

Routine of the family companion during hospitalization of a family member

Cotidiano do familiar acompanhante durante a hospitalização de um membro da família

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Keywords

Daily activities; Family relationships; Family nursing; Hospital nursing service

Descritores

Atividades cotidianas; Relações familiares; Enfermagem familiar; Serviço hospitalar de enfermagem

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Abstract

Objective: To understand the changes in the routine of the family companion during the hospitalization of a family member.

Methods: Qualitative research carried out with 16 family companions of people with self-care dependency in a public hospital. The recorded interviews were conducted individually using a semi-structured script. We used the thematic analysis for data organization and analysis, and discussed in light of theoretical assumptions and the sensitivity proposed by Maffesoli.

Results: Four categories emerged, namely: break of substantial bonds with the children; the abdication of labor activity in favor of being together; hospital rituals in the routine of the family companion; and, self-care and the power of being together.

Conclusion: Staying in the accompanying process overlaps all the daily life activities of the family companions.

Resumo

Objetivo: Compreender as alterações no cotidiano do familiar acompanhante durante a hospitalização de um membro da família

Métodos: Pesquisa qualitativa realizado com 16 familiares acompanhantes de pessoas com dependência para o autocuidado num hospital público. As entrevistas gravadas foram realizadas individualmente, utilizando um roteiro semiestruturado. Para a organização e análise dos dados utilizamos a Análise Temática e discutimos à luz dos pressupostos teóricos e da sensibilidade propostos por Maffesoli.

Resultados: Emergiram quatro categorias: a ruptura do laço substancial com os filhos; a abdicação da atividade laboral para favorecer o estar-junto; os rituais do hospital no cotidiano do familiar acompanhante; o cuidado de si e a potência do estar-junto.

Conclusão: Permanecer em processo de acompanhamento se sobrepõe a todas as atividades da vida cotidiana dos familiares acompanhantes.

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Introduction

Finding a definition for the family has been an attempt of some theories that encounter difficulties due to the complexity of this social group. However, they converge on common themes such as: families are a system composed of units that are interdependent and at the same time connected; families are systems guided by goals aimed at balance and homeostasis; and the environment interferes in their characteristics, as well as in the available resources and in the answers of family before adversities.⁽¹⁾

The adversities interfere with family balance affecting the dynamics of all its members. Disease and disability are common experiences for families and represent a major challenge, since the psychosocial problems caused by a dependent person generate impact on the entire family system.⁽²⁾

The disability and dependency caused by the illness of a family member are more intense in case of hospitalization, causing repercussions in the whole family system, especially when a companion is needed. Although almost always the hospitalized people with some kind of care dependency require support and accompaniment of a family member, the studies do not report the kind of intervention the family should perform during the treatment.⁽¹⁾

Regardless of the interventions performed by the family companion during the care process in hospitals, they experience positive and negative feelings. The negative aspects are related to the changes occurring in their daily life, interference in their routine, physical and emotional stress and financial problems. On the other hand, caregivers feel satisfaction for being able to help their families.⁽³⁾

The hospitalization of a family member disrupts the family structure, changing its dynamics and resulting in attempts of self-reorganization to maintain the balance. Almost always, this reorganization is accompanied by suffering and conflicts, in which the abdication of oneself to care for the other is so intense that some people interrupt their daily lives to carry out the process of accompaniment.

These changes were perceived empirically during practical and academic activities. When conducting a survey on studies with families in process of accompaniment in hospitals, we identified that the literature has been directed to groups in which the Brazilian law grants the accompaniment legally, such as children, the elderly and women in labor. Thus, we found a gap in the accompaniment of people with self-care dependency. However, in this study all these people had a family companion full-time, regardless of age range, authorized by the hospital.

Thus, understanding the changes that occur in the lives of these families during the accompaniment process at the hospital will allow the elaboration of user embracement strategies by the nursing, in order to improve communication, understand the relationships with consequent organization and better quality of care provided to this group in the hospital. The aim of this study was to understand the changes in the routine of the family companion during the hospitalization of a family member.

Methods

This is a descriptive, exploratory study with qualitative and comprehensive approach, carried out in the medical and neurological clinic of a public teaching hospital in the countryside of the state of Bahia, Brazil. These units were chosen because in these places we found a higher concentration of people with self-care dependency accompanied by their family members and accommodated in collective rooms.

People participating in the study were the family companions of people with self-care dependency who met the criteria of age over 18 years and accommodated in collective hospital rooms. The exclusion criterion was the fact of receiving financial compensation to accompany the hospitalized family member. Therefore, this was an intentional sample.

Data were collected from May to July 2014, using the data collection technique of semi-structured

interviews. In total, were interviewed 16 families who met the inclusion criteria and agreed to participate in the study.

Of the 16 participants, three were males and thirteen females. With respect to age range, five participants were in the age group of 50 years old, five in the group of 40 years, two in the group of 30 years, three in the group of 20 years and one in the group of 60 years. Of the 13 women, four accompanied their mother, three accompanied their children, two their brothers and one accompanied their grandmother, husband, nephew and brother-in-law. Among men, one accompanied his wife and two their hospitalized children. All respondents affirmed their faith in God: nine were Catholic; five Evangelical; and two stated they did not have religion.

The interviews lasted thirty minutes, on average, and were held in a private place, in the presence of the researcher and the participant. Data from the interviews were recorded and transcribed. After exhaustive reading, they were decoded and submitted to thematic analysis and discussed through comprehensive analysis, based on theoretical assumptions and the sensitivity proposed by comprehensive sociology.

We used the following strategies to maintain the methodological rigor: the interviews were presented to participants, who approved the final recording result; and we used the criteria consolidated in the Reporting Qualitative Research (COREQ) as a support tool. This consists of a 32-item checklist: in relation to the research team; in relation to the research project and analysis of data; and with respect to qualitative research methods.⁽⁴⁾

The development of this study met national and international standards of ethics in research involving human subjects.

Results

The analysis of the interviews revealed the following: Break of substantial bonds with the children; The abdication of labor activity in favor of being together; Hospital rituals in the routine of the fami-

ly companion; and Self-care and the power of being together.

Break of substantial bonds with the children

The greatest difficulty with being a companion reported by the family members was the feeling of having to leave their children, because some remain in the hospital for several consecutive days. All actors who responded to this category were women. In addition to coping with the separation of their children, they still faced conflicting situations in the interactions and aid relationships with their partners and family members.

Regardless of their children's age, the concern for not being present on a daily basis arises as an ongoing feeling of family members.

The delegation of their children's care to other people causes anxiety and insecurity, especially when they do not find someone to be responsible for this care. The activity of being a companion also interferes with daily activities of other family members, like children who suddenly interrupt their educational activities because their mother cannot accompany them to school due to being at the hospital. However, by following their parents' orders, children transmit a sense of tranquility in order that the accompaniment can be done with less concern.

The abdication of labor activity in favor of being together

In this thematic category, the speeches reflect that the feeling of being together with the other in a situation of disease in the hospital overlaps the need to develop work activities, since people abdicate the latter for being a companion.

The hospital rituals in the routine of the family companion

In the third category, the relatives reported the hospital routines they must follow, both when entering and leaving the premises and in relation to accommodation and freedom during their stay in the process of accompanying a family member. Hospital

rules are very different from those experienced and established at home.

Self-care and the power of being together

The fourth and final category showed that during the activity of accompanying their relatives, the family companions abdicate the care of their healthy daily lives to strengthen the bonds of affection during the illness and hospital stay.

The emotional exhaustion and necessity of rest at night are compromised by the need to be together with their relative. Life outside the hospital is suspended: studies; boyfriends; husbands; children; leisure; and the care for their health and physical appearance are not considered to favor the activity of accompanying the family member.

Changes in the routine of family companions are felt and described in all aspects of life; in the relationships with their children, those at work, in their marriage, leisure, and in the care for their health.

Discussion

The limitations of this study relate to its qualitative method that does not allow generalizations. However, the results are relevant for understanding the changes brought to the life of the family members accompanying hospitalized people, which must be considered by the nursing staff.

The results showed that thirteen of the study participants were women, so the main daily life changes occurred in their lives. Although they show disposition, solidarity and sensitivity to remain as companions in the hospital, they are also the most affected by changes in their daily routine.

A study conducted in the United States showed that the care experience for men and women is different due to the different forms of socialization and roles assigned to them in society. From childhood, women are prepared to take responsibility for the family meals, for performing manual work and the care in case of illness of a family member. Thus, women may have more

negative experiences than men during the care process. This same study showed that female family caregivers are mostly mothers, daughters and spouses.⁽³⁾

The accompaniment of people with self-care dependency is carried out mostly by women in the age group of 36-59 years, showing the diversity of roles played by these women: they are mothers, daughters, sisters and spouses.⁽⁵⁾

Historically, women are responsible for the care of the home and children. Given this assumption, being together as a companion in the hospitalization of a family member triggers the feeling of having to break, even temporarily, the bond with their children, who are left at home and cared for by other people. The break of this relationship does not happen only with small children; adults also need care and support, and the family companion suffers with the distance.

Despite suffering with the break of a substantial bond with their children, these women have positive and satisfaction feelings for being in the accompaniment process, and this causes that the physical and emotional loads are not perceived as heavy.⁽⁶⁾

The care provided to the hospitalized family member by the family companion is a response of the families to meet a new and extremely stressful situation. These family caregivers rely on the sense of maintaining the survival of human beings at various stages of the life cycle. The family dynamics is changed in face of this process, triggering difficulties in decision making and interactions with other family members.⁽⁷⁾

The hospital stay for long periods causes conflicts because some family members feel abandoned and may show sadness. This fact is considered as a negative experience, given that during the hospital stay the family caregiver has less free time for the other family members.⁽³⁾

In the second thematic category, the abdication of labor activity in favor of being together, the family companions report changes in their work routine. A study shows that even with the active participation of several family members in the care, in most times, the responsibility lies with a particular

family member. Thus, the primary caregiver experiences a disruption in his/her way of life, characterized by the absence of boundaries between his/her private life and the patient's life. Thus, there is less time for work, leisure, and the social, family and affective life.⁽⁸⁾

For being together in the accompaniment process, it is necessary to deny the individuality in an almost self-destructive movement. The family companions give up their work activities to stay in the hospital. The need to care and be together with the ill family member hinders the work activities.⁽⁹⁾

The hospitalization of a family member affects the desire to live and the work activities of the family companion because of the need to stay in the hospital often for long periods of time.⁽¹⁰⁾

By strengthening the logic of being together, despite the disruption of work activities and the suffering caused by this break, family companions understand that staying in the hospital is their moral duty with the relative. The frustrations and suffering generated by the experiences of changes and difficulties bring a sense of responsibility to the family companion, as well as the obligation to be firm, encouraging, helping and giving strength.⁽¹⁰⁾

Another aspect that emerged from the speeches as an interference in the daily life of families is the hospital routine, presented in the third category called "The hospital rituals in the routine of the family companion". Prolonged hospitalization and the need that family companions remain with the ill person interfere negatively on the family dynamics, the need to work, and the compliance with hospital rules, considered strict, originating the feeling of impotence.⁽¹¹⁾

The hospital as part of modern society has set up a working process based on rules and routines, with pre-established schedules to meet the service needs such as visiting hours, care liability limits, control of sleep, bath, temperature, food, among others. The hospital was not planned nor directs its standards for family caregivers.⁽¹²⁾ From this perspective, the familiar rhythm of life is not always compatible with the schedules of most hospitals because the

family members normally have their jobs and other activities.

The changes occurring in the dynamics of families who accompany their hospitalized relatives arise from inner needs, emotional balance, external pressures, such as the break of the work routine and financial difficulties. All these factors interfere with self-care, quality of life and there may be feelings of depression, anxiety, anger, sadness, fear, guilt and frustration. A study pointed that these caregivers are more likely to have psychiatric symptoms and health problems, including high blood pressure, digestive and respiratory disorders, depression, and of experiencing family conflicts and problems at work more often, compared to people of the same age who do not exercise this function.⁽¹¹⁾

The effects triggered by the hospital stay were observed in the fourth and final category when the family member reflects the abnegation of self-care in favor of being together. Although the family members showed solidarity with the hospitalized relative, in this category, the speeches of respondents demonstrated that living with the disease in the hospital environment weakens the family companion. They refer loss of strength, emotional distress, especially when the person already presents predisposition to emotional fragility. They perceive the hospital as an unpleasant, poor and confused environment, showing feelings of rejection, dissatisfaction, insecurity, and the hospitalization as an interruption of the planned, the disorder of the customary, the urgency of coping with the doubtful, fearful and unknown.⁽¹³⁾

A study conducted in North Carolina (USA) with 488 families showed that family involvement in the care of relatives with dependency resulted in physical burden and depressive symptoms.⁽¹⁴⁾

Family members of hospitalized children revealed that remaining as a companion in the hospital impairs sleep and rest, bringing physical consequences that can compromise one's health. They reported feeling fatigue and lack of time for self-care.⁽¹⁰⁾

The main psychological symptoms associated with family caregivers are those related to depression and anxiety disorders, which cause acute stress.⁽¹⁵⁾

In addition to depressive symptoms, family companions are faced with the abrupt interruption of their daily activities. The activities become those of care for the hospitalized relative in a solidary practice of mutual aid and in the development of charitable actions.

Thus, family companions are more likely to become ill than other family members and friends, because remaining in the hospital environment, the denial of self-care and direct contact with the care dependent person mobilize inner tensions and cause psychological distress.

Understanding the various manifestations of stress, anxiety and changes in family dynamics during the accompaniment of a member in the hospital can determine improvements in the quality of familial care. By understanding these changes and adopting a professional behavior that includes sensitivity and availability to listen to this important group who is increasingly present in care settings, the nursing for the family is strengthened through the global care.

Conclusion

Family companions had significant changes in their lives during the process of accompanying their relative in the hospital. Women suffer for leaving their children and face conflicting situations with other family members and their partner. The feeling of being together is a determining factor for the abdication of all their activities for staying in the hospital. The hospital rules and routines interfere with daily activities due to the incompatibility with the activities of families. Self-care is disregarded in favor of strengthening the being together.

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Collaborations

Passos SSS and Pereira A contributed to the project design, analysis, data interpretation and writing of the article. Passos SSS, Pereira A and Nitschke RG participated in the stages of intellectual critical review and final approval of the version to be published.

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