

ORIGINAL ARTICLE

INSTITUTIONALIZATION OF ELDERLY AND FAMILY CARE: PERSPECTIVES OF PROFESSIONALS FROM LONG TERM FACILITIES

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ABSTRACT

Objective: to identify the family care provided to institutionalized elderly people, perceived by professionals from Long Term Care Institutions for the Elderly.

Method: descriptive and exploratory study with a qualitative approach, developed with 41 professionals. Data collection took place from May 2017 to January 2018, with individual semi-structured interviews. To organize the data analysis process, the Atlas.ti software was used, whose content was submitted to Bardin's discourse analysis.

Results: the perceptions that emerged from the speeches of the participating professionals about institutionalization originated from current and lived experiences. The presence or absence of the family was linked to care relationships, with a distinction of perceptions among professionals from different institutions.

Conclusion: it was observed that family care, as personal experiences for professionals, was significant to build perceptions about the institutionalization of the elderly and the family member as a caregiver.

DESCRIPTORS: Elderly; Homes for the Aged; Family; Housing for the Elderly; Old Age Assistance.

INSTITUCIONALIZACIÓN DE ANCIANOS Y CUIDADO FAMILIAR: PERSPECTIVAS DE PROFESIONALES DE INSTITUCIONES DE LARGO PLAZO

RESUMEN:

Objetivo: identificar el cuidado familiar con ancianos en centros de cuidado, bajo la percepción de profesionales de Centros de cuidado a largo plazo para Ancianos. Método: estudio del tipo descriptivo y exploratorio, con abordaje cualitativo, desarrollado con 41 profesionales. Datos obtenidos de mayo de 2017 a enero de 2018, con entrevistas individuales semi estructuradas. Para organización del proceso de análisis de los datos, se utilizó el software Atlas. ti, cuyo contenido se sometió a análisis de discurso de Bardin. Resultados: las percepciones que resultaron de las entrevistas a los profesionales sobre la institucionalización se asocian a sus experiencias actuales y vividas. La presencia o ausencia de la familia se asocia a las relaciones de cuidado, habiendo distinción de percepciones entre los profesionales de las diferentes instituciones. Conclusión: se notó que el cuidado familiar, de acuerdo a las experiencias personales de los profesionales, fue significativo para construir las percepciones acerca de la institucionalización de ancianos y del familiar como cuidador.

DESCRIPTORES: Ancianos; Institución de Largo Plazo para Ancianos; Familia; Centro para Ancianos; Asistencia a Ancianos.

INTRODUCTION

Population aging is an installed and progressing reality in Brazil, evidenced by the fast demographic transition. Due to decreases in fertility rates, there is a change in the age structure of the population, with the country marked by an increase in adults and the elderly and a decrease in the ratio of children and young people⁽¹⁾.

According to population predictions, Brazil has passed the mark of 28 million individuals over 60 years of age⁽²⁾. Alongside the demographic transition, there was an important change in the Brazilian family panorama, marked especially by the decrease in the number of children; the increase of single-parent homes; the insertion of women in the labor market; and the increase of longevity⁽³⁾. This scenario demands the organization of specialized public services, through the planning of social public policies that can ensure the line of care for chronic conditions and promote healthy aging, to meet the care needs required by the elderly⁽⁴⁾.

Long-term care (LTC) institutions for the elderly enables long-term care for this population. Although it is an outdated way of caring for the elderly, it is not the first option for a large percentage of the elderly and their family members, considering the stereotypes of the LTC, which often link them to family distance and abandonment⁽⁵⁾.

Study shows that institutionalization was related to decreased family bond⁽⁶⁾. However, it can also mean alternative support, protection and protection, especially for those who have no family and those who live in a condition of family conflict⁽⁷⁾.

The main reasons for institutionalizing the elderly are related to demographic, social, family and health factors⁽⁸⁾. Care overload, illness, decreased functional capacity and the lack of a responsible person to provide home care were the main factors associated with institutionalization⁽⁹⁾.

The LTC maintains a bord of professionals from different care, administrative and social areas, which represents a challenge for the organization of an integrated model that can meet the needs of the elderly, each with its own peculiarities. Although the National Health Surveillance Agency recognizes the LTC in a residential character, which also expresses a social role in supporting the elderly, these spaces are strongly marked by care needs⁽¹⁰⁾. In this context, undoubtedly, it is up to the nursing team to provide most of the direct care to the elderly in the institutions.

However, as in other categories, there is a shortage of professionals specialized in Gerontology and Geriatrics⁽¹¹⁾. According to the perceptions of nursing professionals who work in the care of institutionalized elderly, the lack of human resources and the need for geronto-geriatric improvement for the nursing team directly affect systematized and individualized care⁽¹²⁾.

Thus, even though the care modality has been known and practiced for decades, there is still a long way to go to understand the complexity that can involve institutional care relationships. Therefore, it was attempted to know the perceptions about institutionalization, under the eyes of professionals, important actors in this process, who sometimes act directly in care, sometimes observe and experience family relationships. For such, the objective was to identify the family care perceived by the LTC workers.

METHOD

Qualitative research, conducted with 41 professionals from three private LTC, located in the city of Florianópolis-SC, Brazil. The conduct of research in private institutions is justified by considering that the objective of the study was focused on family relationships. Before data collection, the researchers contacted the leaders of some public LTC, from whom information was received that the elderly who resided did not have many ties, nor contacts with their families, with sparse and irregular visits.

This was a convenience sampling, including professionals whose activities required direct contact with the elderly and family members, and who had been working for at least three months at the institution, a period considered satisfactory for the professional to fully understand the institution's work routine and experience the relationships between elderly and family members. Professionals from all work shifts in the following categories were included: coordination assistants (2), general service assistants (4), coordinator (1), cooks (2), caregivers (10), nurses (6), physical therapists (2), speech therapist (1), nutritionists (2), psychologist (1), hospitality supervisor (1) and nursing technicians (9).

Data were collected from May 2017 to January 2018, with individual semi-structured interviews, guided by an instrument prepared by the researcher, which included the characterization of professionals and the research's guiding questions, related to the research objective. With an average duration of 30 minutes, the interviews were conducted in a reserved place, on the premises of the LTC, during the working day, recorded with the aid of a cell phone and, later, transcribed in full to the computer, using the text editor Word.

Data organization was performed using the Atlas-ti software, followed by Bardin's content analysis⁽¹³⁾.

The findings were debated in the light of the Social Representations Theory (SRT), proposed by Serge Moscovici, which concerns the social representations that circulate, intersect and are built in the encounter of everyday life, which makes it possible to know behaviors and communication between individuals⁽¹⁴⁾.

The study was authorized by the managers of the institutions and submitted to the Ethics Committee in Research with Human Beings at the Federal University of Santa Catarina, which approved it according to the opinion no. 2,047,155, of May 4th, 2017. To preserve the identity of the participants, they were identified using the acronym Profes., followed by Arabic numerals, corresponding to the entry in the survey and professional category.

RESULTS

The study participants were 41 professionals in the functions: coordination assistants, general services assistants, coordinator, cooks, caregivers, nurses, physiotherapists, a speech therapist, nutritionists, a psychologist, a hospitality supervisor, and nursing technicians. The most representative category was nursing (nursing technicians and nurses); women predominated, aged between 22 and 65 years, and service time from three months to 22 years.

From the thematic axis "Professionals' perceptions of institutionalization and family care relationships", the first category analyzed was "Professionals' view face to institutionalization".

The perceptions that emerged from the professionals' speeches about institutionalization originated from current and lived experiences, or even through imaginary representation about this reality. In general, previous experiences were associated with

negative aspects, such as calling rest homes the places where the elderly was not well cared for, according to the statements:

It is not that thing of mistreatment that we hear about. Like the old days left the elderly there to die. Then, my perspective completely changed. (Profes. 10, Nurse).

These places, for me, were scary until then. That was the idea I had. Then, when I came, I didn't know anyone, everything was strange. I stayed here a weekday and night at the request of the family, which was for them to be sure (...). I was surprised, you know? Of course, I don't know if all homes are like that. But, here, it's really good, very good. (Profes. 02, Private caregiver)

Before, I had the idea of an elderly man abandoned. Lying on a couch, in an armchair, unkempt, full of pee, I had that vision. But, when I started working here, I changed completely. (Profes. 15, Nurse)

Regarding institutionalization, the interviewees named positive and negative aspects. The physical structure and the technical-administrative staff were positive points, highlighting the organization of the environment, hygiene, comfort, and the active multidisciplinary team. The pre-established routine itself, such as the feeding schedule, correct medication administration, among other routines, was identified as a positive factor.

Regarding the negative aspects, some professionals considered that elderly residents could not be happy, as evidenced in the statements:

I didn't see anyone saying that they are happy to live here. (Profes. 07, Nursing Technician).

Everyone wants them to adapt well, but say: Oh, good, I came to live in a nursing home. It won't happen, it doesn't exist. (Profes. 23, Caregiver of the Institution).

The rupture of the family bond with institutionalization is reinforced in the speech.

Because the family ends up having an idea that brings the elderly person to a home facility and that's it, so that's okay, here he has everything he needs and the main thing, which is contact, he doesn't have. It ends up cutting the family bond and distancing himself. And then he ends up only participating when there is a little party, when the elderly person is sick, but family life, that bond is broken. (Profes. 12, General Services Assistant).

In some circumstances, the professionals recognized a difference in the cases in which the elderly person chooses to live at the LTC, with better coping, than when the decision is made by family members.

Many come on their own, because they do not want to give this work to their children, family members, so many elderly people here are fine, those who come on their own. But many do not, they come because of the will of their children, and they suffer much more. (Profes. 05, General Services Assistant).

I see that only those who came here willingly - which is very rare - are happy. Most are not. (Profes. 35, Nurse)

When asked if they would place one of their family members at the LTC, the professionals, in most cases, responded that it was an appropriate place, especially because they assimilated the professional experiences in the institutions where they worked. However, for some, they would first try to take care of family members at home.

At first, we analyze the possibility of living together (...). But, if it was in a place like this one, that I know they will have all the care, food, everything right (...). And, here, I would know that there are no visiting hours. Visitors have free access. It is one of the reasons for family members to choose this home to bring their elderly relatives. (Profes. 31, Physiotherapist).

At first, I would try to take care, but if it got too difficult, I would put the person into a home. I think it's reliable. I like the work that is done here. (Profes. 10, Nurse).

For a group of professionals, the experience of working at the LTC transformed the way they recognized these places and, therefore, considered it an adequate and safe option for family members to live the elderly age.

I said I was going to quit my job, do something (to take care of the mother), but I wasn't going to leave her. Not today. Nowadays, if it were a good institution, I would put her in. But I would be present. Not only visit now and then. (Profes. 09, Caregiver of the institution).

I think I would prefer to stay with my mom at home. If I were to put her in a rest home like this, I would be without concerns, you know? But it would also be very present, I think I would always be here, as much as I could. (Profes. 15, Nursing Technician).

Some would not place in LTC because they believe that closeness to the family at home would be the best way to provide the necessary care and the best real way of transmitting affection and love. They also expressed feelings of reciprocity of care, since they were cared for by parents, they should, out of respect and obligation, return the care in old age.

I wouldn't put him in a rest home, I would take care of him at home. Because it's kind of lonely. The elderly are dependent on affection. As much as you have all the assistance, medication on time, food, doctor, here they have everything. But they don't have a team that will sit there and talk. (Profes. 20, Nursing Technician).

I wouldn't put him in a rest home. No way, not because there is no care, food at the right time, everything. I can't even think about it. (Profes. 02, Private caregiver).

I would try to take care of her (mother) to the limit. And what she has done for me until today, I owe her this care. (Profes. 01, Private caregiver).

I wouldn't put him in a rest home, because we are poor, and whoever puts it here needs to have money. But I wouldn't put it because my mother has 10 children, and she has to have one of the children who will take care of her. So, if I ever need it, I quit my job and I'll take care of my mother. (Profes. 19, Caregiver of the Institution)

The analysis of the category "Perceptions about family-elderly care relationships" showed that perceptions varied between institutions: in two LTC, the family was considered, in most reports, very present; and in more specific cases, absent. In the third LTC, there was no predominance of presence or absence in the professionals' statements, a more consistent division of conditions was noted. And yet, the difference was reflected in the family's perceptions as a caregiver; the most present family was linked to greater care relationships with the rest home's elderly, when compared to absent family members.

In the two institutions where the family, in general, was considered present and close to the elderly, the family members were mainly characterized by being interested in the routine of institutional life and participating in decision-making about the lives of the elderly.

Family members participate a lot in their lives here. There is always a family member discussing a subject or other about the rest home with the management. (Profes. 31, Physiotherapist)

Some families pick them up on the weekend for a walk, some families come here to have lunch with them, some families are here every day with the elderly... and, that's why, I say that they are quite present. They bring in grandchildren, great-grandchildren, it is a family relationship. (Profes. 17, Nurse).

The family's care for the elderly was evidenced by the professionals in the following aspects: attention to the care provided by the institution; hiring private caregivers;

institutionalization itself, especially due to high financial investment; sharing moments during meals; the respect; concern for individual needs; and the escort in medical consultations.

In the third institution, in which the family was considered in some cases present and others absent, the participants exemplified the situations, with an agreement in the cases mentioned.

I think some take care, some who do, they care a lot, but some who ... Sometimes, even when they go to the hospital, sometimes they need a caregiver, they are not able to stay. (Profes. 19, Caregiver of the Institution).

Depends on which elderly, depends on which family... most have a very loving relationship, very close (...) some relationships are specific, it's the same as the owner (...) that I told you. She, for not having raised her children, they come only once a month, that day, they bring everything she needs for the month, an allowance, as well as medications and a visit, a walk around and that's it. (Profes. 03, Nurse).

Likewise, in this institution, the family absence was related to conditions of abandonment, in the view of professionals:

Yes, several elderly people complain about the absence of the family, they miss it because in the end they feel abandoned. (Profes. 18, Caregiver of the Institution).

The elderly man who dressed up for Christmas to go to his son's, and the son came here on a motorcycle, so he couldn't take him, his father was all dressed up, with perfume on and he didn't take him. (...). I think it's sad, I wouldn't want that for myself. I keep thinking: don't they think about it? "oh, I'm going to do it for my father, because in the future, we don't know what the children are going to do to me", I see the abandonment of some and I find it sad. (Profes. 29, Nursing Technician).

DISCUSSION

The results showed that some professionals used the term rest home to report previous experiences or perceptions about the institutionalization process, resulting in stereotyped characteristics, especially related to abandonment and neglect in caring for the elderly. Even though the interviewees distinguished the LTCs in which they worked from past experiences, looking for rest home references can reveal traces of the negative burden that institutions still recall, as reported in a study, in which professionals related the rest home lexicon to some stigmas still present today in LTC⁽¹⁵⁾.

Negative stereotypes and prejudices are included in the category of the silent zone of social representations, that is, they are spaces of representations that, although they are present and common to a certain group, can be veiled in the speeches, during the investigation⁽¹⁶⁾. Thus, the reference to rest home was manifested in the interviewees' statements, since this denomination is related, besides family abandonment, situations of abuse by professionals.

Institutionalization was recognized positively and negatively by the workers of the LTC investigated. As these are private institutions with a long experience in the city, these places have a structured organization, both by physical and human resources, represent safety, comfort and competence on the part of the professionals involved in the care process. This was one of the main positive aspects pointed out by the interviewees, especially when comparing previous experiences, usually in public institutions, appreciating the services offered by current private institutions.

In research on the perceptions of professionals about institutionalization, positive aspects were related to emotional assistance: support, safety, affection and the possibility of socialization among the elderly and, also, by physical assistance, through specialized care and accessibility⁽¹⁷⁾.

The negative aspects were related to the feeling of sadness of the elderly, perceived by the professionals to be away from family life. Likewise, in another study, professionals recognized the elderly as fragile due to family abandonment, characterized by sadness and isolation that affect the dignity and self-esteem of elderly residents⁽⁸⁾.

In general, the LTCs were recognized as an adequate place for the elderly to receive the necessary care. The statements also signaled that the family members made the right decision about institutionalization, as they could not provide care at home, but provided the necessary assistance.

Many professionals hesitated about the possible institutionalization of their elderly family members. A new object causes a change in the universe of the subjects' representations, considering its interest and relevance for the group in which it is inserted. However, the elaboration of representation uses not only the immediate context, but also the past, and creates future expectations(18). In fact, in the speeches of the professionals, cultural beliefs related to home and family care for the elderly were evidenced.

As in another study, family relationships were varied, with situations in which the family was present and kept the bond, and circumstances in which institutionalization meant the withdrawal and even rupture of the link, in the case of an absent family⁽¹⁹⁾.

In another study, the professionals' perceptions of the family of institutionalized elderly people showed the absence of family members, in some circumstances characterizing family abandonment, as they did not always attend the institution. For these workers, strengthening and preserving bonds, through family participation and emotional support, could contribute to minimizing the feeling of abandonment experienced by some of those elderly people⁽¹⁹⁾. The care provided by the LTC is not a substitute for family care, it is important to consider the family and its functionality as the focus of care in the care planning of the elderly⁽²⁰⁾.

The presence or absence of the family was linked to care relationships, with a distinction of perceptions between institutions; it was observed a more homogeneous look in two institutions, in which in general the family was considered present, while in the third, the attention was more heterogeneous, with an evident distinction between the family considered present and caregiver, and those absent who did not keep relations of care.

Another factor considered in the differences found is the fact that in the third institution the elderly were more independent, with more preserved cognition, greater interaction with professionals, and thus complaints, reports and expressions of sadness were perceived more clearly and may influence the positioning of professionals.

Professionals working in care build representations in everyday life and in their technical training, which grants scientific knowledge⁽²¹⁾. Thus, the movement of bringing a certain object to the field of familiarity is evident, naming and defining together the different aspects of everyday reality⁽²²⁾.

Recognizing how representations are expressed is important to identify the organization of social conduct and communications in the face of relations with the world and others⁽²²⁾. In this way, when a representation is created by a group of professionals, such as the one that defines what a family caregiver would be, can be interpreted as a lack of care for the elderly, the family member who does not fit in this role. However, these roles are defined by a very fragile line, since the past relations between the elderly and the family can also influence the attitude adopted in the present. There is a requirement from society for the family to be present and not to abandon the elderly, supported even in legal

aspects.

In an international study that evaluated the experience of family members in caring for institutionalized elderly people, it was shown that family participation was related to closeness to the team, as well as the relationship of trust between them, open dialogue about the elderly, being invited to complete tasks, respected by their knowledge and recognized by the team as part of the care⁽²³⁾. In this perspective, the team's communication with the family members of the elderly can be a facilitating instrument in family cooperation and participation, as well as a barrier, when used only to report incidents or clinical changes, not valuing the family as an important coworker in care practices or decision-making⁽²⁴⁾.

Anyhow, the family figure was very important and evident in the interviews, as present or absent families. It was observed that family care, as personal experiences for professionals, was significant to build the perception of the institutionalization of the elderly and the family member as a caregiver.

FINAL CONSIDERATIONS

The study allowed to identify that the professionals establish affective bonds during the work process in the LTCs, also reflecting on the perceptions about the experienced family relationships. While they recognize the importance of family presence in the daily lives of institutionalized elderly people, they add and accept care relationships as constituted between family-elderly, often becoming an obstacle to their concreteness.

The LTCs are a complex system of relationships, which will be built in a very individual way, making it necessary to rethink assistance aimed at people included in the specific daily life of the institutions. One limitation of the study is to carry out the study only in private LTCs, highlighting the need for further studies in this area, to cooperate with the construction of care systems that consider the individuality of the institutionalized elderly being, the insertion of the family in this context and specialized care.

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