Guiding Questions for the focus areas of the IX Session of the Open-ended Working Group on Ageing: Long-term care and palliative care

Contribution of the Portuguese Ombudsman

March 2018

1) In your country/region, how is long-term care for older persons defined and provided for in legal and policy frameworks? What types of support and services are covered?

In Portugal, long-term care has traditionally been provided by the private and social sector, (mainly through non-profit-making institutions), as not sufficient public offer ~~ever~~ existed. In 2006 the public sector created the National Network for Continued Integrated Care (RNCCI, in the Portuguese acronym), jointly financed and coordinated by the Ministry of Health and the Ministry of Labour, Solidarity and Social Security, in order to pursue a public policy of long-term care~~.~~.

The law establishing the RNCCI defines long-term care as «the set of sequential health and/or social support interventions, resulting from a joint evaluation, centred on the global recovery understood as the active and continuous therapeutic and social support process, which aims to promote autonomy by improving the functionality of the person in a situation of dependence, through rehabilitation, readjustment and social and family reintegration»[1]. In a nutshell, long-term care encompasses rehabilitation, readjustment and social and family reintegration, as well as the provision and maintenance of comfort and quality of life.

The RNCCI has a broad scope of application, and no specific rules on ~~-~~elderly exist. Long-term care is ~~-~~provided to anyone who is in a state of dependency[2], regardless of their age. Although it is foreseen that «elderly with criteria of fragility» are eligible to access the network[3], effective access depends on the pre-existence of an incapacitating clinical condition.

The RNCCI is made up of units with multidisciplinary teams (with representatives from both the health-care and the social security departments) that are organized at two levels of operationalization: regional level and local level.

Long-term care is provided by:

a) Internment units, aimed at guaranteeing clinical and functional stabilization of the person (there are three typologies: *Convalescence Units*; *Medium-Term Care and Rehabilitation Units*; *Long-Term Care and Maintenance Units*);
b) Day-care units, aimed at providing health and social support in order to promote the autonomy of people who do not have conditions to be cared at home (it operates on an outpatient basis, eight hours a day, usually on weekdays);
c) In-hospital teams, which are responsible for preparing and managing clinical discharges, directing patients to the most appropriate long-term units;
d) Home teams, which promote home-based responses through primary health care units.

---

[1] Article 3(a) of Decree-Law 101/2006, of 6 June, amended and republished by Decree-Law 136/2015, of 28 July.

[2] Dependency is widely defined as «the situation whereby someone cannot carry out the activities of daily living by itself, due to lack or loss of physical, psychic or intellectual autonomy, resulting or aggravated by chronic illness, organic dementia, post-traumatic sequelae, disability, severe and or incurable disease at an advanced stage, absence or lack of family or other support » (Article 3(h) of Decree-Law 101/2006). In addition, implementing provisions clearly explicit that persons with an exclusive need for social support are not admitted. ~~(é possível identificar essas medidas?).~~

[3] Article 31.1(c) of Decree-Law 101/2006.

In general terms, the RNCCI ensures the following services: medical attention, nursing care, physiotherapy, diagnose examinations, prescription and administration of medicines, psychosocial support, hygiene, comfort, food, socializing and leisure.

As far as the affordability of long-term public services is concerned, heed should be given to the fact that albeit the health care provisions are fully financed by the Ministry of Health, patients have to co-pay for the social services provided within a *Medium-Term Care and Rehabilitation Unit* or a *Long-Term Care and Maintenance Unit*. The amount of the co-payment is calculated according to the income of the patient's household[4].

On its turns, under the private system, patients are fully responsible for the payment of the ~~long~~ **long-**term care, which is usually very expensive.

2) What are the specific challenges faced by older persons in accessing long-term care?

The ageing rate in Portugal has been growing up in last years while the percentage of young people (0 to 14) and of working age people (15 to 64) has been decreasing. In 2016, about 21% of Portuguese population were 65 or older, ~~-~~making a ratio of 148 elderly people per 100 young people. Moreover it is estimated that, in 2050 older people will represent more than 30% of the total population[5]. The increase of life expectancy does not necessarily mean a *healthy* life expectancy.. On the contrary, there is a high prevalence of chronic diseases or disability situations among older people and their index of dependency has evolved significantly[6].

In this context, the RNCCI is currently unable to respond, in a timely manner, to all people in need. This is aggravated by the fact that the status of the "informal caregiver" is not yet recognised by law, leading to discouragement (if not even preventing) of family members or others from taking responsibility for older persons support in a home-basis[7].

Three main consequences arise from those gaps:

a) Overcrowding of internment units – waiting lists to get a vacancy on an unit are very long and vary from region to region, which is problematic from the point of view of the principle of equality[8];

---

[4] A pernicious effect results from the application of this rule as it jeopardises the access to RNCCI of the economically most vulnerable. According the relevant law, the calculation of the co-payment takes into account all income (including work, capital and real estate ~~-~~earnings, as well as social benefits) received by all members of elderly's household~~-~~. One case recently submitted before the Portuguese Ombudsman mirrors this tproblem. An elderly, earning an old-age pension of about 400 Euros, was demanded to co-pay 650 Euros as a condition to access long-term care within a *Long-Term Care and Maintenance Unit*. The calculation of the co-payment took into account the patient´s sister's income of around 600 Euros, with whom the complainant lived. It turns out that the sister lived with the patient in order to help her physically (as she was deaf, mute and blind), and also to help herfinanciallysince the patient's pension was not sufficient to cover all the essential expenses incurred (for example, in what regards housing and medicines).

[5] Statistical data on resident population in Portugal can be found at https://www.pordata.pt/Portugal.

[6] The main causes of *Years Lived with Disability* (YLD) and of the *Disability Adjusted Life Years* (DALY) in Portugal could be found in http://www.healthdata.org/portugal.

[7] The legal statute of the "informal caregiver" is currently being debated in the Portuguese Parliament. The initiatives under discussion are focused on the recognition of a set of rights to the caregiver (the only right recognized by current law is the right to rest up to 90 days in a year – see below footnote 10).

[8] The Portuguese Ombudsman has received several complaints against the long waiting periods for access to a long-term care unit. This may have serious consequences in cases where the course of time hinders the full recovery of the patient. The problem is that patients are called on a first-come/first-served basis (and not according to clinical priorities) and the law does not foresee a ~~a~~ maximum delay for addressing the requests, in

b) Abandonment and inappropriate internment for social reasons, which generate relevant public expense and great social costs – despite clinical discharge, older people remain often hospitalized because, on the one hand, there are no vacancies in the RNCCI and, on the other hand, families do not have the capacity or conditions to receive them at home, nor to pay for their stay in a long-term private unit[9];
c) Social, economic, physical and mental vulnerability of informal caregivers - informal caregivers often become at a greater risk of poverty, unemployment, isolation, depression, exhaustion and stress[10].

3) What measures have been taken/are necessary to ensure high-quality and sustainable long-term care systems for older persons, including for example:

- **Sufficient availability, accessibility and affordability of services on a non-discriminatory basis?**
- **High quality of services provided?**
- **Autonomy and free, prior and informed consent of older persons in relation to their long-term care and support?**
- **Progressive elimination of all restrictive practices (such as detention, seclusion, chemical and physical restraint) in long-term care?**
- **Sustainable financing of long-term care and support services?**
- **Redress and remedy in case of abuse and violations?**

Despite the RNCCI was intended to provide structured responses to people in a state of dependency in all life stages, ten years after its creation it was evident that the majority (about 85%) of its users are older people. Special attention was then given to the ageing process through a better understanding of the phenomenon and its determining factors. In this context, a Development Plan was drawn up with a view to increase, between 2016 and 2019, the capacity of existing responses, favouring domiciliation and community responses.

---

contrast to what happens in access to other health care provisions, for example, hospital consultations and scheduled surgeries. The role of the Ombudsman has been to ensure that patients have access to long-term care within a time socially and clinically acceptable for their condition, if necessary, by referring the patients, free of charge, to private institutions able to provide the service of comparable quality and within the appropriate time frame.

[9] According to the latest data, referring to February 2018, 960 people were hospitalized in the National Health Service (NHS) for social reasons (representing 6% of the internment capacity of NHS). Most of them are older people. This represents financial costs estimated of 100 million euros in one year (see article in the daily newspaper *Público* – https://www.publico.pt/2018/03/17/sociedade/noticia/quase-mil-pessoas-internadas-por-nao-terem-para-onde-ir-1806992 – giving the "Social Interments Barometer" of the Portuguese Association of the Hospital Administrators as source)

[10] Portuguese law assigns the informal caregiver the right to rest up to 90 days a year through the patient's internment in a *Long-Term Care and Maintenance Unit* (Article 17(3) of Decree-Law 101/2006). The Ombudsman has received many complaints from informal caregivers alleging difficulties in exercising their right to rest. Their requests are often denied on the grounds that there is no vacancy to accommodate the older person in an internment unit for the wanted periods.

This instrument – the "Development Plan of RNCCI 2016-2019"[11] – states several goals in order to ensure high-quality and sustainable long-term care systems. We may highlight the following:

a) Enhance the facilities availability, by increasing vacancies in all typologies of units, especially in large urban centres[12];
b) Reinforce community responses to minimize accessibility constraints due to the overcrowding of internment units and due to the distance between the patient's home and the vacant unit (which is more critical in rural areas);
c) Provide high standards of quality to health care systems, whether private or public;
d) Promote awareness raising on ageing process and its determining factors, among health professionals, informal caregivers and in the society as a whole ;
e) Promote a comprehensive care approach, grounded on evidence-based care and on diagnostic evaluation (through multidimensional and multi-professional assessment);
f) Implement a paradigm change favouring a personalized care system, and leading to a person-centred rather than disease-centred approach,. In this regard, it is envisaged the creation of the "patient manager" with the ability to coordinate the entire trajectory of the patient and their support in all health-related decisions;
g) Optimized the use of information technologies as a way of guaranteeing the articulation between all levels of care and of reducing costs.

A National Coordination Commission was established to guarantee the fulfilment of the targets foreseen in the "Development Plan 2016-2019" as well as the articulation of all competent entities.

As for redress of violations and without prejudice to other redress mechanisms generally available, installation and operation of private units are supervised by the State, which imposes administrative sanctions on offenders.

4) What other rights are essential for the enjoyment of the right to long-term care by older persons, or affected by the non-enjoyment of this right?

Rights essential for the enjoyment of the right to long-term care

As a component of the right to health, the right to long-term care comprises two main dimensions: a positive dimension and a negative dimension.

Regarding the positive dimension, citizens are entitled to require from the State the adoption of all appropriate measures (*v.g.* of legislative, administrative, budgetary and judicial nature) towards the full realization of the right at stake (it is the obligation to fulfil as enshrined in international human rights law). The enjoyment of the right to long-term care thus implies the fulfilment of the right to access the health and social provisions and related facilities with sufficient availability, accessibility (physical, economic, informative) and quality.

In respect of the negative dimension, the State has the obligation of respect, refraining from interfering directly or indirectly with the enjoyment of the right, and protect, preventing third parties to interfering therewith. In this regard, Portuguese law clearly states that within the RNCCI the following rights of the person in a situation of dependency must be respected (Article 7 of Decree-Law 101/2006): right to dignity; right to preserve identity; right to privacy; right to information; right

[11] https://www.sns.gov.pt/wp-content/uploads/2016/02/Plano-de-desenvolvimento-da-RNCCI-2016-2019-Ofi%CC%81cial-Anexo-III.pdf.

[12] More than 500 new inpatient responses are planned to be available in the current year (https://www.sns.gov.pt/noticias/2017/12/29/reforco-nos-cuidados-continuados-2/).

to non-discrimination; right to physical and moral integrity; right to exercise citizenship; and right to informed consent.

Rights affected by the non-enjoyment of the right to long-term care

The non-enjoyment of the right to long-term care namely affects the right to an adequate standard of living, the right to the enjoyment of the highest attainable standard of physical and mental health, as well as, ultimately, the right to self-determination.

5) In your country/region, how is palliative care defined in legal and policy frameworks?

The long-term care policy is pursued through the National Network for Palliative Care (RNCP, in the Portuguese acronym) implemented in 2012, which is coordinated and fully financed by the Ministry of Health.

The law establishing the RNCP defines the palliative care as «the active, global and coordinated care , provided by specific units and teams, in hospitalization or at home, to patients suffering from an incurable or severe illness, in an advanced and progressive stage, as well as their families, with the main objective of promoting their well-being and quality of life, through the prevention and alleviation of physical, psychological, social and spiritual suffering, based on the early identification and rigorous treatment of pain and other physical problems, as well as psychosocial and spiritual problems»[13].

The coordination of RNCP is carried out at national level in operational articulation with regional and local structures. At a local level, the palliative care is provided by:

a) Palliative care units, aimed to provide care to complex acute clinical situations, namely in hospitalization (within a hospital or another health institution);
b) In-hospital teams, aimed to support the implementation of the individual plan of care for hospitalized patients suffering from severe or incurable illness at an advanced and progressive stage;
c) Community teams, integrated in primary health care, aimed to provide palliative care to patients at home and to support families and/or caregivers.

Pursuant to the *European Association for Palliative Care* (EAPC), the RNCP addresses, at current stage of development, two levels of care:

a) The "Palliative Approach", used in services where patients with palliative needs are occasionally treated;
b) The "Specialized Palliative Care", provided by specialized multidisciplinary teams with specialized skills focused on optimizing the patients' quality of life.

6) What are the specific needs and challenges facing older persons regarding end-of-life care? Are there studies, data and evidence available?

In Portugal, the palliative care organization is recent and still incipient. In order to meet the national needs the "Strategic Plan for de Development of Palliative Care for 2017 –2018" was adopted[14]. Accordingly, in this biennium it is therefore expected to overcome some major challenges:

[13] Base II(a) of Law 52/2015, of 5 September, and Article 3(b) of Decree-Law 101/2006, of 6 June, introduced therein by Decree-Law 136/2015, of 28 July.

[14] https://www.sns.gov.pt/wp-content/uploads/2016/11/Plano-Estrat%C3%A9gico-para-o-Desenvolvimento-CP-2017-2018-2.pdf.

a) Understaffing and inadequate training of personnel on ageing-related issues, particularly in case of dementia (with a view to overcome this gap it is intended, on the one hand, to create mechanisms that encourage graduate and post graduate specialization on ageing and, on the other hand, to include a curricular unit dedicated to palliative care in the degrees of health professionals, such as Medicine, Nursing, Psychology, Social Work[15]);
b) Inefficient articulation between the three levels of care that coexist in Portugal (primary health care, hospital health care, long-term care) ensuring the patient's easy mobility between networks according to the needs and strengthening the palliative approach carried out by all health professionals;
c) Lack of support to the informal caregiver and the whole family of the patient;
d) Inability of response of the community support teams.

Data on the number of patients in need of palliative care, human resources, palliative care units and capacity, can be found in the content of the Strategic Plan.

7) To what extent is palliative care available to all older persons on a non-discriminatory basis?

The legal framework on this matter is overarching. There are no specific rules on the access of the older people to palliative care.

In order to guarantee equality of access to palliative care, the Base Law on Palliative Care stipulates that «no citizen may be disadvantaged or discriminated on the basis of his/her economic situation, area of residence or pathology»[16]. In alignment with the international human rights law and the Portuguese Constitution, discrimination based on other grounds, such as age, is also obviously proscribed.

8) How is palliative care provided, in relation to long-term care as described above and other support services for older persons?

Although the RNCCI and the RNCP are independent, the units of RNCCI may provide palliative actions, depending on the needs, as a part of promoting the well-being of users[17].

9) Are there good practices available in terms of long-term care and palliative care? What are lessons learned from human rights perspectives?

From an human rights perspective, one may underline the following existing practices:

---

[15] In this regard, it should be noted that the Portuguese Ombudsman had received complaints from gerontologists who complained about the absence of legal regulation on Gerontology as a profession, relying on a Parliament's recommendation addressed to the Government (Parliamentary Resolution 92/2013, of 31 May). The Ombudsman considered that this is a matter for political decision – domain that is outside the institution's mandate – and closed the file.

[16] Base V(2) of Law 52/2012, of 5 September.

[17] Base XIV(3) of Law 52/2015, of 5 September and Article 34(4) of Decree-Law 101/2006, of 6 June, introduced therein by Decree-Law 136/2015, of 28 July.

a) A positive discrimination measure was established in favour of patients of nursing homes with cooperation agreements with the Social Security, which gives them priority on access to *Long-Term Care and Maintenance Units*, up to a maximum of 10% of their capacity[18];
b) The Health Authority and Social Security services issued a manual of articulation aimed at guaranteeing that those who are not referred to the RNCCI enjoy an effective continuity of health care and social support in the post-discharge[19].

For the future, the adoption of a legal statute for the informal caregiver is of utmost relevance on the path to deinstitutionalization and to grant the essential human rights of older persons, while entitling caregivers with a set of legal rights.

[18] Order 3020/2011, of 11 February.
[19] "Manual of Articulation between Health Authority and Social Security for Planning Hospital Discharges", disclosed by Joint Circular 3/2015, of 10 September (available in http://www.acss.min-saude.pt).