Objective: to report the application of the Nursing Care Systematization to the patient with Amyotrophic Lateral Sclerosis.

Method: it is a case study, carried out in April 2011, in an internment unit of Medical Clinic of a public hospital at Salvador/Bahia/Brazil. For data collection we used a printed of the nursing history and a physical examination. The study was supported by the Theory of Basic Human Needs.

Results: establishment of a bond between family and patient and, deep physical examination; the nursing diagnoses were identified from the needs of the patient/family and nursing interventions designed to cope with this illness.

Conclusion: the multidisciplinary approach of care is extremely important for the cares to be performed by the health team, thus having a need for further studies and reflections from the health professionals to deal, in an integral manner, with the patient carrier of Amyotrophic Lateral Sclerosis.

Descriptors: Nursing Care; Nursing Process; Case Studies, Care planning to the Patient.
INTRODUCTION

The Amyotrophic Lateral Sclerosis (ALS) is defined as a neurodegenerative disease, of unknown etiology, with progressive and lethal neuromuscular implications. It is a disease that affects the motor neurons and results in progressive atrophy of skeletal striated muscles, progressing to death in about 3-4 years, and usually it occurs in adult men. Thus, the progressive muscular atrophy limits the habitual activities of the individual, making it a subject completely dependent for the execution of self-care, which brings out feelings of anxiety, sadness and despair for himself and his family.

The disorder is usually perceived by the decrease of functional capacity of the client, and gradually it starts to reach the respiratory muscles, which is the main cause of death in carriers of this disease.

To get a better understand about the motor mechanism that is responsible for progressive muscular atrophy, it is necessary to conduct a retrospective with regard to the role of motor neurons in this process. The motor neurons establish a communication between the nervous system and the voluntary muscles, those through which we play movements and activities from the will. Firstly, the cerebral neurons send messages to the neurons located in the spinal cord, and these do the same for the voluntary control muscles. In such way, the clinical signs of ALS are manifested in the upper and lower limbs and, later, in other regions of the chest and neck.

The signals perceived in ALS are quite variable. The affected individuals often have a focal asymmetric weakness of the extremities, which is evidenced by difficulty in moving, frequent falls or difficulty for keeping the handle; or bulbar findings as dysarthria, dysphagia, sialorrhea (drooling), weakness in the facial muscles, neck, among others. These symptoms culminate with the commitment of the diaphragm, causing difficulty in breathing and, consequently, chronic dependence on ventilation, or death from respiratory arrest.

The etiology of the ALS remains unknown. It is believed that the causes are multifactorial, involving genetic, environmental and endogenous factors in interaction, thus having the production of the neurotoxicity that is responsible by manifestation of this disease. From clinical and experimental studies, it have been found that immunological and inflammatory factors, and the participation of cerebral cells may have involvement in disease etiology.

To establishment of diagnosis of the ALS, many clients roam around in the health services until get a reliable result about what affects them. The diagnosis is basically differential, from the clinical examination grounded with neuropathological tests of exclusion, which hinders an early intervention for controlling of this disease. At the end of the 80’s, a criterion of diagnostic support, the El Escorial, was developed, which was upgraded over the next decade. The patients should be assessed and have their diagnoses made at the Reference Center for Assistance to People with ALS.

For inclusion in the treatment protocol, patients should bring the following items: have a diagnosis of 1 - defined ALS, 2 - probable ALS or 3 - probable ALS with laboratory support, by the criteria of the World Federation of Neurology, revised in 1998 - Criteria of El Escorial.

From the progression of disease, paresis and plegia, the individual see himself in the midst of a total loss of its functional independence, finding itself stuck in his primordial garment - the body. The development of disease occurs in a relatively fast manner, which makes it more difficult the adaptation of the subject to the new limitations that are imposed by the illness.

The motor neuron diseases are part of a group of illnesses that have a major impact on the life quality of individuals, being the target of many studies by becoming a current concern of professionals who find themselves unprepared in face of these kinds of diseases.

The fast progression of this disease and the severity of muscle commitment interfere with subjectivity, personality and way of understanding of itself body and its role by the individual, totally affecting its function and social participation hitherto exercised. His positioning in the face of society generates feelings of hopelessness, failure, low self-esteem, despair and fear of the unknown.

The nursing professionals often feel insecure and unable to provide the care and the ideal support for this subject who is going to die, as demonstrated by studies conducted with patients in the end-of-life process. By means of direct experience in caring for a client carrier of ALS, during the experienced traineeship period, ambivalent situations of insecurity and compassion stimulated the execution of this present report. This process experienced in conjunction with the patient...
and its family has provoked changes in life, as a person and a future professional of nursing, noting that, during graduation, few mechanisms for coping with situations of suffering and of the death process are learned and incorporated by students of nursing.

Furthermore, developing this study showed how far our country, Brazil, is limited regarding the production of knowledge that involves the clients related to this thematic, as well as the nurse’s actions before these subjects, who evolve into clinical pictures of total dependence with regard to the basic human needs.

From this study, it was possible to discover that the nursing cares go far beyond technical-scientific procedures, and that knowing truly “touch” the other is one of the most significant ways of care that we can play as health professionals.

**OBJECTIVE**

- Report the application of the Nursing Care Systematization to a patient with Amyotrophic Lateral Sclerosis.

**METHOD**

It is a case study, which is a method widely used in medical sciences as a tool for recognition and survey of data about a certain disease, and possible necessary cares to perform the assistance of the individual, considering its individuality and subjectivity. 

The subject chosen for this study was 41 years old and male. The choice by this client was made in the third week of practice of the curricular component Supervised Curricular Internship I, in April 2011, in a university hospital of the city of Salvador-BA, Brazil, after observations regarding the need for nursing interventions, difficulties of communication, mechanisms of support and coping by health staff in direct contact with this patient.

The Theory of Basic Human Needs was the main axis of the nursing process that was conducted. Data collection was performed from the printed of the standard nursing history of the institution, which is comprised of sociodemographic information, knowledge and experiences of the health-disease process by the individual, their beliefs and support networks, interpersonal relationships, among much other crucial information for providing a humanized care and with good quality. The nursing history was designed from the communication and the establishment of a bond with the patient and his family, by means of systematic dialogues with their family members, and also through a non-verbal communication conducted by the graduating student woman and the client; he already showed impairment in his voice.

For the preparation of this present study, the client was asked about his interest of participating of it, from the visual communication that was established, along with the authorization by the responsible relative. It is noteworthy that when the patient is admitted to a teaching hospital, he signs the authorization term of the act of admission on possible needs of clinical case study, being instructed about its conduction and confidentiality of information, as recommended by the Resolution 196 / 96 of the Brazilian National Health Council, which refers to the ethical aspects for researches involving human beings.

After analyzing the data collected, a physical examination was performed, thus enabling the formulation of nursing problems, from objective data. The survey of nursing problems was subsidized by means of the analysis of the needs presented, and the nursing diagnoses were proposed from the definition. Subsequently, the interventions were planned in accordance with the problems identified in the patient under study, focusing our attention on integrity of the care during the process of caring and the nursing cares.

**RESULTS**

Through dialogue together among the client, family and student, it was possible to obtain information about the life history, habits and expectations of the subject and his family, through an average of three meetings, until a bond could be signed.

Nursing History: Client - C.O.S. - 41 years old, male, brown, non-practicing Catholic, a native of Salvador, he is married, father of two children, and was admitted to the unit on the date 26.07.09 with a medical diagnosis of ALS for 4 years. He was found bedridden for incapacity for voluntary movement of the limbs, however, with maintained sensitivity, lucid, aware, aphasic. Among the sociodemographic data, the subject had the occupation of painter until the starting of symptoms; he made occasional use of alcohol beverages; had a cycle of friends that he met frequently; sporadically, practiced sport and had a habit of watching the games.

Regarding the physical examination: normochromic ocular mucous, anicteric sclerotic, spontaneous ocular opening; skin with scarring lesions in hemithorax D,
hydrated, presence of a tracheostomy tube in assisted-controlled ventilatory mode, vesicular sounds well distributed with diffuse snots; flat and flaccid abdomen and painless to palpation, with diet via gastrostomy 65ml / h; extremities well perfused, without edema, upper and lower limbs (atrophy) in spasticity; moderate depletion of muscle tissue (clavicle and temporal) and adipose (face). Diuresis and stools present and with normal aspect, sleep preserved. Anthropometry: estimated weight = 56.4 kg; estimated height = 1.82 m; BMI = 17.02 kg/m² (low weight). Vital signs: Afebrile, RF= 16 ipm, CF= 62 bpm, AP= 100 x 60 mmhg. MV: SO2= 98%; FIO2= 40%; Peep= 5 cm/h2O. There was a need for aspiration 4-5 times a day, being conducted by physiotherapy and nursing, with moderate volume of thick and white secretion.

After collecting the personal data of the client and the analysis of his biological, psychological and spiritual basic needs, it was possible to trace the primordial problems of him and the nursing diagnoses with their respective interventions. The nursing diagnoses that were traced are listed below:

- Impaired verbal communication;
- Self-care deficit: bath/ hygiene;
- Hopelessness;
- Ineffective airway clearance;
- Diarrhea;
- Impaired physical mobility;
- Imbalanced diet: less than body requirements
- Risk of aspiration;
- Risk of infection;
- Risk of damaging the skin integrity.

It is important to note that the problems and needs of the client could be expressed by a considerably larger number of nursing diagnoses, the degree of dependency, physical and psychological condition in which he found himself. Nevertheless, due to the inability to intervene in so many needs in the short time on the internship and, because of the need for learning and make a discussion on technical and scientific part of the nursing, there was a greater focus on diagnoses related to the pathophysiological aspects of the client.

**DISCUSSION**

The care is the primary object of the nursing practice, and for that it occurs it is necessary that nursing is based on scientific models and processes of care which are able to ensure the status of science. The nursing care is made from art and science, and for that it happens in a dignified manner it is necessary that desires exist, relationships and attitudes among those people who interact. The health-disease process is intrinsically personal, a unique and particular experience of each human being and it is necessary that the nurse-client relationship makes strong and true bonds.

The nursing cares provided to clients in the hospital environment are complex acts, full of symbolic elements, rich in meanings, which make nurses drive their actions always taking these meanings in consideration. For the execution of these cares, the nurse depends on social interaction with people who are there to make the context of the unit: patients, companions, health staff and other people in the care environment.

For that an authentic care is provided, it is necessary that the health professionals practice a constant reflection on each case and context in which it is inserted, which will enable a greater understanding of the ways of coping that can be adopted by the subjects with which they interact; knowing their conceptions of value, body, health and disease, life and death, autonomy, suffering and dignity, thereby producing a truly humanized care.

An integral and humanized care occurs from the time that the nurse is able to understand the client from its complexity and multidimensionality, and it is need to develop and employ skills, furthermore of acquiring sensitivity, for that promote other forms of communication, whether verbal or non-verbal. However, many professionals have demonstrated not knowing therapeutic communication techniques able to establish a true bond with the patients, especially for those with limited speech, it is a fact which should be questioned, discussed and reflected by the health staff and the academic community.

When faced with the onset of a chronic disease, the individual adopts attitudes and practices of coping that will enable a redefinition of its existential process as a human being. The acquisition of scientific knowledge about their clinical situation provides important support in empowering of the subject and its treatment adherence. Through the search for knowledge, the individuals who are suffering from chronic diseases see themselves more able to cope with the limitations imposed by the illness.

Thus, one of the essential nursing interventions for the starting of the care process is the exchange of knowledge about
the disease, either by the individual or the family, thus allowing an exchange of scientific, cultural and individual skills from the actors who are in interaction.

The life quality of the individuals with chronic diseases should be a key target of activities and provision of the nursing cares and it must be constantly in accordance with the needs that are pointed out by the client as priorities and essential. Know and respect their decisions, opinions, attitudes and desires are intrinsic attitudes to the process of care, based on the pursuit of life quality of the individuals with chronic diseases. The stimulus to self-care, even if it is seemingly non-existent, is a practice that the caregiver must hold, giving to the individual, “object” of its care, a prominent position before its present and future.  

Hence, based on the problems identified and diagnoses found, interventions were traced together with the nursing staff and the responsible teacher, thus enabling an individualized care with better solvability.

The main interventions that fit in this case study involved: the stimulation and maintenance of autonomy of the client, despite all physical constraints imposed by the illness; the establishment of methods to facilitate the verbal and non-verbal communication of the team with him; the inclusion of the family in the care process, strengthening its ability to solve the problems and confidence before the future of the client; the provision of ongoing psychological support to the client and his family; the maintenance of semi-intensive nursing cares, as the need for aspiration, the regular change of position, the nasal lubrication, the systematic control of vital signs, among others.

The need for establishing an effective non-verbal communication appeared to be urgent, because the communication keeps the link that connects the human being to their environment. The voice, the gestures, the body and facial expressions enable the communication and the interaction among individuals.  

In the hospital environment, there are some clients who do not make contact verbally, for being tracheostomized, intubated or with neurological sequelae, with losses of cognitive activity. Even so, the nurses interact with these types of clients.

There are several techniques of communication that are able to replace, alternatively, the speech, whether on a temporary or in a permanent form. The Extended and Alternative Communication (EAC) is any communication which replaces the verbal form of speech, helping people who have limitations in gesticulation. The EAC must reduce the difficulties and negative consequences in the development of people with impossibilities of verbal expressions, such as limitations in social interaction, learning and personal autonomy.  

Other more sophisticated techniques have been quite used in several countries, such as visual communication, in which by means of blink of an eye or facial expressions, the individual is able to express its ideas and thoughts.

Another need that has become the focus of nursing care was the participation and the role performed by family in the care process. The implications and negative answers that are present in the self-image and the self-concept of the client - about its own being - are able to greatly impair the process of acceptance of its condition, its treatment and the new reality imposed, because it is through the image that the individual keeps itself in interaction with world. Thus, the family and its social ties are important to facilitate the acceptance of the individual regarding its illness and its limitations.

The family constitutes itself in a bond of support, but it also presents foundation needs. It is necessary that it is able to readjust and reorganize itself, so that provides the necessary care for others and for itself. The clients who have disabling and incurable diseases need special attention, as well as their families, so that effective strategies are implemented.

The labor with these families includes the need for reflection and reinforcement of existing emotional bonds, which will be able to provide support for both actors in interaction. The need to recognize the implications of the disease to the family context must be an axis present in the conduct and in the nursing cares, since they allow that the exchanges and the bond are implemented of a sincere and solidary manner. Thus, the nursing should be able to provide the necessary support, in conjunction with the interdisciplinary team, to the client and to the family, who run into constant obstacles. However, the nursing, often, has difficulties to implement its activities, as the present case has shown.

Other interventions have been identified as essential for the care of the client - C.O.S. - as use of music, periods of reading, changing of the positioning of the bed in the private room, or even change the private room, because the patient was in the same room since his admission, 2 years ago. These
procedures aforementioned were some of the possible interventions. Some of them have not been implemented for some reasons, such as: the rigor of protocols and guidelines of the institution; lack of private room near to the nursing post, which did not allow an immediate care in case of major need; impossibility of changing the position of bed in the room, due the location of the ruler of gases; and lack of encouragement and interest from the client in the ludic activities, mainly because of the depressive process experienced by him.

The inability generated by chronic diseases involves multidimensional aspects, which are the result of interaction among physical, social and institutional factors. The body should not be understood as an object for scientific purposes, of intervention and classification, as preached by the hegemonic medical model, but as a biological phenomenon and of social production. From this model, the disease and disability are seen as items to be combated, becoming the main targets of the health practice. Accordingly, the nursing needs to adopt proactive attitudes and skills that are grounded on socio-anthropological reflections of the health-disease process, able to problematize the process experienced by the other, the object of its care.

CONCLUSION

The aim of this case study was to perform a visualization of the problems and needs of the client with ALS and the social, emotional and physical implications that this disease triggers in the life of an individual, thereby providing subsidies so that nursing can research and create new coping strategies together with the subjects, family members and the health team involved.

Through this study, it was possible to plan priorities in actions performed by the nursing staff to better serve the client who has this type of diagnosis. It is noteworthy to emphasize the extreme need for attention and care to this client, who is in a severe process of vulnerability and dependence of all caregivers, viewing it as a whole, correctly intervening to achieve a better adaptation to the new reality that the disease has imposed on its lifestyle.

The use of the steps of the Nursing Care Systematization - Sistematização da Assistência de Enfermagem (SAE) makes that the gaze before the problems faced by the customer more sensible (humanized) and completeness, enabling reflection and decision-making by the nursing professionals. Nonetheless, the lack of tools for this practice by the institution showed itself like a limitation to the application of care identified, because the team lacked a systematic approaching for the implementation of activities to be performed.

The hospital in question has only one stage of historical of the SAE, which hindered the implementation of nursing diagnoses and their interventions by the authors. Some changes were conquered by the initiative of the graduating student woman, along with the referential nurse of that unit and the teacher who is responsible for the curricular internship of the public university in question.

The ALS, by being a rare disease and hard for doing a diagnose, has few studies and effective treatments for delay its immutable implications, thus having the need for a better preparation of the health care team to deal with the reality that this complex disease brings with itself, including, necessarily, the nursing staff, since this is the team which establishes ongoing and direct care to the clients.

The role of nursing in caring to the client goes far beyond procedures and therapeutic conducts that are just technicist, it is important to promote the comfort and the best possible adaptation of the client to the reality of a chronic and disabling disease as the ALS, requiring a greater confrontation, integration, participation and accountability of all health staff for the adaptation of the client, along with the family, which see itself alone and anxious about the dependence and suffering of a loved one.

From experience of the pupil as a graduating student of nursing, it was possible to realize the need for greater awareness and major approaching from the nursing team in caring for the client in the end-of-life process. The feeling of helplessness experienced was able to provoke concerns; being perceived that none really effective and full care can be performed if it is not covered by the whole multidisciplinary team that is involved. In this context, it is necessary to produce more studies on this thematic and prioritization by the nursing staff for the creation of mechanisms and skills in the care to be offered to the individual and its family.

In this context, researches and studies in nursing must be performed, in order to qualify the professionals of the nursing staff to deal with the reality of the clients with ALS.
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