Changes in occupational roles of caregivers of persons with disabilities visual

As alterações nos papéis ocupacionais de cuidadores de pessoas com deficiência visual

ORIGINAL ARTICLE

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ABSTRACT: *Introduction*: Visual impairment brings changes and reorganizations in the occupational life of the person affected by it and their families/caregivers. *Objective*: To describe the profile and understand the configuration of occupational roles of informal careers of people with visual impairments, treated at a university research center in a large city. *Methods*: Descriptive and correlational study, conducted using the "Role Checklist". Seventeen people participated in the study. Statistical analysis was performed based on frequency. *Results*: It is noted that most caregivers are female 82% (n = 14), with 64% (n = 11) being mothers. Regarding occupation, 65% (n = 11) did not work, and 59% (n = 10) have low education. We observed that all occupational roles had decreased comparing the past achievements of frequencies with the present, in other words, before care, more occupational roles were performed by researched subjects roles than after the start of care. Among these occupational roles, those which suffered the most declines were the worker (65%/n=11), student (59%/n=10) and family member (24%/n=4). *Conclusion*: caring for a person with visual impairment in this study has showed significant consequences such as losses or changes in occupational roles, especially for workers, as well as changes in routine and overload.

KEYWORDS: Role; Caregivers; Vision disorders.

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RESUMO: *Introdução*: A deficiência visual traz mudanças e reorganizações na vida ocupacional da pessoa que a tem e de seus familiares/cuidadores. *Objetivo*: Descrever o perfil e conhecer a configuração dos papéis ocupacionais dos cuidadores informais de pessoas com deficiência visual, atendidos em um centro universitário de pesquisa em uma cidade de grande porte. *Metodologia*: Estudo descritivo e transversal, que foi realizado utilizando aplicação do instrumento "Lista de Identificação dos Papéis Ocupacionais". Participaram da pesquisa 17 sujeitos. A análise estatística foi realizada baseada nas frequências. *Resultados*: Nota-se que a maioria dos cuidadores é do sexo feminino 82% (n=14), sendo 64% (n=11) mães, em relação à ocupação 65% (n=11) não trabalham e 59% (n=10) tem baixa escolaridade. Observa-se que todos os papéis ocupacionais apresentaram diminuição nas frequências de realizações do passado para o presente, ou seja, antes do cuidar, mais papéis ocupacionais eram realizados pelos sujeitos pesquisados do que após o início do cuidar. Dentre esses papéis ocupacionais, os que mais sofreram quedas foram os de trabalhador (65%/n=11), estudante (59%/n=10) e membro familiar (24%/n=4). *Conclusão*: O cuidar de uma pessoa com deficiência visual, neste estudo, mostrou consequências importantes como perdas ou mudanças de papéis ocupacionais, principalmente o de trabalhador, bem como alterações na rotina e sobrecarga.

DESCRITORES: Papel (figurativo); Cuidadores; Transtornos da visão.

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INTRODUCTION

A caregiver is needed for the performance of any type of caregiving activity[1]. It is a general agreement in literature that the role of the family in caring for disabled people is of extreme importance and make this caring action possible[2,3]. Caring is a byword for diligence, partnership, responsibility, occupation, concern and affection to the person who is being looked after[4].

The birth of a disabled child brings a new reality to the family, causing several changes in habits and in possible social projects of the family[5]. At several situations, the disabled person needs care, what gives the family caregiver big responsibility which he/she might not be ready to take[6].

The informal caregiver tends to face the unknown, considering that, in many cases, there is no option, being the only available family member to play this role. This forces the person into situations in which he/she has no mastery, having as consequence: the interaction with uncertainties, overcharges, routine modification, role changes and risks to his/her own health[6].

Usually, caregivers cannot have the support of other family members or friends, because of the distance or difficulties in accepting this function[7]. A family member who accepts to be a caregiver faces several problems like difficulties in dealing with the impairment, problems in his/her occupational life, problems in his/her social life and in the quality of his/her life as a whole[8].

The caregiver is needed from diagnosis to the rehabilitation and the adaptation of the disabled person[9].

This research had as its focus the informal caregiver, the one that has family connection to the patient and takes the responsibility, directly or not, in caring for a sick and/or dependent family member[10].

Taking care is a complex and, depending on the type of impairment and its level, the tasks change and can influence on a smaller or larger scale the routine of the caregivers[11]. Frequently, being a caregiver takes the individual to neglect his/her own health, and physical, mental, emotional and social well-being[12]. This happens for several reasons, among them, lack of time, the impossibility of leaving the patient alone and tiredness. Leisure moments are restricted in the life of a caregiver, causing social isolation[7]. Consequently, many are get ill and suffer from numberless social impacts like depressions, tension, wearing of love relationships, loss of perspective in life, routine changes, interruptions of daily tasks, financial problems, among others[12].

When seeing the patient suffering, the caregiver starts to distress him/herself, having insecurities, thinking that maybe he/she will not be able to deal with, provide and help on the necessities and on the conflicting feelings of the patient, which can demonstrate rage, denial and aggressiveness. Facing all those aspects is very emotionally demanding and in some cases, losses on the performance of the activities and on the social participation can occur, leading sickness[12].

Being a caregiver involves activities and specific behavior related to this role, this way, caring for someone is considered an occupational role. Roles are considered as the union of behaviors predicted by society, formed by culture and determined by the people who play them. The individuals perform their activities according to the occupational roles they took in the course of their lives[14].

Through the occupational roles, the individuals organize the time to perform their personal activities, then satisfying the demand of society[15]. The occupational roles assist individuals in building up their personal and social identity[16]. Usually, the chosen and performed occupational roles of every individual throughout the course of their life influence all of their daily tasks[17].

Occupational roles are internalized and consist of the essential productive daily activities of individuals[18]. A person plays many roles on a same day. A man can be a father, a husband, worker, friend and co-worker. Thus, the behavior and living ways are determined by the roles that this individual plays[19].

The meaning and the need of duties the individual takes depend on the circumstances, personal motivation and experience. An effective performance in each occupation only happens when these occupations, the environment and the individual present a relationship and a balanced performance. This balanced relationship is essential so that the caregivers perform their activities in a satisfactory and efficient way, affecting their daily achievements[20].

The role of the caregiver is one among others in occupational roles. Understanding how it is performed in accordance to other taken roles helps in developing a balance in several areas of the subject's occupational performance[21].

Once the family has someone in disabled conditions, there can be several changes in the daily routine, in the function and in its identity. The family structure, many times, is not fit to ensure the health needs and the safety of the disabled family member, creating the need of environmental and behavioral changes, considering new responsibilities, rules, actions and functions[22]. This way, adaptations can be made in the family structure, allowing its members to obtain new competencies, perform new roles and more adequate functions to the needs and existence of the family member deficiency[22].

The family tends to be the main origin of the informal caregiver, with adult and older adult women leading this type of caregiving. It is known that, in some situations it is common to determine this choice: parental proximity (wives and daughters), physical proximity, affection proximity and the fact of being a woman[23].

When a family member plays the role of caregiver, the workload is higher, mainly for caring in a fulltime basis[24]. This overload is due to the daily care activities and their continuity, what can cause higher stress and tiredness levels[23].

The mental components like emotional aspects, mental health, vitality and social aspects, can be damaged by the caring actions. There are more problems of sleeping disorders and tiredness, probably due to the caregiver going to bed later and interrupting the sleeping process in order to perform care[25].

As there is no effective result when caring, frustration and tiredness from the routine also hit the caregiver. Thus, if there is a low level of satisfaction towards life, this in fact can create some limitation for the caregiver[25].

There are situations in which the family member cannot offer an adequate answer to the needs and requests of those who are in need, leading to a destabilization of the caregiver. For some caregivers, the division of care can lead to frustration as if it declared his/her impossibility of performing all the tasks without the help of others, what prevent them from seeking help. There are caregivers who believe that they are the only ones who will know how to look after the user and, consequently, they do not delegate the tasks to other people[26,27.]

It is important to emphasize that there can be financial losses for the caregiver and his/her family, because sometimes the caregiver needs to quit his/her job in order to give assistance to the patient[12].

Understanding the complexity of the task of caring for a visual disabled person includes considering the meanings that the caregiver gives to it.

It is necessary to highlight that the majority of caregivers, in Brazil, has very few or no support (guidance and information) to give effective assistance to disabled people, just like to him/herself[7].

OBJECTIVES

To characterize and to get to know the configuration of the occupational roles of informal caregivers of visual disabled infants or adults in activities of student, worker, volunteer, caregiver, house chores, friend, family member, religious, hobbies, participant of organizations and other roles and to observe if there is a relevant difference in the configuration of occupational roles before and after being a caregiver.

MATERIALS AND METHODS

This is a descriptive and transversal study. This model was chosen once it is more appropriate when getting to know and describing the characteristics of determined population and searching for the relationship among different study factors are intended[28].

The collection of data happened in a specific room of the Rehabilitation Center of a public university in the countryside of São Paulo, during the months of September and November in 2013. The average time of application of the instrument was 15 minutes, being performed by a single researcher. All the participants signed an informed consent form, approved by the Committee of Ethics in Research of the University, in September 2013, under the no. 393.727.

The sampler was non-probabilistic and by convenience. Seventeen subjects were included, which satisfied the following criteria of inclusion: Above the age of 18 caregivers, from both sexes, who have accompanied visual disabled users in the services of the ambulatory and signed a consent term.

The research was done with caregivers of visual impaired people, by the application of instrument “Occupational Roles Identification List”, culturally adapted and validated in Brazil[14,16].

This is a self-assessment instrument, used to obtain the perception of the individual in the main occupational roles throughout life (past, present and future), just like the degree of importance that he/she puts to each of these roles. The following roles present: student, worker, volunteer, caregiver, from home, friend, family member, religious, hobbies/amateur, participant in organizations[14,16].

This study has put caregiving as a milestone between past and present, meaning, in the past the person was not a caregiver of the visual impaired person, but in the present, he plays this role.

The collected data were analyzed statistically through a spreadsheet created by the insertion of binary data, in which the negative answer was given to a zero value (0) and for the positive answer, value of one (1). Adding up the positive values, the frequency of the variant studied in this project was obtained. The analysis of the results was obtained by observing the frequency of the variant in the studied population and, eventually, described.

RESULTS

The caregivers accompanied visual disabled children or adults (blindness or congenital or developed low sight) in the services of different ambulatories of the rehabilitation service. Within the accompanied patients (17), 5 were children (up to 12 years old), 3 were teenagers (from 12 to 18 years old), 7 were adults (from 18 to 60 years old) and 2 were elders (from 60 years old). In relation to the children, they were all congenital low sight carriers. In relation to the teenagers, two were congenital low sight carriers and one was a congenital blindness carrier. Among the adults, four were developed blindness carriers, two were congenital blindness carriers and one was a congenital low sight carrier. At last, among the elders, one was a developed low sight carrier and the other a developed blindness carrier.

The sampler was made of 17 subjects, being 14 females. The average age is 44 years old, with a standard deviation of 13.8. The average of education level is 8 years of studies (standard deviation of 4.7), being 7 people with incomplete high school (Table 1).

Amon the subjects who took part in the study, thirteen were active (76%), and only six (46%) work outside home (Table 1).

The average caring years, to the day of the interview, was of 7 years (standard deviation of 6.66), and the majority of caregivers (11) were mothers. It was observed that the caregivers who looked after visual disabled people the longest were mothers and wives (Table 1).

Table 1 - Sample characterization (n=17)

		f	%
Sex	Female	14	82
	Male	3	18
Age	Average	44 years-old	
Work Condition	Active Working	6	35
	Do not work	7	41
	Retired	4	24
Occupation	Autonomous	7	41
	Registred	5	29.5
	Housewife	5	29.5
Educational Level	Illiterate	1	6
	Elementary School Incomplete	7	41
	Elementary School Incomplete	2	12
	High School complete	4	23
	College education complete	3	18
Marital Status	Single	2	12
	Married	14	82
	Widow	1	6
Caregivers	Mother	11	64
	Father	1	6
	Husband	2	12
	Wife	1	6
	Children	1	6
	Aunt	1	6
Period of Caregiver	Average	7 years	

Data about past period indicates that most of caregivers performed more occupational roles than in the present.

The roles the subjects want to retake the most or continue to perform on future was worker and hobby/amateur (100%) (Table 2).

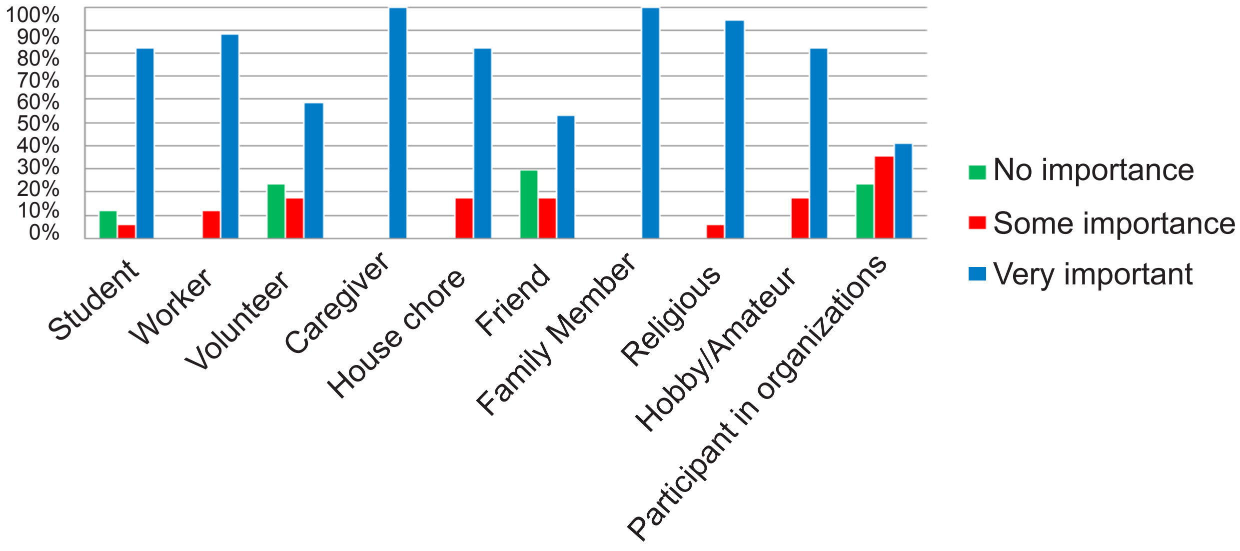
Table 2 - Occupational roles distribution throughout time (N=17)

Occupational Roles	**Past**		**Present**		**Future**	
	f	**%**	***f***	**%**	**Ƒ**	**%**
Student	15	88	2	12	12	71
Worker	17	100	6	35	17	100
Volunteer	7	41	1	6	13	76
Caregiver	17	100	16	94	16	94
House chore	16	94	15	88	16	94
Friend	14	82	8	47	11	65
Family member	16	94	12	71	16	94
Religiouse	15	88	13	76	15	88
Hobby/amateur	16	94	14	82	17	100
Participant in organizations	6	35	2	12	9	53

Occupation roles that went through a decrease only in the present, when comparing to other occupational roles, were worker (65%), student (59%), and family member (24%).

According Graph I, the roles which presented major importance for study's subjects were caregiver (100%), and family member (100%), followed by religious member (94%), and worker (88%). The roles of worker and student, which represented major importance for subjects (88% and 82%, respectively) had a considerable decrease in its performances during the present (65% and 59%, respectively). The worker role also had high aspiration to retake on future (35% on present to 100% on future), considering Table 2 distribution of occupational roles over time.

Graph 1 - Distribution of importance level for occupational roles



DISCUSSION

Among the research subjects it is observed the predominant population is of females (82%). This data is reinforced by literature, when quoting the woman figure is predominant amid people who assume the role of caregiver[29]. The feminine figure still is significant as caregiver on the current culture[30].

In another research with caregivers of people physical or mental disability, it was pointed out that 100% were women and mothers[7]. It was also affirmed by a research about caregivers of elderly people, which presented the result of 100% caregivers being female[21].

It is important to highlight also the population researched is on working age, although most of them do not work. Considering data for labor condition, 76% of caregivers are active, which means, they are not retired, however, from those ones, only 35% work outside home. Those caregivers reported they do not get a registered employment, or a better placement on labor market for not having prepare to take care and monitor the visual impaired individual on rehabilitation services. Is possible to assume that the fact of taking care of someone eventually difficult a productive life, in other words, formal professional practices.

Such data have shown there is an alteration on the occupational worker role when there is a rupture that may lead to decreasing family income and also frustration and dissatisfactions[25,31].

The most frequent caregiver was the mother (64%), in other words, females sex, physical proximity (live together), and affective closeness (parent). Another study also performed with caregivers has reported that 96% population were mothers, a fact also justified by the bond with child[32]. An important information is that mothers of visual impaired children go through more stress than mothers of children that do not present such condition, relating more to behavior resulting aspects of the child than other factors[33].

Other studies have pointed out that most of caregivers were family members and also female[21,32,34]. This fact may be explained by social and cultural standards of responsibilities care to be connected to the feminine figure. In this way, the woman is overloaded for being responsible for several duties and care tasks for other members of the family, with house chores, with work outside home, and children education, in addition to specific care for the patient[32].

The caregiver also being a family member becomes the main social enabler, helping on the performance of essential personal care, and daily life activities (DLA), and daily life instrumental activities (DLIA) of the visual impaired individual.

According to data from this research, the worker role was the most compromised by taking care of a visual impaired individual. In addition such role is presenting a relevant decrease on the present, also was one of the most exercised until now. With a high level of retake pretension on the future, and considering as an important role, it is clear the subjects of this research feel the need and willing to resume exercising the occupational role as a worker, demonstrating such alteration is a great loss.

Many caregivers from the subjects of this research reported they had stopped to work or they undergo inferior position jobs with lower incomes than the previous job they performed before becoming caregivers. Many times, the caregiver gives up the own professional activities due to caretaking[12,32,35]. A A research shows that 20% of caregivers lost their jobs, and 31% of families that had a relevant loss of financial reserves, and 29% lost main income [36]. When a family member quit working, it may occur a financial loss for the caregiver and family.

Considering variations of period of taking care of and caregiver age, it was registered they had their daily life, tasks and occupational roles changed. A study has pointed out that the most reported aspects by caregivers had acquired anxiety, stress, depression, loss of quality life, lack of social support, being justified by developing strategies and adaptations to cope with care routines and to relief own overload[32].

Occupational role of a family member has kept constant throughout time. The family is the main support source as much for the caregiver as for the individual who is being taking care of, both can be assisted by family members[11]. It is observed this role has presented a decrease of current frequency. It is common the estrangement from relatives and friends, due to own responsibilities as caregiver[36].

Another occupational role that also has kept relatively constant was religiousness, having a small increase on frequency for retake, in other words, from the beginning of taking care of a visual impaired individual, and being considered a role of major importance. Religion may be one of the confrontation possibility types of situations as illness, traumas or stress; many times the caregivers use resources of religious order to understand and cope with the patient disability, and also own daily difficulties[37].

The caregivers who used religion or spiritual beliefs to help themselves to cope with the experience as caregivers had a better quality relationship with care recipients, which were then associated with lower levels of depression and overload[38].

The occupational role as hobby/amateur had a small decrease on current performance, but all subjects wish to retake/initiate this role on the future, and being considered by most of them as very important. Most part of subjects reported their main hobby was to watch television at home. Hobby is an important item of life quality, as it can be considered a strategy of coping or scape, as well to the volunteered. Also seen as a way to enjoy life, this role has great importance for the subjects who went through a stress process[39].

There are few researches approaching occupational roles for caregivers of one subject, however, three studies were found about such topic. A research approached the occupational role for caregivers of elderly people. The study presented a result the occupational roles that had most decreases throughout the process were: worker, volunteer, friend, family member, religious, hobby/amateur, and participant in organizations. Such decline was justified by the fact those roles were performed outside the domestic environment, the ones which have not presented loss (caregiver and house chores) were roles performed within domestic environment[21]. Comparing those data with this study, it has been observed there was also a small decrease on roles as caregivers and house chores, as well there was a great decrease on roles of caregiver, volunteer, and friend.

Another study approached how occupational roles from caregivers of victims with traumatic brain injury (TBI). The result pointed out the worker role presented a small decrease, even presenting a great importance to the subjects. However, 30% of those caregivers reported work alterations. The roles as friends, amateur, and family member presented a great decrease[40]. A similar result was found in our study.

A research performed with caregivers of patients in palliative care presented similar result, relating occupational roles to the study with caregivers of TBI victims[41].

To take care of a person with visual impairment had as consequence the alteration or rupture of several roles performed by their caregivers.

CONCLUSION

There is a relevant difference on setting occupational roles before and during the caregiver role. All occupational roles presented declines on the performance attendance from past to present, which means, before taking care, most of the researched subjects held more occupational roles than after the beginning of the process.

The most affected role to care for a person with visual impairment, being considered of great importance for the subjects of this research, is as a worker. It was also found that roles as house chores, family and religious member have been kept relatively constant despite care, other roles being of minor relevance for the subjects in this research.

This research may be considered the beginning for future researches. The greatest limitation was the impossibility of division into groups, considering age range or type of visual impairment for then compare the alterations on occupational roles according to specific characteristics. For new researches, this limitation may be solved, as well as the expansion of caregivers for people with different types of disabilities.

Occupational therapists handle with patient and family members on a daily basis for a more effective treatment. Most of those patients require caregivers which may suffer alterations of occupational roles and illness, due to major care overload. In this way, it is needed the occupational therapist to consider those possible alterations, embracing and assisting the caregiver on daily difficulties, allowing to have a better life quality and performing a proper care.

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