

Freedom of choice and dignity for the elderly

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Overview of the condition of elders in Portugal

The total Portuguese population is 10.602 millions. According to the last population census (INE, 2002), the elderly constitute 16.4% of the total population (1,702,120 individuals), surpassing the amount of young people (16%). The expected percentage of old people in Portugal in 2050 is 32% of the population. The majority of elders are women (59%). The life expectancy is nowadays 79.4 years for women and 72.4 years for men and the actual dependency ratios will almost double in Portugal from around 23% to 45% in 2050.

The following data appears in a study of the demographic and socio-economic situation of the National Institute of Statistics (INE, 2002). The rate of illiteracy amongst the elders is 55.1%, being higher for women (64.7%) than for men (41.3%). The number of families with at least one elder person is 32.5%. Amongst the families with elders 50.5% consist of one elder person living alone and 48.1% correspond to couples of elders. The number of families of elders is growing and the multigenerational type of family is decreasing. Most of the elders are not working (81%) and those who are still working usually do it in agriculture. As expected, domestic activities like cooking, cleaning and washing are still performed by a significant majority of women whereas gardening, shopping- and administrative works are performed similarly by both sexes. The most important social activities considered by elders are talking to neighbours (68% do it every day) and watching TV every day, which is the leisure activity mentioned by 96% of elders. There are no other major activities so the level of physical activity and community participation is very low (in average less than 5% of individuals mention participation in social activities and most of them referred being seated all day). Women declare 'poorer health than men and the majority of them went to the doctor at least once in the last three months. One third of the elders may be considered poor, using either the criteria for type of household and home equipment or earnings, mostly if they live alone. In fact, recent figures show that Portuguese elders are very deprived but their social and psychological condition is nevertheless mostly unknown (INE, 2000).

The demographic ageing in Portugal is not uniform. There are "younger areas" along the North shore and really aged ones in the interior and rural regions. In addition to the main causes of demographic ageing around the world there were specific reasons in Portugal, where significant migration to foreign countries (e.g. France and Germany) occurred, particularly in the 60's, in addition to the rural-urban migration of the youngest, to escape poverty, or to find better jobs. This territorial asymmetry requires, in our view, different policies for old people, since elderly in rural areas do not have family members nearby, and their social network only involves peers, with similar needs of care, making it difficult to obtain informal care outside the couple. The risk of poverty is higher for old people reinforcing their vulnerability and the aged rural areas had a poverty risk of 33% in relation to 16% in urban areas.

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Based on a national overview of 920 clients distributed by the three types of services (Nursing Homes, Day Care Centers and Home Care) we listed below the main categories of answers by item: 1. Motive to choose a particular social equipment: About 34% choose the facility because it is near the residence and 25% because the equipment deliver adequate services. 2. The hygienic condition of the facility: the overall hygienic condition of the equipments were rated as good or very good by 93.5% elderly; the refectory by 94.3% and the WC by 91.5% of elderly. 3. The quality of human resources: elderly rated as good or very good 91.6% of the technical staff; 90.4% auxiliary staff and 90.5% of the administrative staff; the quantity of staff was rated as sufficient by 80% of elderly; 4. The burden of family finance contribution: 61% considered the price they pay for the service as reasonable and 26% considered it expensive. 5. Major problems found: the amount of fees was rated as the major problem by 51% of people and 21% pointed the lack of activities and occupational ateliers. 6. Quality and adequacy of the social service: the overall quality and adequacy of the equipment was rated as good or very good by around 90% of the elderly. 7. Satisfaction: 75% of old people declare they were very satisfied with the service and 24% said they were satisfied.

The assessment of the quality of equipments and services for old people is quite good although we should be cautious when interpreting the data. As we will discuss later the quality of care and the dignity and freedom of choice is not always guaranteed for old people in Portugal. When people escape poverty and exclusion environments by gaining access to social services, they tend to overvalue them, even though the level of social quality is insufficient. Many services and equipments need urgent improvement namely with respect to privacy (e.g. most of the facilities only offer double rooms) and self-determination, and in general the right to choose and decide, to have access to information and counseling and quality care that goes beyond subsistence (supply of basic needs like shelter, food and hygiene) DGEEP, MTSS, 2007.

Social Protection and Pension expenditure

In May 2007 there were 1,758,952 people receiving old-age pensions (IIES/MTSS, 2007). According to Eurostat (2006-07) the percentage of expenditure on social protection in Portugal in 2003 was 24.3% of GDP whereas the mean for EU-25 was 28%. Social protection corresponds mainly to transfers to relieve the burden of old age risks (8.9% of GDP). The social protection expenditure per capita in Portugal was around 4000 euros in 2002. Not surprisingly the intervention area with the greatest increase (41%) was old age.

Based on data published in the 'Carta Social' (MTSS, 2007) and in Martin et al. (2007) the estimated percentage of people aged 65 and older living in Nursing Homes in Portugal is around 3.5% (55,266 individuals) corresponding to an occupancy rate of 0.96 of the available places. About 41,204 (2.6%) old people attend day centers that have an occupancy rate of 0.69 of the capacity of centers and 67,716 (3.9%) receive home care corresponding to 0.92 of the capacity of agencies. This means that around 127,086 old people (8%) are currently receiving support from the Ministry of Labour and Social Security (MTSS) to face their needs associated with growing old.

Other recent policies for old people: National Action Plan for Inclusion (NAPincli) 2006-2008 (ISS/MTSS, 2006)

We will focus here exclusively on the objectives devoted to old people although they appear integrated in a larger plan to eradicate poverty and social exclusion. In Portugal 21% of the population lived below the threshold of poverty risk in 2004. The elderly are particularly vulnerable to poverty and 29% are poor (30% women and 29% men). The worse situation in 2004 was the one of 41% of households with one old person, and 31% of households comprising two adults where at least one was 65 years or more. The risk of poverty of the pensioners was 26% in relation to 13% of active people. About 66% of elderly had a monthly income inferior to the national average. Proposed measures, being currently implemented include:

Measure	Description	Target
Solidarity Supplement for old people (CSI)	Supplement from the solidarity subsystem for pensioners over 65 years. It is a supplement to the preexisting income. The amount is defined by reference to a threshold established annually and the allocation is differentiated according to the concrete situation of each pensioner applying to it.	Ensure all elderly, over 65 years old and with low income a supplement to increase their overall income to a minimum threshold of 4200€/year (at 2006 prices)
Pilot Project in restore old people's own houses	Improve basic housing conditions and mobility of the elderly receiving home care, preventing institutionalization and dependent situations	Finance 570 actions in old people houses with home care in 3 districts in the mainland.
Project to expand Social Facilities network - PARES	Support the expansion, development and consolidation of the social equipment network in the mainland, creating new places in social facilities in the areas of childhood, old people and disabled people	Create 19000 places in Nursing Homes and Day Centers until 2009.
Long-term care networks	Promote the offer of services such as: <ul style="list-style-type: none"> - Short term admittance in alternative to the hospital rationalizing hospital resources; - Lon-term admittance for old and dependent people; - Day units to promote autonomous life in the community. 	Create until 2008: <ul style="list-style-type: none"> (a) 997 beds in recovery units for short term health care (b) 1139 beds in units to provide medium term health care and rehabilitation (c) 2270 beds in care units to provide support services and long term admittance (d) 814 day care units / autonomy promotion (e) 326 beds for palliative care
Voluntary Service	Create a National Voluntary Service Network through local promotion to support old people	Ensure organized action in at least half of the councils of the country until 2008.

Long term care

The National Network of Integrated Long term care was created in Portugal by law in May 2006. Based on an agreement between the Ministry of Health and the Ministry of Labour and Social Security, it establishes the network to deliver continuous care to dependent people, independently of their age. The objectives include maintaining people in their own homes, with home care, whenever possible; rehabilitation and social integration and personalized and quality care. Services include institutional care, ambulatory care. There are four types of Units: (1) short duration for convalescence; (2) medium duration for rehabilitation; (3) long duration for maintenance and (4) units for palliative care.

According to the first report (RRCI, 2007) with the evaluation of the first year of implementation, based on a sample of 44 units and 1381 clients, data shows that the mean age was 72 years, 80.2% of people were 65 years old and over and those between 80 and 84 years old represent 20%. Most of the users came from the hospital (68%) and stay a mean of 33 day in convalescence units, 72 days in rehabilitation units.

The Portuguese context and trends of care for the elderly

The perspective of thousands of people with disability in the near future (30% to 50% of old people 80 years and over, Paúl, 2007), requires urgent planning of diverse health and social care. In a recent study of Portuguese old people living in the community (n=437) which we are extending to the all country, we obtain a worrying picture of elderly with very high levels of psychological distress (32% of old people, comparing with 20% of Great Britain old people, Paúl et al, 2006), cognitive decline (18%), disability in IADL (72.3%) and in ADL (64.8%). This alerts us for a specific problem that is the dignity of people with mental health problems, generally ignored, and people with dementia in need of special care, which is almost inexistent in Portugal. And the problem of other particular and also growing risk groups of elderly, like for instance handicapped people, that now live longer and survive their caregivers which are usually their parents. The family caregivers and the family responsibility in caring is another core aspect to be discussed, particularly in southern EU countries. Should we enforce even more the family support? How and with what consequences for family members, and society?

One major difficulty is the lack of qualified staff to work with old people. It is critical to implement a more participative culture, based on dignity and freedom of choice amongst elderly who grew up in the authoritarian culture of the dictatorship existing until 1974 in Portugal that did not promote autonomy and certainly not freedom of choice.

The actual political aim in Portugal is to establish the basic infrastructure to support old people's needs. The trend is to keep, whenever it is possible, people in their own homes and communities and expand the network of equipments mainly Day Care Centers and Home Services for old people. Considering that the low income of old people was a major problem to assure their wellbeing, the state, through the MTSS, is trying to raise the monetary income of old people to acceptable levels of welfare. Currently it is being implemented, in the scope of long term care, a change in the cooperation between agencies and in the relation between providers and users who receive direct monetary support to pay the service. This trend will probably contribute to increment dignity for old people.

The question now is who will provide care; who will pay for it (e.g. financial sustainability); how to guarantee access to care, and last but not least the quality of care. To be able to make choices (freedom of choice) means on one hand the existence of choices, and on the other hand the power to decide, that means not only self-determination (empowerment) but also the material conditions (e.g. financial), to implement the choice. In Portugal, both of these last conditions are not guaranteed. To a large majority of old people there are very few alternatives to NGOs (around 80% of the total agencies delivering care to old people), financed by the state, which only deliver basic social care, and poorly articulated with the national health care system. The existing alternatives to NGOs are very expensive services and equipments for upper class clients. The shortage of offers does not promote competition for clients, and a deprived market does not stimulate new valuable initiatives. How can we speak about freedom of choice in the Portuguese context? The central point seems to be not private versus governmental social and health services, but the amount of supply and the quality of care available to every old people.

We will select the enlargement of social and health care network and the quality care as the Portuguese priorities to first guarantee dignity for the elderly. In our view, we should extend the offer looking at the same time carefully at the standard of care provided, using the criteria of the Amsterdam declaration on quality of care, creating EU indicators and culture bounded standards. In that respect we are very committed to take into account seriously the “Charter of Rights for People in Need of Long –Term Care and Assistance” and implement it as a framework to improve quality in the scope of rights of older people.

Discussion

Taking in consideration the Swedish experience some aspects were suggested for analysis:

Relevance for Portugal of the Swedish report (Hellqvist & Lofgren, 2007) and experience, and the discussion paper on “Freedom of choice and dignity for the elderly” by Tesch-Romer (2007), it is important to underline the emphasis on the dignity of elderly depending on the capacity and freedom of choice, and how this should be assumed as a general feature within policies. However due to the clearly huge differences between the current state of the existing social and care services for old people in both countries, we wonder how to combine the investment on basic services and freedom of choice. Is it not the full coverage of services to everybody a prerequisite for the freedom of choice? What is the relation between freedom of choice, and sufficient and diverse supply of care for the elderly?

In what concerns **Transferability** of policies we question how dependent is freedom of choice of decentralized political systems, as Portugal is a centralized country where regionalization was defeated in a national referendum in 1998. The experience under analysis is based on a very different type of local power with responsibility towards health and social care. Another major issue is the traditional family role in taking care of the elderly as a common basis in southern European countries. How does freedom of choice contribute for a better arrangement between informal and formal care? Is it going to reinforce and undervalue the female role in informal care? It seems that currently in Portugal the priority is providing access to care, namely to vulnerable groups, rather than freedom of choice. The major questions that should be raised and debated at a national level are: (1) Does the freedom of choice result in different benefits for different social groups? (2) How do you intend to integrate informal care? (3) How to avoid replacing financial costs by social costs?

Recommendations towards the Swedish experience

Keeping in mind the meaning and comprehensive dimension of the reported experience, we recommend some improvements in order to better link health care and social care. We suggest the creation of an independent and recognized committee to coordinate and follow up, integrated care.

The importance of the partnership between public and private entities was underlined. In this respect some documented experiences, following similar rationale, emphasize the need to pay attention to the sub-contracting procedures, due to the need for an extra level of assessment and monitoring.

In brief, we consider the questions about dignity and freedom of choice for the elderly to be critical aspects for the wellbeing of old people but we have to contextualize the discussion considering the actual development of monetary benefits, social services and facilities in each EU member state, so that we can guarantee an acceptable level of health and social care, accessible to everyone. In parallel we should encourage the diversity of providers and services, facilitating the freedom of choice.

Although we have a lot of possible indicators of quality of care, we should go deep in this discussion at EU level, to be able to settle what basic services versus supplementary services are.

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