

Feelings for the acceptance of the family caregivers' role

Summary

INTRODUCTION. Despite the progressive reduction of the members in family aggregations, families continue being the main support source to homebound people, whether in their direct caregiving, or in the psychological support and social contacts. Thus, it is questioned: What feelings lead to the acceptance of the family caregivers' role?

PURPOSE. To identify the feelings evolved from the acceptance of the caregiver's role.

RESEARCH METHODS. Descriptive, exploratory qualitative research carried out with family caregivers of dependent elderly. Data collection was developed by means of questionnaire application and logbooks. The guiding question was "Why do you have to care?" After the results, it was held the content analysis.

RESULTS AND DISCUSSION. Two hundred and twenty-six (226) answers were analyzed. The following categories were elaborated: feeling of recognition, feeling of responsibility, feeling of affection, feeling of obligation, feeling of interest, feeling of availability, feeling of acceptance from the social context.

CONCLUSION. Apprehending the feelings involved in the acceptance of the family caregiver's role enables health professionals to elaborate actions and strategies to strengthen such acting.

KEYWORDS: FAMILY CAREGIVER; CAREGIVER; FAMILY; HOMEBOUND PERSONS; NURSING.

Introduction

Along the past decades, average life expectancy has increased worldwide, reaching the global average of around 70 years and around 80 years in developed countries. The outlook for the number of Americans with 65 years or older is to double to 98 million, from 46 million, until 2060, and the participation of the population with 65 years or older, regarding the total population, will increase almost 24%, from 15%¹.

Such development was reached especially due to sanitation, medical advances, increase in the standard of living and decline in child death rate. Although the increasing life expectation reflects on positive human development, new challenges have been faced, as the severity and speed of cognitive decline, physical frailty and psychological impairment vary among the individuals. Thus, aging is intrinsically associated with biological and cognitive decay².

People with 65 years or older have complex health care needs and use health care services more often when compared with younger people¹. That occurs because the technological breakthroughs in medicine, and in gene-

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ral, the improvement in socioeconomic conditions have contributed to increase population's longevity, but also to a higher prevalence of chronic diseases and dependence in daily life activities.

In face of the population aging, the increase in need for supporting dependent older people emerges as a priority problem. Thus, families have more and more taken on the role of family caregivers³.

Family caregivers are people with stronger affection, kinship, friendship or neighborhood relationships rather than contractual ones, who help dependent individuals in their health care needs⁴. Assumedly, family caregivers are usually single women, housekeepers or unemployed who live with the dependent individuals⁵.

There are essentially four determining factors for the acceptance of the caregiver role, as follows: family relationship, co-habitation, the gender of the caregiver and the cared person and the kinship determinants. However, those factors are not determining for a family member to accept and become a caregiver. Other elements may influence that decision⁶ (Martín, 2005).

Considering that such feelings are powerful, pervasive, predictable, sometimes deleterious, sometimes beneficial drivers for decision-making⁷, this study objectified to identify the emerging feelings in the acceptance of the family caregiver's role.

Research methods

Exploratory, descriptive, qualitative study, with content analysis⁸ as the method used for understanding the accounts. Held at a Local Health Unit and two more health care centers in Portugal. Local Health Units comprise a hospital and four health care centers.

The population entailed 266 family caregivers who rendered care for functionally impaired individuals, divided in two groups. The first one was the target of an intervention program, implemented in the six subsequent months before their dependent family members' hospital discharge, and the second one was the control group, which followed the usual procedures of the studied health care services.

The participants were selected according to a time-sequential sample of patients admitted to the medical unit of the aforementioned hospital, functionally impaired, in need of help to carry out the daily life activities.

Data collection was held by means of a questionnaire with 28 questions and logbooks. In this study, the question presented and discussed will be: Why do you have to care?

For data analysis, answer categorization and similarity were held, turning to the logbooks for concept definition. Those answers were classified according to: the questionnaire identification number, the gender of the family caregivers, and whether they belonged to the experimental or the control group. From that identification, designations to each one of the identified feelings were attributed. Concomitantly, definition and correlation with the existing literature were established.

This study was approved by the ethical boards and administrative commissions of the institutions where it was developed. Each participant was informed on the objectives and goals of the study, as well as the procedures used along the investigation. They were also informed on their self-determination right and assured that their refusal would not interfere in the normal course of the health care. Based on the Helsinki declaration of the World Medical Association, participants signed the free informed consent form.

Findings

Questioned about the reason why they cared, from the total of the participants ($n = 266$), 85% (226) of the answers was obtained. The excluded 15% (40) was due to improper answer or the participants did not answer.

The categorized feelings, according to the answers, were: recognition, responsibility, affection, obligation, availability, interest, and the acknowledgment of their role in face of the social context.

Recognition defined as "to know something for what it is, act or effect of recognizing (to distinguish certain singularities)"⁹ occurred when the caregivers justified their behaviour due to the cared person's behaviour, that is, the patient should be awarded for his/her current actions. It usually evolves from gratitude, and it can be seen as a reward or an award for good attitudes. Ex.:

I had to change my life, but my sister deserves it, she cared for our parents by herself, that's why it isn't hard for me to do it (E2).

My mother cared for many elders, that's why there must be someone to take care of her carefully and affectionately, as she did (E41).

Responsibility is the "possibility to predict the effects of one's own behaviour and correct it based on such a prediction"⁹. In this category, answers unveiled that the caregiver felt responsible for caring, as there was nobody else qualified to care for the sick individual. Ex.:

I have no friends, I live alone, but I don't want them in a nursing home (godmother and mother), definitely at home, with all the possible help (C25).

There is nobody else, and I don't want to put her anywhere else (E135).

Affection, considered a positive emotion toward people, is a restricted type of emotions following some interpersonal relationships⁹. That feeling was raised when a family caregiver reported to be concerned with his/her dependent family member, and unfolded answers of a friendly/loving relationship.

Many things, the affection, everything he did to me (C130).

I like him, and he's my father (E132).

The feeling of obligation, defined as "the coercive character imposed on an interpersonal relationship by juridical law or moral regulation" was attributed to answers which unveiled a lack of alternatives on the part of the family caregiver under the conditions of the dependent family member⁹. Thus, the caregiver renders care because there is nobody else to take over him/her.

Because there is nobody (C274).

Where should I take him to? (C267).

The feeling of interest, understood as "something that raises or awakens will or wish for something"⁹, was attributed to those who assumed that the caregiver took on this role in exchange for a self-benefit.

I'm taking care of my brother-in-law, but I don't know what's going to happen, because my wife's sister wants her share in the inheritance, as the house we've lived in belongs to their mother, and if I go to an apartment, I won't take her brother because we can't do it, she'll have to stay with him, or I don't know how they're going to work this out, because she never wanted to take care of him (E24).

My daughter got married, and stayed at my mom's, when her grandmother passes away, she's gonna inherit the house, that's why I think I have to take care of her (C85).

As for availability, "quality of whom is available"⁹, evolved when the caregiver considered him/herself as the most qualified person for

FEELING WHICH LED FAMILY CAREGIVERS TO CARE PER GENDER

1

Feeling	Experimental Group		Control Group	
	Female % (n = 93)	Male % (n = 19)	Female % (n = 100)	Male % (n = 14)
Recognition	22.6 (7)	10.5 (2)	2.0 (2)	7.1 (1)
Responsibility	24.7 (23)	10.5 (2)	0.2 (20)	14.3 (2)
Affection	23.7 (22)	10.5 (2)	36.0 (36)	50.0 (7)
Obligation	22.6 (21)	57.9 (11)	22.0 (22)	28.6 (4)
Availability	12.9 (12)	0.0 (0)	11.0 (11)	-
Interest	-	5.3 (1)	1.0 (1)	-
Social context	8.6 (8)	5.3 (1)	8.0 (8)	-

FEELING THAT LED FAMILY CAREGIVERS TO CARE

2

Feeling	Experimental Group		Control Group	
	n = 112	%	n = 114	%
Recognition	9	8.0	3	2.6
Responsibility	25	22.3	22	19.3
Affection	24	21.4	43	37.7
Obligation	32	28.6	26	22.8
Availability	12	10.7	11	9.6
Interest	1	0.9	1	0.9
Social context	9	8.0	8	7.0

the role, then it was outlined as the availability category, ability to dispose of what is one’s state of being willing to. Understanding as available what can be used, being accessible, free, not busy.

We’re family and live next door (C117).

I was fired on June 30th and my mother had that on July 1st (E207).

And still the acknowledgment of their role in face of the social context, understanding context as “the set of entities (things or events) somewhat correlated where each one of those entities has such a character that other sets of entities may have the same character and be connected by the same correlation”⁹, it is the “Cluster of factors, circumstances where a situation, an event lies within”, and social as what belongs to a society, or has its structures or conditions. This category evolved when the caregivers’ answers assumed that they cared for because they understood it as their social role.

Law abides, our wedding, and we want to comply with the law (C156).

Because I have a marriage contract (E172).

I’m the only woman (E43).

In table 1, it is evidenced that in the experimental group, obligation to do that was the reason why caregivers took on this role. Moreover, a high number also found that they had responsibility for the cared individual, and also, they were bound by the affection. In the control group, the same categories were mentioned, however, to those caregivers, affection was the most reported reason. In both groups, only one caregiver reported caring for interest.

By looking at table 2, we verify that the most reported reasons by women for caring continue being responsibility, affection and obligation, in both groups. By observing male caregivers, the most reported reason in the experimental group was availability and obligation, unlike males in the control group, who reported affection. Women referred more to caring for their implied role in the social context.

Discussion

It is assumed that caring means to preserve life, warranting the satisfaction of several essential needs. For dependent individuals, the presence of a caregiver is indispensable, and he/she is usually a close relative¹⁰. Family caregivers start their job in hospital settings and carry it on to home settings¹¹. Among the activities carried out by family caregivers, it can be pointed out bathing, toileting, diaper change and turning in bed, activities which cause physical overloading, mainly if they are carried out every day, without taking turns with other family members, improper physical facilities and equipment¹².

The role of the family caregiver has been performed by women, single, housekeepers or unemployed who live with the dependent individual¹³. That is explained, among other factors, by the gender-identity factor, which holds women as responsible for family care, by the socio historical context, with moral and religious attributes, and by the historical, cultural inheritance, present in the multigenerational interaction, where the gender division for household-family care is strengthened by elderly individuals’ attitude, who prefer to be cared by women¹⁴.

However, an opposite movement has been observed, and the male presence in caring has redefined new roles, that is, besides their financial share, men have been taking on the caregiving role, formerly carried out by women¹⁵.

To both genders, daily caring routine is gradually mentioned as stress-generating in caregivers, due to: the recurrent lack of knowledge; insecurity and fear on how care will be delivered at home, the deprivation of social life; the halt or postponing of life projects; the willingness, dependence and/or obligation to share and follow up caring; the scarcity of financial resources; the family conflict to make the decision of whom will be the caregiver; the indecision whether institutionalizing or not; the apprehension for the cared individual's health status; the concern with the other family members, with their jobs, and with the new required adaptations¹⁵.

Caring a dependent individual is anchored in the idea of exhaustion, obligation. That brings forth anguish, whether by suffering with the cared individual, or by the helplessness felt when something goes beyond their potential of assisting the care recipient¹⁶.

Becoming a caregiver demands time, coping with difficulties, dedication and, sometimes, family organization, routine, habit changes and balance of activities¹⁵. Therefore, it is a different event for each person, simultaneously bringing about positive and negative feelings.

The emotional aspect related to follow up and participate in the disease process weakens caregivers' health due to the exposure to stressful situations, and also, due to the number of hospitalizations, tasks to monitor, aggravation of previous illnesses, scarce socioeconomic resources, the feeling of grief for the limitations of the individual and their withdrawal from social life¹⁵.

Thus, family caregivers' job consists of an exhausting physically and psychologically activity, invisible and hardly recognized by the society most of the time.¹⁷ Other difficulties faced by caregivers include financial stress, patients' conflicts and insufficient social support, bringing about overburden and suffering¹⁸.

Some feelings described in the literature are gratitude, love, responsibility, satisfaction and closeness, in opposition to feelings such as obligation, displeasure, suffering, commitment to patients' welfare and resignation¹⁵. The mentioned feelings are mostly related to a pre-existent family relationship¹⁹.

That leads to reflect on how the occurred changes in family arrangements may interfere with the care of dependent individuals in the future, as there have been several ways of family organization in the current world, which are continuously changing, thus transforming the way family members relate among themselves. That implies a redefinition of roles and a redistribution of duties among the family members¹⁹.

Disregarding the feeling which led to the onset of caring, family caregivers need to be endowed with the feeling of caring, thus, it is possible to tie caring to the demanding aspects of individuality of the being, leading the subject to have greater autonomy and independence¹⁶.

Among such decisions and responsibilities, the need for caregivers to find balance is pointed out. Regarding the division of care, it has been observed a moderate trend to the fact that caregivers who do not share their tasks, are prone to having a higher level of overburdening. That finding corroborates what can be observed in the literature²⁰. Sharing care with the secondary caregiver contributes to less overburden²¹.

In that sense, professionals from the healthcare team act as mediators between patients and family caregivers¹¹, proposing support strategies in order to reduce the levels of overburden, emotional discomfort and stress. Among those strategies, encouragement to participate in interactional groups, self-care teaching and meeting caregivers' health needs¹². Moreover, caregivers' inclusion in decision making, the increase to information access, the possibility of sharing caring experiences, the existence of a secondary caregiver,

and the connection with social support foster mental health¹⁸.

Thus, it is deemed necessary higher involvement of patients and their family caregivers in the management of chronic health conditions, encouraging identification and personal goal search in a partnership with health professionals. Therefore, by supporting the practice of defined goals with clinicians, it is promoted higher involvement and reduces the probability for patients to articulate in an unrealistic way or try to achieve unattainable goals²².

It is nurses' attribution to interact positively in this process of learning, instructing individuals to care for the other, without neglecting themselves¹⁶. As resolutions, health interventions, personal welfare and caregivers' social support can be pointed out. For that, there must be nurses' collaboration to qualify family members/caregivers to render care, including them as nursing clients, besides instructing the social network to the importance of sharing and division of tasks¹⁵.

Conclusion

The capacity and willingness to take on the long-term responsibility for dependent individuals rely on many circumstances and motivations. Apprehending and understanding the way family caregivers view and experience their new capacity are essential for the development of professional intervention strategies, which facilitate the transition to assure the adaptation according to their health projects.

Such understanding has the potential to reduce family caregivers' overload, as the identification of feelings to accept the role of family caregiver enables nursing to promote health strategies for that population.

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Promotion of adjustment to the exercise of parental role in adolescence

Summary

INTRODUCTION. Parental exercise itself constitutes a very demanding challenge – however, when pregnancy occurs in adolescence, often unplanned, it converges tasks of different stages of development, irreversibly modifying an identity, roles and functions, not only of the young woman, but also of her family.

OBJECTIVES. Applying the Dynamic Model of Family Assessment and Intervention (MDAIF), by Figueiredo (2012), and assessing the impact of nursing care in the promotion of skills for a transition to the parental role's exercise in the teenager and her family.

METHODS. Qualitative study, conducted based on MDAIF, as a theoretical and operational reference, in clinical and community context in Primary Health Care, based on the process of family intervention who experienced an adolescent pregnancy. Seven nursing consultations to family were carried out, as a unit, from April to May 2016.

RESULTS AND DISCUSSION. Extended family, with several subsystems and strict limits. Middle-class family. Although unplanned, and the antagonistic relationship with her parents, the instrumental and emotional support provided by them became critical in adapting to motherhood and the newborn's development.

CONCLUSIONS. With MDAIF's use, nurses have developed their skills for a personalized approach to the family, centered on the adaptation and holistic transition to the parental process. It also made it possible to respond to the identified family needs, not only through the restructuring of a parental and personal identity, based on values, personal and professional goals and priorities (the teenager pursued her academic training), but also promoting a family environment based on trust and harmony.

KEYWORDS: ADOLESCENT; PARENTING; EMOTIONAL ADJUSTMENT; PRIMARY CARE NURSING.

Introduction

According to the World Health Organization, about 16 million girls aged 15 to 19 and some one million under 15 give birth every year¹. Complications during pregnancy and childbirth are considered the second cause of death among girls with the same age group, globally.

Currently, teenage pregnancy assumes itself as a problematic situation of great interest around the world. In Portugal, despite the recent decriminalization of abortion (2007) and the evident efforts that have been made, either through awareness campaigns for the use of contraceptive methods, through the implementation of Sexual Education in schools or the disclosure

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of free access to planning consultations family and reproductive health; and the delivery, also at no cost, of contraceptive methods in Primary Health Care; it is verified that these strategies, already adopted, are still not enough. To the apparent disinterest, disinformation or inefficient training of the target group, the teenagers, the approach to this subject is particularly important.

Parental exercise itself constitutes a very demanding challenge, as it emerges from the construction of basic skills and knowledge in caring for, protecting, developing and bonding (parents-child), with the birth of the first child. However, when pregnancy occurs in adolescence, often unplanned, it converges tasks of different stages of development, irreversibly modifying an identity, roles and functions, not only of the young woman, but also of her family.

Factors that may influence the reproductive decision

The factors that can influence a reproductive decision can be divided into individuals (age of the adolescent, adolescent cognitive skills,