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Perspectives of Elderly Portuguese on Residing in Care Facilities: Rebuilding the Reputation of Long-Term Care in Post-COVID Era

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Abstract

The paper investigates how older Portuguese adults view residential care facility life, and through the screening of their attitudes, preconceptions, and expectations, it attempts to determine how the research participants would consider residential care facility life during post-pandemic recovery. The COVID-19 outbreak has changed the perception of people about long-term care (LTC) institutions negatively, promoting more vulnerabilities than safety nets in most cases. Through interviews and focus groups analysis of the qualitative data, this study finds the major determinants that may affect the attitudes of the residents, such as the social stigma, autonomy, trust, and emotional well-being. The results give an idea of the way the LTC homes can change their image, enhance person-centered care, and restore the trust of the community in a post-pandemic world.

Keywords: ***Long-term care, elderly perspectives, nursing homes, post-pandemic recovery, Portuguese older adults, care facility reputation, aging and autonomy, institutional trust, stigma in eldercare, quality of life.***

1.Introduction

The pandemic of COVID-19 highlighted the weaknesses that are in the long-term care (LTC) facilities, especially with the health, independence, and emotional condition of older adults. The lack of the structure, quality, and social perception of the care institutions was reflected nowhere better than in nursing homes, where the pandemic had a catastrophic effect due to the previously existing gaps in addressing the problem. Similarly to all other European countries, nursing homes in Portugal were highly criticized for their failure to act properly during the crisis, be it unpreparedness to face the public health emergency, eight-five years of systematic neglect, and under-resourcement. These facts have not only forced stakeholders to doubt the working abilities of such institutions but the image and confidence that is felt by society in the long-term care systems.

In that regard, it is crucial to evaluate the opinion of Portuguese older people about nursing homes as well (pre- or in the post-pandemic period)(1). Their opinions give critical background into the stand of the society and their cultural aspirations and on which any reform whether structural or a matter of perception must be constructed. Although various research studies have assessed the quality of care on the institutional or medical level, few of them concerned themselves with the stories and lives of prospective or actual users of LTC services. It is important to comprehend their attitudes as part of the continual process associated with humanizing aging, the empowerment of autonomy, and the need to turn institutional care, which has always been viewed as an indicator of abandonment, into an indicator of support and dignification.

Most spheres of cultural values (mainly family values) have always defined the perception of long-term care in Portugal. Familismo, which incorporates the idea that the family is the only resource that can care about its aged members has consolidated the notions in the society which hesitate to have elderly people institutionalized. It is a cultural context that makes it more difficult to normalize nursing home care and in many cases, admissions can be seen as a very final step towards care- usually associated with family breakdown, neglect or abandonment. Although contemporary Portuguese social policy is becoming more modernized, such entrenched philosophy remains at play to determine the way elderly people are assessing the idea of living in care homes.

COVID-19 pandemic, however, has added new scales of concerns and doubt. The fact that the media covered extensively the outbreak in nursing homes, depicted residents who were left unattended, ill-nourished, or facing shortage of medical services, has heightened mistrust and the fear of people. Institutional care may be seen as unfortunate but unsafe even by older people who are already reluctant to leave their autonomy. It increases the imperativeness of rebuilding not only the procedure of care, but the reputation of nursing home as the stable and human-friendly place(2).

The reputation of LTC services still needs to be restored after the pandemic, and to achieve this the process should start by addressing the criticism of the services and negative stereotypes as they were even before the pandemic. These also are tied to emotions such as isolation, depersonalized care, privacy deprivation as well as cases of abuse and neglect. The most remarkable thing is that these perceptions were shown by a significant number of older Portuguese citizens even before the pandemic, which means that they were far more profound. COVID-19 acted more as a magnifying glass rather than a source of these apprehensions due to which they were directly emanated either in the eyes of policymakers or the masses.

An important aspect of this process shall be to re-frame the role of older adults not only as those receiving care, but as contributors and stakeholders with the ability to influence reform. Their observations are necessary to introduce the person-centered care models focusing on dignity, inclusion, and the preferences of the individual. By hearing what they have to say, we can abandon some top-down criteria of what constitutes sufficient care and open the door to a redefinition of quality that focuses on more than metrics and efficiency along the lines of emotional safety, interpersonal respect, and interesting things to do each day.

In addition, the notion of human rights should be incorporated into rehabilitating LTC by the way of its public image. Instead of perceiving safety and well-being as a choice or conditioned and affected by resources, it is important to understand that autonomy, the provision of quality healthcare, respect, and dignity are basic needs of older people(3). The issue of quality of life should not be overlooked by the nursing homes, who have to protect not only the life but also the quality of life. This will involve drawing a culture of care that recognizes residents as individuals with their story, relationships, and goals as opposed to passive bystanders in a clinical context.

In Portugal, where institutional system of social and health service is still fragmented, the mainstreaming of the medical care in the nursing homes is a big challenge. Most LTC establishments do not have on-site medical help or are understaffed, which is additionally negative in times of public health emergencies. Elderly residents with physical disabilities or those with cognitive impairments, who are considered the most vulnerable groups are particularly vulnerable in such de-integrated systems. To handle this, systemic investment, a change to the legislation, and the training of the professionals are to be implemented, which is facilitated by a rebranding campaign that can help to convince the population in the safety and reliability of such institutions.

The proposed study will examine what Portuguese older adults experience concerning life in nursing homes with a particular analysis of how such experiences are perceived before and during the COVID-19 pandemic. It tells stories using qualitative techniques, not only of worries regarding the quality of care and agency, but more fundamental emotional and moral considerations of aging, dignity and the definition of community. Our focus on the voices of the old Portuguese citizens would help to build the evidence-based basis of LTC systems reform not only at the policy or practice level but also at the level of people consciousness.

The results of this research also could be applied to the European discussion on the long-term care, especially in the countries with the analogs of the familistic traditions. They act as a reminder that the image of institutional care should be restored not only hand in hand with the actual improvements. Nothing restores trust, unless it is to build trust by being open and accountable, to listening to the very individuals such systems are [designed to serve].

The following sections of this paper provide a detailed review of available literature on the subject and the overall approach used to conduct the research, as well as the in-depth thematic results and discussion of how these findings can be used to inform LTC approaches in the future(4). Most significantly, this study commemorates the need to change the paradigm associated with the care delivery, which merely helps to control aging, to that of one which elevates and glorifies aging.

2.Methods

The study takes its basis on a qualitative research framework that aims to look and examine the subjective nature of older adults in Portugal in terms of their views on institutional care facilities. It is a component of a larger sociological study that is carried out in the frames of the HARMED project it is a multidisciplinary initiative dedicated to the issue of elder abuse, its causes, and health-related implications. The rigorous approach that was used was designed in such a way that it puts more focus on individual narratives, and it is regarded as the means of acquiring rich and unbiased opinions of individuals who belong to age 60 and above and live in the community. Unlike an approach, which identifies pre-determined hypotheses (or categories) the study was inductive. It was focused on prompting spontaneous thoughts of older people regarding the experience of abuse, neglect, and structural susceptibility(5). Since the original purpose of the HARMED study explicitly did not involve exploring

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the environment of nursing homes, its appearance during the interviews was a matter of natural evolution, a theme that eventually became the most prominent one as it was brought forward by the participants in a wide variety of ways and with a heavy amount of emotional concern.

TABLE 1 Overview of Methodological Framework

Component	Description
Study Design	Qualitative exploratory design using semi-structured interviews
Study Context	Conducted within the HARMED project (focused on elder abuse and violence)
Participant Criteria	Community-dwelling adults aged 60+ from the EPI-Porto cohort; cognitively intact; mixed experience with abuse
Sample Size	45 participants (20 men, 25 women)
Sampling Strategy	Purposive sampling to ensure variation in age, gender, socioeconomic status, and experience with violence
Data Collection Period	April–May 2018 (pre-COVID-19)
Interview Protocol	Semi-structured interviews conducted by senior researchers; audio-recorded and transcribed
Key Themes Explored	Elder abuse, neglect, institutional care, long-term care perceptions
Emergent Topic	Nursing homes discussed spontaneously by 23 out of 45 participants

2.1 Design and Framework of the Research

The qualitative part was planned on the basis of flexible semi-structured interview protocol. The given approach offered to frame the work which made it adjusted both to type of inquiry and relaxation based exploration, just enabling the interested members to explore freely whatever idea, memory, or interpretation stimulated their minds. It was an exploratory design by nature and allowed the interviewers the opportunity to pursue new tracks of discussion as they came along. Their purpose was not merely to gather opinions but to demonstrate the hidden interpretation of older people of such notions as care, autonomy, institutionalization, and relations among people. The overall research, HARMED, took mixed-methods approach. The initial portion of its work was in large-scale survey research, as well as biomedical examination, carried out in terms of clinical examination and biological collection. The next stage as will be reported here changed into qualitative field work utilizing a sub sample of the survey group. Such congruence helped to endure uniformity of demographic and psychosocial characteristics through the phases of the study, elaborating both detail and contingency meaning of findings.

2.2 Recruitment and Sampling of the Participants

Forty five older adults participated in the qualitative interviews. All the actors had taken part in the initial stage of the HARMED project and were recruited out of a long time-population-based cohort (EPI-Porto) that had been tracking the populations of the Porto metropolitan area since 1999. The participants were chosen in the following way: they were community-dwelling people aged 60 years and above, with preserved cognitive abilities, which had been evaluated during the previous survey procedure.

In order to guarantee demographic and experiential diversity in the sample, a purposive sampling was employed. The variables used in the selection of the participants were age, gender, the level of education, level of income, and whether the person has experienced abuse or neglect previously. Significantly, the ultimate sample consisted of those people who have gone through some form of violence (physical, psychological, financial, or sexual) previously and those who have not. This balance made it more possible to view institutional care with a wider variety of lenses, bereft only of traumatic events.

The number of participants was reached and interviewed in the period between April and May 2018, before the COVID-19 pandemic had emerged. The interviews were held in the premises of the Institute of Public Health in Porto, in the safe and comfortable environment to the participants. This assisted in guaranteeing psychological safety and transparency in the interviews(6).

2.3 Methods of Collection of Data

The interviews themselves were carried out by highly competent senior researchers of the HARMED project team which instills consistency, ethical sensitivity and rich knowledge of the research themes. Audio-recording of the

conversations was done after the informed consent of the corresponding participants which they recorded on their own and, then, transcribed verbatim, in order to perform the analysis. Interviews took place between about 30 minutes and almost three hours, which shows the openness and dialogic character of the data collection procedure. However, this area in the original interview guide was not devoted to the topic of nursing homes, but 23 out of 45 interviews (about 51 percent) mentioned this topic spontaneously. When mentioned, the interviewers were to pursue the subject further where they asked the participants to expound their perceptions, experiences, and emotions, about institutional eldercare. This aimless occurrence gave credibility and substance to the stories documented.

2.4 Ethical Considerations

The HARMED study with its qualitative part received the approval of the joint Ethics Committee at the University of Porto Medical School and the São Joao University Hospital Center. Written informed consent was obtained by all the participants before their participation. Participants agreed to take part in the study and were given the choice to allow audio recording as well as the consent to use anonymized data to publish research. During the project, the anonymity of the participants and the confidentiality of data came to be strictly observed.

Analytical Approach

A thematic content analysis of the transcripts was conducted with the help of NVivo 12 software and R 1.6 packages to facilitate ease in coding, categorizing and identifying patterns. The analytical cycle was the following:

- Initial Coding: The transcripts were coded including pre-stipulated themes (such as experience of violence) and emergent material (such as spontaneous mention of nursing homes).
- Reliability: Same interviews were coded by two researchers, after which they met and had an agreement at reducing the discrepancy, providing reliability among coders and reducing the interpretive bias.
- Development of themes: Segments of coded data were reviewed in order to determine recurrent motifs, patterns of association as well as differences in perspective(7).
- Contextual Linking: It involved comparing the themes to demographic information collected on the participants (their age, gender, previous exposure to abuse, and so forth) so that the researchers could determine whether some kind of correlation or a pattern could be observed in the stories.

The conclusion to this analysis was that certain key thematic areas were identified such as the framing of becoming a resident of a nursing home as a kind of emotional violence; dissatisfaction with quality of care; infringement of autonomous and rights issues; and the fear of inequality and increased vulnerability in institution.

Noteworthy, the data analysis procedure favoured the voice of participants. The occurrence of identical issues and the expression of emotional tonalities and authenticity of the narrative were identified by the employment of direct quotations. The analysis procedure was also context-sensitive to what makers of statements said and with what sort of manner.

3.Results

This section is about thematic findings elaborative of the qualitative interviews carried out with 45 community-based Portuguese older adults. Despite the fact the focus of the interviews was around the experience and perceptions of violence and abuse, over half of the participants (23 out of 45) raised the issue of nursing homes spontaneously when describing some context in which these issues are important. Their views demonstrated that there was overall a negative depiction of institutional care, especially of long-term residential care. It is interesting that these themes were not associated only with the personal experience as they seemed to mirror the cultural, emotional, and social perceptions. The analysis framework will be kept under five broad concepts namely; (1) Confining a person in a nursing home is a form of emotional violence; (2) The perceptions of low quality of care is actually a manifestation of neglect; (3) Relegating people to an institutionalised setting is a violation of their rights and autonomy; (4) Particularly vulnerable groups of people; and (5) The general description of the participants and their narratives.

3.1 Overall Profile of Members

The 45 interviewed people consisted of 25 female and 20 men between 60 and 87 years. A large number of persons did not attain secondary level, and majority were married or widowed. A sampling strategy was selected to assure diversity in the life experiences of the sample, specifically regarding an exposure to violence. About 60 percent (27) of the respondents had been victims of any case of abuse (physical, psychological, economic, and or sexual) within the 12 months preceding the interview(8).

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Of the 23 participants who talked about nursing homes, 15 experienced abuses. Interestingly, this implies that negative perceptions of care institutions did not exist only because of the experience of trauma in the past. The age, gender, or marital status were variables that did not make such difference in raising the issue of nursing homes by participants. This further affirms the point that their views could be a widely held one among old folks, irrespective of life background.

TABLE 2 Thematic Summary of Participants' Views on Nursing Homes

Theme	Description	Example Quotations
1. Institutionalization as Emotional Violence	Nursing home placement perceived as abandonment by family and loss of social value	"They just leave them there and never visit." (Interviewee 22)
2. Poor Care as Neglect and Abuse	Reports of rough handling, lack of hygiene, insufficient medical care, and emotional coldness	"She died of sadness after being taken from her home." (Interviewee 19)
3. Violation of Rights and Autonomy	Residents feel deprived of freedom, autonomy, and transparency in treatment; institutions seen as profit-driven	"They just want to get people in, take their money, and move them out fast." (Interviewee 33)
4. Amplified Vulnerability of Certain Residents	Residents with dementia, no relatives, or low income face greater neglect and mistreatment	"People with Alzheimer's are the ones treated worst because they can't complain." (Interviewee 2)

3.2 Admission to a nursing home as an Emotional Violence

Institutionalization was not always such a choice of any service on the part of the participant, but has been viewed as a symbolic means and sign of abandonment. The feeling of moving out of the house and transferring to a nursing home was perceived as emotionally traumatic especially in case it was instigated by the adult children. This decision was a lost cause of family solidity and traditional standards of intergenerational care to many people.

Some of the interviewees clearly compared the admission to an educational institution with some form of emotional abuse or familial neglect. Other terms were being discarded or thrown away, whereas others told stories how their acquaintances became poor or died a few months after they moved to care homes citing grief or lack of meaning as the cause. Almost all of these accounts contain strong emotional responses including sadness, resentment, and fear, as these perceptions get so ingrained.

3.3 Examples of Reckless Care, or Negligence and Mental Injury

Nursing homes were often discussed as the settings where low-hallmark care provision, depersonalized processes, and inadequate staff interactions occurred. Noticeable aspects of neglect reflected by participants related to physical and emotional aspects of neglect. Some of them were mistreatment, failure to take proper hygiene and also there was poor medical observation and there was a cold treatment by those in charge who were careless in terms of their emotions(9).

The reports showed that there was a shortage of staffers, inadequate training, and insensitivity that affected the systematic abuse against residents. Others during the interviews reported basic care being done in degrading ways with little regard given to the residents, they would be spoken to in an abusive manner or handled as objects to be moved around. Also indicated in the list of inhumane treatment were the use of restraints, over medication and absence of individual diets.

It was also repetitively a psychological violence issue. The participants outlined an institutional environment that entailed routine, inactivity, and disconnection in the emotions. They said those environments were not conducive to mental or emotional health and that residents were simply waiting to die, forgotten in a chair, or railroaded into mental quietude.

3.4 Violation of Rights and Freedoms by Institutions

One of the key issues which the participants shared was the fact that nursing facilities do not always safeguard the autonomy, dignity and even the rights of residents. According to the arguments of the interviewees, the life in such institutions was organized within the frames of severe routine and universal practices, where there was no space to reflect individual tastes or personal identity.

Others pointed fingers at the administrators of these facilities who were accused of putting more to their economic gains at the expense of the residents, to the point of forcing residents to sign over wealth or restricting their right to good food and healthcare. Others explained that there was a staging or limitation of visits by family and the complaints of the residents disregarded and sedated. There was no transparency, external oversight, and accountability, which was considered a factor that promoted the environment of abuse and disempowerment.

3.5 Greater Vulnerability of Particular Groups of Residents

Participants kept referring to the fact that not all groups of residents were as vulnerable as others. Those individuals who have some cognitive decline, are not very mobile, or do not have close relatives were considered to be at higher risks of being neglected and abused. Not having a voice or ability to speak up against the situation and speak on your own behalf was regarded as one of the main factors that contributed to the increased amount of abuse.

Another indication given by the interviewees was that the quality of care depended on the economy level, i.e., economic inequalities. People with fewer funds were said to be directed to under funded or unlicensed facilities where labor and the quality of service was especially lacking. Some participants advised that there were so-called illegal homes that were not held accountable in their operation and offered little support.

It was generally felt that nursing homes were a reflection of the social disparities of the outside world and in most instances intensified the same. The neediest health residents became increasingly vulnerable to abuses.

Results in a Nutshell

Through the findings, it has been established that mistrust toward institutionalized elder care is pervasive and deep-rooted in older Portuguese adults. The hegemonic discourse describes nursing homes as the arena of abandonment, depersonalization, emotional or physical abuse rather than a safe refuge. This is in connection to not only anecdotal reports, but also cultural and social norms relating to the task of growing older and also having to educate children.

Instead of perceiving LTC as a qualifying means of supportive aging, the participants perceived them as a failure on part of the family and society. The area of concern at the operational level was not limited solely to deficits too such as staffing or medical access but also to breaches in the ethical and emotional aspect of care autonomy, dignity and later life meaning(10).

Although these views have been published prior to the COVID-19 pandemic, they provide essential information on attitudes of older people toward institutional care. Since much of the gaps identified were exacerbated or publicized during the pandemic, these pre-crisis attitudes probably anticipated, and now contribute to, persistent difficulties of restoring the reputation of Portuguese nursing homes to the minds of the general population.

4.Conclusion and Future work

The present study provides useful qualitative information on the views of the Portuguese of older adults on the topic of institutional care, or nursing homes, in particular. Based on the thematic interpretation of interviews performed prior to the COVID-19 pandemic, it is quite evident that the nursing homes were seen as a source of suspicion, desolation, and emotional denial by numerous older people. These institutions were often related to abandonment, depersonalization and loss of autonomy- way before the pandemic revealed their weaknesses even further.

Notably, it can be seen that these negative perceptions are not just isolated experiences or direct victimization. Instead they represent common assumptions about life, customs of family responsibility, and fears of the humanness and properness of long-term institutionalized care in Portugal. Not only were nursing homes physically restricting places but the nursing homes were places where a lot of the emotional, psychological and ethical needs of residents went unmet.

Although not the primary theme of the data collection, the COVID-19 pandemic could most probably exacerbated these concerns. The original cynicism of trusting institutional care has been enhanced by high profile episodes of neglect, understaffing, and poor crisis planning in the health crisis. Therefore, restoring the reputation of long-term care facilities, at present, becomes possible only when infrastructural or procedural improvement is not an adequate solution anymore. It requires change in the cultural and structural form in which the aging, care giving and lives of the institutions are perceived and practiced.

The first step toward restoring faith in the LTC needs to involve recognizing the older persons as informed stakeholders whose opinions should informed formulation of reforms. Their focus on human dignity,

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personalization, independence of care, and significant participation speaks about a schema of the person-centered approach to care that distracts attention to the traditional custodial care. Furthermore, it is mandatory nowadays to provide sufficient staffing, education, health care, and ethical governance in the institutions.

Policy-wise, the post-pandemic approach should be two-layered, constituting (1) a systematic improvement of the regulatory, healthcare, and labor environment in LTC facilities and (2) a social attempt to recontextualize aging and care as such that are worth respect, investment, and sympathy. However, unless the emotional and symbolic importance of nursing homes as interpreted by older adults is brought into the stir of change, practical reforms can hardly go on to restore faith in these facilities.

To sum everything up, the perceptions and prejudices older Portuguese adults were sharing with us throughout the study help to understand their intensive distrust of nursing homes and the necessity of the change. Such attitudes are not to be viewed as an opposition to care, but rather a wakeup call to transform the LTC industry to an industry that really cares about making aging with dignity, choice and humanity a reality. Portugal, along with other aging societies, can only arrive at a care system that would warrant its older generations through the incorporation of their voices into the policy and practice.

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Conflicts of interest

The authors have no conflicts of interest to declare

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