CARING FOR CAREGIVERS

Family caregivers of patients with chronic illness

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DE COLOMBIA

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Introduction

Caring for caregivers, family caregivers of patients with chronic illness; this research is aimed to those nursing students and professionals, who are interested in getting to know standards of care, as well as those who are responsible of patients with chronic illness. This experience implies challenges, difficulties, and special requirements, which generate special care programs -through other people's experiences, analysis of literature, and research-.

This book is based on the *Caring for caregivers Program*, designed by a group of Professors at Universidad Nacional de Colombia, School of Nursing, aimed to strengthen those caregivers' abilities to care. Thus, the key features that contributed to the creation and development of the program are set out throughout this book. Participants' names have been changed to help preserve anonymity.

The concepts of *chronic illness* and *caregiver* have been defined in order to have a wider context. The situation of caregivers is also described with research results that built the basis for creating the program, which led to build some other academic programs: the *monitoring*, the *social support* and the *discharge from hospital plan* programs. This contributed to the consolidation of the current research line.

The roots of the *Caring for caregivers Program* come from the line of the chronic patient care research, created in 1994, through the Nursing Master's degree program at Universidad Nacional de Colombia. At the beginning, it was led by three professors who have developed some joint and complementary projects, thus, contributing to this research from their experiences of caring patients and families of children, adults and seniors.

Another member joined this research back in 2006; she is a professor at the School of Nursing who had studied a Master's degree in health services Management, developing a new research sub-line on the "oncology patient care".

Regarding research, this group has advised 36 master's final papers on this field; three specialization works on cardio respiratory nursing related to either chronic care or its quality, and 25 undergraduate dissertations.

This path has led to acknowledge different groups' experiences: adults with cancer or neurological disorders, elderly with dementia, diabetes, arthritis, and children with cystic fibrosis, neurological diseases and cancer. Hence, needs were set according to what it was observed in order to modify aspects regarding lifestyle, pain, limitation, mutilation, alteration in socialization and fear of death.

Likewise, the needs of chronically ill dying patients, as well as the experience of living with chronic illness, the spiritual dimension at and chronicity levels were identified in general terms. Finally, from 2000 onwards, the importance of analyzing the situation of caregivers was identified with significant achievements; as a result of this process there has been an important impact on the quality of life and shortcomings in the caring ability.

These results generated new needs, so that in 2002, the *Caring for caregivers of patients with chronic illness program* was institutionalized through a series of workshops aimed to promote the caring ability.

This program was assessed, supported by COLCIENCIAS[1] from 2003 to 2005, 12 months in total, through a quasi-experimental design. Thus, we measured the caregivers' caring ability in general terms, through some of the following components: knowledge, courage and patience, using the CAI® Ngozi Nkongho in 250 caregivers of patients with chronic illness in Bogota and some surrounding towns. Results were constructive and showed a possibility to be validated in other contexts.

In 2007, the multicenter study network and the assessment of the *Caring for caregivers program* ® started; it was supported by Universidad Nacional de Colombia: Research Department -DIB[2]- as a response to link networks of researchers in Latin-America throughout eleven settings; it involved eight cities in Colombia: Santa Marta, Cartagena, Cucuta, Ibague, Villavicencio, Girardot, Chia, Bogota, and three other countries in Latin-America: Argentina, Guatemala, and Panama.

Thus, there was an answer to the question: -What is the effectiveness of the *Caring for caregivers program*® when developing caring abilities in family caregivers of

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[1] Translator's note: Colciencias is the Governmental Administrative department of Science, Tecnology and Innovation in Colombia. http://www.colciencias.gov.co/

[2] Translator's note: DIB stands for *Dirección de Investigación,* which is Universidad Nacional de Colombia: Research Department http://www.dib.unal.edu.co/

patients with chronic illness in different regions of Colombia and in three different countries in Latin-America?

This study was completed by August 2008; results did illustrate the effectiveness of the program. The impact led to the consolidation of the *Chronic patient care network*, which aims to establish mechanisms for academic and professional exchange in Latin-America regarding caring for chronic patients and their families.

Thus, a new project was designed to be carried out from 2008 to 2010: a multicenter study led by this research group. The objective was to determine the effectiveness -through advanced technology- of social support in family caregivers of patients with chronic illness, in the Latin American network nodes that were established in nine cities within Colombia: Bogota, Santa Marta, Cartagena, Cucuta, Ibague, Chia, San Gil, Bucaramanga, Girardot and in Guatemala, Chile and Mexico; it was also projected to be expanded to any country in the American continent.

The www.gcronico.unal.edu.co webpage was created as a joint project, in order to provide attention, from an interdisciplinary perspective, to the needs of individuals, families, and caregivers in chronic illness situations. It consists of consultations and services provided through integrated networks for patients, family caregivers, professionals, students, researchers, and other people who might be interested in this field.

This guide is intended for professionals and nursing students to share essential information meant to care for caregivers, and it is based on a holistic research program.

It provides a program to caring for caregivers program; it is based on an innovative model.

It defines concepts such as *chronic illness, family caregiver,* and *care program.*

It describes the family caregiver’s situation through *nursing research studies.*

Facts: this is a guide aimed as a research reference to be available for support and assistance.

1

Chronically ill patients and their family caregivers.

The chronic illness

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Defining chronicity

Pablo Santana was apparently a healthy person; his life, he says, seemed to be perfect: "*-Everything was successful*". Suddenly, he began experiencing a constant stomachache. The first days he paid little attention to this symptom, but it persisted, so he decided to go the hospital.

This patient shares his experience: -*"They run some tests, and the doctor's face showed something was wrong. I looked at the television screen which showed my stomach and I saw something was different. I dared to ask without hesitation: What did you find? The doctor said, I don't like this, but I'll send it to pathology"*.

Thus, his whole life changed: it was cancer. Eight days later he had been scheduled for surgery; most of his stomach was to be removed. From then on, a new experience for this man's life had started; he ended up facing what is known as *chronic illness;* its real cause is yet unknown; it is insidious and usually deteriorates patients.

The word *chronic* comes from the Latin *chronicus*, and this at the same time from *povucós*, which is the Greek word for *time*; it is an adjective, used in health sciences, to describe a long duration illness or a constant condition during a period of time, so it implies chronology; it is a persistent situation that started long ago.

Chronicity also refers to the quality of chronic. It is used to describe people's living condition that lasts for a long time, having an impact on them, their families and social context, as it was Mr. Santana's case, the patient we have mentioned above.

The word and its meanings

Depending on each perspective *chronicity* may have different definitions. When it is conceived as a *state*, it is characterized by the unwillingness and incapacity associated to the presence of prolonged and irreversible pathological changes, which causes a residual disability. If it is understood as a *process*, it refers to the progressive deterioration experienced specifically by each person involved in the process, which includes families and groups. Therefore, chronicity is continuous and changing; it has alternating rhythms and implies changes in daily life and in all dimensions of human beings. This process often requires supervision, observation, special care, adaptations, and rehabilitation, specifically higher social intervention and health services.

Chronicity is also a permanent crisis that affects patients, their families, and their living conditions. In a regular crisis, people may look back to analyze what happened. However, the present may be confused with the past, thus, a period of difficulties and confusion starts. This condition explains the difficulties that people living in this situation go through.

For all these reasons, chronicity becomes an interesting phenomenon for nursing, which defines the condition, the process, and the individual and collective crises of living the experience of chronic illness with its meanings, consequences, and responses.

In this sense, chronicity may be identified through monitoring patterns of life. It is possible to describe it, as a phenomenon of totality, through any person or group involved in this experience.

Chronic illness

Chronic illness is a medical condition defined as the disruption of normal operation for a minimum period of six months. There shall be chronic illness when a process is perceived as threatening or disabling; it lasts for a long period of time and cannot be cured quickly or easily; its nature is multi-causal, and in most cases it is not contagious.

The chronic illness may also be defined as an organic and functional disorder that is permanent, incurable, and irreversible, with periods of remission and relapse; it modifies people's lifestyle; it has no limits: no matter age, gender, educational background, social class, ideology, or hierarchies; it invades patients, their families, and their social groups.

The chronic illness is usually cyclical and atypical; it affects autonomy, independence, development; it has unpredictable effects that affect the chronically ill person's self-image and self-concept.

However, the experience of living such situations, in many cases, lead people to be more creative in order to overcome the limitations or requirements of life, seeking to transcend or become socially included.

Chronic illness is also characterized by an impact on all the people involved; it requires contact with health care institutions; it demands medical attention, where the main focus is the person and the person's family. On the other hand, it creates significant social and financial implications that affect the person directly.

Chronic illness differs from acute illness in the degree of uncertainty caused by different forms of manifestation and the complex family members' reactions, since the person is affected by constant changes. In most cases, the person gradually loses the ability to perform daily life duties. On the contrary, when the person faces some other kind of conditions, patients and their families understand that after a procedure or treatment they go back to what they were used to; having just a limitation as a consequence.

Another difference between chronic illness and another kind of illness is the way it affects family, as the main care agent. When caring for a patient with an acute illness the effort is temporary; everything is chaotic, but only for a short period of time. On the contrary, in chronicity, care implies a long process and it tends to be increasingly more complex and demanding. In many cases, the person deteriorates physically, which alters this person's roles.

Chronic illnesses are associated -less frequently than acute ones- to infectious conditions. That is why chronic illnesses sometimes are considered non-communicable illness. Chronic illnesses are multi-factorial, while acute illnesses are recognized just by one causal agent and other stimuli that may be affecting their appearance or prognosis. In that sense, it is easier to identify an illness and associate it with an agent or a pathological condition; whereas, a chronic illness is difficult to identify them, as well as the links to complex psychosocial factors they entail.

Classification of chronic illness

Chronic illness may be categorized in a wide variety of ranges. Although, there are six approaches that illustrate the complex nature of this condition:

Chronic illness *according to the predominant problem*

This classification does not take into account illness itself, but the person's experiences, problems, and meanings. Therefore, it is important for understanding the chronicity phenomenon from the nursing perspective.

There are four groups included in this category: those conditions that require a lifestyle change in order to improve the prognosis; those that generate pain, limitation or mutilation; the ones associated with occupational factors, such as exposure to toxic agents, radiation, pesticides or noise; and the ones associated with acute alterations that may result in chronicity as a consequence of infection or trauma.

Chronic illness *according to the way the chronic illness starts*

According to the onset of the illness condition, it generates three categories including illnesses that start all of a sudden, those that are very insidious and gradual, which are the most common ones, and illnesses that may deceive because they appear and disappear, with high risks of exacerbations at any time.

Chronic illness *according to the course of the illness*

They are related to the course of the illness itself. It is possible to recognize at least four groups: those with a slow, active, and progressive trajectory; those with a constant presence and relatively stable; those with an irregular trajectory; and those with a relatively fast and devastating course.

Chronic illness *according to the prognosis*

Illnesses that are related to life expectancy may be classified as follows: those that do not involve the person's life directly; those that do involve the person's life directly; those with a guarded and sometimes variable prognosis; those that depend on the combination of internal and external factors of the illness, affecting the completely person's life, which is known as terminal illness.

Chronic illness *according to the phase of the illness*

According to the state of the illness some phases may be recognized which allows classifying them on how to cope with the illness; i.e. illnesses in shock and disbelief phase; being aware of the change phase, stable phase, crisis or exacerbation phase, and in resolution or terminal phase. Some authors admit additional phases, such as: pre-path, setting the path, stability, instability, acute, crisis, crisis return, deterioration, and proximity to death.

Chronic illness *according to the system is the illness is related to*

It is the way the illness manifests through the person's body. There are a variety of categories, for instance: the ones affecting the person's body system, such as respiratory, cardiac, renal, neurological, metabolic diseases, and so on.

Another category might be related to the ones without an organic impact, but with a cognitive or mental impact instead. Within this group different personality disorders may be found, such us: psychopathology or sociopathology, as well as those characterized by mental retardation. Finally, there are mixed-type illnesses: those that generate physical and cognitive impairment, causing inability to perform daily activities and affecting roles according to age and illness condition, for instance: Parkinson's dementia.

Living with chronic illness

When people become aware of their illness situation they may either identify their illness as associated with an unmet need, or they may know their illness without reasonable or evident manifestations. Just in few cases, the illness causes dramatic changes in health.

Since there, patients know their diagnosis and acknowledge their condition thereafter. This announcement is not always warned with the piece of advice regarding the life change to be faced. This might be shocking for some people, but they do not actually understand its magnitude. For some others, it is devastating.

In both cases, the illness indicates an affected health state, which will prolong irreversibly, with an uncertain prognosis. Uncertainty, regarding possible limitations, pain, unpleasant sensations, as a matter of fact, the threat of death appears in some cases.

According to those patients who have experienced living with a chronic illness it implies different conditions: feeling trapped, rejection, denial, anger, sadness and, in most cases, a deep uncertainty.

> *-"My life changed, I'm not the same person. I can’t work as I used to; I have to spend time in activities that I had never carried out before and even I have to eat food that I had never thought of eating before"; Pablo Santana’s testimony, after surgery.*

This situation is also illustrated with examples of expressions by people who have been diagnosed with chronic illness: *"I do not think I can make it", "Why me?", "I can’t believe it"; "I do not want people to worry about me."*

Thus, this experience affects the entire life of patients, with some relevant expressions in different areas of their life.

Physical expressions

Pain, feeling of loss, modification of movement, alteration or lack of body control, sexual dysfunction, diet modification, disturbance in rest, sleep, elimination, breathing, and tissue integrity; these are all common physical signs of chronic illness.

Psychological expressions

Regarding the psychological field, the illness is generally expressed through suffering, lack of autonomy, lack of knowledge, anxiety about the unknown, anguish, fear to inspire or not to inspire feelings of pity and sorrow, powerlessness to change the facts, and loss of dignity.

Social Expressions

Social expressions in chronic illnesses are marked by the collapse of the daily routine, due to the need to be absent from work or school in order to commute to medical appointments.

Some people may require hospitalization, but the system is unkind which makes the experience even more complex. For instance, they have to wait for a long time and sometimes get unkind attention.

There is also a deep loneliness sensation, isolation, and the feeling of being a burden to others; especially, when the roles of others are affected by the patient's health condition. Some people are limited to modify their daily activities, as they depend on their family or professional caregivers' help. Decision making on their lives is delegated to their caregivers.

Those situations, in which autonomy is affected, as well as privacy, are complicated, because it is necessary to share with other people intimate activities such as: toileting, bathing and getting dressed. This creates a complex sense of change, which is difficult to handle by all the people involved.

> *-"I felt ashamed for a long time, my daughter had to give me a bath and cleanse me after elimination," says a paraplegic man, who had to accept his privacy change.*

Spiritual expressions

At the spiritual level, illness is expressed in the closeness or distance of patients towards their beliefs and religiousness. It affects the existential level as it implies existence changes, the relationship with oneself, with others, and with God, or a higher being or power. These expressions seem to have a huge impact in determining the direction of health facing illness.

Perceptions of chronic illness

It has been observed that people come to perceive illness in many ways throughout many years of research; this also depends on their own experience. Most of these approaches are not mutually exclusive.

Illness as change

Some people perceive the illness situation as a change or a sequence of changes, which have to be wholly or partially handled; thus, people seek to adapt through conditions that help the situation to be more manageable.

Illness as an enemy

Some people perceive illness as an enemy, as something hostile that adversely invades the person's body, creating a dichotomous situation of rejecting their own existence. Thus, ill people generate large-scale internal conflicts, they become fighters against themselves or they tend to depersonalize from their own nature.

Illness as punishment

Several people live the situation of illness as a kind of punishment for their mistakes; this feeling is common in those who have lived habits of vice or debauchery that contradict their beliefs and cultural frames. In some cases, people feel this punishment is unfair; but some others they take it as an opportunity to amend those previous life situations and want to redeem their guilt through illness.

Illness as weakness

For some other people, illness means weakness or an infantile strategy to attract love, this perception is associated with values of the contemporary lifestyle, in which beauty, strength, and vigor have a remarkable position.

Illness as a coincidence

Another explanation people use to understand the reason why they go through an illness state is related to bad luck. Some people are even relieved because they say illness affected them instead of affecting their loved ones, assuming there is a limit illness quota. For some other people, fear of illness attracting more illness disturbs their tranquility.

Illness as the end

In some other cases, illness is perceived as an irreparable loss or as an irreversible functional change, where there is very little hope. This is the most common perception in fatal prognosis situations.

The combination of all the circumstances surrounding the experience of living with a chronic illness, including perception, generates different life expectancies, and sometimes radical changes in a person's life. Eventually, we must admit that the inexplicable chronic illness progression might seem associated to a particular disposition of the state of mind. However, sometimes it is different.

In addition to all those consequences previously outlined, the loss of self-concept, welfare, independence, comfort, physical appearance and functional changes, remain to be a major challenge when living a chronic illness experience, despite all those personality differences within the context in which they arise.

The impact of chronic illness for each individual is related to: personality characteristics, the illness severity, the illness duration and symptomatology, as well as the degree of its consequences. These impacts also depend on the type and time of therapeutic interventions, on the person's perception of the illness and the quality of relationships with close people -especially with family-.

When analyzing the impact of illness, there is always a relationship throughout the underlying pathological condition, the level of social support, and the illness consequences.

To a large extent, the person uses some coping mechanisms, such as denial, anger, an insatiable quest for healing or deep sadness; they determine how people eventually accept their reality and how they grow through this process. However, under these circumstances, being supported by others and feeling unconditionally loved and treated as a human being is probably the most important aspect of them all.

Family caregivers

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A chronically ill person needs constant support that a health care professional cannot provide alone. Therefore, family caregivers play a significant role in the development of this task, where it is vital to acquire knowledge of the problem to understand this experience.

Targets are established when facing the situation of caring patients with chronic illnesses; they require multiple interventions which include: meeting health care, psychological, social, and financial needs, among others, that become family caregivers' challenges.

Those health targets are related to managing signs and symptoms such as repetitive, concomitant and irreversible pain and disability. The psychological targets include reactions regarding coping with the illness. The social targets essentially have to do with the prevention or minimizing isolation. Financial issues are related to possessions and acquisition of financial resources, which increase constantly and unpredictably. These are all usually long term situations.

In most cases, care is conducted to satisfy the patient's needs. The caregiver is usually forgotten; this person is the family member who is with the patient, facing care responsibilities, in most cases, caregivers do not have the support they do required, regarding their own welfare.

Who is a caregiver?

Chronically ill people need a person who accompany them in their tasks and provide them with basic assistance all the time, that person caring for the patient is a *caregiver*. For the most part, they are linked through a family relationship, a bond of commitment, who takes over the responsibility for caring, sharing, making decisions and taking on behaviors with regards to the individual that is being cared for.

As a result of their research Pinto and Sánchez (2002)[1], describe a caregiver as a family member or social group that is responsible for caring an ill family member

The caregiver represents a solution to attend the ill person, in many cases without having reached an explicit agreement among all the family members.

Caregivers have to change their life in order to take on special assignments, which brings worries and stress due to the responsibility of caring for another person who depends on the caregiver to perform daily life activities. Thus, caregivers have to deal making decisions that affect their own existence as well as the one of the person that is being cared for. To sum up, caregivers are in charge of the moral and unavoidable commitment to care for their ill relative or friend[2].

Caregivers and care circumstances

The situation of being a caregiver is full of circumstances that generate a huge impact in their life, with common specific feelings. The most significant being that of *powerlessness*.

Mui (1992)[3], took what had been described by Davidhizar, to identify factors influencing the feeling of powerlessness and classified them into *personal, environmental* and *situational*.

Among those personal factors quoted by this author there are the individual characteristics, including all kinds of socio-demographics aspects. For example, if the caregiver and the person cared for are young, adults, old, men, women, from a different race; results turn out to be quite different depending on each case. Characteristics may also vary depending on culture, profession or daily activities and the relationship between the caregiver and the person cared for.

Personal perceptions become relevant here as the product of previous experiences and the ability to cope, which may involve feelings of sadness, loneliness, anxiety, and mistrust to handle the situation. Environmental aspects refer to support and resources to face illness.

Finally, there are situational factors that may integrate the two previous ones, including the influence created by the kind of illness. These factors are all framed in duties that the caregiver is to be in charge of.

Caregivers' duties

It is difficult to explain the caregivers' duties because they highly depend on the family and the person with the chronic illness. When the caregiver is a middle aged woman, some of their most common roles are those of: workers, mothers in their upbringing period of life, wives helping their couples; they are often caregivers of a parent or an ill child.

The main challenge for family caregivers –essential when carrying out their duties- is to know the person with the chronic illness: how this patient reacts to the illness, as well as coping with it and his dependence on their caregivers. Furthermore, caregivers need to know themselves: in terms of their abilities when someone depends on them. Caregivers are a specifically vulnerable group to experience the devastating effects of stress[4, 5,] related also to household activities like cooking, washing, cleaning. Caregivers are to assist their ill relative to move from one place to another, with personal hygiene, as well as with money and goods management.

Likewise, caregivers are to monitor and provide the person that is being cared for with medications; handle conflict situations i.e. when the person does not quite accept treatment or when illness symptoms increase; to help the person cared for also to communicate -when there are communication difficulties-; to scratch, change body positions, among other related care duties.

Caregivers' classification

Ebersolone and Hess -quoted by Pinto and Sánchez (2000)[6]- classified caregivers based on their caring role, which is important to keep in mind for determining their availability and responsibilities. Thus, Ebersole and Hess classified caregivers into five different groups: *anticipatory, preventative, supervisor, instrumental*, and *protective*.

A caregiver's testimony states that from the exact moment he learned his father's diagnosis, he offered his father food every two hours trying to avoid complications. Then, he could be classified as a *preventive caregiver* as he provides caring, alternating the environment and available resources; he also provides assistance or services to either prevent or slow down the patient's deterioration process.

Another caregiver's testimony states: -"*I turn my mom's body constantly; I rub some lotion on her skin four times a day and twice at night; I am always trying to prevent skin lesions";* this caregiver might be considered as an *anticipatory caregiver,* she understands the situation of the chronically ill person and makes decisions based on future needs and according to an expected development.

A *supervisor caregiver* verifies the development of required actions and identifies needs through permanent caring support; an example of a supervisor caregiver would be caregivers who assign their father's care to their sisters due to their work. This testimony states: -*"I am constantly calling them to check out on my father, I go visit him, I care about his treatment or any possible complications".*

A *protector caregiver* wants to provide total protection to the patient, despite those events that can't be prevented because of the illness status, as a caregiver's testimony who states: -*"He will have plenty of care, as long as I am alive, I will provide him with anything he may need."*

In another testimony, a man whose mother was ill stated: *"I'm responsible for monthly medicines costs, I can't visit her, but I always think of her, I am worried about her condition."* He is an *instrumental caregiver*; he cares for the costs of survival and daily life activities; it is a procedural kind of care.

As determined by Sánchez (2001)[7], being a caregiver means living in a different way: modifying daily duties, making decisions, taking up new responsibilities, carrying out tasks and actions of physical, social, psychological and even religious care, in order to meet the changing needs of the patient. Thus, providing care generates feelings, which sometimes allows closeness and stability. Some other times generate different reactions and overwhelming sensations in caregivers, to confront or avoid their situation and context.

What caregivers are to face

- Caregivers have to address their situation in the middle of a complex structure that requires efforts to guide decision-making, along with the burden of care.

- Caregivers develop a close relationship with the patient; so close that they may exclude other family members.
- Caregivers even tend to abandon their own needs, which increases fatigue levels and makes the caring task more difficult. Moreover, caregivers and their family take on the patient's job and role within the family, in order to meet contributions and productivity requirements.
- Social isolation increases in caregivers, they have less time for friends, thus, contacts get reduced, and they only get involved in their care circle.
- The tandem of *caregiver-person receiver* faces crises due to a lack of knowledge, understanding, and acceptance. Caregivers are not always prepared to face these caring tasks, tensions, efforts that care implies.
- Caregivers are exposed to family conflicts that -in most cases- are generated by the emotional impact of accepting the ill family member's new condition; a person who used to be totally independent, now is totally limited, dependent, with a progressive reduction of his functions.

Some authors have documented the most common difficulties that caregivers face with their chronically ill relative[8, 9, 10, 11, and 12.] For example, a mother with painful experiences by means of having to give up her child with a specific expected diagnosis. A similar case is that pain experienced of being death diagnosed, or when there are natural and genetic features of the illness that are threatening[13].

However, by exploring the everyday experience of parental caregivers of children with chronic terminal illness, it is understood that to the extent care is provided with permanent dedication, values are redefined, satisfaction increases and changes are handled according to the child's own development. Thus, there is a positive coping with adversity in general terms[14].

Caring for the child in daily life develops a learning process in which caregivers achieve a beneficial adjustment to daily life[15]. Nevertheless, there is a different way of perceiving and coping with that responsibility for the caregiver caring for an old person with chronic illness; it has an impact related to loss acceptance, and a need of gratitude[16].

It is not easy for most people to face the fact that a close family member depends on them, despite those different attitudes that are taken in either case. A person does not become a caregiver overnight; most of the causes of the patient's dependence involve a progressive deterioration, associated with an increasing need for help in daily living activities, i.e. having a shower, getting dressed, moving around, eating, and hygiene habits.

Fatigue or burden manifestations

Many caregivers, unconsciously work beyond their possibilities and end up forgetting about their own needs. Thus, they hurt themselves and also those who are being cared for.

Caregivers frequently feel overwhelmed, they rush everywhere, and say they need time to perform care activities. Sometimes, caregivers experience trouble sleeping, constant loss of energy, chronic fatigue, tiredness, isolation, excessive consumption of caffeine drinks, alcohol, and tranquilizers. Caregivers also experience physical difficulties: palpitations, trembling hands, stomachaches, headaches, lack of concentration, apathy towards people and those activities that used to be their object of interest; appetite increases or decreases.

Caregivers also tend to get angry easily; they give too much importance to small details; they are prone to accidents and struggle overcoming depression or anxiety; they do not acknowledge physical and psychological symptoms or tend to justify them through external causes.

A female caregiver tells how she used to think she would not be able to handle such a task during the first months caring her mother; this caregiver felt hopeless, exhausted and nervous. However, she says that she eventually learned to accept and cope with the experience.

At the beginning of the care experience caregivers are not fully aware they will be the family member in charge, who will work the hardest and will take most of those care responsibilities. Caregivers do not know they will probably be in a long term situation that may involve a progressive timeline and energy.

For this reason, the process of becoming a caregiver -longer or shorter depending on different aspects- is of utmost importance because it has a substantial influence on care procedures as well as the fact of how caregivers feel performing their role.

-"The experience of being a caregiver significantly modifies people's lives; it goes beyond a simple task or responsibility towards another person to create a way of life and a different relationship with the person cared for, with themselves and with the world around"[17].

Care varies depending on gender. Women by nature understand chronic illness as a daily living situation. They take care of their children, their parents, those around them. A woman tends to be perfectionist, observant and almost instinctively seeks to preserve life; she quite understands aspects regarding the illness, the daily problems, and environmental conservation.

On the contrary, men are foresighted, organized, and responsible, as well as more practical; in that sense, men participate and help facing care issues that women sometimes do not take into account. Men communicate better with healthcare professionals and are a lot more practical and balanced at decision making.

What does it mean to be a caregiver?

If being a caregiver were a professional field, Ana Ortega would have all the merits for holding such a title, as she spent a long time of her life taking care of her parents, both of them with chronic illness; she says: -*"I looked after my parents, my dad with multiple sclerosis and my mom had rheumatoid arthritis,*".

The challenge of this caregiver was not easy, but it was quite rewarding for her, she says: -“*caring for someone facing chronic illness is a satisfying experience; it requires effort, dedication and, in many cases, sacrifices, investing more time in the person cared for than in you. It can also mean discovering personal qualities, skills or talents that otherwise* *would have not even been noticed; it helps acknowledging skills and strengths hidden until then".*

As this caregiver states, caring her parents taught her to perceive life in a different way: -*"to appreciate what is really important within a human being: respect, dignity, understanding, acceptance of diversity, and most significantly, the feeling of loving one another which makes us sympathetic and tolerant, as well as smile, feel good, be happy providing care, with personal fulfillment and immense inner peace".*

Reasons for assisting a relative

Most caregivers agree that taking care of their relative is an unavoidable moral duty, a social and a family responsibility, rules that must be respected. However, this is not the only reason they mention.

Some reasons are altruistic, i.e. they justify care as a need to keep the welfare of the family because the patients' needs are understood. Other reasons involve reciprocity; caregivers assert they had been cared for before, so they care in return. Other reasons may be related to feelings of guilt from the past, social commitment, avoiding family, friends, and acquaintances' censure or because the caregiver is the only person available to be in charge of the situation.

Other people report they find a deep meaning in the care experience as it makes them feel helpful and important[18]; it seems, caregivers' commitment, dedication and ongoing support provides them with satisfaction and experiences that strengthen them coping with care management and their problem solving skills in illness situations[19, 20]. Likewise, there are caregivers who are caring for elderly people as a way of thanking them for what they have received throughout life[21].

The personal point of view and coping strategies for chronic health conditions are perhaps the most important aspects in determining the meaning given to a caregiving experience. When the illness is perceived as a waste of time, money or affection, the feeling of powerlessness may increase, which produces caregivers' feelings of sadness, loneliness or anxiety. If caregivers feel they are just in disadvantage, there is no confidence enough in order to handle the situation.

Caring for someone who needs day and night attention is difficult. However, all families try to organize everything in order to face caring demands in the best possible way. Surely, everyone may recall an experience as a caregiver. Some people perhaps have had the privilege of helping a loved one in a situation of chronic illness and sigh when thinking about what it meant to them.

This experience is related different issues, such as financial resources, time availability, and tangible support -family and social ones-. When there is no concern regarding financial issues, stress levels are lower.

Likewise, there are features related to the chronic illness that might have an impact on the caregiver. For example, multiple reports regarding caregivers taking care of patients with impaired mental sphere show how devastating it is to interact with these patients. When patients do not remember or recognize their caregivers, they go through psychological stress; many caregivers assert it is like taking care of a stranger.

Caregivers' needs

Needs are associated with *insufficiency* and *lack of*. For caregivers, needs are the requests and activities demanded by the chronically ill person; multiple care resources are required: personal, family, social, and, of course, those resources required by the person cared for.

Personal needs

There are many challenges to be faced when caring for a person with chronic illness; these challenges alter the caregiver's personal life, such as loneliness, not knowing how to comfort and relieve the person that is being cared for and others' judgments, as caregivers seek to fulfill the care receiver, sometimes, without success.

A caregiver in distress says: - *"When my daughter went through her first hospitalization, I was told she had cancer* (crying), *the doctor left and no one told me how to handle this".*

There are also cases of powerlessness when caregivers feel they are not able to diminish the care receiver's pain or suffering. This is a testimony of a caregiver: -" *Today my dad told me: I'm not afraid of dead, what happens before death is what worries me! What should I do to comfort him?"* another caregiver asserts: - *"I feel really stressed out; I do not know what to do with my son when he is in so much pain".*

In addition, sometimes caregivers are afraid of being supervised, they are afraid of people's judgments and that the others believe their task is not enough, for instance, another caregiver shares: -*"My sisters always criticize me, I feel judged; I do not feel good about what I do when I take care of my mom".*

Sometimes inner peace seems to be lost due to all the matters that are to be addressed. A confused caregiver says: -*"If I am working I am always wondering how my father is; when I'm with my dad, I think about what I'm going to do with so much work. I'm never alone!"*

These testimonials reflect some of the caregivers' feelings, who not only have the challenge of caring the physical requirements of their care receivers, but they are also exposed to a series of circumstances that generate new needs also. The following are some challenges caregivers have to face.

Understanding the illness

Understanding the problem affecting the patient's health as much as possible and analyzing its possible behavior is really important. The caregiver requires exact guidance on the illness' behavior and how it may have different consequences in each person.

Care giving guidance

Caregivers must be aware of the situations his relative has to face, for instance: to help him move from one place to another; to manage medications, taking into account the importance of the exact time to administer the treatment; to think of precautions that have to be taken into account, medical controls, and the need to contact the medical team (psychologist, therapist, nutritionist, social worker, physician, or nurse).

Guidance on the use of environmental adaptations

Some environmental adjustments as simple as placing the bed in the room, installing a switch to turn on/off the light, and other environmental adaptations have been identified by different therapists when visiting the patient's home; they all happen to be essential in daily care.

Guidance to the caregiver himself

It is necessary to guide caregivers on the importance of ensuring their own self-care, because they need to rest, accepting the support provided by other members of the family and involving others in the caring task.

The use of networks

Some organized groups strengthening and guiding caregivers spiritually, socially, and emotionally are useful to support and help caregivers not to feel alone.

Finally, it is quite important that not only the person cared for but also family members acknowledge and value the caregivers' activities. Thus, it has constantly been confirmed that caregivers' attitude and knowledge are key factors for patients' environment, welfare[22, 23], to meet their needs.

The family needs of caregivers

Caregivers and their chronically ill relative are involved in the situation within their own family, so their needs are related to the common illness experience, as it has been identified through the following testimonials:

A caregiver said that since his father suffers from Alzheimer's illness, his family is in fear, especially when his father gets aggressive; it's difficult to find care supporters in this situation. Another caregiver states that when they have to decide what to do with their mom, everyone in the family argues, gets upset and it is difficult for them to accept tasks assignment because they all are quite independent.

These cases illustrate the conflicts that families may go through regarding their relatives with chronic illness. Besides, this entire burden always lies on caregivers.

However, in some other cases the situation helps strengthening family ties, and even makes people more diligent; a caregiver says: - *"Since my dad had the accident and was confined to bed, we are more united and supportive to each other; we all want to help,"*.

Another caregiver shares that in his family they have to skip certain things because money is not enough: -*"My sister's treatment is very expensive and the health system does not cover all the treatments she requires."*

There are cases in which all the members of the family become caregivers: - *"Everyone in my family takes care of my dad; we all are experts now,"* says another caregiver.

The family has all the responsibility regarding the person affected by a chronic illness. Therefore, they undertake the role played by the ill person so far. Those activities that are usually replaced are related to productivity or household chores when the patient is a mother.

Morton and Lawrence (1995) examined 97 marriages and 186 relatives of patients diagnosed with some form of dementia. They sought to analyze the association between the severity of the illness to the family's health and welfare. Consequently, they found that the course of an illness was associated to the quality of care and it had a negative effect on the family's welfare. By contrast, the use of available services was not associated directly to the family's health and welfare, but to the severity of the illness instead[24].

When there is a member of the family in a situation of chronic illness, time for social relationships is reduced. It is essential that all family members get involved in the process of caring for their ill relative, learning about chronicity, support networks, and generating constant dialogue. Otherwise, the family is usually exposed to forget their own needs, which might trigger a progressive fatigue, leading to more difficulties and stress. Then, it is urgent to assign rest hours and ask others for support.

During the chronic phase it is also vital to maintain the required effort at the time of a crisis, especially in terminal stages, when support and guidance are extremely essential.

Moreover, families have financial demands due to the financial burden that an illness implies; it requires a resources distribution change because most of the income is invested in the ill relative's medical treatment. In most cases, this significantly affects the family's financial state and the basic livelihood.

This means that families may benefit from other groups and associations that promote meeting needs and fundraising activities.

Some research results have confirmed what had been described by Holicky (1996)[25], who studied children care and identified them as hidden victims of illness and disability. Holicky pointed out that parents as caregivers, tend to abandon themselves on physical, mental, emotional, social, and financial issues, and bind themselves to the need to care, reducing their own self.

Some other authors also found valuable aspects regarding families in caring experiences with formal support groups that are made up of various health professionals. According to the results, issues like information about the illness, available resources, and ways of coping are particularly important for caregivers; these tools help caregivers to meet their own needs.

Experience with groups of patients with illnesses like cancer, neurological disorders, dementia, arthritis, cystic fibrosis, and their caregivers reflect their most common feelings as: -*"We are tired of so many medicines"; "I have seen so many doctors"; "I'm living at the hospital"; "I can't do what I want to"; "what's the meaning of life?"; "Only God allows me to continue with this situation";* these are all their constant statements. Testimonials like these have prompted the interest of our research group towards family caregivers.

Caregivers as a focus of interest in nursing

The wellbeing of caregivers, their families and the ill person will be strengthened when nursing achieves a broader and a more human understanding of care. It is also important to understand that each individual is a different human being, with a unique life story. Care has a variety of meanings within the field of nursing[26].

Watson (1988) states: *"Care is a nursing ideal; the target is protection, exaltation, and preservation of human dignity."* Boykin and Schoenhoffer (1993) describe care as "*the nursing action that enters the patient's world with the intention of knowing the other person, recognizing him/her as a living and growing person in care."*

These concepts support the analysis of caring for caregivers of people experiencing a chronic illness, whose crisis are countless, ongoing, and limitless; it is a need and also a challenge.

The illness itself is not what is being cared for but people who are affected by a chronicity situation. The process of living with chronic illness is not inert; perceptions are associated to cultural values, ideologies, and religious beliefs. The feelings about the situation change throughout the long course of the illness and these situations have a meaning related to the illness itself, to specific symptoms and to labels on the situation.

The experiences in a situation of chronic illness create new experiences that change the lives of the ill person and those of family caregivers themselves. These situations confront the reality of death as part of human existence, the progressive limitation of functionality, and the lack of control over life.

In chronic and terminal illness situations the chronically ill person and caregivers have to interact with unknown and rejected systems. Continuous changes make it even more difficult, generating uncertainty and powerlessness. However, constant care in a long and indefinite time creates also experts.

It is important to prioritize care regarding premises and the situation under analysis through its most important aspects: social support in order to bear the burden and to strengthen potentials that contribute to the quality of life.

Social support acquires a special dimension here. For the main caregivers people who help them are absolutely important, as it is stated by one of the caregivers: *"Support provided by others is really meaningful every day, because that's where the really important things happen, when one faces the real experience of a chronic illness"*[27].

For this reason, it is necessary for nurses to properly measure the social support available for caregivers; it involves assessing and having tools for intervention. The following are several examples on how to do so.

Ebersole and Hess (1992) have caregivers to do their own analysis in terms of size, ability, availability, functions, possible crisis factors, resources, and the environment.

Size refers to the number of people available in the family: children, grandchildren, nephews, nieces, relatives and/or confidants. *Ability* refers to the economic status of each one of them: poor, low, medium, medium high, high. *Availability* is the frequency of commitment, which may be measured on a monthly, weekly, daily, or constant basis. *Functions* are possible contributions for patients or their relatives, regarding financial, functional, housework, transportation, or counseling issues. *Aggravating factors* correspond to other demands such as work, travel, small children and teenagers. The *crisis* refers to health deterioration, changing jobs, moving to a new house, loss or death.

Another example is stated by Hilbert (1990)[28], who posed the assessment of social support as an essential element in the interaction of human beings in situations of chronic illness. He defines it as helping caregivers to cope better with that experience of caring for their relative.

Meanwhile, McCarron (1997)[29] describes a support system for families with cancer patients; she establishes caregivers seek for professional help when their loved one is in pain, when the situation causes frustration and doubts are weighed down.

After studying each specific situation, this researcher highlights the importance of supporting families in creating a structured environment in coping with feelings of guilt, the meaning of each experience, control of adverse effects, questions about sexuality, feelings of depression, management of the financial burden and decision making when death is imminent. She also suggests, as relevant, encouraging families to seek for help and maintain a close relationship with each member of the family.

How to handle the burden of care

Within this interest of nursing in caregivers, it is essential to analyze the intervention on how to handle the burden of care. Researchers have proposed and demonstrated the effectiveness of different strategies to reduce caregivers' feeling of burden.

Clark and Standard (1996)[30] defined the multidimensional analytical model that studied the impact of the patient's situation in caregivers' life and its influence in the subjective perception of caregivers, when performing tasks perceived as burden.

Different categories may be measured based on this model, such as: categories of limitation, burden and impact, identifying situations and feelings, as the overwhelming and even stressful care giving responsibility. The relationship of the caregivers' role, stress, the negative effects affecting the caregivers' health and the care relationship should also be taken into account.

This model proposes interventions of support, guidance, approach and detachment techniques. The first one refers to the increased interdependence caregiver-care, new roles and definition of targets to find more altruistic rewards. The second one is related to increase support networks for establishing physical and psychological distance between the caregiver and the family, in order to ease the burden.

Strategies for Caregivers

- To ask for explanations of what it is unknown or not fully understood.
- To determine the actual capacity of independence of the person cared for.
- To ask for help from other family members preventing a burden.
- To carefully assess resources and needs for home care.

- To obtain information about support groups from people in similar situations.
- To rest from time to time or take some time off.
- To join support networks.
- To find meaning in the responsibility of care.
- To make decisions in a systematic way.
- To accept the person cared for as he/she is now, not as he/she used to be.
- To balance protection and autonomy of the person cared for.
- To recognize their own needs as caregivers, as it is important to recognize them when caring for another person.
- To learn how to handle and deal with frustration.
- To discuss the revival of feelings of loss, on specific situations.
- To share knowledge on family and community management.
- To develop networks of care with families and close social groups.
- To deal with feelings of guilt, worthlessness and hopelessness.
- To identify realistic ways to support the person cared for.
- To be ready and supported by an emergency network to meet unforeseen situations.

When there is evidence of negative effects, caregivers must accept they need help and also that asking for help is not a sign of weakness. Nurses can be mediators to guide the family, facing the decision-making process.

It is necessary to seek opportunities for caregivers to express their feelings and concerns to the entire family, to be motivated to make joint decisions coping with the chronic illness and the person cared for.

The suggestion is to guide caregivers towards a healthy lifestyle, which allows recovering from fatigue and stress, encouraging them to get enough sleep. If they cannot do it at night, they need to rest during the day when their relative is resting; caregivers also need to exercise on a regular basis, avoid isolation and leave then house and look for relatives, friends or individuals who can help them out in their caregiver tasks.

One of the most important things is to learn to feel good. This is not to eliminate negative feelings, it is just natural that negative feelings come up, but just be aware of them recognize them in order to learn to control them. For example, take time to solve problems, address them one by one, look on the bright side of things, keep a good sense of humor and move away from feelings of guilt as a result of not addressing the patient's needs and demands or involuntary mistakes.

It is also important to relieve sadness and depression, by identifying the situations that caused them in order to avoid them and perform activities that are rewarding (reading, chatting with friends, listening to music, watching TV), in a good measure.

Caregivers should join other people and families living in similar situations, this promotes support and knowledge on possible solutions, anticipating difficult situations, preventing problems and making future plans for decision-making prior more critical situations.

Finally, the spiritual welfare, it is a key factor in difficult situations that provides resistance, guides people and gives meaning to life. Each family takes the spiritual field on their own way; the most important thing is acknowledging it. Experience shows that without the spiritual welfare it is not possible to face the suffering of a chronic illness appropriately.

2

Current situation of family caregivers

Characterization of family caregivers in Latin America

Lucy Barrera Ortiz
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In Latin-America, chronic illness is in the top of morbidity and mortality along with acute illnesses; these factors tend to increase. Thus, non-communicable chronic illnesses (NCD) have been documented in recent years to be increasing[31] as well as some advances in their diagnosis and management[32].

New provisions at health institutions have a problem: the supply of services does not meet the real needs of users (patients and families); in many cases users are excessively vulnerable and they are even required to pay an unnecessary cost that involves their life quality.

Fortunately, Colombia has become aware of the problems generated by NCD and their impact on communities' health. Therefore, strategic interventions are under study in order to modify some main risk factors[33].

Similarly, specific programs were proposed and implemented, both domestically and some others along this region, which are important advances in this field[34]. Although, real diagnosis of NCD problems are analyzed and there is a higher number of assistance programs that support patients and their families in this situation.

Efforts to treat the illness are rare and, in most cases, they do not include family caregivers, who go through the biggest impacts along with patients.

Therefore, this research has focused on acknowledging, through common characterization, caregivers of patients with chronic illness in Latin-America in order to provide a more effective response to their needs.

Method

Characterization emerged as a mechanism to understand family caregivers of patients with NCDs, calling to integrate efforts among nurses and other health professionals. The main purpose is to get closer to the people involved and their efforts, in order to offer a social response and seek a semantic agreement that supports conceptual and operational progress. The objective is to visualize common work facing the challenge of family management of individuals with NCDs.

Therefore, with this purpose in mind and based on regional research during a decade, the *Research Group of Universidad Nacional de Colombia on caring for patients with chronic illness and their families* consider these topics as key ones and that they all should be included in studies related to caregivers of patients with chronic illness at a regional level.

The development of this characterization scheme was conducted with full ethical surveillance, such as observing and analyzing before starting each research approach. The input was important to qualify nursing care; to give participants information about the project's objectives, methods and usefulness of results and also making sure participants know that their participation was voluntary.

Information on each case had a confidential approach; it had an institutional endorsement and juries' approval. On the other hand, work and feedback on this proposal was collective, with nurses from each participating country.

The caregiver's role towards the person with NCD in Latin-America has some defining characteristics; despite similarities with other regions, this role has characteristics that somehow make it unique and different.

For this reason, it is necessary to answer who, how, and how many these caregivers are, through a characterization analysis. Hence, the final product of this work is the use of a theoretical proposal through a characterization analysis.

Results

These results have two components: First, a tool design to identify family caregivers in Latin-America. Second, identifying the results of applying this instrument in some studies conducted in seven Latin American countries.

The following are the components of this tool and the results of its application. By the end, it includes the format of a conclusive characterization of this research study.

Gender

This instrument proposes to analyze the caregiver's gender as there are significant differences between a male and a female caregiver. There are also different social implications on who plays this role.

In general, men's behavior tends to be more rational; women's behavior is more emotional. They usually care for their children, parents, and husbands', which makes social acceptance of their role a lot easier. Moreover, female caregivers are characterized by caring more carefully, providing a better quality of life style to the person cared for. However, evidence shows that men tend to be heard in difficult situations and touch others in their role as caregivers.

These research findings confirm that, the caregiving responsibility generally falls on *women:* eight out of ten family caregivers are women[35]. In most cases, they must address the needs of patients with NCDs and also those of the rest of the family.

Women most often provide personal and instrumental care and are more involved in inspection and surveillance tasks. They also take on the hardest daily tasks and the ones that require a higher dedication.

Claudia Jácome[3] is a devoted caregiver. She has cared for four relatives. Nowadays, she is caring for her brother-in-law, who has a deep wound in his chest after an open-heart surgery. Claudia is a smiling and energetic woman, who does

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[3] Her name has been changed to protect her identity.

not hesitate to say that she would care for more people who may need help. She explains: - “*I’m moved when I see someone suffering*”.

She has a clear vocation, will, and patience. *"At critical nights I always attended her,"* she says referring to her mother, who died from diabetes complications. Claudia knows she has been deprived of lots of things because of her work, but she confesses she feels a great satisfaction to provide care; she even got away from her own children, they chose to leave, because their mother was not usually there.

For Mrs. Jácome it is clear that people need her help and that *"not everybody has the fortune of having an ill person to care for"* she states.

There are lots of women like Mrs. Jácome, who is extremely devoted, caring for chronically ill people. Strangely enough, women are more willing to do so.

Therefore, it is not surprising that older people to be cared for in Latin-America live with their families; when they have enough financial resources, family care is supported by external women working in domestic service, who -most of the times- do not have health insurance service[36].

Cultural notions about male and female roles may influence this responsibility. For women over 60 and men over 75, it has been found that their daughters or daughters-in-law are the ones providing the main resources, both in everyday activities as well as in illness or other kind of crisis.

These findings also indicate that men are more supported by their wives than vice versa. A woman tends to marry an older person, affecting spouse functionality.

Apparently, one of the reasons why most caregivers are women is that they are better at providing care, since they have more ability regarding abnegation, suffering, and generosity.

Despite the predominance of women in the field of care, men are progressively participating in care tasks nowadays, which indicate a continuing change of this situation.

Age

The tool proposes a classification according to each person's age that separates -legally- minors, young adults, older adults, and the elderly.

The studies conducted with this instrument showed that the dimension of care is experienced differently when the caregiver is less than 17 years old. For example, activities may be very well developed thanks to their physical ability, but at the behest of their personality development.

Minors tend to have more courage to take risks, but their perseverance tends to be lower from that of older people; for them caring for someone, is simply a function that can be taken on when they want to, without feeling a real commitment to their relative. For some others, it means abandoning their school or to do it in extremely difficult conditions, without enjoying the advantages of this period of life.

People from 18 to 35 years old -productive period-, had projected goals for their lives, and now they feel frustrated, in many cases. Caregivers are also starting their parenthood stage, which implies most of their energy. Therefore, patient care competes with their main responsibility as parents.

Caregivers from 36 to 59 years old have been referred to as the *"sandwich" generation*. Although, this group reflects more serenity and experience, the caregiving task is accompanied by job roles and, sometimes, the upbringing process too. It is important to highlight that the young Latin-American culture usually live with their family until they get married or become independent after being financially sound.

Regarding older caregivers, as they get older, people begin to have a more vulnerable health status, which may be affected because of the care burden. And it is the "work" of caring that includes personal and instrumental care, monitoring, and supervision. Likewise, management and the relation with health services imply also to provide emotional and social support. To sum up, *'to be in charge of'* the person who is being cared for"[37].

The age relationship of the caregiver-patient binomial was also included within the instrument, as it is important to know if the caregiver is either older, about the same age or younger than the care receiver. This information allows us to study an aspect of each person's problems in the care relationship, as well as potential strengths in the social support systems that are implied, especially within the family.

Research findings indicate that caregivers, in most cases, are younger than the person cared for. Mothers usually are children's caregivers. There are also differences in children[38] care, adults[39] and elderly[40], especially regarding the kind of social support available for each group.

Educational background

Acknowledging the level of education is also important within the Latin-American context. We must think that the basic levels of education provide strengthening of personal and social relationships, thus, social integration. Making sure that a person can read ensures an accurate management of medicines and other aspects of care that are often communicated through written prescriptions.

It is common that older caregivers from low socioeconomic layers are illiterate. Studies with this instrument show that the highest percentage of caregivers has a low or middle schooling, which means an incomplete elementary or high school level. In some cases, caregivers who cannot read or write have also been identified[41], which generates a constant challenge to work for better access to information.

Marital status

To include marital status in the characterization analysis provides valuable information in order to know the caregiver's basic social network. A young caregiver, looking for a stable romantic relationship, is quite different to a female caregiver who has a consolidated or dissolved relationship. Caring is also different when the caregiver has had a previous loss experience, i.e. in the case of widowhood.

There is evidence in this research that most caregivers live with a couple. For many caregivers, besides their responsibilities towards the person they care for, caregivers should take on their wife or husband, mother or father, daughter or son role and have functions within a family group, which requires also dedication and time[42].

Having a couple is a support factor for many caregivers, for example, when making difficult decisions, but sometimes the couple is very demanding and makes it difficult for caregivers to comply with their role.

Profession

There is a direct relationship between the caregivers' profession and their caring ability for another person. Some caregivers have "service" professions and have the characteristics that care requires. Some others, however, reject this kind of work.

For those caregivers who stay at home, their routine does not change drastically; fatigue often becomes more noticeable, even though they have more time available. Those caregivers working independently at home have more contact with the person they care for, different from a student or an employee, who has very limited time to provide care. Then, some caregivers have to quit their jobs or change their lives to take on caring tasks, which implies changes on personal development, self-esteem and social support. There are also financial consequences, which become more critical in financially disadvantaged caregivers due to the increase in the costs of care of people with NCDs.

On the other hand, exclusive dedication to care will lead to a restriction of social life: avoiding going out with friends, getting closer to family members. Caregivers with more demanding jobs do not even have time for their own care, neither to perform other tasks nor to manage their own time.

Socio-economical Background

It is necessary to know the patient's socioeconomic situation because caring is different when the minimum necessary requirements are available and when they cannot be fulfilled.

In this regard, we have documented the socio-economic difficulties generated by care and how hard the situation is with these limits. The instrument used in this research included the socio-economical stratification as an objective parameter within the Colombian population. In countries that do not have this criterion, it was modified by the social classification used in each country.

This research shows that chronic illness affects all social strata and there are similar numbers of caregivers in high, medium and low social strata.

Continuity of care

A basic aspect of care reciprocity[43] is: knowing the person who is cared for and knowing oneself. If the caregiver accompanies a person with NCD since the diagnosis, he has continuity in the process, and a better knowledge consequently. When a caregiver has been intermittent, he/she should obtain as much information as possible, maintaining positive routines and trying to avoid negative experiences.

The application of this research instrument indicates that in most cases family caregivers of NCD patients have continuity in their care duty.

Care time

It is also important to identify how long a person has taken on his/her caregiver role; this aspect influences the level of knowledge. Differences in perceptions of the caregiver role change throughout different periods and variations; more importantly in the first six months. Several authors point out different stages in the process of chronicity, which validate the implementation of this instrument.

Burden Perception

To feel that the situation is very demanding or too long may be psychologically and physically catastrophic. Assessing the family caregiver’s perception on the care burden is evidence that several individuals are engaged in this work for twelve or more hours, seven days a week and they have lived with it for over a year. Therefore, fatigue and stress are more evident.

Relationship

It is common for Latin-American families to be directly in charge of the care task. The difference among family ties implies a variety of relationships and feelings, to the level that the experience of care varies greatly depending on the kind of relationship between people with NCD and their caregivers. For example, care is different when there has been a previous positive experience with an ill person than when it has been negative one.

In the relationship between spouses when one member of the couple suffers deterioration in health and needs help with daily life activities, the primary caregiver is usually the one in better health condition, even though his/her health condition may also deteriorate throughout the process.

For children there is filial love or a big responsibility feeling, which ensures a more lasting care. Thus, in any life situation involving change, caring for a relative is difficult and requires constant adaptation, which can create tensions depending on the degree of reciprocity in the relationship.

However, in this culture, it is easier to accept help from a very close person or relatives than that of friends, neighbors and institutions, as it is perceived as an obligation or a sign of affection. Nevertheless, familiarity does not rip the sense of privacy or intimacy apart, especially in cases of female caregivers who resist seeking or receiving help from others.

- *"My mom had a hard time accepting us changing her diaper. This was one of the most difficult things ever. Then, she ended up accepting it, but she prefers us women to do so, not men"* says Martha Lucia Alba, who has cared for her mother for over nine years.

When care comes from children to parents, it represents a strong emotional impact especially for the elderly. Accepting that parents cannot fend for themselves and it is necessary to take on a reverse role. Deciding where, when, and how, to invest effort and energy is difficult, especially with high demands for help from people who are cared for. The application of this instrument in different countries of Latin-America reflects a match in this feature.

Functionality of the receptor

It has been documented the fact that: at a lower functionality rate a higher burden and feeling of depression. Therefore, acknowledging the level of functionality helps to have a clear perspective of the caregiver's difficulty or opportunity within care.

In the characterization that was carried out, the care receiver level of functionality was included and reviewed through the PULSES scale[44], as it is applicable to all ages. It is a practical scale that can be applied by either the caregiver or by the health professional.

The application confirmed its broad applicability and indicated heterogeneity in the participant's levels of dependency.

Diagnosis

Knowing the medical diagnosis allows to register NCD in health systems. This is key information in order to organize support groups with similar problems. Application of this instrument reflected a broad agreement on the region's epidemiological profile.

Debate

Knowing the characteristics of caregivers has promoted to develop a profile of this population in Latin-America. In terms of gender, it is mostly represented by women, most of them in their working age, who are in charge of multiple roles.

Family caregivers mostly care for seniors, even though chronicity of young people tends to increase. Many caregivers do not have good reading and writing skills; schooling tends to be rather low. Their marital status shows that they often live with their couples, which sometimes means they don't have a chance for a break.

Their daily work is affected by their care role and many of them even lose their jobs and end up devoting themselves to home care. Their socioeconomic status is varied and there is particular difficulty in the lower layers of society, where financial concerns are common when dealing with this situation.

It is common for caregivers to be alone and have been caring for their relative since the beginning of the situation, which gives them good understanding of care management. Care time varies from one situation to another, but care time for those caregivers in this research tends to be for over eighteen months, leading them to feel a burden, reflected in the number of hours devoted to care, which tends to be higher when there is not enough support.

In many cases, people are cared by parents, spouses and children; their functionality varies, caring for people with moderate to severe disability is the most frequent scale. The top medical diagnoses are: secondary chronicity due to accidents, cardiovascular illness, cancer and respiratory illness.

This draws to the conclusion that it is extremely important to reach semantic agreements in the Latin American region in order to establish groups' profiles interested in nursing care. One of these sources must be family caregivers of people with NCDs, in order to understand and respond appropriately to caregiving, to promote the creation of public policies and health education in this field.

The following is the characterization instrument designed by the *Caring for patients with chronic illness and their families Research Group at Universidad Nacional de Colombia* in order to analyze family caregivers in Latin-America. It was implemented by researchers from seven Latin American countries in order to test its usefulness.

INSTRUMENT

Characterization of caregivers

1. GENDER
☐ Male
☐ Female

2. AGE
☐ Under 17
☐ From 18 to 35
☐ From 36 to 59
☐ Older than 60

3. TAKING INTO ACCOUNT THE PREVIOUS AGE GROUPS, THE AGE
OF THE CARE RECEIVER (Patient) is:
☐ Older than the caregiver
☐ The same age range as the caregiver
☐ Younger than the caregiver

4. THE CAREGIVER CAN READ AND WRITE
☐ Yes ☐ No

5. EDUCATIONAL BACKGROUND
☐ Incomplete primary school
☐ Completed primary school
☐ Incomplete High school
☐ Completed High school
☐ Technical degree
☐ Incomplete Undergraduate studies
☐ Completed Undergraduate studies

6. MARITAL STATUS
☐ Single
☐ Married
☐ Divorced
☐ Widower
☐ Common-law marriage

7. PROFESSION
☐ Housekeeper
☐ Employee
☐ Independent
☐ Student
☐ Another ______________________

8. HOUSING SOCIO-ECONOMIC STATUS [4]
☐ Stratum level 1
☐ Stratum level 2
☐ Stratum level 3
☐ Stratum level 4
☐ Stratum level 5
☐ Stratum level 6

9. DO YOU CARE FOR THE CHONICALLY ILL PERSON SINCE THE FIRST DIAGNOSIS?
☐ Yes ☐ No

10. HOW LONG HAVE YOU BEEN A CAREGIVER
☐ From 0 to 6 months
☐ From 7 to 18 months
☐ From 19 to 36 months
☐ More than 37 months

11. No. OF HOURS YOU THINK YOU SPEND IN CARE EVERY DAY
☐ Less than 6 hours
☐ From 7 to 12 hours
☐ From 13 to 23 hours
☐ 24 hours

12. ARE YOU THE ONLY CAREGIVER?
☐ Yes ☐ No

13. WHAT KIND OF SUPPORT DO YOU HAVE?
____
____
____

14. RELATIONSHIP TO THE PERSON CARED FOR
☐ Wife / Husband
☐ Mother / Father
☐ Daughter / Son
☐ Grandfather / Grandmother
☐ Friend
☐ Another ______________________

15. PULSES
☐ 6-8
☐ 9-11
☐ 12-24

16. PATIENT'S DIAGNOSIS: ________
____
____

Reference: Universidad Nacional of Colombia, School of Nursing, Research Group on care for patients with chronic illness and their families

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[4] *Translator's note:* Colombia's social strata has been divided as follows and has been extensively used by the government:
Stratum 1: Lowest income.
Stratum 2: Low-Middle class.
Stratum 3: Middle class.
Stratum 4: Upper middle class.
Stratum 5: Upper class.
Stratum 6: Wealthy.

The family caregiver's caring ability for a person with chronic illness

Lucy Barrera Ortiz

The person with chronic illness lives a particular situation, involving the family and specifically the main caregiver; this commitment requires the development of an ability to successfully meet those wide caregiving demands.

In this chapter the caring ability is presented as well as the *"Caring for caregivers"®* program, which was developed to strengthen the caring ability for patients with chronic illness based on specific definitions and interpretations; this research product was coordinated by the School of Nursing at Universidad Nacional de Colombia in different parts of Latin-America.

Caring ability

Skilled caregivers are those who get to know their care receiver, understanding the person with the illness is dependent on the caregiver. Caregivers are also the ones that get to explore and use their own abilities in a situation of caring for a chronically ill person.

There are several definitions aiming to incorporate the concept of ability, they include: the competence degree of an individual facing a specific objective or the innate ability or acquired ability to perform an action, ability to execute it, and the ability and willingness to negotiate and achieve objectives. Abilities depend on -internal or external- motivational capacities and factors.

Care provided by the caregiver has been described as: a human characteristic, an obligation, an affective interaction, an interpersonal intervention or a therapeutic process[45]. Moreover, the caring ability is defined by authors such as Schumacher and Stewart (1998) on parameters that include *self-efficacy*, *competence, preparation* and *quality*[46].

The expertise of care is understood as a positive view regarding skills and behavior during the process of caregiving; it includes feelings of competence, satisfaction and well-being regarding tasks. It is associated with specific needs that require assistance from the caregiver.

Caregiver's self-efficacy

The caregiver's self-efficacy is defined by Haley et al. (1996) as the confidence towards the management of the care receiver's disabilities and behavioral problems; this definition is derived from cognitive appraisal and management of stress theories in terms of sensible aspects that caregivers consider regarding care and their own lives.

The competence to care

Pearlin et al. (2002) describe competence as the adequacy of caregivers in performing their role, what they can do, the appropriate aptitude regarding a specific state of being. The authors analyze competition through questions like: How much have you learned about the treatment in a difficult situation? Do you consider yourself a good caregiver? How safe do you feel?[47].

These questions may also focus on the degree of cognitive development and ability to perform tasks and cope with stress derived from the caring activity.

The quality parameter

Levine et al. (1997) define it as the degree of excellence that the caregiver offers to the care receiver, reflecting their interaction, generating mutual growth. Hence, caregivers count on knowledge, abilities and resources necessary to fully provide the required care.

During the care experience routines are set and activities have meanings and outcomes of satisfaction and wellbeing. In this setting, actual and potential problems are identified in order to generate actions, preventing and solving problems.

Phillips et al. define the *quality* of care as the degree to which those identified needs are met, including six dimensions: maintenance of the environment, provision of physical, medical, psychological care, respect for human rights and financial management; these are evaluated on a scale that include three subscales, they are: environmental, psychological and physical. This assessment prepares a training protocol for caregivers.

It is important to determine that the caregivers' ability is conditioned by their knowledge and by a possibility to change attitudes, values, beliefs, experiences and feelings over time. In general caregivers' ability depends on many factors, among them: responsibility, the family role as father/ mother, son, daughter, brother, sister, experience, personality, support, time, acceptance, patience, and feelings in relation to the experience itself.

The skill care acquisition was analyzed under the model of Benner (1984)[48], which is described in the following five levels.

1. Beginner: they have no previous experience with the situation that must be faced. Therefore, there are difficulties to differentiate relevant and irrelevant aspects.
2. Advanced Beginner: they may have an acceptable performance, at least partially, being in charge of the caring responsibility, sometimes, based on the guidance from others; they have enough experience to master some aspects, but have trouble controlling them from a broader perspective. At this stage, they feel immensely responsible of care giving, but they truly rely on advice and intervention from others.
3. Competent: This level is characterized by a conscious and deliberate planning. These caregivers are able to determine what current and future situations are important and which are not, developing new standards and procedures based on inputs and outputs.
4. Efficient: these caregivers perceive the situation as a whole and are more skilled than competent caregivers; they are able to recognize the main aspects and have an intuitive control of the situation thanks to previous information.

5. Expert: they have the ability to recognize the situation, but not only based on rules. They also have an intuitive control and are able to identify the source of the problem, without wasting time. They understand the situation, needs and implications of care, from a previous experience.

Benner points out those indicators determining the scope of each of these levels that are taken from practice and are reflected in the changes that show the acquisition of abilities. There is a transition from just relying on principles and rules to use the specific and previous experience, going beyond analytical thinking, acquiring intuition through analyzing the entire care case.

Skilled caregivers move from being individual observers, outsiders, to take a stand on it, which is reflected in decision-making, leading to a more appropriate activity.

More information on the caring ability

The international Nursing Outcomes Classification of Care (NOC[49]) illustrates that the caregivers' ability is very complex; it is related to the role they adapt to, their decision making, responsibility for direct care, supervision or accompaniment and the development of tasks that vary throughout different scenarios in which care is provided.

According to their statements, caregivers hold the leading role in home care and must have preparation enough for this responsibility and willingness to do so. Knowledge on the illness and its development is fundamental to take on the caregiving role, as well as its medical treatment, how to implement and manage it, prescribed activities, required monitoring, possible emergency situations, financial resources, when to contact health professionals, to identify social support networks, information on equipment acquisition and usage. Positive reward demonstration by the care receiver is also part of this ability[50].

Caregivers' satisfaction has been analyzed under the same classification, including indicators such as sense of control, self-esteem, lack of feelings of anger, resentment, guilt, depression, frustration, burden and ambivalence. Likewise, issues such as feelings of certainty about the future, the perception of connection, of available social resources, spiritual wellness and non-use of psychotropic drugs. The use of financial resources, relationships with other family members, social interactions and relationships with friends, and even with pets are also analyzed[51].

NOC also has tools for assessing the skill in the caregiver-care receiver relationship, which include indicators such as effective communication, patience, harmony, calm, assertion, companionship and caregiving attitude. Furthermore, there are the long-term commitment, acceptance and mutual respect, collaborative problem solving, and sense of responsibility[52].

Similarly, there are proposals on the NOC classification that evaluate the ability and the caregiver's potential of persistence, through the analysis of: the mutual satisfaction of the caregiver- care receiver relationship, expertise in direct care activities and in the use of services required by a care receiver, the caregiver's social supports, resources to provide care and the possibility for the caregiver to have a break and the opportunity to rest[53].

As for the caregiver's performance -according to the same international classification of nursing- the confidence in solving problems, recognizing changes in the care receiver's health status, the ability to anticipate to their needs, getting and monitoring necessary services are fundamental. Solving problems and being confident in performing required tasks is considered part of this performance[54].

The NOC identifies sources of stress reported by caregivers as follows: physical, psychological, cognitive, abnormalities in social interactions, perception of a lack of social support, lack of time to rest, change in the work routine and severity in the alteration of the caregiver-care receiver relationship[55].

Caregivers' physical health is reflected, according to NOC, in the patterns of sleep, blood pressure, energy level, physical comfort, ability to move, resistance to infection, physical function, weight, gastrointestinal functioning, medications, available services and general health perception[56].

Additionally, the caregivers' adaptation to hospitalization of a loved one is evident in the confidence they have towards other colleagues, keeping up the desired control over care, participation as desired and the maintenance of the relationship caregiver-care. Besides, communication with caregivers' agencies, sharing their experiences about change, releasing their guilt and anger feelings, the use of conflict resolution methods, the feeling of comfort with role transition, the ability to consent required treatment, the supply of items that give comfort to the patient and communicating care needs not verbalized by the care receiver[57].

Some of the established indicators to assess the caring ability are: those of direct performance, providing social support to the patient, assistance with daily life activities, awareness of the illness development, treatment plan and its implementation, monitoring the care receiver's health status, the anticipation of needs, being unconditionally positive and having confidence in performing those required tasks[58].

Finally, there is that measurement on the caregivers' caring ability proposed by Nkongho (1999), based on a phenomenological study which included the Caring Ability Inventory (CAI) [59]. It quantifies the degree of ability of care that a person can have with others. Its development was based on a care concept proposed by Mayeroff as a relationship that must comprise knowledge, changing rhythms, patience, honesty, trust, humbleness, hope, and courage.

According to this author, skilled caregivers go through a sense of belonging and connection and are also stable and resilient to stress; they admit, through building the inventory that people feel and behave differently in relationships with others so there may exist or not a caring ability.

For her, this level of knowledge is useful for planting strategies, in order to guaranty the required care for a dependent person. Nurses, she says, identify the affective side of the caring, so the patients get more focused in the tasks that they do. This distinct perception may reflect the immediate needs for the ill, by contrast with the long-lasting terms that carers could have.

Care, which is always associated with a human expression of survival, is only deployed in the caring ability. Who had been cared is generally the one able to care. As Rogers express, quoted by Nkongho (1999), the grow it enables is mutual, sensitive, and sympathetic, and must keep in mind at least three elements: who helps' authenticity, positive recognition to the other person and the empathetic comprehension.

These three conditions can be observed in any caregiving relationship such as parent-child, teacher-student, manager-personnel and therapist-client.

Based on four assumptions underlying the Caring Ability Inventory Nkongho argues: that it is multidimensional, with cognitive and attitudinal components, all individuals have the potential to be caregivers, and people can learn how to provide care and that caring is measurable.

The proposed Caring Ability Inventory recognizes the need for human survival through its 37 items, organized into three categories, originally presented by Mayeroff (1971): knowledge, courage and patience. The inventory can identify if different people have these dimensions in high or low proportions, so those with high proportions can be role models or mentors for those with rather low ones.

This caring ability is more important in some situations and professions than others. Therefore, the author recommends the inventory as a vocational guide and as a counseling tool for those who want to take on roles that involve care abilities, such as family caregivers of patients in chronic illness situations[61].

Studies on the caring ability

The *Caring for patients with chronic illness and their families Research Group at Universidad Nacional de Colombia* has been interested since 1996 in recognizing the caring ability of family caregivers under Nkongho's proposal, to illustrate, confirm or complement those approaches described and, more significantly, to establish a diagnosis in different settings and scenarios in Latin-America. The following is a brief summary of some of these works.

One of them was to develop the ability in family caregivers of children with cystic fibrosis. The results show that although some parents have roles in their children care, the majority of caregivers are women, they are usually mothers. Men tend to get tired easily and many of them look for substitutes in difficult situations. Women, particularly mothers, tend to be more persistent in care and in their attendance to support and guidance meetings (Barrera, 1994-2001)[62].

On the other hand, this study showed that caregivers have a feeling of frustration and hopelessness as well as difficulty to find effective support among them. The creation of groups' sessions has promoted the possibility of social pressure to seek better attention and achievements in some medicines' prices. There are common feelings in their problems because they realize there are other people going through similar difficulties with their children and that a person different to their own family is interested in understanding their pain.

Despite this possible source of social support, those crises, stress and emotional upheavals make them very vulnerable to have difficulties within the relationship.

Parents appreciate the nurse's help, as it facilitates meetings; they feel the nurse cares about them, guides them in how to handle situations of illness, how to deal with it and what to do in order to enhance self-esteem.

Nevertheless, together with their nurses, parents assert there are difficulties in working with support groups for parents of children with cystic fibrosis because of the cross-infection risk among children. For this reason, they cannot meet with all family groups. So, now there are meetings at home in response to the reality of people in this situation.

Another aspect reported by Barrera is that in their efforts to change the course of their children's disappointing evolution, caregivers endlessly seek alternatives different from medicine that so far, do not offer the expected solution. Thus, many caregivers take on overprotective behaviors in their fear of losing their children. Mothers experience anguish over the minor's death, abandoning themselves and even forgetting other family members, they tend to break their relationships with their couples and they no longer socialize.

For this reason, in most cases, children are dependent on their age care or health conditions and this dependence is a prominent feature of their personality. This situation is very worrying because it limits their socialization and development possibilities[63].

In a study on families' lifestyles, Barrera (1998)[64] found another important element to understand the caring ability. According to her, caregivers, most of them women, are the decision makers on nutrition for all family members; they have basic information about healthy lifestyles, but their behaviors are more associated with culturally learned patterns.

It was also identified that in nutritional patterns of school children there are important differences from weekdays to weekends, as the presence of the mother at home implies a different behavior for the family. Weekday's decisions have more to do with the intervention of teachers. For this reason, the author suggests that when changing lifestyles both parents and teachers must be addressed as caregivers of children and that there is a need to identify inherited cultural patterns, otherwise, there comes a conflict that eventually will affect the caregivers' caring ability[65].

In Cuervo's research (1998)[66], aimed to understand the perception of caring behaviors, it is stated that it may vary from caregiver to care receiver. This study compared the perception of care behaviors among patients with their nurses and assistants in the Emergency Department of La Victoria Hospital, in Bogotá. It was found that both groups had few common priorities.

The group of patients provided quite homogeneous answers, saying that it was a priority for them to be treated like real human beings; they should be called by their own name; that they should be told in advance about their medical procedures, and feel safe that a qualified individual is being responsible for their care. For the group of nurses and nursing assistants, the priorities in care behaviors were not so similar; some of them stated that fair and humane treatment was important, but some others valued more formal aspects, such as the ability, technique, punctuality, training, etc.

Sanchez (1998)[67], and Pinto and Sanchez (2001)[68] in their work with people experiencing -actual or potential- chronic illness, argue that the caregiver's ability is the key for the care receiver's feeling of well-being. In their first research, caregivers mentioned they are concerned regarding difficulties with loneliness, lack of accessible health services and the costs of treatments. In the second research, it is clear that family behavioral patterns in health depend heavily on cultural models that have been modified by environmental influences, where there are more threats facing a healthy lifestyle that may prevent or delay the development of chronic illnesses or reduce their impact on functionality.

These authors report that it is necessary to strengthen family caregivers' abilities and to work on proposals that include interaction with the environment, all of them focused on encouraging behaviors that minimize known risk factors in the symptoms and complications of chronic illnesses.

Through Pinto's research study (2000) at the Instituto de Seguros Sociales[5] in Cundinamarca, it was found that caregivers, mostly women, required guidance to improve caregiving, as these caregivers do not know how to enhance their care giving abilities.

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[5] *Translator's note:* Instituto de Seguros Sociales is a governmental entity providing health services and pension plans in Colombia.

Patients reported that their lives and those of their caregivers had been modified; they even had to reorganize everything. Caregivers often abandon themselves, establishing new routines and look for support; it is a new experience as they did not use to require this support before. This author states that the supports required by patients with chronic illness and those of their caregivers are of a specialized nature related to spiritual, social, psychological and physical levels.

Many of those patients interviewed by Pinto reported that the essential support for their own and their caregivers' welfare had been of a religious nature through prayer groups. They also reported that their caregivers had a great relief derived from calls and monitoring of health institutions, which in many cases means a significant rupture[69].

On the other hand, in Camargo's research study (2000)[70] regarding the experience of living and caring with a chronic illness situation, and Macias et al. (1998)[71] explore the concept of totality. They studied those life stories of patients undergoing hemodialysis and proved that the caregivers' presence, attitude, and skills are key elements as part of their environment and welfare for people experiencing chronic illness.

Galvis (2001)[72] and Romero (2001)[73] reported similar findings in their research studies in Villavicencio, Colombia. They analyzed social support for patients with chronic illness and found that family members acquired a leading role in the life and care of these individuals.

Meanwhile, through another research study in the same city, Pinzón (2001)[74] links those perceived social supports to the coping ability of ill people and found no statistically significant relationship among variables. However, its conclusions supported the findings of previous researchers.

Silva and Cardona (2001)[75] established similar findings when they observed the patients and nurses' perception of care behaviors at the Intensive Care Unit of Santa Clara Hospital, in Bogotá. Along with Cuervo, they also detected a higher homogeneity in the views of patients than that of nurses. Although their research study used a different instrument, patients pointed to the humane treatment and the ideal company as a priority in caregivers' behaviors.

Meanwhile, Alvis et al. (2001)[76], in the same line, aimed to describe the experience of receiving humanized care in adults that had been recently hospitalized. People reported that in humanized care, the caregiver, being a nurse, has behaviors such as greeting using their names, keeping eye contact, being warm, friendly, kind, addressing the patient's family, being proactive and demonstrating the ability, which makes them feel they are in good hands.

Another research study with caregivers of children in situations of neurological chronic illness, Pinto and Barrera (2002)[77] argue that parents' ability to carry out caring tasks can be increased with knowledge of the situation, stress management, and by looking for effective support.

Moreno, Torres and Vargas (2002)[78] measured the caregivers' caring ability with hospitalized patients at the Instituto de seguros Sociales, Clínica San Pedro Claver Hospital. They found that in general terms, they have a high ability performance, with the highest score in the *value* category and the lowest one in *knowledge*. Authors noted that despite these findings contrasted with the previous ones, it is an important contribution to the nursing work, as health education plays a key role in this field.

Barrera, Blanco, Figueroa, Pinto and Sánchez (2006)[79] identify a similar situation of behavior in three groups in an international research aimed to study the caring ability of family caregivers in Argentina, Colombia and Guatemala; it was conducted in a population of 270 caregivers, around a quarter of these caregivers have a high ability level, even though some others do not have an optimal level, which suggests more risks and deficiencies in care.

Despite these achievements, and some others under current development, there is still a long way to draw key paths in strengthening the family caregivers' abilities to provide care. This approach and its outcomes motivated to create the *Research Group on care for patients with chronic illness and their families* and validate the "Caring for caregivers" program®.

The caregivers' quality of life

Natividad Pinto Afanador (ɫ)

The caregiver's tasks take time, dedication, willingness, love and patience. Depending on how these aspects are handled the welfare of people is affected, hence, their quality of life, because not only patients are vulnerable to the chronic situation, but also their caregivers.

Quality of life (QOL) was defined from Aristotle[80], who regarded it as the pursuit of goodness, happiness or living well. In 1946, the World Health Organization described health as "a complete physical, mental and social welfare state" and defined quality of life as crucial welfare nowadays. Likewise, from research and politics, it requires patients and their families "quality of life" assessment, when the influence of technological advances is higher, as well as the increase of health care assistance of ill patients and survival rates[81, 82].

The quality of life became a priority in Western society after World War II; during the 1960's and 1970's surveys to describe quality of life were conducted in different countries, especially in the U.S. For Padilla, Grant and Ferrell (1992)[83], QOL is a multidimensional concept that is characterized by welfare aspects that are important to the person; it involves interaction among health and psychological, spiritual, socioeconomic, and family functioning.

Other studies define QOL as the difference between the actual lived experience and what patients want or the ideal state in which they wish to live. A study by Calman (1984) includes in its questionnaire an inquiry on the QOL of patients with muscle illness. Thus, questions were asked to patients for them to rate their current status in relation to their ideal state and the worst thing they could imagine happening in their lives[84]. Thus, it is possible to see the difference between what they wanted their life to be and what it actually was at the time.

For caregivers, QOL may be affected due to the problems that occur as a result of long and intense days of care. Losada et al. quoted by Roca, state that caregivers of patients with cognitive and functional impairment devote an average of 11 hours a day to caring responsibilities. In the case of family caregivers of patients with Alzheimer's, they devote from 60 to 75 hours per week[85].

Understanding QOL as a multidimensional concept[86, 87], the number of dimensions may vary, but in most cases, it includes those described above: physical, social, psychological, and functional health components[88, 89, 90], in addition to the multiple dimensions of a person's life, such as access to information, knowledge and development opportunities.

From this perspective, it also involves personal judgments, and mental abilities that at the same time are necessary to evaluate a person's level of satisfaction towards life[91, 92]. It does not mean a positive QOL just because it is based on what people feel when they are satisfied or dissatisfied. It is rather a dynamic concept.

Therefore, those long hours of work, stressful situations, high levels of functional dependency, the progressive deterioration of the ill person, the lack of formal or family support, the lack of care resources, the loss of family and social roles, and the lack of knowledge and experience to deal with care situations, lead family caregivers to live with a burden and constant fatigue that affect their QOL negatively [93, 94].

The evaluation of QOL throughout time is influenced by changes in the development of roles. Ferrans et al. defined it as "the feeling of well-being that comes from satisfaction or dissatisfaction with areas of life that are important for people"[95].

Since not all people share the same values system, it is an evaluation of what it is important or meaningful for each individual, whether it is positive or negative. Taking this concept in the caregiver's life, both effects are evident, and they contribute to the understanding between care and the impact that is generated[96].

Definitions of QOL include subjective and objective indicators of physical and physiological phenomena; some specific ones such as income, home maintenance and physical function are usually used as measures that in the end fail to show *how* individuals perceive and experience their existence. However, subjective evaluations define the experience of life more precisely.

By studying subjectivity, we must bear in mind that the way people feel or think about something is different and it is directly influenced by contextual factors. Some of them are cultural, eco-environmental, and risky regarding their physical and mental health.

At social and community levels individuality is transcended in addition to ties with others. For this reason, "quality of life is a relative concept; it depends on each social group and of what each group establishes as the ideal situation of welfare, as well as the access to a range of goods, services, rights and respect for a person's values".

Each group identifies its own trends in social terms of welfare. Therefore, it is necessary to differentiate different lifestyles, goals, ideals, ethics, and idiosyncrasies of social groups for analyzing each difference among them.

For example, in societies that have already met their basic needs in terms of goods and services, welfare goals are more oriented towards the personal, professional, family, and social, fulfillment of each social group. Thus, the concepts of welfare rely on their own standards, developments, and definitions of welfare. As it was stated by White: (2007)[97] values, desires, and ideals vary noticeably throughout time as well as within levels and layers built by social structures.

Quality of life would be historically and culturally constructed with values bound by the variables of time, space and imagination, with a degree and scope of development in each particular age and social group. Thus, it would be unrealistic to unify the criteria around it; it is a controversial concept that implies different definitions.

It is also necessary to think of quality of life within the chronic illness experience, especially when the person has a disability. The importance of social integration for an individual is an important issue, despite the diversity that distinguishes one individual from another. This approach may also be applied to a family caregiver.

Quality of life and caregivers

It is essential to recognize how the quality of life of caregivers is affected when they must learn to live with a person affected by a chronic illness. Caregivers are conditioned by different situations that require time and cause stress; there are no free Sundays or holidays to rest, particularly in cerebrovascular, cancer, AIDS, arthritis, multiple sclerosis, illnesses. Caregiving in these cases is a huge demanding task.

It is quite difficult to face the fact that a close person depends on you to continue adapting to daily life. In the vast majority of cases, caregivers unexpectedly assume this role. This is because most of the causes of dependence from patients with chronic illness involve slow and progressive deterioration associated with an increased need for help in daily life activities.

At the beginning of the situation, caregivers are not fully aware that they are the family members who will have most of the care responsibility and who will effort the most. Nor, that they are in a situation that may prevail for a long period of time and will possibly involve a progressively increasing commitment in time and energy.

Accepting the caregiver’s role, a more or less long process depending on many factors, is of utmost importance as it substantially influences the way in which care is provided and how the person feels about it. Life changes and reorientations are necessary so that caregivers are able to do what they like and want to do.

How is quality of life?

The *Caring for patients with chronic illness and their families Research Group at Universidad Nacional de Colombia* undertook a review of the quality of life of family caregivers and patients with chronic illness through the instrument developed by Betty Ferrell (1997): "Measuring the quality of life of a family member who provides care to a patient"; it identified four components or dimensions, they are: psychological, physical, social, and spiritual.

Physical well-being

It refers to symptoms control and relieve, as well as the preservation of functions and independence (including functional ability, physical health and general symptoms).

Psychological well-being

It is the search for control when dealing with a life-threatening illness; it is characterized by emotional issues, change of priorities and fear of the unknown, as positive life changes (it includes a sense of control, depression, fear and happiness).

Social wellbeing

It provides a way of not only approaching the illness and symptoms, but also to the person in context; it acknowledges the individual with an illness, relationships and roles; it focuses on negative family stress (sometimes stress can be positive), social isolation, financial issues, and sexual functions.

Spiritual well-being

It is the ability to keep on hoping and gaining meaning from the illness experience, characterized also by uncertainty; it involves the issues of meaning and life purpose, hope, uncertainty, and transcendence (Ferrell et al. 2002)[98].

The instrument of quality of life by Ferrell et al. evaluates this condition through 37 items, from a subjective perspective, out of which 16 are positive and 21 negative.

This instrument has a degree of validity and reliability of 0,89 and the consistency showed an alpha of 0,69 within the four dimensions. The evaluation of each item was carried out through the Likert scale of 1 to 4, for an adaptation proposed by this group to the author. The scale includes four items: (1) absence of problem, (2) somewhat of a problem, (3) problem, (4) a lot of problem, depending on the variable to be assessed. This instrument has been validated and used in a wide variety of research studies.

Since the family plays a meaningful role in the orientation of chronic patient care it is necessary that nurses in health institutions -even when the patient has not yet been discharged- nurses should encourage a shared caring activity with the family as much as possible, so that they all get ready for the future. This process should start as soon as the ill person goes home: they are to face unfamiliar tasks in the middle of a high vulnerability situation.

Diaz (1996)[99] research on patient's QOL reported an increasing prevalence of hypertension, depression and heart problems rather than controlled ones. Another important element in the relationship of chronic patients and their caregivers is that of violence and mistreatment. In the case of patients with dementia, they manifested physical aggression towards their caregivers, as a result of an organic disorder; there is also mistreatment and negligence from caregivers towards patients.

A study of 180 patients and 180 caregivers showed 17% of mistreatment and violence from caregivers towards patients and 4% of violence from patients towards caregivers.

Another research study, in Colombia's Department Valle del Cauca, measured the predominance of the caregiver's syndrome and caregivers' psychosocial characteristics of caring for disabled elderly. The APGAR family score results showed a high proportion of family dysfunction in caregivers -81.3%- and -62.7%- in non-caregivers. This could be explained by the presence of a chronically ill person at home[100].

At the beginning of the illness, families try to adapt and organize in order to meet their needs, but eventually, just one member of the family is the one supporting and responsible the ill person, devoting most of the time to direct care.

To sum up, the work of family caregivers is a commitment experience; it implies time and patience, skills, qualities and essential attitudes in performing daily life tasks for the family member. However, family caregivers may be exposed to changes in their own welfare due to the changes of their lifestyle.

Thus, social restrictions emerge, limitations on the use of free time and privacy, difficulties and discussions within their own family and even alterations in health; plus, feelings of loneliness, misunderstanding, oppression and depression.

These manifestations may be associated to the so called caregiver's syndrome: a stressful situation with high risk of overflowing and draining resources, affecting their health conditions, mood and modifications of the perception thresholds of the patient's pain and suffering [101; 102].

It has been documented that there are major changes in caregivers as well as health symptoms and problems such as gastritis, anemia, fatigue, insomnia, headache, back pain, malnutrition, depression, anxiety, and stress[103].

All this shows that the experience of care giving a person with chronic illness significantly affects the quality of life; it usually tends to deteriorate physical, psychological and social levels. But it happens to be different at a spiritual level.

Research studies on family caregivers' quality of life

The following is a summary of recent research on this topic, as shown by Peralta and Ortiz (2006)[104].

RESEARCH PROJECT	QUALITY OF LIFE OF FAMILY CAREGIVERS WHO CARE FOR CHILDREN IN SITUATIONS OF CHRONIC ILLNESS AT THE NATIONAL CHILDREN HOSPITAL BENJAMIN BLOOM, DEPARTMENT OF SAN SALVADOR, CENTRAL AMERICA, II SEMESTER 2003
Author(s)	Sonia Merino de Herrera
Assessor	Lucy Barrera Ortiz
Year	2004
Methodology	Descriptive quantitative study
Objectives	To compare the quality of life of family caregivers who care for hospitalized children in situation of chronic illness to the quality of life of family caregivers who care for children in situations of chronic illness who attend clinic consultation at the National children Hospital Benjamin Bloom.
Conclusions	– When comparing the quality of life of these two groups of family caregivers of children in situations of chronic illness, both groups showed behaviors that affect all categories of quality of life, with significant impact on their physical and psychological well-being; it moderately affected the social well-being and the spiritual had less alteration. – In comparison, the group A is more affected in the quality of life that the group B, especially in the physical and psychological levels. This change responds to the situation of burden and stress of the family member who is hospitalized. – The adult female family caregiver (group A and B) continue to have a primary role in the tasks associated with caring, even though this role has also increased in men. The situation was worrisome because as the demand for care has grown, women have had less chance to care for themselves and for others, experiencing higher levels of exhaustion, thus, their general physical health has been affected. – The fact that family caregivers of both groups are in their adulthood means having to fulfill several roles because they are at their maximum life project productivity and development. This condition has caused a vulnerable factor to live the devastating effects of stress, experience more subjective than objective burden, and therefore settle at an intermediate range of manifesting psychological disorders due to not having control of the things that happen in life, which affects life's fulfillment.

RESEARCH PROJECT	COMPARISON BETWEEN THE QUALITY OF LIFE OF FAMILY CAREGIVERS OF PATIENTS WITH DIABETES WHO ATTEND THE HOSPITAL INPATIENT SERVICE TO THE QUALITY OF LIFE OF FAMILY CAREGIVERS OF PATIENTS WITH DIABETES WHO ATTEND AN OUTPATIENT'S PROGRAM AT HOSPITAL DR. TORIBIO BENCOSME, MOCA, ESPAILLAT PROVINCE.
Author(s)	Isabel Maritza Núñez Fernández
Assessor	Natividad Pinto Afanador
Year	2004
Methodology	Quantitative descriptive and comparative study
Objectives	To compare the quality of life of family caregivers of patients with diabetes who attend the hospital inpatient service to the quality of life of family caregivers of patients with diabetes who attend an outpatient's program at hospital DR. Toribio Bencosme, Moca, Espaillat province, during the first half of 2003.
Conclusions	– Regarding the degree of dependence (PULSES), it was found that group B has a higher degree of dependence than group A, as in group B caregivers are caring patients who have diabetes and when hospitalized have major complications such as amputations, and vision loss. This group has a larger emotional and stress burden, therefore, greater risk of having an impact on their own health. – For nursing the findings related to physical well-being show a motivation to meet care for the caregiver from their own symptoms and needs, with the aim that caregivers grow through care. – Quality of life in terms of psychological well-being in both groups had no difference. However, it was the most affected one. Caregivers expressed their fears, depression, anxiety, malaise, anxiety, despair, and lack of strength by having to deal with the burden that care generates. – It was identified that social well-being is also altered, concluding the needs and requirements of social support for caregivers, especially in group A. – Quality of life regarding the spiritual well-being in these two groups found out that group B feels more uncertainty, has less hope, they have lost their mission or purpose of what they were supposed to live, even though both groups recognize their relationship with God. – The role of nursing in order to improve caregivers' quality of life is quite important, since all kinds of help, advice, and support throughout the process represents hope to relieve the caregivers' burden.

RESEARCH PROJECT	COMPARISON OF THE QUALITY OF LIFE OF FAMILY CAREGIVERS OF PATIENTS WITH HIV / AIDS ON ANTIRETROVIRAL THERAPY, TO THE QUALITY OF LIFE FOR FAMILY CAREGIVERS OF PATIENTS WITH HIV / AIDS AND NOT RECEIVING ANTIRETROVIRAL THERAPY, AT THE INSTITUTO NACIONAL DEL TÓRAX Y HOSPITAL MARIO CATARINO RIVAS, HONDURAS, JUNE-NOVEMBER 2003
Author(s)	Berta Elizabeth Álvarez
Assessor	Natividad Pinto Afanador
Year	2004
Methodology	Comparative descriptive study from a quantitative approach
Objectives	To compare the quality of life of family caregivers of patients with HIV / AIDS and on antiretroviral therapy to that of family caregivers of patients with HIV / AIDS and not receiving antiretroviral therapy at the Instituto Nacional del Tórax and Hospital Mario Catarino Rivas, Honduras, June-November 2003
Kind of research	Exploratory, descriptive, comparative from a quantitative approach
Conclusions	– Groups A and B showed an impaired quality of life in the physical well-being, with alterations on different scales, their most severe problems are pain, fatigue and appetite changes. – The contribution of these findings are related to physical well-being which must be object of study for nursing in the future, as well as the management of symptoms that is a critical component of nursing practice in different subjects. Therefore, it is necessary to approach caregivers and symptoms management to achieve physical well-being, through symptoms control and relief, keeping functional areas and independence. – Most caregivers have a marked deterioration in the quality of life associated with psychological well-being, as they showed alterations or manifestations below the average value scale. It could be argued that this deterioration is the result of performing their role as caregivers and the consequences of being a caregiver, including being exposed to stress, depression, isolation, emotional burdens, among others. – Studying the quality of life within the social wellbeing provides the opportunity to know the context in which caregivers are and how they are affected in their social roles; this is a key element within quality of life, as caregivers are social beings in an environment such as society.

RESEARCH PROJECT	QUALITY OF LIFE OF FAMILY CAREGIVERS OF PATIENTS WITH A CHRONIC DISABLING ILLNESS
Author(s)	Orfa Nineth Morales Padilla
Assessor	Lucy Barrera Ortiz.
Year	2004
Methodology	Descriptive, comparative and cross-sectional research with a quantitative approach
Objectives	To compare the quality of life of family caregivers of patients with a chronic disabling illness and are treated in the outpatient program at the Hospital Nacional de Ortopedia y Rehabilitación Doctor Jorge Van Ahn, to the quality of life of family caregivers of patients with a chronic disabling illness at the Hospital de Rehabilitación del Instituto Guatemalteco de Seguridad Social, during March 2003.
Conclusions	– Due to the increase of disabling chronic illnesses, low coverage in the first level of care and the lack of attention and protection of family caregivers at the institutional and nursing levels, the situation is quite complex for the person with the illness and the family caregiver; it could lead to an alteration of their quality of life.

Research study on spirituality in patients with chronic illness and their caregivers

Beatriz Sánchez-Herrera

Through a research study conducted by the *Caring for patients with chronic illness and their families Research Group at Universidad Nacional de Colombia*[105] it was found that loneliness, uncertainty and fear about making decisions without understanding the implications and without health institutions or professionals support are some of the feelings expressed by many families when caring for a chronically ill person.

These cases reflect the value of spirituality while living a chronic illness experience. During these experiences, people change their relationship towards themselves, as they start to communicate with God, saints or a higher level; they also communicate differently with others and with the world. This experience involves multiple meanings and raises the question of checking on values.

The Caring for patients with chronic illness and their families Research Group at Universidad Nacional de Colombia acknowledged the relevance to organize the work of care in chronicity within the experience of human health. Thus, patients and users linked to this research were asked about their care problems; they complained of not being able to change their lifestyle, pain, limitations, loneliness, fear, distress; in short they are all those aspects that are part of the situation and are far away to be included in a medical diagnosis.

After this survey, the problem was divided into five major groups in order to study and address users' concerns. The first group focused on re-conceptualizing practice within the conceptual model of Margaret Newman[106], which takes health as an expanded consciousness and seeks to create it within illness situations. The second group seeks to motivate them in lifestyle changes. The third group proposed finding relief in painful situations, limitation and mutilation. The fourth group intended to understand problems related to stigmatization, socialization, institutionalization, home restriction and care responsibilities. The latter aimed at supporting loss and grief processes.

In the fourth group, there is the caregivers' situation. Some of them have big restrictions on the dependence of their relative who is under care, life changes or concerns for the present and the future.

By studying the experience of family caregivers of people with chronic illness, a study by the same group found some constant conditions: self-neglecting behaviors, care tasks, different coping responses, feelings, needs to judge and make decisions, recognizing the situation as a different experience, the link in the relationship with the person cared for, the support received from individuals and groups, change of life, perception of proximity to death and transcendence[107].

People experiencing an illness, whose characteristics were similar, were studied in a parallel research[108]. Transcendence had a special significance for all the people involved in the experience of care in chronic illness situations. This evidence confirmed caregivers' observation, for over twenty years of work as they acquired a different sense of life, manifested in many cases through silence, contemplation, search for meaning, family rituals, intentional work and religious practices, among others.

According to Luz Helena Pinzon, a carer who have spent twelve years of her life taken care of her daughter, who suffers paranoid schizophrenic, "God and The Virgin are the only ones that have given me the strength for not to faint". She says that through all this time she has embraced praying and learn, indeed, to do not see any problem in the fact that his relative depends on her.

This is one of the ways in which some carers find their spiritual dimension and reframe some of their attitudes in life. Some come in different ways.

Transcendence is another way in which spirituality is lived and leads those people involved in it to reflect on themselves, to grow in daily living activities; this is reflected in a time of great consciousness, intense sadness and satisfaction, of deep introspection and rupture. Ordinary events often come to be experienced in an extraordinary way within transcendence.

Likewise, spirituality is reflected in maturity, due to the person's development, in which there is an expansion of the limits and orientation towards life perspectives and broader purposes. This phenomenon is significant for the well-being of those who face chronic illness situations such as caregivers or receivers.

Spirituality from research

If the spiritual component is of such magnitude, it is necessary to ask why it is not addressed as a priority as regards of care in chronicity situations. This work arises as a first step in responding to this concern and offers an organized and systematic overview.

Thus, it addresses issues related to spiritual welfare of the binomial *family caregiver-receiver*, which is recognized as the strongest one in cases of patients with chronic illness. This review aims to describe and analyze studies on how it is lived and how to promote spiritual welfare on a group of caregivers, as well as the people they care for.

Spiritual well-being

It is a sense of inner harmony, including the intrapersonal relationship; interpersonal relationships with the natural order, (existential component) with God, a higher power or force (religious component). Spiritual well-being is manifested through creative expressions, family rituals, meaningful work and religious practices; it can be measured through direct communication with each person. Hence, Ellison's[109] approaches were studied.

Family caregivers of a person with chronic illness

Several authors have defined the concept of family caregivers[110]. For this research, it is used the definition by the *Caring for patients with chronic illness and their families Research Group at Universidad Nacional de Colombia*, in which family caregivers are relatives or people close to the family, who take on the responsibility of caring for a chronically ill person. Family caregivers provide support on physical, psychological, social, and spiritual aspects of daily life. Family caregivers also participate in the decision-making process within care, supervising everyday activities, influencing the coping process and seeking to compensate the ill person's dysfunction.

People with chronic disabling illness

At this point, the concept of health by Newman is used. He asserts that a person with disabling chronic illness permanently moves through time with expressions of the illness itself. This is associated with irreversible pathological changes, which generates residual disability and requires special care, rehabilitation, and observation phases. Hence, there is a state of frequent ailment impacting the people involved in this situation[111; 112].

Experiencing situations of chronic illness is associated to spirituality in a particular way; it has a therapeutic value in people who go through this life crises. However, the spiritual wellbeing of people going through the experience of care, in the middle of chronicity disabling situation, is rather unknown or even ignored.

Therefore, this research addresses a specific field that requires searching for specific alternatives designed to ensure a better quality of life for caregivers and patients. No other recognized research studies have addressed this field in Colombia so far, despite its importance. Hence, it is aimed to get answers in order to cope with the caregivers' inner harmony as well as the one of the person they care for.

State of the art

Several studies facilitate understanding the experience of family caregivers and receivers in situations of chronic disabling illnesses. The following is a collection of recent studies in this field. Some of them related to the burden of care, its benefits, the spiritual experience in caregivers and receivers, the impacts in their relationship, the social and professional support actions that may modify this experience.

We must remember that family has always been a natural caregiver agent of patients in situation of chronic disabling illness. Although, the tendency is rather limited to the core family members: mother, father and children. Additionally, some other factors like restriction of home space and the changing role of women have also changed, by taking the role of caregivers as one of their main responsibilities. This issue is so evident that has come to be regarded by many theorists as a natural part of family crises[113].

The number of families who take care of their chronically ill relative tends to increase as hospital care might be too expensive. Family members provide the long-term specialized care; among their fears and lack of knowledge on specialized procedures, they seek to maintain the quality of life of their loved ones[114].

The impact of chronic illness on family members' health and welfare is broadly documented[115] as well as its relationship with the alteration in quality of life[116, 117]. Likewise, the impact of these situations in the community has also been registered[118] and the positive aspects of working with families living these care experiences[119].

Several authors point out factors that modify the family caregivers' experience[120]: personality, knowledge of the illness, available resources, the personal perception and meaning of the situation, coping strategies, the degree of prediction caregivers may have regarding the health situation. These are all crucial factors on the way of going through this experience[121; 122; 123; 124; 125; 126].

There are different ways of being a caregiver[127]. According to this responsibility, there might be: a main caregiver, a support caregiver, an available and committed caregiver, a caregiver who feels absolved by caring activities and responsibilities, and the pretentious caregiver who does not take part directly in care, but always has an opinion on how to do things more effectively. The latter is usually devastating for the main caregiver due to the feelings that these kinds of attitude may create[128].

For instance, Martha Lucia Alba has been a caregiver for her mother who has got Parkinson's illness. She stated that the most difficult experience had been trying to understand her brothers; she had always been the main caregiver. Her brothers somehow wanted to intervene and even blame her when the situation complicated.

Whatever their role is, caregivers in this study are those individuals associated with a situation of dependence produced by chronic illness; they have high risks of getting ill and even die due to a prolonged stress experience associated with care duties. Even with these risks, there are not services for caregivers yet, as most of them are just focused only on patients.

Care and spirituality

In a phenomenological study conducted using the Colaizzi's method, the experience of female family caregivers of patients in a situation of chronic illness was broadly described. It was conducted with eighteen women over 15, who live in Bogotá and had been responsible of a person with chronic illness, for more than twelve months, -during the last five years-.

The study included active female caregivers living in rural and urban areas, from different profiles, ages, socioeconomic backgrounds, levels of knowledge on the health field, God believers and nonbelievers, workers or housewives. It also included some caregivers who had already lost the person they used to care for.

The description of this study indicated that the experience of being a caregiver of a person in a situation of chronic illness is to live in a different way; it implies modifying the caregivers' habits: making decisions, taking responsibility and performing tasks and actions regarding physical, social, psychological, and religious care. Meeting the patient's varying needs is the main target and gradually acquiring the ability to get through, sometimes even getting over the most knowledgeable experts.

This experience may require seeking for tangible or intangible support that may be either effective or ineffective creating a variety of feelings that, sometimes, provide closeness and stability, but some others they might be overwhelming. Thus, caregivers may react on their own accordingly, when they are to confront or avoid the situation within their context.

In that closeness to death, this situation leads caregivers to learn about the value of life and health, as well as going beyond limits in order to perceive what is truly important for the other person. Therefore, caregivers grow in understanding their own existence, transcending, getting into a broader context, which modifies their attitudes and redefines their spiritual nature.

It takes place by maintaining a close link with the person being cared for; they share up their own identity. There is protection, acknowledgment, gratitude, complicity, mutual dependence and compassion. This raises the question: are the relationship, dedication, and life itself "as what they have been desired and expected?" (Sanchez, 2001)[129].

These findings supported the understanding of what it means to be a family caregiver. It goes beyond of just having a job or being responsible for another person. Being a caregiver implies to create a lifestyle and a different relationship with oneself, with the person cared for and the entire world. These findings are ratified by the person who considers that the experience of caregiving is a spiritual journey of love, loss, and renewal[130].

A study by the same group, and addressed to home care, concluded that caregivers required guidance to improve their care because most of them do not know how to perform care activities. Patients stated their lives have different routines and they are provided with support that was not previously required. In some cases, they feel abandoned due to their condition[131].

Two research studies on the experience of going through situations of chronic illness and exploring the concept of totality in these people's life stories lead to conclude that for the caregivers' presence, attitude, and knowledge are key factors that are part of the patient's environment and welfare[132, 133].

Information management and performance of family roles within care seem to be results of cultural patterns[134]. It has been observed that in Colombia, most caregivers are usually persistent women; they often seek for assistance and guidance, while having feelings of frustration and hopelessness, with difficulties to find effective support[135].

Spirituality in relation to perception of burden or benefit

Some authors have suggested that the caregivers' role brings stress and conflict between the accompanying tasks they perform and their social, work and personal life. Sometimes, stress grows into a sense of burden because caregivers feel ill and perceive low social support[136, 137]. They cannot get enough rest[138], or have a rather unsatisfactory relationship with the person cared for[139, 140]. Martha Lucia Alba, caregiver, says: "People, especially other family members, do not understand that one gets tired and needs space. They think it is just an ordinary job".

In other cases, the care relationship generates excessive dependence and care receivers do not take the active role they should[141]. Women are most likely to be affected in these situations, especially those who are in their thirties[142; 143].

Stress is identified by a number of factors reported by caregivers such as physical, psychological and cognitive limitations. There is an alteration of regular performance of the role and social interactions; perceptions of low social help and poor support systems of health care. Moreover, caregivers do not usually have enough time for themselves; their resting activities are rare. There is impaired regular work performance, or the caregiver-care receiver relationship is altered depending on the severity of the illness[144].

Personal, family and social factors affect the level of stress and resilience in caregivers. Moreover, stress decreases when caregivers feel they comply with the necessary skills for problem solving, but in the opposite case stress increases[145].

Those demands of caring for an individual come from different sources that may generate a burden. In the case of care, it always has sensible and subjective components. The subjective burden can be defined as the attitudes and emotional reactions to the experience of caring. On the other hand, the sensible burden is the degree of disturbance or changes in various aspects of caregivers' life.

Age and the way people become caregivers are the best predictors to get a sense of the sensible burden. Alternatively, it has been documented that high self-esteem, control, and other psychological resources have a significant impact on the perception of the caring burden and contribute to decrease its levels in the main caregivers and their supporters[146].

Some authors show that, at times, the disability is more associated with social reactions than to the illness itself. According to their report, those complications of caring for a chronically ill person involve deficits in coping, extreme dependence, difficulties in interpersonal relationships, perceptual challenges, vocational limitations, low energy, and motivation[147].

In addition, as a double-way phenomenon, it was found that the patient's perception as a burden for the caregiver is associated to depressive symptoms, poor health status, low income, less spiritual activity, and negative acknowledgment of the caregivers' behavior[148].

The feeling of burden seems to be generated by the responsibility of caring for another person who is dependent on many aspects of daily life and by the stress of being constantly making decisions that affect their loved one and their own life. Caregivers indicate that these obligations are often overwhelming.

Caregivers perceiving or going through a care burden experience, stress, and depression increased when patients deteriorate and get more dependent. This is significantly associated with the emergence of some illnesses such as depression, physical problems, mental, and permanent fatigue[149].

A Latin American study reported physical symptoms in caregivers due to the burden of care; they are related to the musculoskeletal system and are followed by general symptoms[150]. Another study conducted in the United States on caregivers of patients with cerebrovascular illness, showed that some health conditions are associated more closely with this feeling of burden[151].

The burden of care as a result from the demands of an ill person, threatening the caregivers' physical or mental well-being, the persistent difficulty in caring or physical, sociological, financial or social problems. They all may vary according to the subjective caregivers' perception, to their mental health, and to the patients' cognitive integrity [152, 153, 154] or to families' conditions and structures[155].

Family members usually find it difficult to handle patients with behavioral problems and their burden increases when they live with them. However, other problems arise in a separate household; they are also quite related to stress. According to the records, people who share a household have a higher restrictive activity and a less strained relationship.

Finally, it has been explored that when the role of the caregiver is overburdened in physical, emotional, financial and social levels, the individuals with the illness are more likely to be institutionalized or abused[156].

The burden has been a key concept in analyzing the impact of care on the family. Since it was first defined, it has been widely used in the research of the caring process and its effects. Therefore, the feeling of caregivers' burden is perceived as an important factor, in both the use of long-stay services and caregivers and care receivers' quality of life[157].

Research has mostly shown examination on the burden, stress, and depression as outcomes of care. There are very few studies that assess the quality of life which is particularly striking, specially, in caregivers of people going though long term chronic illnesses[158]. Nevertheless, some tools that allow assessing these factors have been developed so far[159].

In a prospective descriptive study, developed to explore the caregivers' medical, social, work and financial problems, it was found that they suffer from diverse personal, psychological, social and physical changes that affect their personal and family life, as well as the person they care for. This creates a particular state of vulnerability.

A direct and individual survey was carried out for research purposes. It collected data on care, family relationships caregivers-care receivers and the major social, labor, and financial challenges that caregivers face in their daily tasks.

Results show that caregivers are hidden or unknown patients because of the different changes they undergo, so they require an early diagnosis and prompt intervention before any damage is irreversible. This characterizes the so-called "caregiver syndrome": the existence of multiple symptoms, which affects all areas of the person, with clinical, social, financial, and some other consequences that may lead to such frustration, so caregivers may resign their work. This will have as many consequences for caregivers as for their care receivers[160].

Another group of researchers conducted a study with 3000, 50-65 years old- female caregivers. It confirmed that the caregiver's anxiety and emotional stress increase proportionally with the number of years they have devoted to caregiving. According to their findings, the more time they have devoted, the more likely to undergo emotional distress and physical limitations. These results provide new information on possible effects on health care for other people and understand how it affects welfare it self[161].

A research meta-analysis of family caregivers suggested that 73% of research studies focused on the perception and effects of the caregiver's burden, 5% on the caregivers' level of depression and only 22% on their subjective welfare, achievements, knowledge, and cognitive skills or on the development of care receivers' symptoms[162]. A subsequent study assessed these elements in home care and demonstrated similar findings[163].

The closed focus of stress, burden, and depression partially shows the reality of the care experience in chronicity situations. However, it limits the perception of broader aspects regarding the impact on caregivers and care receivers; it decreases the effectiveness of provided services. These findings claim the urgency of a health promotion system that leads to the awareness on quality of life and to a more relevant and comprehensive concept in order to determine the impact of chronic illness situations in caregivers and care receivers.

The care experience and the experience of feeling a burden are significantly related to spirituality. People usually get closer to their God amid difficulties, looking for a source of help or an ally in order to bear these situations.

However, it has been identified that loneliness is quite significant in family caregivers and care receivers. However, introspection time is less, due to the discomfort produced by the illness and the overwhelming burden of care.

From a literature review, it could be noted that there is a common feature among those caring for their loved ones, because of the emotional impact they go through. It is an intense sadness because care receivers are in pain, they lose their skills and they never get back to their previous life.

According to the testimony of a caregiver, the most difficult thing is when the person who is being cared for is in intense pain. This caregiver shares: -*"You feel powerless with no alternatives to reduce that suffering"*.

The caregiver is affected, because there are changes in the family dynamics. Life changes all of a sudden and it keeps on changing continuously. Within the efforts to get adapted, there is no time to think and overcome the painful aspects imposed by these kinds of experiences. Those simple daily activities, such as: dressing up, walking, having a shower and thinking clearly, might be a simple natural gift for every else. However, these activities become the main purpose of life within care.

It might result very frustrating when healthy people, with no serious problems, complain about things that have a way out. Likewise, when people have behaviors of social privilege, which demonstrate they do not fully understand the situation. Then, stress and isolation are constant when taking up the care responsibility.

There are some more common features that have been identified. It is another shared emotion that is not usually acknowledged: the growth of an inner strength that most caregivers did not know they had. Caring for an ill family member is a path that, regardless of the pain, it strengthens people's will to continue living. It is a source of hope; the power to make the difference; a clever way to solve difficult problems; the harsh test to overcome. This calls the attention of what is really important in life and recognizes those who have not traveled this path[164].

Even though many caregivers would interchange their own life for an easier one, or even exchange their own health and welfare conditions with their care receiver. Caregivers do not deny their extraordinary courage to accept reality.

It has been proved that when caring for a loved one it is difficult to step back and see the extraordinary things that are carried out throughout this situation. The lack of time and society with its implications and values make caregivers to be invisible. However, in the end, caregivers are the ones bearing one of the largest burdens in chronic illness situation. Unfortunately, just a small number of people and institutions do think and work for caregivers. It is necessary that caregivers themselves recognize their own value, in order to change this situation.

The benefits of caregivers and care receivers' interaction are related to the levels of satisfaction, reciprocity, companionship, personal growth, among others. Caregiving may be perceived as a mutual exchange process in which rewards are based on making life worthier, while one's life is also dignified and transcendent through that dedication[165].

Caregivers have to make choices based on an organized structure that guides tasks, as the ability to systematically organize the caring plan that leads to accurately achieve the expected goals and fulfill human needs. At the same time, it supports the full understanding of behavior itself, preventing adverse reactions from caregivers and care receivers, which allows them to maximize the benefits of the experience. Caregivers' persistence, potential, welfare, performance, physical health, and resilience are also ways to acknowledge and strengthen the benefits of such an experience[166; 167; 168; 169; 170; 171; 172].

However, by reviewing the state of the art, there is no further evidence of an emphasis on spiritual well-being.

The caring ability and its relationship with spirituality

The caring ability involves caregivers and care receivers. It is modified by the decision-making process, responsibility, supervision, or support and the change of assignments in different scenarios. The family is the protagonist in home care. Activities are usually based on the ill person.

There should be enough training to meet the person's needs, such as: willingness, knowledge, and acceptance to take up either a caregiver or care receiver role; expressions of positive rewards towards the other person, participation in decision making, knowledge on the illness itself, on the medical treatment and its administration as well as the necessary equipment to do so according to requirements; adequate monitoring and emergency situations' management.

To have backup plains in the responsibility; to know about the management of the financial resources, about when to call healthcare professionals, about the available support networks and to trust in own skills are essential aspects that a skilful familiar carer must possess[173].

The caring ability was evaluated based on the professional and the family caregiver's knowledge, courage, and patience[174, 175]. However, there are not known reports of these conditions in patients. But the acknowledgment of the ability as a phenomenon involving the two persons' interaction is important in order to get the support required. The experience of chronic illness does not select candidates with a particular profile, but not all people develop or show a potential for care. Some people may not have any interest to do so. Some others have different skills what provides them with personal wealth. In several cases, the abilities' expression does not depend on skills, but on internal or external motivational factors[176].

Care, which is always associated with a human expression of survival, is manifested in the caring ability. The caregiver-receiver relationship requires effective communication, patience, harmony, serenity, assertion, stimulation, companionship, attitude, long-term commitment, acceptance, mutual respect, collaborative problem solving, and a common, shared sense of responsibility and membership[177].

The person who has been under care is usually able to care after another person. The growth that is generated by caring is mutual, sensitive, and comprehensive; it must have at least three elements: the authenticity of the caregiver, the positive acknowledgment towards the other person and an empathic understanding. These conditions are necessary in any skilled care relationship[178].

Caregivers and Patients may have an ability to find meaning in their process, keeping a meaningful link, making all the necessary decisions to determine the course of action and to carry out activities according to moral principles[179].

Humans seek to understand the reason and purpose of a disabling illness situation as thinking, spiritual and emotional beings. Spiritual questions include, among others: Who am I? And what does this disability mean for my life? Why me or why my family? What did I do? Why does God allow this to happen if God is good? Why doesn't God make us healthy? A variety of coping strategies, spiritual religious and nonreligious, may be used to answer these questions[180].

Spirituality may influence the overall coping of giving or receiving care, by reducing the feeling of burden, increasing the caring ability, and acknowledging the benefits of the experience. In research terms, it has been classified as spirituality in the caregiver, the care receiver, and their relationship[181].

Research on caregivers' spirituality defines it as the focus to look for meaning[182; 183; 184; 185;] regarding suffering[186; 187;] optimism, positive emotions[188,] religion and religious beliefs[189; 190]. It has been documented in caregivers as a way to change their situation to something new, which leads to personal growth[191; 192; 193; 194; 195; 196].

The caregiver's suffering usually turns into spirituality[197]. Some aspects of this experience may also cause the highest grief, and that's when health professionals should intervene to lessen these consequences and improve their quality of life[198; 199].

Spirituality has to do with caregivers' multiple roles and the social context coping with the illness situation. Therefore, it has been perceived as an important factor in general health, through the adjustment to the illness and the positive coping in the midst of stressful life experiences. Thus, some caregivers become care receivers, and some care receivers, despite their illness, have a role as caregivers[200].

Families dealing with these experiences go through a social change, although there are a variety of reactions[201]. Some of these families declare they live within joy and sorrow[202], but it apparently indicates a positive spiritual coping when the care receiver is a child with disabilities. Thus, it is not common in families going through a different kind of situation[203; 204; 205; 206; 207].

Furthermore, some studies exploring care receivers' spirituality include strategies on coping, religiousness, and welfare[208, 209, 210, 211, 212, 213]. Coping strategies are, among others, praying, deep thinking, use of religious objects, consideration of religious services, talking to the family and to the priest[214].

Individuals in situations of chronic illness often go through a lack of harmony between their mind, body, and spirit. To meet the demands of the illness, they must find meaning and keep up with a life project, as they may feel a lack of control over life. Hence, the use of spiritual strategies to find values, strength, support and determination is quite common, so they eventually get to an empowerment process, finding meaning and purpose in life. Transcendence may help people, even if they are believers or not, to face their illnesses by finding meaning, purpose, and hope[215].

Spirituality may help them to undertake the crisis and grow in a special way; it is a path in which the experience is meaningful in order to grow as human beings[216].

Spiritual coping strategies may work for humans all around the world[217]. Some of these strategies are common for believers and skeptics. For example, meditation/contemplation in which individuals, connecting with their own self as well as others, family and friends, finding and acknowledging their strengths. They hope things may get better, which helps in giving and receiving love; appreciating nature and art from different perspectives. However, believers usually use more familiar ways to relate to God or that being they perceive through their religious practices as a source of strength, protection, and hope[218; 219].

According to research, being conscious of a shorter lifetime, may lead care receivers living in situations of chronic illness to look for meaning and purpose. It fosters coping with the crisis[220; 221; 222; 223].

Finally, within the caregiver-care receiver relationship, high levels of harmony, cohesion, and other factors in the family, are constructive in the social and cognitive development of people in situations of chronic illness and family adaptation [224; 225; 226; 227; 228].

Spiritual Health

Spiritual well-being for caregivers and receivers is analyzed as the general state of spiritual health which is evident by the presence of meaning, purpose, and plenitude in life; by a high desire to live, believe, and faith in oneself, others, and God. It is also associated with characteristics such as age, health and social status, as well as the reciprocity between caregivers and care receivers[229].

Several authors argue that culture and gender are associated with the level of meaning within the experience. For example, African-American caregivers and women have shown a higher level of religious commitment than Caucasians and men. African-Americans find a more rewarding experience and give more meaning to the caring experience than the others[230; 231; 232; 233; 234].

Two studies reported spirituality in both caregivers and care receivers. The first research study was carried out with elders and their caregivers (from the community) and showed that the spiritual bond between them enables interaction results[235].

The second research study was carried out through a descriptive qualitative approach. It analyzed spirituality in 60 caregivers and 60 care receivers who were able to communicate quite accurately and willing to participate. Care receivers were dependent, at least in basic or instrumental activities of daily living; their cognitive skills were intact.

They were 30 Caucasian dyads of care (binomial caregiver-patient) and 30 African-Americans ones. Care receivers were aged between 52 and 98 years old; their diagnoses included multiple chronic conditions like congestive heart failure, stroke, and arthritis. They were aged 24 - 84, most of them over 65. 42% of the cases were spouses, 37% children, 8% relatives and 13% others. Most care receivers lived at their caregivers' place, in the urban area. 83% of the caregivers were women. Regarding care receivers, 70% were female and 30% male.

The experience of care, by the dyads, was studied based on a semi-structured interview with caregivers and care receivers, from the researchers' experience and a literature review. Some topics included: the illness history, finance and emotional issues, social cost and benefits of care, factors that either enabled or blocked care, health professionals' perceptions, assistance sources, knowledge, care definitions regarding gender, coping with stress, self-care, balance between care and life, goals, satisfaction, advice for others and their perception on the quality of care.

Most of the answers regarding spirituality emerged when caregivers and receivers were asked about how they had coped with giving or receiving care. Some answers came from questions on how the caregiver had learned to provide care. Since not all individuals in the interview mentioned spirituality, they were asked questions on this topic in a second interview, but no additional information was found.

It seems that participants mentioned spirituality without giving any specific reasons or it was just not considered part of their lives, even being asked specific questions on this topic. In quantifying caregivers' answers, the percentage, out of the total sample, in terms of spirituality is equivalent in men (80%) and women (82%). African-American caregivers have more spiritual responses than Caucasians.

The most common answers were related to formal religion. Female patients' answers (81%) were more spiritual than male ones (66%). The most common issues were related to formal religion and positive attitude. Caucasians and Afro-American care receivers had similar answers related to spirituality.

During the interviews, they mentioned positive and negative comments about spirituality. Some broader categories that emerged were related to *coping* and *meaning*. The sub-themes for *coping* included formal religion and social support; for *meaning* they were related to positive attitude, payback or reward.

Some caregivers and care receivers talked about formal religion as a coping aid in giving and receiving care. Formal religion considered as churches and religious elements such as prayers, Bible reading, and watching the ceremony on television. Praying was constant for most of them. They mentioned praying when they were asked about how they were dealing with their situation. Some others used spirituality to learn the task of caring for themselves or those affected by the illness.

Some of them usually pray for others, care receivers usually pray for their caregivers. Both care givers and receivers read the Bible as a coping mechanism similar to prayers. The Bible was often close to those surveyed, which validated these data of this research study[236].

Religion is a significant factor for these groups. For some of them, the church is a source of support, but this relationship is affected by the illness experience. Some of the participants assert that their assistance to a church became less frequent. However, some others now go to church more frequently. One group declares they cannot be present in different activities due to their limitation or responsibility. However, those who do manage to be present in different activities give a special value to these kinds of activities as self-care or leisure experiences[237]. The importance of church attendance is similar to that stated by some other authors[238; 239.]

Attitude was perceived as a potential aid in giving or receiving care. A positive attitude demonstrates that caregivers and care receivers relate to each other according to their role. The two members of the dyad recognized their own positive attitude and that of their counterpart as an extremely favorable situation[240; 241]. According to caregivers, distress may be seen as a negative attitude[242].

Both caregivers and care receivers mentioned their own positive attitudes. Some identify spirituality in terms of reward for giving or receiving care[243]. Rewards are related to feeling good, doing what it is expected in order to avoid punishment from God or to get other future rewards. Others asserted that God has allowed things to happen[244]. Some others acknowledged spirituality as a central life component[245].

Some Catholic religious people claimed the importance of communion for their spiritual life. Those participants who are restricted to be at home stated that Church representatives do not visit them, so they miss the formal religion that was once part of their lives[246].

Regarding meaning, besides the aforementioned positive attitude, retribution, and reward, some aspects related to a core philosophy of life, guiding behavior standards and being the center of human existence were also identified in this research study[247]. This search for meaning in giving and receiving care is also reported by some other authors[248; 249; 250].

Moreover, this study shows that some caregivers and care receivers who handle their spirituality as the most important factor in their lives were able to get help when they needed it, even without mentioning God. It is evident that they had had a special interpretation on spirituality for a long time[251; 252; 253].

Other authors have reported that a very deep meaning may be found through caregiving[254]. However, it is not so, when it is due to an obligation or to overcome feelings of loneliness.

In some cases, there is meaning but there may also be a lack of identification as part of the process. That is why, the simple caregivers' social approval received by different members of formal and informal groups is enough to increase or acknowledge their own worth[255]. In spite of this, the wealth that comes from being a caregiver fails to protect people from some other pressures that are also experienced in this task. Negative effects affect the person's health and also the caring relationship itself[256].

The meaning of caregiving can be seen as a moderator of those difficulties experienced by caregivers. The values and beliefs that support their role allow identifying benefits and results, in order to understand positive aspects. Some caregivers, who have lived this experience positively, focus on the rewards of altruism, self-satisfaction, fulfillment, and life's purpose. Although, they always mention some difficulties in their role, they communicate enthusiastically their motivations, which have kept them on, as well as the personal satisfaction derived from caring for another human being[257].

Care may have different meanings for a person or society. Some authors identify three main meanings: the ontological meaning, i.e. the caregiver as a sign of being alive; the anthropological meaning as a sign of being a caregiver; the ethical meaning or duty of care[258].

Researchers found some common elements using thinking and focus groups work technique, when trying to interpret the power of the caregiver-care receiver's encounters in terms of spiritual matters. The importance of the spiritual set for these encounters and the primary role in identifying spiritual needs produces a referential framework to be implemented in a caregiving practice. The spiritual work confronts the people involved in their ability to face illness as an intense experience of meaning. Thereby, spirituality helps those patients to understand their own experience. Reciprocity, through a spiritual connection, has also been identified as a significant factor in renewal, satisfaction, and healing results[259].

These findings were complemented by another author, who asserts that some factors such as: an increased spiritual activity, higher financial resources, better health status and a younger condition, predict a higher caregiver - care receiver reciprocal behavior[260].

Another research group analyzed those difficulties of living with a disability and how they mean a spiritual challenge. Participants in this research questioned the relationship of their situation in relation with religious issues, such as: sin, divine judgment, miraculous healing and the relevance of their faith. Some other examples of challenges that have been identified in this research are: questioning God repeatedly and looking to get closer and away from God. Both caregivers and care receivers reported personal, family and social responsibilities in order to cope with a chronic illness situation. Nonetheless, caregivers mentioned guilt more frequently than care receivers[261].

People's expressions of inner spirituality go beyond the boundaries of life in a sense of purpose and wholeness with the universe. Altruism, self-actualization and life purpose are reported as the conditions that give meaning to caregivers on their experiences caring people with chronic illness[262].

Some other research studies indicate there is a common need to find meaning in life looking for good health and welfare[263]. Likewise, care receivers need to find meaning in their illness and the hospital stay experience[264].

Social support and spirituality

Caregivers who have a high level of satisfaction from family, friends and professionals' social support -either emotional or instrumental- experience less negative effects in crises[265, 266, 267]. They also argue that loneliness and lack of support causes suffering[268]. These findings are particularly important when analyzing religious support in those families affected by a disability situation.

Effective social support is described as a resource of specific value in the chronic illness experience being either a caregiver or a care receiver. This support is provided by different institutions -predominantly religious institutions- social groups, close friends and family members. The caregiver-care relationship itself is indeed a social support form. Regarding religious institutions, one fact is that while most religions address and give meaning to suffering. Those that seek theological explanations for disabled people do not have a sound answer in this regard[269].

There have been a few attempts to determine whether different religions or religious organizations give a different meaning to disability as such. Some studies indicate that different beliefs give different titles to the adjustments families go through[270]. However, some more recent studies do not support this premise[271; 272].

Research studies aimed at analyzing spirituality in the experience of providing and receiving care indicated that religion and its members are significant sources of support. However, this experience is different for each individual. Some patients state that, church representatives stop visiting them, without communicating any reasons. Others, however, claim that spirituality provides significant support. They perceive support from religious institutions when it is provided to the care receiver, while the caregiver attends to religious services or leaves home to have a break. Sometimes, church representatives visit them to mitigate their loneliness; it makes them feel part of a community that supports them[273].

Religious beliefs are often regarded as support for people. It has been documented that they can help in the caregiving task and in positive affection[274; 275; 276], which is associated to optimism. Everything indicates that caregivers with high levels of optimism have low negative feelings ranges, indicating that they are capable of putting away harmful feelings in stressful situations[277; 278].

Religious belief systems, besides a formal religious practice, may promote acceptance and may help family members to give meaning to the situation of disability[279, 280, 281, 282, and 283]. Research is currently advancing towards building support to acknowledge that spiritual beliefs are a stabilizing force in people with disability and their families as these beliefs provide assistance in positively dealing with their situation and generate multiple benefits. Parents may experience higher stress and a perception of religious punishment due to religious faults or a poor parenting performance[284].

In a qualitative-interpretative point of view research, was explored how disabled people and their relatives, all enrolled in Christian churches, use their spiritual beliefs for make sense about the illness situation, and for face the challenge of living with a disability. Was reported that their experiences had closed them in a notable way with the spiritual beliefs and the church in which they receipt special support.

We found a positive influence of various religious factors associated with disability in the participants' responses. God is in the center of their concerns and challenges and they use the Bible and faith to give meaning to their existence.

Although religious support from the Church promoted a positive adaptation to the disability, this is not so important for participants and their relationship with Jesus Christ. It is what people believe in which influences their reactions, some of them are happy and enjoy life, despite the stress associated with a disability. This showed, according to researchers, the belief that God has a better plan for their lives. For some others, enjoying life, coexisting with pain and grief of what life could have been[285].

Another research study found that caregivers and care receivers acknowledged religion as an important social institution that allowed them to grow at a spiritual level. Despite the usefulness of the Church and beliefs, some factors such as: theological confusion surrounding disability, public attitudes, and limited integration of spirituality in health care by professionals, can lead most people to internalize negative messages that contribute to their rejection of spiritual beliefs[286].

In another research study, several participants commented on their perception of a poor Church response to host and support them, while asserting that disability generates fear and leads people around to evade them. According to these participants, it is necessary to overcome this negative perception, which can be achieved through cooperative service. People with disability know they have something to offer their fellows. These patients also feel they are regarded as limited resources by the religious institutions, because they might generate more costs instead of production. They quoted -as examples- the risks of expensive modifications to create physical access for them and the loss of members in specific tasks[287].

Some research suggestions regarding religious support include emotional, spiritual, social and practical factors. They emphasized that people living this experience have common needs and talents towards others. Therefore, it is suggested to make efforts in order to promote theological understanding of the disability experience; to look for new ways to promote religious support. Data suggests there is a need to build a care model, complementing the traditional one, oriented to short term crisis management. Hence, support is more related to the caregivers' perspective[288].

A research study carried out in Colombia with chronically ill patients and their family caregivers found that the support they needed was related to social, psychological, and physical factors, especially to get specialized treatments and spiritual support. Several patients reported that religious support through praying groups was essential for them and their caregivers. On the other hand, they stated that their companions feel great relief when health institutions call and monitor them, which in many cases means valuable encouragement in the midst of achievable tasks[289].

Thus, it is clear that caregivers and receivers describe a deep grief associated with the disability that others may not understand. Public and private social support systems continue to be distant to their needs and are not enough to provide hope in daily life or a respite to avoid tiredness and fatigue in the task of giving and receiving care. Despite this, religious institutions are recognized as a significant source of social, real or potential support.

Support services for caregivers

Checking health professionals' interventions to people in situations of chronic illness, it was found that these interventions are intended to: ease the burden and depression, to increase the subjective welfare and the caring ability and that most of these effects persist after seven months. There is also evidence that psycho-educational support, psychotherapy and a combination of some other interventions, with a multi-component approach is even more effective to improve caregivers' wellbeing in the short term.

Although there is a lack of randomization that limits the conclusions of several studies, meta-analysis results suggest that some interventions have a larger effect. It is less specific in the variables (psychotherapy, psycho-educational and multi-component). Some others have more specific effects on special outcomes (the care receiver training and support interventions). Authors recommended implementing interventions as justifiable and advisable, while maintaining realistic expectations on results. Caregivers' objective burden may be reduced to certain degree, but it is impossible to eliminate it completely[290].

Respite services have been defined as a "continuous relief"; a service or group of services that give the caregiver a temporary relief, a break from their role. These services include support and companionship at home, home meals delivery, transportation to medical appointments and agencies of health care and home visits[291]. Additional services include: counseling to the caregiver as a support activity, training, and guidance[292].

The respite has been identified as an effective strategy in individuals who experience increased loss of competence to carry out daily living activities and require constant supervision or assistance.

Relief may be provided by an informal or formal health care network, through a government financial support, a nonprofit agency, an organization or through services that include certain costs[293]. Respite services for caregivers are available in assisted living facilities and homes. Any benefits have been identified yet of non-structured recreational activities[294].

Some authors analyzed the benefits of respite programs as a way to meet caregivers and receivers' needs. It was found that these programs delay institutionalization. Others found that these services are not effective in regards to a significant relieve of the caregivers' burden[295]. They added that respite aid is achieved only if direct care is provided[296].

Providing respite services for people with illness, in social institutions such as day care centers allows them to have an opportunity to interact with peers and social activities with meaning[297]. Many of these aids are linked to hospital institutions[298].

These respite home and distance services give caregivers more time, reduce their stress, and increase their ability to socialize with friends, so it is an opportunity for them to be in a better condition. In addition, ill people benefit from an increased socialization, stimulation and interaction with peers, special activities for them by trained people and caregivers who are experts on home care[299].

However, some researchers reported finding no significant change in caregivers' feelings regarding their welfare when they get respite services[300]. Many of these programs report low demand and difficulties in recruiting participants[301].

Informal caregivers tend to isolate and avoid support services. The reasons they argue are lack of knowledge on available services and a need of guidance and training, in response to the ill person's respite need and their own. Apparently, the experience of family care generates guilt when caregivers leave and find it difficult to give themselves a "time off from the situation." Findings indicate that some caregivers think these services are expensive and inflexible. They often do not perceive a caring attitude towards people with problems that last a long time. For many of them, respite services are intended for a final stage, rather than as an available service at an early stage[302].

In many cases, it is the caregivers' attitude that prevents the use of respite services. Especially, those who prefer to provide informal care all by their own; they often resist and do not trust the quality of these services[303].

It has also been pointed out that respite services are not usually used by informal caregivers' networks, as they are concerned about individuals' health and functional problems management. Informal community links are necessary to enable caregivers' constant access, commitment, and available resources[304].

When services are based on the community, they promote a sense of familiarity and cultural sensitivity among the people who provide it and those who benefit from it. The clarity in the criteria for admission and exclusion of users and training of individuals who work with suitability and sensitivity, as well as access to meet caregivers and receivers' needs has been rather effective[305].

It is necessary that the truce allows caregivers and receivers to feel free of caregiving responsibilities. The respite experience meant" a cognitive journey" to recognize the need of being outside the world of just being a caregiver, giving themselves permission to go out with adequate social support to ease their respite[306]. Everything suggests that full decoupling is not helping the relationship, but the balance between bonding and separation allows harmony in caregiver-care relationships[307].

However, in a study with 116 caregivers and receivers, the highest quality of life was associated to: self-esteem, the ability to manage income, quality of caregivers-receivers' relationship and the family coping skills. The lowest quality of life was associated with the total time of the illness, the lowest family coping skills and the inability to manage income[308].

A longitudinal research on respite effects, in 130 caregiving families of frail elders who received care services from a reference center, at home, and at institution, was aimed to measure the effect of respite within the medium and long terms.

Results showed improvement in the quality of life, caregivers were in a better mood; they expressed deep satisfaction with the respite and reported positive results about the program. However, none of the evaluation variables changed significantly. Thus, these researchers questioned whether the survey instruments were as sensitive as required in order to closely measure the amount of change throughout time[309].

Another study with 68 caregivers, 68 people with chronic illness and 62 healthy adults who were not caregivers, measured the quality of life in their emotional, social, financial and physical levels. These findings indicate that caregivers' quality of life is related to the perception of the person cared for. Caregivers' and care receivers' differences were not significant from a statistical perspective. The fact that the responses did not decrease significantly was analyzed as a positive result within the caregivers' crisis and their tense situation. However, in the total scores of both actors there was a difference indeed[310].

Another research study on the support of family caregivers for the home care management, took a random sample. The intervention was a regularly scheduled home visit by a registered nurse. She taught the caregiver about the condition of the person cared for: how to provide care, to have a weekly respite, and to allow the caregiver to attend a support group monthly. Results showed depression, anxiety and a low quality of life. Although the responses of depressive symptoms and anxiety remained constant, the standards on the quality of life increased in the experimental group and decreased in the control group[311].

Although the sample was not enough to demonstrate statistical significance, researchers believe that there is a crucial difference in the clinic. The study is important because it was possible to identify some group interventions that may suggest an improvement in the caregivers' quality of life, despite the presence of emotional symptomatology.

Another research study, in which 256 caregivers of dependent care receivers were interviewed, examined the impact of care in the quality of life. Researchers did not only use a specific measure of quality, but multiple ones such as stress, social and family life, loneliness, anxiety, depression, and a health self-report. The findings indicate that family members care for their relatives at a great cost to themselves. Thus, it is an invitation to also take into account caregivers and other family members' needs as part of integral attention in the field of chronicity[312].

Among the problems associated with caregivers' research, there was identified a lack on the specification of the caregivers' needs; care receivers are not taken into account as they should and there are many gaps resulting from subjective caregivers' benefits[313].

Furthermore, on self-administered research instruments, family caregivers tend to report fewer problems than what the ones they actually have[314]. Individuals are often recruited from formal sources, such as diagnosis or treatment centers, or self-help groups, which are why there is a bias grouping[315]. Moreover, most family caregivers involved in this research are middle-class women, who live in the city, caring for relatives with dementia[316].

There is a large increasing population of family caregivers whose quality of life receives little or no attention. This includes: family caregivers of children and adults with chronic illness that causes technological dependence, as well as caregivers of individuals with neurological disorders and traumas. Research shows a direct relationship between the years that are spent in care with increased caregiver's emotional stress. Thus, people who had cared for their relative for a short time disclosed a slight higher level of anxiety than those who did not carry out that caring task. However, those who had been caregivers for many years revealed the highest rates.

Researchers measured these rates by the amount of: happiness or unhappiness, the levels of sleep or insomnia, and the crying outbursts of those involved in caring for others. However, they did not find similarities in terms of caregivers' physical limitations. In contrast, the longer they had been in their caring activity, the lower levels of physical limitation they showed.

The level of social support in people with chronic illness was explored in three studies conducted in our setting. Results indicate that family members take a leading role in these people's life and care[317, 318, 319]. Based on these findings, the importance of spiritual experience should be considered when meeting the challenges of life imposed by the situations of chronic illness and death, to work for their quality of life.

Nevertheless, research studies show that care routines with patients are limited to physical aspects, as well as entangled in technology management, rarely considering psychological aspects, and what is more, without addressing a spiritual component.

The main needs of people who have experienced illness and death of a loved one are related to information, companionship and support in decision making[320; 321; 322]. When there is pain, limitation and mutilation, they argue that their caregivers play a key role in their quality of life's perception[323]. Of course, the experience of being a caregiver of a person with chronic illness is linked to a spiritual dimension which, in most cases, is a healing force [324].

Meeting groups offered caregivers to combine social pressure in order to look for better and high-quality attention. Thus, they have found feelings of universality in their problems, so they realized that is not only them having difficulties and that someone different from their own family cares about their grief[325].

Some other studies also conducted in Colombia show that caregivers have difficulties with loneliness, the lack of accessible health services and the costs of medical treatments. They also acknowledged the members of the Church who are willing to help.

It is therefore essential to make proposals that include social support and the environment, to encourage behaviors that minimize risk factors, which have been identified as complications in chronic illness. These proposals should address church support for those who demand it.

Participants state that nurses' support them organizing meetings, providing guidance on how to handle situations and deal with the illness, and to improve self-esteem. The two participants of the study state that there are significant difficulties in the support groups' work because of the patients' health risk and their difficulties attending meetings. Therefore, they require home service, so they do not need to commute, in response to their reality, to better meet their needs[326; 327].

Caregivers' caring ability can be increased by improving their understanding of the situation, stress management and the search for effective support[328]. Since these experiences create an interconnection among different family members, it is necessary that social support networks identify these experiences as a whole[329].

A research study proved spirituality is a powerful social support source. It was concluded through the spiritual and secular response of 25 caregivers and religious parents of 19 Chicano families that have children with chronic illness. Specific interviews were analyzed through interpretative technology and a symbolic interaction framework.

Six categories emerged from this research. It included different expressions of religiosity from the experience itself: identifying God as a key factor in the outcome of the child's illness, recognizing a close link between God and the child's health care, being parents who take an active role to facilitate God's will, having a commitment towards God due to the fact of being a family, seeking mediation from others before God, and keeping faith to promote optimism.

Families take responsibility for the illness without any fatalism; they do not take the results as default or unchangeable. They take on secular and spiritual actions instead, seeking to ensure the best childcare and to find ways to intervene for the child and the family's favor before God[330].

Another research study has found that, in some cases, caregivers have a chronic illness. In that sense, stress and their multiple roles interfere with the medical treatment of the illness in daily routines. However, religion has a special supporting effect that allows them to think of the simultaneous experience of their roles[331].

Similarly, a research study, conducted in southern England, was aimed to examine the unmet needs of informal caregivers; it also aimed to compare their perspectives to the ones of those around and professionals. Its hypothesis was that a poor acknowledgment of needs may have implications for the caregivers' welfare, in that sense, for the ability to keep up with their role.

Needs were defined as a service or resource that would mean a benefit on health condition. Thus, face to face interviews with caregivers and disabled participants (randomly selected from disability records) and telephone interviews with professionals were conducted. The "needs assessment" questionnaire of South Hampton and "the health status" of caregivers were used throughout this process. Caregivers showed a similar health status of those people from the general population.

They usually consider as unmet needs, the short periods of domestic help and the respite care. Caregivers who reported this kind of needs also showed poorer levels of mental health and vitality in comparison to those caregivers who did not. Similar numbers of unmet needs were found in participants with disabilities, professionals, and caregivers themselves.

Caregivers and disabled patients agree on their unmet needs in a 52%. Caregivers claim, more than disabled participants, to have unmet needs related to short breaks and domestic help.

The tests match in 59% for family and professional's caregivers. Family caregivers claim more unmet needs for short breaks than professional caregivers, who, simultaneously, identified more unmet needs regarding respite care. Authors conclude that, with a line based on the current legislation, caregivers' needs must be addressed independently, especially the ones related to community support and flexibility with short support services, developed specifically to meet their needs, including spiritual ones[332].

During the last twenty years, both research and testimonials argue that quality of life for families facing this situation is different from those families that are not facing a chronicity situation[333; 334; 335; 336; 337]. Some other authors assert - from the analysis of quality of life- that social support and assistance required by caregivers and people suffering from disabling chronic illness should include: physical, social, psychological and spiritual welfare[338].

Consistently with holistic care giving, support professionals should effort more constantly in order to ensure spiritual needs and resources are taken into account when caring for people within chronicity. This need for comprehensive care for both parties has also been widely documented[339; 340; 341].

The role of nurses and other professionals

Health professionals might work with clergy members and counselors trained to help individuals and families to manage spiritual issues that arise from these life experiences, mainly, through sources that comprise chronic disabling conditions.

In that sense, religious institutions should be encouraged to address the disability and assist those living with it. It is important to encourage absolution from guilt and to establish meaning, reconciliation of people with disabilities and family harmony. Early intervention support to promote these achievements should include all the people involved[342].

Key questions are necessary to assess features, as well as inviting to a communication on the spiritual needs and concerns. Moreover, to remind that receptivity to others' spiritual needs requires an approach to our own spirituality.

Education is also a key factor. There have been lessons' experiences by nurses teaching church members who want to help patients at home. A small respite program may be created to relief and simultaneously support caregivers and receivers[343]. Some attempts to strengthen social skills have also proven to be quite effective[344].

Nurses and other professionals help patients and their families through small community groups, promoting networks. These professionals may engage in social programs and take their leadership and expertise there to solve community needs. To this aim, working consciously one's attitudes in care are essential factors. Moreover, when caregivers and receivers express their mercy rather than pity is also essential[345].

It is mandatory to seek an active role for care receivers, which in many cases, despite nursing theoretical recommendations, does not take place in real practice[346].

Those affected by this experience wish spiritual and practical relationships with individuals that understand their experience, since being “different” and their health condition generate isolation. So opportunities to share feelings associated to these events are mandatory. Listening to them carefully promotes spiritual welfare. People, who adapt effectively, look at difficulties and usually share their experiences. Quality of life may be different for those living in situations of chronic illness, so it is still important to promote self-care and help[347].

It is essential to highlight that training in treatment management has been proved to be quite useful, especially when caregivers and receivers are required to live at home, in a situation of dependence on technology[348].

Planning should be scheduled by the family and the care receiver. It requires open communication without overusing power, locating users as the center of activities and involving the community. The contemporary social model of disability and professions ought to focus on helping to ease environmental restrictions that keep people with disabilities away from a good quality of life[349].

The role of the nurse is necessary to reinforce a positive attitude. Increasing optimism might help, for it to be genuine the nurse must know users for a long time. A nurse may assist in finding a positive meaning or reward in giving and receiving care. This knowledge might have been acquired from extended home care, caregivers’ support group or from working with the care receiver. It has been documented that if the family has a priest related to this person, he might also help in times of trouble[350].

In the rehabilitation department, nurses are in a privileged position to conceptually understand and help exploring problems of family in caregivers and receivers' quality of life. Family caregivers' health care and their quality of life are crucial areas for future research, when home care becomes a feasible alternative in institutional care.

Nurses, who go to the household and find services associated with formal religion, should ask caregivers and patients if a church representative supports them. Regardless, nurses ought to notify priests, so that whoever visits their household is ready to assist the family in the best possible way.

Some authors have documented, from experience, observation and research that nurses must transcend a model to look for suitable caregiver-receiver relationships. It would guarantee effective assistance at home, especially in circumstances that are threatening within care[351, 352].

Records show that professionals may play a significant role in facilitating the caregiver's and the chronically ill person's a life of formal religion. Any other formal religious aspects like prayers, readings, music, and television should be encouraged for those who find them useful and when they take into account these kinds of suggestions[353]. Meanwhile, holistic care must include caregivers and receivers' worldview, so that they express their religious desires freely, even when, due to cultural reasons, there is conflict agreeing with the medical treatment[354].

A nursing integral vision may detect, in due course, a negative impact of care. It is necessary to analyze the alignment level of the person with disability in consultation and home visits, caregivers and the family's environment, in order to directly and indirectly achieve a better life quality[355]. The use of interpersonal theories is recommended as a conceptual framework through educational sessions with the staff group in order to develop prevention strategies in case of aggressive management or adverse events[356].

It is important to consider the context where care is provided, in order to simultaneously take into account: spirituality, daily life stress and the multiple caregivers' responsibilities, as well as the impact generated by the illness. Therefore, approaches should consider closer relationships among professionals, family and church[357].

The state of the art shows that the experience of chronic disabling situations, by family caregivers and receivers, is quite steeped into spirituality. This experience is often stressful and generates a sensible and a subjective burden, but it also generates personal growth benefits for those who may find a transcendent meaning, as expanding their consciousness.

Caregivers as well as care receivers have multiple roles and risks that must also be addressed. Hence, it is worth highlighting the importance of nurses, and the urgent need for a deeper understanding of the spiritual dimension. In the research that was carried out during the last decade, most studies have been descriptive and their applicability is quite restricted, so they hardly support these situations. There is also limited information on the human experience of care and its positive aspects through which people are empowered, regardless the care burden, difficulties, and exhausting routines.

Once, a professional nurse was visiting a caregiver and her son with fetal malformation; he was dependent in all aspects. When the nurse saw him, she could not hide her shocking reaction towards the child's physical aspect. Then, the caregiver herself said: -"*I know people think that my son is a monster, and you may see him like that too, but he is a cute boy; the day you see him as a cute boy, you will be able to help me*". Since then, as stated by the nurse, she learned to determine the caregiver's significance: -"*If you can see the care receiver beyond his/her physical appearance, it would be easier to understand what to do,*" she says.

True health is the strength of life; it means strength within suffering to face death. It is not only a body's condition, but the soul power over different physical conditions. Professionals who help people affected by impairment, whether they are caregivers or receivers try to promote health that transcends physical, cognitive, and emotional limitations in order to achieve spiritual welfare[358].

In order to complement this information, the author of this paper carried out a quantitative-comparative study, with a planned sample of 80 people divided into two groups. The first group was made up of 43 chronically ill patients at the rehabilitation service at the Telethon University Hospital- Clínica Universitaria Teletón-, and the second one, 37 family caregivers, who were registered in the caregiver's program at the same hospital. The Spiritual Well-Being Scale by Ellison® was used; open questions were asked with reference to their personal relationship with God, a superior being or higher power, their relationship with other people, and their relationship between their current health status and spiritual life.

The findings of this study support the conclusion that these experiences are associated to a different human development level. There is an expansion of our own boundaries and orientations towards broader life perspectives and purposes. Thus, nursing was ratified as a science, as an art with integral care as a priority, spirituality as part of life, seeking to expand consciousness in those who go through these kinds of situations.

The study found that caregivers are under stress and high risk of illness because of their care life experiences. Thus, the spiritual dimension is an important factor for the human experience of giving or receiving care in a chronic disabling illness situation, which involves the entire human being.

Likewise, these findings proved that creating health in a disabling illness experience requires a unique focus that accepts humans as integral beings and their close relationships with the surrounding environment. Hence, the conceptual health model of expanded consciousness proposed by Margaret Newman is a useful guide to work on the spiritual dimension of care in chronic disabling situations, which demands to check the binomial caregiver and care receiver simultaneously.

A way to address the spiritual dimension of care in chronic illness situations is through the perception of the spiritual well-being as a sense of harmony with oneself, with others, and with a superior power or God. Ellison's spiritual well-being scale was a useful tool to measure caregivers' spiritual well-being, not only on its feasibility at an institutional level, but as a key support to Newman's conceptual model.

The spiritual well-being scale identified in caregivers and care receivers at the Universidad de La Sabana Hospital was rather high. It was higher at the religious level than at the existential. When comparing all levels of spiritual well-being of caregivers and care receivers, there is a higher spiritual well-being in the care receivers group, the difference shows a confidence level of 90%.

Moreover, when comparing religious levels on caregivers and care receivers on their spiritual well-being, the religious dimension seems higher in care receivers. However, the difference is not statistically significant.

Still, comparing the existential dimension shows a higher level in care receivers. This difference was indeed significant with a 90% confidence.

Finally, this study verifies several findings reported throughout research literature and shows the importance of spiritual well-being when caring for people who take up caregivers and receivers roles in situations of a chronic disabling illness.

The spiritual dimension may be an important factor to share for those living these experiences, which bring them closer to many answers regarding pain and human suffering and may have larger impact over time, as a source for coping with a condition, with implications for quality of life in the long term.

Conclusions

Building care for people, who are experiencing a chronic illness and their family caregivers, requires a different approach that provides integral meaning to their situation.

Exploring the spiritual well-being implies a direct and active role by the binomial caregiver - care receiver. It also demands an assessment of their life patterns and the experience they go through, which is a requirement to expand their spiritual potential as a healing element.

Health professionals should be trained in the spiritual dimension of care, including it as an important therapeutic element in situations of chronic disabling illness. The nature of this dimension and the complex experiences approach demand a new individual effort. It requires an interdisciplinary perspective, as well as supporting permanent rehabilitation and coping processes that are also complementary for the beneficiaries of this kind of support.

There is a lack of policies on care for caregivers as well as long-term care services. In all cases, a specific approach to the spiritual and general well-being of people with a chronic illness should be incorporated.

Based on research, it is necessary to integrate the spiritual dimension of care to work on developing caregivers' skills and to socialize these findings with other institutions, including religious ones. The objective is to set workspaces in a health dimension that has not been addressed comprehensively. The spiritual dimension of care can no longer be seen as a precious jewel in a box, in which there are worse social problems of chronic illness every day. Real care is called to produce operational deeper answers that have the expected impact on family caregivers and their care receivers' quality of life.

3

“Caring for caregivers” ® Program

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Introduction

The core of a scientific theory is characterized by an effective use of models and associations[359]. They, along with science, strengthen the knowledge of any field. Therefore, this chapter presents the creation of a caring model for caregivers of people with chronic illness. It is the result of a research study carried out from 1996 to 2005.

The objective is to socialize the steps in the construction of this proposal and suggest a scheme to organize reflective thinking, regarding care for family caregivers of people with chronic illness, leading to interact with them during their experience and support them in their role. It is also expected to develop knowledge and logical connection throughout different areas.

The model is a simplified representation of a complex reality; it is only useful when it corresponds to that scenario and when important elements are well built and considered[360]. This model is originated from organizing vague and complicated ideas into a coherent structure, which allows giving meaning and generating new perspectives. The model requires an abstraction, i.e. a conceptual development that preserves the general characteristics of objects and acquires increasingly wider relationships into an integral structure[361]. The power creator is one of its qualities.

The scientific method helps to recognize and solve a problem that has not been addressed completely or satisfactorily explained. Then, a series of hypotheses and questions are generated in order to build a model within a theoretical context, which is subject to all internal and external criticism. It shall be carried out through a crosscheck process that must address that problem in the end. Models generate two types of knowledge: forms or facts. Forms: meet or satisfy a theoretical assumption. Facts: are more complex and are often integrated within a general theory[362].

However, the most used method of solving problems in nursing is the systematic process. Nevertheless, this method should not remain focused on the main problem in nursing, but on the contrary it should be based on a specific case, from a beneficial and humanizing perspective vis-à-vis patients, families or communities. Likewise, methods must be flexible, looking for a holistic and unique approach, where caregivers and care receivers are creative and co-participatory. These proceedings should be originated from the practice itself. In case different methods are hazardously adopted from other disciplines, it may indicate "low analysis ability from nursing". Furthermore, using automatic standardized methodologies and isolating care are inaccuracies, in which the care subject is simply engaged as a research object[363].

In nursing, models and theories may arise either inductively or deductively. Inductively, when they are theoretical propositions derived from observing and systematizing new information, based on qualitative research processes; deductively, when premises generate new hypotheses, to the extent that new hypotheses are supported and proved through practice, generating new theories.

The way in which hypotheses arise is often linked to practice. Hypotheses lead to a new research linked to other disciplines. All models must meet certain requirements, which are rather general and simple as to: be made up of propositions; link concepts; guarantee testable and hypothetical basis; be consistent with valid theories, principles, and laws.

Along with the impetuous appearance of nursing models during the 1950's and 60's, most research studies paradoxically used taxonomic models. It concluded with the creation of the North American Nursing Diagnosis Association (NANDA) in 1982, which in due course defined the human response patterns within nine categories. This taxonomic model aims to analyze the classification of phenomena based on similarities or common characteristics[364].

Going back to the taxonomic model used in nursing, its object of study - according to NANDA criteria - is the reciprocal action or interaction of people and their physical, mental, social, financial, or any kind of environment[365]. In general terms, this definition clarifies the object of nursing models and the minimum way to find those common features that require to be classified.

Classifying nursing models includes theoretical, functional, and personal models[366]. Theoretical models focus on the definition and organization of ideas and concepts, rather than practical tools. Functionalist models -leading this research- are guidelines for nurses to collect data and communicate it, which standardizes and audits practice through its structure. These functionalist models might be or not linked with the theoretical models previously mentioned. Finally, personal or mental models, that are frequently used, are involuntary mental expressions of a personal pattern. Nonetheless, they seem to be less relevant and pertinent from the generated knowledge.

Different strategies have been developed through specific models for caregivers of people with chronic illness such as objectively lowering the amount of care by the caregiver (respite pause, strengthening care receivers' abilities), and interventions that improve the caregivers' well-being and coping abilities (psycho-educational, psycho-therapeutic support and from multiple support sources).

Consecutively, these procedures generate counseling and intervention models that are classified according to the criteria that are being used. These criteria may be connections concerning counselors, patients, actions to be performed, types of interventions, structures, as well as the institution in which interventions are carried out[367, 368.]

The following is a classification of models, presenting and classifying research carried out by the *Caring for patients with chronic illness and their families Research Group at Universidad Nacional de Colombia*:

TABLE 1

Classification of Models

CLASSIFICATION	MODEL	ACTION OR DEFINITION
Orientation models	Psychometric model	The counselor is the expert in a technical series.
	Clinical-medical model	The counselor carries out a diagnosis and designs an intervention plan.
	Humanistic model	Process of assisting individuals in positive environments and relationships.
Intervention models	Counseling model	Direct action on the individual to make up deficit situations.
	Consultation model	Direct action on groups or individuals, through therapeutic, preventive or development approaches.
	Technological model	Process of information and resolutions of limitations through the use of technological means.
	Services model	Direct action on a group of members of the population which is at risk or deficit.
	Program model	Interventions through direct actions model on groups.
	Services model performed by programs	Direct intervention on groups after needs analysis, followed by planning, prioritizing, and designing intervention programs that satisfy them.
Models leading interventions	Basic models	Clinical interventions, programs, consultation.
	Mixed models	Psycho-pedagogical models.
Organizational Models	Institutional models	Conducted by governmental and nongovernmental entities in towns, cities, departments, and countries.
	Private models	Undertaken by groups, centers, teams, etc.

Retrieved from: Esperanza Bausela H., *Modelos de orientación e intervención psicopedagógica: modelo de intervención por servicios* (Psycoeducational counseling models: model of services intervention). *Revista Iberoamericana de Educación*, 34(3). Organization of American States, November 25th, 2004.

Therefore, the care model for caregivers of people with chronic illness is: functional, humanist, service oriented, consequential because it involves different steps to reach a specific goal. This model is also representative as it reproduces caregivers' characteristics as the basis for its construction. Additionally, it is predictive because it announces possible outcomes of a change based on the degree of success of individuals in a certain process. Some references that were checked have some interventions that could lead, as in this case, to design care models for family caregivers of people with chronic illness. Nevertheless, those designs have been proposed for different contexts[369, 370, 371, 372, 373, 374, 375, 376, 377, 378].

Background

Back in 1996, a new field of study, meeting the requirements of the chronicity growing phenomenon, was proposed to address the demands of a new epidemiological profile in Colombia. Thus, the *Chronic Patient Care Group* was created based on different interests concerning teaching, research, and extension education.

This research group was shaped by professionals trained in child, adult, family care as well as care management. This group projected a new field of study and research on care for chronic patients and their families at the Universidad Nacional de Colombia School of Nursing. Since then, seven specific subjects have been taught through the Nursing Master's degree program; some of them were also available for undergraduate students from different areas at the university.

Likewise, there have been 72 studies in this field. Different caregivers' matters have been analyzed nationally and internationally. Based on this, there is a characterization describing caregivers, in terms of gender, age, marital status, education, social background, causes, time, and intensity of the experience, support / burden, plus the patient's level of functionality. Additionally, family and personal problems, experiences, support systems, and quality of life topics have identified; there has been significant progress in conceptual aspects.

During these years, the *Chronic Patient Care Group* -supported by Universidad Nacional de Colombia School of Nursing- has been working on several publications and multicenter projects: building a field of study in chronic patient care (2000); international seminar on caring for caregivers (2004). Furthermore, this progress, the permanent analysis of scientific and technological advances, plus offering a special program for caregivers of people with chronic illness led to build a caring for caregivers' model.

This model works as a response to strengthen the ability of care, as a significant feature because it is related to those managing chronic conditions and their well-being. Therefore, this model may become a protective agent in their quality of life.

This model was built based on a caregivers' systematic observation, taking into account their characteristics and how they respond to different conventional and innovative interventions, such as, support to develop care abilities.

Its main objective is the search for alternative care for Latin American caregivers of people with chronic illness. Then, while supporting knowledge construction, it meets multiple needs and individuals. For this process, available evidence worldwide was included.

A literature state of the art shows that health professionals and family relationships in the path of chronic illness is closely related to uncertainty and everyday life management, which may be demonstrated at different times, not always in a sequential order. The first stage comprises expectation, anxiety, and trusting characterized by a wish for acknowledgment and respect for their daily activities, in which caregivers seek for cooperation to solve problems.

The second stage of disappointment, characterized by perceiving just small changes in their situation, dissatisfaction, frustration, fear, and a perceived lack of control with concerns on themselves and family protection. The third stage corroborates the importance of support assistance, alliance and trust, in a more selective way that sets out each other's expectations and perceptions. Fears to ask questions might be overcome. Support and recognition are available.

The main objective of a support model in a chronicity experience is the caregivers' well-being, no matter the phase of the relationship. Caregivers themselves are responsible for the person cared for in the end, so caregivers should be strengthened to support themselves and their families. Therefore, it is essential that caregivers are acknowledged, in every single aspect of their quality of life: their health, help from other families and institutions, emotional support, appreciation and recognition, information on how to care for the person cared for, care problem solving, ability to react towards difficult behaviors by the person cared for, their way of dealing with a certain care situation and how to overcome new, unknown, unpleasant or even frustrating situations.

The Latin American context has a large number of people with disabling chronic health problems, who are cared by family members, most of the time. This means inner workings are altered in these families. Unfortunately, health insurance systems in our countries do not have long-term care models, neither appropriate support for people with chronic disability nor their families.

Caring for Caregivers Model

Concepts

Some essential concepts within the Caring for Caregivers' model are:
1) Family caregivers' care abilities
2) Family caregivers
3) People with chronic illness
Some complementary concepts are:
1) Courage
2) Patience
3) Knowledge

Caring ability for family caregivers

The caring ability is related to those people who take on the main caregiving role and their potential care for their relative in situation of chronic disabling illness. This ability includes a cognitive and attitudinal dimension, which are identified and measured under indicators of knowledge, courage, and patience[379]. The caring ability may be measured through direct communication with each person.

People with chronic illness

Within this context, *a person with chronic illness* refers to that experience of going through a functional and organic disorder that produces permanent disability and requires long periods of care, palliative treatment and creating a monitored life style adaptation. People living in these situations are active and transcendent human beings with the ability to grow during care. Margaret Newman's conceptualization[380] is used here. It establishes health as an integral pattern, including illness and no illness related expressions and considers the individual holistically expressed through a specific pattern.

Awareness about these patterns may be useful for people to become aware of their interaction with the systems. Living in a situation of disabling chronic illness requires identifying yourself as a person whose pattern moves in terms of a chronic illness that is persistent over time, which generates a residual disability. It is associated with irreversible pathological changes and requires special or palliative care because there is no cure for it so far. The disabling chronic illness experience is perceived as a dysfunction that blocks the possibility to fulfill his role for more than six months according to expected parameters.

Family caregivers

Family caregivers take on the responsibilities of caring for a loved one, a relative, who is in a situation of chronic illness. They go through a decision-making process. Family caregivers carry out or monitor daily life activities, seeking to offset the dysfunctions of the care receiver.

Knowledge

Sometimes care is referred to as a simple matter of good intentions or warmth, but this art and science include understanding others' needs and being able to meet them properly. It is important to know care receivers: their strengths, limitations, and needs and how they may achieve personal growth.

This knowledge must involve general and specific aspects that may be used at a right time and place. Caring comprises implicitly (nonverbal) and explicitly (verbal) knowledge. Caregivers usually know more about their care receivers than what it is actually expressed. Likewise, there is direct knowledge (completely) and indirect knowledge (just some information).

Courage

There is courage when the unknown and uncertainty must be overcome, without anticipating what will happen next. Value is not blind: it is informed by introspection based on past experiences. It is open and sensitive to the present. Confidence on others and the caring ability grow, bringing courage to go into to the unknown, without courage, trusting would not be possible. The higher the feeling of going into the unknown is the more value to care is required.

Patience

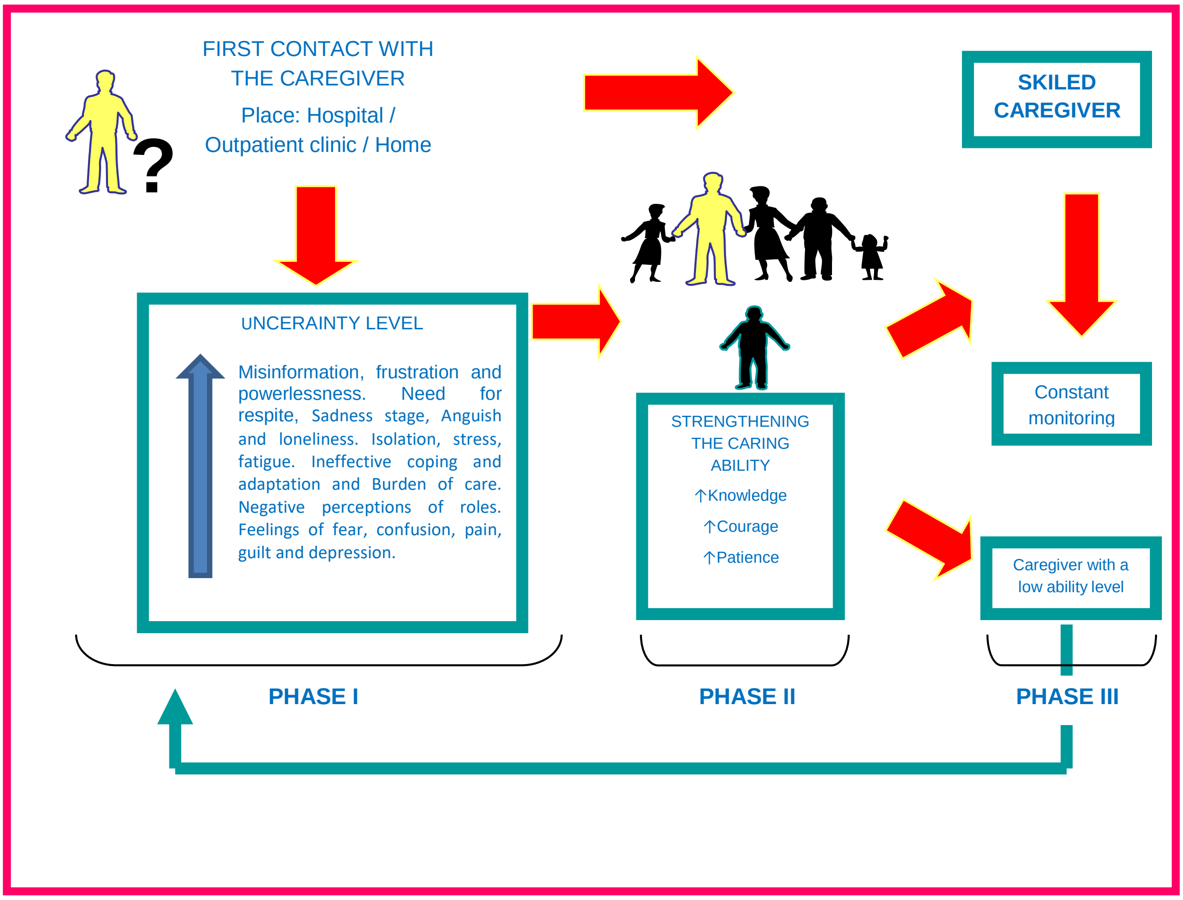
Patience is an important ingredient in care. Individuals are allowed to grow at their own pace and way. There is not usually enough time for the other person, which makes people impatient. Therefore, when people get impatient, time becomes even more reduced.

Patience is the kind of participation with the other person in which giving is complete. There might be huge misunderstandings just regarding time. Patience implies to be a good listener, understanding the people in distress, to be there for them, giving them space to think and feel. Instead of concerning about time and space, it would be better to say that a patient person magnifies the room, while the impatient person narrows it.

Being patient includes tolerance expressed in respect for other's growth and the appreciation of "leisure" and freedom that characterizes growth. Patience provides caregivers the opportunity to learn, acknowledge and discover others and themselves, thinking on getting the opportunity to care.

Figure 1

The Caring for Caregivers Model



Reference: Caring for the Chronic Patient Research Group. School of Nursing, Universidad Nacional de Colombia. Colciencias, 1996-2005.

BASIC ASSUMPTIONS OF THE CARING FOR CAREGIVERS' MODEL

The caring for caregivers' model has eleven basic assumptions listed below:

1. There is a primary caregiver in most families with disabling chronic health problems.
2. The events experienced by a family caregiver are unique and changing; they should be taken into account according to their context.
3. The primary caregiver's caring ability can be assessed and strengthened.
4. The caring ability consists of knowledge, value (courage) and patience.
5. Finding meaning is an option for people who provide care to their loved ones in an illness situation.
6. The meaning given to the experience of being a caregiver tends to be associated positively with the caring ability.
7. People can be assisted in the process of finding meaning through caregiving, but everyone is responsible for developing their own and individual perspective.

8. Finding meaning through caregiving is not an easy or quick process; it involves a combination of time, effort and ability.
9. Finding meaning goes beyond the question the why question and answers questions like: what should I do in this situation?
10. Skilled primary caregivers acknowledge themselves and their family; they are proactive in creating solutions in chronic illness management.
11. A support model for family caregivers of people with chronic illness enables to get information about their life situation in order to generate appropriate responses that help family caregivers.

Phases of the caring for caregivers model

This model has three phases in different times related to the caregivers', the care receivers' and their relationships context. These phases do not always have a strict sequence.

- *First phase:* caregivers go through a high degree of uncertainty; information is limited, there are high scales of frustration and need for respite, feelings of helplessness and constant periods of sadness, anxiety, loneliness, among others, which reduce the caring ability. This reduction creates also environments of isolation, stress, fatigue, ineffective coping and adaptation, high burden of care, negative perceptions of their roles (caregivers, parents, etc.) fear, bewilderment, pain, guilt and depression.

- *Second phase:* it comprises an intervention to strengthen the caregivers' caring ability. It is aimed to increase caregivers' knowledge, courage, and patience abilities.

- *Third phase:* it identifies a change in the caring ability, with skilled caregivers that require ongoing support or no skilled caregivers that require increasing their abilities; it would mean to go back to the first phase.

Professionals know caregivers are skilled when they demonstrate knowledge, courage, and patience through their behavior, which impacts the relationship with the care receiver positively. Skilled caregivers acknowledge and strengthen themselves from their care experience.

The **"Caring for Caregivers" Program ®**

The "Caring for Caregivers" Program ® is offered to primary caregivers of people with chronic illness, who contact this service directly or through health professionals, associations or other reference services.

It is aimed to help caregivers to discover their experience and analyze it, so that caregivers themselves identify their strengths and limitations, as well as the benefits of the caregiving process and the growth and empowerment opportunity, which impacts the performance of their role. To sum up, this program has been designed to strengthen the caring ability in family caregivers of people with chronic illness.

Description

The "Caring for Caregivers" Program ® has three levels aimed to strengthen each of the caring ability components. It has been strategically organized to have a weekly session during ten weeks. It has three modules: the first module aimed to strengthen knowledge abilities; the second one to strengthen courage abilities, and the third one to strengthen patience abilities.

Once completed, participants can restart the program, if necessary, or go through a permanent support plan to meet new care situations that were not included within the general instructions. The post-program support is provided upon demand, on a constant or occasional basis either personally, online, or by telephone.

In the first session new group members are introduced, including caregivers who start the program and coordinators. Students, professors, young nurses and people who have previously participated in the program are also guests on a voluntary basis to assist new caregivers and comment from their experience within the program.

In *module I* there are three workshops to strengthen awareness aimed to get information from caregivers: Who are the ones sharing the experience of giving and receiving care? How to prepare to continue caring for a relative in a situation of chronic illness? What do we know and what would we need to know to be skilled in caring for our relative and ourselves in this life experience? (See Table 2).

TABLE 2

Module I "Caring for Caregivers" ®. Program

WORKSHOP	OBJECTIVE	CONTENT
The caregiver's experience	To build a workspace with knowledge, acknowledging those involved in the process of family care around the chronic illness experience.	Recognizing the nicest and most important characteristics in the person who is being cared for. Acknowledging the most important caregivers' qualities that are useful in their being family caregivers task. Checking the activities caregivers think they can do for the person they care for.
The care receiver's experience	To build a special environment that allows the family to analyze and enhance care for caregivers and receivers.	Reasons to take up the caregiver's role. Difficult aspects for caregivers when taking up caring tasks. Aspects that build caregivers' confidence. Caregivers' fears. Aspects that assess caregivers' process. Taking into account care receivers when planning care activities. Identifying care aspects. Solving concerns on care training.
Knowledge required understanding and facilitating the caregiver's role	To create a workspace to reflect on the knowledge acquired and required to care skillfully as family members is in a situations of chronic illness.	Caregivers' performance in self-care. Areas requiring to be modified in self-care. Preserving the caregiver's health. Communicating with other caregivers.

Reference: Caring for the Chronic Patient Research Group. Design and assessment of a program for the development of care abilities in family caregivers of people with chronic illness. School of Nursing, Universidad Nacional de Colombia. Colciencias, 2003-2005.

Module II has three workshops with topics that build on caregivers' courage, such as the process of decision-making in care; social skills, social support and caregivers' empowerment (see Table 3).

TABLE 3

Module II “Caring for caregivers”®. Program

WORKSHOP	OBJECTIVE	CONTENT
Profits of caring a person with chronic illness	To create a workspace for thinking on courage as a caregivers' major profit in the care process.	Similarities among caregivers. Facing care difficulties. Matters that make caregivers brave when caring in a situation of chronic illness. Identifying one's courage.
Decision making in the caring task	Apply a decision making model for understanding that problems in care have no solution but alternatives with different degrees of viability.	Applying a decision making process to care situations.
Social skills and the importance of empowering caregivers' role	Building a space to analyze and recognize the support that caregivers receive when caring for their family member experiencing a situation of chronic illness.	Strengthening social support networks. Anticipating support and actions to deal with emergencies.

X|x|: Caring for the Chronic Patient Research Group. Design and assessment of a program for the development of care skills in family caregivers of people with chronic illness. School of Nursing, Universidad Nacional de Colombia. Colciencias, 2003-2005.

Module III has also three workshops that start by identifying what make caregivers impatient and what ease their minds. Then, there is a review on how to enhance the patience ability through meaning; it is also identified what each caregiver think of being skilled in care; setting goals for their relative and their own care (see Table 4).

TABLE 4
Module III "Caring for caregivers"® Program

WORKSHOP	OBJECTIVE	CONTENT
Patience as an essential feature in care	To create a workspace to reflect on patience as a necessary component for human beings growth within the care process.	What calms or gets a caregiver impatient. To identify caregivers' patience.
The experience of transcending being caregiver	To build a personal and family space to reflect on how to raise work goals in knowledge, courage and patience, in order to strengthen those skills as caregivers.	Setting targets to get knowledge, courage and patience.
Patience associated to the caregivers' care ability	To search for meaning to reevaluate the experience of being a caregiver.	Skilled caregivers. Caregivers with new goals and strategies. Caregivers identifying themselves as competent individuals who need help, counseling and rest. Caregivers' empowerment. What will happen in the future and how to get ready.

Reference: Caring for the Chronic Patient Research Group. Design and assessment of a program for the development of care skills in family caregivers of people with chronic illness. School of Nursing, Universidad Nacional de Colombia. Colciencias, 2003-2005.

Each of these modules has two face to face sessions and a non-presential one. In the last sessions, participants agree to develop activities with their family and their environment. They all are coordinated by the workshops' advisors.

The program plans constant self-assessment. These sessions have feedback time by participants where they evaluate each of the workshops with their advisors. When each module is completed, the family caregiver participant fills out a written evaluation. Results are taken into account to adjust the program according to participants' suggestions and requests and to define the needs complementary support plan.

“Caring for Caregivers” ® Program, Workshops guidelines

Workshop 1. Knowledge

Topic: The experience of being a caregiver

Addressed to: Family caregivers of people with chronic illness

Objective: To create a workspace of knowledge and acknowledgment of the people involved in the process of family care around a family member with chronic illness.

Time: Two hours

Place: face to face lesson.

Workshop Guide:

Here you will find a few simple questions. Please think carefully before you answer and be as honest as possible. Sharing feelings and issues related to your caregiving experience may help you and others to grow in the caregiving ability.
You have 10 minutes to answer. Then, answers will be discussed, and a final conclusion will be analyzed with the group.

Questions

1. What do you think are the three nicest characteristics in the person you care for?

2. What do you think are your three most important characteristics that are also useful in your task of being a family caregiver?

3. What activity could you do so that the person you care for gets to acknowledge his/her nicest characteristics?

4. What do you think you can do so that your relative recognizes your strengths as a caregiver?

5. Based on your experience, please write a short message that may help some other family caregivers who are not familiar with caregiving tasks.

Workshop 2 Knowledge

Topic: The care receiver's experience

Addressed to: Family caregivers of patients with chronic illness

Objective: To create a workspace that allows the family members to analyze and improve training in a situation of chronic illness.

Time: Two hours

Place: Home

Instructions

You will work on this task at home.

Here are a few simple questions for you and your relative(s) to answer. Please discuss these questions; your answers should be as honest as possible. Sharing these thoughts may enrich and help you grow in your caregiving abilities.

The time to be devoted for this activity is 30 minutes.

In the next session the answers will be shared by each participating family through a general analysis with workshops participants.

If you cannot answer these questions with your relative(s), then, do it on your own, but please, be sure to answer them all.

Questions

1. What motivates you to take on the caregiver's role?

2. What is the most difficult thing of being a caregiver?

3. What gives you confidence to be a caregiver?

4. What scares you?

List three aspects that let you know that you are fine and three that let you know you are not fine.

I AM FINE WHEN…	I AM NOT FINE WHEN…

How do you include the care receiver when planning his/her care?

1.
2.
3.

How do you include the caregiver when planning your own care?

1.
2.
3.

Name three special kinds of care you have achieved or should achieve with the care receiver and indicate whether they have already been achieved or not:

KIND OF CARE	ACHIEVED	TO BE ACHIEVED

Name three special kinds of care you have achieved or should achieve to yourself as a caregiver and indicate whether they have already been achieved or not:

KIND OF CARE	ACHIEVED	TO BE ACHIEVED

Based on your experience as a caregiver, what topics or questions would you suggest for reflecting on the degree of preparation necessary to be a good caregiver?

1.
2.
3.

Workshop 3 Knowledge

Topic: required Knowledge to understand and facilitate the caregiver's role

Addressed to: Family caregivers of patients with chronic illness

Objective: To create a workspace to assess the acquired and required knowledge to skillfully care for a family member with chronic illness.
Time: Two face to face hours

Instructions
During the meeting, you will reflect on the following aspects (10 minutes).

1. How do you take care for your own health? (Include in this question aspects related to physical, psychological and emotional levels, sleep, blood pressure, physical activity, energy level, comfort, movement, risk of infection, weight, digestion, medications, available services, etc.).

2. What do you need to change in your care and how do you intend to change it?

3. Once the guide has been filled out, think, along with your group, on the best way to communicate to your peers the exercise's results, in order to share useful aspects to preserve the caregivers' health (10 minutes).

4. Write down a short message to your peers about health care and its importance for caregivers.

Knowledge Workshops - Assessment

Please assess the knowledge workshops through by filling out the following format:

CHARACTERISTIC / SCORE	☒☒ EXCELLENT	☒ VERY GOOD	☒ GOOD	☒ FAIR	☒☒ POOR
Interesting					
Useful					
Important					
Innovative					
General assessment					

What did you like the most?

What was the tool that you found the most useful?

Suggestions:

WORKSHOP 4. COURAGE

Topic: Benefits of the process of caring for people with chronic illness

Objective: To reflect on the worth or courage as a major benefit in caregiving.

Addressed to: Family caregivers of people with chronic illness

Time: Two hours

Place: Home

WORKSHOP GUIDE

1. Caregivers tell an anecdote related to their caregiving experience, where they had to make a difficult decision that culminated with a positive result.

2. Answering three questions:

   a. What are the most difficult aspects when caring for a relative in situation of chronic illness?
   b. What aspects make a caregiver to be courageous?
   c. What do caregivers have in common?

3. Reading (attached): “Caregivers’ worth”

4. Asking about and discussing on the reading exercise.

Closing activity

Workshop 4 Reading

CAREGIVERS' COURAGE

The caring task can last only a few months or several years. Sometimes, it can be a lifetime commitment. It varies depending on each situation.

Some caregivers are close family members; others may be distant family members, just friends or neighbors who are committed to the person with illness, this is why, caregivers' location changes. Although, most of them live in the same place, it may vary depending on the care receiver's health condition.

For some caregivers, their role implies to be in charge of another person who depends on them. For some other caregivers, direct care is in delegated to somebody else. Some other times care is shared; while some family members help the ill person with daily life activities related to food, clothing and transportation, others may visit, pray, provide company, go to the doctor, and provide help to carry out specific activities in which special support is required.

Then, what is the caregiver's fundamental characteristic? What is the difference between caring for a spouse in a situation of chronic illness and caring for a parent who is not independent anymore? What is the difference between caring for a child and caring for a neighbor?

Several research groups on caregivers have aimed to answer these questions, in order to define their conditions and characteristics. From our practice, we may say that the common feature among family caregivers is the emotional impact they go through.

1. Caregivers usually have an intense sadness because the person they care for is suffering or losing abilities and they won't go back to their regular life.

2. Caregivers are affected because the family's dynamics changes.

3. Life changes quite rapidly and continuously due to those efforts to adapt to the new situation every day. There is not much time to think and to overcome the painful aspects caused by these experiences.

4. Simple daily activities, such as getting dressed, walking, bathing, and thinking clearly, in other terms, those activities everyone else consider are a natural matter become life's challenge.

5. There is frustration when healthy people and without serious problems complain about things that can be solved; i.e. *somebody else sits in my favorite spot*, *or takes our taxi*, they demonstrated they do not understand our situation.

6. Stress due to not having enough time to rest or for ourselves.

7. There is isolation when caring responsibilities are assumed.

These caregivers' experiences bind them to develop an understand pain, lost dreams and others' fears. Shared emotions are certainly something that characterize caregivers and brings them together.

But there is another common feature, another shared emotion that we do not recognize as often as we should: the inner strength that most caregivers did not know they had. Caregiving is a path that strengthens us in reflection, love and renewal.

1. It is the strength to continue regardless pain.
2. It is our wellspring of hope.
3. It is the power to make a difference.
4. It is the clever way to solve a difficult problem.
5. It is the fireproof that we have to achieve in order to get knowledge and survive.
6. It is what makes us appreciate and understand what is really important, which is different to those who have not traveled this path.

Our inner strength is the gift of care; it is the payment for withstanding pain. Although many would change it, so their loved one could have an easier life, health and welfare; caregivers have an extraordinary courage.

When one is so concerned, with such responsibilities there is no time to recognize these processes. When caring for a loved one, it is difficult to step back and see the amazing things done.

The lack of time and society, through their desires and values, make caregivers invisible. Caregivers have the greatest burden of care in situations of chronic illness and very few people or institutions take it into account.

The School of Nursing of Universidad Nacional de Colombia does not want this to happen anymore. Therefore, we are working so that caregivers get what they deserve for their hard work. It is necessary that caregivers themselves recognize their worth, acknowledge their personal achievements, draw their power and express it freely. We hope that caregivers have a sense of self confidence, believe in their own ability to have control over situations, with a sense of pride, self-respect, and personal worth.

In general terms, caregivers use their inner strength to help their loved ones and accept those care moments. We need caregivers to start using this strength in order to take better care of themselves, to feel proud in what they do and what they are, as well as to experience love for themselves and their loved ones.

The true definition of caregiving falls within the ability to grow, to be proud of being a caregiver, understanding skills, loyalty and character.

Family caregivers may be recognized by their emotions and spirit, by a kind of sadness in their eyes, but also by their hearts' determination. *They are very special people.*

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WORKSHOP 5. COURAGE

Topic: Social skills and the importance of empowering caregivers in their caregiving role.

Addressed to: Family caregivers of people with chronic illness

Objective: To analyze and acknowledge who are the caregivers' main support systems when caring for a family member with chronic illness.

Time: Two hours

Place: Home

Workshop guide

Here you will find some tables; please think carefully before filling them out and be as honest as possible. Identifying who your real supporters are will help you to strengthen the courage to face the task of caring for your relative, so your caregiving ability will increase.

Take the time to answer, discuss with your family, if you want to, to share these answers. In the next face to face session, please hand in the tables with your answers. Complete the attached tables as follows:

Supporters:

Name: Someone you would call because you trust their response in case you need immediate help.

Relationship: types of kinship.

Need/ Problem: Describe briefly how they would support you on those activities and situations you must deal with regarding the care of your relative.

For example:

NAME	RELATIONSHIP	NEED / PROBLEM
María Cristina	Sister	Stays with him when I have to leave. Provides money to buy medicines. Helps me in caring activities (bathing, feeding him)
Beatriz	Friend	Helps me to make difficult decisions
Lucila	Aunt	Lends me money
Juan	Brother	Takes my relative to the doctor

Supporting institutions

Name: Health, social, group institution.

Membership: Type of relationship, the person is a customer or part of the institution.

The institutions' target population: If you have someone to respond promptly to your request, because you are close to him or her.

Need/Problem: Briefly describe the type of request.

Institutions answer: Describe how you perceive the institution's answer.

For example:

INSTITUTION	MEMBERSHIP	PERSON	NEED/ PROBLEM	INSTITUTION'S ANSWER
Clínica del Niño (Hospital)	I.S.S.[6] customer	Doctor Jiménez	When ill	I have to wait for three hours
Church	I belong to the praying group of this church	Priest Pedro	Spiritual assistance	Successful-Satisfactory
Clínica del Niño (Hospital)	I.S.S. customer	Outpatient Nurse service	When I am confused after a medical consultation	Successful-Satisfactory

---

[6] *Translator's note: I.S.S.* stands for *Instituto de Seguros Sociales,* it is a Colombian governmental health institution.

TABLE 1

Caregivers

NAME	RELATIONSHIP	NEED / PROBLEM

TABLE 2

Care institutions

INSTITUTION	MEMBERSHIP	PERSON	NEED/ PROBLEM	INSTITUTION'S ANSWER

WORKSHOP 6 COURAGE

Topic: Decision making in the caring task.

Objective: To apply a decision making model for understanding that care problems have no solution, but alternatives with different viability degrees.

Addressed to: Family caregivers of people with chronic illness

Time: Two hours

Place: face to face session

Workshop guide

1. Warm up.

2. Teamwork activity: an example of a situation in which a decision for the future must be made will be discussed, by applying the model attached.

3. Then, individually or in small groups, apply the model to other situations. To this aim you should:

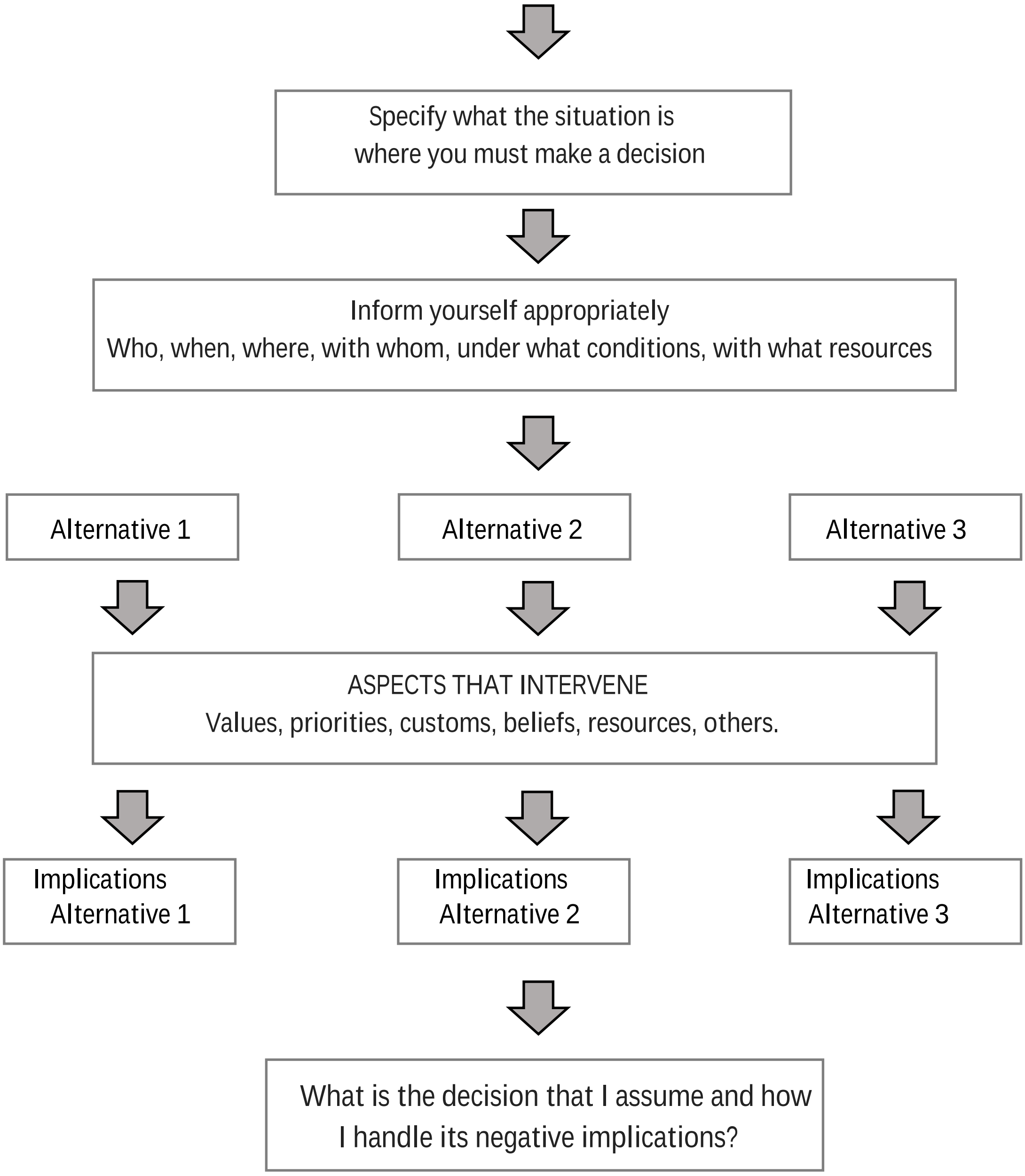
    a. State the problem situation in which you must make a decision.
    b. What information do you have? Answer the questions: who is involved, when, where, who with, circumstances involved, available resources, etc.
    c. Describe your alternatives.
    d. State those features involved: values, priorities, customs, beliefs, resources, and others.
    e. What implications does each possible decision have?
    f. Now, check which of these is available in order to assume and foresee how you to handle its negative implications.
    g. Remember that those caregivers' decisions through the caring process are not silver bullets, despite their good intentions. They will also have negative implications. Therefore, you should not feel guilty.

4. Closing activity.

Two tables have been attached.

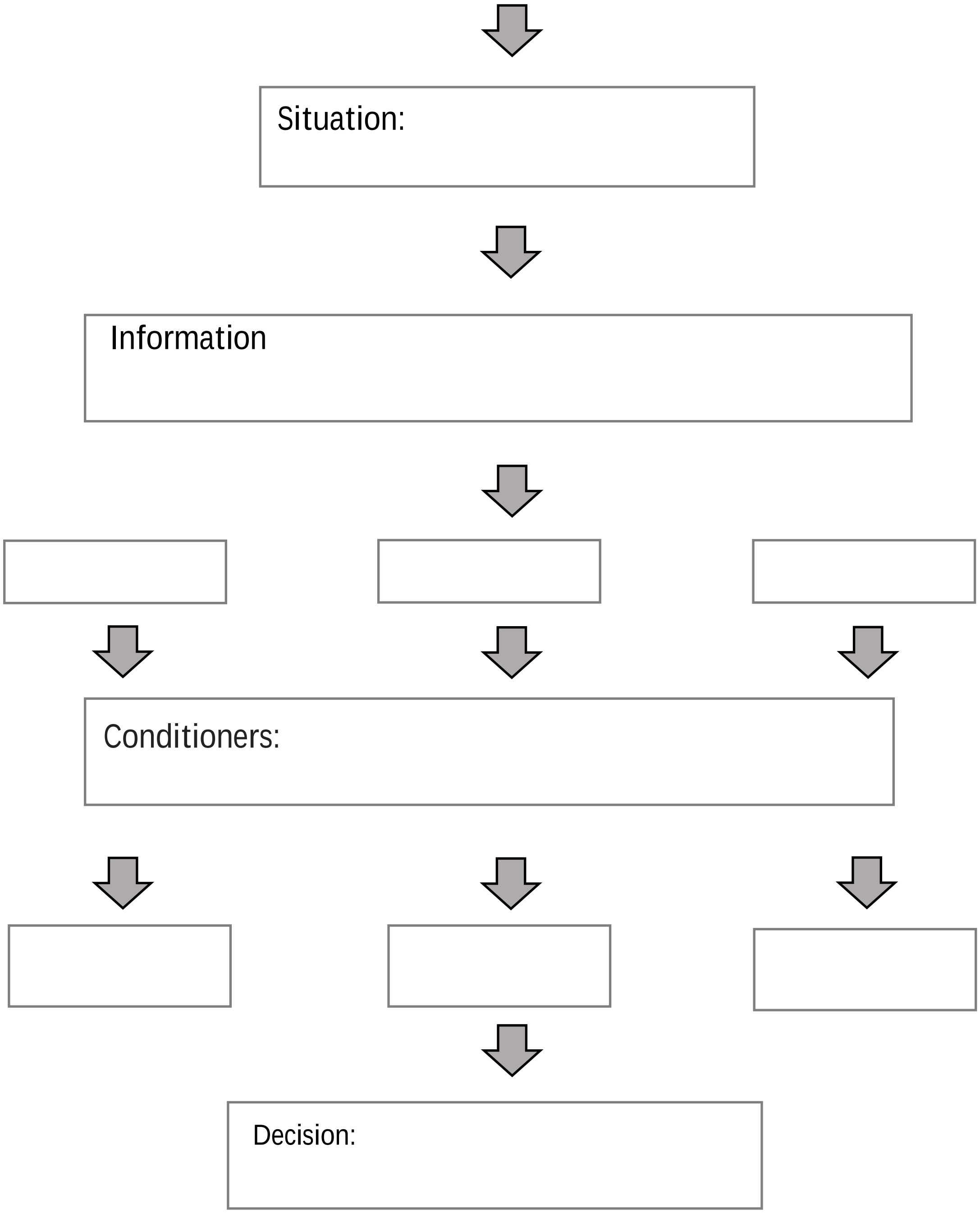
TABLE APPENDIX 1 TO WORKSHOP 6

MODEL OF DECISION MAKING
FOR THE CAREGIVER



The decisions that the caregiver makes in the care process
they have good intentions and *should not make him feel guilty*

MODEL OF DECISION MAKING
FOR THE CAREGIVER



The decisions that the caregiver makes in the care process
they have good intentions and *should not make him feel guilty*

Attached Table (Workshop 6)

Courage Workshops - Assessment

Please assess the knowledge workshops through by filling out the following format:

CHARACTERISTIC / SCORE	⊠⊠ EXCELLENT	⊠ VERY GOOD	⊠ GOOD	⊠ FAIR	⊠⊠ POOR
Interesting					
Useful					
Important					
Innovative					
General assessment					

What did you like the most?

What did you find the most useful?

Suggestions:

WORKSHOP 7 PATIENCE

Topic: Patience as an essential feature for the caregiver

Objective: To reflect on patience as a necessary element to grow in the process of care.

Addressed to: Family caregivers of people with chronic illness

Time: Two hours

Place: face to face session

Workshop Guide

1. Activity on patience.
2. Please answer the following questions, individually or in groups.

WHEN DO I GET IMPATIENT OR ANXIOUS?	HOW COULD I HANDLE IT IN A BETTER WAY?

HOW DO I GET CALM AND RELAXED?	HOW CAN I KEEP ON BEING CALM AND RELAXED?

3. Thinking based on reading (attached).

READING WORKSHOP 7

Patience, an Essential Virtue in Care *

An Englishman once asked William Pitt what quality was most essential for a Prime Minister. One person had said, “Eloquence,” another “knowledge,” and yet another “hard work.” “No,” said Pitt, “it is patience or self-control” (In Pursuit of Perfection, Charles Hugo Doyle, p. 133)

Patience is a necessary virtue for everything. In some cases, that virtue is required to wait, to take time in the middle of the rush of life. We would like to see things happening according to our own will and we want immediate changes. As a kindergarten teacher once said: "Lord, please give me patience, but please give it to me immediately!"

Patience is also the ability to tolerate, understand, suffer and endure setbacks and adversity with strength, despite fatigue. This, like all virtues, must come from us in the first place. We must be patient with our own weaknesses, our mistakes, and our imperfection. Almost certainly, we identify things about us that we do not like. For example, we should be faster, friendlier or more intelligent, but we are not, so we get impatient.

It is important to start this task by recognizing those things about ourselves that get us impatient. It is usually the thinking of those things that get us impatient from others. Getting to know you is fundamental: to understand those things that bother me and the ones that comfort me.

The task of caring for a relative in a situation of chronic illness takes a lot of patience. To get used to the situations that must be faced, to get away from emotions, despite being alone caring for the person we can never be alone, but just caring for the other person; full of fears, screams, impressions that take the serenity to think away and actually invade us without letting us rest.

Moreover, we need to be patient to confront those who do not help, who judge all the time, and people or situations that, in our opinion, are annoying. In some cases, we can pretend to be patient, i.e. listening with indifference, without getting upset or expressing emotions, trying to escape from the situation as quickly as possible, giving short answers in order to ignore our own feelings. Thus, we avoid hurting another person, and even ourselves.

Most people usually get impatient when there are too many activities to be accomplished and fail trying to accomplish them all. Most people think they know and have the ability to perform a specific role and yet, things have a different outcome. Sometimes, although people are sure of their knowledge and experience, they feel they do not know anything at all. Unexpected setbacks disappoint them, there is constant extreme fatigue; they feel frustrated when they see their personal goals increasingly distant and unreachable, having to bear annoying situations, or performing tasks with others, who do not have the skills, knowledge or expertise yet.

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* Chronic Patients Caring Group. Paper based on a bibliographic review of the topic inside the Project “Design and evaluation of a programme for developing care skills in chronic ills patients’ familiar carers”. Nursing Faculty, National University of Colombia. Colciencias, 2003-2005.

Sometimes, they even feel things are worse than ever before. Later, they insist once again that a new situation is now worse than ever before. Thus, they are in this anxious attitude back and forth. They are not yet aware that this is a challenge to achieve the most important moment in one's life.

Patience is not only the virtues that in difficult moments may help us endure annoying situations, but also a full and harmonious attitude towards life that makes us fit our own impulses and desires to an accurate pace. It is the art of not taking the apple out before time, but knowing also how to cultivate it.

In our imagination we wanted to be great, we wanted to be heroes, achieving the unachievable. We do not realize that those dreams that no one can achieve may be devastating to the spirit. It is necessary to accept ourselves as we are, perhaps anonymous, but certainly unique. Our patience is affected by wanting to do what we cannot and wishing things we do not have. What helps us to have peace of mind is just to be caregivers with an open heart, essential in our own history.

This world values and seeks comfort, pleasure and status, so there is no room for pain and family service. Virtues such as patience, resignation and humbleness are not valued in proportion. Life goes by quickly. Therefore it is necessary to take some time and reflect on the value of patience, not to be overwhelmed. In the end, what is the aim to run on a mad rush at a full speed? When we get mad, results are usually contrary to our wishes. How do we expect our lives to have more sense and be kinder to ourselves and others?

Throughout time, the experience and training acquired as caregivers lead to maturity, which may help skillfully facing challenge and caring for the person in the best possible way. It helps the person cared for and caregivers to grow as a human being and have a worth life.

It is important to change those things that usually lead to get impatient. For example, when waiting for a long time for a medical appointment: why do people get upset? Maybe, reading a magazine or a book while queuing might help.

It is important to have a friendly face, instead of showing impatience and doing things reluctantly. It would be healthier to include that activity as if it were part of a regular schedule, time and tasks, so that it is possible to wait willingly. Despair is not worthy; before we react we should take time to listen, think, and give assertive opinions.

Patience always rewards: to maintain and improve relationships with the person cared for, family, friends, and coworkers. We will obtain the desired results in this work to which we have devoted so much time and effort. The person who is patient and sensible to cope, calmly, and with inner balance, achieves a better understanding of the circumstances and creates peace and harmony around him. Sometimes, we feel that we might surrender. In these times we need a call to "be aware". Patience and self-control are constantly tested through suffering.

Suffering is common to everybody, but it may be different for each person, if it is accepted with a proper aim. Patience is strong when others are accepted the way they are. Patience does not exclude the desire to alleviate suffering, but it certainly excludes a negative attitude towards suffering.

It may be easy to think that our problems are worse than those of others, but nobody has complete control on them. There are enough problems for everyone; it has always been like that. Real patience is a difficult virtue. It is hard to stay calm at difficult times, hardship and distress, being in charge of so many duties in life and with a fatigue battle constantly testing our patience. Maybe, when we find meaning in what we do every day, when we know that opportunities might not be there twice, even though we do the same thing over and over, maybe we can be more tolerant, more forgiving regarding others' mistakes, as well as more willing to help.

As it happens with al virtues, patience is accomplished gradually. Initially, we have a genuine desire to get it. It must be activated through daily thinking. Then, we have to solve difficult situations, not to let those little difficulties and contradictions destroy our inner peace. Finally, to understand the value of our love, that needs to be expressed through helping the other. Kind hearts are certainly able to succeed, no matter how weak and shy the person may seem.

You need to learn how to wait and fight with persistence, convinced that routinely overcoming a fault or acquiring a virtue is not achieved through violent efforts, but through humility and confidence. Being patient with everything, especially with ourselves, especially, when we are educating children or promoting care.

We must consider those flaws of the people we care for; we all struggle with commitment. On the one hand, being impatient leads to fail in that attempt of caring for others. On the other hand, being patient does not mean stop educating the one you love in the correct moment, but it is necessary to look for the best opportunity so that words reach the care receivers' heart.

Patience is required during difficult situations, such as: illnesses exacerbations, poverty, and those difficulties that occur in an ordinary day. For instance, when the telephone does not work or it doesn't stop ringing when we are busy; a traffic jam that makes us late for an important appointment; forgetting taking some test results to the doctor's office; getting an unexpected visit at the wrong time. In short, some odds which are not very transcendental and make us react desperately. In these daily life events a strong manifestation of personality is required.

Patience goes together with humbleness. They fit and respect time and events and have their own limitations. Patience and humbleness are essential. It is not possible to change others, it is just possible to get to know, understand, and seek change in oneself.

Patience is not passiveness in suffering or not reacting to put up with things. Patience means strength, accepting with serenity pain and life's hardships. It is also necessary to persevere, to be cheerful no matter the circumstances. Patience encourages moving on without thinking of what would take peace away.

It also helps to calmly endure difficulties and have serenity in life's difficulties. There are always obstacles along the way and that they can only be overcome through patience. Therefore, patience is caregivers' supreme virtue, which allows them to reach knowledge and courage.

WORKSHOP 8 PATIENCE

Topic: The experience of growing up being a caregiver

Objective: To reflect, individually and in group, in order to set knowledge goals, courage and patience to build skills as caregivers.

Addressed to: Family caregivers of people with chronic illness

Time: Two hours

Place: Home

Workshop guide

You will find a diagrammed train attached. In this train there is a locomotive that reflects direction and three cars for one goal each.

a. Set a target in one car regarding something you should know better. Answer now how it will benefit you and the person you care for.
b. In another car set a target on something that requires more strength (courage). Answer now how you and the person you care for will benefit.
c. The last car is to set a target on something you should know better. Answer now how it will benefit you and the person you care for.

Now, the most important part: the locomotive. Please think of the objective of being a caregiver and state within the locomotive what guides the path of this train. For instance, those reasons you will have to proceed on your way in the right direction.

You can share the activity with your family, if you want to; it will also be discussed with your fellow program participants in the next meeting.

THE TRAIN OF THE FUTURE

Rumbo:

Knowledge Goal

Patience Goal

Courage Goal

WORKSHOP 9: PATIENCE

Topic: A skilled caregiver thinks of the future

Objective: To reflect on both the caregiver and receiver's future.

Addressed to: Family caregivers of people with chronic illness

Time: Two hours, face to face session.

Workshop Guide: Please answer these questions as shortly as possible.

1. What does it mean to be a caregiver for you?

2. How have you grown from this experience?

3. What kind of things should you forgive and thank to keep on growing?

4. What is your life plan from now on?

Caregivers are quite exceptional people, who have a huge heart and go through love, loss, and renewal at the same time. Everyone has the ability to serve others. However, just sometimes this happens to enhance people's spirit.

We would like to conclude these workshops by acknowledging and expressing our most sincere congratulations to those who have gone through the difficult and wonderful experience of care. Thank you all for sharing your experiences. Our home will always be open to listen to you and support you. We are always committed to protect and it will always be until we get to change some of the conditions required to effectively support family caregivers.

Thank you for your generous contributions, for relying on this project, and for taking some of your valuable time and feelings that have helped us understanding some of your care needs.

The following is a special message by Natividad A. Pinto(ɨ), Lucy Barrera O, Beatriz Sanchez H. and the project promoting the caregivers' caring ability support team.

Patience Workshops - Assessment

Please assess the knowledge workshops through by filling out the following format:

CHARACTERISTIC / SCORE	☒☒ EXCELLENT	☒ VERY GOOD	☒ GOOD	☒ FAIR	☒☒ POOR
Interesting					
Useful					
Important					
Innovative					
General assessment					

What did you like the most?

What did you find as the most useful tools?

Suggestions:

4

Academic products related to the “Caring for Caregivers”® Program

Boosting strengths” Project proposal to monitor caregivers

Lucy Barrera Ortiz

Natividad Pinto Afanador(ɫ)

Beatriz Sánchez Herrera

Identifying some caregivers require constant monitoring on their caring experience has been vital. It is also important that caregivers themselves acknowledge some elements and reflect on difficult situations where solving problems and finding solutions have been hard. Thus, it will enhance this process contributing to their growth.

Some topics were identified based on a social support scheme, which claimed to be expanded. They were specifically described in workshops allowing individual and group expressions, so that caregivers share their experiences and learn from each other.

This monitoring program includes eight sessions that take place throughout different topics, as shown in Table 5.

TABLE 5

Workshops of the ***“Boosting strengths” Project proposal to monitor caregivers***

NO.	WORKSHOP	OBJECTIVE	CONTENT
1	Stress or difficult situations management	To Identify stressful situations and develop strategies to address them.	Acknowledgment of stress from negative and positive perspectives. Identifying those situations that cause stress in caring and daily living. Strategies for caregivers to reduce negative stress.
2	Home emergencies management	To identify and manage home emergencies in order to build alternatives.	Identifying and assessing an emergency situation based on experience. Strategies to cope with emergencies and difficult situations, especially falls, poisoning, respiratory distress, etc.

3	Loss management skills	To strengthen skills in order to manage mourning	Describing loss situations, reactions; learning from those situations. Sharing with other caregivers' loss situations and their strategies.
4	Caregivers' rights and responsibilities	To identify rights and duties To suggest standards and basic tips for caregivers	Describing what caregivers know, think and feel about their rights and responsibilities as family caregivers. Group discussion on caregivers and care receivers' rights. Legal tools to guarantee rights and duties in caring for the chronically ill person.
5	Guilt Management	To think about guilt management and develop management tools	Getting to know and identifying how guilt is expressed. Guilt experiences, learning about a positive perspective of guilt.
6	Physical pain management	To identify pain management skills	Being familiar with elements to increase or reduce physical pain. Describing an experience of pain. How to react. Learning about simple strategies that may decrease pain sensation.
7	Medication management at home	To indicate guidelines for home care regarding specially medications management	Overview for a correct and effective use of medicines to keep track on the treatment and a stable illness. Consultancy in medicine management on individual clinical files.
8	Social support networks asking for and providing help	To provide tools to ask and provide help To learn about processes that boost social support networks	What is social support? Strategies and benefits. Asking for and providing help as social support networks strategies. Social support available mechanisms. Describing experiences and learning about social support. Social support networks' benefits.

This level should be guided by professionals who acknowledge in family caregivers an expertise and potential elements that should be acknowledged in group sessions.

WORKSHOP 1 BOOSTING STRENGTHS

STRESS MANAGEMENT IN DIFFICULT SITUATIONS

Address to: Family caregivers of a person with a chronic health condition

Objective: To determine stressful daily life situations for the caregiver or the ill person in order to address those difficult events.

Time: Two hours

Instructions: Here are some ideas on stress management and a few simple questions for you to answer truthfully.

Workshop

1. Warm up activity. Reading: “Stress Management"
2. Answer questions, individually, related to factors that trigger stress and reactions.
3. Some examples of stressful situations are to be analyzed, as well as some strategies to reduce stress.
4. Conclusions shall be shared with the group; activities to control and manage stress will be suggested.

STRESS MANAGEMENT

Stress is a response to an event, but not an event itself. Stress might be controlled. Therefore, some stressful episodes may directly affect some people, but not others. For example, a long journey to work in the morning can make a person anxious and tense, because this time is used to be worried[381]. However, the same trip may be relaxing for another person, enjoying this time alone without distractions.

Understanding that you have control over stress might help to develop positive strategies to deal with it.

How do we respond to stress?

Under stress, our body responds in a similar way as when we face physical danger. It is automatically ready for the challenge (fight); it gets strengthened to get away from danger (flight). Our heart beats faster, blood pressure increases, breathing becomes rapid and shallow. Your nervous system gets ready and your muscles get tense.

Stress might be positive or negative. When it is positive, it provides feelings of excitement and challenge. For example, when competing, when you have a new job or when you have a baby. When it is negative, you feel out of control or under constant or intense pressure, and you find difficult to concentrate. This usually impacts your body as it can play a harmful role in your health. For instance, your heart rate or blood pressure may increase. Stress might cause headaches and intestinal disorders. The cortisol hormone that is released with stress, it may suppress the immune system, making your body more vulnerable to infections or illnesses.

Stress is associated with situations or events that you may find difficult to handle. The way we perceive things is also affected in this regard. Your stress may be related to external factors such as family, work, unpredictable events, or internal factors such as high or unrealistic expectations, perfectionism, negative attitudes and feelings, irresponsible behavior, and an unhealthy lifestyle[382].

Questions

How do you react in stressful situations?

Describe a difficult and stressful situation. Try to remember exactly those details on how you reacted.

Write down the main reasons and causes for you to get stressed out.

What can you do to mitigate or avoid sources of stress?

Strategies to reduce stress

- Focus on those events you are able to change. For situations that are beyond your control, find ways to adapt and stay calm.

- It is different to be aware of stress and to know how to change it.

- Look at your stress list. Think carefully why these items in your list are so annoying. For example, if your busy day is a source of stress, ask yourself if it includes too many things to do or if you are not organized enough.

The following techniques may help you reduce sources of stress, by managing better those things you cannot control.

- Lifestyle Change

Plan your day. You can start by getting up 15 minutes earlier to reduce rush. Do unpleasant tasks early and finish them. Learn to delegate responsibilities to others. Say NO to added responsibilities or commitments, if you cannot take them. Do not feel guilty because you are not productive all the time. *Take occasional breaks, get enough sleep, and eat healthy.*

- Solve problems with an ability to face them

State the problem. Answer: What is bothering you? Why are you worried? How do you react to these kinds of situations?

Make a list of possible solutions. Make decisions on what you really want; think what prevents you from carrying it out and what you need to achieve. Select options that represent better outcomes[383].

RESPONSE TO EMERGENCIES AT HOME

Address to: Family caregivers of a person with chronic health problems

Objective: To identify and handle emergencies when caring for a family member at home in order to build alternatives.

Instructions:

Here you will find some simple questions for you to answer. As you answer, think about your experience as a caregiver; identify potential needs for emergency management related to care.

Time: Two hours

Workshop

1. Warm up activity. Individually write down about an emergency situation that you have faced, how you handled it and how you think it could have been prevented.

2. Examples on each emergency situation will be analyzed as well as some strategies to address them.

3. As a group, suggest activities to prevent and handle the following situations:
    - Falls
    - Poisoning
    - Shortness of breath
    - Some others

QUESTIONS

Describe an emergency situation with your ill family member at home?

How did you handle it?

What do you think you need to know about stress management to achieve control in such a situation?

What do you think you can do to prevent this situation?

HOME EMERGENCIES RESPONSE ACTIONS

If you know how to responsibly and calmly manage emergencies, you can avoid complications and anxieties that may affect you.

In order to face an emergency with *your family member* you should take into account:

- Some preventive actions may even prevent complications or further damage.
- Not all people have the capacity to deal with emergencies as they may get too shocked because their health conditions do not favor their immediate reactions or because they do not know what to do or how to do it properly.
- It is necessary to know some response techniques for them to be effective; being familiar with response actions in advance guarantees to be confident acting timely, promptly, efficiently and quietly.
- Remember: emergencies do not alert in advance, on the contrary they may happen anytime, anywhere. So an immediate response may save a person's life, prevent complications and extra costs.
- We have all been in an emergency situation in which acting calmly and quickly means a person's life or death. Hence, it is extremely important to know different techniques to be effectively used.

To achieve this, it is necessary to apply the so-called *early actions.* They are: *checking, calling and responding.*

The first principle: *checking* should be applied to identify problems and risks; it should evaluate the patient's condition and determine the cause of the accident.

The second one: *calling* is important to immediately ask for help; it will be much more effective if the main problem has been carefully identified. To know who to call and the required service, count on necessary resources to respond immediately to that urgency. It is also necessary to know in advance the emergency telephone number of the health insurance company.

The third principle: *responding,* relates to first aid techniques to prevent serious complications. You must ensure that they are safely provided, along with knowledge and responsibility.

The most important thing is prevention

FALLS

Falls are the most frequent home accidents. In most cases, these situations are associated with disorders such as muscles' weakness, deficiency in senses organs or consciousness alterations.

What should be assessed?

- There is loss of consciousness and a blow on head, back or chest.
- Blow without external injury (contusion).
- It is a hard blow with external wound (trauma) and hemorrhage.
- It is a sharp blow with a bone fracture.
- There is severe pain and deformation of a joint (dislocation).
- There is a severe pain in a joint, without deformation (sprain).

What to do?

The person shouldn't stand up immediately. Make sure there are no fractures or lightheadedness. In case of strong shocks, without an injury, it is possible to use ice packs. If there are wounds, stop the bleeding by putting pressure on the injury with a clean cloth.
If the cause of the fall has been a faint:

- Lay the person down and lift his/her feet to get a faster blood flow to his/her head.
- Rub his/her wrists, neck and forehead with alcohol. Do not rub alcohol on the person's nose.
- Do not give anything to drink or eat until some time has passed and the person feels better.
- Once the person feels better, cover him/her well because sometimes after having fainted there is a feeling of shaking chills that remains.

Preventing

Some rules must be followed in order to prevent falls, by patients and their surrounding environment. Falls can be very serious.

Physical environment

- Avoid soil materials that are slippery, too waxed or polished.
- Set a non-slip base between the carpet and the floor. Make sure that the edges of rugs and mats are not dangerous.
- Avoid objects lying on the floor, otherwise you might trip over. This is common in households with children (where there are toys on the floor).
- There must be handles for available support in the bathroom, in the toilet and bathtub.
- Rooms, corridors, and stairways' lighting must be available.
- Stairs should have handrails.

Habits

- Wear comfortable, well-adjusted, non-slip (rubber) and comfortable heels shoes. It would be good to use canes or walkers.
- Make sure that daily tools are available; climbing on chairs or ladders shall be avoided.
- Install a light switch at the bedside, so that access to it is easy, before getting up.
- Get out of bed slowly, remaining a few minutes on the edge, before getting up completely.
- If you feel dizzy or weak, try to sit down and avoid walking around.

POISONING

Poisoning may be due to a kind of food that patients do not tolerate or to medicines side effects.

What should be assessed?

- Identify signs such as vomiting and diarrhea.
- Abdominal pain.
- Behavioral changes.
- Different effects from those expected on the medications being administered.

What to do?

- Prevent dehydration.
- When there are symptoms like nausea or vomit, avoid fluids to hydrate, as they stimulate nausea.
- When diarrhea occurs patients may get hydrated through special food like guava, carrot, rice, potatoes.
- *How to prevent poisoning?*
- Food should be washed thoroughly (wash fruits and vegetables), preserved (frozen in containers or vacuum seals), cooked (avoid meat and seafood).
- You must check food's expiration date.
- Do not take medications that have not been prescribed by the doctor.
- Medications must be stored according to suggested conditions by the manufacturer (cool and dry, frozen).
- Medications must be kept in their original labeled package. Keep the descriptive pamphlet to have the medicine's information available.
- It is recommended to know about the details of the medications, their purpose, dose and the number of times they are to be administrated throughout the day. This information should be written on the label.

RESPIRATORY DISTRESS

This situation is characterized by an impaired respiratory function, which has been probably caused by partial or permanent obstruction of the airways or by functional deficiencies that obstruct the flow of oxygen to the lungs, causing fatigue and breathe shortness.

What should be assessed?

- Respiratory permeability (presence of secretions).
- Breath sounds (at the entrance or exit of the air in the upper airways or bronchi).
- Cough (dry or productive).
- Shortness of breathing (faster, slower, shallow breathing).
- Pale skin; purple lips and nails

What to do?

- When there are secretions, keep good respiratory tract hygiene and administer saline solution 4 to 5 inches in each nostril, in a sitting position. Keep the patient always in a semi-sitting position or sitting during this procedure.
- When there is productive cough, induce the patient to hold exhale at the time of coughing, which helps to expel mucus or phlegm.
- When breathing sounds are of bronchial origin, like a whistle, is due to a spasm. You must have the prescription to use bronchodilators.
- When the alteration is in the upper respiratory tract, you can use a vaporizer to inhale vapor by heat at a distance of 50 cm for 15 minutes.
- When the care receiver uses prescribed oxygen at home:

    - Before administering it, remember to clean his nostrils and keep nasal hygiene.
    - Do not increase the oxygen flow, without ensuring there is no obstruction (bronchospasm).
    - Avoid sudden changes in the oxygen flow (like connect and disconnect when the patient is to carry out activities such as going to the bathroom). It should be lowered down progressively.
    - Do not administer dry oxygen.
    - Do not use oil-based lubricants in nostrils.

Preventing

- Avoid prolonged, continuous exposure to environmental contaminants such as smoking and being immersed in contaminated environments.
- Avoid sudden temperature changes.

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SKILLS TO HANDLE LOSSES

Address to: Family caregivers of a person with chronic health problems

Objective: To identify and establish some skills to handle losses.

Instructions:
Go through the reading. Then, you answer the questions. While doing this, think about your experience as a caregiver. Please identify a situation of loss you have faced. Finally, analyze the messages of the story "The falling of a leaf called Freddy."

Time: Two hours.

Workshop

1. In groups, please read the *story*.
2. Individually, write about a situation of loss that you have faced and how you handled it or how it could have handled.
3. Then, in groups, you will share and analyze those examples of situations and experiences.
4. Finally, some conclusions will be drawn in order to strengthen the ability to handle losses.

Reading

Losses are attached to life processes; they may have a temporal dimension: those having to do with the past (what I used to have and I don't now) the present (what I have and I'll lose) and the future (what I wanted to have and now I'll have to give up). They are related to an initially threatening *farewell*. It is related to a link that cannot continue and is projected onto memories and feelings that are neither good nor bad; they can be either pleasant or unpleasant.

Losses generated by the so-called *grief*, which is related to a process that evolves from the time of the event until its resolution. First there is *shock* with the news as well as *denial*: "No", "it cannot be true", "could it be possible that they are wrong?" and so on. Then, *anger / rage:* "Why her, why if she is so young," "why, if she is the best", etc. Then, *negotiations*: "If she can live until December I promise I will..." which leads to make promises. Thus, while faith is a fundamental element, sometimes it could be confused with a kind of business, it is part of the grief process, and it may even be a healthy alternative to face this situation.

Later, there is *depression* when nothing works or things change. It is necessary to be able to say good bye, it is useful, and such sadness must be respected. Last, but not always in a specific sequence, there is *acceptance,* that is to understand and assimilate loss, to be ready for things to be different.

We have heard statements that reflect the feelings related to losses, as it is detailed below, they have been taken from interviews with people who care for their relatives in chronic illness processes or those living it at the moment of the interview.

"This illness is killing me; a year ago they cut off my finger and today it is my foot. Could it be possible they cut off my entire leg? It would be easier to die". "When I remember her, I think how pretty she was and then she gained weight with the treatment, got hairless, her skin got damaged, it was horrible, she suffered so much; she used to be a happy person, and at the end, she could not even move".

In other cases, there is deep sadness and helplessness: *"Good thing you came! From talking to her (points to his ill mother), or talking to myself, I find no difference. Sometimes, I think I'm going crazy". "I cannot eat what I like, I have to take lots of medicines and the worst thing of all is that I feel I am a nuisance." "One really thinks that is going to die, so God will decide. Anyway, you cannot do anything to change your fate but I think of my daughters, my husband and I get really sad. Anyway, my husband has been so good, he does not deserve this. "*

Hearing these testimonies, we acknowledge the importance of identifying skills to handle losses and to have attitudes like the one proposed by George Sand in his teachings on grief: *"Shall my memories not poison any of life's pleasures. But don't let those pleasures destroy or despise my memory."*

THE FALL OF FREDDIE THE LEAF:

A Story of Life for All Ages,
By Leo Buscalgia
Tanslated by: Clara Granda, Roberto and Daniel Vélez

Dedicated to all children who have ever suffered
a permanent loss, and to the grownups who
could not find a way to explain it.
This tale is also dedicated to Ronald, Meredith,
Stephanie, and Julia, who are actually involved
in the spring of their lives.
Also, to Barbara Slock my editor for 10 years,
who always will be the most beloved and
appreciated leaf in my tree.

Retrieved from: The fall of Freddie, the leaf [DVD]. 16 minutes. México: Ebesa Movies

Spring had passed. So, had Summer.

Freddie, the leaf, had grown large. His mid-section was wide and strong, and his five extensions were firm and pointed.

He had first appeared in Spring as a small sprout on a rather large branch near the top of a tall tree.

Freddie was surrounded by hundreds of other leaves just like himself, or so it seemed. Soon he discovered that no two leaves were alike, even though they were on the same tree. Alfred was the leaf next to him. Ben was the leaf on his right side, and Clare was the lovely leaf overhead.

They had all grown up together. They had learned to dance in the Spring breezes, bask lazily in the Summer sun and wash off in the cooling rains.

But it was Daniel who was Freddie's best friend. He was the largest leaf on the limb and seemed to have been there before anyone else.

It appeared to Freddie that Daniel was also the wisest among them. It was Daniel who told them that they were part of a tree. It was Daniel who explained that they were growing in a public park. It was Daniel who told them that the tree had strong roots which were hidden in the ground below. He explained about the birds who came to sit on their branch and sing morning songs.

He explained about the sun, the moon, the stars, and the seasons.

Freddie loved being a leaf. He loved his branch, his light leafy friends, his place high in the sky, the wind that jostled him about, the sun rays that warmed him, the moon that covered him with soft, white shadows.

Summer had been especially nice. The long hot days felt good and the warm nights were peaceful and dreamy.

There were many people in the park that Summer. They often came and sat under Freddie's tree. Daniel told him that giving shade was part of his purpose.

"What's a purpose?" Freddie had asked. "A reason for being," Daniel had answered. "To make things more pleasant for others is a reason for being. To make shade for old people who come to escape the heat of their homes is a reason for being. To provide a cool place for children to come and play. To fan with our leaves the picnickers who come to eat on checkered tablecloths. These are all the reasons for being."

Freddie especially liked the old people. They sat so quietly on the cool grass and hardly ever moved. They talked in whispers of times past.

The children were fun, too, even though they sometimes tore holes in the bark of the tree or carved their names into it. Still, it was fun to watch them move so fast and to laugh so much.

But Freddie's Summer soon passed. It vanished on an October night. He had never felt it so cold. All the leaves shivered with the cold. They were coated with a thin layer of white which quickly melted and left them dew drenched and sparkling in the morning sun. Again, it was Daniel who explained that they had experienced their first frost, the sign that it was Fall and that Winter would come soon.

Almost at once, the whole tree, in fact, the whole park was transformed into a blaze of color. There was hardly a green leaf left. Alfred had turned a deep yellow. Ben had become a bright orange. Clare had become a blazing red, Daniel a deep purple and Freddie was red and gold and blue. How beautiful they all looked. Freddie and his friends had made their tree a rainbow.

"Why did we turn different colors," Freddie asked, "when we are on the same tree?".

"Each of us is different. We have had different experiences. We have faced the sun differently. We have cast shade differently. Why should we not have different colors?" Daniel said matter-of-factly.

Daniel told Freddie that this wonderful season was called Fall.

One day a very strange thing happened. The same breezes that, in the past, had made them dance began to push and pull at their stems, almost as if they were angry. This caused some of the leaves to be torn from their branches and swept up in the wind, tossed about and dropped softly to the ground.

All the leaves became frightened. "What's happening?" they asked each other in whispers.

"It's what happens in Fall," Daniel told them. "It's the time for leaves to change their home. Some people call it to die."

"Will we all die?" Freddie asked.

"Yes," Daniel answered. "Everything dies.

No matter how big or small, how weak or strong. We first do our job. We experience the sun and the moon, the wind and the rain. We learn to dance and to laugh. Then we die."

"I won't die!" said Freddie with determination. "Will you, Daniel?"... "Yes," answered Daniel, "when it's my time."

"When is that?" asked Freddie. "No one knows for sure," Daniel responded.

Freddie noticed that the other leaves continued to fall. He thought, "It must be their time." He saw that some of the leaves lashed back at the wind before they fell, others simply let go and dropped quietly.

Soon the tree was almost bare. "I'm afraid to die," Freddie told Daniel. "I don't know what's down there."

"We all fear what we don't know, Freddie. It's natural," Daniel reassured him. "Yet, you were not afraid when Summer became Fall. They were natural changes. Why should you be afraid of the season of death?"

"Does the tree die, too?" Freddie asked.

"Someday. But there is something stronger than the tree. It is Life. That lasts forever and we are all a part of Life."

"Where will we go when we die?"

"No one knows for sure. That's the great mystery!"

"Will we return in the Spring?"

"We may not, but Life will."

"Then what has been the reason for all of this?" Freddie continued to question. "Why were we here at all if we only have to fall and die?"

Daniel answered in his matter-of-fact way, "It's been about the sun and the moon. It's been about happy times together. It's been about the shade and the old people and the children. It's been about colors in Fall. It's been about seasons. Isn't that enough?"

"That afternoon, in the golden light of dusk, Daniel let go. He fell effortlessly. He seemed to smile peacefully as he fell.

"Goodbye for now, Freddie," he said.

Then, Freddie was all alone, the only leaf on his branch.

The first snow fell the following morning. It was soft, white, and gentle; but it was bitter cold. There was hardly any sun that day, and the day was very short. Freddie found himself losing his color, becoming brittle. It was constantly cold and the snow weighed heavily upon him. At dawn the wind came that took Freddie from his branch. It didn't hurt at all. He felt himself float quietly, gently and softly downward. As he fell, he saw the whole tree for the first time. How strong and firm it was! He was sure that it would live for a long time and he knew that he had been part of its life and made him proud.

Freddie landed on a clump of snow. It somehow felt soft and even warm. In this new position he was more comfortable than he had ever been. He closed his eyes and fell asleep. He did not know that Spring would follow Winter and that the snow would melt into water.

He did not know that what appeared to be his useless dried self would join with the water and serve to make the tree stronger. Most of all, he did not know that there, asleep in the tree and the ground, were already plans for new leaves in the Spring.

Questions

Write about a loss situation

How and what were your reactions to that loss?

What would you like to learn to better respond to similar situations?

What do you think you could do to positively deal with loss?

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WORKSHOP 4 BOOSTING STRENGTHS

CAREGIVERS' RIGHTS AND DUTIES

Address to: Family caregivers of a person with chronic health problems

Objectives:

- To identify caregivers' rights and duties.
- To propose rules and basic tips for family caregivers.

Instructions:

Read the text; then, you will find a few simple questions to be answered. As you answer, think about your experience as a caregiver regarding to what you know, think and feel.

Time: Two hours

Workshop

1. In groups, read the text.
2. Individually, answer the questions taking into account what you know, think and feel regarding your rights and duties as a family caregiver.
3. Then, share your thoughts with the group.
4. Thus, some basic agreements on caregivers' rights and duties shall be concluded.

Reading

Caregivers' rights and duties

Rights and duties are considered vital for all human beings, as they respond to those needs of self-respect and freedom.

Rights and duties may be individual, social, and cultural; they are determined by the needs and situations and embodied to protect people.

It is well known that all human beings have the right to a good physical and mental health as well as to a welfare and independence environment to develop skills in a dignified and comprehensive way. For individuals and families living with impaired health, this law implies the ability to have access to health and rehabilitation services, in an efficient and timely manner.

In our situation, it is necessary to identify what our duties and rights are, some of them are:

The first duty is to recognize the rights that are addressed firstly by the Government, which legitimizes them in a regulatory system, with the community's recognition, through the 1991 Colombian National Constitution, which allows citizens to participate in making public decisions; some of the most important mechanisms are: the right of petition, the "tutela" action[7], the enforcement action, the legal complaint.

It is necessary to know and use these rights. As caregivers spend a lot of their time and in caring, helping and supporting their dependent family members, they must know they also have basic and inalienable rights.

As a result accepting consciously their responsibility regarding the people they care for, they must also accept a responsibility towards themselves.

For these reasons, it is very important for caregivers to learn and teach the following rights:

As a caregiver, myself [384]

- I will care for myself. This will help providing a better care to my family care receiver and to keep my energy throughout the care process.
- I will ask for help to my family, friends and support organizations, even though the person I care for or a family member disagrees.
- I will keep areas of my life that do not include the person I care for as if he or she would not need my help. I will try to meet the needs of the person I care for, but I will also take some time to satisfy my own needs.

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[7] Translator's note: The 1991 Colombian Constitution implemented a legal complaint named *"Acción de Tutela"* to those events that represent imminent risk for any individual.

- I will allow myself to feel frustrated, angry, and sad; I shall occasionally express other negative feelings.

- I won’t admit manipulation attempts, by the person I care for or any other family member, through guilt, anger or depression, whether they are intentional or not.

- I will accept consideration, affection, forgiveness and acceptance, from the person I care for, and my family for what I do.

I will try to offer the same in return

- I feel proud of my achievements, try to see the challenges of each day through a good attitude and courage, and cherish value that, sometimes, it is necessary to meet the needs of my loved one.

- I will acknowledge that I have become a caregiver, like thousands of other spouses, siblings, adult children and friends. I have a right to expect initiatives at local and national level, to ensure that caregivers are acknowledged and receive support.

Questions

To be answered individually

What are the actions I may carry out to accomplish the right to a good health condition?

What actions should I take to fulfill the right to develop all my skills in a dignified and comprehensive way?

What laws do I know that allow me to have access, efficiently and timely, to health and rehabilitation services?

The following questions are to be answered in groups

1. Which do you think should be the caregiver's rights?

What are my rights as a family caregiver of a chronically ill person (*write the name of the illness here*)?

What are the rights of my care receiver? My family member with (*write the name of the illness in here*)?

Conclusions

From group analysis an agreement will be signed based on the following Decalogue: the caregiver and the person cared for. It is necessary to read each of them and indicate which of these statements the group agrees to sign in the agreement, once it has been established.

Caregivers' agreement[385] (Group agreements shall be marked with a tick). You all may suggest any others, if you agree to do so.

- Express yours feelings freely when tensions arise, remaining in silence evokes resentment that afterwards turns against the other person.
- Do not carry all the responsibilities; share them with other people nearby; even with the person you are caring.
- Avoid overprotection and fear, to avoid stifling desires to live and accelerating a deterioration process.
- Avoid thinking you know enough. Ask specialists and people with experience for advice every time there is a new problem.
- Do not confuse the illness with the person. No one is responsible for the change of life and overwork.
- Talk whenever differences of opinion arise. Do not try to impose your will or fall before emotional blackmail.
- Always try your best. Whenever you feel you cannot achieve something, ask society for help.
- Do not try to anticipate. Ask questions, avoid assumptions.
- Find time for your own activities, anyone will benefit if you spoil your life.
- Keep an optimistic and active attitude despite the evolution of the illness. Do not give up.

Signed in agreement by: ___________________ Date: _______________

Care receivers' agreement[386] (Agreements shall be marked with a tick). You may suggest any others, if you agree to do so.

- Do not insist on what you can no longer achieve on your own. Do not allow others to do what you still can do.
- Learn to adapt or change the environment to your favor with technical aids in order to replace any affected functions.
- Get together with people going through similar situations. Thus, your effectiveness will increase.
- Perform any sensory or intellectual activities that are not limited by the illness. Keep your physical activity as much as possible, without getting too tired.
- Find ways to be helpful to those around you. Collaboration reduces effort.
- Do not let depression, despondency and unwillingness master you. They make your condition worse and lead nowhere.
- Allow imagination to be the tool that allows you to escape from isolation caused by the illness and links you to others.
- Do not feel inferior about being different; claim your right to be happy, just like any other human being.
- Search your particular beliefs to get the strength to keep going, you will find that the best in you cannot be affected by the illness, if you do not allow it to.
- Do not lose hope. Nobody has ever been completely healed, but someday someone will for sure. Maybe it's you!

Signed in agreement by: ____________________ Date: ____________

Notes

The right of petition

The “tutela” action

The enforcement action

The legal complaint

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GUILT MANAGEMENT

Address to: Family caregivers of a person with chronic health problems

Objective: To reflect on guilt management and create tools to control it.

Instructions:

Please read the *text.* Then, you will find a few simple questions for you to answer. When responding, discuss your experience as a caregiver and answer with your own testimonies.

Time: Two hours

Workshop

1. In groups please read the *text* you will receive.
2. Individually, please explain what you feel regarding guilt management.
3. Then, in groups please introduce yourselves to the group and share your opinions.
4. Based on this, a proposal will be drawn to plan strategies for guilt management by generating tools to control it.

Reading

We experience guilt in our life; if it is not handled correctly it may lead to a kind of blockage. Being aware of this fact will help us overcome guilt and not to turn this guilt into punishment.

Guilt is preceded and it is highly related with our scale of values. If there is a mismatch between our ideal performance and reality, it will cause painful personal conflicts that will lead to any of the following reactions:

- Intra-punitive reactions: we feel guilty for what is happening.

- Extra-punitive reactions: we blame others for everything, including our problems, as a way to avoid responsibilities.

- Impunitive reactions: we think that nobody is guilty of anything whatsoever, no matter what the circumstances are.

When we feel guilty our challenge is to turn that feeling into solutions or alternatives to repair the damage that we are causing. Forgiveness is a possibility that helps overcoming guilt.

If guilt affects us so much that it lead us to an emotional situation that keeps us away from a clear analysis, it would be necessary to visit a professional who can help us find the right solutions.

Questions
Why did I feel guilty?

What did I learn through this experience?

Some things I have done to overcome guilt feelings are:

Please describe a situation in which you have overcome that guilt positively.

Conclusions

1. Blaming others or yourself may generate a kind of relief, but it does not solve processes. There is real personal growth only when we learn from our own mistakes.
2. In any kind of mistake it is important to check what our responsibilities are, as well as my partners' responsibilities. Finding this path is essential for a caregiver.

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WORKSHOP 6 BOOSTING STRENGTHS

PHYSICAL PAIN MANAGEMENT

Address to: Family caregivers of a person with chronic health problems

Objective: To acknowledge and apply abilities on physical pain management.

Instructions:
Please read the *text.* Then you will find a few simple questions for you to answer. As you answer, please analyze your own experience as a caregiver and share your thoughts from your experience.

Time: Two hours

Workshop

1. In groups, please read the text.
2. Individually, describe an experience on pain management of you have gone through and how you handled or could have handled it.
3. Then, in group discussed and analyze group members' examples of situations and experiences.
4. From this point on, your ability to handle pain will be strengthened.

Reading

Physical pain management

Pain is an inevitable experience. It is associated with stimuli that may cause damage and suffering. We have all suffered, as it is one of the most distressing experiences of an illness.

The meaning people give to the experience of pain depends on the ability to bear it, accept it and manage it. For this reason, we require abilities to accomplish relief.

We, caregivers, acknowledge that pain is a warning mechanism that alters the person's well-being and causes emotional and behavioral reactions. It is a sign, an alarm warning on an urgency that leads us to look for help.

Pain is expressed through gestures, words and behaviors, but this is manageable, i.e. what the person expresses might mean something else or, sometimes, different symptoms of an initial cause. Crying, complaints, aggressive expressions, rejection, still, even after physical pain has disappeared. Back pain requires attention, it may manifest hidden problems.

The phenomenon of pain is influenced by several factors: some factors may increase pain, but some others decrease it. Pain increases with fatigue, sadness, tension, fear, uncertainty, inactivity, isolation, worry, and, particularly with anxiety and depression. Anxiety accompanies and intensifies acute pain, whereas depression accompanies chronic pain. Some factors that reduce pain are: rest, joy, hope, optimism, relaxation, tranquility, security, entertainment, employment, restorative sleep.

To recognize these factors might help both us and our relative to better cope with pain, understanding its causes and what happens, predict and control its process, and also soothe and calm down.

The important thing is not the idea we have about the pain suffered by our relative, but how he perceives this pain.

Questions

What kinds of situations related to pain have I gone through?

How have I dealt with pain?

What do I think it is necessary to learn and manage about pain?

WHAT TO DO?

The most important thing is to look for relief and every action you carry out will strengthen your ability to achieve it:

1. It is important to count on professional support. So, look for a health professional who:

- Is an honest and reliable person.
- Is highly knowledgeable about pain.
- Is willing to support you.
- Is willing to talk to the family.
- Is a good listener.
- Makes you feel comfortable.
- Encourages you to ask questions.
- Allows you to disagree.

Besides, make an effort to learn as much as possible about that pain experienced by the patient.

2. Identify the patients' pain specific characteristics:

- Location
- Intensity: slight – intense
- Description: sharp, heavy, burning, exhausting, acute, agonizing, itchy.
- Start up
- What alters pain: potentiates it, relieves it.
- Effects: Causes nausea, changes in mood.
- It is caused by treatment effects or from the activities to relieve it.

3. Set goals to achieve pain relief.

When a person is in pain, pain becomes the center of attention; some other important things are relegated. Fun, it is necessary, it provides an opportunity to think about lifestyle and what can be done to handle pain. Goals mean you have something to fight for.

- Describe what you want to achieve, how, when, and how much relief you want achieve.

- Choose activities such as accompanying the ill person permanently; listening to complaints and expressions of pain, exercising, massaging, relaxing, distracting, heat or cold (as prescribed by the doctor), work, drugs.
- Follow up.

For example:

Regarding exercise, emotions and behavior, stress and relaxation, leisure and entertainment activities, work, and medicines.

Objective ....(Exercise)
When do I want to achieve it? ......(A week)
How am I going to achieve it?........(Stretching)
How to measure it? ....(Time and results)

- Some people are resistant to set goals, they think it is "silly"; in case you are one of those people, you may ask yourself: are the things we are doing nowadays to handle pain working? Would it cause any damage attempting new techniques?

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WORKSHOP 7 BOOSTING STRENGTHS

ADMINISTRATING MEDICATIONS AT HOME

Address to: Family caregivers of a person with chronic health problem

Objectives: To identify and apply abilities on administration of medications at home.

Instructions:
Read the *text*, and then please fill out the form with the information on the medications of your relative's treatment.

Time: Two hours

Workshop

1. Please read the text in groups.
2. Individually, fill out the form you will receive.
3. Then, in groups discuss and analyze examples of situations and experiences when administrating medications.
4. Thus, some conclusions will be drawn to better handle pain.

Reading

Administration of drugs

Medications or drugs are pharmaceutical products with therapeutic aims, used to prevent, diagnose and treat illnesses for the benefit of the person to whom it is administered to.

For a safer administration of certain medication at home, it is important to understand the assimilation process within the body, which is defined by the basic pharmacological principles: pharmacokinetics, pharmacodynamics and biological half-life.

Pharmacokinetics is related to the action, absorption, elimination, distribution, metabolism and product characteristics. Pharmacodynamics is the interaction that takes place within the body; it also determines incompatibilities. Biological half-life is the time the drug takes to obtain the expected concentration in the body, for example, pain relief, control of blood pressure, reducing cholesterol levels, among others. Given this, it is important to highlight indications, contraindications, and side and expected effects within a period of time necessary to get certain desired effect.

Each person reacts differently to medicines. For example, a big person needs more medication than a thin person. Likewise, the body's performance varies in newborns. In the elderly is slower than in young people and children. Thus, each person reacts according to his/her own characteristics, difficulties and situations, which influence the process of assimilation described above.

The interactions that occur when multiple medications are administered simultaneously or mixed with food should be taken into account. The time interval between two or more drugs may potentiate or decrease their effect, relieving or increasing side effects intensity.

The essential thing is to have a clear medical prescription, including the method of administration, schedule, any required conditions, actions and expected effects.

CARING FOR PATIENTS WITH CHRONIC ILLNESS AND THEIR FAMILIES RESEARCH GROUP
UNIVERSIDAD NACIONAL DE COLOMBIA
MEDICATION ADMINISTRATION FORMAT

CAREGIVER'S DATA	
Name	
Age	
Telephone	
Address	
e-mail address	
Relationship to the patient	

PATIENTS' DATA	
Name	
Age	
Medical diagnosis	

NUTRITION	
Route of administration	
Schedule	
Diet	

NOTES

(Use this space to write additional information that you consider important)

DRUGS

DRUG	ROUTE OF ADMINISTRATION	DAILY DOSE	ADMINISTRATION TIME	TREATMENT START DATE	FOOD/LIQUID TO ADMINISTER MEDICATION	PATIENTS' DISCOMFORT/ NUISANCE WHEN RECEIVING MEDICATION	ARE YOU FAMILIAR WITH SIDE EFFECTS AND INTERACTIONS?

DRUGS	ROUTE OF ADMINISTRATION	FREQUENCY	SCHEDULE	COMMENTS
Antigout drugs: Allopurinol-colchicine	Oral Parenteral	Every 4 hours Twice a day Once a day	6-10-14-18-22-02 6-12-18-24 6-20 8	Do not administer with ANTI-INFLAMMATORY drugs
Anti-infective drugs	Parenteral	Every 4 hours Every 6 hours Every 8 hours Every 12 hours	8-12-16-20-24-02 6-12-18-24 8-16-24 6-18 / 8-20	
Anti-infective drugs: ampicillin, clarithromycin and cephalosporin	Oral	Every 8 hours Every 12 hours	6-12-18-24 6-20	A long time before/after meals
Anti-infective drugs: amoxicillin	Oral	Every 8 hours	8-16-24	Administer on a full stomach
Anti-inflammatory: acetylsalicylic acid, diclofenac, ibuprofen, piroxicam	Oral	Every 12 hours Every 8 hours Every 6 hours Once a day	8-18 8-14-20 8-14-20-02 12	Administer on a full stomach
Antianginal drugs: isosorbide dinitrate	Oral	Every 8 hours Every 12 hours	6-14-22 6-18	
Antihypertensive drugs: enalapril, captopril	Oral	Every 12 hours	6-20	A long time before/after meals
Antitussive drugs: codeine, paracodina	Oral	Every 8 hours	6-12-16	Before meals
Antacids: Sucralfate, milpax	Oral	3 times a day	7:30-11:30-17:30 10-14-20	Do not administer with antibiotics 2 hours after meals
Antianemic drugs: ferrous sulfate, folic acid	Oral	Once a day	12	Administer with food
Antiemetic drugs: alizapride, ondansetron, Plasil	Oral	3 times a day	7:30-11:30-17:30	Half an hour before meals

DRUGS	ROUTE OF ADMINISTRATION	FREQUENCY	SCHEDULE	COMMENTS
Antiflatulent: pancreatin	Oral	Once a day	17:30	Half an hour before meals
Anticoagulant drugs: enoxaparin, warfarin	Oral/Parenteral	Once a day	20	
Antidepressants: fluoxetine, amitriptyline	Oral	Once a day	22	
Anticonvulsants: carbamazepine and valproic acid	Oral	Every 8 hours Every 12 hours	6-14-22 6-18	A long time before/after meals
Antiulcer medicines: ranitidine, omeprazole	Oral	Every 12 hours	6-20	A long time before/after meals
Corticosteroids: Prednisone	Oral	Once a day	8	
Diuretics: furosemide	Oral	Once a day Every 12 hours	6 6-16	
Hypolipidemic: lovastatin	Oral	Once a day	22	Night metabolism
Inotropic drugs: digoxin	Oral	Once a day	8	After taking heart rate (up to 50 per minute)
Laxatives: fibogel	Oral	Once a day Twice a day	8 8-16	Plenty of liquid
Digestive regulator: cisapride	Oral	3 times a day	7:30-11:30-17:30	Half an hour before meals
Vitamins:	Oral	Once a day	20	
Hormones: thyroxine sodium	Oral	Once a day	6	On an empty stomach (in the morning)

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SOCIAL SUPPORT NETWORKS
ASKING FOR AND PROVIDING HELP

Address to: Family caregivers of a person with chronic health problems

Objectives:

- To identify processes towards the construction of social support networks.
- To set elements to ask for and give help.

Instructions:

Read the *text*; then, answer some simple questions. As you answer analyze your experience as a caregiver and share your thoughts on how you consider it would be easier to construct networks.

Time: Two hours

Workshop

1. Read the text in groups.
2. Answer the questions individually.
3. Afterwards, in groups, share and analyze examples, your own situations and experiences.
4. Consequently, draw conclusions on how to ask for and offer help. Likewise, it will be proposing to construct a social support network.

Reading

Social support is considered an essential element in the interaction of human beings as it is the basis to deal with situations that affect personal development, performance and fulfillment. In situations of chronic illness this support represents the support for the family caregiver to ease and cope with the experience of caring.

House (1979)[387] states that social support has the following behaviors or actions: emotional, appreciative, informational and instrumental support. Once we identified them, we understand they are part of the natural helping behaviors required to solve problems, identify resources, strengthen and defend rights and duties. It might be taken as an emotional, supportive, problem solving, personal influence and family advocacy behavior.

The relationship structure of social support is the social network, group of relationships or connections among people to provide care and social support, as a spider web that holds and comprises relationships for a common purpose.

Importantly, social support received and provided by the network's members, so that equitable positive and beneficial help is achieved.

For family caregivers, to generate social support means to ask for help; to recognize and accept that support from others is necessary in order to stay on track and help to overcome difficult situations.

This is accomplished by:

- Creating groups in order to share experiences among people whose lives have been disrupted by the same problem; it provides a sense of adaptation, where you may learn from others experience: one feels more acceptance, there is also advice exchange, directly from experience, and most significantly, it is an opportunity to meet new friends, who might stand as practical support.

- Creating information networks, which is accomplished by identifying and integrating places, guides, resources, and existing institutions in order to solve problems and provide guidance on how the care process is taking place.

- Instrumental support provision, which refers to behaviors that help the person who needs help; it is a tangible support of material aid, physical tasks and duties within caregivers' role.

- Emotional support: This item is related to family, spiritual and personal interactions, that is to say, with their own lifestyles and perceptions of the situation.

Social integration is an opportunity that builds alliances; it is accomplished through assertive communication that requires attitudes to inform and to be informed by verbal, written and virtual media. The latter is vital nowadays, as it is part of massive communication that forces us to master it. Through virtual media, we request services, acknowledge support, identify processes, exchange experiences, ask for help, get to know resources, have opportunities for reflection with others, being connected and belonging to a network where it is possible to help and be helped.

Questions

Describe in which specific situations you require help

Describe your weaknesses and strengths when asking for help

What do you suggest to become part of a family caregivers' network?

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Social support proposal

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The social support proposal experience has enabled our research group to recognize social support as an important resource that plays a key role in strengthening caregivers' caring ability for patients with chronic illness. It has also a mediating effect in stressful and illness situations; social support reduces stress significantly, which generates also a better quality of life.

This is why we have developed a series of social support workshops for family caregivers of chronically ill patients, so that they have some basic tools to be generators of such social support.

It was used as strategy to support *social support dyads* that are described as a voluntary system of peer support, similar to that found in informal, one to one or in networks, support groups. They consist of two people going through the same situation; they provide each other with assistance, information, instrumental, emotional and spiritual support. They are strengthened by sharing their knowledge and experiences.

Our research group has identified that during the first two levels of the program, family caregivers reach certain level of caring ability based on their experience and what they have learned through their situation, this knowledge allows them to support other caregivers who are going through the same experience. There is a significant degree of transcendence implicit in this kind of care.

It is important to acknowledge dyads as a social support network. Belonging to a network certainly helps in problematic situations, as there are people who to trust in and who to ask for support, reducing stress. It may also influence health and welfare positively and directly, to the extent that it contributes to human needs, safety, social contact, belonging, esteem and affection. Support networks can directly reduce stress levels in different ways and thus indirectly improve the person's health condition.

What is social support?

Social support is often defined in terms of those resources provided to a person by others[388]. Barron[389] indicates three main levels of conceptual analysis implicit in the definitions: social networks structural relationships (interactions with friends or relatives, participation in social groups, etc.), functions (emotional, self-esteem, belonging, identity, etc.) and objective / subjective analysis (actual support received *versus* perceived support).

Currently, it is assumed that perceived social support is one of the most important variables in an individuals' health status and welfare; it is related to health in different ways and, possibly, through various mechanisms[390].

Some research studies argue that higher perceived social support is related to higher levels of good health. This might means it is important for people to count on this support, which leads to decrease the perceived impact of the illness. Additionally, the moderating effect of other factors influencing welfare especially those related to stressful life events (Cohen and Wills[391], Flecher[392], Tsasis[393], Martinez, Garcia and Maya[394]).

It has been reported that the perception of social support by patients with HIV contributes to their adaptation to the illness so their health status is better. The presence of social support decreases those harmful effects of stress, and its absence may actually accelerate the course of HIV infection[395].

Likewise, we have identified that social support can promote continuity of health care and it is part of global policies when caring in chronic illness situations. A section of this work has focused on people with illnesses through specialized associations and very little experience with family caregivers.

Social support is described as an aid to the ill person or caregivers so that they adapt and cope better with their experience, by sharing their knowledge with others. The concept is considered as an essential element in humans' interaction. There are three dimensions: affective (demonstrations of love, companionship and empathy), instrumental (aid or assistance in tangible needs) and confidential (possibility of having people to communicate with), according to the DUKE-UNC-11 scale.

In situations of chronic illness, social is described as helping caregivers so they cope better with the experience of caring for their relative. Hilbert has divided it into five categories (1990)[396]: personal interaction, guidance, feedback, tangible support and social interaction.

Personal interaction: it is the emotional support for appropriate coping in different situations through the chronic illness process.

Guidance: it is the main support received by the caregiver through education and information.

Feedback: the feeling that the person who supports caregivers agrees with them and supports their thoughts and actions.

Tangible support: the material aid and assistance in physical tasks and work performed by caregivers.

Social interaction: it is the support for caregivers to keep their relationships with other groups, families and institutions working on their needs.

What are social support networks?

A *social network* is a set of relationships or connections among people, in order to care, provide social support, like a spider web. It supports and includes relationships with a common purpose.

Then, a social support network in a chronic illness situation will be a set of people, institutions and groups that provide emotional, spiritual, instrumental, informational support through guides and constant feedback in order to enhance the experience of caring for a person with chronic illness.

There are several strategies for social support from individuals and communication tools. From individuals there are dyads and support groups. Within communication tools there are different strategies through media (telephone, television, radio, etc.) and virtual tools like the internet.

Dyad as from the concept reported by literature: is defined as "two individuals who are characterized by their permanence in time, mutual actions and a contract with personal items, their main feature is their personal interdependence, i.e., mutuality and reciprocity through an interpersonal relationship"[397].

When caring for people with chronic illness there may be several types of dyads: a) caregivers and the chronically ill person[398, 399, 400, 401, 402, 403, 404, 405, 406, 407, 408,] b) caregivers and nurse[409], c) the chronically ill person and nurse[410,] d) family caregivers. The latter being of two types: a) family caregivers who are part of the same family[411,] b) family caregivers from different families going through the same situation.

Overview

Some authors have also reported that having social support networks available promotes mental health and reduces depressive and anxiety episodes[412]. Some researchers identify social support as a protective factor for mental disorders[413] because just being supported by a person who is always there to support you [414] promotes mental health, as well as feelings of control and self-control of situations when caring for an ill person.

At a first glance families are perhaps the social support network that is supposed to work on the ill person and the caregivers' needs, when they begin the chronic illness experience. The family care receiver will definitely benefit from this strategy, but caregivers do not recognize or perceive the possibility in their context, or they do not identify themselves as a network set.

As for the description of this third level: the main objective is to strengthen family caregivers and the person with chronic illness social support through the support of dyads. To this aim, sessions have been developed, with three stages in order to strengthen social support.

FIRST STAGE

It consists of grouping participants by support groups according to chronicity situations. For instance, there are groups according to the health conditions: heart illness, degenerative illness, mental disorders, and cancer. Then, family caregivers should look for a counterpart and thus constitute a corresponding dyad of support. This counterpart is usually a person who has space and time difficulties, so he/she cannot attend the workshop.

The main objective of this stage is to strengthen the ability of caring through training caregivers, so they are able to provide social support to others with experience-based tools. Through the organization of workshops by groups, aspects like the emotional, spiritual, instrumental support, leisure strategies and resources are addressed and strengthened. At this stage, it is useful to measure results using the "*Inventory of social support in chronic illness*".

Each topic is drawn from skilled caregivers' experience. It is carried out through a pre-guide per session.

TABLE 6

Workshops to strengthen social support - First stage

NO.	WORKSHOP	OBJECTIVE	TOPICS
1	Emotional and spiritual support	To identify known emotional and spiritual support strategies.	Description of the emotional and spiritual received and offered support. To measure abilities to provide emotional and spiritual support. Strategies for emotional and spiritual support.
2	Instrumental support	To identify the experience with instrumental forms of support.	Description of instrumental support in caregiving experience. Wounds, commuting, procedures, medications, specialized training management.
3	Leisure strategies	To provide current leisure strategies	Space for recreation and relaxation a strategy within available resources (music therapy, yoga, reiki, meditation, etc.).
4	Available Resources	To identify current resources available within health systems and others.	Sharing information about available resources with health institutions and other special health services.

SECOND STAGE

The development of support dyads starts at this stage. To this aim, skilled caregivers seek or are assigned a non-experienced caregiver to start a mentoring process. The strategies used for communication will be considered during the development of the process.

The guides that were used in the first stage become the tool used for family caregivers in this second phase. Each caregiver has the *Guide to provide social support;* the first part consists of a daily field and a second booklet divided into subject areas with step by step social support.

This stage is divided into two modes: face to face session and non-face to face session. In the non-face to face session family caregivers must have a conversation and interview with the non-skilled caregiver by telephone or home visit to share their experiences from the viewpoint of knowledge that was raised at the first level. In the face to face session, the skilled caregiver socializes with support groups the situation and experiences of the non-skilled caregiver. The team work should be guided by the workshop's moderator through solution-oriented questions and by exploring options for the non- experienced caregiver, that come to share with other caregivers who perhaps have gone through a similar situation (see Table 7).

TABLE 7

"Caring for caregivers"® Workshops: support networks
Social - second stage.

NO.	WORKSHOP	CATEGORY	OBJECTIVE	TOPICS
1	Knowledge and identification of needs	Non presential	To interview the person who will be the counterpart of the dyad support	Interview, caregivers and the person cared for data, experience as a caregiver and identification of problems, difficulties and needs.
2	Socializing dyads 1	Presential		
3	Support and guidance	Non presential	To plan meetings and describe social support.	Arrange meetings according to availability. Tell experiences and provide mutual orientation according to experience.
4	Socializing dyads 2	Face to face		
5	Using other support strategies	Non presential	To identify the availability and possibilities of resources for the non-skilled caregiver.	To describe and share support resources. To share information on availability. To strengthen the list of available resources.
6	Socializing dyads 3	Face to face		
7	Strengthening emotional and spiritual support	Non presential	To create opportunities to strengthen emotional and spiritual levels.	Visits, calls and meetings in order to share feelings and strategies that can be carried out to reduce anxiety.
8	Socializing dyads 4	Face to face		
9	Sharing and instrumental support	Non presential	To offer instrumental care services for recreation.	Replace, support in activities, and provide information, integrating other groups. For Instance: exercise, dance, praying.
10	Socializing dyads 5	Face to face		
11	To create leisure opportunities	Non presential	To plan leisure activities with the dyad.	Recreational activities program. To arrange caregiving activities.
12	Socializing dyads 6	Face to face		

THIRD STAGE

This stage is related to the implementing social support networks aimed to recognize the network's benefits as an ally for those who need and seek the same support and generate networks for mutual learning. Joining those already established networks and helping spread them is essential for their growth, and can create new networks, sharing experiences with others who have not yet reached the level of knowledge and understanding of the illness, that others have already achieved.

Caring for people with chronic illness and family caregivers should use technology as a tool to ensure coverage, satisfaction and positive results in the quality of life[408]. Support may be provided through Internet technology[409]. For this reason, it requires training in the use of such tools, which are considered for the development of third stage (see Table 8).

LEVEL	WORKSHOP	OBJECTIVE	TOPIC
Intermediate	Identifying the internet and how to navigate.	To acquire knowledge about the basics of internet, how to navigate and Its use.	Information on what is, what it does and how to surf the internet. Functions, basic tools of Internet Explorer, and some search engines that are in the network, such as Google. Key recommendations when using Internet Explorer.
	Creation of an e-mail account.	To have access to an e-mail account.	Websites where you can access to an e-mail account. Creating an email account. How to have access and sign out an e-mail account. How to send e-mails. How to use and identify functions in the e-mail account.
	Practical use of the email account.	To put into practice the knowledge acquired on the use of an e-mail account.	Guided practice of how to log in and out and access the e-mail account. Send e-mails. Receive e-mails. Participate in chat rooms.
Advanced	Assessment of previous levels.	To identify the extent and type of knowledge acquired in previous levels.	Individual preparation of a written document. Sending e-mails and checking the e-mail account.

TABLE 8

Technology Training - Computers and Internet

LEVEL	WORKSHOP	OBJECTIVE	TOPIC
Basic	Identification of computer parts and how they work.	Explain how to operate each part of the computer.	Presentation and explanation of the parts of the computer and its functions. Turning the computer on and off.
	Microsoft Word Introduction.	To get familiar with each program and its use.	Information on what the Microsoft Word program is and what is used for. Basic Microsoft Word functions and tools.
	Creating documents with Microsoft Word	To provide information on how to create documents in Microsoft Word.	How to access the Microsoft Word program. Practice drafting a letter. Aligning a paragraph, change font and other properties. How to handle the keyboard to use capital letters and symbols.
	Individual practice of handling Microsoft Word.	To acquire skills in creating Microsoft Word documents.	Guided Practice in creating documents in Microsoft Word. How to insert an image and change color in the font or page.
Intermediate	Identifying the internet and how to navigate.	To acquire knowledge about the basics of internet, how to navigate and Its use.	Information on what is, what it does and how to surf the internet. Functions, basic tools of Internet Explorer, and some search engines that are in the network, such as Google. Key recommendations when using Internet Explorer.
	Creation of an e-mail account.	To have access to an e-mail account.	Websites where you can access to an e-mail account. Creating an email account. How to have access and sign out an e-mail account. How to send e-mails. How to use and identify functions in the e-mail account.
	Practical use of the email account.	To put into practice the knowledge acquired on the use of an e-mail account.	Guided practice of how to log in and out and access the e-mail account. Send e-mails. Receive e-mails. Participate in chat rooms.

LEVEL	WORKSHOP	OBJECTIVE	TOPIC
Advanced	Identifying the website: Caregivers of patients with chronic illness.	To identify and access the *caregivers of patients with chronic illness program* web page.	How to join the group's website. Identifying each link of the website. Access the link of the program and identify the objectives and all its specifications.
	Access to the support Network link and the Contact Group in the website.	To access and use the services that provided by support networks and the *Contact Us* link on the website.	Access to the support networks link. Identifying support networks available to the group and how to make use of them (i.e. contact them). Access to Contact Us link. Using this support way, and service provided by the group's webpage.
	I can also be a virtual support network.	To link caregivers who are part of the group as a virtual support network.	Identify each caregiver as virtual support network. Explanation of the meaning and characteristics of a virtual support network. How the knowledge acquired during the course provide training on how to be a better support virtual and personal network. Practice as a virtual support network.

WORKSHOP 1 SOCIAL SUPPORT NETWORKS

EMOTIONAL AND SPIRITUAL SUPPORT

Address to: Family caregivers of people with chronic illness

Objective: To identify from experience emotional and spiritual support strategies.

Instructions

Read the *text*, and then find a few simple questions to be answered. Please discuss your experience as a caregiver and share your opinion on how to build emotional and spiritual support strategies.

Time: Two hours

Workshop

1. Read the following general aspects on what emotional and spiritual support is.

Emotional support according Pilar Matud: *"refers to aspects such as intimacy, attachment, comfort, care and concern"*[417]. Emotional support is to provide security, acceptance and encouragement in difficult moments.

"Spirituality encompasses the philosophical ideas about life and its purpose, and has the power to shape and the meaning to be, know and do, which can be identified as a unifying impulse, as a basic internal guidance system for human welfare, which motivates you to choose relevant relationships and search"[418].

To address vital and existential crises, adults need to develop forms of support that enable hope for the future and, in turn, have standards of conduct to guide them in their social life. *"The person grows spiritually and is supported by those who offer support, including religious figures who inspire devotion and spiritual support that are important when dealing with adversity"* [419].

Their contributions and recommendations are essential in the process of building our social support network.

We invite you to answer the following questions:

1. Have you ever received emotional or spiritual support? Write about it. How was it?

2. Have you ever provided emotional and spiritual support to another person? Please, write down about this experience briefly.

3. What has been this emotional and spiritual support?

4. What kind of information, guidance or piece of advice have you provided to a person who has required emotional or spiritual support?

5. Do you currently feel able to provide emotional or spiritual to another person? Yes_______ No______. Explain your answer.

6. If the answer is no, what do you think are the missing elements to provide emotional or spiritual support?

WORKSHOP 1 SOCIAL SUPPORT NETWORKS

INSTRUMENTAL SUPPORT

Address to: Family caregivers of people with chronic illness

Objective: To recognize from experience instrumental forms of support, provided and received.

Instructions

The following are a series of questions related to the capabilities of instrumental support and areas for you to present your experience in this kind of support.

1. According to you: what elements do you consider give you the ability to provide instrumental support?

2. Have you ever received instrumental support? Yes___ No___
How has it been?

3. Have you ever provided another person with instrumental support?

4. Write down your experience with this instrumental support.

5. What kind of instrumental support do you think you need right now or might need soon?

Instrumental support

Regarding the types of support, instrumental support is also called tangible support, in which the kind of aid provided is practical and concrete. "It means taking actions or providing with materials or services to solve practical problems" such as helping to perform some tasks or processes.

Instrumental support was established as:

Guide: offering advice, information and instruction. Caregivers do not count on knowledge enough to support their actions carefully. The main aid they receive is:

- Health education
- Information

Physical Assistance: sharing physical tasks and duties. They are decisive in the caregiver's role. They are based on tangible support:

- Bath
- Transportation
- Administration of medications
- Food Assistance
- Toilet assistance
- Shopping
- Housework
- Administrative processes
- Substituting the caregiver

Feedback: in behavior, thoughts or feelings. It may be identified when it is supported by thoughts and actions. It is most felt when it is provided by a person who has lived a similar experience.

Premises to provide instrumental support

Instrumental support focuses on the actions taken for an ill relative to prevent complications or further damage.

For instruction to be effective you should: know about care techniques, practice those techniques in advance, and feel sure to act calmly.

Not everyone may be able to provide the instrumental support in the same way:

- Because they may get overwhelmed easily.

- Because health conditions do not favor immediate action.
- They do not know what to do or how to do it properly.

Steps to organize instrumental support

1. *To identify problems and risks,* the patient's and the caregiver's conditions.

2. *Request support to a health services entity*: the health services team has knowledge, experience, ethical and legal responsibility to provide instrumental support.

3. *Attention,* which refers to the implementation of first aid techniques to avoid complications.

WORKSHOP 3 SOCIAL SUPPORT NETWORKS

LEISURE STRATEGIES

Addressed to: Family caregivers of patients with chronic illness

Objective: To offer existing leisure strategies.

Instructions

- Join the leisure activity scheduled for this workshop (one hour).
- Answer the following questions and share experiences with your peers.

1. How does this activity contribute to lessen the burden of care?

2. What similar strategies do you know and suggest to other caregivers? Describe any necessary resources, time spent, required elements and other features.

ACTIVITY	PLACE	REQUIRED ELEMENTS	REPORTS

WORKSHOP 4 SOCIAL SUPPORT NETWORKS

AVAILABLE RESOURCES

Addressed to: Family caregivers of patients with chronic illness

Objective: To identify available resources within the health system and other means.

Instructions

1. According to your experience, describe the services that most appeal to you, that have been offered by your Health Care Insurance Institution. For example: ambulances, home visit, medications, supply elements at home, etc.

SERVICE	HOW DID IT HELP?	HOW DID YOU GET THIS SERVICE (TELEPHONE, ADDRESS, ETC.)	SOME OTHER RELEVANT ASPECTS

2. When you need a service you do not know yet, what kind of media do you use to find those resources? Tell us about your experience.

3. What services should be considered to make the caregiver's work a more positive experience?

Field Journal

PERSONAL DATA
MAIN CAREGIVER (skilled caregiver)

Name
____

Age
_______________ years old

SUPPORTING CAREGIVER

Name
____

Age
_______________ years old

Name of the person who is being cared for
____

The main caregiver's health condition
____

Back up Caregiver
_______________Age:

Relationship with the main caregiver
____

Time of care
____

EXPERIENCE AS A CAREGIVER

What is your experience as a caregiver?

NEEDS SEARCH

What kind of problems has my supporting caregiver identified when caregiving?

What kind of difficulties has my supporting caregiver identified when caregiving?

____

____

____

____

____

What needs has my supporting caregiver identified when caregiving?

____

____

____

____

____

MEETINGS SCHEDULE

Date and place of meetings with my supporting caregiver

PLACE	DATE	OBJECTIVE

MENTORING, GUIDANCE AND SUPPORT

Experiences of my supporting caregiver and guidance that I have been able to provide according to my experience

MONITORING

SUPPORT STRATEGIES

What kind of support do you have to provide care?

____

____

____

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EMOTIONAL AND SPIRITUAL SUPPORT

Visits and phone calls I make to my supporting caregiver related to emotional and spiritual support

____

____

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____

INSTRUMENTAL SUPPORT

LEISURE ACTIVITIES

SOCIALIZATION OF DYADS (CAREGIVER AND CARE RECEIVER)

SUPPORT NETWORKS

Hospital Discharge Plan

Lucy Barrera Ortiz
Natividad Pinto Afanador(ɫ)
Beatriz Sánchez Herrera

Preparation for Home Care

The *Preparation for home care Program* is a set of specific and individualized activities performed by a professional nurse. It has been developed for people with chronic illness and their family caregivers. Its main purpose is to support and strengthen the ability of home care through guiding, supporting, identifying needs and main problems or potential ones that arise from a chronicity situation.

This program consists of personalized assistance to family caregivers, by promoting the wellness of the person cared for through protection, recognition of others, mutual growth and the enhancement and preservation of life. The emphasis is on strengthening the family caregiver, coping with the experience of caring for a relative.

The program represents a strategy of hospital care that allows providing a humane and appropriate health service, with user satisfaction. It is addressed to the *caregiver* who is, mostly, a relative, and also becomes our patient within the General Care Plan[420].

Vivader (1990)[421] states that the preparation for home care has to do with the hospital discharge plan; it is part of the general care plan addressed to hospitalized patients and it immediately starts at the admission.

According to this, the follow up process is established with a nursing process bases and principles for the preparation of hospital discharge, home organization, monitoring care guidelines, and the management of treatment, rehabilitation and convalescence stages.

Preparation for hospital discharge

Since the moment the person is hospitalized, the caregiver should consult and be guided on the arrangements for hospital discharge. Therefore, the caregiver needs to know how carry out care at home, administer treatment, including medications and care and follow up consultations.

- Before the patients' hospital discharge

The patient should only be discharged when there is absolutely certainty that someone will care for him/her at home, with the welfare conditions and continuity of the treatment.

Here are some questions the caregiver should ask before hospital discharge:

1. Regarding the care receiver:
   What medications should be administered? What is the dose? What kind of care might be required? What are possible side effects?
   What are the patient's condition and needs?
   How to move the patient with and without help?
   What to do in difficult situations?
   What and where are the special health services, such as physiotherapy, occupational therapy, psychotherapy, etc.?
   What are the instructions concerning aftercare, follow-up or home visits?

2. Regarding caregivers:
   Are they aware why the person was hospitalized and the received treatment?
   Are caregivers physically and mentally able to provide care?
   Do they know who to consult to in case of an emergency?
   Does the caregiver have the necessary support?
   Do they know how to get ready to meet the relative's limitations and needs at home?

To answer these questions completely, the process to be followed is described as follows:

- Nursing activities

Care activities are explained as follows:

1. Assessment
    - Daily activities carried out with the person with chronic illness
    - The patient's physical exam
    - Preparation conditions for the family caregiver home care
    - Specific treatment the patient should follow to regain or maintain his/her health status.

2. Care planning, based on valuation, including special needs to be presented at the end of hospital service, with a monitoring, control and evaluation process, determining the effect and impact of the plan.

3. Basic and follow up activities: statement of control remissions for the *caregiver* to obtain support services that enable compliance with ongoing treatment and care required by the patient in the medium and long term.

The hospital discharge plan includes a systematic and organized scheme which is part of the nursing process stages:

STAGE	OBJECTIVE	COMPONENTS	INDICATORS*
Assessment	To obtain data details on the person with chronic illness and caregiver's health	1. Interview 2. Physical examination	Filling out appraisal forms (Forms of assessment of the person with chronic illness and family caregivers).
Nursing diagnosis	Stating nursing diagnoses for the person in situation of chronic illness and family caregivers.	a. Descriptive label or title b. Definition c. Defining characteristics, high risk, and welfare.	List of possible diagnoses in people with chronic illness and the family caregiver in accordance with the classification of nursing diagnoses NANDA[1]
Care plan	To establish and implement nursing care, in order to strengthen the caregiver's caring ability to prevent, reduce or eliminate problems and to define follow-up actions.	To establish care priorities. Approach to the patient's goals and his caregiver aimed outcomes. Development of care activities. Complimentary documentation, support material.	List of activities hierarchically based on the Nursing Interventions Classification NIC[2]
Follow-up	To monitor the stage right after the hospital discharge of the person with chronic illness and the family caregiver.	Conduct monitoring activities at the doctor's office or by telephone in order to check: 1. Adaptation to special needs 2. Communication 3. Movement	Follow-up interviews Assessment of the ability of care and preparation for home care based on nursing outcomes classification NOC[3]

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1. North American Nursing. Diagnosis Association. Nursing Diagnosis definitions & classification Philadephia, PA: North American Nursing Diagnosis Association. 1999.
2. McCloskey Dochterman, Joanne; McCloskey, Joanne C.; Bulechek, Gloria M. Clasificación de Intervenciones de enfermería (NIC). 4 ed. Elsevier España, 2005. 1072 pages.
3. Sue Morread, Marion Jphnson, Merodean Maas. Clasificación de resultados de Enfermería (NOC): Proyecto de resultados Iowa. 3 ed. Elsevier España, 2005. 920 pages.

Assessment

The nurse who is in charge of the hospital discharge plan should take requirements for appropriate assessment of the chronic patient.

- *The professional nurse beliefs*: nurse's attitudes and motivations. According to Pinto[422], there must be an attitude of willingness to give and receive in order to facilitate the meeting that is free, flexible, warm, expectant, and neutral, without authoritarian behavior and focused on what happens in the other person's personality. This behavior encourages patient cooperation and facilitates the inter-relationship that should gain a foothold among the professional caregiver and care. The acknowledgment of the other person in the call of care is an essential element in the relationship between patients and caregivers.

- *Knowledge on chronic illness*: nurses must have a solid knowledge about care of patients with chronic illness that enables them to assess the individual's health status. Knowledge also provides a broad vision in recognizing features of functionality, dependence, identifying potential risk factors for people living situations of chronic illness.

- *Communication:* according to Pinto (1998)[423] solutions through dialogue are truly a constructive form, as far as those dialogues meet requirements that contribute to effective communication.

For individuals and families facing chronic illness with wide experience in dealing with it, the requirements can be described in the following basic premises:

- The person who is committed to communicate knows that his/her interlocutor has to cope and is willing to listen.

- Avoid believing one is right about everything or that dialogue is transmitted to an interlocutor to persuade him/her, he/she is someone to talk to instead. Dialogue is bilateral, not unilateral.

- The person talking, is concerned with finding a correct solution, and therefore, for an understanding with an interlocutor. "Understanding each other" does not always mean achieving full agreement.

- The final decision in order to be the correct one, has not to cater to individual or group interests, but universal ones, that is, the interests of all the people involved.

- *Assessment objectives:* the nurse must determine what is proposed with the discharge plan offered, using resources, tools and space required to develop assessment for caregivers of patients with chronic illness.

Assessment to patients with chronic illness

This first phase involves an organized collection of comprehensive data and health status of the person with chronic illness. Information is obtained through different sources: primary, medical history and care. Thus, considering there are two ways of collecting information in nursing: basic data collection and specific data.

Basic data collection: it is addressed to collecting exhaustive data from the person and his processes of physical, psychological, functional, and socio-cultural development; it is often used during the first contact with the patient.

Specific data: selected according to a specific problem related to the illness; it may be performed during the first contact, but it often demands continuous assessment[424].

The following aspects are identified in the individual with chronic illness and caregivers, Carpenito (1987):

- Current and past health status
- Functional patterns
- Capabilities and limitations
- Response to these changes
- Response to therapy and care (medical and nursing)
- Risk of potential complications

Interview

The nurse collects a set of data about the situation of patients with chronic illness and caregivers through a clinic interview. It is initially established on an informal basis, to raise awareness and knowledge about the patient. It consists of a conversation between a nurse and a patient during the course of care and then a formal interview is carried out in order to obtain and register data on instruments to systematically guide and monitor. It consists of three parts: introduction, body and closing[425].

Introduction: it starts with an approach phase, focused on creating an enabling environment which develops a positive relationship.

Body: it corresponds to the purpose of the conversation focused on obtaining necessary information on the patient's health condition. It starts from the reason why the person is consulting a health professional and his/her main health concern and some other areas such as medical history and family information. Data is registered in structured or semi-structured formats.

Closing: it is the final phase of the interview. New items should not be included. It is important to summarize the most relevant data. It is the basis for establishing planning guidelines for care, with expected results.

Finally, it is important to remember that the interview allows obtaining two types of information: verbal and nonverbal.

Verbal techniques

Questioning: it is useful to obtain information, clarify answers and verify data.

Repeating or reformulating: it consists of repeating or otherwise expressing what has been understood through the patient's response to confirm and deepen on the information provided.

Additional sentences: stimulating the continuity of the verbal process of the interview.

Nonverbal techniques

They facilitate or enhance communication through the interview. Nonverbal components convey a message more effectively than even the most common spoken words; they are facial expressions, body language, gestures, touch and speech.

Physical Examination

This concept is related to the patient's physical and functional assessment. The physical inspection is performed in cephalocaudal direction, according to the problems and specific signs and symptoms of chronic condition included in the instrument (Appendix 1).

Functional assessment is performed through the level of functionality PULSES profile, which determines the functionality, the degree of dependence (Appendix 2). Physical examination allows to obtain data for comparison and to confirm subjective results obtained during the interview.

Assessing the caregiver

As with the patient in a situation of chronic illness through informal and formal interviews, the family caregiver awareness is identified to take in the responsibility for assistance and home care. This is done by the instrument *Preparation for home care by the family caregiver* (Appendix 3); as well as the caregiver's caring ability is set by applying the CAI -Caring Ability Inventory- (instrument Appendix 4) which ultimately determines nursing interventions, as knowledge of the illness, management of equipment, and support networks[426].

Nursing diagnosis

According to the information in the assessment of chronically ill individuals and their caregivers, the nurse states determining diagnoses on the problems that favor, the tasks of identification, validation, standardization and classification of health problems that should be treated. The most complex needs are a priority and maintenance and long-term needs are at a secondary level (Appendix 1).

Some components of the nursing diagnoses accepted by NANDA for design and description are:

a. *Descriptive label or title:* it is a concise description of the health problem (actual or potential). It is a phrase or word that represents a pattern.

b. *Definition:* it expresses a clear, specific, precise meaning of the category.

c. *Defining characteristics:* each diagnosis has a title and a specific definition. This is what gives the meaning of the diagnosis itself; the title is merely suggestive[427].

Some types of diagnosis[428] set out at the nursing consultation are:

- *Actual:* it represents a state that has been clinically validated by main and identifiable features.
- *High risk:* it is a clinical judgment that an individual, some people are more vulnerable to developing the condition than others in the same or similar situation.
- *Possible:* they are statements that describe a predicted problem, additional data might be needed. The nurse is to confirm or exclude information.
- *Welfare:* clinical judgment about a person, group or community in transition from a specific level of welfare to another one. Two facts must be present: desire for a higher level of welfare and current effective state or function.

Caring plan

Once evaluation and nursing diagnosis statements are carried out, there is a planning care phase; during this phase nursing care is planned in order to strengthen the caring ability for the caregiver, to prevent, reduce or eliminate identified problems and to define follow-up actions with the following assumptions.

- *Set up priorities of care. Selection:* hierarchical organization of identified problems.
- *Approach to the patients and caregivers' goals with expected outcome:* in order to determine outcome criteria, description of expected outcome by individuals and professionals.

It should be described in terms of observable behaviors or measurable realistic changes, taking into account available resources. They should be set at short and long terms.

- *Formulation of self-care activities:* specific tasks that nurses or caregivers perform to accomplish objectives.
- *Delivery of support material:* booklets with home care guides for basic care procedures (see Appendix 5).

Core nursing and monitoring activities

Core nursing and monitoring activities are to assess the impact of caring actions on the person with chronic illness and family caregivers. Likewise, assessing adaptations to be carried out at home for specific purposes such as daily activities, communication, and movement requirements.

This assessment is carried out through an interview, through direct observation; it is registered in the assessment tool (Appendix 1).

Results show whether the care plan has been effective, in order to make adjustments or additions, make decisions about unfulfilled goals and to identify the illness progression, as well as the caregiver’s training.

Monitoring should be done in proper time to weekly, monthly or every six months develop a plan according to the person and family caregivers’ situation in order to ensure care continuity. It can be carried face to face at an office or by telephone, according to the person’s address, the caregiver’s availability or access to the institution.

Adjustment to special needs

Caring for a family member is a responsibility that affects all aspects of life. It is therefore necessary to consider the caregiver's needs and those of the ill family member.

The first need is the caregiver's relationship with the patient and other people around, which is affected by receiving a person, who used to be independent and healthy, and now is disabled because of a chronic illness. Some relationships are strengthened; others are altered, compromising lifestyle.

What to do?

The way the person being cared for is addressed, affects the way he/she feels. It is important to respect his/her needs. If respect and trust are set, there may be a beneficial relationship.

- Privacy should also be respected. It is suggested that caregivers ask themselves this question: if I were in that situation, how would I like people to treat me? Care is based in this question. The person being cared is unique and is entitled to know what happens. Take time to explain and, if possible, make decisions together.

- It is necessary to assess the extent of help needed, gathering information about the illness and treatment effects.

- Reset a daily routine that allows involving the ill family member in the home life, having in mind:

  - How much rest might he/she need?
  - What kind of diet does he/she need?
  - What are his/her physical possibilities?
  - What medications does he/she take?
  - What kind of treatments does he/she have?

- Tools for adaptation

Patience will be required while adapting to a new environment and a different way of doing things.

- Rest: encourage him/her to take things calmly. Both the patient and the caregiver should rest during the day and sleep whenever they feel tired.
- Exercise: If the patient has mobility problems, encourage light exercise. In turn, the caregiver needs a daily routine in order to relax.
- Company: the ill family member should never be alone. It would be necessary to look for a substitute, analyze the convenience of visitors,

make sure the patient is ready for this, and always ask him/her how he/she feels.

Communication

Most of us express through spoken language. However, we also communicate through nonverbal patterns. When caring for a relative it may be helpful to understand his/her body language, as well as to know how to use on your own.

Communication

Most of us express ourselves by the spoken word; we also communicate through non-verbal forms. When one takes care of a relative could be helpful to understand their corporal language and to know how to use one's own.

What to do?

- Learning to interpret body language will help to care for a relative more effectively; avoiding eye contact could be a sign of depression or low self-esteem, body hugging and putting a hand on the face may be a sign of pain. The gentle touch can convey kindness and support, sitting can be less intimidating than standing up.
- When caring for a person with limited speech, sight or hearing, these difficulties are overcome by adapting to a new way of communicating. Accessories should be available to help people with sensory disabilities to improve their communication skills and promote independence. Among those objects are: pencil and paper, computers to type what they want to express, displaying and point to pictures of things used frequently.

  Do not change the way you talk. Remember that hearing loss can lead to feelings of isolation. When talking, always have a face to face contact, so you can read the other person's lips. Learn to use the bass tones of your voice, as the hearing-impaired person is more likely to hear bass tones. Use non-verbal communication, such as signs, as much as possible.
- When a person has cognitive problems, impairment or memory loss, he can be helped using active sentences like "it's time to eat! It is 12!" You should express yourself through specific and concrete information: "The appointment to the doctor is on May 11th at 8 am at the hospital", you should avoid just saying: "hospital appointment on Thursday." You should also ask direct specific questions: "Would you like some coffee?" rather than simply saying: "what would you like to drink?". On the other hand, all clocks

at home must be synchronized with the current time. Distribute reminder notes strategically, such as: "turn off the oven." Capture their attention and provide safety, for example, by smiling, giving a hand to the person.

Movement

When receiving a patient with limitations, the first thing to do is to analyze all the possible changes at home for it to be safer, and check on any necessary adjustments and accessories, to facilitate movement.

What to do?

- Adapt all electrical systems at home; increase light sources and supply. Install non-slip floors and safety bars in the bathroom.
- The types of accessory requirements depend on the degree of movement of the person; they should be adjusted and measured by a physiotherapist. Canes provide a minimal support while walkers provide a maximum support. If you have an accessory, encourage your relative to use it whenever possible, he/she will get used to it and his/her independence will increase.
- For a cane to be the correct length it should reach your wrist when your arm is well outstretched; your arm should bend slightly to get it.
- Crutches provide stronger support than a cane and the patient can use one or both. They must have non-slip rubber tips.
- There are walkers without wheels, front wheels and four wheels. This structure provides firm support. The person bends over, clutching both hands.
- There are two types of wheelchairs: manual wheelchairs with large wheels so the person pushes the wheels and moves, and engine wheelchairs used outdoors to travel long distances. Never attempt to lift the wheelchair on your own when someone is sitting. If the chair has a seat belt, make sure it is properly adjusted before using it. Always check the brakes and wheels' pressure.

- Although the patient is not heavy, never attempt to lift him/her on your own.
- The bed should be high, so that the caregiver may attend the patient without being in an uncomfortable position for a long time. The bed should also be placed away from the wall so that it may be moved from both sides. The patient should be moved by at least two persons. Put a sliding blanket under the patient, from the shoulders down to the middle of the legs. Each person takes the ends of the blanket and moves the patient towards the desired direction.

Thus, home care is not easy, but it is important to understand how rewarding, satisfying it is and all the benefits of this experience. The caregiver is in a unique position to provide the care receiver a quality of life that would not be possible elsewhere.

Caregivers have the *freedom* to plan their schedule, which allows relative control and freedom that is not possible at the hospital. Hence, it is possible to provide *personal* care with details and likes that are only satisfied at home, such as the bed, the type of food, routines that people are used to, the *comfort* of being cared for at home, in a family environment, close to people who love each other.

Also, caregivers have the *pride and satisfaction* to give their relative the best, strengthening their relationship and bringing people together[429, 430, 431].

Dissemination and understanding the program

There should be a means of dissemination, in order to provide the patient and caregiver available information.

- Details of the program
- Identification of the Health Institution
- Logo of the program
- Appointment's Date and Time
- Doctor's office

Monitoring ID card

This instrument is used by the nurse to identify, monitor and register controls appointments.

The Monitoring ID Card consists of:

- Front:
  Program's Logo
  Program's Name
  a. Program's Name

- Back cover
  Name
  - Age in years
  - Caregiver's name and relationship to the patient
  - Telephone number
  - Address

- Controls and monitoring
  Control number
  Date
  Nursing diagnosis
  Care Plan
  Recommendations

Appendice

Appendix 1

Hospital discharge program

Adult with chronic illness, medical assessment form

DATE : (d d / m m / y y y y)
Health care insurance: _
LAST NAME _ NAME : _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _
DATE OF BIRTH: (dd / mm / yyyy) ENTRY DATE: (dd / mm / yyyy) DISCHARGE DATE: (dd / mm / yyyy)
CAREGIVER'S NAME _
HOME ADDRESS: _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ TELEPHONE NUMBER: _ _ _ _ _ _ _ _

1 . ADULT WITH CHRONIC ILLNESS MEDICAL ASSESSMENT

1. GENDER ☐ Male ☐ Female

2. AGE
☐ Under 17
☐ From 18 to 35
☐ From 36 to 59
☐ Older than 60

3. TAKING INTO ACCOUNT THE PREVIOUS AGE GROUPS, THE CAREGIVER'S AGE IS:
☐ Older than the caregiver
☐ The same age as the caregiver
☐ Younger than the caregiver

4. YOU CAN READ AND WRITE
☐ Yes ☐ No

5. EDUCATIONAL BACKGROUND
☐ Incomplete primary school
☐ Full primary school
☐ Incomplete High school
☐ Full High school
☐ Technical degree
☐ Incomplete Undergraduate studies
☐ Full Undergraduate studies

6. MARITAL STATUS
☐ Single
☐ Married
☐ Divorced
☐ Widower
☐ Common-law marriage

7. PROFESSION
☐ Housekeeper
☐ Employee
☐ Independent
☐ Student
☐ Another ____________________________

8. SOCIO-ECONOMIC STATUS OF YOUR HOUSE
☐ Social Stratum 1
☐ Social Stratum 2
☐ Social Stratum 3
☐ Social Stratum 4
☐ Social Stratum 5
☐ Social Stratum 6

9. HOW LONG AGO WERE YOU DIAGNOSED WITH CHRONIC ILLNESS?
☐ From 0 to 6 months
☐ From 7 to 18 months
☐ From 19 to 36 months
☐ More than 37 months

10. No. OF DAILY CARE HOURS
☐ Less than 6 hours
☐ From 7 to 12 hours
☐ From 13 to 23 hours
☐ 24 hours

11. ARE YOU THE ONLY CAREGIVER?
☐ Yes ☐ No

12. WHAT KIND OF SUPPORT DO YOU HAVE?
____
____
____

13. RELATIONSHIP WITH THE CAREGIVER
☐ Wife / Husband
☐ Mother / Father
☐ Daughter / Son
☐ Grandfather / Grandmother
☐ Friend
☐ Another ____________________________

14. PULSES
☐ 6-8
☐ 9-11
☐ 12-24

16. PATIENT'S DIAGNOSIS: _______________
____
____

2. ADULT WITH CHRONIC ILLNESS MEDICAL ASSESSMENT

<table>
<tr><th colspan="5">GENERAL INFORMATION</th></tr>
<tr><td rowspan="10">VITAL SIGNS:
Blood pressure:_______________
Heart rate:___________________
Respiratory rate:_______________
Body temperature:_____________
CURRENT WEIGHT:
PREVIOUS WEIGHT:
SIZE:
PAIN YES ☐ NO ☐
1__2__3__4__5__6__7__8__9__10__</td><td colspan="4">MEDICINE:</td></tr>
<tr><td>MEDICINE</td><td>ADMINISTRATION FORM</td><td>DOSE</td><td>TIME</td></tr>
<tr><td></td><td></td><td></td><td></td></tr>
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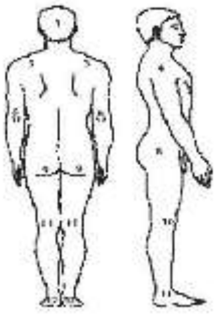
</table>

<table>
<tr><th colspan="2">NUTRITIONAL AND METABOLIC PATTERN</th></tr>
<tr><td>FOOD:
Patient is ndependent to eat ☐
Patient needs help to eat ☐
SNG ☐
Dentures ☐
Type of diet ____________________</td><td>SKIN AND MUCOUS MEMBRANES:
COLOR:
SKIN TURGOR:
INJURIES AND LOCATION:
PRESSURE ULCERS ☐ DEGREE:
INTRAINSTITUTIONAL ☐ EXTRAINSTITUTIONAL ☐
ULCER RISK (BRADEN SCALE)</td></tr>
<tr><td colspan="2">AREAS INVOLVED</td></tr>
</table>



REMARKS:

____

____

ELIMINATION PATTERN

URINARY ELIMINATION:
FREQUENCY: ________________
COLOR: ____________________
ODOR:_____________________
STREAM GAGE :_______________

FECAL ELIMINATION: FREQUENCY:
____
CONSISTENCY: _________________
COLOR:___________________
ODOR: _________________________

INCONTINENCE:

URINARY ☐

FECAL ☐

CONSTIPATION ☐

COLLECTOR ☐

DIAPER ☐

INCONTINENCE ☐

OSTOMY ☐

DRENAJE ☐

URINARY CATHETER ☐

SINCE:____________________

REMARKS: ____

PHYSICAL ACTIVITY – EXERCISE PATTERN

MOBILITY:

INDEPENDENT ☐
IN BED ☐

PATIENT NEEDS HELP IN REGARDS TO:

GETTING UP ☐
WAL ING ☐
PROSTHESIS ☐
CANE ☐
WHEELCHAIR ☐
REAHBILITATION ☐

HYGIENE:

INDEPENDENT ☐

PATIENT NEEDS HELP IN REGARDS TO:

PERSONAL HYGIENE ☐

IN THE SHOWER ☐

GETTING DRESSED ☐

UNDRESSING ☐

REMARKS: ____

REST AND SLEEP PATTERN	
INSOMNIA ☐ DROWSINESS ☐ NIGHTMARES ☒☒☒☒☒ ☐	DAILY HOURS OF SLEEP:________________ REST: YES ☒☐ NO ☐☒ RITUALS TO FALL ASLEEP☒ YES ☒☐ NO ☐☒ WHICH KIND OF RITUALS?:___________
REMARKS: ____ ____	
COGNITIVE - PERCEPTUAL PATTERN	
CONSCIOUSNESS STATE: AWARE ☐ CONFUSED ☒☒☒☒☒ ☐ DISORIENTED ☐ AGRESSIVE ☒☒☒☒☒ ☐ PATHOLOGICAL ☐ ANY OTHER: ____________________	AVERAGE LANGUAGE SKILLS: YES ☒☐ NO ☐☒ MEMORY: RETROGRADE ☒☐ RECENT ☐☒ HEARING DIFFICULTIES☒ YES ☒☐ NO ☐ SEEING DIFFICULTIES☒ YES ☒☐ NO ☐☒ HEARING AID YES ☒☐ NO ☐☒ GLASSES YES ☒☐ NO ☐☒
REMARKS: ____ ____	

ROLES PATTERN		
ACTIVITY DEGREE: HIGH ☐ MEDIUM ☐ LOW ☐	FAMILY RELATIONSHIPS: GOOD ☐ SO SO ☐ NO SO GOOD ☐	DECISION MAKING YES ☒☐ NO ☐ **CLOSE FRIENDS**☒ YES ☒☐ NO ☐☒ FINANCIALLY INDEPENDENT YES ☒☐ NO ☐☒
REMARKS: ____ ____		

ANY OTHER PATTERNS

NURSING PROCESS
NURSING DIAGNOSIS:
GOALS: SHORT TERM: MEDIUM TERM: LONG TERM:
CAREGIVING PLAN:
ASSESSMENT:
DISCHARGE PLAN:

NURSE IN CHARGE:	DATE:
CONTROL DATE:	**DOCTOR'S OFFICE:**

<table>
<tr><th colspan="4">CAREGIVING PLAN MONITORING</th></tr>
<tr><th>DATE</th><th>NURSING CARE</th><th>RESULTS</th><th>SIGNATURE</th></tr>
<tr><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="4">REMARKS:</td></tr>
</table>

GENERAL REMARKS:

Child with chronic illness, medical assessment form

DATE : (d d / m m / y y y y)
Health care insurance: _
LAST NAME _ NAME : _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _
DATE OF BIRTH: (dd / mm / yyyy) ENTRY DATE: (dd / mm / yyyy) DISCHARGE DATE: (dd / mm / yyyy)
CAREGIVER'S NAME _
HOME ADDRESS: _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _TELEPHONE NUMBER: _ _ _ _ _ _ _ _

1 . CHILD WITH CHRONIC ILLNESS MEDICAL ASSESSMENT

1. GENDER ☐ Male ☐ Female

2. AGE
☐ Newborn
☐ Unweaned baby
☐ Baby
☐ KIndergarden
☐ Primary-School
☐ Teenager

3. TAKING INTO ACCOUNT THE PREVIOUS AGE GROUPS, THE CAREGIVER'S AGE IS:
☐ Older than the caregiver
☐ The same age as the caregiver
☐ Younger than the caregiver

4. YOU CAN READ AND WRITE
☐ Yes ☐ No

5. EDUCATIONAL BACKGROUND
☐ Incomplete primary school
☐ Full primary school
☐ Incomplete High school
☐ Full High school
☐ Technical degree
☐ Incomplete Undergraduate studies
☐ Full Undergraduate studies

6. MARITAL STATUS
☐ Single
☐ Married
☐ Divorced
☐ Widower
☐ Common-law marriage

7. PROFESSION
☐ Housekeeper
☐ Employee
☐ Independent
☐ Student
☐ Another ____________________________

8. SOCIO-ECONOMIC STATUS OF YOUR HOUSE
☐ Social Stratum 1
☐ Social Stratum 2
☐ Social Stratum 3
☐ Social Stratum 4
☐ Social Stratum 5
☐ Social Stratum 6

9. HOW LONG HAS THE PATIENT BEEN DIAGNOSED WITH CHRONIC ILLNESS?
☐ From 0 to 6 months
☐ From 7 to 18 months
☐ From 19 to 36 months
☐ More than 37 months

10. No. OF DAILY CARE HOURS
☐ Less than 6 hours
☐ From 7 to 12 hours
☐ From 13 to 23 hours
☐ 24 hours

11. THERE IS ONLY ONE CAREGIVER?
☐ Yes ☐ No

12. WHAT KIND OF SUPPORT DO YOU HAVE?
____
____
____

13. RELATIONSHIP WITH THE CAREGIVER
☐ Wife / Husband
☐ Mother / Father
☐ Daughter / Son
☐ Grandfather / Grandmother
☐ Friend
☐ Another ____________________________

14. PULSES (see appendix)
☐ 6-8
☐ 9-11
☐ 12-24

16. PATIENT'S DIAGNOSIS:_______________
____
____

ENTRY MEDICAL DIAGNOSIS ____

____

OUTCOME ____

____

____

____

____

____

TREATMENT ____

____

____

____

HOSPITAL DISCHARGE DIAGNOSIS ____________________________________

____

CHILD'S CONDITION FOR HOSPITAL DISCHARGE _________________________

____

HOSPITAL DISCHARGE PLAN ____

____

____

2. CHILD WITH CHRONIC ILLNESS MEDICAL ASSESSMENT

<table>
<tr><th colspan="5">ENERAL INFORMATION</th></tr>
<tr><td rowspan="9">VITAL SIGNS:
Blood pressure:________________
Heart rate:_____________________
Respiratory rate:________________
Body temperature:______________
CURRENT WEIGHT:
PREVIOUS WEIGHT:
SIZE:
PAIN YES ☐ NO ☐
1__2__3__4__5__6__7__8__9__10__</td><td colspan="4">MEDICINE:</td></tr>
<tr><td>MEDICINE</td><td>ADMINISTRATION FORM</td><td>DOSE</td><td>TIME</td></tr>
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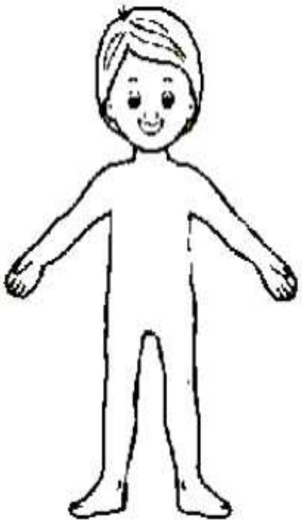
</table>

PHYSICAL CHECK UP
Consciousness state:
Head:
Neck:
Thorax:

PHYSICAL CHECK UP

Abdomen: ____

- Ostomysed patients:
  Location: ______________________________
  Last treatment: ______________________________
  Wound characteristics: ______________________________
- Food:
  Dependent to eat: ______________________________
  Independent to eat: ______________________________
  Nasogastric intubation: ______________________________
- Elimination:
  Diarrhea: ______________________________
  Flatulence: ______________________________
  Presence of fat: ______________________________
- Urinary elimination:
  Frequency: ______________________________
  Characteristics: ______________________________
- Extremities:
  Characteristics: ______________________________



Other findings: ____

____

____

NURSING PROCESS

NURSING DIAGNOSIS:

GOALS:

SHORT TERM:

MEDIUM TERM:

LONG TERM:

CAREGIVING PLAN:

ASSESSMENT:

DISCHARGE PLAN:

NURSE IN CHARGE:	DATE:
CONTROL DATE:	**DOCTOR'S OFFICE:**

CAREGIVING PLAN MONITORING			
DATE	NURSING CARE	RESULTS	SIGNATURE
REMARKS:			

GENERAL REMARKS:

____

____

____

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Taken from: Claudia Sanchez, Erika Castillo, Giovanni Ortega, Hernan Carpenter; Leyviy. Baron, Natividad Pinto Afanador . *Strengthening the ability of caring for caregivers of adults living a situation of chronic illness as an intervention strategy that contributes to a dignified life in the F.C.I. during the second semester, 2004*. School of Nursing, Universidad Nacional de Colombia. Undergraduate paper to apply for the professional title of nurses. 2005.

Appendix 2

PULSES PROFILE

Please indicate below key information in order to *identify the level of functionality of the person you care for.* When the care receiver is functional the scale shows lower numbers, and when he/she is more dependent it shows higher numbers.

Instructions:

1. In item P you should indicate the degree of stability of the illness. If the patient requires supervision of one or more health professionals less often than every three months, choose (1); if he/she requires monthly monitoring (2); weekly (3); whether he/she should be monitored daily (4).

2. In item U, you must include the level of functionality, as follows: (1) totally independent; (2) independent with some sort of adaptation or equipment; (3) the patient requires human assistance; (4) the patient is totally dependent to carry out activities.

3. In item L, you must include the level of functionality, as follows: (1) totally independent; (2) independent with some sort of adaptation or equipment; (3) the patient requires human assistance; (4) the patient is totally dependent to carry out activities.

4. In item S, you must include the level of functionality, as follows: (1) totally independent, (2) independent with some sort of adaptation or equipment; (3) the patient requires human assistance; (4) the patient is totally dependent to carry out activities.

5. In Item E, you must include the level of functionality, as follows: (1) totally independent, (2) independent with some sort of adaptation or equipment; (3) the patient requires human assistance; (4) the patient is totally dependent to carry out activities.

6. In item S, mark (1) if there is no alteration in social aspects; (2) if it is mildly altered; (3) if it is severely altered; (4) completely altered.

7. At the end, add the numbers you have chosen.

ITEMS OF PULSES FUNCTIONALITY SCALE		SCORE			
P	Stability of the illness	1	2	3	4
U	Use of the upper body	1	2	3	4
L	Ability to move	1	2	3	4
S	Sensory capacity	1	2	3	4
E	Bowel elimination	1	2	3	4
S	Social activity	1	2	3	4
Total					

Reference: Hens, M. Pulses Profile (1957). En: Ward, M. J. & Lindeman. C. A. (Eds.), Instruments for measuring nursing practice and other health care variables. Washington, D.C., US Government Printing Office, 2 Vols. DHEW Publication, 1979 (1):431-433.

Appendix 3
Preparation for home care by the family caregiver

Please mark an X in the number that indicates the best option for you:

ÍTEM	NONE ☒☒	LIMITED ☒	NOR OOD NOR BAD ☒	ENOUGH ☒	VERY GOOD ☒☒
Willingness to take the regiver's role	1	2	3	4	5
Knowledge on the regiver's role	1	2	3	4	5
A sign of a positive rspective by the care ceiver	1	2	3	4	5
The care receiver's rticipation in care decisions home	1	2	3	4	5
The care receiver's owledge on the illness ocess	1	2	3	4	5
Knowledge on the ocedures and treatment to e care receiver	1	2	3	4	5
Knowledge on the ocedures to apply / minister treatment to the rson you care for	1	2	3	4	5
Knowledge on the escribed activity to the rson you care for	1	2	3	4	5

ÍTEM	NONE ☒☒	LIMITED ☒	NOR GOOD NOR BAD ☒	ENOUGH ☒	VERY GOOD ☒☒
Knowledge on the necessary monitoring to care for the patient	1	2	3	4	5
Knowledge on emergency situations in care	1	2	3	4	5
Knowledge on available financial resources for caring	1	2	3	4	5
You have enough financial resources	1	2	3	4	5
Knowledge on when to contact health professionals	1	2	3	4	5
Knowledge on the available social support	1	2	3	4	5
Confidence in the ability to handle care at home	1	2	3	4	5
Caregiver's welfare	1	2	3	4	5
Participation of the care receiver to plan care	1	2	3	4	5
You have supporting plans and strategies as a caregiver	1	2	3	4	5

ÍTEM	NONE ☒☒	LIMITED ☒	NOR GOOD NOR BAD ☒	ENOUGH ☒	VERY GOOD ☒☒
Knowledge on where to get the necessary equipment to attend to the person you care for	1	2	3	4	5
Knowledge on how to handle equipment	1	2	3	4	5
Others:	1	2	3	4	5

Appendix 4

Code: □ □ □ □ □ □

CARING ABILITY INVENTORY[8]

Please read each of the following statements and decide how well it reflects your thoughts and feelings about other people in general. There is no right or wrong answer. Using the response scale, from 1 to 7, circle the degree to which you agree or disagree with each statement. Please answer all the questions.

1	2	3	4	5	6	7

Strongly disagree Strongly agree

1	I believe that learning takes time.	1	2	3	4	5	6	7
2	Today is filled with opportunities.	1	2	3	4	5	6	7
3	I usually say what I mean to others.	1	2	3	4	5	6	7
4	There is very little I can do for a person who is helpless.	1	2	3	4	5	6	7
5	I can see the need to change in myself.	1	2	3	4	5	6	7
6	I am able to like people even if they don't like me.	1	2	3	4	5	6	7
7	I understand people easily.	1	2	3	4	5	6	7
8	I have seen enough in this world for what I need to know.	1	2	3	4	5	6	7
9	I make the time to get to know other people.	1	2	3	4	5	6	7
10	Sometimes I like to be involved and sometimes I don't like to be involved.	1	2	3	4	5	6	7
11	There is nothing I can do to make life better.	1	2	3	4	5	6	7
12	I feel uneasy knowing that another person depends on me.	1	2	3	4	5	6	7
13	I do not like to go out of my way to help other people.	1	2	3	4	5	6	7
14	In dealing with people, it is difficult to let my feelings show.	1	2	3	4	5	6	7
15	It does not matter what I say, as long as I do the correct thing.	1	2	3	4	5	6	7
16	I find it difficult to understand how the other person feels if I have not had similar experiences.	1	2	3	4	5	6	7
17	I admire people who are calm, composed, and patient.	1	2	3	4	5	6	7
18	I believe it is important to accept and respect the attitudes and feeling of others.	1	2	3	4	5	6	7
19	People can count on me to do what I say I will.	1	2	3	4	5	6	7
20	I believe that there is room for improvement.	1	2	3	4	5	6	7
21	Good friends look after each other.	1	2	3	4	5	6	7
22	I find meaning in every situation.	1	2	3	4	5	6	7
23	I am afraid to "let go" of those I care for because I am afraid of what might happen to them.	1	2	3	4	5	6	7
24	I like to offer encouragement to people.	1	2	3	4	5	6	7
25	I do not like to make commitments beyond the present.	1	2	3	4	5	6	7
26	I really like myself.	1	2	3	4	5	6	7
27	I see strengths and weakness (limitations) in each individual.	1	2	3	4	5	6	7
28	New experiences are usually frightening to me.	1	2	3	4	5	6	7
29	I am afraid to be open and let others see who I am.	1	2	3	4	5	6	7
30	I accept people just the way the are.	1	2	3	4	5	6	7
31	When I care for someone else, I do not have to hide my feelings.	1	2	3	4	5	6	7
32	I do not like to be asked for help.	1	2	3	4	5	6	7
33	I can express my feelings to people in a warm and caring way.	1	2	3	4	5	6	7
34	I like talking with people.	1	2	3	4	5	6	7
35	I regard myself as sincere in my relationships with others.	1	2	3	4	5	6	7
36	People need space (room, privacy) to think and feel.	1	2	3	4	5	6	7
37	I can be approached by people at any time.	1	2	3	4	5	6	7

---

[8] Taken from: Nkonghon N. The Caring Ability Inventory . In Ora L . Strickland and Carolyn F . Waltz . Measurement of Nursing Outcomes: Self Care and Coping. New York. Springer Publishing Company, Part III. 1990; (3 y 4) p p . 3 - 1 6

Appendix 5

Handbook for caregivers of children with chronic illness

Authors: Gina Paola Torres, Ingrid Cáceres, Andrea Cepeda, Miguel Duque
Advisors: Natividad Pinto A., Lucy Barrera O., Beatriz Sánchez
Design: Andrés Reyes

ANXIETY

It is a standard experience that all human beings usually go through. It is part of all life experiences such as pain, sadness or joy.

Symptoms of Anxiety

- Stress, nervousness, restlessness, uneasiness, insecurity, fatigue (including tiredness, pressure, loss of intellectual capacity, inhibition of sexual desire and depression).
- Sensation of a lump in the throat, decreased appetite, chills, tremor, dizziness and insomnia.
- Lack of concentration, extreme hypersensitivity reactions without causal consistency, aggressiveness.
- Obvious physical problems such as increased blood pressure, abdominal pain or digestive disorders, headaches.
- The person affected wishes to solve all issues without asking for any help.

Stress

Emotional tension that blocks the proper performance of a task; it appears suddenly and takes over the person as if it were an ambush.

ANXIETY AND STRESS

Caring for a child living a situation
of chronic illness can lead to
conditions of stress and anxiety.
Determine its meaning, prevent and treat
its manifestations.

WHAT HAPPENS WHEN THERE IS TOO MUCH STRESS?

Area of thoughts and ideas:

- Difficulty to focus on a difficult activity.
- Loss of attention.
- Decreased short and long term memory.
- There are random thoughts without logical or coherent patterns.
- The person feels unable to accurately assess both the present situation its projection for the future.

Area of feelings and emotions:

- Difficulty to be relaxed from a physical and emotional standpoint.
- Presence of impatience, intolerance and authoritarianism, and lack of consideration for others.
- The moral or ethical principles that govern one's life are loose and self-control decreases.
- Increased discouragement, decreased desire to live.
- Thoughts of incapacity and inferiority.

Area of attitudes and behavior:

- Stuttering; decreased verbal fluency.
- Lack of enthusiasm.
- Absence at work or school.
- Increased consumption of alcohol, cigarettes, coffee or other drugs.
- Sleep patterns are disrupted. Generally there is insomnia, becoming sometimes in an extreme need for sleep.
- There is a tendency to blame others.
- Responsibilities are put on someone else’s hands.

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We present this material as part of the research design and evaluation of a program to develop caring abilities on family caregivers of people with chronic illness. This research study has been supported by COLCIENCIAS and the School of Nursing at Universidad Nacional de Colombia.

RECOMMENDATIONS TO REDUCE STRESS LEVELS:

Here there are some tips to keep in mind and perform your caring tasks without getting stressed out:

- Organize your time so that you can perform all activities without rushing; from childcare to household chores and work.
- Learn to control your body and mind through relaxation and breathing exercises that help you forget for a moment the issues that you are going through.
- Carry out for recreation and relaxation activities during free time (try not to bring work to your home; enjoy these moments with your family or friends instead).
- It is recommended to wake up early avoiding rush hours.
- Before making public presentations, take a deep breath and keep self-confidence.
- Be sure to provide the child care through love and feeling good doing it, being "good enough" rather than demanding perfection from yourself and others.
- Take a break from stressful situations. Activities such as listening to music, talking with a friend, drawing, writing or spending time with a domesticated animal might help to reduce stress.
- Be part of a group of friends who can help you cope with situations positively, providing support in difficult times, and to favor an appropriate decision-making process.

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DECISION MAKING AVOIDING STRESS

Suggested guidelines for decision making:

1. Do not decide when you are upset, angry. If possible, let some time pass. The next day is usually a good time.
2. Write down all the possible options.
3. List the advantages and disadvantages for each one of them.
4. Look to the past and please answer yourself this question: How did it go when I decided something similar?
5. Project options in the immediate future: What will happen if I choose this? What if I do it this other way?
6. Now choose the option that, agreeing with your principles is more profitable for you and those others involved, in this case your child.
7. Accept this option and its inevitable consequences. Do not think: I wish I had chosen another way!

OSTOMIES

Dear children and parents:
This is a basic guide to strengthen parents or caregivers' ability in caring for their child.

It was written to help handle those so-called *ostomies* (colostomy or gastrostomy) that are required in digestive system alterations of children with chronic illness who cannot eat nor eliminate.

For further understanding, we will explain some procedures, explaining terms, so as to answer questions, provide care and avoid complications.

Some basic concepts

Our digestive system:
As a whole, our digestive system consists of different organs:

- Gastrointestinal tract or digestive tract:

It is a long muscular tube that begins in the mouth and ends at the anus; it is made up of the mouth, pharynx, esophagus, stomach, small intestine and large intestine.

- Glands:

They are located outside the digestive tract, but they dump their secretions into the digestive tract; they are the salivary glands, liver and pancreas.

Stoma:
Cut or opening to the outside that is created in the ostomy.

Ostomy:
It is the opening of a hollow organ to the outside, usually towards the abdominal wall in order to remove waste from the body or to introduce food or medicine.

Types of stoma
1. Sigmoidal colostomy
2. Descending colostomy
3. Transverse colostomy
4. Ascending colostomy
5. Ileostomy

CLASSIFICATION OF OSTOMIES

According to their function

Ventilation:
They are usually located in the neck; their purpose is to keep the airway open to favor this function.

Nutrition:
It is an open conduit for food through a tube into the stomach.

Elimination:
Its mission is to create an exit for fecal or urinary content.

According to time

Temporary:
They are made so that once the medical condition is solved; the bowel movement or urination will be restored.

Permanent:
They are those in which there is either complete amputation of an organ or its closing, when there are no more possibilities.

According to the organ involved

Intestinal: Colostomy (in the sigmoid colon, ascending, transverse, descending), ileostomy.

Urinary: urostomy (ileal or bricker, vesicostomy ...)

Trachea: tracheostomy.

Gastrostomy: stomach to the abdominal wall.
In this material we will discuss specific care for a colostomy, ileostomy and gastrostomy.

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CARING FOR OSTOMIES

Skin:

- The skin around the stoma (peristomal skin) must be kept healthy and without irritations, and it should have the same appearance as the rest of the abdominal skin.
- To prevent irritation or other skin problems, it is important to use an ostomy device whose layer is perfectly adapted to the size and shape of the stoma in order to protect it.
- Never use lotions or ointments which are not specifically for ostomy treatment, since fats or oils prevent the pouch to adhere accurately.

Daily hygiene:

- We recommend washing with mild soap to prevent skin from drying out. You can bathe or have a shower just as before the operation; soap and water will not hurt your stoma.
- You can shower with the pouch (in the case of colostomies) and then change it washing around the stoma and peristomal skin, or you may shower without it; as you prefer, what is most comfortable for you.
- In any case, it is important to rinse it well with water to avoid leaving soap residue that might prevent the pouch to stick rightly to the skin.
- After washing it, it is necessary to dry the peristomal skin without irritating, with cellulose (kitchen towels and toilet paper) and through little touches throughout the area. You shouldn’t rub or use hot or cold air directly in that area, because it would dry the skin, and consequently it would become irritated.
- If your child has hair in the area, cut them off with scissors; you should never shave or use any hair removal products because it could also irritate the kid’s skin.
- Finally, you should not use alcohol or lotions: it would also dry the kid’s skin; it would be easier that it becomes irritated.

Oxygen therapy is a vital treatment for some children who cannot live without support due to their illness condition.

The oxygen dependency is a condition that affects the development of children with chronic illness and their lifestyle.
We want to provide a guide that allows welfare, adaptation and prevents from complications

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COLOSTOMIES

A colostomy is a conduit by the large intestine to the abdominal wall skin; its purpose is to divert traffic or decompress the small bowel and create an artificial opening for fecal contents.

Indications for colostomy

Permanent:
These types of colostomies are made in the left colon so they are exteriorized to the left side of the stomach, in an analyzed place before surgery.

The main indications are: rectum or anal canal cancer, ano-rectal functional disability associated with incontinence, anal and rectal injuries.

DEVICES

1. Collection bags for colostomies and ileostomies

These are the devices that collect the feces through the stoma. They are made of a disposable and reusable plastic; they require special adhesives that hold and protect the skin. There are two types of bags or pouches:

Sealed pouches:
They are disposed every time they are changed. They carry a filter that prevents odor.

Opened pouches:
They may be emptied through their lower end and re-close to continue using it. Sometimes they have a filter; sometimes they do not.

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2. Other accessories

- Belt for holding the pouch.
- Deodorant to put it into the pouch: powder, liquid, tablets, to prevent odors.
- Clamps for opened pouches.
- Filters that prevent concentration of odors.
- Molded resin to fit the device in a complicated ostomy or irritated skin.
- Accessories for skin care: cleansing wipes, cleansing lotions, barrier skin lotions.
- Products to thicken fecal contents inside the pouch.

APPLYING THE ONE PIECE POUCH

1. Wash your hands.
2. Elements should be available and organized previously in order to change or move the position of the bag.
3. If using a cut-pouch, measure the diameter of the stoma and draw it on the protective paper in its exact form and cut the center hole to the required diameter (drawn above).
4. In general, a diameter pre-cut is used to facilitate the application of the pouch. However, it is possible that shortly after surgery the stoma has decreased in size, so it will be necessary to measure it again to adjust the diameter. For this purpose, use a measuring guide for stomas.
5. Check the condition of the skin, if you notice swelling or redness, the skin might have become irritated. In that case, it is necessary to use specific medical products to reduce these problems.
6. In difficult and irregular stomas, a skin protector may be applied on the skin around the stoma and match it to fill scars and skin folds before setting the pouch, thus, preventing feces or intestinal secretions leaks.
7. Wash the skin around the stoma with mild soap, rinse well and dry gently.
8. Remove the protective paper from the pouch and apply it to the stoma area, through a gentle massage in order to achieve good fixation of the pouch to the skin surrounding the stoma; you must be careful that the stoma remains around the center of the bag because if the adhesive is in direct contact, it may irritate the skin and cause complications.
9. After fixing the bag, check it for leaks and seal it properly to prevent the escape of odors; place it in descending order; it can be placed inside daily clothing, checking it out constantly if it is filled.
10. In social events, trips, etc., a small pouch is enough to provide the necessary comfort.
11. In cases of skin irritation or travelling a two pieces system may be used, by changing the bag without detaching the dressing from the skin, thereby facilitating change and a rapid normalization of the skin.

GASTROSTOMIES

A gastrostomy is an opening from the stomach to the abdominal wall skin, with the goal to provide a way to feed children who have difficulty swallowing food.

Indications for gastrostomy

The main objective of a gastrostomy is to establish a feeding pathway in cases where feeding is impossible orally; due to congenital malformations and their treatment (atresia and fistula tracheoesophageal, duodenal or jejunal atresia), neurological disorders, brain tumors, or cancer.

Gastrostomy safety measures

Accidental removal of the tube must be avoided.

- Before administering food, check on all abdominal characteristics: signs of strain, hardening, increased perimeter; if it is normal, continue with the procedure.
- Ensure the permeability of the catheter, rinse with warm water from 5 cc to 10 cc before and after feeding the patient to prevent clogging or food passing with difficulty.
- Measure portions and requirements established by the nutritionist or physician; remember: children in less than 10 kg weigh should be fed 100 cc per 1 weigh kg divided into 24 hours.
- Remember that the amount of food you give the child will be measured before food preparation (blending) and the time of administration should be verified that does not contain thick masses. Moreover, that its viscosity is at average, as thick food can cause clogging and clear food descends so fast that the stomach fails to assimilate it, which may generate diarrhea.
- Food should be at ambient temperature, preventing that the stomach fills with gas and generating colic.
- At the beginning some food will produce diarrhea or constipation due to its composition, especially artificial formulas.

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FEEDING THE CHILD WITH GASTROSTOMY

1. The equipment shall be ready: food, whether artificial or prepared at home, syringe, funnel, gauze.

2. Uncover the gastrostomy catheter and apply the wick technique: Place gauze around the tube or, alternatively, a clean piece of cloth; place the gastrostomy tube completely vertical to facilitate the exit of gases, gastric residues, and for a gastric decompression.

3. Put your child in semi-sitting position and each time you feed wait for a moment while the food completely reaches the stomach.

4. Clean the gastrostomy tube with 5 cc of warm water or saline solution.

5. Place a syringe at the lower end of the gastrostomy tube or a funnel so that food passes slowly through the tube, check its permeability, when you notice food is passing too slowly, suspend and try again.

6. Once you have completed the child's feeding, flush the gastrostomy tube with 5 cc warm water or saline solution to flush the catheter. Do it every time feed the child.

7. Check the tolerance of child feeding. If the child has nausea, vomit or allergies, you would need to inform the doctor.

8. Each time you feed your child, make sure the catheter is securely closed, so that around the gastrostomy it is not wet or leftover food, to prevent infection.

9. Once the child has been fed, keep a calm and comfortable environment to avoid the food is returned.

STEPS TO ADMINISTER MEDICATION TO A CHILD WITH GASTROSTOMY

Remember that sometimes the child is to be administered with some medications, regardless of the presence of the gastrostomy; you should administer medications as prescribed by the health personnel.

When administering medications take into account the following precautions:

- Keep them in a cool place; avoid children to have contact with them.
- Check every time you administer the correct medication.
- Use a syringe to administer medications.
- Medications that are in tablets shall be smashed into pulp before administering them, and dissolved in water if they have no contraindication.

When administering medications take into account take the following steps:

1. Verify that the medications to be administered are the correct ones.

2. Medicines that are in powder or tablets should be dissolved and melt in water, if they have no contraindication.

3. The passage of medicines through a nozzle is different from the feeding one. You may identify it because it brings a white plug and is much smaller. Remember it must remain sealed.

4. Before administering the medicine, rinse the probe with 5 cc of water or normal saline solution to release it from any gastric residuals.

5. Administer the medication with a syringe, slowly, at the indicated times.

6. After administering the medication, flush the gastrostomy tube and close the tube.

7. You should report immediately the doctor any odd or discomfort reaction.

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GASTROSTOMY COMPLICATIONS

- Accidental tube removal. If it occurs, it is necessary to immediately reintroduce it avoiding efforts that might lacerate the stoma or puncture the abdominal wall.
- Bleeding. The gastric wall around the tube may become irritated and bleed frequently. Using creams and solutions might be important for healing, preventing also lacerations and infections.
- Escape of gastric contents by the peri-tube. If the sutures around the tube or the attachments to the anterior abdominal wall are off, it might cause peritonitis (infection of the abdominal wall).
- Formation of a gastric fistula. Once the tube is removed, the remaining fistula usually close spontaneously, there should be no drainage.

Given the above complications is necessary to take the child immediately to the closest health center. It is important to avoid complications and unnecessary procedures.

GASTROSTOMY CARE

For the gastrostomy to heal, it is necessary to consider some key aspects.

Material needed for gastrostomy care:

Warm water or saline solution, gauze, and those accessories described above.

How to clean gastrostomies

- The equipment mentioned above should be nearby.
- Wash your hands.
- Gently lift the gastrostomy button and clean around the skin to remove food waste with soaked gauze with warm water.
- Observe the characteristics of the skin: If it is irritated, there is blood or tissue remains.
- In the former case, apply scar solution: Stomadhesive powder, or a layer of Duoderm Gel to promote skin regeneration.

OXYGEN THERAPY

The oxygen therapy is a special oxygen supply for people with lung problems as sufficient amounts of oxygen cannot be incorporated sufficiently from the natural content in the breathing air into the blood.
The aim of oxygen therapy is to increase oxygen delivery to tissues to the maximum transport capacity.

Indications of oxygen therapy:

- When there is a decrease in children lung capacity to perform an adequate exchange of oxygen and carbon dioxide.
- When the child's ability to inspire environmental oxygen has been reduced, whether by obstruction of the airway or as a result of a previous illness.
- When children are premature have not matured lungs, so they require oxygen therapy to improve gas exchange.

Precautions in the administration of oxygen therapy:
Oxygen therapy is usually well tolerated, but there are certain dangers associated with it.

Oxygen toxicity:
This event occurs when there is an exaggerated increase in oxygen levels required by the body, it may be avoided by keeping the administration of oxygen at a standard concentration, without any sudden or unnecessary increases or decreases.

Retention of CO2:
This might happen to patients who have difficulties with the entry and exit of air. To avoid this, make sure the child has a clear airway, i.e., runny nose, as these obstruct the entry of oxygen into the lungs.

Accidents:
Fire and explosion related to cigarette smoke, oxygen leaks, exposing the bullet to high temperatures.

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MATERIALS USED IN OXYGEN THERAPY

- Case cylinder.
- Disposable Humidifier.
- Nasal cannula for oxygen Venturi.
- Extension tube for humidifier with adapter.

Steps to start the administration of oxygen at home

1. Before administering the oxygen determine the cannula's permeability and the child's airway. For this purpose, place your fingers in the cannula's holes ensuring its functionality and the absence of leaks; in the child check there is not congestion and wash his nostrils insufflating from 2 cc to 3 cc of saline solution.

2. Place the oxygen tank in a safe place of your child's room, where it does not represent any damage; place it on a completely flat surface, so that it does not represent danger to other household members. Make sure it is sealed. Do not locate it near the kitchen or where they may be exposed to high temperatures.

Using different materials

1. Remove the seal from the oxygen cylinder; connect the pressure gauge or clock, which determines the amount and concentration of oxygen in the connector, verifying that it is not leakage of oxygen. Immediately turn on the faucet of the tank to confirm the number of pounds of oxygen, thus, to calculate how long it will last.

2. Identify the oxygen device or product that the child requires. Do not forget that there are *low flow* (less than 3 liters per minute, as the pediatric nasal cannula) and *high flow* (higher than 3 liters per minute as the Venturi; it should be graduated depending on the amount of oxygen the child requires to improve breathing). Keep in mind the physician's prescription.

3. The humidifier is a component to humidify the oxygen, preventing skin and mucous membranes irritation. It consists of a cup with a lid; at the top it has a connection which fits exactly to the bottom of the pressure gauge. In addition, the glass has two marks which indicate the minimum and maximum levels of sterile water to be contained during oxygen administration. Try to keep it between the two marks, avoiding excess or shortage; remember to change at least every 48 hours.

4. If the order by the physician is less than 3 liters per minute, a pediatric nasal cannula should be used. It is a plastic tubing, completely flexible, with two extremities; it has two small holes that attach perfectly to the child's nostril; it also has a connection that attaches to the humidifier. Be careful when placing it to the child’s nose; place it above the ear, preventing the child to sleep on one side and the pressure of the plastic tube over his face cause injury. If the child is a small baby, to prevent he removes it, use two very small micropore tape segments to attach the tube to his cheeks. Remember that this film should be changed daily, preferably in the bath time.

5. On the other hand, if the order prescribed by the physician contains an amount higher than 3 liters per minute, humidifier is not used. This is replaced by another element called nipple; it is plastic made and has two connectors; one big top that adjusts with the final part of the pressure gauge and a small one that is used to connect a single tube (it is plastic, completely flexible, it has two ends with two exactly equal holes). It is the means used to transport oxygen from the nipple to the venturi. The venturi is a very small plastic element comprising two parts: a thin tip that attaches to the single tube end and a wider one that connects to a medium corrugated plastic hose consisting of two ends.

The second end of the corrugated tube is placed on a pediatric mask, that the child will wear and it will provide the amount of oxygen the child needs. By placing this item, take into account the recommendation explained on the nasal cannula, because although this has a better attachment rubber, rubber pressure exerted on the child's face may cause injury.

6. After connecting the elements, you can start the administration of oxygen by opening the regulator of the pressure gauge and placing the hand of the clock in the amount of oxygen to be provided to the child. Keep the following warning signs during the administration of oxygen:

   - Shortness of breath: if you notice that your child is breathing quickly or too slowly, check that the amount of oxygen provided is the correct one, there might have decreased or increased.

   - Purple coloration around the mouth region: Indicates that the amount of oxygen administered is not enough; it may be because that the tank is short of oxygen.

   - Redness on the face through which the nasal cannula or mask rubber is located: you should constantly moisturize the skin to prevent major alterations.

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CHILD WITH OXYGEN THERAPY BATH

1. Remove from the child all the blankets; allow the child's body to adapt to the environment temperature for a moment.

2. While the child adapts to the current temperature, prepare the bath with the water in which you are going give the child a bath. Remember that the temperature should be medium (warm), if necessary prepare a bucket of water with the temperature indicated. Avoid bathing your child with cold water; it may generate a breathing difficulty.

3. Undress your child without disconnecting the oxygen mask and cover him with a towel.

4. Disconnect the oxygen mask carefully: first turn off the pressure gauge and then remove the cannula or mask from the child's face. Avoid placing the mask on the floor as it may acquire bacteria that will then enter into the child's airway.

5. Give your child a quick bath, if he is still a baby you may want to use bathtub; if he is older give him a bath in the bathroom quickly.

6. After the shower, dry his face and apply a moisturizer to prevent skin disorders, then put the cannula or mask and start oxygen administration by opening the regulator of the pressure gauge and placing the hand of the clock in the indicated amount.

7. During the bath you must be aware of any change in the child that may indicate a need for oxygen, such as:

   - Shortness of breath: if you notice that your child is breathing rapidly, stop the bath, put on oxygen again, and when the child has a normalized breathing, resume activity. If more than 10 seconds have passed and the child continues like that, get him dressed and postpone the bathroom for another time.

   - Purple coloration around the mouth region: indicates that the child needs oxygen. Stop for a moment and connect the oxygen mask, when this coloration disappears, restart the bathroom.

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Appendix 6

Daily activities handbook for caregivers of adults with chronic illness

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Design: Andrés Reyes

To Our Readers

When caring for a relative living a situation of chronic illness in daily activities, special support is required to indicate how to do a better job, caring for yourself, and knowing that you are not alone in your caregiving activities.

This *handbook* was created as an alternative to strengthen caregivers' ability of care; it collects some key aspects of daily activities, so that they are available for our readers in a clear and didactic way.

Taking into account there is a limited material support for caregivers, this *handbook* focuses on meeting some of the caregiver's basic needs.

That is why we present this *handbook* from the collective effort of students and teachers who are interested in the strengthening caring skills and supporting Colombian caregivers.

HANDBOOK FOR CAREGIVERS OF ADULTS WITH CHRONIC ILLNESS IN DAILY LIVING ACTIVITIES

IDENTIFY YOUR SUPPORT NEEDS IN ACTIVITIES OF DAILY LIVING

To do so, answer these simple questions:

- Do you get to handle all the situations with your relative every day?
- Do you know what kind of daily care the care receiver requires?
- Do you need more information about caring for your relative in daily living activities?
- Do you have support mechanisms to strengthen your caring ability?
- Do you want to develop a good role as a caregiver?
- Would you like your caregivers to be aware and care about what you might need if you were the person that is being cared for?
- In daily life you have many questions about how to perform care activities?

If you answered yes to three or more questions, this *handbook* may contribute to developing and enhancing your caring ability facing ACTIVITIES OF DAILY LIVING, in regards to key principles, such as courage, patience and knowledge.

Do not put it off ...
Take a step towards
wellness today!

So we invite you
to read it and apply it.

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PERSONAL CARE AND HYGIENE

General bath

What do we understand by general bath?
Surely you have performed this *handbook* for yourself, which is a moment during the day to clean up and feel relaxed.

Through a general bath we contribute to:

- Rest and relaxation.
- Reduce stress and muscle fatigue.
- Improve your self-image, physical appearance and to eliminate odors.
- Care and skin protection, plus to benefit healing processes.

General tips for bathing

- Encourage the person to use this *handbook* as independently as possible. There are some parts of the body that might be difficult.

- Many people do not bathe every day. Ensure that at least the person's face, hands and genitals are cleansed every day.

- Have all supplies ready where the bath will take place.

- Keep a comfortable temperature by closing doors and windows.

- Use latex gloves when you have contact with body fluids or feces.

- Install grab bars. It is very easy to do, although it may require a builder or a carpenter's help, and use materials such as aluminum or porcelain.

- Make sure the floor is not slippery through bath mats, non-slip rubber mats or others.

- Make sure water is at a comfortable temperature, neither too hot nor too cold.

- Provide a chair to prevent an accident and for your convenience.

HELPING WANDERING

- Wandering may be understood as all those activities that involve walking, either with a person or device's help.

- Remember that when a persdon remains in bed for more than two days feels weak, shaky and unstable when getting up, so we should know how to provide support, helping him/her to carry out the activities as independently as possible.

- General Tips

- It is better to start with small sections to walk as fatigue and dizziness may suddenly appear.

- Before you lift the person out of bed, he or she should remain seated for two minutes in order to avoid dizziness and as well as when he or she is standing before starting to walk.

- You should try some passive exercises in bed every day, in order to prepare his/her muscles and joints for physical activity.

- Be physically near the person in case he/she needs help.

- If the person is falling down, do not try to hold all the weight by lifting him/her; put your hands in his/her armpits and bring him/her back, so he/she falls gently, reaching the ground or a chair.

- Clasp your arm with the nearest person's arm and walk on his/her weaker side.

How to use devices

When the person you care for has been in bed for a long time and has impaired mobility, he/she might need the help of a device, such as a cane, a walker, etc...

Cane

It a lightweight and easily movable device, it gets to the waist; it is either made of wood or metal.

There are two classes of canes:

- Simple straight cane.
- Quadruple.
- Let the person who is to carry the cane to use the strongest.
- He should move the cane forward, towards a comfortable distance.
- Then, tell him to move forward the unaffected or his/her strongest leg.
- Remember to repeat these steps again and again to ensure the person's stability and support.

Walker

Walkers are used when a person needs more support or fastening than the one provided by the cane.

It is usually made of aluminum; it has four legs (support points) with rubber bumpers and plastic bars as hands support.

Some walkers have wheels on each of the supports or in the media front, allowing the walker to remain in contact with the ground while the person raises the part nearest the body.

- Remember that the walker should be lifted with each step. Therefore, the person should have some strength to perform this activity.

- Tell the person to move the walker forward approximately 15 inches.

- Then, he should move the right foot to the walker as the weight is on his/her left leg and both arms.

- Then repeat this process with the left foot.

"Get to know your limits as a caregiver and be aware of them."

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BATH IN BED

Do you know how to cleanse your relative while in bed?

Take the work of grooming requires certain skills by caregivers.

Always keep in mind

- Place a blanket or sheet that can be used in bath time.
- If possible, move to stop at an appropriate level to avoid unnecessary effort.
- Wrap your hand with a clean cloth to clean the person's body in bed.
- Cleanse his face starting from the top down. His eyes preferably only with water and dry thoroughly; you should use a different part of the fabric for each eye.
- Place a towel or plastic under his body to protect the bed, but mostly avoiding discomfort for your relative.
- Cleanse his torso and abdomen parts, keeping the genitals covered.
- Note any signs of impairment caused by pain or limitation of movement in any part of the body.
- During the bath friction long, soft and firm, always from the center of the body to the extremities.
- Wash and thoroughly dry the skin folds that form below the buttocks or in the underarm region.
- Encourage and help the person to clean his/her genital area and collaborate with a toilet if possible.

Genitalia care and grooming

You should consider the person's genitalia care, in order to provide a greater well-being.

The hygiene of genitalia is an uncomfortable activity. It is considered so because it involves crossing another person's privacy levels, but care is an activity to be performed appropriately.

"I love her more than ever because I know how much she needs me."

Tips for genitalia hygiene

- Tell the person you will clean his/her genitals, explaining how, why and how he/she may cooperate.

- Observe carefully if the person feels uncomfortable, if he/she feels any embarrassment or discomfort in his/her genital area.

- Remove the sheet that covers the area and if necessary place a towel or plastic below to protect the bed

- Bring his/her legs slightly and clean the genital area trying to expose the area as quickly as possible.

- Note in particular areas of inflammation, swelling, burning signs or presence of pain; examine women as there may be excessive genital flow.

- It should be subtle, soft, well made, not forgetting to rinse out and dry skin thoroughly.

- If necessary clean the person's with toilet paper before you start grooming.

"Be aware of the situation that you are going through as it may last several years; get as much help as possible and as soon as possible. "

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SKIN CARE

Do you think skin should be taken into account within the care plan?

The skin is an important part of the body as it protects us, yet is a very sensitive and delicate system, which is easily injured if necessary care is not well provided.

The skin has some important functions:

- Protection of internal organs, besides being the first line of defense.
- It regulates our body temperature, cools down the human body through sweat, and when it is cold it keeps the body heat.
- Our skin produces a kind of fat that allows the body not to lose water, protecting it against bacteria, softening and lubricating your hair and skin.

Tips for skin care

- Make an observation and palpation (touch) from head to feet to find some kind of damage or risk of injury to the skin.
- Make sure there are no areas of inflammation (swelling), redness, dry skin, bruised or some kind of feeling or of impaired skin integrity. This activity can be performed during the bath time.
- Keep the skin clean and moisturized.
- If the person has incontinence, use a plastic shield to keep the bed dry.
- Put on some lotion to moisturize skin regularly, gently massaging the area, except between the toes as it may cause fungal growth.

- The use of powder on regions, such as feet, armpits and under the breasts is useful to absorb humidity, friction and prevent mildew.

- The shower is a very important care activity; it has benefits such as relaxation, it is an opportunity to observe the condition of the skin and strengthens the link between the person you care and you.

- A vigorous massage with long, gentle friction through distant parts of the body towards the center is very important because it provides relaxation circulation benefits and skin protection.

If there are spots on the skin:

- Remove the factor (object) that is pressing on the skin.

- Change the person's position and avoid further deterioration of the skin, being careful not to hurt the person.

- Examine the skin after 15 minutes, the redness has probably disappeared.

- Do not massage the area.

- Moisturize the skin with a cream lotion gently without pressure.

- Make sure the bed or chair where the person is not creased or is an irregular surface that can cause further damage.

"Be aware that the situation that you are going through may last several years; get as much help as possible and as soon as possible."

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POSITION CHANGES

Your relative needs to change positions when he is unable do it himself.

Remember that the more dependent the person you care is, the more necessary to provide a good posture. Otherwise neck, back pain, and contractures will easily appear.

General Tips

- Using too many pillows under his/her head may produce neck pain.
- Remember, the best thing is to have a smooth and not too soft cushion.
- Check the bed is clean and dry; crumpled or damp sheets increase the risk of skin damage (ulcers).
- In some cases, it is necessary to plan position changes every two hours or when the situation of the person requires it; it is necessary to carry a notebook to register schedules and activities to be undertaken.

Semi-sitting position

- Explain what you will do.
- Elevate the head from the bed.
- Turn lawn the person's head on a small pillow.
- Put a small pillow or towel roll under his/her thighs and ankles.
- Brace the person’s shoulder or arm with pillows or rolls if you do not have control.

Laying face-up

- Place a small folded towel on the lower back.
- Place a pillow under his/her head, covering neck and shoulders.
- Place a small pillow under his/her ankles to elevate his/her heels.
- Keep his/her feet in a proper position by means of a table, footrest or shoes.
- If there is specially affected body side (hemiplegia), place a folded towel under the person's hips, by the injured side and hold his/her affected arm extended away from the body and his/her palms facing up.

Laying side

- Lower his/her head of the person as much as possible.
- Place the person on one side of the bed if possible; ask his/her to do it by him/herself.
- Ask the person to turn to the other side (where you are), help by bending his/her knees.
- Put a pillow under his/her head and neck.
- Flex the person's arms a bit, supporting one over the mattress and on the pillow.
- Place a pillow behind his/her back, bent a little rolling it up through his/her back.
- Place a pillow under the bent leg (covering the entire leg).
- Remember to place shoes to keep a feet correct position.

His/her position may vary a bit by asking the person to rest part of his/her body on the abdomen, his/her arms are on either side of the body, one flexed and the other extended.

"Get to know your own limits as a caregiver and be aware of them."

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We present this material as part of the research design and evaluation of a program to develop caring abilities on family caregivers of people with chronic illness. This research study has been supported by COLCIENCIAS and the School of Nursing at Universidad Nacional de Colombia

MOUTH HYGIENE AND CARE

Our mouth is a very important part of our body. Thanks to our mouth we smile, communicate and express feelings. Oral care is fundamental to the life of the person you care for.

Some things to consider regarding Oral care:

- Older people or people with an illness have a deficiency or limitation with their oral care.
- A reduction of saliva production causes a dry mouth and it may blood.
- Inadequate nutrition with sugar or salt excess may damage your teeth; it is also a risk factor for illness such as diabetes and hypertension.
- If the person uses dentures, remove them, clean them up, keep them in a glass of clean water, and handle them carefully.
- Dentures should be handled wearing gloves, cleaned up with a solution of a cup of water with a tablespoon of white vinegar.

Special care of the mouth:

- You need a towel, some warm water, a toothbrush, a lip moisturizer and some Vaseline, latex gloves and a container for waste.
- Stay at the person's side, if possible, set a towel or a cloth under his/her chin.
- Brush his/her teeth gently and carefully, be careful you do not want to hurt the person's gums.
- Run warm water to rinse his/her mouth if you prefer you can use a syringe to gently rinse the person's mouth.
- Rinse as often as necessary to remove all traces of dental cream.
- Finally hydrate his/her lips with Vaseline or lip moisturizer.

Moving and walking

What do we understand as moving and walking?

They are all those activities that require moving from one place to another with a certain goal, for instance when the care receiver needs help getting out of bed, moving to a wheelchair or indoors.

General tips to help the person

- Encourage the person to perform such activities as independently as possible in order to promote autonomy.
- Always tell what you are doing, for example: "I am going to help you."
- Never attempt to lift a heavier person without the help you need or precautions.

When you help a person to go from the bed to a chair

- Never pull the arms to a sitting position.
- Have a chair ready next to the bed, if it is wheeled, lock it up and then remove or lift

the footrest.

- If possible, ask the person to move to the side of the bed towards you.
- Otherwise, put him/her arm on him/her abdomen.
- Put one leg over the other.
- Turn the person so that hi/her legs are out of bed and lift him up.
- Help him to sit.
- Help the person to get on the edge of the bed.
- His/her feet should get to the floor now, with enough space from each other.
- Place your arms around him/her waist.
- Embrace the person and ask him you slowly slide, and your legs should be slightly bent, hold him towards you.
- Turn his/her body slowly and help him to get off the chair, holding him with one of his/her back, bending your knees.

In some cases it is appropriate to use a broadband (not an elastic one) or a folded blanket so that it works as the arms across his/her back, to hold the person.

When you help a person to pass from chair to the bed

- Face the person and put your left foot in the middle of the feet of the person cared for.
- Ask him/her to hold your waist, then, you go a step backwards or step back bending your knees, telling him/her to stand up.
- Set your knee in front of that leg that the person cannot control.
- Turn the person so that his/her back rests on the edge of the bed; stand next to the person.
- Hold his/her waist.
- Have him/her lying on the bed, helping him/her with your body, so that it looks like you will lie down with the person.

On the way to the shower

Remember that this activity should be pleasant, so it is very important to plan how you will move the person you care for.

- It is better to get the person undressed in the bathroom.
- In the bathroom, assist the person so that he may switch to the other chair, have him/her to hold and rest him/herself on the support tub or armrests of the chair and with the other hand he/she should hold from your neck.
- You, at the same time, bend your knees and your feet should be set apart, try to straighten up so you pull the person up helping him/her up to stand up with your hand on his/her back.
- Before returning to the room, dry the person very well with a towel, even those places where water may get, for example, in those skin folds.

How to transfers without harming his/her body?

Remember that you must stay healthy to provide good care. Muscles and bones of his/her body can get affected by inadequate postures that generate fatigue and muscle tension.

- Get as close to the person as possible.
- Distribute his/her weight between his/her arms and legs to prevent back injury.
- You should prefer pulling rather than pushing, when possible.
- Perform regular exercise to keep fit.
- Wear clothes and shoes that let you move properly without excessive effort.
- Always bend your knees when necessary.
- Keep straight your back and neck.

FEEDING THE CARE RECEIVER

Nutritional advice

Eating is not just about eating to survive or satiate hunger; it is more complex because it must take into account the place where we eat, how we eat, the knowledge we have of what we eat, and the environment around food.
If food meets the needs of the person being cared for, but beyond this is done in a quiet family atmosphere, compression, you are actually fulfilling nutrition that contributes to a better quality of life.

Tips on food

- If possible, you must eat lots of fruits and vegetables every day, depending on medical contraindications.
- Salt and salty food should be regulated.
- Increase fiber consumption in the diet to prevent constipation or any other digestive disorders. Wheat bran, oats, whole grains such as rice, bread, fruits and vegetables, legumes (beans, lentils, and chickpeas) are all high in fiber.
- Reduce fat and sugar consumption in your diet.
- Distribute food in 5 or 6 meals a day; you should eat more often but in smaller amounts.
- Choose simple, light meals and, with little oil, condiments and fat free.
- You should not eat candies, alcohol or sugar as they contain too many calories.
- Water consumption is important in contributing to better digestion, reduce constipation, and prevent urinary tract infections, as long as it is not contraindicated or excessive consumption.
- Consider the care receiver’s likes and preferences and plan the menu together to avoid possible rejection of food.

"Let your relative do all he can by himself, even though this means taking more time."

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Feeding your relative

As caregivers, we must respect the care receiver's dignity and promote independence in this important activity of daily life.

Key points to help feed

- Do not forget the person is an adult, he/she is not a child, do not address to him/her with an attitude of pity or consideration.
- Provide choices to eat.
- Do not draw attention when he/she spills food or refuses to eat. If he refuses to eat, find out why.
- Straws are helpful to drink liquids when there is difficulty holding the glass or the cup, straws allow them eating with less effort and less chance of spills.
- You should ask the person which food he/she prefers to start; if food is cold or hot, if he/she cannot see it is advisable to describe food.
- Offer enough time to chew food before providing more food.
- Make sure lunchtime is a pleasant moment, within a friendly atmosphere, choose a conversation topic interesting for the person.

"Do the best you can within your own possibilities and opportunities."

HELPING FEED YOUR FAMILY THROUGH A CATHETER

When you need to feed your relative through a catheter

Most of us take for granted our daily activities. We choose what we want, the amount and when to eat every day. It is difficult to give up our independence on these decisions. It is also difficult to accept help to be fed by someone else.

Take into account:

- Make sure the catheter is permeable.
- The catheter is a tube that is inserted through the mouth or nose; it goes passes the esophagus into the stomach or, depending on the medical case to the small intestine.
- Check that the catheter is in the stomach.
- Provide the person nice food at a suitable temperature.
- Explain the activity to the person.
- Run warm water through the catheter after giving food.
- Look carefully at the person to check on any symptoms of evident discomfort, or in case the tube was moved in coughing, sneezing, choking or vomiting episodes.

Before you start feeding your relative

- Check that food has not expired and it is at a right temperature.
- Check that the tube is placed correctly.
- Place the person in a semi-sitting position.
- Run water through the tube to ensure that the probe is permeable.

After feeding your relative

- Clean the nasogastric tube with water.
- Keep the person in a semi-sitting for at least 30 minutes to facilitate ingestion and movement of food and avoid a possible aspiration.
- Make sure the person feels comfortable and safe.
- Allow food to pass slowly to complete the amount needed.

"Whenever you need it, ask for help. Do not wait for help to appear spontaneously".

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HELPING YOUR RELATIVE TO EAT

When helping a person to eat

- You should encourage him/her to be independent.
- If it is difficult for him/her to use a fork or spoon, offer food he/she may handle with his/her hand.
- Make sure the person is sitting as long as possible, keeping his/her head tilted slightly forward.
- Make sure the person can see his/her food on the plate, wearing glasses when necessary, the color of the plate should contrast with the food.
- Tell him/her what you are doing, i.e. through sentences like: *"Now let me give you some rice."*
- Some people need to be reminded to chew or swallow.

When he/she has no appetite or refuses to eat.

- Turn off the TV and reduce any other distractions.
- If the person has no appetite, do not put too much on the plate or oversized portions.
- If the person suddenly loses interest in food, check him/her for any pain or in his/her mouth, gums, or discomfort caused by the denture.

"Do the best you can within your own possibilities and opportunities."

ASSESSING THIS MATERIAL

When answering these questions you will contribute through your recommendations to complement the activity of care and the results of the implementation of this information in your role as a caregiver.

How did this material contribute to your role as a caregiver?

- Is the information contained in this Handbook clear and allows you to solve doubts on these matters?
- Do you believe this Handbook’s information contributes to your personal growth?
- Do you consider your work as a caregiver will improve after reading this material?
- Did you know the importance of your role as a caregiver?
- Do you have enough information to make decisions regarding caring for the person you care for?
- Do you think this handbook contains enough information to strengthen the ability of care?

"Take care of yourself / especially at times when you're desperate. Your support is vital to calm fears and provide warmth and dignity to your relative. This situation is difficult, but in the long term, it is also comforting."

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