Rights, Freedom and Opportunities: how are they experienced by the elderly in an institutional context?

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Abstract

The progressive aging of the population has led to a number of legislative measures in this area. However, the way society, in general, looks at aging is also one of the necessary changes. In fact, one of the blocking factors of aging societies is related to the social meaning that is attributed to old age. The strategy of protection for the elderly includes the strengthening of elderly rights, particularly in terms of their independence, active participation, care, personal fulfillment and dignity (Resolution of the Council of Minister nº63/2015). Faced with an aging society, residential structures are one of the important answers for the elderly population in Portugal nowadays, and should enhance the quality of life of the elderly through the maintenance of their identity, rights, independence and autonomy. This part of the study intends to know the experiences of the elderly in residential structures, identifying their perception about their rights, specifically the decision power, freedom, autonomy and opportunities of their exercise. Data was collected through semi-structured interviews with 20 elderly individuals aged 80 to 91 years and treated through content analysis. The elderly consider as important five main rights: the right to care, freedom, health, retirement and active life. More specific rights, such as decision-making and freedom of action and expression, are mainly perceived as non-existent or conditioned in the institutional context. However, the right to autonomy and its exercise are more present. The results show the elderly as a low active part in residential institutions, in which the welfare practices are still dominant.

Key-words: elderly; residential structures; rights; autonomy; decision power; freedom.

Introduction

Both society and the phenomenon of aging are realities in fast transformation, exhibiting tensions and imbalances, that lead to the necessity of looking for new understandings of aging and the role of society in their responses. Aging must be understood in the crossing of diverse changes in the current world, such as: demographic and labor changes, individual changes, family changes and changes of the state role. The first relates to an increase of the aging population and a decrease in birth rate, as well as an increase of labor instability and mobility. According to the data released by the National Institute of Statistics, Portugal has the 4th highest value in terms of proportion of the elderly, i.e., 141 elderly per 100 young people in 2014 (National Statistics Institute [INE], 2015). In the future, the number of young people from 1.5 to 0.9 million is expected to decline and the population over 65 years old will increase from 2.1 to 2.8 million between 2015 and 2080 (National Institute of Statistics [INE], 2017). The familial changes mainly relate themselves to changes in its structure and to the decrease of the availability or possibility to care for elderly relatives. Regarding to individual changes, we can verify that in the elderly there is an increase of vulnerability in terms of health, increasing loneliness, increasing number of people living alone (some in isolation) and more vulnerability due to widowhood. In fact, widowhood is one of the factors that must be taken into account as it drags down the

source of instrumental and emotional support, once the conjugal relationship is one of the main sources of emotional support and of care (Zettel & Rock, 2004). Faced with all this changes emerges the necessity of transferring the care to a professional group, bringing us back to some changes in the state role itself (Neto & Corte-Real, 2013), through the improvement of social equipment networks, and the adoption of a different perspective regarding the elderly, which can valorise their independence and autonomy.

Changes in the role of the state in the face of aging are consonant with the emergence of new perspectives that face it as a phase of biologically susceptible development, but also with gains (Carvalho & Dias, 2011; Baltes & Smith, 2003). Aging starts to be seen as a biopsychosocial phenomenon and as a process that happens differently for each person (Ballesteros, 2007; Fonseca, 2006).

The elderly population is not a homogeneous group, and there are relevant differences, especially between the third and fourth ages which, although different, should be considered complementary (Baltes & Smith, 2003). The third age (between 65 and 75 years old) is associated with the concept of the *young old* and the fourth age with the concept of the *old old*, concepts mentioned by Baltes and Smith (2003) to show this transition happens in developed countries between the ages of 75 and 80 (Olshansky, & Désesquelles, 2001). In the third age there are substantial cognitive and emotional reserves and particular strategies to manage losses and gains, while the fourth age is marked by more pronounced cognitive losses, prevalence of dementias and greater vulnerability in social terms (Azeredo, 2016; Ferreira, Silva, Jerónimo, & Marques, 2013). The balance between gains and losses can be sustained through strategies of selection, optimization and compensation, allowing individuals to find strategies to respond to emerging challenges, to achieve high levels of functioning and to use compensatory efforts to protect those already achieved (Baltes & Dickson, 2001).

In Portugal, in 2015, the Council of Ministers approved a strategy to protect the elderly[1], which sets out several measures aimed at reinforcing: independence, participation, assistance, personal achievement and dignity. The state is beginning to approach the scientific visions of aging and to approach it in consonance, however, it is necessary to comprehend in which measure this new understanding of the elderly person its necessities and rights transposes to the responses of the institutional care.

The institutionalization of the elderly stands out as one of the answers most implemented in Portugal, especially when there is dependence or a concern with its eventual emergence, although this response arises with a negative social connotation (Pimentel, 2001). This type of formal care is provided by private entities, whether or not for profit, as is the case of Private Social Solidarity Institutions[2] (forward PSSI).

Older people residing in most PSSI have medium/low incomes, being part of a social fringe with few resources. Thinking about the mission and characteristics of institutional responses allows us to understand the experience of aging and its quality in this context. The implications of elderly's residence in institutional structures for their quality of life should be considered, considering that the adaptation to contexts of collective living refers to a certain extent to an idea of deprivation of the experience of a world with greater emotional stability and independence (Guedes, 2008). Living in residential structures implies breaking a standard of living, changing social status, limiting autonomy and independence and reducing activities that were habitual. In this sense, there is a need to prevent and overcome the difficulties of living in a collective context, strengthening the quality of life in them.

[1] Resolution of the Council of Minister nº63 / 2015.

[2] They are institutions set up on the initiative of individuals, not for profit purposes, with the purpose of giving organized expression to the moral duty of solidarity and justice among individuals, which are not administered by the State.

The concept of quality of life is already present in the Portuguese legislative guidelines. In the literature, the quality of life emerges as a concept that encompasses multiple dimensions presenting an objective dimension (the real life conditions of the subject) and a subjective one, i.e., the perception about the individual's living conditions (Fernández-Ballesteros, 1998; Irigaray & Trentini, 2009; Schalock & Verdugo, 2010).

Shaclock (2004) identifies eight dimensions of quality of life: emotional well-being; interpersonal relationships; material well-being; personal development; physical well-being; self-determination; social inclusion and human and legal rights. Our opinion is that groups with some vulnerability need to see their rights strengthened, fulfilled and protected. In this sense that we propose to ascertain its meaning for the elderly and their presence in residential structures.

Method

1. Aim of study

The purpose of this part of the study, consist in knowing the perception that the elderly have about their rights, as well as the presence and meaning of the same in the institutional context where they reside. It is intended: i) identify the perception of rights that the elderly think they have; ii) to know the perception about the existing decision-making; iii) identify the existence of possibilities for autonomy and implementation of its decisions; iv) identify the perception about their freedom.

2. Participants

This study was composed by 20 elderly people (10 men and 10 women), with ages between 80 and 91 years old, institutionalized for over a year, in two Private Institutions of Social Solidarity in the district of Évora. For the constitution of the sample, the followed criteria were: a) being in a residential structure for more than one year; b) don't have cognitive impairments identified by qualified professionals; c) being a widower; (d) between 80 and 91 years of age.

3. Instruments and Procedure

Initial requests for authorization and informed consent were made to the institutions and participants. In the case of the participants who don't know read or write, the informed consent was read and their authorization was given verbally. Three exploratory interviews were conducted with open questions. Based on the data from these interviews and on a review of the literature, a semi-structured interview guide about elderly rights were constituted by four themes (General Rights, Decision Making, Executive Autonomy, Freedom) with a total of 11 questions. The interviews were conducted individually, audio-recorded and transcribed in full. To analyze the data we used content analysis (Bardin, 2016). The analysis procedures were organized around a process of categorization of elements grouped according to their common characteristics. Within each question we define categories and subcategories, identifying all units of qualitatively different meaning and forming a unit of record whenever there was evidence that a complete meaning had been expressed[3] (Grácio, Chaleta, & Rosário, 2007).

The criterion of registration consisted in noting the presence of verbalizations belonging to a given category or subcategory in each subject's discourse and not in the number of times they referred them. The quantitative

[3] The coding of the registration units was performed by two evaluation elements in order to control biases, using consensus and reflection techniques to obtain evidence of content validity (Fonseca, Silva & Silva, 2007).

analysis consisted of a simple descriptive analysis using frequencies and percentages to identify the aspects most mentioned by the participants (Schiling, 2006).

Results

The results presented below refer to two distinct but complementary aspects of rights. One concerning the general rights of the elderly population. Another, on specific rights.

General rights of the elderly

The perception of general rights is contextualized by age group (rights of the elderly) and by the specific context of life of these participants (rights in the residenciall structure). The elderly consider that there should be five general rights of this age group: the right to care (N = 18, 6.5%), freedom (N = 4, 1.4%), health (N= 1; 0.4%) and active life (N= 1; 0.4%). Only one participant showed that at this stage in the life cycle they no longer have any rights. The right to care is the most mentioned and is structured mainly by relation to quality of care (N= 8; 2.9%) and affective-relational aspects such as affection and respect (N= 6; 2.2%), is still referred to as quality food, safety, individualization and personalization of care.

"Be well treated" (Suj 7).
"... I think it must be the affection of other people ..." (Suj.20)
"Respect ... to be respected!" (Suj.17).
"There is no shortage of food, but it is badly made, it has no seasoning, it has no taste, then there is no will to eat, everything is on the plate, then everything goes to waste because it has no taste at all" (Suj.11)
"That the people who care for us should take account of our situation ... each in his own way, according to the situation" (Suj.1).

The right to freedom is the second most mentioned right and is conceptualized by the elderly as a general right (N= 3; 1.1%) and as a right to freedom of expression (N= 1; 0.4%).

"The rights of freedom ... They must have the freedom to live, to live" (Suj. 13)
"(...) why should we be practically in a prison ...? You can not talk, you can not say, you can not talk ... that's sad! This is sad "(Suj.4)

With respect to the existence of elderly rights in the institution, there are two dichotomous opinions practically of the same weight: that the rights previously mentioned exist in this context (N= 9; 3.3%) and that they are non-existent (N= 8; 2.9%). Some participants consider that the existence of rights of the elderly is dependent on the caregiver (N= 3; 1.1%).

"They have, they have this right" (suj13).
"We do not have no ... because if we complain we are not heard" (suj.17).
"Sometimes it is not the one who commands ... it is them [the auxiliaries] who walk there" (suj.9)

Specific rights of the elderly in the context of residential structure

The perception of specific rights refers to the rights related to decision-making, executive autonomy and freedom in institution.

The decision-making was explored according to two different aspects: the decision-making of the elderly in the institution and the decision-making of the elderly over their life in general and in a broader way. Participants refer exclusively to the absence of their decision-making power in the institutional context (N=18; 6.5%)

"Choose, me? Nothing ... I have nothing to decide "(Suj.1)
"Nothing, I have nothing to decide in the institution" (Suj.20).

Most of the participants consider that they do not have decision-making power over their life (N= 14; 5.1%), which is associated with conformism, age and health losses, financial power and spouse.

"No ... what I have, I have and it's over. I'm conformed with what I have! "(Suj.1)
"My life is at the end ... I am old, I do not see, I do not walk ..." (Suj.8)
"I do not decide anything, I tell the daughter that I need this or that and everything appears to me ... My daughter is receiving the pension, dividing the money, paying ... buy me everything that is needed and ready" (Suj.12)
"Nothing else ... I do not decide anything else! As a widow, I no longer decide anything! "(Suj.4)

However, others consider that they still have the power to decide on their life (N= 6; 2.2%) in an unspecified general way and regarding carrying out day-to-day activities, visiting their home and family. In any case, this decision-making over their life emerges as circumscribed and limited.

"I still decide my life." (Suj. 19)
"I can decide to sew, so I still do "(Suj.9)
"Few thing, very few ... just go to my house, see my grandchildren ... my life is just going to see them ..." (Suj.5)

The right to autonomy was explored considering the institution's routines, the possibility of choosing activities and carrying out activities outside the institution.

All elderly people report that they can decide on bedtime (N= 20; 7.2%). Regarding the possibility of determining the time to wake up, some say they can decide (N= 12; 4.3%), while others indicate that there is no such possibility (N= 8; 2.9%). In both situations we understand that this decision may be conditioned by the institution's own routines and rules.

"(...) at night, we lie down when we will" (Suj.20)
"(...) I get up at 7am but if I want to get up a little later I also get up ..." (Suj.8)
"It's not like that ... to get up ... if you want to choose that, it changes the work of caregivers ...and its complicated" (Suj.1)

Regarding the possibility of going to the room during the day, some say that they can actually do it (N= 14; 5.1%), while others say they can not (N= 6; 2.2%). Some report that this possibility only exists when they are ill (N= 2; 0.7%).

"Yes I can ... (...) since I came here ... I rarely come, but sometimes I feel like it!" (Suj.9)
"No, that's what they do not let ... they do not let them go to the rooms ..." (Suj.1)
"(...) here, we only stay here if we are sick ..." (Suj.12)

Most verbalizations indicate the possibility of choosing activities (N= 14; 5.1%). However, there is also the idea that there are few opportunities to choose activities of interest (N= 4; 1.4%).

"Yes ... gymnastics, for example ... to the swimming pools (...). I can choose ... other activities do not tell me anything ... and I do not participate "(Suj.5)
"(...) the time that you go here to do things awkwardly, they should have been doing here a school to learn to read ... to say like this" I have this newspaper or this paper and I still know what is saying here ... ". That's what it was, I already said there ... instead of certain things, it was better ... a guy learn to read! "(Suj.3)

Some elderly report a withdrawal from participation in activities (N= 7; 2.5%), due to functional reasons (N= 5; 1.8%), lack of will, loss of interest or due to feeling excluded (N= 2; 0.7%).

"I used to participate more ... not now, I can not!" (Suj.10)
"There are no activities ... they go to the pools ... and there are always the chosen ones, once they invited me, but I said I could not go ... It's just that little group ... just that little group! I am not interested in choosing anything ... "(Suj.17)

When questioned about the possibility of leaving the institution to perform any activity of their interest, we found that most of the verbalizations indicate the existence of autonomy (N= 14; 5.1%). A closer analysis allows us to understand that such autonomy is governed by an "early warning" rule in the institution.

Considering that there is no autonomy to leave the institution (N= 7; 2.5%), it is a prohibition on the part of their children with a conditioning and dependence on the authorization of the institution, or with the existence of functional limitations. Only one elderly reported having no knowledge about this issue (N= 1; 0.4%).

"I can ... no one has hindered me so far" (Suj2)
"No, I have no order from my daughter ... But I can not either. My physique can not, I have pains I can not walk there ... "(Suj.1)
"When I do not want to, that's when they leave!" (Suj.11)
"I do not know if I could if I could not, I have not asked!" (Suj.4)

The right to freedom has been exploited in terms of its existence in the context of the institution, particularly in terms of freedom in action and expression. The perception that the elderly have their freedom in action, or the possibility of acting according to their will, is considered above all as existing (N= 14; 5.1%), as conditioned by the rules of the institution (N= 7; 2.5%) or non-existent (N= 6; 2.2%).

"I have freedom, no one commands me except myself ... I am free ... to do what I know how to do" (Suj.6)
"Whatever you do not, we have rules ... no one can do what they want, we have to have that discipline ... I think it's so!" (Suj.19)
"No! It is not free not! (...) ... I do not have the freedom to go get something and do ... "(Suj.4)

Freedom of expression is also mostly considered as existing (N= 13; 4.7%), although some elderly consider that their opinions have little weight in institutional practices.

"I can ... complain, people complain, but there is nothing to do ... they complain about food ... but there is nothing to do" (Suj.3)

Other elderly express the idea that their freedom of expression is conditioned by the consequences that can arise and by the concrete fear of reprisals or conflicts (N= 4; 1.4%) and can even be non-existent for the same reason (N= 3; 1.1%).

"There is always fear of reprisal ..." (Suj.17)
"I do not, I do not think, I do not want to ... There were people who arrested me ..." (Suj.1)

When questioned about the possibility of making a complaint, most people report they can do so (N= 15; 5.4%) but are afraid of the consequences (N= 15; 5.4%). Residually, others reported lack of knowledge of the possible consequences that such an option might bring (N= 3; 1.1%).

"(...) I can, sometimes it is necessary" (Suj.7)
"I do not think so ... I can not do it!" (Suj.15)
"(...) I do not want to make complaints ... a guy is always avoiding it, because this then falls into their hands and instead of treating a guy well treat him badly ..." (Suj.3)
"I do not know what could happen, I never did ..." (Suj.12)

Conclusion and Discussion

Human rights are one of the most important civilizational achievements emerging as a guarantee of individual and social well-being. These rights are changeable and are evolving. In this sense, the rights of the elderly have been gradually phased in. In addition to all the rights inherent to any citizen, the rights of the elderly are related to: independence; participation; assistance; dignity; respect for freedom and own choices; non-discrimination, social protection, protection against violence and abuse, economic security, health promotion, family and community living. In the 1996 European Social Charter, it was pointed out that institutionalized elders must be guaranteed adequate support in taking decisions on the institution and guaranteeing their fundamental rights (Resolution of the Assembly of the Republic nº 64-A/2001) In the present study, the elderly refer to the right to care, health, retirement, active life and freedom as their general rights. The right to care emerges as the most verbalized right, understood as consisting of a relational dimension marked by affection and respect and a more instrumental one, linked to the basic care of treatment, safety and food.

More specific rights such as decision-making, executive autonomy and freedom in the context of the residential structure were explored. The possibility of making decisions regarding their life in the institution is perceived by the elderly as non-existent. This non-existence is related to two aspects. One, related to the culture, rules and routines of the institution and also to the lack of human resources. Another is the health status of the elderly, which leads them to a state of dependency on the caregiver and a restriction of their wishes, which are limited to basic care without any other aspirations (Jakobsen & Sorlie, 2010).

As in the various legal documents[4] on aging, a situation of physical decline can not mean a reduction of rights and the possibility for the elderly to determine their lives in line with their interests and values. The notion of non-existence of decisions about their lives in general is also conspicuous with a conformism linked to lack of perspective and hope, old age, depleted health, loss of financial control, and death of the spouse. The elderly consider autonomy in terms of sleep and rest routines in the institution (waking and lying during the day or at night). However, we found indicators that the routines of the institution tend to overlap with an individualization based on the free will of the elderly, seeming to be based mainly on rules not only explicit but latent in the institution. The elderly consider that there are activities that can be performed in the institution, but the activities available are more related to aspects of physical and occupational health. In the opinion of some older people, the activities are not very stimulating and do not correspond to some of the yearnings or the role they should play, i.e. to promote lifelong learning. In this sense, measures should be taken to promote greater involvement of the elderly in stimulating and enriching activities that could contribute to an increase in their interest in life and a sense of belonging. The data show the right of the elderly to freedom of expression as quite conditioned by the position of vulnerability resulting from their dependence on their caregivers and the institutional context in which they find themselves.

The rights of the elderly in an institutional context are determined and limited by the same context, which constitutes a risk factor for the preservation of their identity. In short, there are no measures or practices on the part of institutions that seek to effectively ensure a core part of their quality of life, i.e. their rights as citizens and elders.

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