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Implications of family participation in care to the institutionalized elderly

Implicações da participação da família no cuidado às idosas institucionalizadas

Implicaciones de la participación de la familia en el cuidado a las personas mayores institucionalizadas

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Abstract: Aim: to describe how the workers from a Long-Term Care Institution for the Elderly perceive the role and participation of the family in the lives of institutionalized elderly. **Methods:** qualitative research undertaken with 16 workers from the Long-Term Care Institution for the Elderly. The data were collected through a semi-structured interview and used thematic analysis. **Results:** it was verified that the family's role is related to maintaining ties with each elderly relative and to supply their affective needs - in the view of workers. The different forms of family participation in the institution occur through visits, telephone contact and aid in care. **Conclusion:** the family role is to provide support to the elderly through various forms of participation in the institution: minimize loneliness and promote positive feelings of belonging to the family nucleus for the aged.

Descriptors: Homes for the Aged; Workers; Family Relations; Geriatric Nursing

Resumo: Objetivo: descrever como trabalhadores de uma Instituição de Longa Permanência para Idosas percebem o papel e a participação da família na vida de idosas institucionalizadas. **Método:** pesquisa qualitativa realizada com 16 trabalhadores de uma Instituição de Longa Permanência para Idosas. Os dados foram coletados por meio de entrevista semiestruturada e utilizou a análise temática. **Resultados:** constatou-se que o papel da família está relacionado à manutenção de vínculos com a idosa para suprir as necessidades afetivas dela, na visão dos trabalhadores. As diferentes formas de participação da família na instituição ocorrem por meio de visita,

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contato telefônico e auxílio no cuidado. **Conclusão:** o papel da família é prestar apoio para a idosa por diferentes formas de participação na instituição: minimizar a solidão, promover sentimentos positivos de pertencimento ao núcleo familiar para a idosa.

Descritores: Instituição de Longa Permanência para Idosos; Trabalhadores; Relações familiares; Enfermagem Geriátrica.

Resumen: Objetivo: describir como trabajadores de una Institución de Larga Permanencia para Ancianas comprenden el papel y la participación de la familia en la vida de personas mayores institucionalizadas. Métodos: investigación cualitativa, con 16 trabajadores de una Institución de Larga Permanencia para Ancianas. Los datos fueron recolectados por medio de una entrevista semiestructurada y se utilizó el análisis temático. Resultados: se constató que el papel de la familia está relacionado al mantenimiento de vínculos con la anciana y para suplir las necesidades afectivas de ellas - en la perspectiva de los trabajadores. Las diferentes formas de participación de la familia en la institución ocurren por medio de la visita, del contacto telefónico y de la ayuda en el cuidado. Conclusión: el papel de la familia es prestar apoyo para la anciana por medio de diferentes formas de participación en la institución: minimizar la soledad, promover sentimientos positivos de pertenencia al núcleo familiar para la anciana.

Descriptores: Hogares para ancianos; Trabajadores; Relaciones familiares; Enfermería geriátrica

Introduction

Aging may be accompanied by chronic-degenerative diseases, deterioration of functions and weaknesses that inflict loss or decrease of functional capacity, and this set of conditions is denominated senility.¹ The family is often the only source of care for the elderly, requiring a reorganization to meet their obligations. In this context, one can observe changes in the role and configuration of the family, which given the demands of the capitalist world and financial difficulties faced by the majority, creates obstacles for the care of the elderly and maintenance in their home, particularly when in situations of dependence.²

In Brazil, some Long-Term Institutions for the Elderly (LTIFE) have undergone or are undergoing changes in the organization and preparation of multiprofessional teams to offer more appropriate care and improved accessibility for the physical structure.³ Nursing as an essential part of the multidisciplinary care for institutionalized elderly should encompass an integral care, evaluating the spiritual and biopsychosocial aspects experienced by them and

promote an individualized and humanized care with the intention of welcoming the elderly person and their family to the LTIFE.⁴

With the perspective of supporting the elderly and family within a situation of institutionalization, nursing can offer, besides care and physical comfort, emotional support through guidelines. The limitations and difficulties that the elderly and respective family are facing can be minimized through nursing care by identifying their needs and ensuring a better quality of life for all.⁵

The social network of the elderly suffers a decline during the course of life, either because of a possible separation of the children to constitute new families, or the death of relatives and friends, among other factors, rendering the elderly more vulnerable to feelings of helplessness. Family can be understood as the main support for the elderly, however, moving into an institutional context may lead to a decrease and, in some cases, the total absence of family support.⁶

The family represents hope for the elderly wishing to maintain affective relationships and also offers the solution to avoid feelings of abandonment. Regardless of the situation in which the elderly find themselves, family support is fundamental in the aging process, since it motivates a sense of value to life when present and overcomes a lack of perspective when absent.⁷

The family needs to be counseled and encouraged to develop skills to face everyday life with the institutionalized elderly: value their culture, their values and respect their limitations. One of the challenges of aging is the need for health professionals to provide care and to guide the family; working as a team so that it is possible to live longer, with better performance.⁸ It is observed that although aging is a process occurring in everybody, it is necessary to adjust the quality of care in those institutions that receive the aged and to understand the role of family members as care providers. Such a consideration already indicates, in part, the importance of

the elderly-family-health professional triangle in the perspective of an improvement in care within LTIFEs.

In light of the above, the following research question was raised: how do LTIFE workers perceive the role and participation of the family in the lives of institutionalized elderly women? To answer the question, we have as objective: to describe how workers of a Long Stay Institution for the Elderly perceive the role and participation of the family in the lives of institutionalized elderly women.

Method

This is a descriptive research with a qualitative approach. Qualitative research aims to understand and explain the dynamics of social relations, which are the custodians of beliefs, values, attitudes and habits. This modality of research works with the background, experience, daily life and also with the understanding of structures and institutions, as a result of objectified human actions.⁹

The field research was performed in a LTIFE with the capacity to serve 210 elderly women, located in the central region of the State of Rio Grande do Sul, between February and June 2012. At the time of data collection, 188 elderly women were residing in the institution and it counted on a staff of 77 workers. The participants of this study were 16 of the workers at the LTIFE. The sample was intentional considering a representative of each professional category: nurse, physiotherapist, physical educator, social worker, nutritionist, pharmacist, psychologist, pedagogue, nursing technician, executive secretary, chef, cleaning assistant, laundry attendant, porter, maintenance worker and driver.

In order to select the participants, the inclusion criteria were defined as: to be an LTIFE worker with an employment relationship for at least three months; have a minimum workload of 20 hours per week and have some form of contact with the relatives of the institutionalized

elderly women. The exclusion fator was those workers on vacation or on leave of any nature at the time of information collection.

To obtain the data, the semi-structured interview technique was used, containing the sociodemographic characterization of the workers and two questions with the following thematic axes: Tell me how the family of the elderly participates in LTIFE? And, in your opinion, what is the role of the family in an LTIFE? The interviews were carried out by the main researcher, at the participants' own workplace, in a reserved place, with an average duration of 20 to 40 minutes. The data collection was finalized when analysis of the discourses met the questions and the objective of the study was reached.

The interviews were recorded, fully transcribed and read exhaustively and repeatedly, according to the thematic analysis steps⁹ in order to establish the important issues and construct the empirical categories of the study. After these steps, the final analysis was performed, which related the data obtained to the theoretical references of the research.

It should be clarified that gender related issues were not considered in this study. However, to maintain consistency with the people residing in the LTIFE and with the speech of the study participants, the feminine term "elderly woman" [*Idosa*] was used.

The research project was analyzed and approved by the management of the LTIFE and the Research Ethics Committee of the institution in which the project is associated, with the Certificate of Presentation for Ethical Appreciation number 0345.0.243.000-11 issued on 13/12 / 2011, respecting all the steps set forth in Resolution 466/12 on research involving human beings, in accordance with the Code of Ethics of the National Health Council of the Ministry of Health.¹⁰ The researcher invited the participants to participate in the study. The Free and Informed Consent Form was signed in duplicate by all participants. The confidentiality and anonymity of the information provided was assured, and the participants' statements were identified by the letter "W", referring to the term worker and sequentially numbered.

Results

As to the characterization of the study participants, nine were female and seven males, aged 27 to 62 years. The predominant religion was Catholic, reported by 14 participants. Regarding educational level, four deponents had incomplete elementary education, one had completed elementary education, two had completed secondary education, one had incomplete higher education and eight had completed higher education. The income ranged from one to two minimum wages. Regarding the time in the LTIFE, eight participants worked between one and two years, five worked from four to nine years, two from 13 to 14 years and one for 32 years.

In relation to the objective proposed in this study, the results are two categories that emerged from the analysis of interviews: the role of the institutionalized elderly family and the different forms of family participation in the institution.

The role of the institutionalized elderly family

The role of the family according to the participants of the study revealed that it is the main reference for support for the elderly, especially when they are in an LTIFE. The family is singled out as the subject most often mentioned by the aged in their conversations.

The workers' discourses emphasize that the main role of the family is their permanent responsibility for the elderly, even after their institutionalization, without abandoning them, nor transferring the affective responsibility to the institution, but maintaining their family commitment, preserving the ties and cultivating affection with the elderly. In this sense, considering the need for institutionalization of the elderly, the role played by the family in the context of the institution is essential to maintain emotional stability, provide protection and quality of life for the elderly.

The role of the family in an institution is not to abandon, it is to continue to be present, giving support that is the responsibility of the family, that no other professional, nor other institution will be able to fill the role that is the family's responsibility. So the family has to fulfill its role. Cannot take care of yourself, you need an institution, okay! But to continue present, to continue doing your part that is affective, is responsibility and it will never change. (W4)

The role of the family here in the institution is to continue looking after that elderly woman, to continue being part of this family, being part of this life. So, that would allow this assistance, which is even strange to say, but a quality of life, not abandoning her here. (W14)

The staff consider it important to maintain the family's bond with the institutionalized elderly woman for her quality of life. The professionals understand that they can not substitute the bond when a family abandons the elderly, this being their exclusive role which is then absent. They observe that the family would assist in care, mainly because of affective questions, seen as their responsibility, according to the workers' perception.

The staff believe that maintaining the affective bond with the elderly reduces the frequency of health problems. In addition, workers believe that elderly women would be more happy and less sick with family participation in the LTIFE.

The participation of the family would certainly bring more quality of life, well-being and tranquility for the elderly. And for us workers it would also help to work more at ease, and to have more time to dedicate ourselves to their care [...] (W5)

The participation and presence of the family in the institution would change, from the expression in their eyes, I think it would change. The impression I get that they would be happier and more adapted, you know? This is the role of the family! Participate here in the institution! Who knows with the participation of more relatives here, they would present less diseases, maybe they would not be so cardiac, they would not have other problems. (W7)

The participation of their family here brings happiness, their peace. So I think that's the role of the family. They would be quieter, calmer, would not be agitated, and would adapt more to the new home [...]. (W12)

Participation of the family in the LTIFE, in addition to providing more satisfactory emotional conditions for the elderly women, would allow a closer relationship with the workers, favoring the care and adaptation of the residents in the institution.

The family, if it provided affective support for the elderly, would prevent anxiety and depression, frequent symptoms in institutionalization:

[...] I think that the role of the family is to make the elderly feel they still belong to that family group. It is, in this sense, that when I can, I talk with their family, I talk about the importance of participating here in the institution. It is easier if the family is present, also for us to come and intervene. (W8)

If the family member participated more in the institution, I think this would have a very profound impact on the quality of life of the elderly women. They would be less anxious, less depressive, and all this would directly reflect on health. Like, fewer medications, less pain, better quality of sleep. That bond of love, of broken affection with the family, leaves anyone ill. (W4)

[...] if the family were providing for this anguish, this desperate desire and hope of the elderly woman to have the family member here, their care and health would improve. (W10)

The presence of the family can bring about reflexes in the health of the institutionalized elderly, such as: reduction of pain and medication, besides improvement in sleep quality.

Absence of the family generates "anguish", this aggravates the health conditions of the elderly, so the workers see the importance of the family member's participation in the care and improvement of the elderly person's health.

The various forms of family participation in the institution

The participation of the family with the elderly and the maintenance of family ties in the institutional space according to the perspective of the workers occurs mainly through visits:

their family participates visiting here, comes to visit the relative, stay a little, talk, bring gifts and go away, but do not get very involved. (W1)

the family, participates, by sporadic visits, according to their possibilities. (W4)

the family participates coming to visit here. Those who come, they want to know how they are, talk a little. But besides the family coming to visit them, I'm happy when they want to know, how they are here. (W12)

The low frequency of family visits is evident in the discourses of the staff. And when sporadic contact occurs, it is short and lacking in affective and emotional involvement by many families.

The staff of the present study understand that contact between the family and the elderly is a primordial issue in an LTIFE and that it must take place, even if it occurs through a telephone call.

The family of some of the elderly women calls, they themselves tell us: "Ah, my son called today." So that's what I mean, you know? If the family cannot be present here, they can make themselves present through a phone call. I think that we here have to value this participation, it does not have to be just the physical presence. (W13)

There are family members who can only manage a phone call. So by a call they can deal with this lacking when the presence does not occur, either because they do not live in the same city or because they have their own difficulties. And you have to see how happy they are when they get the phone call from someone in the family and spend the day talking. (W14)

This form of participation in the vision of the workers is also important, because through a telephone call they can show care, concern and affection for the elderly, allowing the participation of the families that can not be present physically in the LTIFE. This type of participation demonstrates that such contact transcends the physical presence, resulting in a positive effect for the institutionalized elderly women.

In addition to the availability and willingness of the family to participate in the elderly woman's life in the institution, it is beneficial to also have a bond with the workers as a way of favouring and encouraging the presence of the family, this being a relevant aspect reported by the interviewees.

But I think their family should talk to us, know how they are and have that bond with us. (W1)

I think so, that if the care of the elderly here was integrated between us workers and the family of the elderly women, surely they would be better. (W7)

Situations occur in which some family members become involved in caring for their family member: helping to bed; assisting in feeding; taking to the dentist, exceptionally.

She had a family member who participated here in the institution helping in the care of her relative and even took care of the older women in some way as well, helping to carry her to bed. (W5)

There's a lady's daughter here, she's off duty, and she walks by before she goes home. She comes to help the elderly woman to dinner, because this elderly woman has a hard time eating with her own hands. Sometimes we have to be sensitive and I look out for that relative, because he has doubts, wants to know about the elderly person, or help with care. (W10)

There are some exceptions of families who even take them to the dentist. There is an elderly woman that the family makes an appointment, and asks us if we can take her. Imagine when the familiar, helps, we give all strength we can, because nothing is better than the family. (W7)

Family participation is valued and understood as a means of providing a higher quality of life for the elderly. In addition, they realize that some families want to participate in the care of the elderly in the LTIFE, and they need to be heard and counseled about their doubts. The participation of the family in the institution also facilitates the interaction of the worker with this family, seeking a partnership in the care of the elderly.

Discussion

The discourse of the LTIFE workers demonstrates that the lack of affectivity manifests itself in the daily life of the elderly, affirming that maintaining the bonds with the family structure is fundamental for the well-being and quality of life of the elderly. Studies show that the family bond is fundamental for stimulating healthy aging, receiving support and affection from the family, and that the absence of family can generate feelings of social isolation. 11-12

The discourses show that the role of family involving institutionalized elderly is to participate and be present in the ILPI, thus mobilizing positive feelings, so that the elderly do not feel abandoned, alone, needy or without reference. Therefore, it is considered important that the Family becomes integrated into the institution and accept co-responsibilty for their family member.

A survey evaluating family support for institutionalized elderly dependents has shown that family support is fundamental for maintaining the person's physical and psychological integrity and should therefore be involved in the organization and execution of care. Thus, it is necessary to raise awareness and work toether with families on issues related to neglect, omission of care and abandonment so that the family continues to participate actively in the daily life of the elderly after they are institutionalized.

The study participants reported that assisting and guiding the elderly residents and their families about adaptation in the institution and the guarantee of their rights helps to maintain the bond between workers, families and the elderly. Consequently, the LTIFE has the role of encouraging and maintaining family ties with the elderly. Family integration in relation to informal care has the same importance as care provided by health professionals to achieve holistic support for the institutionalized elderly.

A study in an asylum institution in Australia, on investigating the perceptions and experiences of social interaction of the elderly, identified that the most common methods of communication of the elderly with their family and friends occurred through telephone, letters and computers. ¹⁴ Maintenance of family support is essential for the elderly to feel secure and integrated in places like LTIFE, facilitating their stay, as well as promoting na enhanced bond between the family and the various professionals comprising the multidisciplinary team. ⁸

A study on institutionalized elderly¹⁴ identified that the residents had access to telephones in their rooms and often called their family and friends whenever they wanted. Access to these phones is an opportunity for residents to socially interact and keep in touch with people outside the institution. With more means of contact, it is possible to maintain a sense of belonging with the family, thus empowering the elderly to better control their environment and promote a sense of well-being.⁸

In addition to the forms of participation, the workers also reported that the non-participation of the family can have repercussions on the elderly's difficulty in adapting to the routine of the institution, causing emotional problems, provoking feelings of isolation and anguish arising from their desire to interact with family members.

The LTIFE staff must work so that institutionalization does not symbolize a breaking of affective bonds and termination of care relationships with the elderly person's family. One of the concerns of health professionals is to seek to motivate family members to be more active in the care of the elderly person. In this sense, the family caregiver should be considered as an integral part of this system and not as the only possibility of care for the dependent elderly relative.

It is understood that a family wishing to help in the care of elderly residents in the LTIFE is seeking guidance on applying the care that is appropriate to them. The institution should be willing to become better acquainted with the family context and not be merely restricted to attending the individual needs of the residents; thus fostering care and assistance that also takes into account the needs and expectations of the family.⁸

The family's protection of the elderly requires the promotion of support for its members.¹⁷ The family is considered a fundamental element in the care of its components, however one of the reasons that lead to the institutionalization of the elderly is the reduction of the social support network during aging, such that the elderly person may feel excluded from their family context. Considering this condition, there is a need for the formulation and execution of social policies to support families that meet their needs and those of the elderly in the process of institutionalization.¹⁸

The various forms of participation by the family of elderly residents in the LTIFE are considered positive in the view of the workers of the present study. From this perspective, the participation of the family in the institution emerges as a responsibility that must be shared by

the LTIFE workers and family, aiming at the promotion of quality of care and life. The affective aspect of care emerged as relevant, both in the needs of the elderly, and as an indispensable component in their relationship with family members, and especially with the care professionals.

This study with the workers of an LTIFE shows the syntony between the different categories of professionals working in this institution regarding the importance of family participation and affective bonding during institutionalization of the elderly woman, in order to maintain her physical and mental health. These workers must welcome the elderly residents and their family in the LTIFE, emphasizing that the greater the commitment and partnership among the workers and family, the better and more satisfactory will be the care offered to the institutionalized elderly.

Conclusion

Family participation in an LTIFE can contribute to the elderly having an improved adaptation in the institution, thus presenting better health conditions. From this study, it was verified that the family's role is to provide support so that the elderly do not feel abandoned, and when expressing affection in relations with the elderly, it influences their physical and emotional well-being. The means of contact and participation in daily life by the family members of the elderly are constituted through visits, telephone contact and help in their care.

At the same time, workers can experience difficulties resulting from the absence of the family in the life of the institutionalized elderly woman, because they show no interest in becoming integrated with the institution. They add that any form of participation played by the family in the process of institutionalization is relevant, since it meets the affective deficiency, thereby lessening the loneliness and promoting positive feelings in the elderly, such as still belonging to the family nucleus.

Mediation is suggested to develop activities to maintain the affective bonds of the family in the life of the institutionalized elderly, in order to provide an approximation and mutual exchange within the LTIFE-elderly-family triangle. In addition, it is necessary to plan the means to stimulate family participation in the institution, taking into account the limitations and capacities of each family, so that they feel welcomed and involved in the care of their relative in the LTIFE.

It is important to highlight the relevance of the study for care in an LTIFE, since an understanding of how the staff perceive the role and participation of the family in the daily life of institutionalized elderly, reveals the need to plan alternatives to promote the insertion of the family in the LTIFE. Furthermore, with this research the need for new studies is demonstrated, recognizing the importance of the family as an ally in the care process, especially in this scenario, thereby promoting health among the elderly.

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