The imperative of caring for the dependent elderly person

Maria Cecília de Souza Minayo 1

Abstract This text presents an overview of aging in Brazil and information that highlights the need to create instruments to deal with the exponential increase of the elderly population, particularly those who lose their physical, cognitive, mental/emotional, and social autonomy. Examples of public policies created by European countries, notably Spain, show how they act to protect the most vulnerable individuals and provide support to their families, especially to the informal caregivers. The whole process of protection for the longlived is perceived as a form of social solidarity in which the State and sub-national entities, society, the families and the elderly people themselves participate.

Key words Elderly person, Social protection, Dependency, Autonomy

¹ Departamento de Estudos sobre Violência e Saúde Jorge Careli, Escola Nacional de Saúde Pública, Fundação Oswaldo Cruz. Av. Brasil 4036/7°, Manguinhos. 21040-210 Rio de Janeiro RJ Brasil. maminayo@terra.com.br

Introduction

A brief overview is presented of the aging process in Brazil together with information that highlights the need to create instruments to tackle the exponential increase of the elderly population, particularly those who lose their physical, cognitive, mental/emotional, and social autonomy. Examples of public policies created by European countries, notably Spain, show how they act to protect the most vulnerable individuals and provide support to their families, especially to the informal caregivers. The whole process of protection for the long-lived is perceived as a form of social solidarity in which the State and sub-national entities, society, the families and the elderly people themselves participate. Brazil is at an important junction for decision-making, the acuteness of which has been exacerbated by the economic and political crisis, but this should not preclude the attention and in-depth vision required with respect to the new demands being created by population aging.

The context of longevity in Brazil and in the world

The policies implemented by the Social Welfare States during the period after world war two led to a marked improvement in living and working conditions, contributing towards an increase in life expectancy in almost every country in the world. Since then, a progressive fall in birth rates has been seen associated with other phenomena such as the universalization of education and primary health care, the intensification of female participation in the job market and the widespread availability of family planning. The growth in the number and the ratio of elderly people – with an exponential increase in the population over 80 years of age – has become an irreversible fact¹⁻³.

The Brazilian population has accompanied the aging trend. In 2017, the country surpassed the mark of 30.2 million elderly people in accordance with the Ongoing National Household Sample Survey⁴. In the last five years, 4.8 million elderly people were added to this list, which is equivalent to an increase of 18% for this age group alone over the period. Currently, women represent 16.9 million (56.4%) and men 13.3 million (43.6%). Between 2012 and 2017, the number of elderly people rose in all states of the Federation, with the States of Rio de Janeiro and Rio Grande do Sul having the highest levels,

each with 18.6% of their population aged 60 and above. Amapá is the State with the lowest percentage (7.2%)⁴.

Among other major consequences, demographic and social transformations have significantly altered family structures and the situation of the elderly around the world, including Latin American countries, and have had a tremendous impact on Brazil^{4,5}. Women working outside the home, the drop in birth rates and the consequent reduction in the number of children have had an impact on the replication of inter-family solidarity. The number of people available to act as caregivers is on the decrease, while intergenerational families have increased (great-grandparents, grandparents, sons and daughters and grandchildren co-existing in the same home), which can, on the one hand, represent the possibility for human enrichment. On the other hand, an increase in relational tensions, especially for an elderly person, may arise, in the event they feel left out of family conversation, plans and programs and when lacking adequate physical and socio-cultural space to meet their needs^{1,2-4,6}.

One of the most serious challenges at the present time is the social security issue. The new scenario has brought considerable pressure to bear on the structured systems, which, for the most part, have been organized to respond to a reality characterized by the expansion of salaried employment and by a short life span after retirement. Since the end of the 1970s, the demographic change gained pace, together with the demands made on social protection systems. On the one hand, this involves an added bonus for these countries, since the increase in longevity means that the population enjoys more economic prosperity and greater resources for health, basic sanitation and a healthy diet. On the other hand, there exists an equation which does not square up: for many people the period of retirement can attain 40 or more years, which increases the number of those who leave the labor market, while the number of those who contribute is reduced^{5,6}. For example, the forecast indicates that, from 2039 onwards, Brazil will have more inhabitants over the age of 65 than children up to the age of 14. Furthermore, in 2060, 67.2% of the country's citizens will be considered to be dependent on the adult workforce (aged over 65 or under 15 years of age) for every one hundred citizens of working age⁴. In other words, the socalled Social Security crisis, as it is shaping up today, is fact and not fiction. And this situation can only deteriorate because governments, in

general, refuse to deal with this question in more favorable times, acting only in moments of crisis and without curtailing any privileges. The truth of the matter is that the elderly cannot be held responsible for government abuses and inconsistencies at the most vulnerable time of their lives, since most now receive pensions of one or two minimum wages. Solutions are not that simple and social solidarity in favor of elderly people who are less well-off, must not fail under any circumstances.

From the point of view of the health policy for the elderly, studies have shown the importance of services that focus on the prevention of chronic diseases and invest in some form of multidisciplinary care⁷. This requires re-thinking the hegemonic biomedical paradigm, transforming it into a socio-environmental model that views disease from a life context and comorbidity perspective, and aims to maintain, for the longest period possible, the physical, cognitive, and emotional/psychological health of the elderly. The services currently on offer are, in general, shown to be inadequate, insufficient or incomplete to ensure the prolonged care that this very vulnerable segment of the population requires. The same also holds true for the social services^{2,3,7}.

Amongst the elderly, those with functional impairments and social problems are the ones who suffer the most and are more frequently the victims of violence, negligence or abandonment³. Men and women aged 80 or more are particularly prejudiced in this respect, together with the very poor who do not have the means to sustain themselves, and widowed and single women with physical, cognitive and emotional health problems. In general, this group has needs that are not covered by the services and benefits traditionally offered by the Social Security and Social Welfare Institutes or by routine Public Health services⁷.

Political initiatives in favor of the elderly population

The issues raised above have led to the inclusion of the topic of providing adequate social protection for those experiencing the aging process – in particular for those who acquire functional incapacities – as part of the agenda of European governments, since dependency is considered to be a major contemporary challenge^{8,9} Families alone can no longer be held responsible for the onus of the care of the elderly¹⁰, nor can the more vulnerable be subjected to interminable queues for routine health services and social care. The

major demographic, social and family changes demand the organization of the supply of home care, to support the performance of daily activities, to promote autonomy, and preventative and quality of life actions¹⁰. This demand aims to respond to active and healthy elderly people, as well as the contingent of citizens who suffer from a more or less serious reduction of their functional capacities. It is in relation to this second group that this reflexive study is now focused^{8,9}.

The chart of dependent elderly people was drawn up by the National Health Research (NHR) study conducted in conjunction with the Brazilian Institute of Geography and Statistics (IBGE) and the Ministry of Health (MH) in 2013. The data analyzed by authors, such as Lima-Costa et al.11 reveal the following: 23.815 people were interviewed, in a nationwide representative sampling of the entire population over the age of 60. Of this group, 56.4% were women, reaffirming their predominance in the longevity process; 32.8% were illiterate; 46.5% had between one and eight years of schooling and 21.7% had tertiary education; 14.9% lived alone; 35.6% lived with one other person and 42.3% lived with two or more people. A prevalence of 30.1% was found for at least one limitation of daily life activity (DLA), reaching 43% in the case of illiterate persons; and 29% for those who had basic schooling and 13.8% for those with tertiary education. These statistics highlight, on the one hand, the high proportion of elderly people who have a loss of autonomy; and on the other, the effects of inequality, shown in the group of illiterate persons and in the group with basic elementary education.

Elderly people with functional impairments associated with chronic physical, cognitive, mental or emotional and motor diseases are acknowledged by the World Health Organization (WHO)⁷ as being "vulnerable" or "dependent."⁷ Echoing the WHO, the Council of Europe^{8,12} considers elderly persons to be "dependent" when these individuals, for reasons associated with the reduction or even the lack of some functional capacity, require help in order to carry out their daily activities, requiring the presence of at least one other person to support them. These difficulties are defined by means of two categories: basic and instrumental. The first refers to selfhelp tasks, such as dressing, eating, attending to personal hygiene and moving about, namely daily living activities (DLA). The second refers to the capacity to perform necessary personal and social development activities: participating in the

community, carrying out practical tasks such as shopping, paying bills, fulfilling social engagements, using transport facilities, preparing meals, communicating, looking after their own health and maintaining their own integrity and security, namely instrumental daily living activities (IADL).

Although the measures they have adopted internally are quite distinct, European countries have implemented strategies to reform their social security systems to benefit the elderly and those in a vulnerable or dependent situation as a specific, focused and priority issue. In the 1980s, some countries formulated plans to adapt the mechanisms of social security to the situation of those who, having lost their autonomy, required prolonged care. During the following decade, adjustments were made principally because of budgetary restrictions. However, and in spite of the fiscal crisis, various countries of the European Bloc have been adopting specific regulations to classify the "degree of dependency" of elderly and disabled people and, depending on the seriousness of each case, to organize the provision of pecuniary assistance or care in the form of the supply of services^{8,9,12}.

For example, the German model characterizes the situation of loss of autonomy, based on the amount of time of daily help a person needs. This system establishes three levels of dependency and each one of these corresponds to a level of the social protection offered. In France, classification is made according to the type of help that a person needs. In order to analyze loss of autonomy, a scale is applied that measures functional incapacity. Depending on the degree, the public authorities supply specific social and health care services. Both of these countries created specific laws related to dependency and administer the system with the participation of civil society and finance these by means of collaborative participation between central government, the states and municipalities and the support of the families and elderly and disabled people themselves, such that no one without the necessary financial conditions is left without care^{6,8,9}.

In 2004, Spain created the "White Paper on Dependency" 12, seeking to protect the elderly and functionally-incapacitated disabled people. To cover the costs of this new program, central government divided these responsibilities with the autonomous communities. It was established that these could be public services, authorized by the public authorities or implemented by associated institutions. However, the responsibility

for putting into effect the Law of Dependency was, and continues to be, that of the Ministry of Social Security. For instance, the public and associated entities that look after the elderly comprise a type of catalogue of five different types of services: (1) prevention of dependency situations and the promotion of personal autonomy; (2) home help (support for domestic and personal care activities); (3) day/night centers; (4) institutionalized care, by means of geriatric residences and care centers for people with mental deficiencies or physical disabilities; and (5) home tele-assistance. This last service enables elderly people who have a loss of autonomy, who live on their own and find themselves in a situation of risk, to enter into contact with a specialized care center. Intervention is immediate when personal, social or medical problems are involved, providing security and a better quality of life to the person in their own home. There is also an important support, training and rest promotion program for family caregivers.

From the social security standpoint, Brazil has fortunately arrived at a stage considered to be good, since 84.3% of elderly people receive retirement payments, pensions, the so-called ongoing cash benefits, or some other form of official support⁶. And, recently, the Superior Court of Justice, in the first session held on August 22, 2018, established the condition that *once the need for permanent third-party assistance is proven, an increase of 25%, as foreseen in Article 45 of Law No.* 8,213/1991¹³, *is due to all models of retirement pensions*, extending the benefits that were previously only granted in cases of retirement for disability.

However, following the example of Europe, Brazil needs a law or a specific strategy to deal with the elderly who have lost their basic and instrumental autonomy and who have become dependent on the care of third parties^{6,14}. They are practically ignored by the State and by society, becoming the individual responsibility of the families concerned or of a few charitable institutions. To understand the scale of the demand, as was done by the PNS in 201310,111, and to qualify these by levels of severity and offer adequate public services, are goals that are now urgently required, especially when it is seen that the fastest growing segment of the population in Brazil is of people aged 80 and above. This is the age bracket that has the greatest probability of being affected by deteriorating physical, cognitive, motor and mental conditions, as the WHO7 and several other authors have emphasized^{1,2,3,7-12,15}.

Some final considerations

The references highlighted in this text draw attention to the social, political and social service sensitivity required to implement several pressing measures.

From the political standpoint, even though several sporadic initiatives have been implemented, Brazilians have still not fully tackled the question of "dependency." Thus, some actions are needed, such as: (1) to define the duty of the State with regards to the irreversible phenomenon of an increase in the population and the dependency on third parties of elderly people who suffer from a loss of autonomy; (2) to establish a formula for joint participation with civil society organizations, the families and the elderly people themselves; (3) to adapt the traditional structure of social security policies to deal with this expanding group; (4) to establish ways to finance the increase in demand and the complexity of services that are becoming increasingly necessary; (5) to improve the situation and training of family caregivers and of formal caregivers; (6) to develop specific local programs and services, to meet the demands of this segment of the population in its varied stages of loss of autonomy.

From the operational standpoint, Brazil needs an agenda of specific and adequate ser-

vices. For this, several questions need to be taken into consideration: (1) to understand the nature of the problem and its meaning for individuals, the family and society. Dependency cannot be restricted to the medical dimension, although it is manifested in functional deficiencies that greatly affect health. It is also associated in a relevant manner to the social isolation that does not allow the elderly to enhance their performance and, sometimes, to lead a more active life; (2) to structure services of an integrated, multidisciplinary and multi-professional nature that offer various methods and possibilities of protection, according to the level of seriousness of the dependencies and the social needs of the elderly; (3) to invest in training professionals who are able to understand, treat and care for elderly people, especially the more vulnerable.

It would seem obvious, but the penny still has not dropped for Brazilians in relation to the accelerated rate of population aging. On the one hand, it is a bonus, namely the sign of an improved lifestyle, the need for social and economic investment in this segment of the population! On the other hand, there is concern about the progressive increase of those who depend on their families, their neighbors, on civil society and on the State, especially on the social and health services! So, longevity emerges as the major novelty of the twenty-first century!

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Article presented 14/09/2018 Approved 25/10/2018 Final version presented 27/10/2018