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Need, unmet need, and shortage in the long-term care market

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Need, unmet need, and shortage in the long-term care market

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Introduction

The revised version of the European Social Charter[1], which was opened for signature in 1996, has a specific clause (Article 13) which concerns social and medical care. This clause recognises that the countries must "ensure that any person who is without adequate resources and who is unable to secure such resources either by their own efforts or from other sources, in particular by benefits under a social security scheme, be granted adequate assistance and, in case of sickness, the care necessitated by his condition." In Article 23, the rights of older people are especially mentioned, both the right to "lead independent lives in their familiar surroundings for as long as they wish and are able", receiving "the health care and the services necessitated by their state", as well as the right to "appropriate support" of the older persons living in institutions. As a consequence, the member states are responsible to ensure that older people are guaranteed access to adequate care. The Charter does not require that that care is provided by the state itself, but rather that the necessary measures be taken - "either directly or in co-operation with public[2] or private organisations".

Furthermore, Principle 18 of the European Pillar of Social Rights stresses the right to affordable long-term care services of good quality, in particular home-care and community-based services. Although appropriate care is generally acknowledged to be essential, several studies have detected the existence of unmet long-term care (LTC) needs (Scheil-Adlung 2015, Muir 2017, Burchardt et al. 2018). Portugal, which is identified as relying mostly on family-based LTC (Tavora 2012, Lopes 2013, Illinca et al 2015), is a typical example of a country where formal LTC for older people is commonly considered to be insufficient (Costa et al. 2014, Barros and Simões 2007), with limited public

[1] The European Social Charter is an international treaty which stipulates the fundamental rights in the field of social policy that the signing countries must guarantee. The signing countries are most of the members of the Council of Europe.

[2] The European Pillar of Social Rights is a set of principals which the European Union proclaimed in 2017, to call attention to the importance of creating a fairer Europe, in recovering from a financial crisis which imposed high social costs.

funding. Therefore, can we say that there is a shortage of LTC in Portugal? If so, how much more formal care is needed?

The objective of this study is to understand the extent of the unmet need for care, the need for more formal care, and the existence of a shortage in the long-term care market, in Portugal, whilst conveniently differentiating these concepts.

Long-term care in Portugal

LTC is defined as "a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with daily living activities and/or are in need of some permanent nursing care" (European Union 2014, p.11). These services comprise health care services and social care services.

LTC is frequently divided into institutional or residential care, and home (or domiciliary) care (Tenand et al. 2020, Goda et al. 2011). Sometimes additional categories are considered, which, together with home care, can be included in a broader classification of "community-based care" (e.g., day centres and assisted living facilities).

In Portugal, there are two networks of formal care providers: the National Network of Social Equipments and Services, for which no medical referral is necessary, and the National Network of Continuous Integrated Care (RNCCI), which offers care to people who are referred by hospitals or by local health units. Those who are eligible to be cared for by the RNCCI must be dependent and must require access to nursing and medical care.

In 2016, LTC expenditure represented 0.5% of GDP in Portugal, whilst the average for the EU was 1.6% (European Commission 2018), despite the high levels of reported limitations in daily activities (European Commission 2019).

The level of expenditure in LTC is recognised as being difficult to calculate (European Commission 2018), on account of the fragmentation of the systems of provision and the existence of cash benefits and in-kind provision. According to the European Commission (2019), in Portugal, 99.8% of the benefits were in-kind, whereas 0.2% were cash-benefits. The corresponding percentages for the European Union were 84.4% and 15.6% respectively. The overwhelming dominance of the value of in-kind benefits exists despite the fact that a larger percentage of dependents receive cash benefits, rather than in-kind benefits. This is revealing with regards to the level of cash benefits received by a

dependent person. In Portugal, 38.6% of total dependents (not necessarily elderly dependents) receive either cash, or in-kind public benefits (European Commission 2019). A severe lack of workers in the Portuguese LTC system is pointed out as being responsible for the exclusion of more than 90% of the older population from quality LTC (Scheil-Adlung 2015). Nevertheless, there has been a substantial effort to expand and reorganise the public provision of care services for older people. The numbers shown in international reports sometimes take the part for the whole: the statistics in the OECD Health Statistics for LTC recipients in Portugal, both for home care and residential care, use data for the RNCCI only, as can be seen in the "Definitions, Sources and Methods". These statistics are used in studies by other entities, for example, by the European Commission (2018, Fig 1), where Portugal appears in last place by far for the proportion of people of a certain age who receive home care. The inclusion of only part of the LTC recipients can be partly responsible for that.

Is the perception of the existence of a lack of care services still accurate? What exactly is the meaning of this insufficiency, and how can we quantify it?

Need

A rights-based approach to LTC should guarantee that people who need care, obtain it. How can we estimate the need for care by older people?

Need is not directly observable. One way to operationalise the calculation of care need is using a variable that identifies the existence of limitations with activities (Kröger et al., 2019, Iparraguire, 2017). Both SHARE and EU-SILC have such questions. In SHARE, the question is PH005: "For the past six months at least, to what extent have you been limited because of a health problem in activities people usually do?" In EU-SILC, the corresponding question is PH030. For Portugal, the last wave of SHARE is Wave 6, with interviews being carried out during 2015. The EU-SILC 2015 is used for comparability. We look at the need experienced by people older than 50 – which coincides with the age frame of SHARE. Although 50 years old is a low threshold for the identification of the later stage of life, as disability increases with age, the proportion of people with limitations in usual activities is by no means negligible before 75 (see Fig. A1). Based on weighted data, and considering only individuals older than 50 also in the EU-SILC, the level of limitations according to each survey is displayed in Table 1.

If we accept that only those who find they are not limited, have no care needs, then the proportion of individuals older than 50 who need care is between 53% and 56%, approximately. If we assume that only the severely-limited really need care, then the proportion of the population older than 50 in need of care would be between 16% and 24%.

Table 1 Percentage of people older than 50 who feel limited in activities which people usually do, because of a health problem

Label	SHARE Frequency	EU-SILC Frequency
Severely limited	23.8 %	16.21 %
Limited, but not severely	29.3 %	39.45 %
Not limited	46.9 %	44.33 %

Note: weighted data.

In SHARE, in addition to the PH005 variable, there are other variables that provide information about the existence of limitations with activities. PH048i, i =1,…10, report the existence of current difficulties, from a list of 10, with certain movements which are required to perform common activities, and which are not expected to last less than 3 months. These difficulties range from walking 100 metres, to picking up a small coin. PH049i i = 1,…15 identify the activities themselves. The list of the fifteen activities where people can feel limitations include, for example, dressing, bathing, or doing personal laundry.

A considerable number of individuals answered that they were not limited because of health problems (variable PH005), but said they had at least one difficulty from the two lists: these represent 14.5% of the total (Table 2). It is possible that the different requirement in terms of length of time of the problem is responsible for explaining part of this gap, or it could be that they correspond to situations where people have difficulties, but do not regard these difficulties to be serious enough to make them feel limited. On the other hand, those people who say they are somehow limited, according to PH005, yet fail to identify any type of limitation from the PH048 and the Ph049 lists, constitute approximately 10.2% of the total.

The prevalence of the need for care depends on which indicator we use. The proportion of individuals with care needs, according to both the definitions of need tend to increase with age, although a noticeable proportion of the 'young' old experience difficulties in the performance of activities (Fig. A2).

Table 2

Limited in activities because of health * At Least 1 in 25 difficulties, Crosstabulation count

		At least 1 in 25 difficulties		
		NO	YES	Total
Limited in activities because of health	Severely limited	69,868	913,507	98,3375
	Limited, but not severely	354,402	861,287	1,215,689
	Not limited	1,338,327	603,708	1,942,035
	Total	1,762,597	2,378,502	4,141,099

Note: SHARE. Weighted data.

Table 3 Need for care according to the different indicators in SHARE

Type of indicator	Prevalence of need
Severely limited in activities for the past 6 months at least (PH005)	23.75%
Limited in activities for the past 6 months at least (severely or not) (PH005)	53.10%
At least one difficulty from the two lists (PH048i and PH049i)	57.44%
Al least one difficulty from the two lists (PH048i and PH049i) and (severely or not) limited in activities for the past 6 months at least (PH005)	42.86%
Al least one difficulty from the two lists (PH048i and PH049i) and severely limited in activities for the past 6 months at least (PH005)	22.02%

Note: Weighted data.

Unmet need

Are these needs satisfied? If the person needs care and receives no care, then the answer is obvious. If the person receives care, there are chances that the needs are satisfied, but it could be that the amount of care is insufficient, or that certain types of care are not available, and thus the needs are only partly satisfied.

SHARE includes some questions about the satisfaction of care needs. One of these is: "Thinking about the activities that you have problems with, does anyone ever help you with these activities?"- PH050. This includes informal care from people in the household. A connected question is: "Would you say that the help you receive meets your needs?" - PH051. This question is directed to those respondents who answered 'yes' to the previous question.

There is also question SP002, which asks about receiving help from someone outside the household during the previous 12 months, be they family, friends, or neighbours. Additionally, SP020 enquires about the existence of regular personal care by someone inside the household for at least 3 months during the previous 12 months.

It is not entirely clear why some respondents say that they receive professional help with personal activities or meals-on-wheels services, but, at the same time, answer that no one helps them with the activities which they have problems with. Furthermore, some respondents who receive help with personal activities from someone outside the household or regularly from someone in the household, still answer that no one helps them with the activities which they have problems with. 10.7% of all those who declare that they have not received help with the activities they had difficulty with, also either said that someone inside the household regularly helped them with personal care, or that they received professional personal care or help from someone outside the household on a daily or weekly basis. This percentage reduces to 4.8% if we also consider only personal care when counting receiving regular care from someone outside the household. One possible interpretation of this result is that, even with such help, these respondents have unmet needs.

As a consequence, we compute two variables of unmet need - *UnmetNeeds1* and *UnmetNeeds2* -, using two different indicators of needs. For the indicator of the non-satisfaction of needs, we use the statement that the respondent does not receive help with the activities that they have problems with, or, despite receiving care, the respondent declares that such help hardly ever, or only sometimes satisfies their needs (Table 4). The *UnmetNeeds1* indicator is less restrictive than the *UnmetNeeds2* one in the identification of need, and consequently the proportion of individuals with unmet needs is higher in the first case: 27.7% vs. 16.3% of people older than 50. All those

individuals who fall in the situation of the apparently inconsistent answers that are described above are selected by our variables of unmet need.

Table 4 –**Unmet Needs**

		UnmetNeeds1		*UnmetNeeds2*	
		Frequency	Percent	Frequency	Percent
Valid	-1.00	10,276	0.2	10,276	0.2
	0.00	2,991,708	72.1	3,466,049	83.5
	1.00	1,148,894	27.7	674,553	16.3
	Total	4,150,878	100.0	4,150,878	100.0

Notes: *UnmetNeeds1* assumes as need, the existence of difficulties with at least some activity listed in PH048i or PH049i. *UnmetNeeds2* assumes as need, the existence of difficulties with at least some activity listed in PH048i or PH049i, together with the identification as being limited to some extent, based on PH005. Values: 1- unmet need; 0- no unmet need; -1- no information. Weighted data.

It is important to note that our data does not properly cover people living in care homes. The target population in SHARE includes people living in care homes, although in some countries, such as Portugal, these people are deficiently covered. The Portuguese sample has 1,675 observations (unweighted). Of these, only 7 are from people who answered that they had been in a nursing home in the last 12 months, from which only 2 permanently. So, the proportion of unmet need is basically by reference to those older people who have needs, but to those that have needs while living at home.

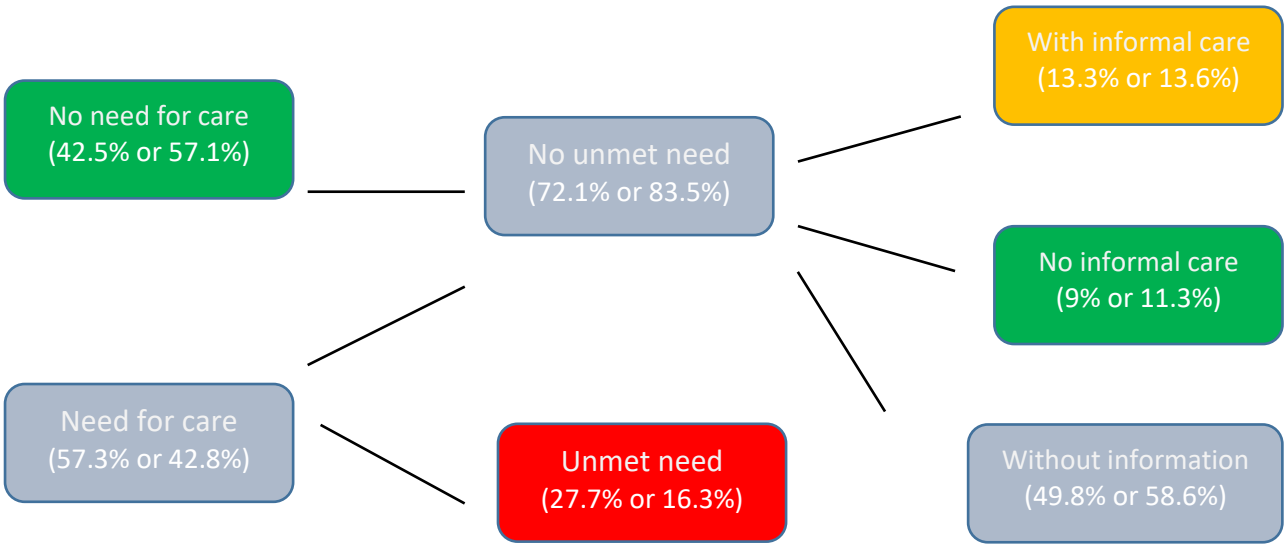
Unmet need and need for more formal care

In the previous section, a large unmet need for care was identified. Does this represent the amount of additional formal care that is needed? Which situations represent a need for more formal care (see Fig.1)?

Clearly the following people do not need more formal care: those who have no need for care, or who have no unmet needs and receive professional help[3] and no informal help.

A person with no unmet needs, but who receives informal care[4] could be interested in receiving more formal care. However, in such a case, we do not know whether the informal care is provided because the formal help was insufficient, or whether it satisfies a preference.

Figure 1. Need for more formal care



Notes: Green: No need for more formal care. Red: need for more formal care. Yellow: possible, uncertain need for more formal care. The percentages are proportions of the total sample. The two numbers inside each parentheses are for the two different indicators of need, as defined above.

In SHARE, receiving regular help from someone in the household[5] is associated with a large problem in terms of missing information, although the same thing does not happen in the case of receiving care from someone outside the household[6]. By combining the information from both variables, we can identify those people who receive some type of informal care, however, by doing this, we will surely underestimate the actual number of persons. With this caveat, 16.5% of all people are

[3] Corresponding to Hc127=1.
[4] Corresponding to SP002 = 1 or SP020=1.
[5] Variable SP002.
[6] Variable SP020.

identified as receiving informal care[7], and slightly more than 13% are known to receive informal care and have no unmet need (Fig. 1). Therefore, some of these people may be interested in receiving some, or more formal care, and they should be added to people with unmet needs when calculating the number of people who would welcome more formal care, either in quantity or in quality.

Is unmet need more associated with not having professional help? Not in our data, according to our two definitions of unmet need. The lambda association measure between the two categorical variables – unmet need and reception of professional help - is zero. Knowing that someone has professional help does not improve our ability to predict whether that person has unmet needs. Either the quantity or the quality of the care received is frequently not satisfactory.

Need for more formal care and shortage

From among the additional formal care that would be welcome, some is not demanded because the price is too high, and some can be demanded, but is not available. Only this second category corresponds to economic shortage, which is described as an excess of demand compared to supply, at the current price. In most cases, need and demand are equalised, which leads to confusion in the conclusions that are reached (Jeffers et al. 1971). However, contrary to demand, need is a concept which does not take into account prices, costs, and financial resources.

An economic shortage would drive prices up in a competitive market, however the LTC market is not a competitive market. In Portugal, as in many other countries (Rodrigues et al. 2014, Lopes 2017), there is a mixed market for care, with a predominance of public funding. The government funds in-kind care services - either by offering the services directly, or by subsidising the private institutions with which it makes an agreement. In Portugal, the dominant type of providers of formal LTC are not-for-profit institutions with government agreements. The price that care users pay is below the competitive market price and is dependent on their income. It is in this category of the market that excess demand can exist. The private, non-subsidised category of the market, with

[7] Even so, the percentage of people identified as receiving informal care is much larger than the percentage of people identified as receiving professional care. Approximately 63% of all those who report receiving professional help with personal care, with domestic chores, or with meals-on-wheels, are also identified as receiving informal care.

higher prices, only operates if the quantity supplied in the public-funded market is insufficient, or the product is differentiated by characteristics that do not exist in the subsidised services.

In a market which is entirely public - where the services are offered at a zero price, users would be interested in consuming exactly the quantity they considered that they need, or felt that they need[8]. In such a situation, unmet need (as assessed by the user) and unmet demand would be the same. "Shortage" would therefore be an unequivocal term.

With a positive price in the public-funded market, there will always be people who consider that they need the service, however they fail to demand them at that price, and thus a wedge is created between need and demand, and unmet need does not equal excess demand. These people do not turn to the private market for the same services, because the prices are even higher.

Considering that the services are homogeneous, all those who demand the services prefer to use the subsidised services. If there was no budgetary constraint, then LTC would be provided to satisfy the total need. However, both the satisfaction of care users' needs and the sustainability of public finances are politically important objectives, and therefore care users' needs compete with other, also important needs for a limited budget. If the budget is not compatible with full satisfaction of care needs, this inevitably leads to excess demand and rationing (Zweifel 2015).

When people demand services at the price they are offered in the subsidised market, but they have no access to these services, then some of these people may become consumers in the private market. Accordingly, discounting for possible product differentiation, the functioning of the private care market without public funding is dependent on the difference between the (higher) price that balances the public-funded market and the price that care users actually pay in that market (co-payments). The lower this actual price paid by care users is, the higher excess demand will be (rationed consumers). The functioning of the private care market is dependent on yet another factor: the difference between the price that providers are willing to accept and the price that those consumers who were rationed in the public-funded market accept to pay. As a consequence, a rationing criterion associated with the purchasing power of the person in need of care, giving priority to the less affluent, increases the probability that a private care market operates.

If there are users who are rationed in the public-funded market, but can afford to consume in the private market, can we then say that there is a shortage in this care market? A rights-based

[8] 'Felt need' is only one of the possible categories of need, according to Bradshaw's (1972) taxonomy. The others are: normative, expressed, comparative, and technical.

approach to LTC should guarantee that users who need the services are able to obtain them. It is the users that need the services and fail to obtain them that are a reason for concern. In such a case, the users fall into one of the following categories:

i. The user finds that even the price in the public-funded care market is too high.

ii. The user demands the services in the public-funded care market, but these are rationed and they cannot afford the price in the commercial care market.

Unmet need of formal Type-ii will be higher:

- The higher the price is in the commercial market.
- The higher are the production costs which are not covered by the price in the subsidised market.
- If those who can access the subsidised market are not those who have the lowest willingness/capacity to pay.
- The higher is the sensitivity of the demand for care to changes in price - for the price range operating above the lower price stipulated by the government.

We can state that the challenge of the social policy maker is to minimise unmet need, subject to the financial constraint. The higher the co-payment, the larger the quantity the government has to pay – but conversely, the larger the Type-i unmet need for formal care. As a matter of equity, the government might opt to practice a lower price, although this would be at the expenses of offering a lower quantity, if the budget is fixed. This only guarantees a decrease in the Type-i unmet need. An overall reduction in unmet need for formal care will depend on whether that reduction of Type-i unmet need more than compensates the Type-ii unmet need that will subsequently be created. Based on the available data, it is not obvious how one can separate Type-i and Type-ii unmet need, that is to say, for the lack of a better vision, we are unable to estimate the dimension of the potential shortage of formal care. To our knowledge, the efforts to simulate and project demand for LTC and compare it with supply in Portugal are, in effect, (very interesting and useful) estimations and projections of need (Cardoso et al. 2012). Nevertheless, we can look for signs of the existence of excess demand.

Signs of shortage

A typical manifestation of shortage is the existence of waiting lists. The data provide information of the average waiting time of someone who is referred to the RNCCI until that person gets a place in the system. This waiting time can be related with the inexistence of a free place, but also with the administrative procedure of calculating the financial co-payment and of confirming that the documents of the application are all in order. Several types of care services are provided in the context of this network with different waiting times for each type. At the end of 2016, the number of people waiting for a place in the RNCCI network was 1,400, although not necessarily all of them were older than 50 – which is the age interval used in the analysis of the previous sections. Nevertheless, these applicants aged older than 50 must be the overwhelming majority, as those users of the RNCCI who are older than 65 are already 85.5% of the total. The waiting list has increased in recent years.

The network of social services and equipments used for the provision of social care under the supervision of the Ministry of Labour, Solidarity and Social Security, and that are identified in the Social Charter may also have waiting lists. The users of this network do not have to be referred by a hospital or a health centre. We do not possess information regarding waiting lists for the services provided under this network, although information regarding the utilisation rates is available. The fact that utilisation rates never attain 100% does not mean that there are no waiting lists, because of the necessary turnover.

The main types of LTC services are residential homes and home care. In the case of both the network of social services and equipments and in the RNCCI, utilisation rates are much lower for home care. Occupancy rates were above 90% for residential homes for the elderly, but below 80% for home care. In 2018, districts like Bragança, Faro, Évora, Viseu, and Aveiro had occupancy rates of the residential equipments above 95%. The occupancy rate of the long and medium term care units was 97% in 2016, at the national level, with 98% in the North and in the Algarve. Very differently, the occupancy rates of the services of home care were only 66% at the national level, with a maximum of 70% in Alentejo.

With these numbers, it is impossible to argue that there is an economic shortage of home care in Portugal, at the national level, but the same cannot be concluded about residential long and medium term care.

Discussion and Conclusions

It is easy to agree that the provision of LTC services for the older population should not be entirely left to the market, because care is a social right, and the market alone would improperly exclude too many people. Recognising that LTC is a human right, governments should intervene and guarantee the protection of those in need. In a world of unlimited resources, only unmet needs of LTC should be a reason for concern. However, because adequate care services are costly and different types of fundamental needs are competing for a limited public budget, some kind of limitation of the public provision of LTC is unavoidable. If public funding is provided in such a way that people pay for the LTC services that they can afford, and the government pays the rest, then there will be no unmet need and no shortage of LTC services. The difficulties in the implementation of this solution include the fact that paying for it could be beyond public budget possibilities on one hand, and on the other hand, that it is not straightforward to identify what each individual can afford.

Therefore, in the real world, public funding - which lowers the price that people actually have to pay for care services, in comparison to the free market price - creates an excess demand for these services. This shortage would not be important if the excess demand in the subsidised market was absorbed by the private commercial providers. However, what is the real cause for concern is unmet need.

Based on SHARE, which targets people aged older than 50, we used two indicators of need, one of which is more restrictive than the other. We estimated that, according to the more inclusive measure of need, which identifies need as being the existence of any difficulty with common activities because of health problems, 53.1% of people aged older than 50 need care, and 27.7% have unmet need. According to the more restrictive definition of need, counting people who report having a limitation in at least one activity, but excluding those who declare that they have not been limited in their daily life during at least the previous six months, the numbers drop to 42.9% for need, and 16.3% for unmet need. If people have unmet needs, then, in principal, they would be interested in receiving more formal care, either in quantity or in quality.

However, if we only count unmet needs, we could be underestimating the need for more formal care, as certain informal care is only provided because formal care is unavailable, with high personnel costs for the care providers. At least 13% of the total sample of respondents are identified as people with no unmet need who use informal care. Accordingly, an enormous need for

additional formal care has been identified, whereby, depending on our definition of need, 27.7%, or 16.3% of the target population as well as the more than 13% who have their needs met by informal care, would welcome additional formal care.

However, this is not to say that there is an equivalent shortage of formal care, or that if this additional volume of formal care was made available at the current prices, it would be entirely used.

Although we cannot estimate the difference between the quantity demanded and the quantity supplied of formal care, there is no indication that there is a shortage of home care services at the national level, , but the same thing does not happen with places in nursing homes. There are several potential explanations for this: there has been a higher investment in home care in Portugal than in residential care (Soares 2019); households are not well-informed about the opportunities of available home care services, or the kinship network provides care when the needs are not too burdensome, but resorts to institutionalization when their relatives need intensive care (Barczyk and Kredler 2019); because home care is considered to be insufficient to guarantee the maintenance of older people with deep needs at home. Indeed, complex health situations associated with the unavailability of support from informal caregivers, , may find a better solution in institutionalization. Another potential explanation is that the price of home care is too high for a part of the population. The maximum level of co-payments for home care is 75% of the per capita income of the household - and 90% in the case of residential care – however the exact value also depends on the number of services contracted and on their frequency of provision. Fixed expenditures, such as rent and medicines, are subtracted from the value of the income used to calculate the co-payments, but even so, it is possible in the case of home care, that any income which is not absorbed by co-payments is relatively small when compared with the amount that the care user still has to pay, given that all basic needs are covered in residential care. The relevance of each of these potential explanations requires further research.

The improvement in the referral times of certain parts of the RNCCI network and the offer of more beds in nursing homes in the subsidised system, both represent a path for the increase in the supply of the type of care which appears to have excess demand. The other possibility is to intervene in the demand side - through the provision of better information regarding home care possibilities, together with a change in the characteristics of the services provided at home – which would make this option a better solution for families' problems. This line of intervention is more in agreement with the EU's Active Ageing Strategy vision of ageing-in-place being a way of

maintaining control over life and of retaining identity - although probably both types of policies are necessary.

This study also calls attention to the existence of needs and of unmet needs of the 'younger' elderly population, which are typically overlooked in the existent literature.

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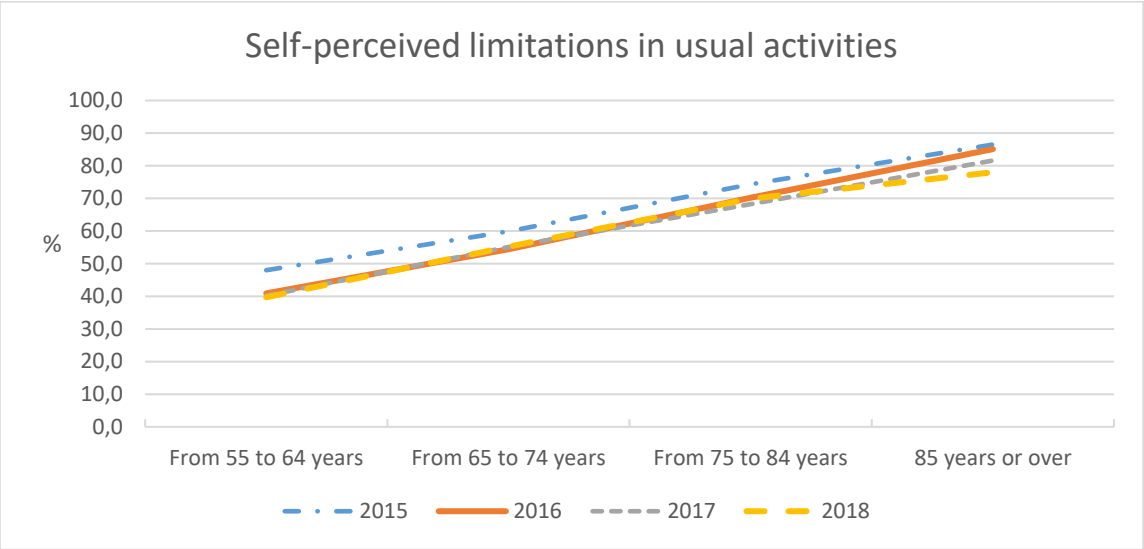
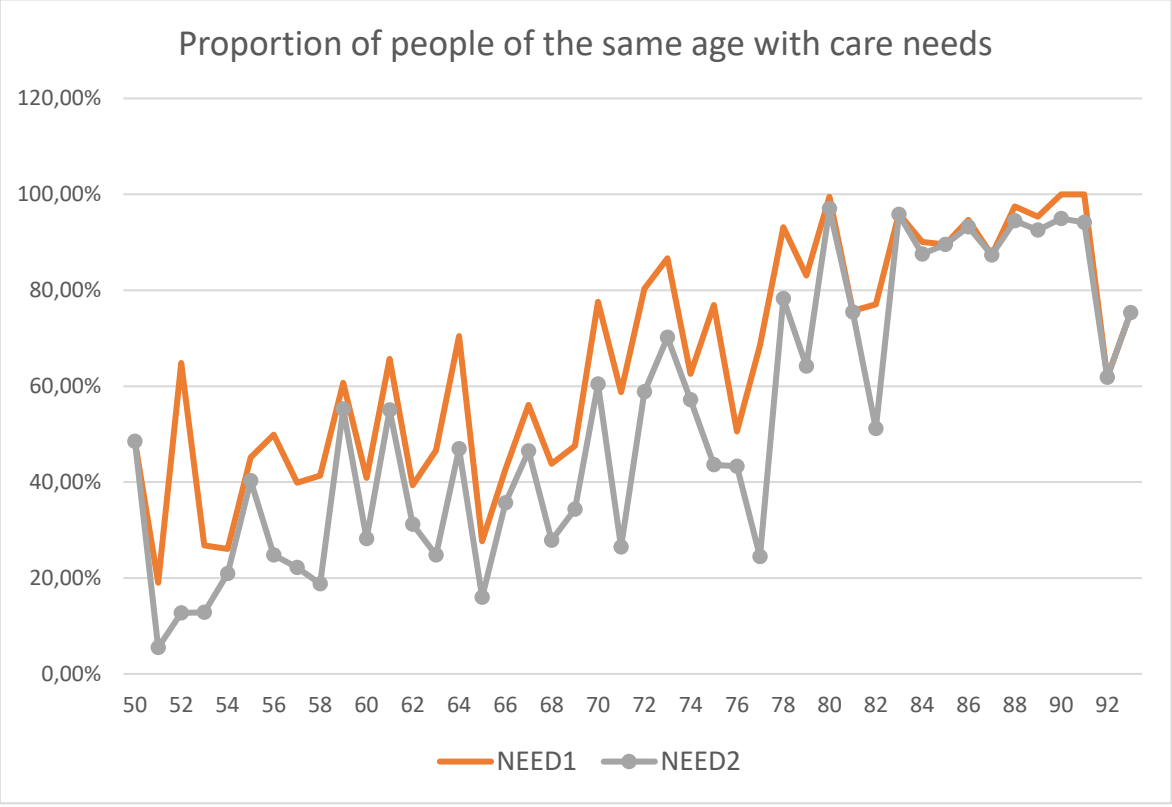
Annex

Figure A1



Source: Eurostat [hlth_silc_06]. Some or severe limitations.

Figure A2



Source: Calculations based on SHARE, wave 6. Weighted data.