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ORIGINAL ARTICLE

ELDERS' PERCEPTION OF THEIR LIVES IN LONG-TERM CARE FACILITIES A PERCEPÇÃO DO IDOSO SOBRE SUA VIVÊNCIA EM INSTITUIÇÃO DE LONGA PERMANÊNCIA LA PERCEPCIÓN DE LOS ANCIANOS SOBRE SU VIDA EN INSTITUCIONES DE LARGA ESTANCIA

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ABSTRACT

Objective: to analyze elders' perception of their lives in long-term care facilities (LTCFs). **Method:** this qualitative, descriptive-exploratory study was conducted with twelve institutionalized elders. Data collection occurred through semi-structured interviews. Subsequently, the data were analyzed and processed by thematic analysis. The research project was approved by the Research Ethics Committee, CAAE 0399.0.043.043-11. **Results:** three categories were evidenced: loneliness of the institutionalized elderly due to the absence of the family; the admission of the elderly in a nursing home; and positive perceptions of the facility reported by the elderly and prospects for improvement. **Conclusion:** elders complained of loneliness. Although they are satisfied, they would rather be with their families. This reveals the current situation of Brazilian elders, and shows the need for a new attitude on the subject, in order to create alternatives to overcome existing problems and improve the quality of life of institutionalized elders. **Descriptors:** Aging; Elderly; Nursing home.

RESUMO

Objetivo: analisar a percepção do idoso sobre sua vivência em Instituições de Longa Permanência (ILPs). **Método:** estudo descritivo, exploratório, qualitativo, com doze idosos institucionalizados. A produção de dados ocorreu por meio de entrevista semiestruturada. Em seguida, os dados foram analisados e processados pela Análise temática. O projeto de pesquisa foi aprovado pelo Comitê de Ética em Pesquisa, CAAE 0399.0.043.043-11. **Resultados:** evidenciaram-se três categorias: a solidão do idoso institucionalizado ocasionada pela ausência familiar; a entrada do idoso na instituição asilar; e as percepções positivas relacionadas pelos idosos sobre o abrigo e perspectivas de melhoria. **Conclusão:** os idosos queixaram-se de solidão. Embora satisfeitos, eles prefeririam estar junto aos familiares. Isto recai sobre o panorama atual do idoso brasileiro, apontando para a necessidade de uma nova postura sobre a temática, a fim de criar alternativas que superem os problemas existentes, visando melhorias na qualidade de vida de idosos institucionalizados. **Descritores:** Envelhecimento; Idoso; Asilo.

RESUMEN

Objetivo: analizar la percepción de los ancianos sobre su vida en instituciones de larga estancia (ILEs). **Método:** estudio cualitativo descriptivo-exploratorio con doce ancianos institucionalizados. Se recolectaron los datos a través de entrevistas semi-estructuradas. A continuación, se analizaron y procesaron los datos mediante el análisis temático. El proyecto de investigación fue aprobado por el Comité de Ética de Investigación, CAAE 0399.0.043.043-11. **Resultados:** se evidenciaron tres categorías: la soledad de los ancianos institucionalizados por la ausencia de la familia; el ingreso de los ancianos en la institución; y las percepciones positivas reportadas por los ancianos acerca de la institución y perspectivas de mejora. **Conclusión:** los ancianos se sienten solos. Aunque satisfechos, ellos preferirían estar con sus familiares. Esto entra en el panorama actual de los ancianos de Brasil y apunta a la necesidad de adoptar una nueva actitud sobre el tema, con el fin de crear alternativas que solucionen los problemas existentes, de modo a mejorar la calidad de vida de los ancianos institucionalizados. **Descriptor:** Envejecimiento; Ancianos; Asilo.

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INTRODUCTION

The World Health Organization (WHO) defines the elderly as individuals aged 60 years and older in developing countries, and as those aged 65 years and older in developed countries, according to the tradition of using this index for several decades.¹ From the demographic point of view, aging means increasing the number of years lived. Alongside the chronological evolution, there are phenomena of bio-psycho-social nature that are important for the perception of age and aging. In Western societies, it is common to associate aging with the end of productive life and beginning of retirement.²

The growth of the elderly population, in absolute and relative numbers, is a worldwide phenomenon and is occurring at an unprecedented level. In 1950, there were about 204 million elderly people in the world: by 1998, almost five decades later, this number reached 579 million people, an increase of nearly eight million people per year. Projections indicate that by 2050, the elderly population will be 1,900 million people, a number equivalent to the child population aged 0-14 years.³

Other important aspects have been put forward to explain this phenomenon. In the view of Andrews⁴, this is due to the fact that since 1950 life expectancy at birth has risen worldwide by 19 years. Today, one in ten people is aged 60 years or older. By 2050, it is estimated that the ratio will be one to five for the world as a whole, and one to three for the developed world. Furthermore, it is important to consider that the aging of the Brazilian population will necessarily occur at a faster rate than that of First World countries.²

This rapid change in the Brazilian age structure can be seen as an opportunity for the country to address some basic problems, particularly issues related to children and youth. However, it also poses new challenges generated by the aging of the population. A current challenge which concerns society as a whole and particularly the elderly, relates to the creation of long-term care facilities (LTCFs). In order to avoid that aging becomes a nightmare or life is felt as just seeing days passing by, it is necessary to create institutions for the elderly which can be considered as true homes for them.

The number of shelters in Brazil is growing every day. Hence the importance of better understanding this segment of institutionalization for the elderly. In order to become an alternative that provides dignity and quality of life, the institution has to break

with its historical image of segregation and become a way out or an option in the lives of elderly people.

Shelters are usually seen as homes which are inappropriate and inadequate to the needs of the elderly. This is due to the fact that most of these homes provide very poor care, do not have a multidisciplinary team to assist them, and have poor provision of basic hygiene care and nutrition. It is necessary, therefore, that nurses contemplate the new paradigms of health care for the elderly and contribute to the promotion of healthy aging, developing an action plan that prioritizes quality of life improvement while maintaining the functional capacity of the elderly.⁵

Another aspect that justifies the conduction of this study is the fact that Brazil has very few social and public health programs aimed at promoting independence and maintaining dependent elderly in their homes. This leads, in many cases, to a premature admission to long-term care facilities such as nursing homes and shelters, which, when properly considered, should be the last resort for frail and dependent elders who can no longer be maintained in their homes. Given the above, this study aims to analyze elders' perception of their lives in long-term care facilities (LTCFs).

METHODS

This is a qualitative, descriptive-exploratory study. Its objective is primarily to understand a problem from the perspective of the subjects who experienced it, i.e., taking into account their daily lives, satisfactions or dissatisfactions, surprises and other emotions.⁶

The research was conducted at a long-term care facility (LTCF) located north of Teresina-PI. The facility was founded in May 1966 and recognized in April 1970, and provides care services for people 55 years or older. 36 elders live there: 20 males and 16 females. They are cared for by a multiprofessional team consisting of 25 employees and including: a physician, a nurse, nursing technicians, a cook, kitchen helpers, a cleaning lady and a janitor. There are also 108 volunteers, "godmothers", a nutritionist, a social worker, physical therapists, among others.

All activities are developed in areas that belong to the facility, which consists of a building with 12 rooms and has a capacity for 50 elders. Its structure meets the necessary conditions to provide a good welcoming and

medical, material, religious and emotional assistance to the elders.

The subjects of this study were 12 elders who live in this facility and are mentally fit to participate in the study, regardless of race, color, religion or marital status. Alzheimer's patients, deaf-mutes, individuals who suffered from some mental impairment or were unable to develop their perceptions were excluded from the sample because their participation would prevent the achievement of the study's objective.

For data collection, we used a semi-structured interview. It was conducted by means of an interview script and individually recorded. Data were analyzed using thematic analysis, which consisted of discovering the meaning cores that make up communication and whose presence or frequency of appearance may have significance for the analytical object chosen.⁷

The research project was authorized by the facility, and was then also approved by the Research Ethics Committee of the University Center NOVAFAP, CAAE No 0399.0.043.043-11. All subjects signed a consent form, thus obeying the ethical and legal aspects described in Resolution No. 196/96 of the Ministry of Health.⁸ In order to maintain their anonymity, the subjects' names were replaced with names of precious stones.

RESULTS AND DISCUSSION

This item deals with the presentation of the data collected through interviews conducted with 12 elders who live in a long-term care facility (LTCF). First, we collected data regarding age, education, religion, marital status and length of stay in the institution. With regard to the age, 5 people (40,6%) were 60-70 years old, 5 (40,6%) were 71-81 years old, and 2 (16,6%) were 82 years old or older. 10 (83,3%) were female and only 2 (16,6%) were male. Regarding the education level, 4 (33,3%) interviewees had not completed elementary school; 3 (25%) had completed elementary school; 2 (16,6%) were illiterate; 2 (16,6%) had not completed high school; and 1 (8,3%) had completed high school.

As for the marital status of respondents, 7 (58,3%) were widowed, 4 (33,3%) were single and 4 (33,3%) were separated. With regard to religion, 11 (91,6%) were Catholic and only 1 (8,3%) was an atheist. Regarding the length of stay in the facility, 5 (41,6%) had been living there for 1-2 years, 5 (41,6%) for 3-7 years and 2 (16,6%) for 8-12 years.

The following categories emerged from the analysis of the interviews: loneliness of the institutionalized elderly due to the absence of the family; the admission of the elderly in a nursing home; and positive perceptions of the facility reported by the elderly and prospects for improvement.

♦♦ Loneliness of the institutionalized elderly due to the absence of the family

Currently, when we think about family, the changes that are taking place in society, and the need to work in order to maintain a decent standard of living, we realize that it may not always be possible for a family to provide the adequate infrastructure or a family member or caregiver to care for the elderly and satisfactorily meet their needs.⁹

The study participants showed in their statements the loneliness caused by the absence of the family. This contributes to the perception that aging is connected to a great feeling of loneliness, as if the elderly had no one but himself, which is shown by the following statements:

I have no family. (Emerald)

I'm alone. (Ruby)

I have no one, I'm from the street. (Jadi)

I have no one, I do not wish to live with other relatives again. (Onix)

After I lost my parents I got depressed. (Topaz)

The loneliness for the elderly are often related to changes that occur within the family, such as the loss of a loved one, family abandonment, their isolation by family members. At this stage of life, family support is necessary due to the frailty of the elderly, their fear of death, and the thought that they have no more value to society. With support, care, love, dedication, respect and appreciation it is possible to assist them in living a more dignified and quality life. However, with aging, the elderly feels lonely and, thus, on his/her own free will or under influence of others, he/she decides to seek a nursing home, which becomes an attractive option when compared to the other options available. The nursing home provides sociability, support, adequate nutrition and general care and hygiene.¹⁰

The isolation caused by the loss of reference and the decline or scarcity of visits with time are the most common factors that lead elders to search for a nursing home. The most common feelings revealed by the elderly, however, are related to homesickness and loneliness, as shown by the lines below:

I would so much like to see my family again, get more visits. (Amethyst)

They have left me here and abandoned me, they never came back, they got me depressed. (Pearl)

My family stopped visiting me, but I really wish to see them again, sometimes I feel wish I could go back home. (Turquoise)

I lived alone, I have nobody, they all abandoned me. (Quartz)

The loneliness of the elderly, in modern times, is related to changes that occur in the family. Thus, modern life conditions may favor the emergence of loneliness in old age, since people's lifestyle and family structure suffer intense changes.¹¹ We know that, in order to provide emotional support to the elderly, it is not enough just to be near them, they need emotional and physical closeness to their children and friends. The latter should be able to support and meet the emotional and social needs of the elderly.

The caring relationship established between families and their elders occurs based on the meaning of family and old age. The responsibility that the children have toward their parents is based on filian love and on the prospect of an expected reciprocity in exchange for the parental care received in childhood.

Thus, the family can be considered as a support to protect frail elders, and the family atmosphere is the best place to deliver care. This perspective is related, among others, to the notion that the family is the primary institution mediating between the individual and his/her surrounding reality.

◆● The admission of the elderly in a nursing home

In this category, we observed that the family is the main responsible for the admission of the elderly to the LTCF. This reflects, in most cases, the situation of dependency of some elders and the care required by them, since they may need personal and social resources and a greater physical and emotional support to cope with the changes and difficulties that arise at this stage of life. This is shown in the statements below:

I came on my own free will. (Emerald)

I decided to come here myself. (Sapphire)

A relative brought me here. (Diamond)

My nice brought me. (Onyx)

My son brought me here. (Turquoise)

The fact that the family searches for these institutions does not agree with what is recommended by the Federal Constitution, Art. 229, which instruct that "the family, the society and the State have a duty to assist the elderly." The Elderly Statute, art. 3,

encourages the care of the elderly by their own families.⁹ Nevertheless, it is not always possible for families to provide the adequate infrastructure or a family member or caregiver to care for the elderly and satisfactorily meet their needs. In such cases, they have to resort to long-term care facilities.¹²

The family's ability to care may be compromised or weakened and, in these cases, the elderly may become an obstacle to the autonomy of their family members, either because of the demands of daily life - which make it impossible for them to conciliate care with home and work activities -, or because they are not able to find one or more family members who can assume the responsibility for caring for the elderly. In this cases, institutionalization is one of the solutions found to the problem.¹³

The growing need for institutionalization of the elderly is a factor that has drawn the attention of the general population and led some segments of society to be concerned about the conditions in which LTFC residents live.¹¹ Institutionalization of the elderly remains a delicate topic. There is still no consensus about its acceptance as an alternative for social support, although the increase in demand for this service is indisputable.¹⁴

Thus, it is necessary to define the profile of the elderly, distinguishing between those who experience successful aging and those who require specialized professional care. Considering these varieties and specifications, a suitable kind of support must be set. In this sense, the admission to a LTCF is one such alternative for a specific kind of elder's profile (dependent or requiring adequate physical support) or at least is considered the most acceptable form of institutionalization.

It must be considered that, culturally, in our society, it is expected that the children (more directly) or other family members take responsibility for the care of their elderly parents, satisfying their material and emotional needs in accordance with the conditions and specificities of each case. Among the main causes for admission of elderly to shelters are the poor healthcare conditions provided by the family (behavioral disorders, need for rehabilitation, lack of financial resources, family abandonment and absence of a caregiver). Oftentimes in these situations the will of the elderly is no longer respected, resulting in the loss of their autonomy and independence.¹⁵ The reports below show similar findings with regard to the dependence of the elderly. Some respondents

pointed out the issue of professional referral - one was taken away from their homes by a social worker and the other by the police. Here are their statements:

The police brought me to the nursing home. (Amethyst)

A social worker came for me at my place. (Opal)

The statements mentioned above relate to the liability of the State with regard to the protection of the elderly. We found that the interviewees came to the LTCF through referral.

The decision to admit the elderly to a LTCF should be taken after all possible alternatives have been examined, such as family arrangements, the hiring of caregivers with some knowledge of nursing or the use of community resources. When they cannot find any viable alternatives and in moments of crisis, families search for shelters or nursing homes.¹⁶

The lack of a caregiver or a competent person to take care of the elderly in certain situations is depicted below. In these cases, the elders need to be under the monitoring of a qualified and prepared person who can meet their specific needs. The limitations mentioned in the interviews relate, almost entirely, to physical aspects, since the subjects reported health problems like blindness and sequelae caused by cerebrovascular accident (CVA).

Because of my age, I have no family and I'm visually impaired. (Emerald)

I went to the hospital because of a CVA and came here to recover and I'm here till today. (Opal)

Due to my husband's death . (Ruby)

I got ill. (Diamond)

The elderly in the aging process goes through several changes, such as physical limitations, mental and psychosocial changes that may often influence their decision to go to a shelter. Changes related to physical aspects are due to the "physical wear" experienced by the elderly, which causes illnesses and functional difficulties.¹⁷

Loneliness was also a reason mentioned by the interviewees. It is evidenced by the loss of a spouse or for not having a family and living alone. Loneliness is a feeling that should be viewed with concern by health professionals, for it causes depression associated with social isolation.

Another reason for institutionalization identified in the discourse of the interviewees was intra-and extra-familial violence (abuse, abandonment and neglect). The data generally confirm that violence against elderly

people usually occur intra-familially. The aggressors are people they trust and have an intimate relationship with (their own children, close relatives, sons and daughters-in-law),¹⁸ as shown by the reports below:

My brother always used to attack me with ugly words and began to despise me, leaving me behind when they would go out as a family. My brother had to leave and I had no place to stay and my sister-in-law took me to the shelter in the promise that I would spend some time here and she would come back to pick me up and that never happened. I got depressed and had other health problems. (Amethyst)

I was living in the street and Margaret brought me here. (Jadi)

I lived with my daughter, who is married, they started to abuse me at home, and the neighbors, sensitized after more than four years of abuse, called the police and I was sent to the nursing home. (Amethyst).

I lived alone in a dangerous neighborhood, and then, I already knew the Frederick Nursing Home because I used to come here to attend the Mass and one day I decided to ring the bell and ask if they had a place for me to stay. (Sapphire)

These reports confirm once again and draw attention to the issue of violence within the family, a phenomenon increasingly present among elders. Such violence is committed, as a rule, by those who should support and care for the elders at this stage of life: their family. Another disturbing finding was the fact that the elderly were being abused by their own children.

Among the abusive acts against the elderly, we highlight the violence that has become an universal phenomenon, and is drawing a growing attention and mobilization from both developed and developing countries. Violence and abuse against elderly people refer to physical, psychological and sexual abuse; abandonment, negligence, financial abuse and self-negligence.¹⁸ It is also important to consider that people from all socioeconomic, ethnic and religious classes are vulnerable to abuse.

The elderly group most at risk for maltreatment and abuse is composed of elders over the age of 80, with some kind of dependency, who have frayed family relationships, financial difficulties, experience social isolation, among others.¹⁹

Moreover, in Brazil, neglect is one the most common forms of violence present both in the domestic context and in the institutional one, and often results in injuries and physical, emotional and social trauma to the elderly.²⁰

In recent years, several services aimed at the elderly care were created in Brazil, such as shelters, multidisciplinary referral centers and institutions responsible for dealing with reports of violence against the elderly. The admission of the elderly to these facilities reveals the temporary or permanent fragility or often inexistence of their family ties. However, it is essential that public policies focus on the social role of the elderly, and prioritize the care and protection of these persons by their families, by institutions and by society.²¹

Thus, the increasing amount of elderly could offer a climate for publicity and politicization about the maltreatment they suffer, making the issue a priority on the agenda of social issues that need urgent interventions. Hence the need for a structure adequate in all respects, so that this population group can be cared for in the best way possible and, thus, the need for admissions to LTCFs can be minimized.

• Positive perceptions of the facility reported by the elderly and prospects for improvement

Despite many critical points highlighted by the elderly in their statements, they also had positive perceptions about living in a shelter, especially with regard to the way they are treated. However, some of them said that, although they like living in the shelter, they miss home and would like to live in their own houses again. Here are their statements:

I like living here, they treat me well.

(Sapphire)

I like it, but I want to go back to my house.

(Ruby)

I like it, but I would like to live in my own house. (Pearl)

I like it, because I'm getting treated here. (Jadi)

Very nice, but I would like to see my family again and get more visits. (Amethyst)

We could infer from the interviewees' statements that, although the elders like living in the shelter and are satisfied with the care provided, they really miss home, which brings us back to the issue of the peculiarities of an individual and the lack of autonomy over their own lives. Most of the elderly residents are satisfied with the treatment they receive in the shelter. They reported that they are treated well and emphasized that this kind of treatment is very important for the health of institutionalized elderly. This fact is evidenced in many studies.²²

This study revealed differing results because respondents showed dissatisfaction

about living in the LTCF studied and many expressed a desire to return home, despite the difficulties and limitations found there.²³ Therefore, according to the data collected, we found that the elderly experience difficulties in dealing with their illnesses and physical limitations caused by their advanced age and the lifestyle they have led. In addition, they are miserable because they miss home and feel abandoned by their families.

Thus, aspects of experiencing the aging process in a LTCF and the life stories of these elders reveal the need to develop strategies for qualification of care and the understanding of their reality, their anxieties and their opinions, in order to further improve the lives of the elderly in the shelter. Professionals (caregivers) also need to establish relationships/connections with the elderly in order to humanize the care provided. In addition, they need to provide opportunities to strengthen the bonds created between the elders and them. This should be done with the goal of making elderly people feel they are at home or perceive the shelter as a home, which should make them miss less their old homes or the daily contact with their family.

It could also be noted that, for some people, the shelter serves as an alternative to help elders escape from abuse and lack of love and affection. The importance of such a place for the elderly was evidenced by one of the subjects.

Well, I do not wish to go back to my family.

Here I am good cared for and loved. (Onyx)

Shelters should be places where elders' physical, mental and social needs are cared for; it should be a space that allows them to maintain contact with society through tours, leisure activities, integration and communication among residents, etc. Thus, respondents revealed their perceptions about living in a shelter. These perceptions are directly related to the kind of services they would like to be offered by the institution studied. Here are their statements:

I wish they made changes in the physical structure and allowed for more access.

(Sapphire)

I wish there was another psychologist, because the time we have to talk to him is very little due to the high demand by the elders and the reduced number of hours offered by the professional. (Pearl)

I wish there were more employees to help us take a shower, because it takes too long in the morning for each elder and we have to wake up very early. (Onyx)

There should be more therapy sessions during the week, the rooms should be more airy and physiotherapy sessions should be offered more often. (Turquoise)

In the statements above, the interviewees reported some changes that should be made to the physical structure of the institution, as well as the need of hiring more health professionals and other workers to help providing hygiene care.

Other elders expressed their wishes for more leisure activities and also for more differentiated treatments depending on the individual pathology of each one of them. Here are their statements:

They should plan more trips to different places, offer more medical consultations and physiotherapy sessions. (Amethyst)

They should provide specific activities depending on the individual needs and conditions of each person. (Emerald)

Finally, respondents showed their perception with regard to nutritional needs, and made some suggestions, from educational lectures to changes in the diet.

I wish they would change the diet, although it is very good, and had more women bathrooms with hot water. (Topaz)

There should be lectures for elderly people about healthy eating or other free topics. (Quartz)

It is important to consider that the multiprofessional approach in the care of institutionalized elders is fundamental for preserving, maintaining and restoring their health. The involvement of a group of workers is necessary because it makes possible an exchange of knowledge between them and the provision of an integral care, appropriate to the needs of this very special population.

CONCLUSION

Although the elderly are aware of the institutionalization process they go through, there is a patent need for a more systematic monitoring of those people who are directly involved in the process - the elderly and their families - in order to promote a clear understanding of these dynamics and motivations. This deserves further and deeper study.

The process of "institutionalization" is closely related to this conflictual representation of themselves, which is twofold: on one hand, they feel welcomed by the institution, because they feel they are no longer recognized as members of society and the LTCF provides all the essential care they need to survive; on the other hand, they feel marginalized by the same social environment,

because they are deprived from the contact with others, and cannot thus actively exercise their citizenship rights, which constrains their freedom of movement, expression and of making their own decisions.

The movement of life of elders who migrate to long-term care facilities is permeated by political, social and biological aberrations. Our country is aging and old age has become the subject of politics. There are only few public policies for the elderly and they are more restricted to healing and immediate actions without long-term effectiveness. Family dynamics often leads families to close their doors to the elderly. Nucleated families, ever smaller physical spaces, the increasing number of women entering the labor market are factors that result in the need of sending children to childcare and elders to shelters.

We may not forget that there must be a greater commitment to training professionals and volunteers (through the development of interdisciplinary and multidisciplinary activities), and to implementing strategies directed at the elder's family, as suggested in the public programs and policies for the elderly. Perhaps if there were more day centers, home shelters, home care services, sheltered workshops or other means for the socialization of the elderly, many of those elders who live in shelters could be maintained in their social and family environment, experiencing the love of and living daily life with their families.

We hope this study will contribute to improve the quality of care provided to elders living in LTCFs. Moreover, we hope other studies are conducted, based on the prospect of improving practices aimed at this group and their health promotion within LTCFs.

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