



Family experience and adaptation to stroke and role of an assistance project

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ABSTRACT. The experience of a family with a chronic disease is, at first, difficult and stressful, making the family unsafe and concerned. We aimed to understand the experience and adaptation of the family to a chronic illness (stroke) and describe the actions developed by a project of assistance at home. This is a qualitative study, Case Study type, conducted with a family assisted through home visits by the Project for Assistance and Support for the Family of Chronic Patients at Home, in Maringá, Paraná State. Data were gathered through consultation of the records of the family in May and June 2009, and data were submitted to content analysis. In the beginning there were many difficulties, however, over time the caregivers provided proper assistance, not considering it an obligation, but incorporating the situation to their normal routine, and they proved to be formidable in the process of care to patients, performing procedures with great skill, commitment and immeasurable love, affection and dedication. Accordingly, the responsibility of a health care professional is to intervene by providing appropriate guidance to the family, assisting in the rehabilitation of the family facing the care to this new condition.

Keywords: family nursing, nursing care, chronic disease, stroke.

Vivência e adaptação da família com o acidente vascular encefálico e atuação de um projeto de assistência a essas famílias

RESUMO. A vivência de uma família com a doença crônica é no início, difícil e estressante, podendo tornar a família insegura e preocupada. Objetivou-se compreender a vivência e o processo de adaptação da família em virtude do acidente vascular encefálico e descrever as ações desenvolvidas por um projeto de assistência no domicílio. Estudo qualitativo, do tipo Estudo de Caso, realizado com uma família assistida por meio de visitas domiciliares pelo Projeto de Assistência e Apoio à Família de Pacientes Crônicos no Domicílio, em Maringá, Estado do Paraná. A coleta de dados se deu pela consulta dirigida ao prontuário da família, durante os meses de maio e junho de 2009, sendo os dados submetidos à análise de conteúdo. No início havia muitas dificuldades, porém com o passar do tempo os cuidadores prestavam assistência adequadamente, não visualizando como uma obrigação, mas incorporando a situação a sua rotina, e estes se revelaram formidáveis no processo de cuidado a pacientes, realizando os procedimentos com muita destreza, empenho e com imensurável amor, carinho e dedicação. Nesse sentido, uma das responsabilidades do profissional de saúde é a intervenção por meio de orientações adequadas à família, auxiliando no processo de readaptação da família frente aos cuidados e a essa condição.

Palavras-chave: enfermagem familiar, assistência de enfermagem, doença crônica, acidente cerebral vascular.

Introduction

Chronic diseases (CD) are health problems that affect individuals for a long time, frequently till the end of their lives. As the world population is aging, due to increased life expectancy, it is directly related to the high indices of existing chronic diseases (BARROS et al., 2006).

The chronic disease can present in three forms: the progressive – like cancer, Alzheimer, juvenile diabetes, rheumatoid arthritis, and emphysema, which has a high degree of severity and cause major damages to the

family; the constant – encompassing brain stroke, single episode of myocardial infarction, trauma resulting from amputation, and spinal cord injury with paralysis, which require constant adaptation of the family, even being predictable for a certain time period; the recurrent or episodic – such as ulcerative colitis, asthma, peptic ulcer disease, migraines, early stages of multiple sclerosis, remission cancer, and mental disorders, this adaptation is completely different, since the patients have some flexibility that allows the movement and several forms of family organization (RADOVANOVIC et al., 2004).

Of the existing current chronic diseases, the most common are the systemic arterial hypertension, diabetes mellitus, and cancer, and among the complications of these diseases is the brain vascular accident (BVA) that usually weakens the person making him totally dependent on care. The BVA is a neurological disease that most often affects the nervous system and is the main cause of mental and physical disabilities, being the main reason for hospitalizations, mortality, and disability in Brazilian population, exceeding heart diseases and cancer, which are the two leading causes of death in industrialized countries (BOCCHI; ANGELO, 2005).

The term BVA refers to the sudden reduction of brain circulation in blood vessels. The complications are varied and may involve high mortality or diverse deficiencies due to neurological sequelae (MACHADO et al., 2009).

The BVA, ischemic or hemorrhagic, transient or permanent, is the cerebrovascular disease with the highest rates of incidence and morbidity resulting in severe disabilities with loss of independence, and often of autonomy, which predicts the need for someone to help performing daily activities, these disabilities often compromise the ability to manage personal and family life (PERLINI; FARO, 2005).

Given this fact, the family starts playing an essential role as caregiver of the diseased members, providing care to these family members and dealing with the fragility of the situation, thus the family becomes the link for the successful treatment of this patient (CARREIRA; RODRIGUES, 2006).

The family caregiver is the person who provides care to the family members with dependence (at higher or lower level). His tasks involve the monitoring of daily activities, like assistance to feed, personal hygiene, routine medication among others; assisting in the recovery and life quality of the person. In this way, the family caregiver is responsible for almost all burdens and care of the elderly with a chronic disease and to whom is reserved the routine work (PERLINI; FARO, 2005; MAZZA; LEFEVRE, 2005).

Each family has specific characteristics that make them unique in their way of being, thus it will present distinct behavior in relation to the need for adaptation in cases when one of its members has chronic disease, but over time there is a restructuration of this family and the responsible for the exclusive care will arise automatically (CANHESTRO et al., 2005).

The caregiver is called informally, but this choice is directly related to four factors: kinship, with the spouses being the most frequent; the sex, highlight

for female; physical and emotional closeness, both highlight parents and children (FONSECA; PENNA, 2008).

The woman always took the role of the major caregiver of an ill person at home. However, this setting can be opposite when she is the ill person. And this tends to be aggravated according to limitations imposed by the disease, such as the case of a BVA victim that had severe sequelae, needing specific care and therefore will depend on the care of other family members, most often husband and offspring (KARSCH, 2003).

Currently, more than at any other time, the demands on health services have been extremely complex, requiring from health professionals better improvement and expansion of knowledge. Great part of this demand comes from care needs that individuals with chronic non-communicable diseases, especially elderly and family members face in daily life at home. On the improvement of professional knowledge depends the improvement of assistance quality that is provided at home during, for instance, home visits where are assisted mainly elderly patients with degenerative chronic diseases (ANDRADE; LOBO, 2007).

The relationship between the nurse and the caregiver must be founded to value the experience that this person already has, should represent an area of two-way learning, recognizing that in this relationship all have to learn. Hereupon, it is important to highlight that the assistance should take into account not only the momentary needs, but also those to come. Thus, it is necessary to equip this family to recognize situations that require professional intervention and to feel free to seek help every time they have doubts when conducting this process. For this, there should be dialogue between the parties, i.e., the family needs to feel welcomed when seeking health services and professionals, in turn, need to recognize and value this demand, and also appreciate the work the family develops at home, since if it did not, the demand for human resources in health area would be even greater, hindering the assistance of quality to these individuals and families.

Considering that the care really happens when there is interaction between health professionals and family (MACHADO et al., 2009), we argue that the relationship between them should value the physical closeness, creativity, respect for customs and cultures and the preparation of the family to take care with the health of the ill member.

In this way, regarding the above, this study aimed to analyze the experience and process of adaptation of family in the face of chronic disease

and to describe the activities developed by an assistance project at home with the family of a BVA victim.

Material and methods

This is a descriptive study with qualitative approach, a case study type. The case study contributes greatly to the understanding phenomena individual, politic, social, and organizational, being indicated to study something unique, although it may be similar to other cases or situations (YIN, 2001).

This study has being defined as an empirical investigation to analyze contemporary phenomena within the context of real life, mainly when the phenomenon and context are not clearly defined. This approach has being used in all academic areas, since it allows a significant holistic assessment of the events of real life, such as the cycles of individual life, organizational and administrative processes, changes in urban regions, international relationships and maturation of some sectors. It reports a singular setting that may function as an early analysis in order to seek the strengthening of broader social relations or a certain study object, contributing to knowledge in nursing, since it values the subjective human issues, prioritizing the person in his individuality, in the relationship with the routine that articulated with the socio-cultural process of his life context, allows capturing the experience of the person according to the meaning that the person assign to this experience (YIN, 2001).

The qualitative approach was used to describe, record and examine the family reality, because this type of approach allows understanding better the everyday, the view of world interconnected with socioeconomic and cultural aspects in front of a problem, according to their own perspectives, that is, allows understanding the expression of feelings, values, fears, attitudes that explain their actions to a specific problem or situation (BARDIN, 2008).

This study was developed with a family attended by the university extension project "Service for Assistance and Support for the Family of Chronic Patients of the University Hospital of Maringá (HUM) at Home", which is linked to the Center of Studies, Research, Assistance and Support to the Family (NEPAAF) of the Nursing Department of the State University of Maringá. The focus was the experience and adaptation of the family with a chronic disease patient and the role of the health staff that work with this family. The family was assisted by the participants of the project for a period of approximately two and a half years (December 2006 to April 2009).

The treatment of CD is based in most cases in the ongoing control of the symptoms, which causes some limitations not only to the patient but to the whole family. Considering this, the State University of Maringá, through the NEPAAF, created in 1996, has developing a university extension project "Service for Assistance and Support for the Family of Chronic Patients at Home", aiming to assist families of chronic patients that have had episodes of hospitalization to conduct care at home.

Data were collected through consultation of family records, more specifically the reports of home visits that contain the record of dialogues held in May and June 2009.

The data were analyzed through content analysis, involving at first the pre-analysis characterized by floating readings of all data, which set up the 'corpus' analyzed, allowing initial interpretations and investigations. Then, the material was exhaustively read, encoded, numbered, classified and pooled. Finally the obtained results were interpreted and categorized, by identifying the interest units, common aspects and drawing inferences (BARDIN, 2008), and the results were discussed based on literature addressing the subject.

The study was developed in accordance to the established by the Legal Resolution 196/96 of the National Health Council referring the anonymity, confidentiality, free and informed consent and freedom to withdraw at any stage of the study. The project was approved by the Research Ethics Committee on Human Beings of the State University of Maringá (Legal Opinion No. 224/2007). The consent form was signed in two copies at the moment of family integration to the university extension project.

Results and discussion

Knowing the family and the patient

It is a low-income nuclear family, made up by three members: father, mother, and son. The son – Love – 27 years, single, college degree, performs self-employment, with monthly income of about two minimum wages. The father – Peace – 49 years, secondary education, and monthly income of two minimum wages.

The mother, Hope, 41 years, five years ago she had three BVA episodes in less than 24 hours, which resulted in 45 days of hospitalization in an Intensive Care Unit (ICU). After discharge, she stayed home for two days and was again hospitalized in ICU for 90 days, presenting recurrent pneumonia, urinary tract and hospital infections. She has pronounced motor and neurological sequelae.

After the second hospitalization, the family received some information about the care with the patient, but it had no practice in the care and felt unsafe by the high number of care procedures the patient required.

By the occasion of the BVA, Hope had 37 years, full production age, playing important role of mother in the education of her young son and as wife. Currently, she is bedridden, quadriplegic, only moves head and shoulders slightly. She presents nystagmus in both eyes, and uses therapeutic lenses because of a sore spot, but she has good visual acuity. She was tracheostomized, and aspired whenever there is secretion. The feeding, water intake, and medication are administered via gastrostomy tube. She uses urinary indwelling catheter for period shorter than 15 days with the use of diapers, and performs weekly private physical therapy and acupuncture. She is currently making use of several drugs, among them: Lisantil, AAS, Nifedipine, Captopril, Tanakan, Isquemil, Fluoxetine, Ivotril and Trisorb.

The BVA has serious medical and social consequences, like physical sequelae, communication, functional, and emotional disabilities, among others. These sequelae lead to some degree of dependence, especially on the first year after its occurrence, since many people that survive to the episode cannot return to work and perform daily activities. Besides that, hospital and social security costs, loss of autonomy among adults and consequent dependence, is other way to express the severity of disabilities resulting from stroke (FALCÃO et al., 2004).

A study revealed that in relation to disabilities set after the stroke occurrence, less than 20% have total recovery, and these disabilities are referred as motor impairment related to reduced movements of the hemibody, from the leg, and at lower proportion, by reduced movements of the arm (FALCÃO et al., 2004).

Family experience and adaptation to chronic disease

Since the stroke episode, the family underwent a complex adaptation, especially at defining the roles of each member, and each one went responsible for some cares to Hope, considering her total dependence status. The situation may be a source of tension within the family. In this context, there is the need of redefining the roles among the family members, by directing a person to be responsible for care, and in many cases the adjustment of the environment in order to satisfy the patient needs, which in general causes an economic and social impact that change the family structure. On the other hand, the family is the point of support and

care to this individual, and in general, seeking help only when the resources are being depleted (BOCCHI, 2004; PERLINI; FARO, 2005).

In this process, the major caregiver from Monday to Friday during the day was assumed by Patience, Hope's mother, so that Peace and Love could continue working. The Hope's mother, to assume this role, needed to reprogram her life, since her routine had been changed, since she continued living with her husband in another neighborhood, being necessary to take two buses to get to the home of her daughter.

After the episode, she started to walk on the treadmill at 4h am, then she does a quick housework, takes a bath, and goes to the home of her daughter, with time for the two men of the house leave to work. She provides care throughout the day, makes the lunch for the Hope's family, and at the end of the day returns to her home. At night she prepares the lunch of her husband for the next day. The time she has to her house chores is on weekends. However, she also stands out that set aside time on Sunday for leisure, in addition, after the incident with her daughter, she started performing physical activity and take better care of her food.

Love is responsible for the integral care to her mother on Saturdays mornings, besides helping during the night. Peace, in turn, is responsible for the care in the evenings, Saturdays afternoons and Sundays.

Interestingly, besides the care with Hope, the family also needs to get organized with house chores, once financial conditions do not allow paying a maid, and the grandmother is not able to perform many domestic activities, since her time is spent almost exclusively with the care and company she does to Hope.

The spouse and the son, by being males, living alone in the house, also had to be adapted to a new family routine and dynamics. The difficulties in relation to the house chores were explicit, since both affirmed that all was made by Hope. They also had a little more difficult to learn how to perform the cares required by the current situation of Hope. But the results pointed out that despite difficulties, insecurities, lack of practice, and ignorance, they now can conduct well the daily care, and perform complex tasks with ease, like aspire the tracheostomy, prepare and administer the gastrostomy tube feeding, bath in bed, promote the prevention of pressure ulcers, care with oxygenation and with the patient welfare. The love, hope and

dedication made the family to learn and seek information about the best way to take care and promote the welfare, according to their limitations, so the patient does not regress in her illness.

In general, men participate of the care in a secondary way, by means of material aid or external tasks, like the transport of the patient and bill payment (EUZÉBIO; RABINOVICH, 2006). But in this case, is the woman that needs care and attention, being completely dependent on other family members, such as husband and son. Thus, it is changed the focus of care, which is now played by man, which assumes the effective role in the household.

The activities performed by the caregivers are developed according to the degree of dependence of the patient, in this way, the more committed the individual autonomy, the greater the demand and complexity of care (PERLINI; FARO, 2005).

It is common that the woman assumes the care of the sick and house chores, even when she works out, which ultimately has impact with major limitations of free time and implications of social life (KARSCH, 2003).

Importantly, the informal care corresponds, in most cases, to that performed by family members, and in situations that include chronic conditions, of occurrences that lead to dependence at short, medium or long term (PERLINI; FARO, 2005).

As for the patient leisure, the Hope's family tries to provide good times, according to the possibilities, and among them: ride to the farm on the weekends, visit of the pastor and friends for prayers every Sunday, religious music in the room during the day, television, especially movies and soap operas, and visits of relatives and close friends.

Knowing the functioning of the project "Assistance and support to the family of chronic patients of the HUM at home"

This project is developed by teachers and students of Nursing since 1996, with the purpose to contribute to reduce the rehospitalization rates due to the lack of information about conducting care at home after hospital discharge. The strategy is to assist for at least six months, with home visits, family of chronic patients that had been hospitalized in the University Hospital. In the beginning, the visits are weekly, and then programmed according to an assistance plan elaborated individual for each family. The discharge of the project occurs when the assistance plan is met/performed or when the family, for any reason, asks for closure.

By being a university extension project, it predicts the participation in educational, assistance and scientific activities, always with the purpose to establish a bidirectional flow between academic and popular knowledge, promoting actions to stimulate the society development. In this way, it is provided to the students the more critical awareness about their own training, besides contributing and instigating the development of a family assistance.

Usually, from 15 to 20 families are assisted per year, and the experience has shown that these families have great fragility in the health of other members beyond the index patient. The main actions developed by the project members refer to orientations of how better conduct the care at home, seek to clarify doubts of families related to the disease, treatment, care needed to keep the disease under control and prevent complications. Furthermore, performs care, trains and supervise the family in the performance of specific cares, aid the family to identify its social network, and to seek resources and aid in the own community, makes referrals to health services, drive the members of the PSF staff whenever necessary, in other words, tries to be with the family in the way of care to the member with chronic disease.

Frequently emerge doubts in relation to the drugs and side effects, associated diseases, and especially the care that may or may not be performed in the case of the diseases. Sometimes the doubts are very simple, evidencing that these families are not being duly guided by the moment of hospital discharge, or at least that they are not prepared to be guided in that moment. This may have important implications when putting into practice the daily care, including making up a rehospitalization reason. There was a case of a patient hospitalized for one or two days because he had metabolic disorder of glucose levels or blood pressure, and when he went home, the family had doubts if should or not administer the continuous medication, either because new drugs had been included in the therapeutic plan or because nothing had been explained.

We work with the idea that more serious doubts always need to be clarified with the doctor responsible for the patient, and that changes in the therapeutic scheme need to be monitored. Nevertheless, the project members have no influence on the health service and for this reason, they cannot expedite appointments with experts, take cuts on queues for surgeries, for specialized tests or any other need of the same type, and frequently this is the expectation of the family,

which when it is not met, requires the withdrawal from the project.

Still regarding the project functioning, it is important to highlight that the records in the charts are performed by Nursing students, under the supervision of teachers, Master's degree students and/or volunteer nurses participating of the study. They are important part of the assistance to the family, once from them is established the assistance plan. The records are made since the first contact of the project members with the family and are complemented as the interactions occur.

On the occasion of integrating the family to the Project, the sick family member and the responsible, generally the caregiver, are clarified about the goals, perspectives, and limitations of the nursing assistance provided, and about the bond between assistance and research. Thus, the caregiver is invited to sign the Integration Term to the University Extension Project, which predicts that the provided care can be propagated in scientific meetings. For this reason, the family also signs the Consent Form in two copies.

At the moment of subscription/integration of the family to the project, begins the filling in of the history of family life, and then is elaborated a nursing assistance plan, as well as discussed and established goals to be achieved. These are updated/amended according to the family needs and patient outcomes. At each visit is performed an evaluation, recorded in the form of nursing evolution, based on the established assistance plan.

All the activities and orientations during the visits are registered in the family chart, which is made up by nursing history and nursing outcomes with survey of problems and needs found. These records are important part of the assistance to the family, since from them is established the assistance plan, besides being important source for data collection to monitor the performance of the project. These records are made since the first contact of the project members with the family and are complemented as the interactions occur.

Performance of the project with the Hope's family

The study patient was inserted from spontaneous demand from her family that knew the project when a neighbor began to be assisted. On this occasion, had three years that the family took care of Hope, but was interested whether the assistance was being done correctly and what else could be done to improve the quality of life of the patient and of the family as a whole. Despite the patient had not been hospitalized in the HUM, but as this was a request, we chose to include this family in the project,

because we could learn a lot with them, due to the extensive experience in caring for, besides the new situation characterized by the active participation of two men in the care.

From the first interactions with the family members to explain about the project, it was established that the three/four first visits would be weekly, since it was necessary to establish *rapport* with all family members to know and understand the other – the family – its singularity, raise problems and needs and identify strengths and weaknesses of the family to assist them.

During the insertion period (about two and a half years), the family received around 30 visits. The consultation to the family records allows knowing the main actions and interventions performed by the project members when related to the following problems/diagnoses of nursing (NANDA, 2006):

a) impaired physical mobility – by the limitation of independent or voluntary physical movements of the body or of one or more extremities – the family was counseled on the importance of changing position every 2 h and why of this action. After understanding the reasons, it was stimulated to establish a program of physical exercises, in order to prevent venous stasis, thrombosis, pulmonary embolism, and pressure ulcers. In addition it was oriented to keep the skin clean and dry, performing therapeutic massages to promote a satisfactory venous return. It was also presented alternatives of solutions to be used at massaging.

b) self-care deficit in bathing and hygiene, as well as in dressing or grooming, due to neuromuscular and musculoskeletal injury – the family was instructed about the importance of the patient to preserve her self-image as much as possible as a therapeutic resource. After understanding the situation, it was established along with Patience that as far as possible, some care that the patient performed before the stroke should be kept, such as: decorated nails, hair always combed, clothes suitable to her. After so many years, Patience is keen to preserve the daughter choices at dressing and painting nails.

c) impaired urinary elimination – when inserted in the project, the family had already been oriented to make interspersed use of urinary indwelling catheter and diapers. The family already knew the importance of preventing urinary infection, including it was one of the reasons that had led Hope to stay a long time hospitalized at ICU. All the care with the UIC were again explained to the family members, and advised Patience to look for the UBS near her residence from two to three days

before the scheduled date to change the catheter, in order to not forget the fact.

d) impaired feeding – the difficult in swallowing caused Hope to be fed through gastrostomy. The family is properly instructed about the care with the gastrostomy, with the way to prepare the food and the administration.

e) presence of tracheostomy – the reduced effectiveness of coughing may cause the accumulation of secretions that need to be often aspirated, moreover it is necessary to fluidize the secretions to ease its elimination. The family has the equipment to perform this technique that is performed correctly three times a day. It was very important the guidance in relation to the care during suctioning, since the tracheostomy can be a risk factor for the entry of oropharyngeal secretions or fluids into the tracheobronchial airways.

f) keep the physical and mental integrity of the patient – Patience shows great skill and interest to keep the brain activity of Hope, so that she talks to her daughter all the time, tells stories, discuss the progress of the soap operas that they watch together, and even those that they watch separate. She explains that this is good to keep the brain activity of Hope. The television or radio is always switched on.

g) promote and favor the communication – the reduction in the amount and in the pattern of incoming stimuli, along with a decreased response to such stimuli was always a concern for the family of Hope – which believed that because the sensory perceptions visual, auditory, kinesthetic, and tactile, were impaired, it would certainly bring loss to the recovery of Hope. In this way, the son began to create his own way that at the same time stimulate the senses and eases the communication of Hope with the surrounding environment – for that the family uses a notebook to the record of letters previously selected by her when a second person spells it.

h) maintenance of a social network – it was possible to observe the increased willingness of community, once the pattern of community activities serves to adjust and solve problems in order to meet the demands or needs of the community. The social network allows controlling the stressors and frequently has the resources to help solving problems. The network has allowed the supply of actions with pleasant stimuli, for example when the patient is taken for walks in a farm on the weekends, the visits of friends, relatives and the pastor. Furthermore, Hope spend much of her time watching movies and soap operas on television, always accompanied by her mother that encourage her to reflect about the events.

i) impaired home maintenance – the interventions of the project were frequently directed to the other members of the family. Despite three people take care of Hope day and night, the risk of overload is very present, and the members of the nuclear family alone are not able to maintain independently the home, and also by having the family processes disrupted, marked by the change in relationship and functioning of their family.

The aid of Hope's mother is essential and the project members knew the risks if she had assumed to take care of her daughter day and night. For this reason, there was a concern to always discuss these issues with Patience, Hope, Peace and Love. In this way, Patience was always encouraged to take care of her own physical and mental health, by means of performing physical activities, maintaining her own social network, and a married life regardless of the condition and need of the grandson and son in law. Peace and Love, in turn, are subjected to the risk of tension for the caregiver role, since they have difficulties to perform this action, once the quantity, duration, and high complexity of these tasks represent risk factors to trigger stress.

In the specific case of this family, the project members throughout the visit period sought to encourage the caregivers, once the full-time assistance to a completely dependent adult is very stressful, causing physical, psychological and social impacts on the caregivers. The physical ones mainly refer to problems in spine, considering the effort in moving the patient, which is especially reported by the Hope's mother, who has been performing more efforts. Among the psychological impacts, stands out the stress, in which the Hope's mother said that in many times she felt tired by being in the same room all the time and every day, but she is pleased to be able to provide care to her daughter. In relation to the social impact, it affects both the relatives/caregivers and the patient, since her general status impose limitations to her social relations, because she cannot easily leave home, and on the other hand, the family members cannot leave her alone, and so they are also deprived of social interaction that once have experienced.

Given this, regarding the clinical manifestations resulting from BVA, the health staff, especially the nurse, has a duty to develop and implement a care plan that takes into account all the needs of the patient and assist the recovery. Moreover, this assistance should not focus only the patient but also the family, since the participation of the family members in the rehabilitation positively affects the general condition of the patient (CHAGAS; MONTEIRO, 2004).

Home care is essential for the treatment, since the recovery after a stroke may be long. In this way, the family members, direct caregivers, need to be prepared to exercise this role. Besides, the family is disrupted when face this incident, due to the impacts caused by the BVA, and thus, may feel difficulties to assist the patient by the complexity of care (CHAGAS; MONTEIRO, 2004).

The presence of health professionals on home visits (HV) is the main emotional support that the families receive, easing the delineation and achievement of goals in order to reduce wear and difficulty of dealing with the situation (MARCON et al., 2004). The family members are valued when receive the nursing team in their homes, becoming an event of paramount importance in their daily life (CANHESTRO et al., 2005).

During all visits, we aimed to develop a full relationship person-person and person-family through dialogues with the caregivers and as far as possible with the patient, using the notebook and small gestures/signs with the head.

In the beginning, according to the reports of the caregivers, there are many difficulties, but over time they incorporate the activities of house chores and care with Hope in their daily routines. Now they provide proper assistance, and do not face it as an obligation neither have vain hopes that the situation of Hope will change, although they believe that some aspects can be improved, and this is the belief that makes the family to pay a health plan that allows performing a physical therapy at home at least three times a week, or even acupuncture for sensory stimulation.

In the course of the visits, the goals have been achieved, and then the visits have become less frequent, fortnightly, monthly and bimonthly for some time. After detecting that the family members were completely prepared to take care of the patient, and that the project members had already contributed to the possible, the patient was discharged from the project, i.e., the monitoring has ended, since the initial goals were achieved, that is, of aiding the family to face the situation.

Language codes developed by the family with the patient

As one of the sequelae of the stroke Hope had the loss of speech, reducing the communication with other family members. Preoccupied with this, her son developed an alternative way to communicate, which eased the daily life of the patient and of the caregivers. In this process, it is used a notebook and a second person spells the letters of the alphabet. When the desired letter is pronounced, Hope signs with the eyes and head, and the letter is then registered in the notebook.

This process is repeated tireless until forming words and phrases.

The project members assisted to hone this process, by placing the letters into two tables, one for vowels and consonants in the other. The letters were made of colored rubber and sometimes the patient is asked to refer to the color of the letter, in order to stimulate her visual memory.

Since the first visits until the present time, four college notebooks were used to take notes of the sequence of letters that form words and phrases. The development of communication favors the patient autonomy and eases the care process, in such a way that for the patient welfare, it is also necessary that the caregiver is pleased with the work.

Regarding this aspect, the professionals need to aware the family about the importance of encouraging the patient to develop some forms of autonomy. If the caregiver does what the patient is still able to do, just because the task is performed more quickly, he is not stimulating the patient autonomy. And what he believed was beneficial, can have a momentary effect and not in a long term, since with the development of autonomy, the care process is facilitated, and the caregiver can thus return, even partially, his life plan (BOCCHI; ANGELO, 2005).

Conclusion

The family reorganization in the daily life as for the occurrence of stroke sequelae in one family member reflects in individual actions to perform the activities. In this way, there are several changes in the daily life of the caregiver, either psychological or social.

However, developing an alternative communication between family and patient is indispensable to keep a more harmonious relationship, favoring thus an independence and increased self-esteem.

In this way, one of the responsibilities of health professional is to guide adequately the family, aiding in the process of family readaptation facing the care and condition. We believe that the nurse is the most prepared professional to clarify the family about the care to be provided to the stroke victim. This professional may establish a relationship of trust and partnership with the family, working to instruct about the disease, its causes, consequences and especially the best way to address it.

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