term care.

Keywords: Nursing Homes; Home and Community-Based Services; Length of Care; Dependency levels; Portugal

INTRODUCTION

As the pattern of multimorbidity and physical and mental health disorders changes [1], the need for long-term care (LTC) is expected to increase. The term 'LTC' refers to a myriad of services designed to provide assistance over prolonged periods, including basic medical services, rehabilitation, social care, personal hygiene, occupational therapy, education and psychosocial support for both patients and their caregivers [2]. Thus, admission to LTC setting, either in an institutionalized (hereinafter as nursing home, NH) or non-institutionalized (hereinafter as home and community-based services, HCBS) environment, represents a changing point in an individuals' life, usually associated with a loss of functional independence [3].

Since LTC has been increasingly used as a post-acute care setting for individuals requiring rehabilitation and nursing services [3,4], there is growing interest in studying the relationship between residents length of care (LOC) and several other variables: staffing mix [5–9], NH residents at the end of life [4,10], expenditures [7,11–14], LOC risk factors [7,8,11,12,15–17] and individuals' trajectories between care settings [3,11,12,16]. Most of the numerous studies exploring the main characteristics of the risks of NH/HCBS admission [18–20] have found - despite differences in datasets and methods - that demographic, social and clinical features are all important risk factors predictive of both admissions and LOC in LTC.

In Portugal LTC is provided in two settings: at home (HCBS) by teams working in primary care centres, and in three NH Units: i) Convalescence Units (UC) for individuals with an expected maximum LOC of 30 consecutive days; ii) Medium Term and Rehabilitation Units (UMDR), intended for stays of between 31-90 consecutive days; and iii) Long-Term and Maintenance Units (ULDM) with an expected LOC of ≥ 90 consecutive days [21].

Previous research in Portugal has concluded that the LOC has a positive but small influence on patients' outcomes [22]. This work, therefore, looks at a different but parallel question, one so far little studied [4,10]: what is the influence of individuals' dependency levels, registered at admission, on their LOC and can we estimate the average LOC for a new individual entering the RNCCI system? Moreover, we intend to identify the main profile of the lowest and highest consumers of resources.

METHODS

Data source

We used data from the Portuguese LTC monitoring system, which gathers both general (e.g. region of care, care setting and LOC) and specific information on patients using the Bio-psychosocial Assessment Instrument [23]. With this instrument, LTC staff collect data in three main areas [24]: (i) Biological: age, gender and functional status (through testing their ability to perform eight activities of daily living (ADL) using the Katz' ADL index [25]) and three locomotion activities; (ii) Psychological, using the Mini-Mental State Examination [26]; and (iii) Social: marital status and the availability (or not) of support from family and neighbours.

With regard to functional/cognitive status, each activity is assessed using a system of four scores: from 0 (incapable) to 3 (independent), whereby the first two scores (0, 1) may be grouped as "dependent" in the performance an activity and the other two (2, 3) mean "independent".

Data on supply of services included the variable 'number of beds/treatment places per 1,000 inhabitants aged 65 or more years old', created considering the dichotomy patients' setting and region of care. Finally, we used the national tariff for each setting, based on a per-diem model (user/day), as a proxy for costs [27]: HCBS (9.58€), UC (105.46€), UMDR (87.56€) and ULDM (60.19€).

Study Cohort

This cohort consists of 15,752 individuals from all over the country, with admission and discharge in 2015 from the Portuguese public LTC system, receiving care in the HCBS or in one of the three NH settings.

Statistical Analysis

The dependent variable used was the LOC (in days) in each care setting.

Using the scores obtained by the patients in each functional/cognitive activity, we included as explanatory variables the number of activities in which each individual was considered "dependent" (scores 0 or 1) in locomotion, ADL, and cognitive. For all the areas, the number of 0 and 1 scores ranged between 0 and the maximum possible.

Finally, patients' age (in years), gender, social network (availability or not of family/neighbour support) and the number of beds/treatment places per 1,000 inhabitants aged 65 or over, were included as covariate variables.

Regressions

The analysis of how the dependent variable LOC varies with the covariates was performed for each care setting using the Generalized Linear Model (Gamma), in order to account for the skewness of probability function of the LOC random variable, using an identity link function.

In the explanatory data analysis, some atypical behaviour in the LOC variable it was observed (Fig. 1 in Appendix 1). We interpret this as being related to the maximum expected LOC defined for each care setting, not directly explained by patients' characteristics. For this reason, we performed the GLM removing this atypical data and those with a LOC of up to five days. The significance of the covariates, however, did not change after removing the observations, although the estimates for LOC for each type of patient is different.

Finally, based on the results from the GLM models, we can predict the LOC for each set of patients' characteristics and each care setting. As an example, we identified the profile of a low and high type consumer of resources in each care setting, estimated their average LOC and the associated costs.

All analyses were made with *R-Software*, using a significance level of 0.05.

RESULTS

Patients' characteristics

The majority of individuals included in this study received institutional care (59%) (Table 1). Within the NH units of care, 29% were admitted to a UC, 42% to a UMDR and 29% to a ULDM. As for the dependency levels on admission, the average number of activities in which the patient is considered "dependent" in each area is higher among the institutional population than among those receiving home care, and increases as one goes from a shorter (UC) to a longer (ULDM) care unit.

Regarding the supply of care, the number of NH beds per 1,000 inhabitants aged 65 or over is higher than the home care treatment places, indicating the expected predominance of institutionalized care in the system.

Table 1: Patients' characteristics in each care setting

	All population	HCBS	NH	Nursing Homes Units		
				UC	UMDR	ULDM
Population	15,752	6,379	9,373	2,726	3,968	2,679
Age						
Mean (SD)	79.3 (8.3)	79.9 (8.4)	78.9 (8.2)	77.8 (8.2)	78.3 (8.1)	81.1 (8.0)
Gender (%)						
Male / Female	43.7 / 56.3	44.3 / 55.7	43.3 / 56.7	42.2 / 57.8	44.2 / 55.8	43.2 / 56.8
Family or neighbour support (%)						
With / Without support	48.1 / 51.9	61.7 / 38.3	38.5 / 61.5	41.0 / 59.0	32.8 / 67.2	44.2 / 55.8
Locomotion status (Num. "Dependent" activities - Max. 3)						
Mean (SD)	2.57 (0.92)	2.54 (0.93)	2.59 (0.91)	2.47 (1.01)	2.63 (0.89)	2.65 (0.80)
Activity of Daily Living status (Num. "Dependent" activities - Max. 8)						
Mean (SD)	6.42 (2.03)	6.11 (2.25)	6.63 (1.84)	6.16 (2.04)	6.87 (1.63)	6.75 (1.84)
Cognitive status (Num. "Dependent" activities - Max. 10)						
Mean (SD)	4.67 (4.36)	4.06 (4.35)	5.08 (4.31)	3.37 (3.98)	5.32 (4.28)	6.49 (4.10)
Number of beds/treatment places (per 1,000 inhab. aged 65 or more)						
Mean (SD)	0.80 (0.77)	0.15 (0.08)	1.24 (0.72)	0.47 (0.20)	1.11 (0.18)	2.22 (0.37)
Length of care (days)						
Mean (SD)	62.8 (50.4)	68.7 (56.3)	58.8 (45.6)	41.3 (23.0)	65.2 (43.8)	67.4 (58.3)

Legend: HCBS: Home and Community-Based Services; NH: Nursing Homes; UC: Convalescence Units; UMDR: Medium-Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units.

Predictors of length of care

Controlling for all other variables, the most influential and statistically significant variables on LOC are age, male gender, functional status on admission, the number of beds/treatment places and social support (Table 2).

As for age, whereas an additional year increases the LOC of those receiving care at HCBS or UC, the opposite was found for those receiving care at UMDR or ULDM. Although gender was not statistically significant in all settings, being male increased the average LOC more than did being female, specifically by 5.1 and 9.1 days at UMDR and ULDM, respectively.

On dependency levels at admission, only functional status was statistically significant. Whereas for each locomotion activity considered "dependent" the LOC decreases for those receiving HCBS (-1.9 days) or at ULDM (-2.9 days), the ADL status has an opposite influence for those at UC or at UMDR. No statistically significant results were found for cognitive status.

As for the supply of care, although the number of beds/treatment places per 1,000 inhabitants aged 65 or more increases the average LOC in each care setting, with the exception of those admitted to ULDM, its influence is marginal (HCBS: +0.025 days; UC: +0.010 days; UMDR: +0.061 days). As for social support, while the LOC decreases in all settings of care for those with family/neighbour support, this effect is more evident among the longer NH units of care (-12 days).

Table 2: Generalised linear models with Gamma distribution and identify link function by care setting, with Length of Care as dependent variable

Variables	Model 1 HCBS	Model 2 UC	Model 3 UMDR	Model 4 ULDM
Constant	59.293 *** [6.786]	26.019 *** [4.149]	12.601 *** [7.907]	125.706 *** [12.512]
Age	0.199 * [0.083]	0.099 . [0.052]	-0.203 * [0.081]	-0.508 *** [0.141]
Gender				
Female	-	-	Reference	Reference
Male	-	-	-5.170 *** [1.302]	-9.137 * [1.476]
Locomotion status (activities considered "dependent")	-1.916 * [0.793]	-	-	-2.942 * [2.235]
Activity of Daily Living status (activities considered "dependent")	-	0.745 *** [0.201]	0.917 * [0.390]	-
Cognitive status (activities considered "dependent")	-	-	-	-
Number of beds/treatment places (per 1,000 inhab. aged 65 or more)	0.025 ** [0.009]	0.010 *** [0.022]	0.061*** [0.038]	-
Family or neighbour support				
Without Support	Reference	Reference	Reference	Reference
With Support	-8.891 *** [1.485]	-4.850 *** [0.874]	-12.071 *** [1.317]	-12.449 *** [2.192]
n	6,379	2,726	3,968	2,679
Deviance	4,236	842	1,960	1,943
d.f.	6,374	2,721	3,962	2,674
Null Deviance	4,269	860	2,092	1,988
p-value (Pearson Chi-squared test)	0.7605	0.1560	5.06 ^{e-13}	0.7655

Legend: HCBS: Home and Community-Based Services; UC: Convalescence Units; UMDR: Medium-Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units; Signif. codes: p<0.000 '***'; p<0.001 '**'; p<0.01 '*'; p<0.05 '.'; [Standard. Error]

Profile of a lower and higher type consumer of resources

Although it is possible to estimate the LOC for any patient profile for each care setting, we chose to characterise a lower and a higher type consumer of resources. Thus, after adjusting for the variables in the previous analysis (Table 2), several findings can be highlighted regarding the expected LOC (Table 3).

Firstly, with regard to the profile of a lower type consumer, while the expected LOC is similar between those at UC and those at UMDR (30 days), those at HCBS present the highest value (60 days). Secondly, with the exception of those at UC, the profile of a higher consumer has a similar average LOC in the other care settings. Finally, on expenditures per patient, while the average expected costs increase as we move from a short (UC) to a longer (ULDM) care Unit, a higher consumer at UMDR presents the highest average cost of all care settings.

Table 3: Profile of a lower and higher type consumer of resources, their expected average length of care and costs

	Model 1 HCBS	Model 2 UC	Model 3 UMDR	Model 4 ULDM
Profile of a lower type consumer				
Age	65	65	86	89
Gender	-	-	Male	Male
Locomotion status *	3	-	-	3
Activity of Daily Living status *	-	0	0	-
Cognitive status *	-	-	-	-
Number of beds/treatment places **	0.108	0.233	0.917	-
Family or neighbour support	With Support	With Support	With Support	With Support
Expected average LOC (days)	60.24	30.07	33.91	50.01
[95% C.I.]	[57.01 ; 63.47]	[27.05 ; 33.09]	[27.68 ; 40.14]	[45.60 ; 54.42]
Expected average cost/patient (€)	577.10	3,171.18	2,969.16	3,010.10
[95% C.I.]	[546.16 ; 608.04]	[2,852.69 ; 3,489.67]	[2,423.66 ; 3,514.66]	[2,744.66 ; 3,275.54]
Profile of a higher type consumer				
Age	88	86	65	65
Gender	-	-	Female	Female
Locomotion status *	0	-	-	0
Activity of Daily Living status *	-	8	8	-
Cognitive status *	-	-	-	-
Number of beds/treatment places **	0.349	0.753	1.373	-
Family or neighbour support	Without Support	Without Support	Without Support	Without Support
Expected average LOC (days)	85.37	48.40	90.67	92.63
[95% C.I.]	[79.06 ; 91.69]	[46.31 ; 50.47]	[86.52 ; 94.82]	[82.65 ; 102.62]
Expected average cost/patient (€)	817.84	5,104.26	7,939.07	5,575.40
[95% C.I.]	[757.39 ; 878.39]	[4,883.85 ; 5,322.57]	[7,575.69 ; 8,302.44]	[6,176.70 ; 6,176.70]

Legend: HCBS: Home and Community-Based Services; UC: Convalescence Units; UMDR: Medium-Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units; LOC: Length of care; C.I.: Confidence interval.

* Number of activities considered "dependent"; ** per 1,000 inhab. of 65 or over

DISCUSSION

We concluded that the most significant variables in predicting the LOC were older age, male gender, functional status on admission, the number of beds/treatment places and having social support.

Regarding the sociodemographic characteristics, mixed evidence was found in the literature. Although old age and male gender are well-known factors associated with NH admission [18–20], their influence on LOC is not well proven [4,7,8,11,12,14,17]. Contrary to previous research [7,8], we found that age is a significant variable across all care settings, where, an increase in a patient's age decreases his/her chance of having care for an extended period, especially for those admitted in a longer stay NH unit. Our findings on gender are in line with previous research. Although it is not always a significant variable [7,8], when to be considered, males present a lower LOC [4,11,12]. Turning to social support, the two main features that are commonly used to assess its influence on LOC are living arrangements [13,16] and marital status [4,10,17]. Although further investigation is needed on this, the conclusion of this study is in line with several others: a low level of social support is associated with longer periods of care [4,10,16].

There may be two reasons for the role of age, gender and social support in contributing to a lower LOC. Since there is both a higher life expectancy and a greater prevalence of physical and mental health comorbidity among females [1], the absence or the death of a spouse may result in the provision of care for longer periods than for men. Moreover, because those factors are also high mortality risk factors [15,17,22], the lower expected LOC may be a consequence of a higher mortality rate among the individuals with those characteristics [11].

Given the regional asymmetries of the distribution of LTC resources [21], much research has been done on the relationship between the supply side factors and LOC [4,12,14]. The fact that in our study an increased number of beds/treatment places had a residual effect on the average LOC in each care setting may imply that increasing the LTC resources can reduce the waiting list and enable more individuals to have access to this care.

With regard to dependency status, as the number of functional activities considered dependent on admission increases, the average LOC also increases especially at the two NH units more linked with functional recovery. No statistically significant results were found for cognitive status. Although some studies have concluded that a higher level of care at admission was associated with a shorter LOC [10,11], others found that individuals who were more functionally and cognitively impaired had a longer LOC [13,16]. Moreover, a study from Norway concluded that an increase in functional disability increases the use of resources by about 27% [8]. Since in our study an increase in functional disability reduced the LOC for those receiving care either in a longer NH unit or in home care, two different explanations may arise. While in the first case the higher mortality rate may explain the lower LOC [22], the second may be related to the need for these patients to receive more permanent care. Thus, in order to better study the patients' path in the LTC system, it is vital to have information on the transitions between the different care settings, so that staff and policymakers can adjust the care delivery to their needs.

These findings are important for policymakers, but several limitations should be pointed out. Although there is insufficient evidence on the effectiveness of rehabilitation in LTC settings [28–30], the influence of patients' functional/cognitive outcomes on their LOC was not considered. Moreover, as was remarked in a study conducted in England [12], because our study is restricted to publicly-funded care, the lack of information about transfers between publicly and privately-funded care means that it does not reflect the total LOC for all persons. Finally, other variables such as the ability to perform instrumental activities of daily living [8], transitions between settings of care [3,12],

staffing mix [5,6,9] or medical conditions [14,15,17] which may influence the LOC, were not available. Thus, further research is required, exploring the influence of these variables.

CONCLUSIONS

Given the differences between countries' LTC organisational structures, admission criteria and financial systems, these results are best understood, and are most important, in their own culture and setting.

In this study, LOC is highly influenced by the maximum expected stay in the setting to which patients are admitted. As the units are paid a per-diem per patient, it is vital that policymakers implement a monitoring system that assesses the relationship between LOC and patients' outcomes. This measure would not only prevent the maximisation of their revenue through (possibly inappropriate) prolonged stays but also allow for a faster turnover of beds and a reduction in the waiting list.

Moreover, as Units revenues are usually proportional to LOC and more evidence is needed concerning the effectiveness of care. Our findings should be considered in future cost-effectiveness studies aimed at assessing the impact of long-term interventions and preventing that patients being sent to inappropriate care settings. Thus, further research is needed to determine the factors associated with differences in the use of services.

Finally, as LOC usually determines turnover, but robust data have rarely been available, our findings should be taken into account when estimating future demand for LTC services. Thus, it is essential to implement a quality control system in the identification of individuals' dependency levels, to define a Minimum Data Set common to all units and care settings and to adopt a classification system for patients in LTC. Such measures are essential if we are to identify the needs of the population accurately, to define risk stratification models, to assess the performance of care providers - especially concerning the relationship between patients' LOC and outcomes - and to help bring about a more equitable allocation of funding resources.

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REFERENCES

- [1] Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet* 2012;380:37–43. doi:10.1016/S0140-6736(12)60240-2.
- [2] Kaye HS, Harrington C. Long-term services and supports in the community: Toward a research agenda. *Disabil Health J* 2015;8:3–8. doi:10.1016/j.dhjo.2014.09.003.
- [3] Li S, Middleton A, Ottenbacher KJ, Goodwin JS. Trajectories Over the First Year of Long-Term Care Nursing Home Residence. *J Am Med Dir Assoc* 2018;19:333–41. doi:10.1016/j.jamda.2017.09.021.
- [4] Kelly A, Conell-Price J, Covinsky K, Cenzer IS, Chang A, Boscardin WJ, et al. Length of stay for older adults residing in nursing homes at the end of life. *J Am Geriatr Soc* 2010;58:1701–6. doi:10.1111/j.1532-5415.2010.03005.x.
- [5] Nelson A, Powell-Cope G, Palacios P, Luther SL, Black T, Hillman T, et al. Nurse staffing and patient outcomes in inpatient rehabilitation settings. *Rehabil Nurs* 2007;32:179–202.
- [6] Decker FH. Outcomes and Length of Medicare Nursing Home Stays: The Role of Registered Nurses and Physical Therapists. *Am J Med Qual* 2008;23:465–74. doi:10.1177/1062860608324173.
- [7] Dixon S, Kaambwa B, Nancarrow S, Martin GP, Bryan S. The relationship between staff skill mix, costs and outcomes in intermediate care services. *BMC Health Serv Res* 2010;10:221. doi:10.1186/1472-6963-10-221.
- [8] Døhl Ø, Garåsen H, Kalseth J, Magnussen J. Variations in levels of care between nursing home patients in a public health care system. *BMC Health Serv Res* 2014;14:108. doi:10.1186/1472-6963-14-108.
- [9] Rahman M, Gozalo P, Tyler D, Grabowski DC, Trivedi A, Mor V. Dual Eligibility, Selection of Skilled Nursing Facility, and Length of Medicare Paid Postacute Stay. *Med Care Res Rev* 2014;71:384–401. doi:10.1177/1077558714533824.
- [10] Hedinger D, Hämmig O, Bopp M, Swiss National Cohort Study Group. Social determinants of duration of last nursing home stay at the end of life in Switzerland: a retrospective cohort study. *BMC Geriatr* 2015;15:114.

doi:10.1186/s12877-015-0111-3.

- [11] Häcker J, Hackmann T. Los(t) in long-term care: empirical evidence from German data 2000-2009. *Health Econ* 2012;21:1427–43. doi:10.1002/hec.1805.
- [12] Steventon A, Roberts A. Estimating length of stay in publicly-funded residential and nursing care homes: a retrospective analysis using linked administrative data sets. *BMC Health Serv Res* 2012;12:377. doi:10.1186/1472-6963-12-377.
- [13] Newcomer RJ, Ko M, Kang T, Harrington C, Hulett D, Bindman AB. Health Care Expenditures After Initiating Long-term Services and Supports in the Community Versus in a Nursing Facility. *Med Care* 2016;54:221–8. doi:10.1097/MLR.0000000000000491.
- [14] Blackburn J, Locher JL, Morrissey MA, Becker DJ, Kilgore ML. The effects of state-level expenditures for home- and community-based services on the risk of becoming a long-stay nursing home resident after hip fracture. *Osteoporos Int* 2016;27:953–61. doi:10.1007/s00198-015-3327-3.
- [15] Morales-Asencio JM, Morilla-Herrera JC, Martín-Santos FJ, Gonzalo-Jiménez E, Cuevas-Fernández-Gallego M, Bonill de las Nieves C, et al. The association between nursing diagnoses, resource utilisation and patient and caregiver outcomes in a nurse-led home care service: Longitudinal study. *Int J Nurs Stud* 2009;46:189–96. doi:10.1016/j.ijnurstu.2008.09.011.
- [16] Fries BE, James ML. Beyond Section Q: prioritizing nursing home residents for transition to the community. *BMC Health Serv Res* 2012;12:186. doi:10.1186/1472-6963-12-186.
- [17] Wei Y-J, Simoni-Wastila L, Zuckerman IH, Brandt N, Lucas JA. Algorithm for Identifying Nursing Home Days Using Medicare Claims and Minimum Data Set Assessment Data. *Med Care* 2016;54:e73–7. doi:10.1097/MLR.000000000000109.
- [18] Gaugler JE, Duval S, Anderson KA, Kane RL. Predicting nursing home admission in the U.S: a meta-analysis. *BMC Geriatr* 2007;7:13. doi:10.1186/1471-2318-7-13.
- [19] Luppá M, Luck T, Weyerer S, König H-H, Brahler E, Riedel-Heller SG. Prediction of institutionalization in the elderly. A systematic review. *Age Ageing* 2010;39:31–8. doi:10.1093/ageing/afp202.
- [20] Wysocki A, Butler M, Kane RL, Kane RA, Shippee T, Sainfort F. Long-Term Services and Supports for Older Adults: A Review of Home and Community-

- Based Services Versus Institutional Care. *J Aging Soc Policy* 2015;27:255–79. doi:10.1080/08959420.2015.1024545.
- [21] Lopes H, Mateus C, Hernández-Quevedo C. Ten Years since the 2006 Creation of the Portuguese National Network for Long-Term Care: Achievements and Challenges. *Health Policy (New York)* 2018;122:210–6. doi:10.1016/J.HEALTHPOL.2018.01.001.
 - [22] Lopes H, Mateus C, Rosati N. Impact of long term care and mortality risk in community care and nursing homes populations. *Arch Gerontol Geriatr* 2018;76:160–8. doi:10.1016/J.ARCHGER.2018.02.009.
 - [23] Abreu Nogueira J, Girão M, Guerreiro I. Outcomes of physical autonomy in Post Acute and Long Term Care National Network for Integrated Continuous Care Portugal. Lisbon: UMCCI; 2010.
 - [24] Botelho MA. Autonomia Funcional em Idosos: Caracterização multidimensional em idosos utentes de um centro de saúde urbano (Functional Autonomy in Elders: Multidimensional characterization in elderly users of an urban primary care centre). Faculdade de Ciências Médicas da Universidade Nova de Lisboa, 1999.
 - [25] Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW, Katz, S. et al, et al. Studies of illness in the aged: the index of ADL, a standardized measure of biological and psychosocial function. *JAMA* 1963;185:914. doi:10.1001/jama.1963.03060120024016.
 - [26] Folstein MF, Folstein SE, McHugh PR. Mini-mental. A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975;12:189–98.
 - [27] Ordinance no. 184/2015. Ordinance no. 184/2015, 23th of June - Price definition of health care and social support provided in the inpatient and outpatient units of the Portuguese National Network for Long-term Integrated Care [in Portuguese] 2015. <https://dre.pt/application/conteudo/67541740> (accessed February 5, 2017).
 - [28] Forster A, Lambley R, Young JB. Is physical rehabilitation for older people in long-term care effective? Findings from a systematic review. *Age Ageing* 2010;39:169–75. doi:10.1093/ageing/afp247.
 - [29] Crocker T, Young J, Forster A, Brown L, Ozer S, Greenwood DC. The effect of physical rehabilitation on activities of daily living in older residents of long-term

care facilities: systematic review with meta-analysis. *Age Ageing* 2013;42:682–8.
doi:10.1093/ageing/aft133.

- [30] Wysocki A, Thomas KS, Mor V. Functional Improvement Among Short-Stay Nursing Home Residents in the MDS 3.0. *J Am Med Dir Assoc* 2015;16:470–4.
doi:10.1016/j.jamda.2014.11.018.

Appendix 1

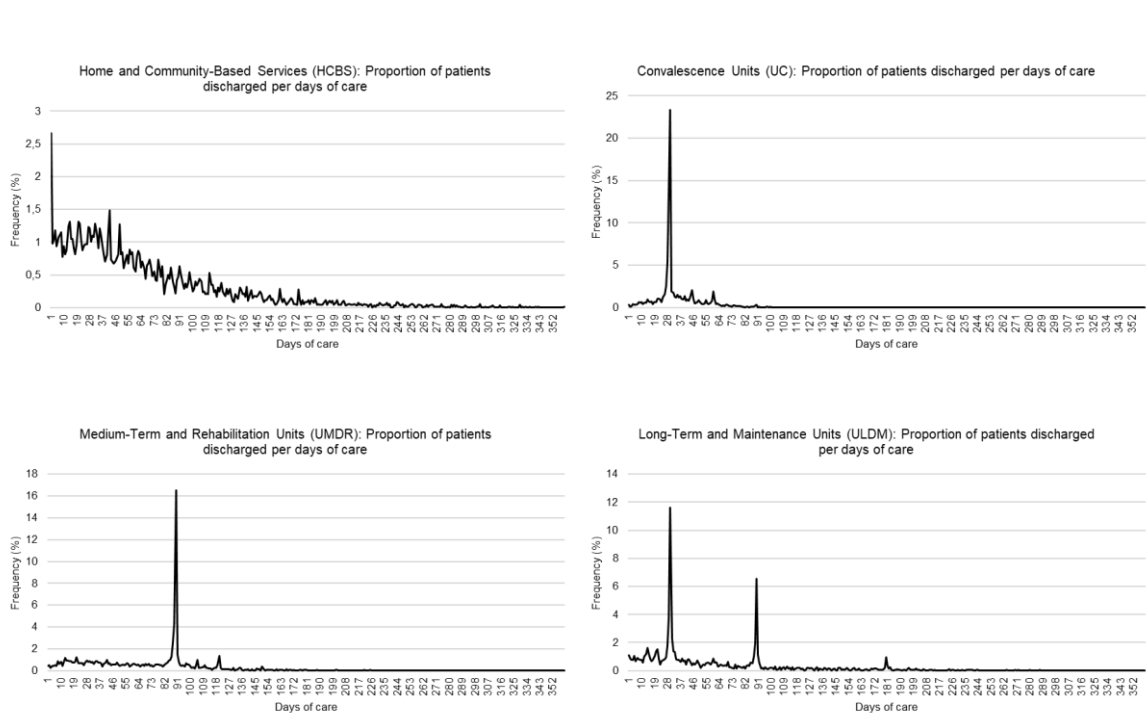


Fig 1: Proportion of patients discharged per days of care, by setting of care

6. CONCLUSIONS

The goals of the LTC system should be oriented to the reduction of physical, cognitive and behavioural deficits; to prevent complications in illness and reduce the pain it causes; to inform, train and educate informal caregivers about the care provided to their relatives; to achieve the highest possible levels of social integration and help to improve the quality of life of every patient and their families.

Until very recently, the public sector was not involved in the provision of LTC in Portugal: it was mainly provided by *Misericórdias* (non-profit-making institutions with a religious background). Therefore, in the light of the growing importance of this sector in Portugal, four main objectives were defined for this thesis: (1) to assess the RNCCI reform, taking into account several core dimensions; (2) to identify of the main characteristics of the LTC delivered in HCBS and the three NH units of care and compare them; (3) to assess patients' outcomes after treatment and; (4) to identify the main predictors of duration of their LOC.

The key findings are summarised and discussed below.

6.1. Key findings

6.1.1. National Network for Long-Term Care since 2006

On the formal creation of the RNCCI in 2006, the plan was to take advantage of the already existing resources (largely non-profit-making institutions), under a partnership between the Ministry of Health and the Ministry of Labour and Social Solidarity. Considering the core dimensions assessed in the first paper, several conclusions can be highlighted:

Beneficiaries

Strength: as in several European countries like France, Italy or Spain (42,89), the services of the RNCCI are available for those in a situation of physical or cognitive impairment, regardless of age and wealth (16). The main goal is to offer universal coverage for both health and social services;

Weakness: recent estimates concluded that, given the lack of availability of beds, around 90% the Portuguese population still have poor access to institutional care (92).

Coordination

Strength: the Portuguese LTC system is decentralised and stratified, being managed at three governmental levels (Central, Regional and Locally) (18,42,88). This type of coordination was decided on in order to improve the implementability of the centrally defined guidelines by allowing them to be adapted to the needs of local populations;

Weakness: although there is LTC in Portugal outside the RNCCI, mainly operated in the private sector, there is no data publicly available on these care providers. On the other hand, the existence of waiting lists and regional asymmetries in care provision (100) may indicate a lack of coordination between the three governmental levels.

Organisational structure

Strength: the provision of care is organised in two main care settings: HCBS and NH. The latter consisting of three types of care units (16), the point of which is to cater for different care needs;

Weakness: the fact that over the last decade the numbers of NH beds per 1,000 inhabitants aged ≥ 65 have been increasing, while the ratio of home care treatment places is decreasing (27–31), shows a predominance of institutional over home care.

Needs assessment

Strength: the existence of a standard assessment instrument across the country called the Bio-psychosocial Assessment Instrument, which collects information in three domains (35): biological, psychological and social;

Weakness: not only does it not allow an integrated assessment of each person, limiting any benchmarking analysis between care settings, it is not used for financial reimbursement purposes, nor does it allow us to identify the level of complexity of patients' illnesses or problems, as do the assessment instruments used for example in Spain (94) and Italy (96).

Financing system

Strength: there are multiple sources of financing, namely public funding ensured by the State Budget, profits from social gambling and betting and means-tested co-payments (42,43);

Weakness: the financing model is based on the number of days of care provided, not by risk adjustment models, which may contribute to a cost increase.

6.1.2. Portuguese long-term care beneficiaries: Characteristics

Due to the scarcity of resources and the importance of providing care according to patients' needs, it is important to reflect on the referral criteria if we are to ensure the correct placement of each person in each care setting. Thus, considering the second objective of this thesis - the analysis of the main characteristics of those receiving HCBS and NH care - it is important that several significant risk factors associated with NH admission were found.

With regard to sociodemographic characteristics, we found that male gender and low social support were significant risk factors for NH admission, in line with previous findings (49,51,55–57,63,81,111). It is possible that, since women have a longer life expectancy and a greater prevalence of physical and mental health comorbidities than men (2), the absence or the death of a spouse could aggravate the level of dependency and the inability to take care of themselves, and consequently increase the likelihood of needing institutional care (49). Moreover, contrary to several studies (49,51,54–57,72,73,81), we found that older age had a small but positive influence on increasing the chance of receiving HCBS care. Although further investigation is needed, since older age is not a referral criterion for LTC admission, it might be that these people have more support from family and other caregivers, which may contribute to delaying admission into an NH facility.

On the influence of chronic medical conditions, the findings in the literature are mixed: whereas some found a higher burden of diseases among patients in institutions (51,54,56,75), others found no statistically significant differences between them and people in non-institutional care (52,71,72). Nevertheless, the findings of this study - that some specific medical conditions (mental illness, diseases of the nervous, the circulatory and the musculoskeletal system) are a significant risk factor for admission to each care setting - might well be helpful in encouraging policy-makers and staff to develop more sophisticated ways of defining specific care plans to take account of the differences in patients' needs.

On people' dependency level at admission, and in line with previous studies (51,56,57,61,70,111), we found that being physically and/or cognitively dependent increases the chance of a person being admitted to an institutional facility, more than it does to HCBS settings.

Finally, after adjusting for several baseline variables, only 74%, 57% and 47% of people were correctly referred to each NH unit of care (UC, UMDR and ULDM, respectively). Although recent studies have found differences in results after controlling for baselines

characteristics (52,71–73), this finding may be a consequence of lack of RNCCI resources, regional asymmetries (92) and care provision not being appropriate for the real needs.

6.1.3. Portuguese long-term care beneficiaries: Outcomes

After identifying the main characteristics of the Portuguese LTC beneficiaries, this study assessed two patients' outcomes: (1) mortality and (2) changes in dependency levels.

On the first one, we concluded that, contrary to the findings of several studies (61,63,75,84,150), people receiving home care have a higher mortality rate than those receiving institutional care. The existence of three NH units of care may help to explain this result. In this case, as we go forward to a unit of care with a longer expected length of care, namely the ULDM, the mortality rate increases and the estimated median survival time decreases. Moreover, although several authors have found that lacking a strong social network is an important risk factor for increased mortality in LTC care (84,86,117,118), it is surprising that in this study not having family/neighbour support has the opposite effect. Further research to understand this result is required. Finally, and in line with previous research, our study concluded that some of the most important risk factors of mortality are having medical conditions such as neoplasms or diseases of the skin and subcutaneous tissue (84,87,150), and being classified on admission as being at a higher physical (84–87,116) and cognitive (84,85,87) dependency level.

With regard to changes in patients' dependency levels, we concluded that most people presented no changes in their cognitive and physical status between admission and discharge.

- On physical status, while 34% of those alive at discharge had shown some improvements (38% in NH; 27% in HCBS), 55% maintained the same status (51% in NH; 64% in HCBS). Results from the literature are not consistent. While the percentage of patients with physical improvements ranged between 44% to 85% in NH (64,115) and from 33% to 45% in HCBS (64,114), those showing no change ranged from 10% to 20% (64,115) and from 20% to 62% (64,114) in the two care settings respectively.
- On cognitive status, this study concluded that 24% of those alive at discharge had shown some improvements (26% in NH; 18% in HCBS) and 61% maintained the same status (57% in NH; 71% in HCBS). Previous studies concluded that whereas the percentage of patients with cognitive improvements ranged from

14% to 85% between NH and HCBS populations, those with no cognitive changes ranged from 34% to 78% (64,119).

Finally, considering the main factors influencing lower dependency levels at discharge, some main conclusions may be highlighted:

- Although there is no consensus in the literature on the social network as an influencing factor for functional improvement – in some studies those living alone were more likely to make a physical recovery (114,115), others concluded the opposite (70) and others found no relationship (79) – our study concluded that some elements of social support reduce the probability of being classified as more independent at discharge. Arguably, assistance from third parties may prevent patients from trying to perform certain tasks on their own, so having some kinds of help may limit their recovery of lost functions.
- Two main conclusions arise on baseline dependency levels. First, being cognitively independent at admission has a positive influence on physical improvement (113–115,124,126,130). Second, a higher level of physical independence at admission not only increases the chances of being classified at a higher cognitive level of independence at discharge (119,126), but it also positively influences the patient's physical level at discharge (114,115,123,124,126,130).

Finally, although some researchers have found that length of care is positively associated with being more independent physically on discharge (63,113,126), our study found only a smaller - but positive - influence on cognitive improvement.

6.1.4. Portuguese long-term care beneficiaries: Length of Care

The main goal of this chapter was to analyse the influence of patients' physical and cognitive dependency status at admission on their length of care (LOC) in each care setting.

We concluded that LOC is highly influenced by the maximum expected stay in the setting to which patients are admitted. Moreover, the most significant variables in predicting the LOC were older age, male gender, having social support, the number of beds/treatment places and function status at admission. No statistically significant results were found for cognitive status.

As for the sociodemographic factors, although their influence on LOC is not well proven (63,137,140,141,144,145,148), we concluded that being older, being male and having

social support decreases the chance of having care for an extended period, especially for those admitted to a longer NH unit. Given these findings, there may be two possible explanations. Firstly, since there are a higher life expectancy and a greater prevalence of physical and mental health comorbidity among females (2), the absence or the death of a spouse may result in the provision of care for longer periods for them than for men. Secondly, because those characteristics are also mortality risk factors (15,146,148), the lower expected LOC may be a consequence of a higher mortality rate among those individuals (63).

With regard to the influence of the supply of care, much research examined the relationship between the supply side factors and LOC (137,144,145). Although regional asymmetries of LTC resources distribution still exist in Portugal (14), we concluded that an increase in the number of beds/treatment places had a residual effect on the average LOC.

Finally, whereas no statistically significant results were found for cognitive status, our results show that as the number of functional activities considered dependent at admission increases, the average LOC also increases, especially at the two NH units more associated with functional recovery. As for previous research (63,73,143,147), the evidence is mixed on the relationship between patients' dependency levels and their LOC.

6.2. Pathways of change

6.2.1. National Network for Long-Term Care since 2006

The universal access, the multiple sources of financing and the sustained increase of admissions are considered some of the achievements of the Portuguese LTC system in the last decade. Nevertheless, the insufficient national coverage in care provision (NH beds and HCBS treatment places), the regional asymmetries and the existence of waiting lists, are seen to be some of its future challenges. Thus, given the Portuguese economic recovery after the Troika intervention between 2011 and 2014, it is vital to unblock the necessary funding to follow up on the protocols already signed between the State and other entities (mainly private and IPSS), so that the full implementation of the RNCCI can reach the forecast coverage ratios.

Moreover, given the scarcity of formal community care, it is essential to reinforce primary care providers with the human and material resources needed to target risk groups and to develop initiatives aimed at maintaining the autonomy of the elderly in their home environment.

Finally, similarly to what is done in other countries (94,96,151), it is vital to rethink the current Portuguese funding system: basing it on a per diem may present a perverse incentive for the LTC system, and perhaps it would be better to use risk adjustment methods based on the people's severity level. This change might help the system to finance more equitably the care units that treat patients with higher levels of impairment, to improve the turnover of beds and treatment places, to tackle existing waiting lists and to ensure greater transparency in the use of public money allocated to the LTC sector.

6.2.2. Portuguese long-term care beneficiaries: Characteristics

Based on the findings of this study, it is crucial that we underline the importance of collecting relevant data in order to design a specific care plan for each patient, including an accurate record of all comorbidities and detailed medical, nursing and social evaluations. In this context, the adoption of internationally validated metrics for monitoring the quality of care provided and for benchmarking between similar LTC settings is of paramount importance. Moreover, sharing the results of each care unit, whether only descriptive or comparative between other similar Units, with policy-makers, staff, patients and their caregivers, will allow not only a greater level of transparency in care provision, but also open up ways of improving the poorest areas of performance.

Finally, policy-makers should become more aware of the coming sociodemographic challenges and their links with people's levels of dependency on NH/HCBS admission: if they do so we will be more able to avoid situations similar to some in this study, in which patients with similar characteristics are referred to different care settings and end up receiving different levels of care.

In this context, attention needs to be paid to the referral criteria: the importance of reducing unnecessary admissions and misplacement in LTC care settings is generally recognised. Thus, the existence of a multidisciplinary case management team may be a key factor in balancing demand and supply needs, in order to guarantee an appropriate use of resources.

Moreover, given that both regional asymmetries in care provision and the predominance of institutional care may negatively influence the referral process, auditing measures should be implemented in order to ensure continuous improvement in the patients' placement.

Thirdly, it is essential that policy-makers pay attention to the staffing mix in order to tailor each care setting with the proper resources to meet people's needs. Indeed, it is vital to invest in primary care staff and to create new care teams in order to increase home care treatment places.

Lastly, since informal caregivers play an important role in care provision, it is of paramount importance to define joint policies between the social and healthcare sectors that protect this "hidden" workforce. Therefore, paid care leave, allocation of allowances, flexible work schedules and stimuli to the growth of respite care to alleviate caregiving burden and stress are some examples of policies to support the informal care.

6.2.3. Portuguese long-term care beneficiaries: Outcomes

The fact that (1) the mortality rate is higher among those receiving home care, and (2) most people present no changes in their cognitive and physical status after treatment, are important findings for policy-makers as they (re)define the goals for the Portuguese LTC system.

Thus, several challenges for the future policy-makers can be highlighted.

Given the influence of the baseline status on patients' outcomes, it is clearly important that health professionals are provided with reliable tools that allow an accurate assessment of patient's dependency levels in order to predict their outcomes more

confidently. The reliability of the currently-used screening tool for dependency levels must be thoroughly reassessed.

Secondly, since the LTC sector focuses on frail people with a high level of dependency, staff and policy-makers must work together in developing and implementing standard monitoring measures to ensure that each setting offers a care programme tailored to each person's needs. Therefore, similarly to current practice in other countries (133–135), it is important to implement patient-reported outcomes measures to support improvement in the quality and safety of healthcare delivery.

Finally, given the low influence of the length of care in improving the patients' independence levels, policy-makers should reflect upon this and assess whether or not stays are really being used to restore lost autonomy, or whether the intensity and frequency of the care provided is not hindering the process of regaining autonomy: that is, is it truly adapted to the individual's care needs?

6.2.4. Portuguese long-term care beneficiaries: Length of Care

The fact that an increase in the number of beds/treatment places has a residual effect on patients' LOC may imply that increasing the resources allocate to LTC in Portugal could reduce the waiting list and enable more individuals to have access to this care, without increasing the average LOC in each care setting.

Although there is insufficient evidence about the effectiveness of rehabilitation in LTC settings (82,83,149) and since costs are usually proportional to LOC, our findings should be considered in future cost-effectiveness studies aimed at assessing the impact of long-term interventions and at preventing patients being sent to inappropriate care settings.

Since this study is restricted to publicly-funded care, the lack of information about transfers between publicly and privately-funded care and the trajectories between the different LTC publicly provided care settings, it may not reflect the total LOC for all persons (63,136,144,147). Thus, for a comprehensive study of patients' path in the LTC system, it will be vital to have information on the transitions between the different care settings, so that staff and policy-makers can adjust the delivery of care to their needs.

Finally, because the Portuguese care settings are paid a per-diem per patient, a monitoring system that assesses the relationship between LOC and patients' outcomes must be implement - in order to prevent the maximization of their revenue through (possible inappropriate) prolonged stays - but also allows for a faster turnover of beds and a reduction of the waiting list. The implementation of a quality control system to

identify individuals' dependency levels, the definition a Minimum Data Set common to all units and the adoption of a homogeneous classification system for patients in LTC are crucial improvements needed in the system. They would contribute to a better understanding of the needs of the population, define risk stratification models, assess the performance of care providers and contribute to a more equitable allocation of funding resources.

7. FURTHER INVESTIGATION

Given the recognition that LTC will be an expanding area in the years to come, two major themes from this thesis should be developed and studied further in order to deepen the analysis in this area: (1) the cost-effectiveness analysis between institutional and non-institutional care; and, (2) the influence of the staff mix and the intensity of care on patients' outcomes.

7.1. Cost-effectiveness analysis

Historically, the LTC system is dominated by institutional care. In recent years, there has been a great deal of interest in expanding the care delivery to a non-institutional setting, mainly based on two ideas. First, people usually prefer to be cared in a known environment, maintaining the integrity of their social network and enjoy a higher quality of life (49–53). Second, in terms of public and private finances, it is possible to provide lower per capita expenditure care in HCBS settings relative to NH, for people with less intensive care needs. Nevertheless, according to Schwarzkopf et al. (2013), “the exact difference in spending on long-term care services has seldom been quantified, and there is even less research that has analysed whether expenditures on health care services also differ between patients in institutions and those living in the community” (81). For that matter, based on the following studies, is still controversial whether (or not) the expenditures on health care services truly differ between the institutional and community-living populations when the patients' dependency levels are taken into account.

For example, in a study concerning 308 elderly people in north-west England, not only almost 30% of the new admissions to NH had low dependency level, these people were more likely to pay for care exclusively from private resources (78). According to the authors, these low dependency admissions are usually cases of respite care and, at the same time, consider to be an attractive population to NH operators with low occupancy.

Moreover, in order to compare the cost-effectiveness of care treatment for 313 stroke patients with severe physical disabilities three months after being admitted in one of three care settings (hospital chronic care, NH and home care), Chio et al. (2001) concluded that when caregivers' labour costs are included in the total costs, caring for this type of patients at home is significantly more expensive when compared to the other two care settings (66). Furthermore, when considering the effectiveness of treatment, findings suggest that caring for these patients with severe physical disabilities in their own homes was also less effective than caring for them in NH or in a hospital chronic care units.

In another cost-effectiveness study for 99 stroke patients, the authors compared both direct (out-of-pocket expenditures, prescription drugs, home care, NH, special equipment, foods and supplements) and indirect (labour cost of family caregivers, patient's loss of earning and transportation the value of the time) costs incurred by patients and families, with changes of physical/cognitive level of dependency after treatment (60). In this case, although the total cost paid over a three-month period was higher among home care patients, after adjusting for the baseline characteristics (i.e., age, gender, marital status and cognitive/physical scores), no significant differences were found in the total cost paid between both populations. When added the effectiveness of care treatment, the results of this study showed that, whereas a one-point increase in the cognitive scores showed no significant differences between the two groups of patients, an increase in physical status was significantly cheaper among those receiving institutional care.

Similar to the previous case (60), a study for demented older people also reached to a similar conclusion (69). In this case, while direct costs such as care services, cost of food and special equipment were higher in NH than HCBS, the indirect costs like the time cost of informal caregivers were significantly higher among home care patients. On the other hand, whereas taking care of people with low physical dependency at home was significantly less costly than within an institutional setting, the care cost of treating people with high physical dependency at home was significantly higher than institutional care person.

In order to study the economic burden of dementia patients in Germany, Schwarzkopf et al. (2013) compared the yearly per capita utilisation and costs for health and LTC services between community-living patients and those in institutions, according to their dependency status (81). They concluded that the overall yearly costs per capita of treating dementia patients in a community-based setting is substantially lower (less than half as much) than institutional care, due to substantially lower LTC expenditures. On the other hand, although expenditures on medication, hospital treatment and rehabilitation were higher within all care levels in community-dwelling, expenditures regarding visits from general physicians and medical specialists were higher among people in institutions.

More recently, a joint study in eight European countries (Estonia, Finland, France, Germany, the Netherlands, Spain, Sweden and the UK) compared costs to society of treating 2,014 people with dementia, between those receiving professional home care but at risk of entering an institution and those recently admitted to institutional facilities (57). Two of the authors' main conclusions can be highlighted. In spite of slight variations

between countries: (1) in home care settings, the average costs of informal, community and medical care accounted for 52%, 36% and 12% of the total costs; (2) in institutional facilities, the nursing home accommodation, the medical care and community care were 94%, 6% and 0.2% of the total costs. In all the countries, overall costs for patients with dementia receiving home care were significantly lower than for those in institutions.

Finally, in California, Newcomer et al (2016) compared the expenditures of acute medical care (e.g. hospital stays, emergency department visits, ambulatory care visits, procedures, diagnostics, therapies, and equipment) and post-acute care (e.g. LTC hospitals, inpatient rehabilitation facilities and physical, occupational and speech therapies) between HCBS and NH users (73). After adjusting for several baseline characteristics (age, gender, race, physical and cognitive dependency level, comorbidities, family arrangement and county characteristics), they concluded that \$3,000 more per month was spent on those initially admitted to a NH facility than on those who entered HCBS. Nevertheless, one of the main limitations of this study is the fact that they did not include out-of-pocket expenditures or the lost income for family caregiving which, based on the previous studies, might be important elements in the overall comparison between NH and home care expenditures.

In conclusion, based on previous research, the two most needed areas of future research would seem to be the following.

First, although home care seems to be less costly than institutional care for the elderly and patients with chronic illnesses, several studies reached to an opposite conclusion when the indirect costs of social involvement in caregiving, especially by family members, are taken into account. They suggest a significant relationship between the type of care setting and the need for informal assistance related to the total costs incurred by families. Second, when assigning each patient to the appropriate care setting and defining their care plan, findings suggest that patients' physical/cognitive dependency levels should be taken into consideration, given their importance in determining the costs and effectiveness for LTC treatment. It seems that home care is sufficient when the patient presents a low degree of dependency and does not require high-intensity levels of LTC services, but when s/he has a high level of dependency and needs several types of care, institutional care represents the more efficient alternative.

7.2. The influence of staff mix and the intensity of care

Staffing is not *per se* an intervention, but it is a critical factor in carrying out interventions to improve the quality of care in the healthcare sector. There has therefore been a growing interest in workforce (re)engineering over the years, seeking the optimal (or at least the minimum) staffing ratios in LTC facilities. These studies have focused on three main professional categories¹: Registered Nurses (RNs), Licensed practical nurses (LPNs) and Nurse Aides (NAs).

Although the definition of a minimum staffing ratio is a vital component to ensure quality of care, it is not necessarily the “quantity of staff” that matters, but the “intensity of care” provided. For that matter, while some researchers have explored specific ratios thresholds like the number of Full-time Equivalent (FTE) staff per resident (152–154), the majority have adopted the number of Hours per Resident per Day (HPRD) (138,152,153,155–166) (**Table 15**).

Table 15: Staffing intensity in Nursing Homes facilities

Ref.	Year	Staffing intensity
(Harrington et al., 2000) (152)	2000	<p>HPRD</p> <ul style="list-style-type: none"> • RN: previous 0.72 (43 min); recommended 1.15 (69 min) • LPN: previous 0.69 (41 min); recommended 0.70 (42 min) • NA: previous 2.1 (126 min); recommended 2.70 (162 min) • Total Nurses: previous 3.51 (210 min); recommended 4.55 (273 min) <p>For facilities with 100 beds or more (RN, LPN, NA)</p> <ul style="list-style-type: none"> • Day shift 1 FTE for every 5 residents (1.60 HPRD: 96 min) • Evening shift 1 FTE for every 10 residents (0.80 HPRD: 48 min) • Night shift 1 FTE for every 15 residents (0.53 HPRD: 32 min)
(Schnelle et al., 2004) (160)	2004	<p>Baseline: 2.8 (168 min) to 3.2 (192 min) NA HPRD</p> <ul style="list-style-type: none"> • Lower quartile homes (P 25): average of 2.7 NA HPRD (162 min) • Upper quartile homes (P 75-90): average of 3.4 NA HPRD (204 min) • Upper decile homes (P 91-100): average of 4.9 NA HPRD (294 min)
(Horn et al., 2005) (161)	2005	<p>HPRD</p> <ul style="list-style-type: none"> • RN: 0.27 (16 min) • LPN: 0.51 (31 min) • NA: 1.7 (102 min)
(McGregor et al., 2005) (162)	2005	<p>HPRD:</p> <ul style="list-style-type: none"> • RN ranged from 0.69 (41 min) and 0.93 (56 min) in not-for-profit facilities • RN ranged from 0.65 (39 min) and 0.71 (43 min) in for-profit facilities • LPN ranged from 0.09 (5 min) and 0.13 (8 min) in not-for-profit facilities • LPN ranged from 0.04 (2 min) and 0.11 (7 min) in for-profit facilities • NA ranged from 1.72 (103 min) and 2.46 (148 min) in not-for-profit facilities • NA ranged from 1.60 (96 min) and 2.13 (128 min) in for-profit facilities • Direct-care staff ranged from 2.46 (148 min) and 3.18 (191 min) in not-for-profit facilities • Support-care staff ranged from 1.05 (63 min) and 1.17 (70 min) in for-profit facilities

¹ Registered Nurses (RNs): refers to a more specialized nurses, in a supervisory position characterized by the observing, assessment and recording of patients' symptoms and progress; Licensed practical nurses (LPNs): provide basic nursing care, providing hands-on care to patients under the supervision of RN and physicians; Nurse Aides (NAs): provide the majority of direct care to patients and consists primarily of helping residents with basic ADL (153,168).

Ref.	Year	Staffing intensity
(Bostick et al., 2006) (153)	2006	<p>15 of the 87 studies reported:</p> <ul style="list-style-type: none"> • RN: 0.06 to 0.25 FTE per resident/bed • LPN: 0.05 to 0.12 FTE per resident/bed • NA: 0.21 to 0.38 FTE per resident/bed • RN: 0.2 (12 min) to 0.7 (42 min) HPRD • LPN: 0.5 (30 min) to 0.7 (42 min) HRPD • NA: 1.95 (117 min) to 3.4 (204 min) HPRD
(Zhang et al., 2006) (163)	2006	<p>HPRD</p> <ul style="list-style-type: none"> • RN: 0.31 (19 min) • LPN: 0.66 (40 min) • NA: 2.06 (124 min) • RN + LPN: 0.97 (58 min) • Total 3.03 (182 min)
(Castle and Engberg, 2007) (154)	2007	<p>FTE per 100 residents:</p> <ul style="list-style-type: none"> • RN: 14.7 • LPN: 16.6 • NA: 33.4
(Harrington, Swan and Carrillo, 2007) (164)	2007	<p>HPRD</p> <ul style="list-style-type: none"> • RN: 0.66 (40 min) • Total Nursing: 3.62 (270 min)
(Nelson et al., 2007) (138)	2007	<p>HPRD</p> <ul style="list-style-type: none"> • RN: 4.04 (range 1 - 8); 241 min (range 60 – 480 min) • Non-RN (LPN/NA): 4.07 (range 0.1 - 10); 244 min (range 6 min – 600 min) • Overall Nursing: 8.11 (range 5 - 14); 487 min (range 300 min – 840 min)
(Konetzka, Stearns and Park, 2008) (165)	2008	<p>HPRD</p> <ul style="list-style-type: none"> • RN: 0.35 (21 min)
(Kim, Harrington and Greene, 2009) (166)	2009	<p>HPRD</p> <ul style="list-style-type: none"> • RN: 0.57 (34 min) for NH complying with the state staffing standard; 0.26 (16 min) for NH not complying with the state staffing standard • Total staffing: 4.01 (244 min) for NH complying with the state staffing standard; 2.79 (167 min) for NH not complying with the state staffing standard
(Park and Stearns, 2009) (155)	2009	<p>HPRD</p> <ul style="list-style-type: none"> • RN: 0.34 (range 0 - 10.23); 20 min (range 0 min – 614 min) • LPN: 0.65 (range 0 - 9.64); 39 min (range 0 min – 578 min) • NA: 1.94 (range 0 - 10.65); 116 min (range 0 min – 639 min) • Total: 2.93 (range 5 - 11.98); 176 min (range 300 min – 719 min)
(Hyer et al., 2011) (156)	2011	<p>HPRD</p> <ul style="list-style-type: none"> • RN/LPN: increased from 1.15 (69 min) in 2002, to 1.18 (71 min) in 2005 • NA: increased from 2.49 (149 min) in 2002 to 2.73 (164 min) in 2005
(Shin, 2013) (157)	2013	<p>The average number of total RN, LPN, and NA was 7.7 (SD = 4.28); 4.95 (SD = 2.86); and 28.32 (SD = 8.53) respectively.</p>
(Lee, Blegen and Harrington, 2014) (158)	2014	<p>HPRD</p> <ul style="list-style-type: none"> • RN: 0.60 (range 0.2 - 1.6); 36 min (range 12 min – 96 min)
(Uchida-Nakakoji et al., 2015) (159)	2015	<p>HPRD</p> <ul style="list-style-type: none"> • Total Nursing: 4.59 (275 min)

Legend: RN: Registered Nurses; LPN: Licensed practical nurses; NA: Nurse Aides; HPRD: Hours per Resident per Day; FTE: Full-Time Equivalent; min: minutes.

As for the *quality* of care, the concept is extraordinarily difficult to define and measure, since it is generally a reflection of the values and goals of each society and their current healthcare system (157). Nevertheless, based on the following research, a wide range

of studies in the literature have found a relationship between staff intensity and patients' outcomes.

According to several authors, a higher intensity of care by RNs, measured by the HPRD, is correlated with several outcomes: more out-of-bed activity (160); lower rates of weight loss and less hospitalisation (161); less use of restraints (163); fewer catheterisations and more improvement on functional ability (161,163,167); fewer urinary tract infections (UTI) (161,165); lower incidence of pressure ulcers (158,161,165); more feeding assistance, more incontinence care, more exercise and repositioning (160,167); better comfort and enjoyment domains of quality of life (157); and fewer falls (167).

A more intensive involvement by LPN staff, measured by HPRD, was found - although not statically significantly - to be associated with rates of ulcers and pressure sores (155), and seems to contribute to more out-of-bed engagement, feeding assistance, incontinence care, exercise and repositioning (160). On the other hand, it is also associated with improvements in functional ability (such as bladder status, skin integrity and mobility), less use of restraints and fewer catheterisations (163). In terms of quality of life, Shin (2013) concluded that when care was provided by full-time LPN, rather than part-time staff, the care was considered more stable, and offered better quality in terms of dignity (157).

Moreover, several authors studied the influence of support staff and concluded that facilities with a higher number of NAs performed significantly better in 13 of 16 quality of the care indicators (e.g. more out-of-bed engagement, feeding assistance, incontinence care, exercise and repositioning) than the facilities with fewer NAs (160). Other authors found that more HPRD of NA contributed to fewer pressure ulcers (161) and lower scores on deficiencies related to the quality of resident care (156), but more prevalence of residents with L-tubes and aggressive behaviours (167). Concerning the quality of care in several domains and its relationship with staffing ratio, Shin (2013) concluded that NAs staff hours had a positive impact on the security domain (157). In other words, since NAs account for the majority of residents' ADL care, the more direct contact hours, the higher the residents' scores for functional competence and security with the care provided.

In conclusion, although the number of weekly hours by professional category was defined in 2011 for each RNCCI NH Unit of care with 30 beds (26), further research is needed to assess the association between staffing mix and quality of care. Thus, based on the findings of the previous studies, several questions arise to offer a framework for further discussion of this issue.

Firstly, what is the most reliable measure to define staffing mix and ratio? Should it be per resident? Per bed? Hours per resident day? Another measure? For that matter, although it is not clear whether the staffing mix could be defined in the same way in all care settings given the RNCCI' organisational structure, is important that each provider provides accurate information about its staff in order to define the best metric for the staff ratio.

Secondly, on care treatment, which quality indicators should be considered in order to assess the relationship between quality of care and staffing mix? Currently, several quality measures are already being used across the literature, either related to patient outcomes (e.g. changes in quality of life, physical status, pressure ulcers or weight loss), or related to facility outcomes (e.g. mortality rate, hospital admissions, average length of care or discharge rates).

Finally, which variables may also be used as covariates to study this relationship between staffing and quality of care? Although these may vary between studies, they usually relate to sociodemographic characteristics, cognitive/physical impairment, facility ownership, size, geographical location, years of experience or length of stay.

8. REFERENCES

1. Rechel B, Grundy E, Robine J-M, Cylus J, Mackenbach JP, Knai C, et al. Ageing in the European Union. *Lancet* [Internet]. 2013 Apr 13 [cited 2018 May 8];381(9874):1312–22. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/23541057>
2. Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet* [Internet]. 2012 Jul 7 [cited 2018 Apr 29];380(9836):37–43. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/22579043>
3. WHO. World report on Ageing And Health [Internet]. Geneva; 2015. Available from: www.who.int/
4. Eurostat. Population Demography Statistics [Internet]. 2018 [cited 2018 Jan 15]. Available from: <http://ec.europa.eu/eurostat/data/database>
5. PCBE. Taking care older people: Ethical Caregiving in Our Aging Society [Internet]. Washington, D.C.; 2005 [cited 2018 Jan 15]. Available from: https://www.thenewatlantis.com/docLib/20091130_taking_care.pdf
6. Kaye HS, Harrington C. Long-term services and supports in the community: Toward a research agenda. *Disabil Health J* [Internet]. 2015 Jan [cited 2018 Mar 28];8(1):3–8. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25445015>
7. Wysocki A, Butler M, Kane RL, Kane RA, Shippee T, Sainfort F. Long-Term Services and Supports for Older Adults: A Review of Home and Community-Based Services Versus Institutional Care. *J Aging Soc Policy* [Internet]. 2015 May 5 [cited 2018 Apr 29];27(3):255–79. Available from: <http://www.tandfonline.com/doi/full/10.1080/08959420.2015.1024545>
8. WHO. Lessons for long-term care policy: The Cross-Cluster Initiative on Long-Term Care Noncommunicable Diseases and Mental Health Cluster [Internet]. Geneva; 2002 [cited 2017 Mar 9]. Available from: http://apps.who.int/iris/bitstream/10665/67275/1/WHO_NMH7CCL_02.1.pdf
9. OECD. The OECD Health Project Long-term Care for Older People Long-term Care for Older People [Internet]. Paris; 2005 [cited 2017 Mar 9]. Available from: www.oecd.org

10. Colombo F, Llana-Nozal A, Mercier J, Tjadens F. Help Wanted ? Providing and Paying for Long-Term Care [Internet]. Health Policy Studies: OECD Publishing. 2011. Available from:
http://ec.europa.eu/health/reports/docs/oecd_helpwanted_en.pdf
11. European Commission. Long-term care in the European Union. Brussels; 2007.
12. Campos L, Saturno P, Vaz-Carneiro A. Plano Nacional de Saúde 2011-2016 - A qualidade dos cuidados e dos serviços [Internet]. Lisboa; 2011 [cited 2018 Jan 15]. Available from: <http://1nj5ms2lli5hdggbe3mm7ms5.wpengine.netdna-cdn.com/files/2010/07/Q2.pdf>
13. Porter M, Teisberg E. Redefining Health Care: Creating Value-Based Competition on Results. 6th ed. Harvard Business School Press, editor. Boston, MA; 2006. 1-505 p.
14. Lopes H, Mateus C, Hernández-Quevedo C. Ten Years since the 2006 Creation of the Portuguese National Network for Long-Term Care: Achievements and Challenges. Health Policy (New York) [Internet]. 2018 Jan 11 [cited 2018 Jan 19];122(3):210–6. Available from:
http://www.sciencedirect.com/science/article/pii/S0168851018300034?_rdoc=1&_fmt=high&_origin=gateway&_docanchor=&md5=b8429449ccfc9c30159a5f9aeaa92ffb
15. Lopes H, Mateus C, Rosati N. Impact of long term care and mortality risk in community care and nursing homes populations. Arch Gerontol Geriatr [Internet]. 2018 May 1 [cited 2018 Mar 8];76:160–8. Available from:
<https://www.sciencedirect.com/science/article/pii/S0167494318300281>
16. D.R. Decree-Law 101/2006. D.R. I Serie A, 6th of July - Creation of the Portuguese National Network for Long-term Care [in Portuguese] [Internet]. 2006. p. 3856–65. Available from: http://www.acss.min-saude.pt/wp-content/uploads/2016/10/Decreto-Lei_101_2006-1.pdf
17. Santana S, Dias A, Souza E, Rocha N. The Domiciliary Support Service in Portugal and the change of paradigm in care provision. Int J Integr Care [Internet]. 2007;7(1):1–8. Available from:
<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1800934&tool=pmcentrez&rendertype=abstract>
18. Santana S, Szczygiel N, Redondo P. Integration of care systems in Portugal: anatomy of recent reforms. Int J Integr Care [Internet]. 2014;14(4):1–10.

Available from: <http://www.ijic.org/index.php/ijic/article/view/URN:NBN:NL:UI:10-1-114781/2426>

19. D.R. Decree-Law no. 119/83, 25th of February - IPSS statutes [in Portuguese] [Internet]. 1983 [cited 2017 May 29]. Available from: <http://www.amu.org.pt/pdfs/Estatuto das IPSS.pdf>
20. Santana S. Reforming long-term care in Portugal: Dealing with the multidimensional character of quality. *Soc Policy Adm.* 2010;44(4):512–28.
21. MTSSS. Social charter: Services and equipment network, 2006 report [in Portuguese] [Internet]. Lisbon; 2006 [cited 2017 Oct 5]. Available from: <http://www.gep.msess.gov.pt/cartasocial/pdf/csocial2006.pdf>
22. UMCCI. Monitoring report on the implementation of the pilot experiences of the Portuguese National Network for Long-term Integrated Care [in Portuguese]. Lisbon; 2007.
23. Freitas S, Simões MR, Alves L, Santana I. The Relevance of Sociodemographic and Health Variables on MMSE Normative Data. *Appl Neuropsychol Adult* [Internet]. 2015 Jul 4 [cited 2017 Dec 29];22(4):311–9. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25531579>
24. DRE. Portaria no. 174/2014, 5th September - Nursing Homes installation and operation conditions [Internet]. 2014 [cited 2017 Mar 3]. p. 18. Available from: http://www.acss.min-saude.pt/wp-content/uploads/2016/07/Port_174_2014.pdf
25. UMCCI. Glossário da Rede Nacional de Cuidados Continuados Integrados [Internet]. Lisboa; 2009 [cited 2017 Mar 3]. Available from: <http://www.acss.min-saude.pt/wp-content/uploads/2016/07/Glossario-da-RNCCI.pdf>
26. UMCCI. Provider Handbook - Recommendations for Continuous Improvement [in Portuguese] [Internet]. Lisbon; 2011 [cited 2017 Mar 3]. Available from: http://www.acss.min-saude.pt/wp-content/uploads/2016/10/Man_Prestador_UMCCI-RNCCI.pdf
27. UMCCI. Monitoring the Portuguese National Network for Long-term Integrated Care - 2008 [in Portuguese]. Lisbon; 2009.
28. UMCCI. Monitoring the Portuguese National Network for Long-term Integrated Care - 2010 [in Portuguese] [Internet]. Lisbon; 2011. Available from: http://www.acss.min-saude.pt/Portals/0/Relatório monitorização do desenvolvimento e da atividade da RNCCI_1º semestre 2014.pdf

29. UMCCI. Monitoring the Portuguese National Network for Long-term Integrated Care in 2012 - Final report [in Portuguese]. Lisbon; 2013.
30. ACSS. Monitoring the Portuguese National Network for Long-term Integrated Care - 2014 [in Portuguese]. Lisbon; 2015.
31. ACSS. Monitoring the Portuguese National Network for Long-term Integrated Care - 2016 [in Portuguese] [Internet]. Lisbon; 2017 [cited 2017 Sep 4]. Available from: <http://www.acss.min-saude.pt/wp-content/uploads/2016/07/RNCCI-Relatorio-Monitorizacao-Anual-2016.pdf>
32. D.R. Ordinance no. 174/2010, 10th of September, which updates the operational conditions of the nursing homes and home care settings of care [in Portuguese] [Internet]. 2014 [cited 2017 Jun 1]. p. 4865–82. Available from: http://www.sg.min-saude.pt/NR/rdonlyres/F1071041-A28D-4B06-8CB5-D640D1D60D80/41897/Portaria174_2014.pdf
33. Instituto da Segurança Social. Practical guide - National Network for Long-term Care [in Portuguese] [Internet]. Lisbon; 2017 [cited 2017 Jun 3]. Available from: http://www.seg-social.pt/documents/10152/27195/N37_rede_nacional_cuidados_continuados_integrados_rncci/f2a042b4-d64f-44e8-8b68-b691c7b5010a
34. D.R. Decree-Law no. 136/2015, 28th of July - Creation of the National Palliative Care Network (Rede Nacional de Cuidados Paliativos - RNCP) [in Portuguese] [Internet]. 2015 [cited 2017 Jun 19]. p. 1–11. Available from: http://www.acss.min-saude.pt/wp-content/uploads/2016/10/Decreto-Lei_136_2015.pdf
35. Abreu Nogueira J, Girão M, Guerreiro I. Post Acute and Long Term Care: instrument for evaluating outcomes National Network for Integrated Continuous Care Portugal. Lisbon: UMCCI; 2010.
36. Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW, Katz, S. et al, et al. Studies of illness in the aged: the index of ADL, a standardized measure of biological and psychosocial function. JAMA [Internet]. 1963 Sep 21 [cited 2017 Feb 5];185(12):914. Available from: <http://jama.jamanetwork.com/article.aspx?doi=10.1001/jama.1963.03060120024016>
37. Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist [Internet]. 1969 [cited 2017

- Dec 26];9(3):179–86. Available from:
<http://www.ncbi.nlm.nih.gov/pubmed/5349366>
38. Folstein MF, Folstein SE, McHugh PR. Mini-mental. A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res [Internet]. 1975 Nov [cited 2017 Feb 5];12(3):189–98. Available from:
<http://www.ncbi.nlm.nih.gov/pubmed/1202204>
 39. Botelho MA. Autonomia Funcional em Idosos: Caracterização multidimensional em idosos utentes de um centro de saúde urbano (Functional Autonomy in Elders: Multidimensional characterization in elderly users of an urban primary care centre) [Internet]. Faculdade de Ciências Médicas da Universidade Nova de Lisboa; 1999 [cited 2017 Dec 22]. Available from:
[https://run.unl.pt/bitstream/10362/15165/1/Botelho Maria Amalia TD 1999.PDF](https://run.unl.pt/bitstream/10362/15165/1/Botelho%20Maria%20Amalia%20TD%201999.PDF)
 40. Abreu Nogueira J, Girão M, Guerreiro I. Outcomes of physical autonomy in Post Acute and Long Term Care National Network for Integrated Continuous Care Portugal. Lisbon: UMCCI; 2010.
 41. UMCCI. Modelo de Referenciação de Utentes na Rede Nacional de Cuidados Continuados Integrados. Lisboa; 2009.
 42. Costa-Font J, Gori C, Santana S. Financing Long-Term Care in Southwest Europe: Italy, Portugal and Spain. In: Financing Long-Term Care in Europe [Internet]. London: Palgrave Macmillan UK; 2012 [cited 2017 Feb 5]. p. 170–86. Available from: http://link.springer.com/10.1057/9780230349193_10
 43. D.R. Decree-Law 106/2011, 21st of October - Distribution of net results of social games [in Portuguese] [Internet]. 2011 [cited 2017 Feb 5]. Available from:
http://www.pgdlisboa.pt/leis/lei_mostra_articulado.php?nid=2580&tabela=leis&so_miolo=
 44. Ordinance no. 184/2015. Ordinance no. 184/2015, 23th of June - Price definition of health care and social support provided in the inpatient and outpatient units of the Portuguese National Network for Long-term Integrated Care [in Portuguese] [Internet]. 2015 [cited 2017 Feb 5]. Available from:
<https://dre.pt/application/conteudo/67541740>
 45. Joël M-E, Dufour-Kippelen S, Samitca S. The Long-Term Care System for the elderly in Portugal [Internet]. Brussels; 2010 [cited 2017 Feb 5]. Available from:
<http://www.ancien-longtermcare.eu/node/27>
 46. D.R. Normative Dispatch no. 34/2007 - Definition of the social support co-

- payments at the Medium Term and Rehabilitation Units and the Long-Term and Maintenance Units [in Portuguese] [Internet]. 2007 [cited 2017 Jun 3]. p. 27412–4. Available from: http://www.acss.min-saude.pt/wp-content/uploads/2016/10/Despacho-normativo_34_2007.pdf
47. OECD. OECD Statistics: Long-Term Care Resources and Utilisation [Internet]. 2017 [cited 2017 Sep 2]. Available from: <http://stats.oecd.org/>
 48. PORDATA. Population Census [Internet]. 2018 [cited 2018 Jan 15]. Available from: <http://www.pordata.pt/Subtema/Municipios/Censos+da+Popula%C3%A7%C3%A3o-204>
 49. Lupp M, Riedel-Heller SG, Luck T, Wiese B, van den Bussche H, Haller F, et al. Age-related predictors of institutionalization: results of the German study on ageing, cognition and dementia in primary care patients (AgeCoDe). *Soc Psychiatry Psychiatr Epidemiol* [Internet]. 2012 Feb 23 [cited 2018 May 8];47(2):263–70. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/21181110>
 50. Hajek A, Brettschneider C, Lange C, Posselt T, Wiese B, Steinmann S, et al. Longitudinal Predictors of Institutionalization in Old Age. Federici S, editor. *PLoS One* [Internet]. 2015 Dec 14 [cited 2018 May 7];10(12):e0144203. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/26658776>
 51. Bartfay E, Bartfay WJ, Gorey KM. Dementia care in Ontario, Canada: evidence of more timely diagnosis among persons with dementia receiving care at home compared with residential facilities. *Public Health* [Internet]. 2016 Jan [cited 2018 May 8];130:6–12. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/26542355>
 52. Blackburn J, Locher JL, Kilgore ML. Comparison of Long-term Care in Nursing Homes Versus Home Health: Costs and Outcomes in Alabama. *Gerontologist* [Internet]. 2016 Apr [cited 2018 Apr 29];56(2):215–21. Available from: <https://academic.oup.com/gerontologist/article-lookup/doi/10.1093/geront/gnu021>
 53. Toot S, Swinson T, Devine M, Challis D, Orrell M. Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis. *Int Psychogeriatrics* [Internet]. 2017 Feb 3 [cited 2018 May 8];29(02):195–208. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/27806743>
 54. Gaugler JE, Duval S, Anderson KA, Kane RL. Predicting nursing home admission in the U.S: a meta-analysis. *BMC Geriatr* [Internet]. 2007 Dec 19 [cited 2018 Mar 28];7(1):13. Available from:

<http://www.ncbi.nlm.nih.gov/pubmed/17578574>

55. Lupp M, Luck T, Weyerer S, König H-H, Brahler E, Riedel-Heller SG. Prediction of institutionalization in the elderly. A systematic review. *Age Ageing* [Internet]. 2010 Jan 1 [cited 2018 Mar 28];39(1):31–8. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/19934075>
56. Penning MJ, Cloutier DS, Nuernberger K, MacDonald SWS, Taylor D. Long-term Care Trajectories in Canadian Context: Patterns and Predictors of Publicly Funded Care. *J Gerontol B Psychol Sci Soc Sci* [Internet]. 2016 Aug 24 [cited 2017 Feb 21];gbw104. Available from: <https://academic.oup.com/psychsocgerontology/article-lookup/doi/10.1093/geronb/gbw104>
57. Wübker A, Zwakhalen SMG, Challis D, Suhonen R, Karlsson S, Zabalegui A, et al. Costs of care for people with dementia just before and after nursing home placement: primary data from eight European countries. *Eur J Heal Econ* [Internet]. 2015 Sep 29 [cited 2018 May 7];16(7):689–707. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25069577>
58. Tomiak M, Berthelot JM, Guimond E, Mustard CA. Factors associated with nursing-home entry for elders in Manitoba, Canada. *J Gerontol A Biol Sci Med Sci* [Internet]. 2000 May [cited 2017 Feb 21];55(5):M279-87. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/10819318>
59. Borrayo EA, Salmon JR, Polivka L, Dunlop BD. Utilization across the continuum of long-term care services. *Gerontologist*. 2002;42(5):603–12.
60. Kim E-Y, Yang B-M. Cost-effectiveness of long-term care services in South Korea. *Arch Gerontol Geriatr* [Internet]. 2005;40(1):73–83. Available from: <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med5&NEWS=N&AN=15531025%5Cnhttp://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed7&NEWS=N&AN=2004491667>
61. Gruber-Baldini AL, Stuart B, Zuckerman IH, Simoni-Wastila L, Miller R. Treatment of dementia in community-dwelling and institutionalized medicare beneficiaries. *J Am Geriatr Soc*. 2007;55(10):1508–16.
62. Muramatsu N, Yin H, Campbell RT, Hoyem RL, Jacob MA, Ross CO. Risk of nursing home admission among older americans: does states' spending on home- and community-based services matter? *J Gerontol B Psychol Sci Soc Sci* [Internet]. 2007 May [cited 2017 Feb 7];62(3):S169-78. Available from:

<http://www.ncbi.nlm.nih.gov/pubmed/17507592>

63. Häcker J, Hackmann T. Los(t) in long-term care: empirical evidence from German data 2000-2009. *Health Econ* [Internet]. 2012 Dec [cited 2017 Feb 7];21(12):1427–43. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/22081484>
64. Lee TW, Yim E, Cho E, Chung J. Cognitive function, behavioral problems, and physical function in long-term care insurance beneficiaries with dementia in South Korea: comparison of home care and institutional care services. *J Am Geriatr Soc* [Internet]. 2014 Aug [cited 2017 Feb 21];62(8):1467–75. Available from: <http://doi.wiley.com/10.1111/jgs.12944>
65. Young Y, Kalamaras J, Kelly L, Hornick D, Yucel R. Is Aging in Place Delaying Nursing Home Admission? *J Am Med Dir Assoc* [Internet]. 2015 Oct 1 [cited 2017 Feb 21];16(10):900.e1-900.e6. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/26433865>
66. Chiu L, Shyu WC, Liu YH. Comparisons of the cost-effectiveness among hospital chronic care, nursing home placement, home nursing care and family care for severe stroke patients. *J Adv Nurs* [Internet]. 2001;33(3):380–6. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/11251725>
67. Xie H, Chausalet TJ, Thompson WA, Millard PH. Modelling decisions of a multidisciplinary panel for admission to long-term care. *Health Care Manag Sci*. 2002;5(4):291–5.
68. Sloane PD, Zimmerman S, Gruber-Baldini AL, Hebel JR, Magaziner J, Konrad TR. Health and functional outcomes and health care utilization of persons with dementia in residential care and assisted living facilities: comparison with nursing homes. *Gerontologist*. 2005;45 Spec No(1):124–32.
69. Kuo Y-C, Lan C-F, Chen L-K, Lan VM. Dementia care costs and the patient's quality of life (QoL) in Taiwan: home versus institutional care services. *Arch Gerontol Geriatr* [Internet]. 2010;51(2):159–63. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/20042244>
70. Kim YH, Kwon CH, Shin HI. Validity of motor impairment scale in long-term care insurance system of Korea. *Ann Rehabil Med*. 2013;37(3):403–12.
71. Lee TW, Cho E, Yim ES, Lee HS, Ko YK, Kim BN, et al. Activities of Daily Living in Nursing Home and Home Care Settings: A Retrospective 1-Year Cohort Study. *J Am Med Dir Assoc* [Internet]. 2015 Feb [cited 2017 Feb 21];16(2):114–

9. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25244958>
72. Lee K, Cho E. Activities of daily living and rehabilitation needs for older adults with a stroke: A comparison of home care and nursing home care. *Japan J Nurs Sci* [Internet]. 2016 Jul 7 [cited 2017 Feb 21];14(2):103–11. Available from: <http://doi.wiley.com/10.1111/jjns.12139>
73. Newcomer RJ, Ko M, Kang T, Harrington C, Hulett D, Bindman AB. Health Care Expenditures After Initiating Long-term Services and Supports in the Community Versus in a Nursing Facility. *Med Care* [Internet]. 2016 Mar [cited 2017 Feb 21];54(3):221–8. Available from: <http://content.wkhealth.com/linkback/openurl?sid=WKPTLP:landingpage&an=00005650-201603000-00002>
74. Rothera I, Jones R, Harwood R, Avery A, Waite J. Health status and assessed need for a cohort of older people admitted to nursing and residential homes. *Age Ageing*. 2003;32(3):303–9.
75. Wieland D, Boland R, Baskins J, Kinosian B. Five-year survival in a program of all-inclusive care for elderly compared with alternative institutional and home-and community-based care. *Journals Gerontol - Ser A Biol Sci Med Sci*. 2010;65 A(7):721–6.
76. Wu C-Y, Hu H-Y, Huang N, Fang Y-T, Chou Y-J, Li C-P. Determinants of long-term care services among the elderly: a population-based study in Taiwan. Forloni G, editor. *PLoS One* [Internet]. 2014 Feb 19 [cited 2017 Feb 21];9(2):e89213. Available from: <http://dx.plos.org/10.1371/journal.pone.0089213>
77. Kane RL, Kane RA. Assessment in Long-Term Care. *Annu Rev Public Health* [Internet]. 2000 May [cited 2017 Feb 7];21(1):659–86. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/10884969>
78. Challis D, Mozley CG, Sutcliffe C, Bagley H, Price L, Burns a, et al. Dependency in older people recently admitted to care homes. *Age Ageing* [Internet]. 2000;29(3):255–60. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/10855909>
79. Frytak JR, Kane R a, Finch MD, Kane RL, Maude-Griffin R. Outcome trajectories for assisted living and nursing facility residents in Oregon. *Health Serv Res* [Internet]. 2001;36(1 Pt 1):91–111. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1089217&tool=pmcen>

trez&rendertype=abstract

80. Kane RL, Lum TY, Kane RA, Homyak P, Parashuram S, Wysocki A. Does Home-and Community-Based Care Affect Nursing Home Use? *J Aging Soc Policy* [Internet]. 2013 Apr [cited 2018 May 7];25(2):146–60. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/23570508>
81. Schwarzkopf L, Menn P, Leidl R, Graessel E, Holle R. Are community-living and institutionalized dementia patients cared for differently? Evidence on service utilization and costs of care from German insurance claims data. *BMC Health Serv Res* [Internet]. 2013;13(1):2. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3543842&tool=pmcentrez&rendertype=abstract>
82. Crocker T, Young J, Forster A, Brown L, Ozer S, Greenwood DC. The effect of physical rehabilitation on activities of daily living in older residents of long-term care facilities: systematic review with meta-analysis. *Age Ageing* [Internet]. 2013 Nov [cited 2018 May 8];42(6):682–8. Available from: <https://academic.oup.com/ageing/article-lookup/doi/10.1093/ageing/aft133>
83. Forster A, Lambley R, Young JB. Is physical rehabilitation for older people in long-term care effective? Findings from a systematic review. *Age Ageing* [Internet]. 2010 Mar 1 [cited 2018 May 8];39(2):169–75. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/20097661>
84. Jakobsson U, Hallberg IR. Mortality among elderly receiving long-term care: a longitudinal cohort study. *Aging Clin Exp Res* [Internet]. 2006;18(6):503–11. Available from: <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med4&NEWS=N&AN=17255640>
85. Lee J, Chau PPH, Hui E, Chan F, Woo J. Survival prediction in nursing home residents using the Minimum Data Set subscales: ADL Self-Performance Hierarchy, Cognitive Performance and the Changes in Health, End-stage disease and Symptoms and Signs scales. *Eur J Public Health*. 2009;19(3):308–12.
86. Hjaltadóttir I, Hallberg IR, Ekwall AK, Nyberg P. Predicting mortality of residents at admission to nursing home: a longitudinal cohort study. *BMC Health Serv Res*. 2011;11:86.
87. Sung K. Predictive factors associated with death of elderly in nursing homes.

- Asian Nurs Res (Korean Soc Nurs Sci) [Internet]. 2014;8(2):143–9. Available from: <http://dx.doi.org/10.1016/j.anr.2014.05.004>
88. Simões J, Augusto G, Fronteira I, Hernández-Quevedo C. Portugal health system review. Health Syst Transit [Internet]. 2017 [cited 2017 Sep 6];19(2):1–184. Available from: http://www.euro.who.int/__data/assets/pdf_file/0007/337471/HiT-Portugal.pdf?ua=1
 89. Le Bihan B, Martin C. A comparative case study of care systems for frail elderly people: Germany, Spain, France, Italy, United Kingdom and Sweden. Soc Policy Adm. 2006;40(1):26–46.
 90. Maarse JAMH, Jeurissen PPP. The policy and politics of the 2015 long-term care reform in the Netherlands. Health Policy (New York) [Internet]. 2016;120(3):241–5. Available from: <http://dx.doi.org/10.1016/j.healthpol.2016.01.014>
 91. Peña-Longobardo LM, Oliva-Moreno J, García-Armesto S, Hernández-Quevedo C. The Spanish long-term care system in transition: Ten years since the 2006 Dependency Act. Health Policy (New York). 2016;120(10):1177–82.
 92. ERS. Access, quality and competition in long-term and palliative care [in Portuguese] [Internet]. Porto; 2015 [cited 2017 Oct 5]. Available from: https://www.ers.pt/uploads/writer_file/document/1647/ERS_-_Estudo_Cuidados_Continuados_-_vers_o_final.pdf
 93. García Ameijeiras MC, Abenaza Guardiola M. Consideraciones para el análisis coste-beneficio en la red sociosanitaria. Rehabilitación [Internet]. 2004 Jan [cited 2017 Jun 5];38(6):362–7. Available from: <http://linkinghub.elsevier.com/retrieve/pii/S0048712004734933>
 94. Salvà A, Roqué M, Vallès E, Bustins M, Rodó M, Sanchez P. Description of the clinical complexity of patients admitted to long term care hospitals in Catalonia during 2003-2009 [in Spanish]. Rev Esp Geriatr Gerontol [Internet]. 2014 Mar [cited 2017 Feb 7];49(2):59–64. Available from: <http://linkinghub.elsevier.com/retrieve/pii/S0211139X13001625>
 95. ARSN. Procedures manual to implement and develop the HCBS [in Portuguese] [Internet]. Porto; 2014 [cited 2017 Jun 24]. Available from: http://portal.arsnorte.min-saude.pt/portal/page/portal/ARSNorte/Contratualizacao/Cuidados_Continuados

96. Francesconi P, Cantini E, Bavazzano E, Lauretani F, Bandinelli S, Buiatti E, et al. Classification of residents in nursing homes in Tuscany (Italy) using Resource Utilization Groups Version III (RUG-III). *Aging Clin Exp Res* [Internet]. 2006 Apr [cited 2017 Feb 7];18(2):133–40. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/16702782>
97. European-Commission. Joint Report on Health Care and Long-Term Care Systems & Fiscal Sustainability Volume 2 Country Documents. Vol. 8014. Brussels; 2016.
98. Wall K, Leitão M, Correia S, Ramos V. Family policies in 2014 and 2015 - Key developments [in Portuguese] [Internet]. Lisbon; 2014 [cited 2017 Jun 24]. Available from: http://www.observatoriofamilias.ics.ul.pt/images/pdf/ofap_relatorio_2014-2015_final.compressed.pdf
99. D.R. Ordinance no. 1087-A/2007, 5th of September- Price definition of health care and social support provided in the inpatient and outpatient units of the Portuguese National Network for Long-term Integrated Care [in Portuguese] [Internet]. 2007 [cited 2017 Jun 16]. Available from: http://www.acss.min-saude.pt/wp-content/uploads/2016/10/Portaria_1087A_2007.pdf
100. NHS. Transparency Portal: Users awaiting for admission at RNCCI [in Portuguese] [Internet]. 2017 [cited 2017 Sep 4]. Available from: <https://transparencia.sns.gov.pt/explore/dataset/rncci-episodios/?sort=data>
101. MFAP. Programme of stability and growth: 2011-2014 [in Portuguese] [Internet]. Lisbon; 2011 [cited 2017 Jun 5]. Available from: <http://www.min-financas.pt>
102. MoU. Portugal - Memorandum of understanding on specific economic policy conditionality [Internet]. 2011 [cited 2017 Jun 2]. Available from: http://ec.europa.eu/economy_finance/eu_borrower/mou/2011-05-18-mou-portugal_en.pdf
103. Costa JL, Mourão V. The risk perspective in Portugal's National Network for Integrated Continuous Care (RNCCI): an evaluation by health experts and decision-makers [in Portuguese]. *Saude e Soc.* 2015;24(2):501–14.
104. D.R. Joint Dispatch no. 259/97, 21st of August – Creation of the Programme of Integrated Support to the Elderly (PAII) [in Portuguese] [Internet]. 1997 [cited 2017 Sep 5]. Available from: <http://www.seg->

social.pt/documents/10152/87923/DESP_CONJ_259_1997/4a846364-eab5-489f-aa6f-9b771ffe71a5

105. Boeckxstaens P, De Graaf P. Primary care and care for older persons: Position Paper of the European Forum for Primary Care. *Qual Prim Care*. 2011;19(6):369–89.
106. D.R. Ordinance no. 50/2017, 2nd of February - Streamlining the referral process by assessing the degree of functionality using the International Classification of Functioning, Disability and Health (ICF) [in Portuguese] [Internet]. 2017 [cited 2017 Sep 5]. p. 608–29. Available from: <https://dre.pt/application/file/a/106390686>
107. WHO. International Classification of Functioning, Disability and Health (ICF) [Internet]. Geneva; 2001 [cited 2017 Sep 6]. Available from: http://psychiatr.ru/download/1313?view=name=CF_18.pdf
108. D.R. Dispatch No. 3618-A/2016, 10th of March 2016 - Creation of the National Programme for Health, Literacy and Self-care [in Portuguese] [Internet]. 2016 [cited 2017 Sep 5]. Available from: <https://dre.pt/application/file/a/73833787>
109. Mestre R. Where do we go? Long-term care network as a national structure: evolution, present, future and financial sustainability of the network [in Portuguese]. In: União das Misericórdias Portuguesas, editor. II Conference on long-term and integrated care [Internet]. Fátima; 2016 [cited 2017 Sep 6]. Available from: [http://www.misericordiasportuguesas.pt/vePDF.php?pdf=upload/pdf/noticias/2_325_Mesa_1_Para onde caminhamos\(2\).pdf](http://www.misericordiasportuguesas.pt/vePDF.php?pdf=upload/pdf/noticias/2_325_Mesa_1_Para%20onde%20caminhamos(2).pdf)
110. O’Caoimh R, Cornally N, Weathers E, O’Sullivan R, Fitzgerald C, Orfila F, et al. Risk prediction in the community: A systematic review of case-finding instruments that predict adverse healthcare outcomes in community-dwelling older adults. *Maturitas* [Internet]. 2015 Sep [cited 2018 Mar 28];82(1):3–21. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25866212>
111. Helvik AS, Skancke RH, Selbæk G, Engedal K. Nursing home admission during the first year after hospitalization - The contribution of cognitive impairment. *PLoS One*. 2014;9(1).
112. Iezzoni LI. Risk adjusting rehabilitation outcomes: an overview of methodologic issues. *Am J Phys Med Rehabil*. 2004;83(4):316–26.
113. Gindin J, Walter-Ginzburg A, Geitzen M, Epstein S, Levi S, Landi F, et al.

- Predictors of Rehabilitation Outcomes: A Comparison of Israeli and Italian Geriatric Post-Acute Care (PAC) Facilities Using the Minimum Data Set (MDS). *J Am Med Dir Assoc*. 2007;8(4):233–42.
114. Fusco D, Boichicchio GB, Onder G, Barillaro C, Bernabei R, Landi F. Predictors of Rehabilitation Outcome Among Frail Elderly Patients Living in the Community. *J Am Med Dir Assoc* [Internet]. 2009;10(5):335–41. Available from: <http://dx.doi.org/10.1016/j.jamda.2009.02.004>
 115. Seematter-Bagnoud L, Lécureux E, Rochat S, Monod S, Lenoble-Hoskovec C, Büla CJ. Predictors of functional recovery in patients admitted to geriatric postacute rehabilitation. *Arch Phys Med Rehabil*. 2013;94(12):2373–80.
 116. Carlson MC, Brandt J, Steele C, Baker A, Stern Y, Lyketsos CG. Predictor index of mortality in dementia patients upon entry into long-term care. *Journals Gerontol Ser A-Biological Sci Med Sci* [Internet]. 2001;56(9):M567–70. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/11524449>
 117. Luo Y, Waite LJ. Loneliness and Mortality Among Older Adults in China. *Journals Gerontol Ser B Psychol Sci Soc Sci* [Internet]. 2014 Jul 1 [cited 2018 Jan 22];69(4):633–45. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/24550354>
 118. Vetrano DL, Collamati A, Magnavita N, Sowa A, Topinkova E, Finne-Soveri H, et al. Health determinants and survival in nursing home residents in Europe: Results from the SHELTER study. *Maturitas* [Internet]. 2018 Jan [cited 2018 Jan 22];107:19–25. Available from: <http://linkinghub.elsevier.com/retrieve/pii/S0378512217306990>
 119. Marioni RE, Chatfield M, Brayne C, Matthews FE. The reliability of assigning individuals to cognitive states using the Mini Mental-State Examination: a population-based prospective cohort study. *BMC Med Res Methodol* [Internet]. 2011;11(1):127. Available from: <http://bmcmmedresmethodol.biomedcentral.com/articles/10.1186/1471-2288-11-127>
 120. Anderson TM, Sachdev PS, Brodaty H, Trollor JN, Andrews G. Effects of sociodemographic and health variables on Mini-Mental State Exam scores in older Australians. *Am J Geriatr Psychiatry*. 2007;15(6):467–76.
 121. Moraes C, Pinto JA, Lopes MA, Litvoc J, Bottino CMC. Impact of sociodemographic and health variables on mini-mental state examination in a

- community-based sample of older people. *Eur Arch Psychiatry Clin Neurosci*. 2010;260(7):535–42.
122. Bagg S, Pombo AP, Hopman W. Effect of age on functional outcomes after stroke rehabilitation. *Stroke*. 2002;33(1):179–85.
 123. Perrig-Chiello P, Perrig WJ, Uebelbacher A, Stähelin HB. Impact of physical and psychological resources on functional autonomy in old age. *Psychol Health Med*. 2006;11(4):470–82.
 124. Jerez-Roig J, de Brito Macedo Ferreira LM, Torres de Araújo JR, Costa Lima K. Functional decline in nursing home residents: A prognostic study. Chen K, editor. *PLoS One* [Internet]. 2017 May 11 [cited 2018 Jan 23];12(5):e0177353. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/28493946>
 125. Phillips LJ, Leary E, Blankenship J, Zimmerman S. Physical Function, Relocation, and Mortality Outcomes in Residential Care and Assisted Living Residents. *J Aging Health* [Internet]. 2017 Nov 1 [cited 2018 Jan 23];898264317740047. Available from: <http://journals.sagepub.com/doi/10.1177/0898264317740047>
 126. Cameron ID, Schaafsma FG, Wilson S, Baker W, Buckley S. Outcomes of rehabilitation in older people-functioning and cognition are the most important predictors: An inception cohort study. *J Rehabil Med*. 2012;44(1):24–30.
 127. Vogt L, Wieland K, Bach M, Himmelreich H, Banzer W. Cognitive status and ambulatory rehabilitation outcome in geriatric patients. *J Rehabil Med*. 2008;40(10):876–8.
 128. Singh R, Hunter J, Philip A, Todd I. Predicting those who will walk after rehabilitation in a specialist stroke unit. *Clin Rehabil* [Internet]. 2006 Feb [cited 2017 Feb 7];20(2):149–52. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/16541935>
 129. Suzuki M, Omori M, Hatakeyama M, Yamada S, Matsushita K, Iijima S. Predicting Recovery of Upper-Body Dressing Ability After Stroke. *Arch Phys Med Rehabil*. 2006;87(11):1496–502.
 130. Gialanella B, Santoro R, Ferlucci C. Predicting outcome after stroke: the role of basic activities of daily living. *Eur J Phys Rehabil Med*. 2012;48:1–9.
 131. Shah SM, Carey IM, Harris T, DeWilde S, Cook DG. Mortality in older care home residents in England and Wales. *Age Ageing* [Internet]. 2013 Mar 1 [cited 2017 Feb 9];42(2):209–15. Available from:

<http://www.ncbi.nlm.nih.gov/pubmed/23305759>

132. NHS. Transparency Portal: National Network for Long-term Integrated Care indicators [in Portuguese] [Internet]. 2017 [cited 2017 Aug 18]. Available from: <https://transparencia.sns.gov.pt/explore/?sort=title&q=rncci>
133. Wiering B, de Boer D, Delnoij D. Patient involvement in the development of patient-reported outcome measures: a scoping review. *Heal Expect* [Internet]. 2017 Feb [cited 2018 Feb 12];20(1):11–23. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/26889874>
134. Kearns T, Cornally N, Molloy W. Patient reported outcome measures of quality of end-of-life care: A systematic review. *Maturitas* [Internet]. 2017 Feb [cited 2018 Feb 1];96:16–25. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/28041590>
135. Fischer F, Gibbons C, Coste J, Valderas JM, Rose M, Leplège A. Measurement invariance and general population reference values of the PROMIS Profile 29 in the UK, France, and Germany. *Qual Life Res* [Internet]. 2018 Jan 19 [cited 2018 Feb 1]; Available from: <http://link.springer.com/10.1007/s11136-018-1785-8>
136. Li S, Middleton A, Ottenbacher KJ, Goodwin JS. Trajectories Over the First Year of Long-Term Care Nursing Home Residence. *J Am Med Dir Assoc* [Internet]. 2018 Apr [cited 2018 Apr 29];19(4):333–41. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/29108886>
137. Kelly A, Conell-Price J, Covinsky K, Cenzer IS, Chang A, Boscardin WJ, et al. Length of stay for older adults residing in nursing homes at the end of life. *J Am Geriatr Soc* [Internet]. 2010 Sep [cited 2018 Apr 29];58(9):1701–6. Available from: <http://doi.wiley.com/10.1111/j.1532-5415.2010.03005.x>
138. Nelson A, Powell-Cope G, Palacios P, Luther SL, Black T, Hillman T, et al. Nurse staffing and patient outcomes in inpatient rehabilitation settings. *Rehabil Nurs* [Internet]. 2007 [cited 2017 Mar 9];32(5):179–202. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/17899990>
139. Decker FH. Outcomes and Length of Medicare Nursing Home Stays: The Role of Registered Nurses and Physical Therapists. *Am J Med Qual* [Internet]. 2008 Nov [cited 2018 Apr 29];23(6):465–74. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/19001102>
140. Dixon S, Kaambwa B, Nancarrow S, Martin GP, Bryan S. The relationship between staff skill mix, costs and outcomes in intermediate care services. *BMC*

- Health Serv Res [Internet]. 2010 Dec 29 [cited 2018 Apr 29];10(1):221. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/20670428>
141. Døhl Ø, Garåsen H, Kalseth J, Magnussen J. Variations in levels of care between nursing home patients in a public health care system. BMC Health Serv Res [Internet]. 2014 Mar 5 [cited 2018 May 3];14(1):108. Available from: <http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-14-108>
 142. Rahman M, Gozalo P, Tyler D, Grabowski DC, Trivedi A, Mor V. Dual Eligibility, Selection of Skilled Nursing Facility, and Length of Medicare Paid Postacute Stay. Med Care Res Rev [Internet]. 2014 Aug 14 [cited 2018 Apr 30];71(4):384–401. Available from: <http://journals.sagepub.com/doi/10.1177/1077558714533824>
 143. Hedinger D, Hämmig O, Bopp M, Swiss National Cohort Study Group. Social determinants of duration of last nursing home stay at the end of life in Switzerland: a retrospective cohort study. BMC Geriatr [Internet]. 2015 Oct 1 [cited 2018 Apr 29];15(1):114. Available from: <http://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-015-0111-3>
 144. Steventon A, Roberts A. Estimating length of stay in publicly-funded residential and nursing care homes: a retrospective analysis using linked administrative data sets. BMC Health Serv Res [Internet]. 2012 Oct 31 [cited 2018 May 1];12:377. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/23110445>
 145. Blackburn J, Locher JL, Morrissey MA, Becker DJ, Kilgore ML. The effects of state-level expenditures for home- and community-based services on the risk of becoming a long-stay nursing home resident after hip fracture. Osteoporos Int [Internet]. 2016 Mar 23 [cited 2018 Apr 29];27(3):953–61. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/26400010>
 146. Morales-Asencio JM, Morilla-Herrera JC, Martín-Santos FJ, Gonzalo-Jiménez E, Cuevas-Fernández-Gallego M, Bonill de las Nieves C, et al. The association between nursing diagnoses, resource utilisation and patient and caregiver outcomes in a nurse-led home care service: Longitudinal study. Int J Nurs Stud [Internet]. 2009 Feb [cited 2018 May 2];46(2):189–96. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/18990392>
 147. Fries BE, James ML. Beyond Section Q: prioritizing nursing home residents for transition to the community. BMC Health Serv Res [Internet]. 2012;12(1):186. Available from: <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N>

&AN=22759346

148. Wei Y-J, Simoni-Wastila L, Zuckerman IH, Brandt N, Lucas JA. Algorithm for Identifying Nursing Home Days Using Medicare Claims and Minimum Data Set Assessment Data. *Med Care* [Internet]. 2016 Nov [cited 2018 Apr 29];54(11):e73–7. Available from:
<https://insights.ovid.com/crossref?an=00005650-201611000-00012>
149. Wysocki A, Thomas KS, Mor V. Functional Improvement Among Short-Stay Nursing Home Residents in the MDS 3.0. *J Am Med Dir Assoc* [Internet]. 2015 Jun 1 [cited 2018 May 19];16(6):470–4. Available from:
<http://www.ncbi.nlm.nih.gov/pubmed/25659622>
150. Shah SM, Carey IM, Harris T, Dewilde S, Cook DG. Mortality in older care home residents in England and Wales. *Age Ageing*. 2013;42(2):209–15.
151. Laine J. RUG-III for exploring the association between staffing levels and cost-efficiency in nursing facility care in Finland. *Health Care Manage Rev* [Internet]. 2006 [cited 2017 Feb 7];31(1):73–7. Available from:
<http://www.ncbi.nlm.nih.gov/pubmed/16493275>
152. Harrington C, Kovner C, Mezey M, Kayser-Jones J, Burger S, Mohler M, et al. Experts recommend minimum nurse staffing standards for nursing facilities in the United States. *Gerontologist* [Internet]. 2000 Feb [cited 2017 Mar 9];40(1):5–16. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/10750309>
153. Bostick JE, Rantz MJ, Flesner MK, Riggs CJ. Systematic Review of Studies of Staffing and Quality in Nursing Homes. *J Am Med Dir Assoc* [Internet]. 2006 Jul [cited 2017 Mar 9];7(6):366–76. Available from:
<http://www.ncbi.nlm.nih.gov/pubmed/16843237>
154. Castle NG, Engberg J. The Influence of Staffing Characteristics on Quality of Care in Nursing Homes. *Health Serv Res* [Internet]. 2007 Feb 26 [cited 2017 Mar 9];42(5):1822–47. Available from:
<http://www.ncbi.nlm.nih.gov/pubmed/17850522>
155. Park J, Stearns SC. Effects of State Minimum Staffing Standards on Nursing Home Staffing and Quality of Care. *Health Serv Res* [Internet]. 2009 Feb [cited 2017 Mar 9];44(1):56–78. Available from:
<http://www.ncbi.nlm.nih.gov/pubmed/18823448>
156. Hyer K, Thomas KS, Branch LG, Harman JS, Johnson CE, Weech-Maldonado R. The Influence of Nurse Staffing Levels on Quality of Care in Nursing Homes.

- Gerontologist [Internet]. 2011 Oct 1 [cited 2017 Mar 9];51(5):610–6. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/21602292>
157. Shin JH. Relationship between nursing staffing and quality of life in nursing homes. *Contemp Nurse* [Internet]. 2013 Jun 17 [cited 2017 Mar 9];44(2):133–43. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/23869498>
 158. Lee HY, Blegen MA, Harrington C. The effects of RN staffing hours on nursing home quality: a two-stage model. *Int J Nurs Stud* [Internet]. 2014 Mar [cited 2017 Mar 9];51(3):409–17. Available from: <http://linkinghub.elsevier.com/retrieve/pii/S0020748913002824>
 159. Uchida-Nakakoji M, Stone PW, Schmitt SK, Phibbs CS. Nurse workforce characteristics and infection risk in VA Community Living Centers: a longitudinal analysis. *Med Care* [Internet]. 2015 Mar [cited 2017 Mar 9];53(3):261–7. Available from: <http://content.wkhealth.com/linkback/openurl?sid=WKPTLP:landingpage&an=00005650-201503000-00007>
 160. Schnelle JF, Simmons SF, Harrington C, Cadogan M, Garcia E, M. Bates-Jensen B. Relationship of Nursing Home Staffing to Quality of Care. *Health Serv Res* [Internet]. 2004 Apr [cited 2017 Mar 9];39(2):225–50. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/15032952>
 161. Horn SD, Buerhaus P, Bergstrom N, Smout RJ. RN staffing time and outcomes of long-stay nursing home residents: pressure ulcers and other adverse outcomes are less likely as RNs spend more time on direct patient care. *Am J Nurs* [Internet]. 2005 Nov [cited 2017 Mar 9];105(11):58–70; quiz 71. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/16264305>
 162. McGregor MJ, Cohen M, McGrail K, Broemeling AM, Adler RN, Schulzer M, et al. Staffing levels in not-for-profit and for-profit long-term care facilities: does type of ownership matter? *CMAJ* [Internet]. 2005 Mar 1 [cited 2017 Mar 9];172(5):645–9. Available from: <http://www.cmaj.ca/cgi/doi/10.1503/cmaj.1040131>
 163. Zhang NJ, Unruh L, Liu R, Wan TTH. Minimum nurse staffing ratios for nursing homes. *Nurs Econ* [Internet]. 2006 [cited 2017 Dec 19];24(2):78–85. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/16676750>
 164. Harrington C, Swan JH, Carrillo H. Nurse Staffing Levels and Medicaid Reimbursement Rates in Nursing Facilities. *Health Serv Res* [Internet]. 2007 Jun

- [cited 2017 Mar 9];42(3p1):1105–29. Available from:
<http://www.ncbi.nlm.nih.gov/pubmed/17489906>
165. Konetzka RT, Stearns SC, Park J. The staffing-outcomes relationship in nursing homes. *Health Serv Res [Internet]*. 2008 Jun 29 [cited 2017 Mar 9];43(3):1025–42. Available from: <http://doi.wiley.com/10.1111/j.1475-6773.2007.00803.x>
 166. Kim H, Harrington C, Greene WH. Registered Nurse Staffing Mix and Quality of Care in Nursing Homes: A Longitudinal Analysis. *Gerontologist [Internet]*. 2009 Feb 1 [cited 2017 Mar 9];49(1):81–90. Available from:
<http://www.ncbi.nlm.nih.gov/pubmed/19363006>
 167. Shin JH, Hyun TK. Nurse Staffing and Quality of Care of Nursing Home Residents in Korea. *J Nurs Scholarsh an Off Publ Sigma Theta Tau Int Honor Soc Nurs [Internet]*. 2015 Nov [cited 2017 Mar 9];47(6):555–64. Available from:
<http://doi.wiley.com/10.1111/jnu.12166>
 168. Spilsbury K, Hewitt C, Stirk L, Bowman C. The relationship between nurse staffing and quality of care in nursing homes: A systematic review. *Int J Nurs Stud [Internet]*. 2011 Jun [cited 2017 Mar 9];48(6):732–50. Available from:
<http://www.ncbi.nlm.nih.gov/pubmed/21397229>
 169. UMCCI. Relatório de monitorização do desenvolvimento e da actividade da Rede Nacional de Cuidados Continuados Integrados (RNCCI) 2009 [Internet]. Lisbon; 2010. Available from: <http://www.arslvt.min-saude.pt/pages/217>
 170. UMCCI. Relatório de monitorização do desenvolvimento e da actividade da Rede Nacional de Cuidados Continuados Integrados (RNCCI) em 2011. Lisbon; 2012.
 171. ACSS. Monitorização da Rede Nacional de Cuidados Continuados Integrados (RNCCI) 2013. Lisbon; 2014.
 172. ACSS. Monitoring the Portuguese National Network for Long-term Integrated Care 2015 [in Portuguese] [Internet]. Lisbon; 2016. Available from:
http://www.inr.pt/bibliopac/diplomas/dl_101_2006.htm

9. APPENDIXES

Appendix 1 – Care coordination levels, main responsibilities

Table 16: Main responsibilities of the Regional and Local Coordination Teams

Entity	Main responsibilities
Regional Coordination Teams (ECR)	Disclosure of information to the public regarding the RNCCI
	Analyse proposals for a better integration of the RNCCI responses
	Monitor and control financial spending
	Ensure the quality of care
	Monitor and control of activity provided
	Ensure equity and adequacy of access to the RNCCI
	Training for professionals
	Budget forecasting of the regional implementation plan
	Guarantee articulation between institutions and partners
Local Coordination Teams (ECL)	Ensure coordination between entities at the local level
	Support and monitor the implementation of contracts
	Assume the beneficiaries' placement process
	Update the information system of the RNCCI
	Ensure the compliance of the discharge plan
	Support and monitor the use of RNCCI resources
	Promote partnerships for the provision of continuum care

Source: Author's extrapolation based on the RNCCI national reports (22,26)

Table 17: Main responsibilities of the Discharge Management and the Integrated Continuous Care Teams

Entity	Main responsibilities
Discharge Management Teams (EGA)	Located in the acute hospital
	Formed by at least a physician, a nurse and a social worker
	Identify and referral patients in the hospital with criteria to receive care in the RNCCI
	Avoid unnecessary stays in acute hospitals
	Improved discharge management of the acute hospitals
	Identify the best type of RNCCI response for each patient
Integrated Continuous Care Teams (ECCI)	Located in primary care
	Formed by at least a physician, a nurse and a social worker
	Identify and ensure correct criteria for referral of patients living in the community to the appropriate care facilities
	Assess peoples' dependency levels
	Provide care at patients' home, and other facilities, nursing, physical therapy, medical care and occupational therapy
	Monitor the evolution of the patients' dependency levels

Source: Author's extrapolation based on the RNCCI national reports (22,26)

ADMISSÃO NA RNCCI Data: ____ / ____ / ____						Inquérito referente a 4 semanas antes		MAB - Método de Avaliação Biopsicossocial								Classificação	
		SEXO		IDADE		Data de nascimento: ____ / ____ / ____ Idade: ____ anos Iniciais: ____		Respondeu ao inquérito: o próprio o prestador de cuidados		Pontuação							
		feminino masculino		80 ou mais anos 65 a 79 anos 50 a 64 anos 18 a 49 anos													
P1	Queixas Musculo-esqueléticas *	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P2	Queixas Visão *	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P3	Queixas Audição *	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P4	Queixas Pele *	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P5	Queixas Outros Órgãos/Sistemas *	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
BATERIA II - AVALIAÇÃO DE RISCO E QUALIDADE DE VIDA																	
QUEIXAS DE SAÚDE																	
OBI	IMC - Índice de Massa Corporal (kg/m²)	peso * _____ altura² = ____		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
OBI	CINT - Cintura - feminino (cm) CINT - Cintura - masculino (cm)	1ª medida (1+2+3)/3 = ____ cm 2ª medida (1+2+3)/3 = ____ cm		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
ESTADO DE NUTRIÇÃO																	
P6	Nº de Quedas (último ano)	nº _____		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P7	Momento de Quedas	ou _____ dias; ou _____ meses		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P8	Motivo de Quedas	_____		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P9	S sequelas de Quedas ocorridas	_____		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
QUESTÕES ADICIONAIS																	
P10	Andar em casa, dentro de edifícios	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P11	Andar na rua	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P12	Andar em escadas	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P13	Locomoção e meios para visão e audição	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
BATERIA III - LUCRO E LOCOMOÇÃO																	
P14	Lavar-se/tomar banho	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P15	Vestir-se/despir-se	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P16	Usar a sanita e/ou bacio/urinal	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P17	Deitar-se/levantar-se da cama	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P18	Sentar-se/levantar-se de cadeiras	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P19	Controlar a urina	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P20	Controlar as fezes	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P21	Alimentar-se/comer	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P22	Autonomia Física e meios para visão e audição	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
BATERIA IV - AUTONOMIA FÍSICA																	
P23	Usar o telefone	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P24	Fazer compras	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P25	Preparar refeições	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P26	Tarefas de vida da casa	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P27	Lavar/tratar da sua roupa	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P28	Usar transportes (onde não pode ir a pé)	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P29	Tomar os seus medicamentos	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P30	Gertir o seu dinheiro	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P31	Autonomia Instrumental e meios para visão e audição	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
BATERIA V - AUTONOMIA INSTRUMENTAL																	
P32	Triste / deprimido *	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P33	Nervoso / ansioso *	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>
P34	Outras Queixas Emocionais *	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>							<input type="checkbox"/>

QUEIXAS EMOCIONAIS		média: (P32+P33+P34)/3 =	0 0 a 0,9 mau	1 1 a 1,9 insatisfatório	2 2 a 2,9 satisfatório	3 3 bom
P35	Ano	Em que ano estamos	0 não responde/ não sabe / errado			3 certo
P36	Mês	Em que mês estamos	0 não responde/ não sabe / errado			3 certo
P37	Dia do mês	Quanto são hoje	0 não responde/ não sabe / errado			3 certo
P38	Estação do ano	Em que estação do ano estamos	0 não responde/ não sabe / errado			3 certo
P39	Dia da semana	Que dia da semana é hoje	0 não responde/ não sabe / errado			3 certo
-	OT - Orientação no Tempo	média: (P35+P36+P37+P38+P39)/5 =	0 0 a 0,9 má	1 1 a 1,9 insatisfatória	2 2 a 2,9 satisfatória	3 orientado no tempo
P40	País	Como se chama o nosso país	0 não responde/ não sabe / errado			3 certo
P41	Distrito	Em que distrito vive	0 não responde/ não sabe / errado			3 certo
P42	Terra	Em que terra vive	0 não responde/ não sabe / errado			3 certo
P43	Casa	Como se chama esta casa	0 não responde/ não sabe / errado			3 certo
P44	Andar	Em que andar estamos	0 não responde/ não sabe / errado			3 certo
-	OE - Orientação no Espaço	média: (P40+P41+P42+P43+P44)/5 =	0 0 a 0,9 má	1 1 a 1,9 insatisfatória	2 2 a 2,9 satisfatória	3 orientado no espaço
ESTADO COGNITIVO		média: (OT+OE)/2 =	0 0 a 0,9 mau	1 1 a 1,9 insatisfatório	2 2 a 2,9 satisfatório	3 3 bom
P45	Estado Civil	em relação a união a outra pessoa	0 viúvo / separado / solteiro			3 casado / união/facto
P46	Nº de coabitantes na sua residência	nº _____ coabitantes	0 vive só			3 vive com outros
P47	Tempo em que está só nas 24h	está só: _____ horas	0 8 ou mais horas			3 menos de 8 horas
P48	Ter com quem desabafar / ter confidente	falar de assuntos pessoais	0 não tem confidente			3 tem confidente
-	IS - Isolamento Social	média: (P45+P46+P47+P48)/4 =	0 0 a 0,9 mto isolado	1 1 a 1,9 isolado	2 2 a 2,9 pouco isolado	3 3 não isolado
P49	Escolaridade: _____ (estudos completos) nº anos _____		0 0 anos/analfabeto	1 1 a 6 anos	2 7 a 12 anos	3 13 ou mais anos
P50	Profissão: _____		0 não qualificado	1 qualificado	2 intermédio	3 especialista
-	HL - Habilidades Literárias	média: (P49+P50)/2 =	0 0 a 0,9 baixas	1 1 a 1,9 insatisfatórias	2 2 a 2,9 satisfatórias	3 3 boas
ESTADO SOCIAL		média: (IS+HL)/2 =	0 0 a 0,9 mau	1 1 a 1,9 insatisfatório	2 2 a 2,9 satisfatório	3 3 bom
P51	Andar a pé na rua	nº horas / semana: _____				
P52	Ginástica ou desporto	nº horas / semana: _____				
P53	Outra actividade física	nº horas / semana: _____				
-	AF - Actividade Física /semana	soma: P51+P52+P53 =	0 0 horas	1 menos de 2 horas	2 2 a 4 horas	3 4 ou mais horas
P54	Refeições habituais - assinalar:	Peq Almoço Meio Manhã Almoço Lanche Jantar Ceia Outra(s)				
-	R - Nº de Refeições /dia	nº refeições _____	0 0 a 2 refeições dia	1 mais de 6 refeições dia	2 3 refeições dia	3 4 a 6 refeições dia
HABITOS		média: (AF+R)/2 =	0 0 a 0,9 mau	1 1 a 1,9 insatisfatório	2 2 a 2,9 satisfatório	3 3 bom

Perfil Biopsicossocial

MAB

BI / Passaporte: _____

☐ U. Convalescença

☐ U. Média Duração Reabilitação

☐ U. Longa Duração Manutenção

☐ U. Dia Prom Autonomia

Nota: 0 / 1 / 2 / 3 - consoante a classificação obtida nos DOMÍNIOS

* Considerar 9 se não for possível medição de peso e obtenção de respostas relativas a queixas

Appendix 3 – Treatment places

Table 18: Nursing Home units of care by NUTS II: number of beds

NH typologies		2008	2009	2010	2011	2012	2013	2014	2015	2016
NUTS II										
UC	North	219	251	278	332	313	297	297	157	157
	Centre	106	142	172	202	202	202	202	236	251
	Lisbon and Tagus Valley	115	124	124	157	157	157	157	167	199
	Alentejo	40	58	58	135	135	135	135	135	135
	Algarve	50	50	50	80	60	69	69	69	69
NUTS II										
UMDR	North	244	420	504	518	552	552	576	619	737
	Centre	327	437	511	581	597	607	637	719	775
	Lisbon and Tagus Valley	207	215	281	385	408	446	518	673	720
	Alentejo	98	107	127	159	159	186	186	186	203
	Algarve	46	74	74	104	104	104	104	109	143
NUTS II										
ULDM	North	387	602	697	891	965	1 114	1 293	1.360	1 534
	Centre	424	603	722	779	822	996	1 152	1.247	1 332
	Lisbon and Tagus Valley	244	351	423	571	634	844	910	1.041	1 119
	Alentejo	120	203	261	292	391	424	425	425	431
	Algarve	150	183	183	219	219	314	314	338	307
NUTS II										
UCP	North	27	35	35	43	53	46	36	41	51
	Centre	24	14	40	45	45	45	35	69	69
	Lisbon and Tagus Valley	34	53	63	75	68	77	77	139	139
	Alentejo	8	6	12	17	17	17	17	19	19
	Algarve	0	10	10	10	10	10	10	10	10
Total		2,870	3,938	4,625	5,595	5,911	6,642	7,160	7,759	8,400

Legend: UC: Convalescence Units; UCP: Palliative Care Units; UMDR: Medium Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units.

Source: Author's extrapolation based on the RNCCI national reports (27–31, 169–172)

Table 19: RNCCI total supply by NUTS II: NH beds and HCBS treatment places

Care setting		2008	2009	2010	2011	2012	2013	2014	2015	2016
NH	NUTS II									
	North	877	1,308	1,514	1,784	1,883	2,009	2,202	2,177	2,479
	Centre	881	1,196	1,445	1,607	1,666	1,850	2,026	2,271	2,427
	Lisbon and Tagus Valley	600	743	891	1,188	1,267	1,524	1,662	2,020	2,177
	Alentejo	266	374	458	603	702	762	763	765	788
	Algarve	246	317	317	413	393	497	497	526	529
HCBS	NUTS II									
	North	n.a.	n.a.	1,410	1,660	1,730	1,720	1,690	1,673	1,623
	Centre	n.a.	n.a.	1,557	1,522	1,412	1,313	1,101	1,062	887
	Lisbon and Tagus Valley	n.a.	n.a.	2,744	2,093	1,969	2,129	2,076	2,136	2,105
	Alentejo	n.a.	n.a.	402	617	582	541	549	549	564
	Algarve	n.a.	n.a.	1,950	1,440	1,490	1,350	1,350	1,165	1,085

Legend: NH: Nursing Homes; HCBS: Home and Community-Based Services; n.a.: not available.

Source: Author's extrapolation based on the RNCCI national reports (27–31,169–172) and Portuguese demographic statistics (4)

Table 20: RNCCI total supply (NH + HCBS) by NUTS II per 1,000 inhabitants ≥ 65 years old

Care setting		2008	2009	2010	2011	2012	2013	2014	2015	2016
NH	NUTS II									
	North	1.69	2.20	2.49	2.87	2.98	3.12	3.34	3.22	3.59
	Centre	1.91	2.42	2.89	3.17	3.27	3.60	3.91	4.34	4.59
	Lisbon and Tagus Valley	1.45	1.50	1.74	2.25	2.34	2.75	2.93	3.48	3.67
	Alentejo	1.52	2.09	2.55	3.36	3.92	4.25	4.25	4.27	4.40
	Algarve	3.31	3.81	3.73	4.78	4.49	5.59	5.50	5.74	5.70
HCBS	NUTS II									
	North	n.a.	n.a.	2.32	2.67	2.74	2.67	2.56	2.48	2.35
	Centre	n.a.	n.a.	3.11	3.00	2.77	2.56	2.12	2.03	1.68
	Lisbon and Tagus Valley	n.a.	n.a.	5.36	3.96	3.64	3.84	3.66	3.68	3.55
	Alentejo	n.a.	n.a.	2.24	3.44	3.25	3.02	3.06	3.06	3.15
	Algarve	n.a.	n.a.	22.95	16.65	17.02	15.18	14.93	12.71	11.70

Legend: NH: Nursing Homes; HCBS: Home and Community-Based Services; n.a.: not available.

Source: Author's extrapolation based on the RNCCI national reports (27–31,169–172) and Portuguese demographic statistics (4)

Table 21: Nursing Home units of care by NUTS II: number of beds per 1,000 inhabitants ≥ 65 years old

NH typologies		2008	2009	2010	2011	2012	2013	2014	2015	2016
UC	NUTS II									
	North	0.42	0.42	0.46	0.53	0.50	0.46	0.45	0.23	0.23
	Centre	0.23	0.29	0.34	0.40	0.40	0.39	0.39	0.45	0.48
	Lisbon and Tagus Valley	0.28	0.25	0.24	0.30	0.29	0.28	0.28	0.29	0.34
	Alentejo	0.23	0.32	0.32	0.75	0.75	0.75	0.75	0.75	0.75
	Algarve	0.67	0.60	0.59	0.92	0.69	0.78	0.76	0.75	0.74
UMDR	NUTS II									
	North	0.47	0.71	0.83	0.83	0.87	0.86	0.87	0.92	1.07
	Centre	0.71	0.88	1.02	1.15	1.17	1.18	1.23	1.37	1.47
	Lisbon and Tagus Valley	0.50	0.43	0.55	0.73	0.75	0.80	0.91	1.16	1.21
	Alentejo	0.56	0.60	0.71	0.89	0.89	1.04	1.04	1.04	1.13
	Algarve	0.62	0.89	0.87	1.20	1.19	1.17	1.15	1.19	1.54
ULDM	NUTS II									
	North	0.75	1.01	1.15	1.43	1.53	1.73	1.96	2.01	2.22
	Centre	0.92	1.22	1.44	1.54	1.61	1.94	2.22	2.38	2.52
	Lisbon and Tagus Valley	0.59	0.71	0.83	1.08	1.17	1.52	1.60	1.79	1.89
	Alentejo	0.69	1.13	1.46	1.63	2.18	2.37	2.37	2.37	2.40
	Algarve	2.02	2.20	2.15	2.53	2.50	3.53	3.47	3.69	3.31
UCP	NUTS II									
	North	0.05	0.06	0.06	0.07	0.08	0.07	0.05	0.06	0.07
	Centre	0.05	0.03	0.08	0.09	0.09	0.09	0.07	0.13	0.13
	Lisbon and Tagus Valley	0.08	0.11	0.12	0.14	0.13	0.14	0.14	0.24	0.23
	Alentejo	0.05	0.03	0.07	0.09	0.09	0.09	0.09	0.11	0.11
	Algarve	0.00	0.12	0.12	0.12	0.11	0.11	0.11	0.11	0.11

Legend: UC: Convalescence Units; UCP: Palliative Care Units; UMDR: Medium Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units.

Source: Author's extrapolation based on the RNCCI national reports (27–31,169–172) and Portuguese demographic statistics (4)

Appendix 4 – Paper II: Additional results

Figure 4: Patients in each care setting, by age and gender

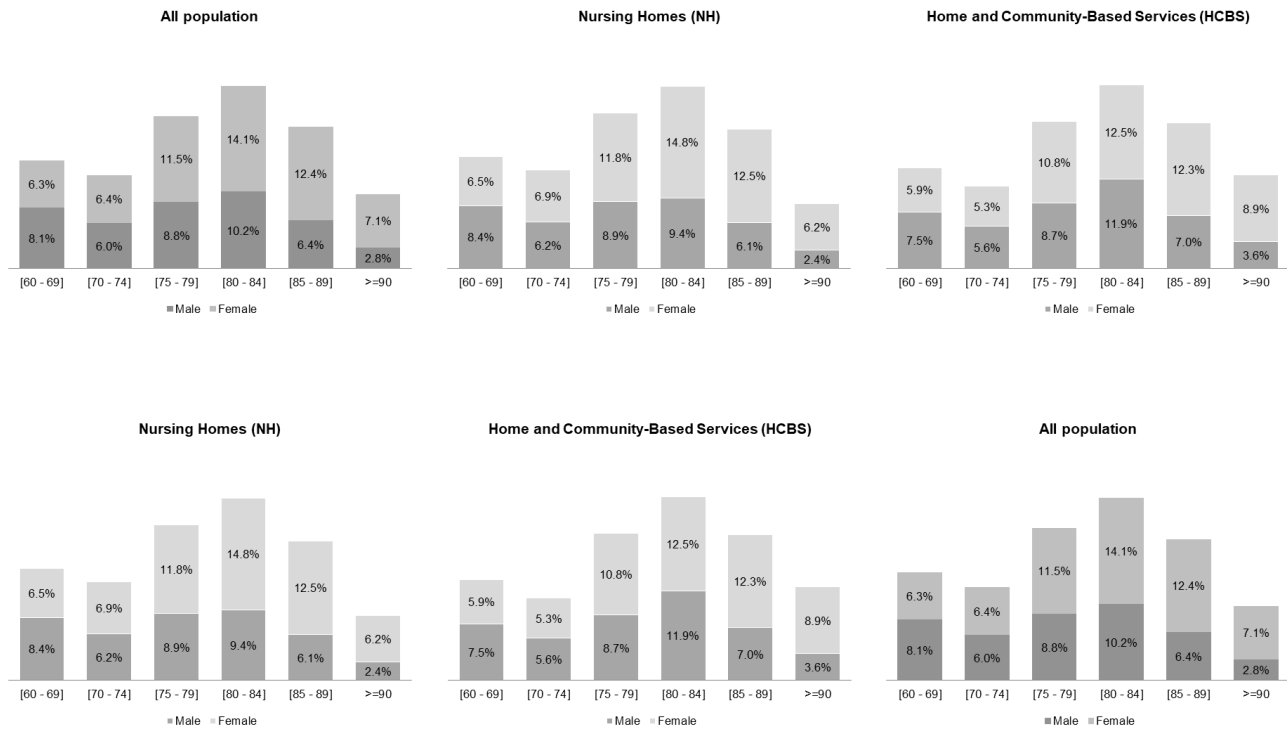
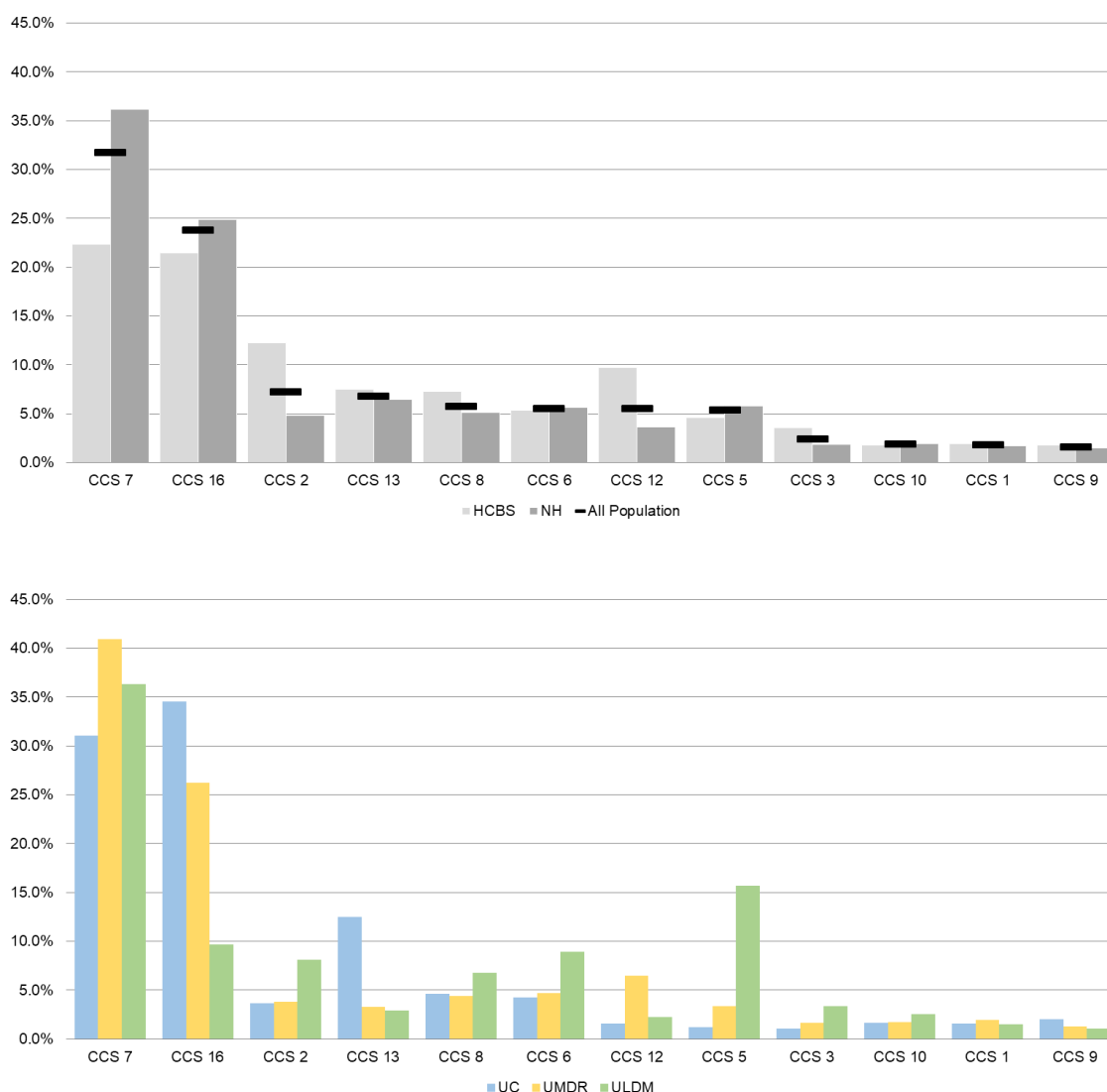


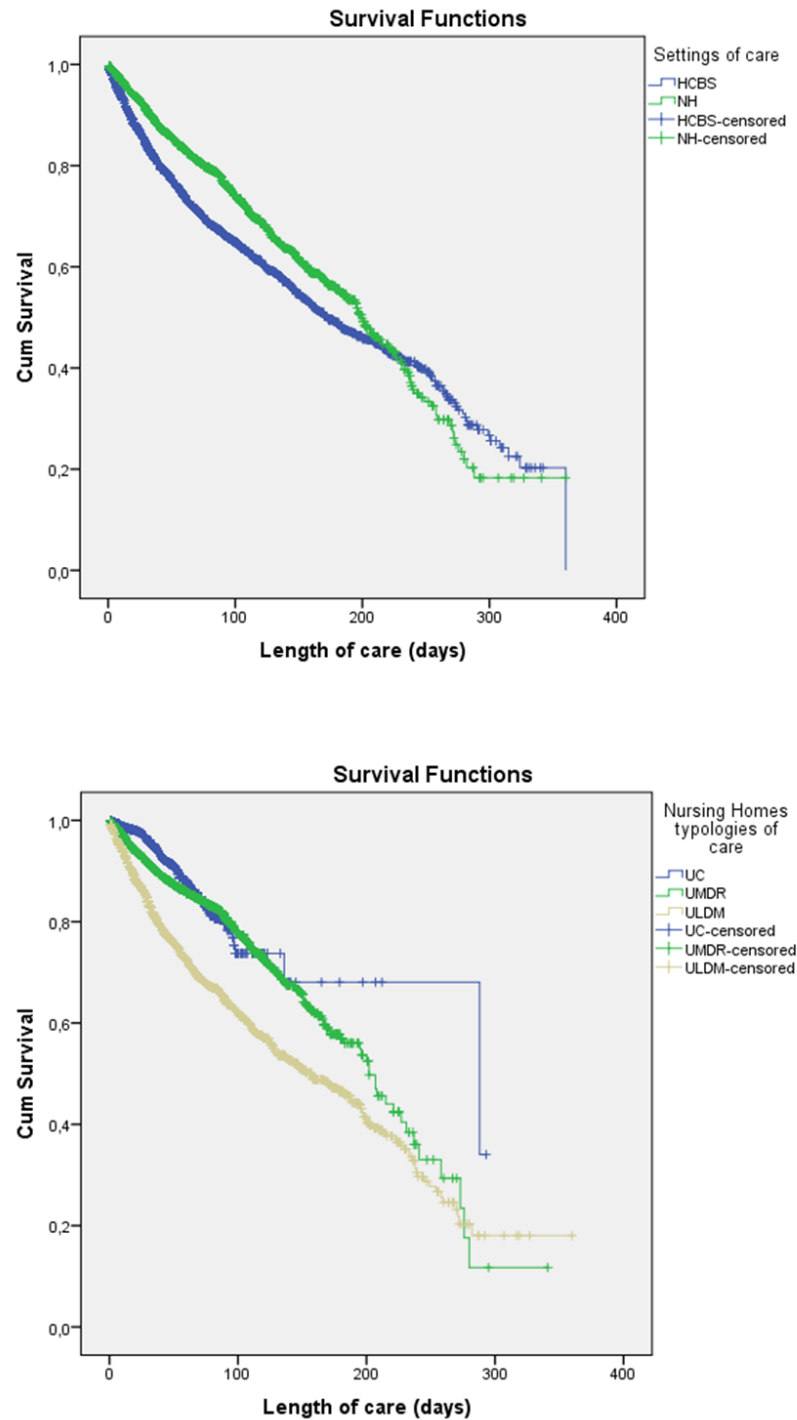
Figure 5: Proportion of patients in each Multi-level Clinical Classification Software groups (Agency for Healthcare Research and Quality), in each typology of care (%)



Legend: Clinical classification Software groups (CCS): CCS 1: Infectious and parasitic diseases; CCS 2: Neoplasms; CCS 3: Endocrine, nutritional and metabolic diseases and immunity disorders; CCS 5: Mental illness; CCS 6: Diseases of the nervous system and sense organs; CCS 7: Diseases of the circulatory system; CCS 8: Diseases of the respiratory system; CCS 9: Diseases of the digestive system; CCS 10: Diseases of the genitourinary system; CCS 12: Diseases of the skin and subcutaneous tissue; CCS 13: Diseases of the musculoskeletal system and connective tissue; CCS 16: Injury and poisoning.

Appendix 5 – Paper III: Additional results

Figure 6: Kaplan-Meier survival curves in each care setting



Legend: HCBS: Home and Community-Based Services; NH: Nursing Homes; UC: Convalence Units; UMDR: Medium-Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units.

Figure 7: Patients' cognitive dependency levels at admission and discharge in each activity assessed, by care setting

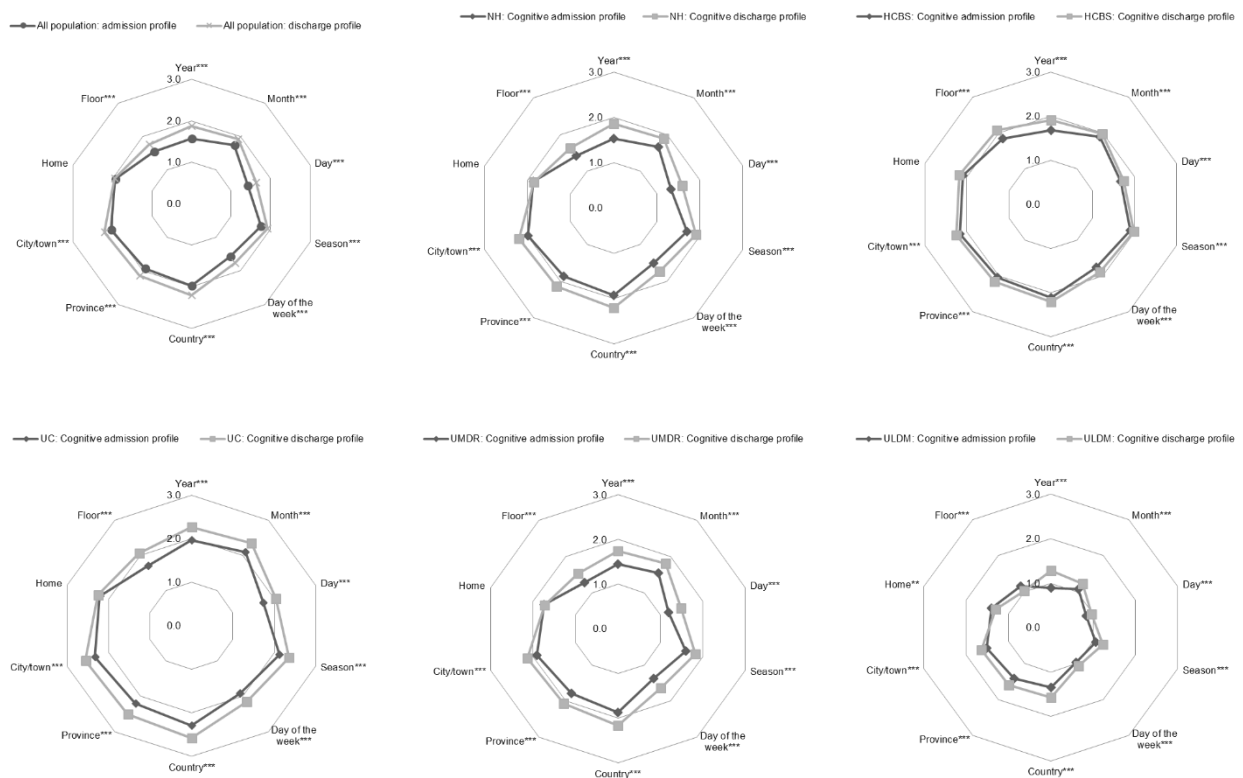
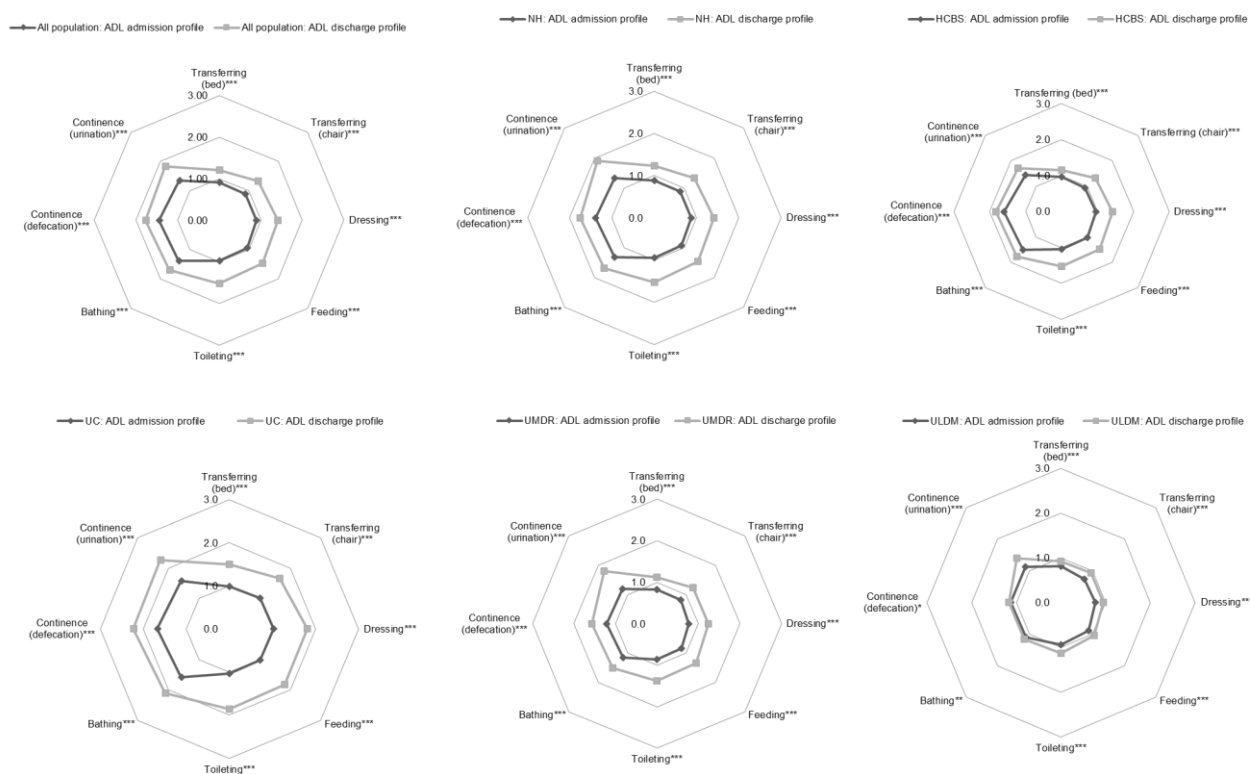


Figure 8. Patients' physical dependency levels at admission and discharge in each activity assessed, by care setting



Legend: HCBS: Home and Community-Based Services; NH: Nursing Homes; UC: Convalescence Units; UMDR: Medium-Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units.

* significant at $p < 0.1$; ** significant at $p < 0.05$; *** significant at $p < 0.001$

Table 22: Percentage of people who had changes in their cognitive status between admission and discharge

		Status at discharge				Total (N)
Status at admission		Bad	Unsatisfactory	Satisfactory	Good	
All population	Bad	66.2%	8.6%	6.5%	18.6%	6,056
	Unsatisfactory	27.3%	25.4%	13.9%	33.4%	1,829
	Satisfactory	11.1%	12.0%	21.7%	55.2%	1,787
	Good	9.1%	5.1%	9.9%	75.9%	6,890
Home and Community-Based Services	Bad	72.0%	7.8%	5.7%	14.4%	1,506
	Unsatisfactory	21.7%	31.1%	14.2%	33.0%	437
	Satisfactory	9.2%	9.5%	29.4%	51.9%	422
	Good	5.3%	3.0%	7.2%	84.5%	2,461
Nursing Homes	Bad	64.3%	8.8%	6.8%	20.0%	4,550
	Unsatisfactory	29.1%	23.6%	13.9%	33.5%	1,392
	Satisfactory	11.6%	12.7%	19.3%	56.3%	1,365
	Good	11.2%	6.3%	11.4%	71.2%	4,429
UC	Bad	45.1%	11.2%	10.0%	33.7%	1,254
	Unsatisfactory	24.6%	19.9%	15.0%	40.4%	532
	Satisfactory	8.7%	12.1%	16.9%	62.3%	652
	Good	7.0%	5.5%	10.7%	76.8%	2,330
UMDR	Bad	64.0%	9.6%	6.9%	19.5%	1,818
	Unsatisfactory	30.7%	24.1%	13.3%	31.9%	618
	Satisfactory	13.9%	10.5%	20.6%	55.0%	505
	Good	12.2%	7.2%	13.1%	67.6%	1,423
ULDM	Bad	81.1%	5.9%	4.1%	9.0%	1,478
	Unsatisfactory	34.7%	30.2%	12.8%	22.3%	242
	Satisfactory	15.4%	20.2%	24.0%	40.4%	208
	Good	23.4%	7.2%	10.2%	59.2%	676

Legend: UC: Convalescence Units; UMDR: Medium Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units.

Note: Only those alive at discharge were analysed.

Table 23: Percentage of people who had changes in their physical status between admission and discharge

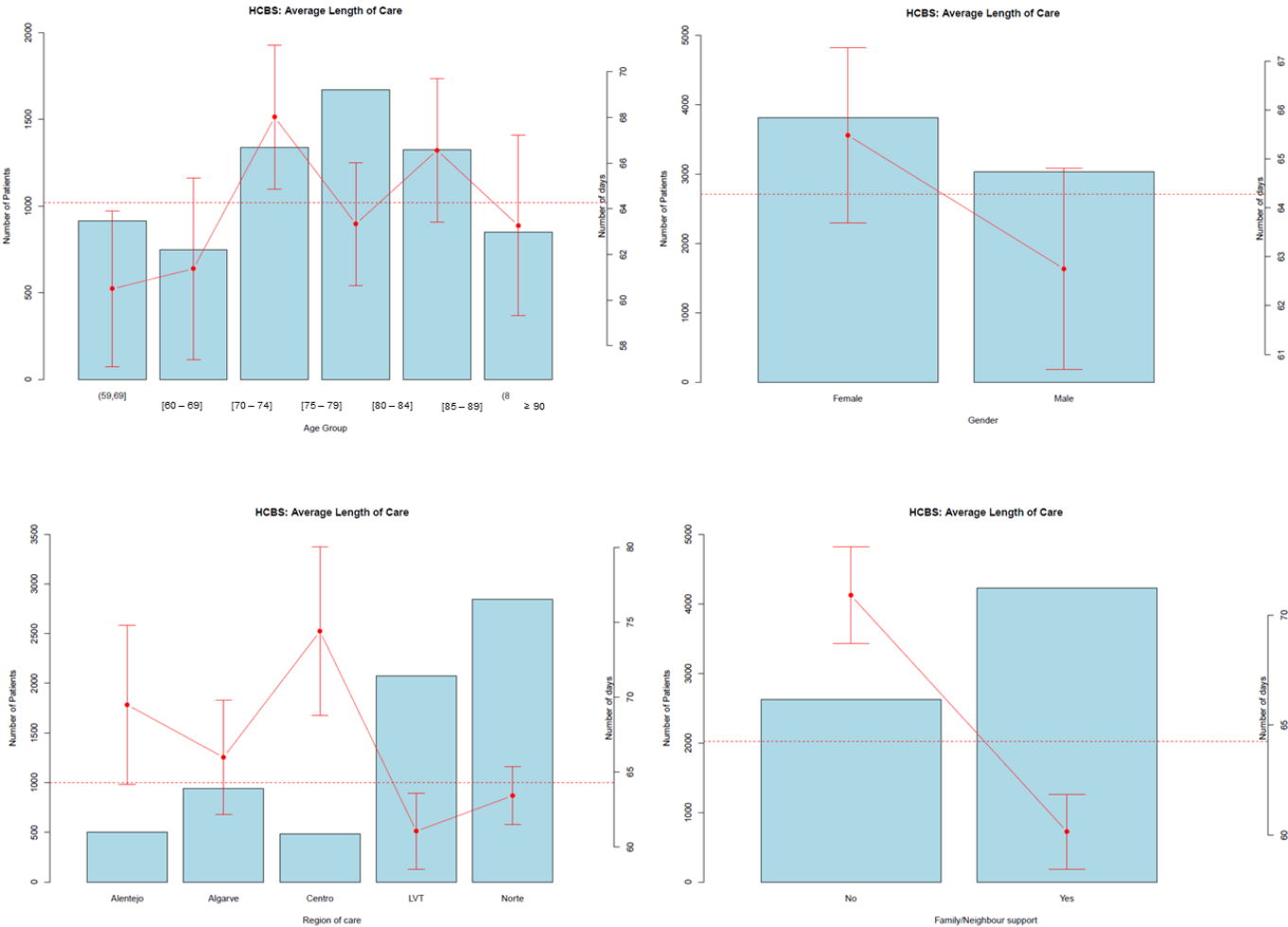
Status at admission		Status at discharge				Total (N)
		Incapable	Dependent	Autonomous	Independent	
All population	Incapable	55.0%	36.2%	6.8%	2.0%	6,447
	Dependent	16.0%	55.0%	19.0%	10.0%	9,222
	Autonomous	2.8%	33.7%	39.9%	23.6%	466
	Independent	0.7%	18.7%	12.4%	68.1%	427
Home and Community-Based Services	Incapable	66.0%	26.7%	5.2%	2.2%	1,821
	Dependent	13.7%	62.4%	16.4%	7.5%	2,631
	Autonomous	4.4%	32.2%	45.0%	18.3%	180
	Independent	0.0%	15.5%	9.8%	74.7%	194
Nursing Homes	Incapable	50.7%	39.9%	7.5%	1.9%	4,626
	Dependent	16.9%	52.1%	20.0%	11.0%	6,591
	Autonomous	1.7%	34.6%	36.7%	26.9%	286
	Independent	1.3%	21.5%	14.6%	62.7%	233
UC	Incapable	34.5%	49.0%	13.9%	2.7%	1,313
	Dependent	10.6%	48.3%	26.8%	14.2%	3,192
	Autonomous	1.9%	28.1%	42.5%	27.5%	160
	Independent	0.0%	16.5%	14.6%	68.9%	103
UMDR	Incapable	51.1%	40.9%	6.3%	1.8%	2,070
	Dependent	23.6%	54.3%	14.9%	7.2%	2,179
	Autonomous	0.0%	38.7%	30.6%	30.6%	62
	Independent	5.7%	26.4%	17.0%	50.9%	53
ULDM	Incapable	67.3%	28.6%	2.8%	1.2%	1,243
	Dependent	21.6%	57.8%	11.2%	9.4%	1,220
	Autonomous	3.1%	46.9%	28.1%	21.9%	64
	Independent	0.0%	24.7%	13.0%	62.3%	77

Legend: UC: Convalescence Units; UMDR: Medium Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units.

Note: Only those alive at discharge were analysed.

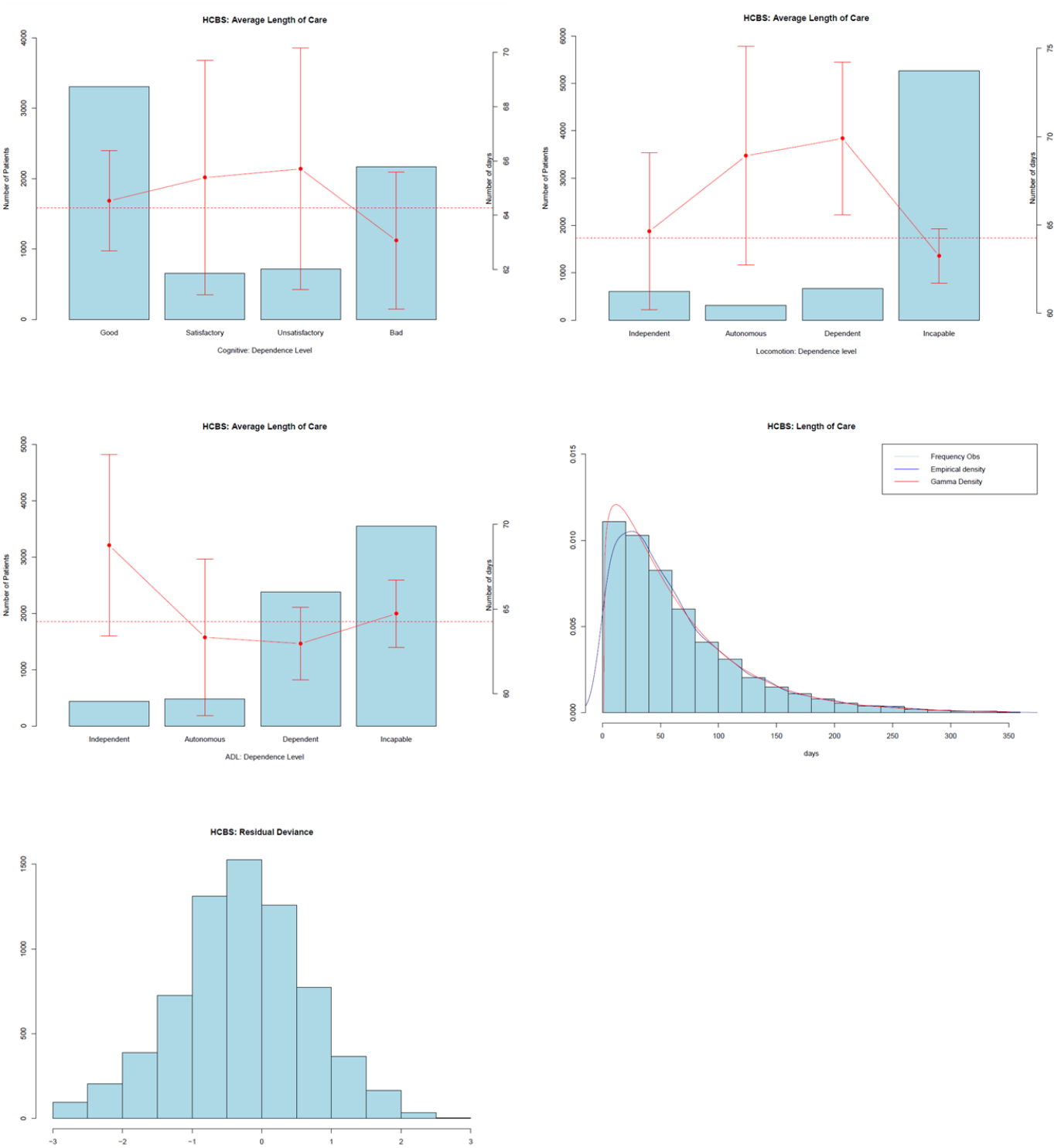
Appendix 6 – Paper IV: Additional results

Figure 9: HCBS: Length of Care by age group, gender, region of care and social support



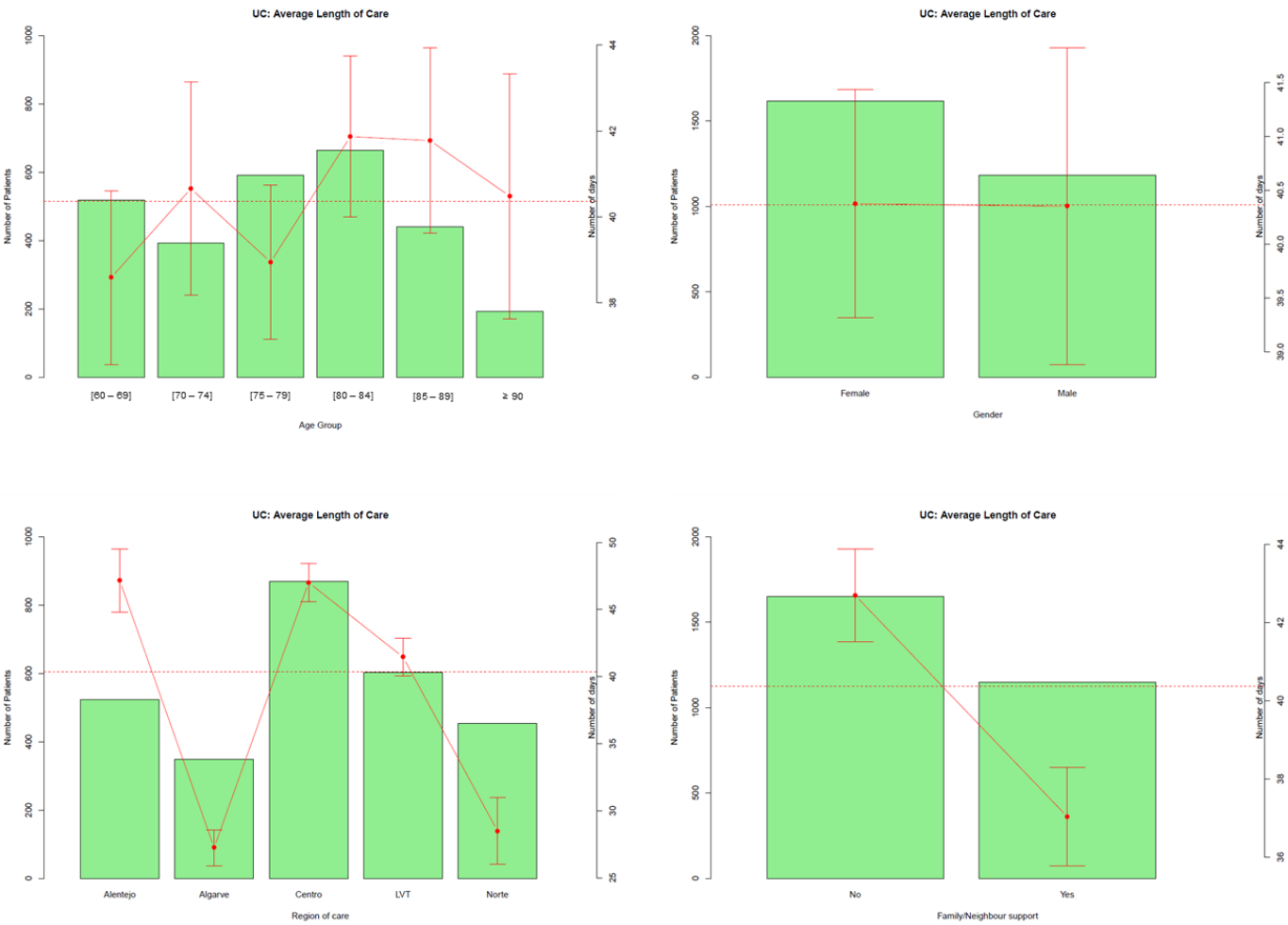
Legend: HCBS: Home and Community-Based Services.

Figure 10: HCBS: Length of Care by cognitive, locomotion, ADL, Gamma density and residual deviance



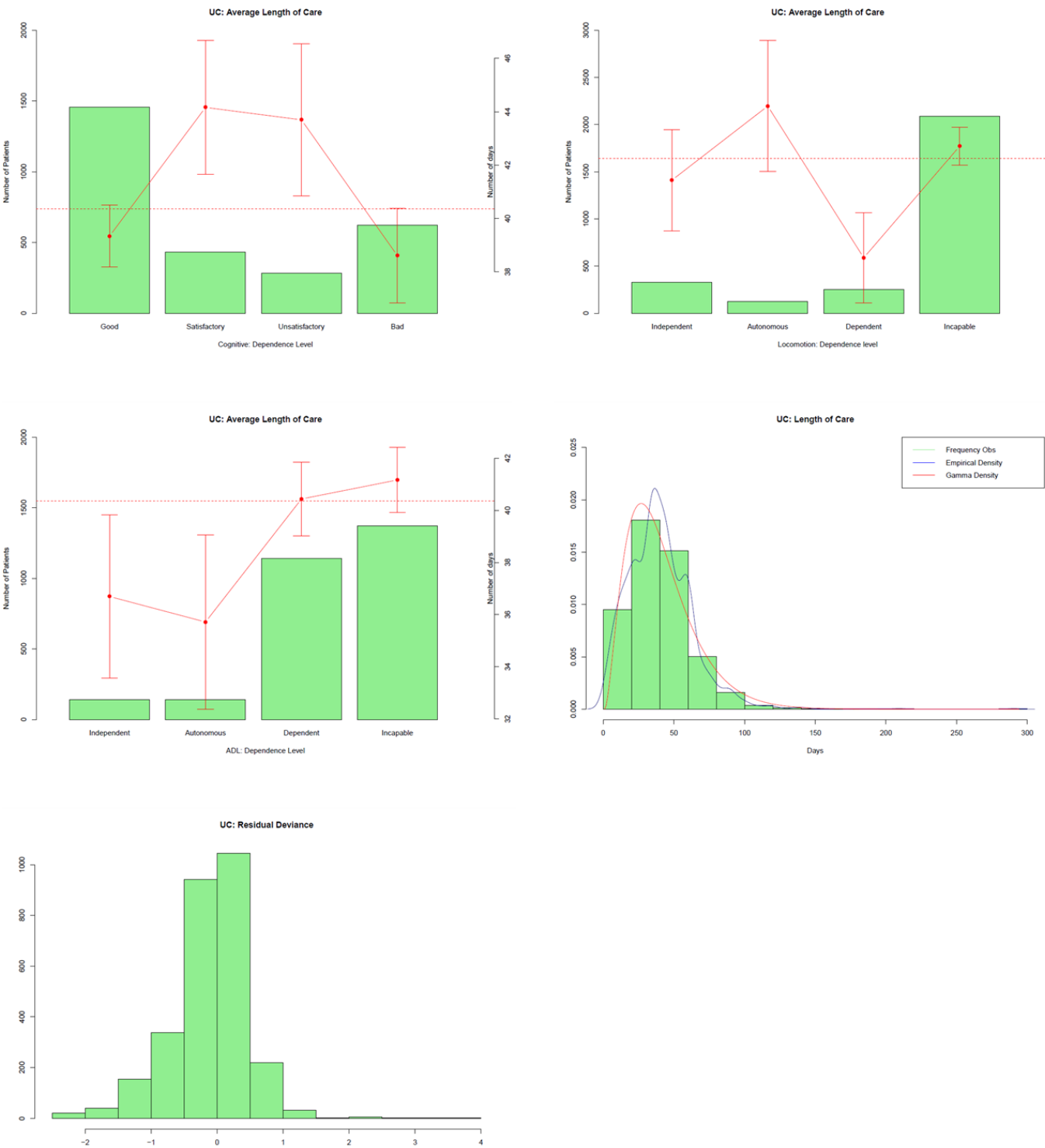
Legend: HCBS: Home and Community-Based Services; ADL: Activity of Daily Living.

Figure 11: UC: Length of Care by age group, gender, region of care and social support



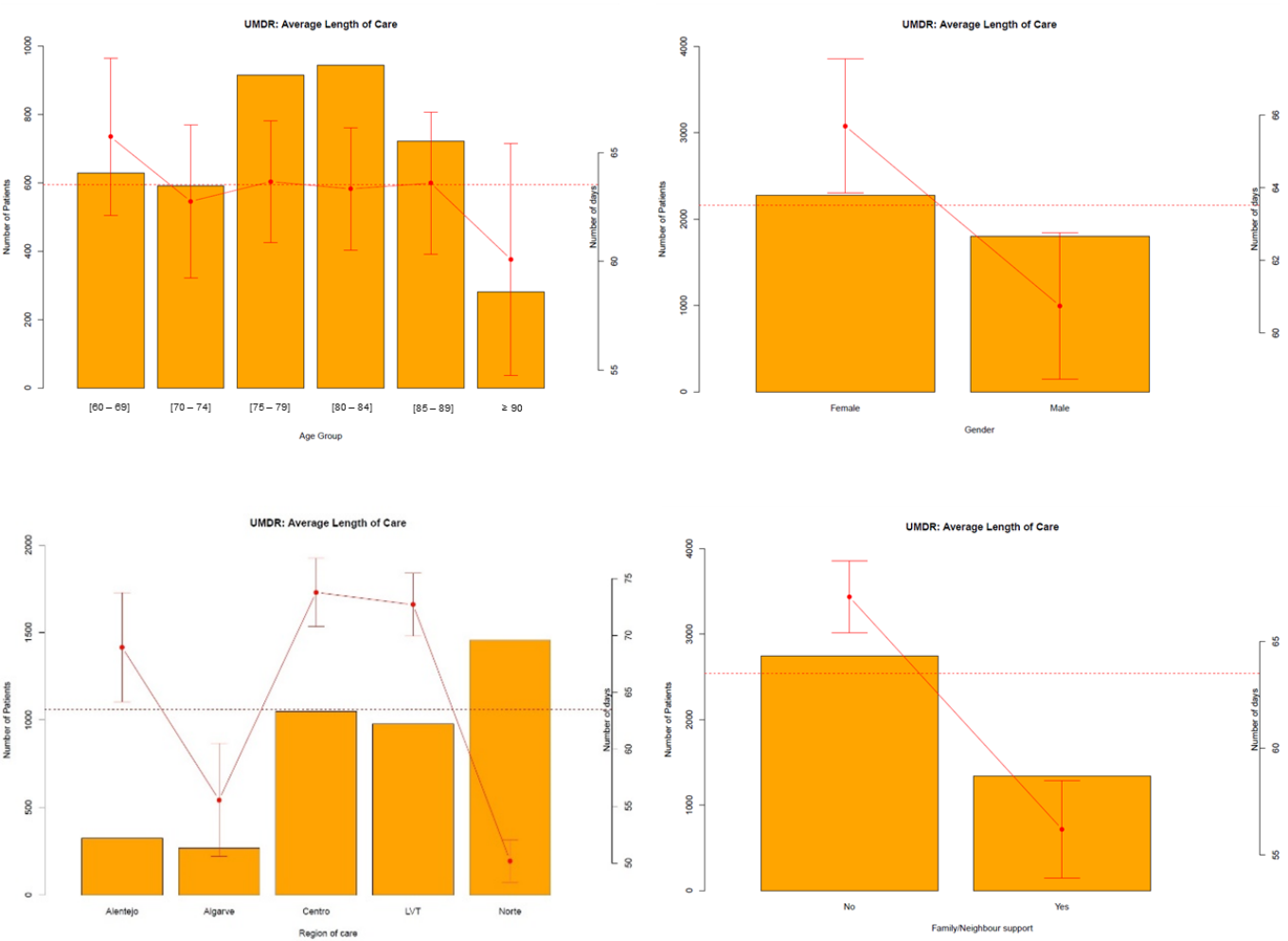
Legend: UC: Convalescence Units.

Figure 12: UC: Length of Care by cognitive, locomotion, ADL, Gamma density and residual deviance



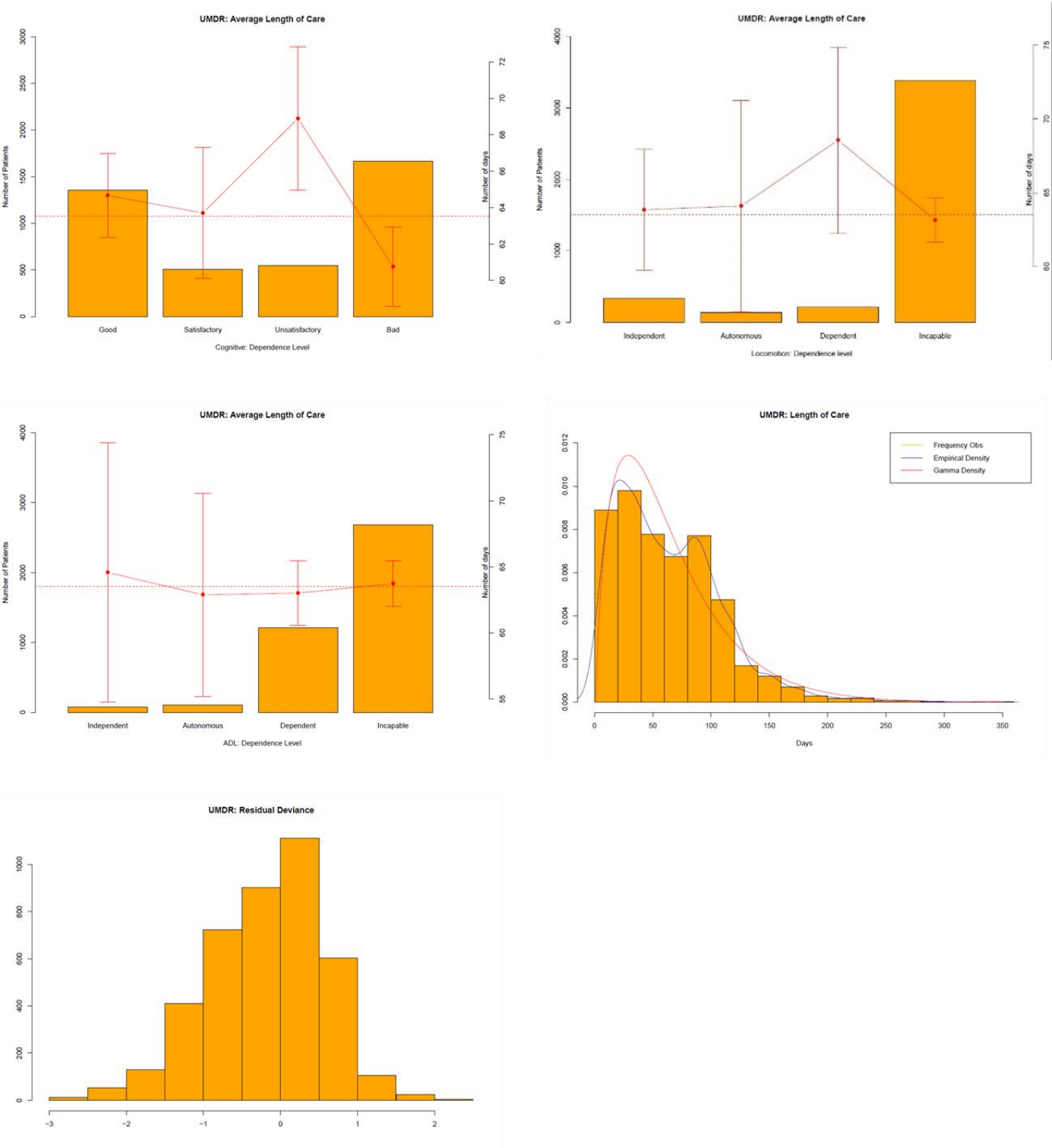
Legend: UC: Convalescence Units; ADL: Activity of Daily Living.

Figure 12: UMDR: Length of Care by age group, gender, region of care and social support



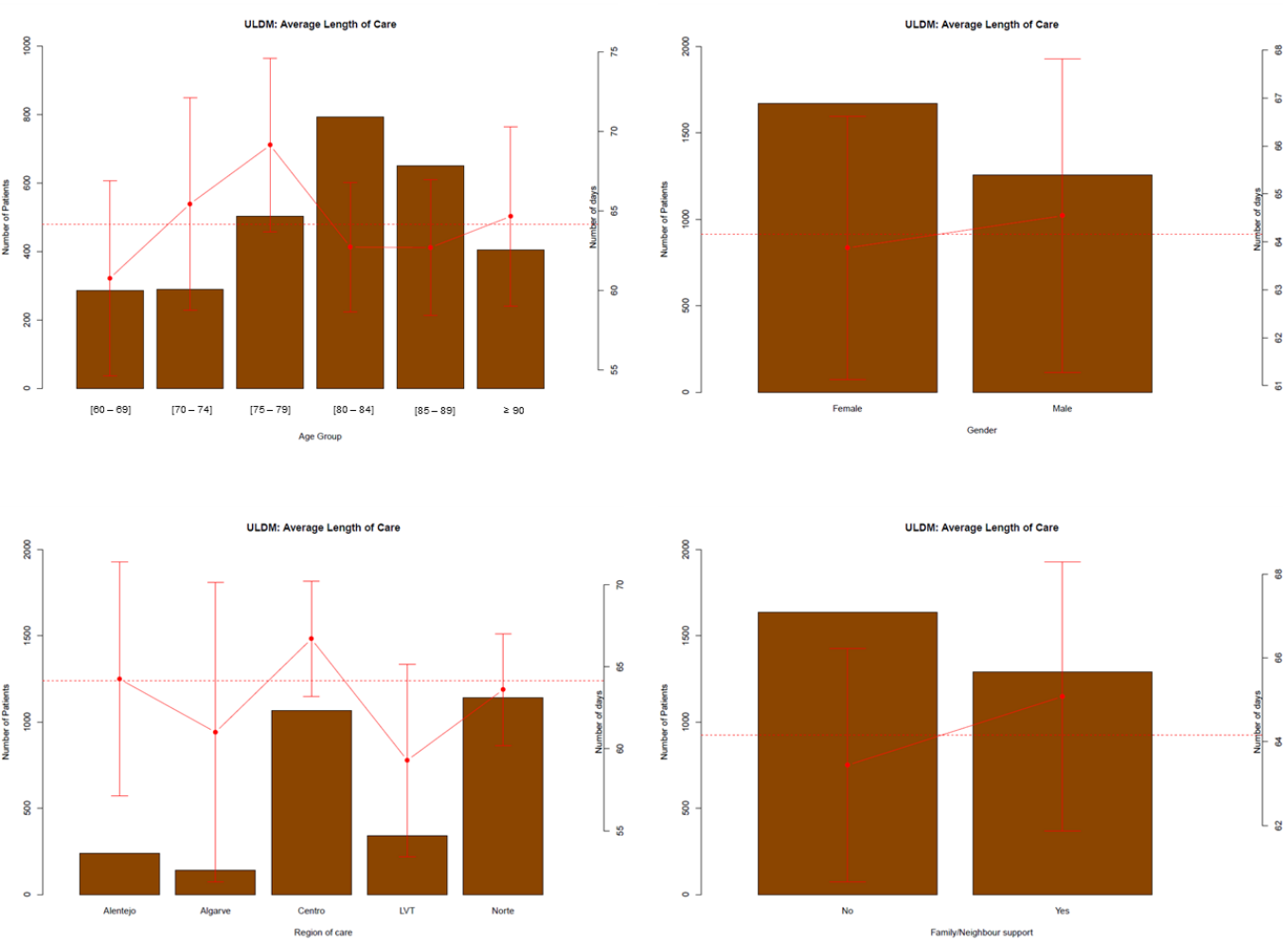
Legend: UMDR: Medium Term and Rehabilitation Units.

Figure 13: UMDR: Length of Care by cognitive, locomotion, ADL, Gamma density and residual deviance



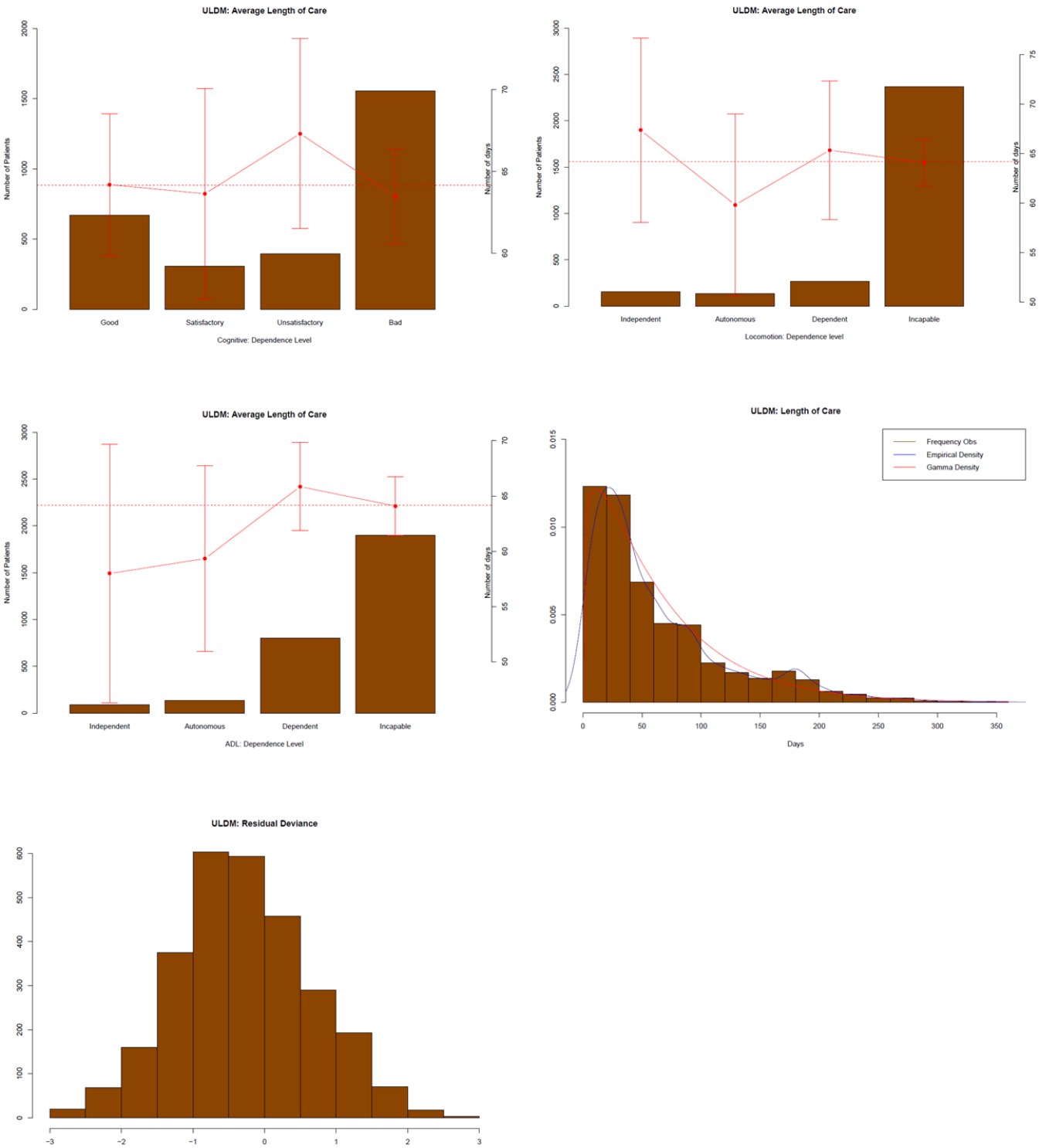
Legend: UMDR: Medium Term and Rehabilitation Units; ADL: Activity of Daily Living.

Figure 14: ULDM: Length of Care by age group, gender, region of care and social support



Legend: ULDM: Long-Term and Maintenance Units.

Figure 15: ULDM: Length of Care by cognitive, locomotion, ADL, Gamma density and residual deviance



Legend: ULDM: Long-Term and Maintenance Units; ADL: Activity of Daily Living.