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Institutionalization of Older Adults: The Perspective of Older Adults and Family Members

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ABSTRACT

Objective: To identify the reasons that led to the institutionalization of the older adult, from the perspective of the older adults themselves and of the family members.

Method: A study of the qualitative-descriptive type, having as its subjects 14 institutionalized older adults and 35 family members of older adults living in three Long-Term Care Institutions for Older Adults in the city of Florianópolis, Brazil. The data were analyzed in the light of the Theory of Social Representations by means of Bardin's method of content analysis. The diverse information collected was organized through the Atlas.ti software (version 8) for the analysis of qualitative data.

Results: It was observed that the family relationships and their structures exerted an influence on the institutionalization process, as well as the life stories of the older adults and their family members, their interpersonal relationships, and the life structure at the time of institutionalization. Some feelings were identified in the institutionalization process, such as conformism, guilt and insecurity.

Conclusion: Recognizing these feelings can contribute to the appreciation of the individualities and the family context in the institutions.

Keywords: Older adults, Long-Term Care Institutions for Older Adults, Family, Family Relationships

INTRODUCTION

Over the last few decades, the Brazilian demographic census has been showing a process of population aging and transformations in family organization and in the reproduction levels, indicating greater diversity in relation to the types of families and household arrangements [1]. Recent data estimated a fertility rate of 1.77 children per woman in 2018, with a reduction to 1.66 in 2060 [2]. Family arrangements are less traditional: there was an increase in the number of common law marriages, divorces, reconstituted families, in which at least one of the spouses can have a child from a previous relationship, and single-mother families, consisting of mother and child(ren) [1]. The increase in life expectancy also changed the profile o

f the older adults, a factor of great significance for the economy. Currently, a greater number of older adults remain in the workforce after the age of 60, despite being already retired, also representing an important collective of individuals who are economically responsible for the household, in addition to an increase in the number of older adults who live alone, especially women [3]. If on the one hand people live longer, being productive and contributing to society, on the other hand, health conditions that can hinder and affect aging are also delayed [4]. A study on trends in the health of the aged population, based on data collected by the National Household Sample Survey (Pesquisa Nacional por Amostras de Domicílios, PNAD) observed a decrease in some chronic diseases or conditions, but functional disability remained stable, with an increase in the prevalence of Systemic Arterial Hypertension (SAH) and Diabetes Mellitus (DM) [5]. The current panorama consists of families growing smaller and women working more with full-time regimes and also being responsible for their household and their children. Older adults are living longer and often live alone [6]. The family structure is frequently not prepared to be supportive and to meet the care needs in the household, when older adults have some functional disability [7]. Given this context, Long-Term Care Institutions for Older Adults (Instituições de Longa Permanência para Idosos, ILPIs) emerge as one of the

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possible responses of our society in relation to supporting the care that must be provided to the older adult. An in-depth study on ILPIs in Brazil, concluded in 2010, showed that only 1% of the aged population lived in these institutions [8]. Most of the ILPIs in Brazil are philanthropic (65.2%), followed by private (28.2%), and public (6.6%) [9]. Private ILPIs tend to have a higher proportion of dependent and semi-dependent residents, with provision of medical services in 86.3% of the institutions, suggesting that institutionalization of higher-income older adults in an ILPI results from greater physical/mental dependence. The new institutions studied in the period were mostly private and for-profit, with more significant growth between 2000 and 2009 [8]. Thus, considering the current demographic changes and the need to consider ILPIs as facilities for care support for the older adult, this study aims to identify the reasons for that led to the institutionalization of the older adults, which may contribute constructing this knowledge.

METHOD

Study design

A study of the qualitative-descriptive type, in the light of the Theory of Social Representations (TSR).

Setting and population

The study was developed in three private ILPIs in the city of Florianópolis, Santa Catarina, including 14 older adults and 35 family members as participants. Located in the southern region of the island of Florianópolis, ILPI-A was founded more than 35 years ago, is linked to the Catholic Church, has ample space and apartments to house 46 older adults. During the data collection period, 36 older adults, predominantly women (33 women and three men), lived in the institution, with ages varying from 67 to 100 years old. ILPI-B is located in a neighborhood near the central region of the island, was founded in the 1980s, and is linked to the Methodist Church. During the data collection period, 28 older adults lived in the institution, 22 women and six men, with ages varying from 63 to 102 years old. ILPI-C started its activities in the 1990s in a family house that was enlarged and structured to provide housing and health care services. During data collection, there were 32 older adults living in the institution, 27 women and five men, with ages varying from 69 to 96 years old.

Selection criteria

This research included those residents who had been institutionalized for at least three months and with preserved mental cognition, as assessed by the Mini Mental State Examination (MMSE). The criteria adopted for the inclusion of the family members were the following: being over 18 years old, paying regular visits to the institutionalized older adult at least four times a month and/or accompanying him/her in activities outside the ILPI, such as medical consultations and leisure activities. The study excluded older adults who did not reach appropriate MMSE scores, those who reported lack of family bonds, and those unwilling to participate in the research.

Data collection

The data collection period extended from May 2017 to January 2018, in one institution at the time, and respecting all the stages proposed for the research: observation, data collection in medical records, and semi-structured individual interviews. The objective of the observation was for the researcher to get to know and become familiar with the institutions. In the records from the medical charts, diverse information was searched to obtain sociodemographic data of the aged population, their medical history, and daily use medications. The semi-structured interviews were conducted individually with the study participants by means of specific instruments for older adults and family members, contemplating guiding questions in relation to the institutionalization process and the reasons that led to institutionalization. The data were collected in three institutions, totaling 96 older adults living in these ILPIs during the data collection period. The mean age of the older adults was 87.5 years old, 70 of them were women and 26 were men, and there was clear predominance of diagnoses of SAH, DM, dementia, heart disease, and stroke sequelae. This population was characterized by high cognitive decline, especially due to advanced dementia, preventing them to participate in the research. Of the 96 older adults living in the three institutions, all assessed according to the MMSE, only 14 were included as research participants, 12 being women and two being men, with ages ranging from 77 to 93 years old. The main reason for non-inclusion was cognitive decline, present in 67 older adults. The institutionalization time of the 14 older adults who were the study subjects varied between one and 33 years. Mental cognition was assessed using the MMSE, with scores ranging from 25 points (minimum) to 30 points (maximum), with the cutoff value established by Brucki. Regarding the family members, 30 were women and five were men, aged between 49 and 73 years old. The predominant degree of kinship was son/daughter (26), followed by niece (3), daughter-in-law (3), grandson/granddaughter (2), and wife (1). The individual interviews with older adults and family members were conducted in spaces of the ILPIs, using instruments with guiding questions specific for older adults and family members and lasting between 40 min and 1h 30 min. These interviews were recorded on a cell phone and later transcribed in full by the researcher.

Data analysis and treatment

To analyze the data collected content analysis was used, a method proposed by Bardin that comprises a set of communication analysis techniques using systematic and objective procedures to describe the content of the

messages [10]. To organize the diverse information collected, the Atlas.ti software (version 8) [11] for the analysis of qualitative data was resorted to. The data were annexed through individual documents in Word format. Each document was read individually, with the program highlighting the important segments, called quotations. Subsequently, the codes were attributed for coding the documents typifying them by a word or group of words from each quotation.

Ethical aspects

The research respected Resolution 466/12 of the National Health Council (Conselho Nacional de Saúde, CNS), where all the participants signed the Free and Informed Consent Form (FICF), being submitted to the Committee of Ethics in Research with Human beings of the Federal University of Santa Catarina (Universidade Federal de Santa Catarina, UFSC) and approved with opinion number 2,047,155 of May 4th, 2017. In order to preserve the participants' anonymity, the older adults were identified using the letter I. ("Idoso" in Portuguese), followed by the name of a flower and the participant's real age. The family members were identified using the acronym Fam. followed by the Arabic number showing the order of their inclusion in the research, and their degree of kinship in relation to the older adult.

RESULTS

The following thematic axes were worked on in the description of the results of this manuscript: 1st Axis-"Perceptions of the older adults on the institutionalization process and on living in an ILPI" and the category called "Reasons for institutionalization"; 2nd Axis-"Perceptions of the family members on the institutionalization process and on the family care relationships" and the categories called "Institutionalization process" and "Life dynamics in relation to the institutionalized older adult". In the analysis of the 1st thematic axis, "Perceptions of the older adults on the institutionalization process and on living in an ILPI", and of the "Reasons for institutionalization" category it was observed that the family relationships and their structures exerted an influence on this process. Some aspects were indicated as guiding factors for such decision-making, such as: feeling that they could bother their family members; perceiving that the family did not have the structure to provide them with appropriate care when it was needed; for understanding that the life dynamics of their family members would be affected in the cohabitation with the older adults; or in situations of conflicts between older adults and family members living in the same household. Also, regarding this circumstance, in which the older adult made the decision to live in an institution, at some moments feelings of conformism emerged, such as in these speeches: But we have to accept or to give up, either one or another (I. Amaryllis, 88 years old). Then I knew that I was coming here, that I was going to stay here. What was I supposed to do? I had to work it out (I. Orchid, 90 years old). In opposition, in the situations in which the decision was made by family members, some older adults showed that they were comfortable at the moment of institutionalization, marked by conflicts and anger, especially when the older adult did not participate in the process of choosing the institution. As already described, in this case there were also speeches related to the feeling of conformism and acceptance of institutionalization, as if there was no alternative for these individuals to live their old age. For example: (...) my daughter brought me, but I didn't like it. No, no, no... I accepted, life is like this right, it had to be like this, she also couldn't take care of me, then I had to be somewhere (I. Tulip, 87 years old). In general, moving out their own homes or out of the family to an ILPI did not occur naturally, as part of the aging process experienced by the older adults interviewed. The speeches revealed that the individual and family histories eventually led to a moment when institutionalization was inevitable, especially in the situations in which the older adult demanded a higher care burden. The older adults' life before the ILPI can be divided into those who lived alone and those who lived with family members. For the older adults, living alone was associated with widowhood, as was indicated by the family members as a source of concern and discomfort. Consequently, in the impossibility of living with their older adults, choosing institutionalization became the best decision for that moment, from the perspective of the family members. But it is important to note that such process was not simple or easy for most of the interviewees, as it involves many feelings, stereotypes and the very family history. When analyzing the 2nd thematic axis, "Perceptions of the family members on the institutionalization process and on the family care relationships," and of the "Institutionalization process" and "Life dynamics in relation to institutionalized older adults" categories, many particularities were observed in the process: in the life histories of the older adults and their family members, in their interpersonal relationships, and in their life structure at the time of institutionalization. Considering the older adults who lived with their family members, the first aspect of institutionalization refers to the great care demand presented by the older adults, resulting from physical and/or cognitive sequelae and in older adults affected by dementia, especially Alzheimer's Disease (AD). In relation to this aspect, in many cases the older adults had been living for several years with their family members, who were the support to meet care needs until institutionalization. The difficulties in keeping older adults with great care demands cohabitating with their family were presented as factors that determined the search for an ILPI that could meet the care demands. One of the difficulties reported refers to the physical and emotional overload experienced by the caregiver family members, leading to situations of exhaustion and family conflicts.

Even in such circumstances, the choice of the ILPI was considered as the last resource, in the impossibility of the family to care for their older adults, as illustrated by the following report: I realized that I did not have the psychological structure to bear a situation like this, day and night, day and night, because I would not have help from my siblings, I would not have and that was when I also realized that it is better for me to come here, at least give her a little affection and attention, rather than taking her to my house and keep mistreating her, turning her into a burden in my life (Fam. 10, Daughter). Another issue raised refers to the difficulties in maintaining a team of professional caregivers in the house, considering the increase in the financial charges for this professional category, difficulties in establishing relationships of trust, and the very adaptation in the relationship between older adults and caregivers. The choice for caregivers was an attempt by the family members to keep the older adults in the house. However, as exemplified in the report below, institutionalization was considered as the last-resource solution to meet the older adult's needs: She stayed in my house until 2012 and I had three employees, then the domestic worker law came into force and I would need to have five employees and we couldn't afford a house with two people and five employees. Then, it was something that became technically unfeasible and I was faced with the obligation of seeking a home for my mother (Fam. 09, Daughter). In cases when the older adults lived alone, situations of dementia were determinant for the family to look for an institution. The major emotional impact of the older adult's disease on the family was evidenced, which had already faced the process of discovering the disease, its consequences, and the resulting limitations for its members. In many cases, dementia decharacterized the older adults, brought a new personality, and placed them in situations of danger, making it impossible for them to perform self-care and to continue living alone. Some reports clearly evidence these conditions and the difficulties faced by the family members: One day she called us and told she killed the neighbor with a hoe and that the house was all covered in blood, I arrived there and she showed the bathroom and there was nothing of the sort (...) and suddenly you see a person who was an example for you, she was a professor, she took care of you, and it is hard to see her in this situation (Fam. 31, Daughter). I remember I arrived home, she was lost in the street (...) she was crying at the table, with the bills, saying that she did know what to do with the difficulties in thinking that she had been having (Fam. 15, Son). Also in these conditions, the family members tried to keep the older adult in the house, resorting to private caregivers. However, corroborating the already mentioned transcriptions, there is much difficulty in maintaining a relationship of trust and bonds with these professionals, due to the complexity of care required by older adults with dementia. This process experienced by the family members was permeated by some feelings such as guilt, suffering, sorrow and doubts whether the best decision was being made. A moment of rupture is portrayed while institutionalization was carried out because, in many situations, there was the need to get rid of possessions and also of relationships such as close and daily coexistence, as exemplified in the following speeches: When she starts to tidy her things up, she is seeing and somehow participating. She was frightened, we saw that. And then, you forget, everything. All the courage or the reason for doing the things, it's lost. She gets lost and the emotional side becomes more important (Fam. 01, Daughter). The feeling is like of impotence, that you can't provide everything (Fam. 25, Daughter). Therefore, although acknowledging that the ILPI is the best place for the older adult at that moment, in the face of such situation, some family members showed the need to be quite present in the institution's routine, as a way to compensate, so that the negative feelings resulting from institutionalization were mitigated with regular visits, such as in the following example: I don't feel guilty because I'm always here, I think that it's the reason why I always come here, it's a way to overcome the fact that she's not living in my house, right? (Fam. 10, Daughter). In addition, in association with these feelings, there were reports of families that suffered prejudice and discrimination for taking their older members to institutions. In some speeches, prejudice was also evidenced by some of the interviewees, reinforcing the presence of the negative stereotype in the ILPIs. I'm not against these things of nursing home, but I find it sad because the person lives with the family and then the family puts them here (Fam. 02, Niece). (...) I came from the inland, and there nobody puts parents or grandparents in nursing homes, we take care of them (Fam. 21. Daughter-in-law). It is evidenced that the life dynamics of the family members interviewed is conditioned at many moments to the life of the institutionalized older adults, since the families are responsible for providing hygiene materials, continued-use medications, and laundry. In addition, when there is the need for a medical consultation or even for leisure activities, there is mobilization and preparation for this to occur. Some speeches reveal harms to family members' personal lives for the older adults' needs to be met. For example: I end up doing things that prevent me from working and from earning my living. So that I can give him the attention he needs (Fam. 12, Daughter). In opposition to the panorama presented, it is important to highlight some situations in which the institutionalization process occurred more naturally, with no situations of suffering or conflicts, especially when the decision came from the older adult. Some points converge in these stories and can contribute to avoid that the moment of aging living in an ILPI be marked by negative aspects, namely: the decision was spontaneously made by the older adults with no impositions or demands by the family members; the older adults participated and chose the institution where they would live; family support was very

present after institutionalization. The following reports exemplify these situations: Of course, I felt sad to being separated from my children, I thought that it would not be the same without them, that they would move with me and so on, but none of this happened (I. Bromeliad, 80 years old). So, this is our concern, to provide the best care we can deliver, a matter of time or keeping him active and also being with the family (Fam. 17, Son).

DISCUSSION

The decision for institutionalization was most of the times taken when the older adults realized that the family would not manage to provide the necessary support, or that they could cause any inconvenience, and even when there were already situations of conflict. For the family members, looking for an ILPI was often the last resource, after attempts to take care of the older adults in their own house and/or with the support of private caregivers in view of the great care demanded by the older adults. A study conducted with 250 institutionalized older adults about the prevalence of dementia and about the main reasons for them to live in ILPIs evidenced that, in 74.4% of the cases, the main reason was the great need of care presented by the older adults. These older adults presented high prevalence of dementia, nearly 32%, with AD being the most frequent diagnosis [12]. The many and varied care measures required by the older adults were strongly evidenced in this study as a triggering factor for institutionalization, either due to sequelae of chronic diseases or to the process of dementia and its consequent limitations. In a case-control study on the factors associated with institutionalization, the main diseases and complications in the gross analysis were AD, Parkinson's, other unspecified dementia, and motor sequelae of stroke, which impaired cognition and functionality [13]. The relationship with the caregivers in the household was pointed out as a problem by the family members, both due to lack of knowledge on specialized care demanded by older adults and due to the difficulty in establishing a relationship of trust. The financial aspect to maintain private caregivers was also mentioned by some participants, especially after the legislation that regulates domestic worker contracts, leading to high financial charges for the family and/or the older adults who often would require 24/7 professional care. The new family and social configuration of the last few decades may have changed the ways of bonding and intergenerational relationships, impairing the functions of protecting and caring for the dependent older adult to perform the activities of daily living [14]. In a research study on the level of functional independence of 97 older adults in two ILPIs it was observed that most of the sample was single, did not have any children, lived alone in their own house, and decided to live in institutions because they presented some degree of dependence in performing the Activities of Daily Living (ADLs) [15]. The absence of sons and daughters was also a relevant cause for institutionalization [14]. The moment of institutionalization was marked by an ambiguity of feelings in the family members, who could feel relieved in knowing that the institution was providing the required support but also experienced feelings such as guilt, fear, and insecurity. The authors reiterate the existence of these feelings, because they consider that it is not simple to choose institutionalization, since the family has to deal with feelings of failure, shame, and impotence arising from not feeling able to offer the care required by their relative [16]. The role of the caregiving family is very strong in our society and, despite all the changes that took place, the responsibility for the parents' care still lies mainly on the children, preferably at home. The difficulties experienced by the family members can be related to the representation of our society on family care, because this modality of care is rooted in our cultural heritage. Social representations are built collectively: they are not created by a single individual, they are shared by groups and reinforced by tradition [17]. They attribute meaning to the world, to the reality in which the individual is inserted, and this meaning is communicated from one person to another [18]. In a study on the social representations of care and old age, care for the older adult was seen as a family responsibility [19]. The representations have two distinct functions: conventionality and the prescriptive character. Firstly, conventionality concerns the fact that objects, individuals, or events are classified into a given category. There is a certain obligation of fitting a given object, even if it does not perfectly match. It is conventions that allow us to distinguish the significant messages, being related to conditionings imposed by representations, language, or culture [17]. Secondly, the prescriptive nature of the representations is defined by Moscovici as an irresistible force imposed on us that can be understood as a ready-made response. Some representations are not created by individuals but are only retransmitted, re-presented. Therefore, certain representations are not the way of thinking about something but, on the contrary, they exert an influence on the way of thinking and have an authoritative nature, as a result of the transformations over time [17]. Under this perspective, care for the older adult is strongly associated to family care in our culture. Taking Elsen's studies as a reference, family care can be understood based on a world of meanings within each family and is built inter- and intra-generationally, where the older individuals take care of younger at certain moments and receive care from them at other moments [20].These aspects are also strengthened by the Brazilian legal system, because family care is expressed in the 1988 Federal Constitution and was reinforced by the 1994 National Policy on Older Adults and the 2003 Statute of the Older Adult [20-23]. In a research study on the social representation of care and of the family caregivers of older adults in the household context, the central core of care was characterized by words like love, affection, patience, and health. The “family caregiver” category was related to

dedication, altruism, and safety, being necessary that the caregivers give up their own lives to guarantee older adult's care [24]. These representations emerged from the family caregivers themselves, herein reasserting the aspects of affection and self-denial involved in the process of family care and its authoritative nature. At the same time that the act of institutionalization breaks with the representation of home family care, there is also the confrontation against stereotypes related to the ILPIs. These institutions still have a negative image crystallized in assistentialism [25], because their origin is related to nursing homes or shelters directed to poor people who needed shelter, targeted to Christian charity, with no public policies to support their organization, in a mixture of abandonment and rejection [26]. In some of interviewees' speeches, there was concern in making a distinction between the ILPI where the older adult was living and the traditional asylum, reinforcing the idea that the family was very present and, thus, that there was no abandonment. The concepts of Social Representation and stereotypes are interconnected, referring to the images that societies created about the others. In the anchoring process, the most simplified categorization is related to the stereotypes, being the way in which the individuals position themselves towards social objects [27]. Therefore, the image that is reproduced about the ILPIs can contribute for them not to be seen as an option in the natural process of aging but, in many situations, they are understood as the ultimate resource due to impossibility of offering home care.

CONCLUSION

It is important to explain the social interactions in the processes involved in institutionalization, since the ILPIs are pointed out as an emerging resource for aged individuals. The current perspective of population aging and the change in the family profile indicate a direction for older adults who remained economically active for a longer period of time but who will not always be able to rely on family care support, when needed. This paper made it possible to know the reasons that led to institutionalization and the feelings involved in this process from the perspective of older adults and family members. In some circumstances, the older adults expressed conformism and acceptance with regard to this process, understanding that the family would not manage to meet their care needs but, at the same, they showed the desire of not living in the ILPIs. In opposition, in the impossibility of taking care of the older adults, the family often faces feelings of guilt and suffering. Many families resorted to the ILPIs when their family members required too much care and, in many of these occasions, older adults with cognitive decline did not acknowledge this process and were not able to express themselves. Most of the situations experienced in this institutionalization process were taken when there was already family wear out or burden. In few circumstances was institutionalization chosen as a place for older adults to enjoy their old age, with no associated situations of conflict. Considering that the representations result from the perceptions about the world, where the ideas and attributions are responses to stimuli of the environment where we live, responses that are related to a certain definition, common to all who belong to the same community. The social representations contribute to understanding the meanings of the institutionalization process and thus provide support to face this reality. It is important for the professionals working in ILPIs to be aware of these pieces of information on feelings and meanings, considering the individualities and the family context, so that there is appropriate planning about older adult's life and welcoming of the family in the institution. The results found in this study may contribute to knowledge on the reality experienced in the ILPIs, so as to break with some stigmas related to this process, whereas reinforcing the need for studies focused on this population. Knowing the reasons that lead to institutionalization from the perspective of the older adults and the family members favors the development of new assistance models compatible with the reality faced nowadays. The main difficulty found in the study was the older adults' cognitive decline, thus making it impossible to deepen on the data from the perspective of these participants. It is suggested that future studies investigate the reasons for the institutionalization of older adults in public ILPIs, identifying other care relationships, not only those established by blood ties.

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