

The Meaning of Assuming Dependency at Home of a Person with Cardiovascular Surgery: the Vision of Informal Caregivers

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Objective. Herein, the study sought to understand the significance for informal caregivers of assuming the dependency at home of an individual subjected to cardiovascular surgery. **Methods.** This was a phenomenological interpretative study conducted with eight adult participants, home caregivers of individuals with cardiovascular surgery discharged from intensive care units to their homes. An in-depth interview was used as technique to collect the information and the procedures proposed by Cohen, Kahn, and Steeves were used for analysis. **Results.** Caregivers of individuals with cardiovascular surgery at home face situations that lead them to taking on the dependency of the person being cared. The significance participants granted to the experience was the lack of preparation to deal with it due to the unexpected way it emerged. This created a difficult situation, where feelings surfaced, like misgivings, fear, and stress during the time dedicated to caring. In some cases, the caregiver prolonged the dependency of caring for

another. **Conclusion.** Undertaking the dependency of a person at home meant to caregivers coping with new situations without preparation. This dependency stirs feelings and sometimes limits participation by the person in their own care.

Descriptors: caregivers; cardiac surgical procedures; self care; qualitative research.

El significado de asumir la dependencia en casa de una persona con cirugía cardiovascular: la mirada del cuidador informal

Objetivo. Comprender el significado para el cuidador informal el asumir la dependencia en el hogar de una persona sometida a cirugía cardiovascular. **Métodos.** Estudio fenomenológico interpretativo realizado con 8 participantes adultos, cuidadores en casa de personas con cirugía cardiovascular dados de alta desde las Unidades de Cuidado Intensivo (UCI). Se utilizó la entrevista en profundidad como técnica de recolección de la información y los procedimientos propuestos por Cohen, Kahn, y Steeves para el análisis. **Resultados.**

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Article linked to the research: El significado de la experiencia de cuidar en casa a una persona con cirugía cardiovascular: la mirada del cuidador informal.

Conflicto de intereses: ninguno.

Fecha de recibo: Marzo 17, 2017.

Fecha de aprobación: Mayo 10, 2017.

Cómo citar este artículo: Tamayo FD. The Meaning of Assuming Dependency at Home of a Person with Cardiovascular Surgery: the Vision of Informal Caregivers. Invest. Educ. Enferm. 2017; 35(2): 232-242.

DOI: 10.17533/udea.iee.v35n2a12

El cuidador en el hogar de una persona con cirugía cardiovascular se enfrenta a situaciones que lo llevan a asumir la dependencia de la persona cuidada. El significado que otorgaron los participantes a dicha experiencia fue la falta de preparación para afrontarla, debido a la forma inesperada de cómo surge. Esto generó una situación difícil, donde afloraron sentimientos como temor, miedo y estrés durante el tiempo dedicado al cuidado. En algunos casos, la dependencia del cuidado del otro se vio prolongada por parte del cuidador.

Conclusión. Para el cuidador, asumir la dependencia de una persona en el hogar significó afrontar nuevas situaciones pero sin la preparación adecuada. Esta dependencia genera sentimientos y, en ocasiones, limita la participación de la persona en el propio cuidado.

Descriptor: cuidadores; procedimientos quirúrgicos cardíacos; autocuidado; investigación cualitativa.

O significado de assumir a dependência em casa de uma pessoa com cirurgia cardiovascular: A visão do cuidador informal

Objetivo. Compreender o significado que tem para o cuidador informal, assumir a dependência em casa

Introduction

Humans experience situations that modify their vision on reality and motivate processes of adaptation toward new contexts and circumstances. Adapting to the change from being healthy to being ill is a complex process for the individual and for the family group, which is why it is necessary to identify phenomena from everyday life that permit coping satisfactorily with the problems caused by an illness to face caring for a relative. Especially, the person subjected to cardiovascular surgery shows conditions that merit for their care to take place under specific characteristics, according to the needs derived from the surgical procedure and the implications it produces. Within the current context, these people are discharged early from the hospital to continue their health recovery and rehabilitation in the company of their relative at home. This change calls for the person's health care to be carried out by someone who, according

de uma pessoa submetida a cirurgia cardiovascular.

Métodos. Estudo fenomenológico interpretativo realizado com 8 participantes adultos, cuidadores em casa de pessoas com cirurgia cardiovascular dados de alta desde as Unidades de Tratamento Intensivo à casa. Se utilizou a entrevista em profundidade como técnica de recolhimento da informação e os procedimentos propostos por Cohen, Kahn, e Steeves para a análise.

Resultados. O cuidador de uma pessoa com cirurgia cardiovascular em casa, se enfrenta a situações que o leva a assumir a dependência da pessoa cuidada. O significado que outorgaram os participantes a dita experiência foi a falta de preparação para afrontá-la, devido à forma inesperada de como surge. Isto gerou uma situação difícil, onde apareceram sentimentos como temor, medo e estresse durante o tempo dedicado ao cuidado. Em alguns casos a dependência do cuidado do outro se viu prolongada por parte do cuidador. **Conclusão.** Assumir a dependência de uma pessoa no lar significou para o cuidador afrontar novas situações sem preparação. Esta dependência gera sentimentos e em ocasiões limita a participação da pessoa no próprio cuidado.

Descritores: cuidadores; procedimentos cirúrgicos cardíacos; autocuidado; pesquisa qualitativa.

to the characteristics of how they provide care, is considered an informal caregiver.⁽¹⁾

The term “informal caregiver” refers to the person in charge of continuing with the care at home, favoring the satisfaction of needs in all the spheres of the person being cared. Informal caregivers become the central axis for the maintenance of the individual's wellbeing and offer permanent support. In this process, these types of caregivers accept commitments and duties that, besides, they consider their own.⁽²⁾ Taking on this role at home is a difficult task due to the sudden and unexpected way it occurs, demanding modifications in the habitual behaviors of individuals to reach the goals proposed in relation to the requirements of care. Different studies conducted with patients dependent on care^(3,4) show that homecare is a complex situation requiring training and constant companionship from the person providing it, which on few occasions is received. These home

caregivers must find alternatives to help satisfy care needs and contribute in their recovery, further diminishing the degree of dependency and promoting their self-care.⁽⁵⁾

During homecare and upon assuming the dependency from another, informal caregivers of individuals with cardiovascular alterations⁽⁶⁾ identify needs, perceptions, and emotions associated to this situation, leading to the elaboration of strategies to cope with it. Most caregivers manifest anguish, depression, and fear due to the unknown and poor information about the future of their relative. Thereby, accepting the dependency of another at home becomes an important element within care due to the relationship established between both individuals, which sometimes reaches such a high degree of commitment that it impedes the recovery of the person who is ill, given that it limits the person's self-care instead of encouraging its practice. This situation occurs specially with cardiovascular patients who face a moment of dependency for care that, in most cases, is transient.⁽⁷⁾

The context in which the study problem is immersed is developed both in the social scenario as in the disciplinary. In the social setting, caring for patients at home has become a space increasingly used to diminish hospital stay, which does not mean that in all cases it is the appropriate measure, given that many patients require at home the type of care that often those by their side do not have the capacity or knowledge to provide. This leads to making it necessary to establish new conducts and forms of family organization at home that allow caregivers to acquire knowledge and availability of time for care and assume the dependency of another. Within the disciplinary context, the problem is focused on understanding the phenomenon of caring and the significance of relatives assuming it when they face it at home. Knowing the circumstances of care, the difficulties, strengths, and meanings accepted by the caregiver, will permit the nursing discipline to implement strategies aimed at promoting homecare centered on the patient's recovery and rehabilitation, guaranteeing the state of wellbeing of the persona conducting the care.

Finally, this study was carried out with the purpose of understanding the significance for informal caregivers of assuming the dependency at home of an individual subjected to cardiovascular surgery, which permits recognizing qualities and specific needs in these caregivers that differentiate them from assuming the dependency in relation to other health conditions.

Methods

This study used qualitative research methodology with a phenomenological interpretative approach. This was achieved by using in-depth interviews as the technique to obtain descriptive stories based on the caregivers' experiences. The interviews were audio recorded, transcribed, and organized by themes to interpret subsequently the information. Ten interviews were applied to eight participants (two participants received a second interview each to clarify some results). The interviews were held in the participant's home in a setting isolated from the rest of the family; this activity lasted between 60 and 90 min. To insure the confidentiality of the information, the stories were identified with the letter E and each person's initials.

Information saturation was reached with eight participants, six women and two men between 18 and 65 years of age; all had some degree of schooling and lived in the city of Medellín, Colombia. The participants were located upon inquiring about settings where informal caregivers existed with similar characteristics, like social support networks and homecare services, with the aid of the snowball strategy, given that each new participant reported knowing somebody with a similar experience to theirs. With each participant, an initial telephone contact was made to agree on a meeting to explain the objective and study methodology. To select the participants, these had to be adults experienced as home caregivers of adult patients with cardiovascular surgery who had been discharged from an ICU. The time elapsed, as informal home caregiver and the time between the experience of caring and the moment of the interview was not considered

as selection criteria. It should be noted that two people invited to participate refused to do so due to their lack of time and because they did not want to recall the experience.

After the meeting, the interviews were transcribed and confronted by reading the text and listening to the audio to validate the data digitized and – in turn – provide a global recognition of the information gathered. Approval and monitoring were obtained from the committee on bioethical affairs in the Research Branch at Universidad de Antioquia (Act number 14-25-618). Each person participating in this study did so voluntarily by signing an informed consent.-

Information analysis used the procedures proposed by Cohen, Kahn, and Steeves who state that organization and analysis of information implies going from text drafted with the information obtained during the field study through data collection, to a narrative text that is significant for the readers who gathered the information. ⁽⁸⁾ Detailed, meticulous and repeated reading of the data obtained is called “diving into the data”, which permits establishing an initial interpretation identifying the essential characteristics of each interview. This stage constructed labels or titles for these meanings.

The thematic analysis began after understanding the text, underlining outstanding phrases, thus, seeing the emergence of tentative themes and significant texts that support the results. All the data were examined line-by-line and labeled with the tentative themes by grouping and comparing them to each other. Starting from this point, analysis was performed of each of the themes and subthemes, which would permit responding to the objective of the study. Information collection and analysis was done simultaneously as fieldwork advanced. Information saturation was reached through the analysis of the stories obtained; evidencing that no different answers were obtained that permitted generating the creation of new themes or subthemes. All the information was analyzed manually.

Principles of rigor of qualitative research were followed to ensure congruence between the question, the literature, data collection strategies, and analysis. Transferability was achieved by making an exhaustive description of the characteristics of the context in which the research took place and of the subjects who participated. Credibility was obtained by contacting the participants prior to reporting the results, to return the information and seek their approval, stating that the results agreed with what they had wanted to express. Agreement was reached through the textual transcription of the audio obtained from the in-depth interviews, which were conducted by the researcher. This research work was carried out in the city of Medellín, Colombia, between March 2015 and February 2016.

Results

Individuals in charge of caring at home for an individual who has undergone cardiovascular surgery face different situations that lead to assuming the dependency of the person being cared as theirs. The significance participants give to the experience was related to the lack of preparation to confront it, given the unexpected way in which the disease and the cardiovascular surgery emerge. All this created a difficult situation in the caregiver, where feelings, like misgivings, fear, and stress surfaced throughout the time dedicated to caring. Sometimes, it was possible to identify how the caregiver prolonged the dependency for care by a third party.

Assuming the dependency of another

Upon returning home after a hospital stay, the person faces reality with notable differences with respect to their daily life, given that self-care activities previously performed in autonomous manner, quite often need assistance from another person. This person in most cases is a relative who does not have formation or knowledge of how to care and see themselves placed as informal caregivers. Thereby, this informal caregiver emerges from the dependency of the

sick individuals, to help, support, and even satisfy their needs: *...my mother would leave him food, but when she returned at night she would find all the food in the refrigerator because he did not remember he had to eat and was not able to take things out to heat them* [ELMA12].

This dependency generates a need for companionship, which produces changes in the family dynamics and leads to a redistribution of functions among the members of the family group; consequently, caregivers modify their labor, personal, and social routines to have periods of time that permit their assuming the new role of being mindful of the needs of the other and – in turn – seek help and participation from other relatives: *...so we had to start looking for someone to stay and keep him company; my mother stopped working and decided to take care of him all the time* [ELMA13]. The person cared for subjected, by the disease or by the limitations of the surgical procedure, to a state of dependency on people who are in charge of caring for them, which is reflected in situations, like bathing and feeding, which must be carried out in company and with the aid of the caregiver. The relationship established is not exempt from producing certain reactions like discomfort and mutual annoyance: *my father was in a state in which he obviously did not want to depend on the people caring for him; therefore, for him it was uncomfortable as it was for us to have to do certain things, like accompany him to the restroom* [EACJ18].

Regarding care related to basic needs, like bathing, going to the bathroom, skin care, and ambulation, there is a progressive learning process as the caregiver confronts the situation: *I did not even know how to clean him; I would wonder if this was the way to clean him. One somehow did it and, within my capacities felt, it was the right way* [ELJT6]. When caregivers faced this new situation at home, they established interventions based on the activities carried out by the health staff during the hospital stay. This meant having two different forms of care; in the first place, care they define as delegate or assigned and in the second place, care destined to intervene the basic needs of daily living,

which they define as daily care: *...he always got up at 9 am; I would have his breakfast ready, he ate it, bathed; and then we'd go for a walk* [EMTJ9]. This whole process of caring at home creates a relationship between the caregiver and the person in which the first is in charge of watching over all the needs of the other, who – in turn – sees the caregiver as a figure of support and companionship during the recovery process, for their physical and emotional requirements: *...I was watchful over him, he would hold on to me to walk and I was like a walking cane for him* [EMTJ10].

By being so involved with caring, informal caregivers take on the activities of the person being cared as their own and begin to see the person they are caring as part of themselves. This situation sometimes limits the persons being cared from carrying out their self-care activities because everything is done for them. As goals are met and the results are derived from correct actions, caregivers feel satisfied: *feeding was very difficult, sometimes he would eat, other time he would not eat; however, I kept insisting and tried to feed him what he liked most ...I always gave him his food because he might choke on it* [EMTJ11]. During this whole process of companionship and homecare, relationships are secured and bonds become stronger, with the emergence of a reciprocal relationship of dependency in which caregivers feel they are doing things well due to expressions of satisfaction from the person being cared in relation to the care received: *...he refused my caring for him because he did not want; but when he was hospitalized and I had to stay with him in the clinic, he started assuming that and I was super happy that I was a very good nurse and was doing it well* [ELJT28].

During the course of this relationship of dependency, companionship and support are important aspects for the care process to the point that the patient cannot be left alone for fear of what may happen: *...for me, leaving him alone was a problem because I thought he could fall or get hurt; in that part I feel that they depend on what the other person does for them* [ELJT33]. This relationship of companionship created between

the patient and the caregiver increasingly becomes stronger, to the point in which the caregiver can feel that if he is not present at all times, this would mean that he is leaving him alone. Somehow, this shows how the caregiver limits the person's independency on aspects from their daily living: ... *if he does not have someone to stay with him, he is going to feel very lonely; in that part, I feel they are quite dependent...* [ELJT35].

Lack of preparation: without knowing how to care

When informal caregivers accept the dependency of care, a situation is generated in them that becomes difficult, when they realize they do not have enough information or necessary knowledge to offer care in the expected manner. *When he gets home, it is difficult because I believe one does not have enough information to offer care* [EACJ3]. This lack of knowledge on how to act upon certain situations generates in the caregivers doubts on the correct way to perform the care, which causes – in many cases – a state of guilt when thinking of the risk of making a mistake and doing things badly: ...*you then feel a degree of guilt of having been able to do things better, but I did not know how to do them* [ELJT7]. The necessary knowledge to assume the dependency is acquired through observation and practice. This is how they learn to conduct certain activities and tries to imitate them at home according to how they saw it being done by the health staff during hospitalization. This becomes a challenge for the caregiver when individually performing the activities the formal caregivers carried out for the person: *the nurse would come in to bathe him and I paid close attention to how she moved him, how he was bathed; I even asked the nurse how to do it* [ELJT12]. Only until the moment of assuming the care do questions and concerns emerge on the adequate manner of caring, these doubts have no opportunity of being solved until the moment of returning to the hospital for follow up appointments or consultations. These questions permit improving the informal caregiver's technique: *when you finally face caring for the other and have the opportunity to go back to*

hospitalization, you find those questions that need to be asked and a bit of guidance from the staff [EACJ29].

During the initial stages of homecare, informal caregivers do not clearly identify when and in which situations they have to recur to the hospital. This lack of clarity makes them feel insecure on how they must act upon a given situation: ...*there are things you do not manage to identify and that makes you recur to emergency several times* [EACJ4]. After having clarity on the adequate way of caring at home and feeling the confidence of doing it well, caregivers start seeking support in other family members to have some options to act upon an unexpected situation, leading them to design plans or rapid action alternatives in case any emergency arises. *I sought support from my daughters; I waited for things to happen to see what had to be done. Sometimes I called them and told them: I am in the hospital with your father* [EMTJ28].

A difficult situation

The act of assuming the dependency at home is a difficult experience for the informal caregivers, above all when they have had no prior approach to these types of situations, which generates new conditions for which they are not prepared: *for me it was a difficult experience because we really had never had a similar situation. I had never had to care for anyone* [ELJT1]. For informal caregivers, the experience of caring at home represents a situation that must be assumed suddenly; it is surprising and demands adequate action, with the intention of seeking wellbeing and avoiding harm even when there is no training, which causes emotions and feelings: *It is like a shock and an impact having my father at home* [EACJ1].

This difficult experience for caregivers becomes increasingly complex, given that they can sense that the actions they carry out do not help produce the expected wellbeing in the person cared for or because of the increased difficulty of the actions due to changes in the health condition: ...*as time passes, it becomes more difficult for me, he no*

longer wants to eat anything [EALB21]. Along with the feeling of shock caused by homecare, informal caregivers live situations of stress that appear at several moments. One of these occurs when they confront care and discover they do not have the tools to carry out the activities required: *...it stresses you because you do not know what to do, plus the pressure of this being a relative, who is such an important person in your life...* [ELJT26].

Stress increases with time, at every moment situations of ambivalence are experienced with respect to how to proceed because of the insecurity and lack of training, which leads caregivers to think of the adequate manner of performing the activities: *stress is generated from thinking whether I will or will not take good care...* [EACJ17].

Likewise, insecurity leads caregivers to feeling fearful upon the possibility of the occurrence of some event that requires immediate action and which places at risk the life of the person being cared. This fear is associated to different factors, like being alone with the person and not knowing how to respond upon a given situation: *...I was quite scared that at any moment he would again have an arrhythmia or any other thing, of being alone at home and suddenly something happening* [EMTJ23]. The different actions of caring, their complexity, frequency of performance, and confronting the dependency of the patient toward the caregivers, lead to physical and mental weariness, which becomes evident in the development of their other activities, like work or recreation. This weariness is not always recognized in front of other people who make up the family group. The overload of activities and lack of rest contributes to increased stress: *the companionship you had to have with him at all time, because having to spend the night with him in the same bed and the next day having to go to work is a tiring and exhausting process* [ELJT25].

Discussion

Assuming the dependency of caring at home for a patient after cardiovascular surgery is a difficult

situation that leads to a series of modifications in the living conditions of the person in charge of care. One of the most important changes is the modification of habits in the person who is ill, which must be assumed by the other family members. Most of the time, the role of caregiver at home emerges unexpectedly and there is no clarity on how to conduct these activities at home. This finding coincides with that by Zambrano *et al.*,⁽⁹⁾ who state that informal caregivers are in charge of proving care to dependent individuals, assuming this activity in volunteer manner and without receiving or expecting economic remuneration for this function.

For the participants, being the home caregiver means being watchful of the person's needs, providing support and companionship at every moment to achieve wellbeing and comfort. This person acquires a series of commitments and responsibilities related to caring for another; they accompany the whole illness and recovery process at home, related to activities that range from the personal care of the individual to dependency for all their daily activities. Assuming this dependency generates a change of the caregiver's role within the family dynamics. Barrera⁽¹⁰⁾ found that the responsibility of covering the needs of the sick person is granted by different reasons, like maintaining the family wellbeing, reciprocity if they were previously cared for, gratitude towards the person being cared for, and – frequently – because they are the only close person who can do this.

During this act of caring, informal caregivers encounter a series of situations that in most cases they do not know how to intervene, which go from feeding to other more complex situations, like bedside care, which generates in them the need to develop care skills. Nkongho⁽¹¹⁾ defined care skill as “the way of relating with the care receptor, which requires commitment from the caregiver to interact and understand this skill as a way of living and not as a collateral task”. This is how caregivers develop this skill, experience a sense of belonging and bond, and are stable and resilient upon stress.⁽¹²⁾ With this care skill emerges a dependency from the person toward the informal

caregiver, evidenced by the participants as the need to perform activities for another.

Dependency is an important aspect in experiences of illness, to the point that it has been reviewed from different disciplines to achieve better understanding of the term. The European Council defined dependency as “the need for help or important assistance for everyday activities. A state in which people find themselves due to reasons involved with the lack of or loss of physical, psychic, or intellectual autonomy, having the important need for care and help to conduct activities of daily living and, particularly, that referring to self-care”.⁽¹³⁾ According to this definition, dependency has certain characteristics; one of them refers to the need for support by a third person, during a real situation that is observable and occasionally modifiable. The other aspect to highlight is that it has to do with activities that are potentially measurable and are related to the degree of performance of a given activity, but not to the cause that originates the situation of dependency.

The degree of dependency by the sick person toward the caregiver is difficult to measure in these cases because it is determined by the illness' compromise in bodily functions and by the way of responding to it, which are specific to each person.⁽¹⁴⁾ The participants in this study had to conduct homecare according to the patient's needs, a situation that led them to permanently support and accompany the person, establishing a relationship around the dependency to achieve the other person's wellbeing. All this affected the everyday lives of the caregivers because they had to modify their daily activities, like quitting their work and spending nights without rest to care for their relatives. It is not rare that in the priorities the participants establish on said needs there is coincidence with that proposed by Henderson,⁽¹⁵⁾ who refers to the importance of nutrition, elimination, and mobilization, which represented the greatest dedication of time and effort by the caregivers.

To undertake these activities, caregivers seek the necessary knowledge to help to satisfy partially or totally any of these basic needs, according to

the individual's lack of autonomy. This situation justified implementing new activities in everyday life and which had not been done before; consequently, informal caregivers faced many moments when they did not know how to respond correctly and began to intervene intuitively in the way they felt appropriate. This coincides with that found by Montalvo *et al.*,⁽⁴⁾ who say that initially knowledge in the group of caregivers is guided by a low level of preparation to assume their role. The first activities carried out by home caregivers refer to those conducted during the hospital stay and are delegated to them to continue the care at home, like maintaining the bed's head part elevated, administering prescribed drugs, changing the patient's position, and maintaining the family member comfortable and calm. The other group of activities has to do with routine care, emerging from the needs of daily life, like feeding, bathing, and ambulating, among others; and although these were not considered difficult to perform, they did require other knowledge and skills achieved over time and with practice. This learning coincides with that reported by Vargas⁽¹⁶⁾ who states that most caregivers learn to care on their own during the daily practice, and manage it by doing, making mistakes, and getting it right in their actions.

According to the aforementioned, caregivers have two types of meanings for care at home: one is called delegated care because it has to do with care that had to be done in the hospital and continue at home; the others are called everyday care, which refer to all those conducted habitually in the same place. This agrees with Luengo *et al.*,⁽¹⁷⁾ who indicate that caring at home includes different types of care; according to basic needs, like feeding, elimination, rest and sleep, hygiene and comfort, mobilization, and stimulation. These types of care seek a minimum of wellbeing, at the same time that they can deteriorate the state of health of the person if not done adequately.

Daily performance of all these care activities builds among people a close and special relationship due to the characteristics that comprise it. This relationship constitutes a space in which

caregivers do their best to generate wellbeing and comfort in the sick person, by satisfying their basic needs and those, which because of their health condition; they cannot perform on their own. A relationship of support, companionship, and communication is established to favor the person's recovery.

Informal caregivers also accept a special function upon sensing the needs of care as their own, that is, they feel that if they do not carry out the activities for the person nobody will do it, and sometimes limits the person's self-care actions by keeping them from conducting their activities autonomously. In this sense, for informal caregivers moments in which the patient improves are satisfactory and reasons for joy. Likewise, it causes frustration when the patient's evolution and participation are not adequate. Montorio⁽¹⁸⁾ has documented how caregivers can show different manifestations over time, like health problems, psychological and social alterations associated to the burden assumed by caring. In this regard, the participants refer to the need to conduct care activities not only to satisfy another but also themselves.

This relationship between the caregiver and the person being cared establishes moments of strong union between both, securing bonds of trust, improving communication, making the care process lighter and less tiring, generating in both gratitude for adequately assuming the current situation of their family environment. For their part Ferrer *et al.*,⁽¹⁹⁾ state that during the whole care process, caregivers receive certain help and indications from the experiences of other relatives who have gone through the same situation. However, Roca *et al.*,⁽²⁰⁾ evidence that many informal caregivers perceive they are irreplaceable and essential in care, manifesting that they do not know who could care for the patient in case they could not do it.

Lack of knowledge on how to care meant for the participants one of the biggest difficulties when assuming the dependency of the person being cared at home. Several authors coincide

in that caregivers are not prepared for homecare; Gómez,⁽²¹⁾ for example, in a study of caregivers, states that the person who is already in care, and who is committed to it without preparation, needs to acquire knowledge that clears doubts and concerns caused by the patient's unexpected and disorderly behavior. Similarly, Pinto *et al.*,⁽²²⁾ pose that in Latin America people who are engaged as caregivers do not have adequate guidance, evidencing in them important deficiencies in care skills.

One of the first doubts that emerge in caregivers is related to how to act upon an emergency or a situation that gets out of control, that is, how to know when to go back to the hospital or stay home. According to Jofre,⁽²³⁾ the appearance of a health problem determines the need to make decisions, which must respond to a diagnosis, treatment, or lifestyle changes. The determinants for which decisions are made are triggered by new circumstances and transitional situations of development.

We must add other doubts and worries related to the correct way of caring for the person to favor their recovery and not cause harm to the concern of how to act upon an urgent situation. Deciding on what type of food to provide, what medications to administer, what exercises or changes in position to perform all become the principal internal questions caregivers ask themselves, without obtaining correct answers because they do not have sufficient information or training to achieve it. These situations lead caregivers to seek alternatives that allow them to obtain adequate information to provide care. One form of learning is related to the opinions and indications given the person being cared, that is, the orientation of how the person would like some activity or procedure to be done to feel more comfortable.

Throughout this process of assuming the dependency of care, informal caregivers experience a series of feelings that mean for them the emergence of set of elements that affect everyday life and obligate them to make plans and strategies to conduct the care. The feelings are described by Vargas⁽¹⁶⁾ as stimuli from the

physical and social environment, which in hand with other processes, like learning, memory, and symbolization, recognize and interpret meanings to elaborate perceptions. Upon these situations, caregivers experience feelings that can help enhance care, or – on the contrary – intervene negatively in its execution. According to Barrer,⁽¹⁰⁾ caregivers are exposed to emotions and feelings; some positive, like the satisfaction of contributing to the wellbeing of their loved one – and some negative, like feelings of guilt, impotence, loneliness, and fatigue.

During the early stages of home care, caregivers feel it is a difficult experience for which they are not ready. This makes it more complex to develop skills and creates situations of stress that caregivers do not know how to face. Stress leads caregivers to feel incapable of practicing care and adequately satisfying needs, finding a sense of impotence that participants denominate as shock. Fear and misgivings surface in caregivers during the early stages of the process, given that these are new functions and roles in their lives that cause uncertainty about what may occur.⁽⁶⁾ This uncertainty is conceptualized by Mishel *et al.*,⁽²⁴⁾ as the person's incapacity to determine the significance of events related to the disease, being incapable of assigning defined values to objects or events and, hence, not being able to predict the results due to lack of information and knowledge. Other sensations noted in the participants are frustration and impotence, when they realize that the efforts made to maintain the person's wellbeing are not enough. Finally, the weariness of the caregiver role is evidenced; according to Moreira *et al.*,⁽²⁵⁾ to the extent the patient becomes dependent on care due to the evolution of the disease, the caregiver assumes several self-care activities, which after a period of time overload the caregiver's daily capacities and provoke physical fatigue.

This study concludes that for informal caregivers undertaking the dependency at home of an individual subjected to cardiovascular surgery meant a difficult situation given the unexpected manner in which they had to face new situations for which they were not prepared. The sudden

way in which the disease appears in this group of people is a differential factor with other health conditions that also cause dependency in care. This dependency generated – in turn – in caregivers feelings of misgivings, fear, and stress during the whole care process. This relationship of dependency sometimes limited participation in self-care from the person being cared, due to the degree of commitment assumed by the caregiver, which can even prolong the dependency in care. Knowing this significance, permits the nursing discipline to create spaces and strategies that allow providing education and formation to informal caregivers on how to conduct activities of wellbeing and comfort demanded by the sick person, to develop the necessary skills for caring. With caregivers having sufficient preparation, it is likely that the situation will be considered less difficult and lead to the surfacing of new feelings.

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