

## FAMILY EXPERIENCES POST-ACUTE MYOCARDIAL INFARCTION

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## ABSTRACT

This study aimed to describe the family experiences post-infarction. Qualitative, descriptive and exploratory research, carried out with six families of post-infarction patients. Data collection was conducted in families' homes, in the period of February to May of 2012, through observation and interviews with the family. The software Atlas Ti 6.2 was used to code the interviews and the data were explored with thematic analysis. Two categories emerged "Difficult times": immediate consequence of acute myocardial infarction for the families; and "We reeducate ourselves – we can adapt ourselves": current experience of families. The immediate post-infarction experience is permeated by several feelings, with the need for families to adapt to fit into the needs. The current experience shows changes in families due to the disease. The family is the main responsible for the care giving, although Nursing should exchange and share knowledge.

**Descriptors:** Nursing. Family. Family health. Myocardial infarction. Chronic disease.

## RESUMO

*Objetivou-se descrever as vivências da família no pós-infarto. Pesquisa qualitativa, descritiva e exploratória, realizada com seis famílias de pacientes pós-infarto. A coleta de dados ocorreu no domicílio das famílias, no período de fevereiro a maio de 2012, por meio de observação e entrevista com a família. Foi utilizado o software Atlas Ti 6.2 na codificação das entrevistas e os dados foram explorados com a análise temática. Surgiram duas categorias: "Tempos difíceis": consequência imediata do infarto agudo do miocárdio para as famílias; e "Nos reeducamos – a gente se adapta", vivência atual das famílias. A vivência imediata pós-infarto é permeada por variados sentimentos, necessitando adaptação das famílias para adequação às necessidades. A vivência atual demonstra modificações nas famílias devido à enfermidade. A família é a principal responsável pelas práticas de cuidado, porém a Enfermagem deve atuar na troca e no compartilhamento de saberes.*

**Descritores:** Enfermagem. Família. Saúde da família. Infarto do miocárdio. Doença crônica.

**Título:** *Vivências da família após infarto agudo do miocárdio.*

## RESUMEN

*Se objetivó describir las experiencias de la familia en el postinfarto. Estudio cualitativo, descriptivo y exploratorio, realizado con seis familias de pacientes postinfarto. La recolección de datos se la realizó en los hogares de las familias, de febrero a mayo de 2012 a través de observación y entrevista con la familia. Se utilizó el software Atlas Ti 6.2 en la codificación de las entrevistas y los datos fueron explorados con el análisis temático. Emergieron dos categorías: "Tiempos difíciles": consecuencia inmediata del infarto agudo del miocardio para las familias y "Hacemos una reeducación – Nosotros nos adaptamos": experiencia actual de las familias. La experiencia inmediata postinfarto es permeada por diversos sentimientos que requiere adaptación para adecuación a las necesidades. La experiencia actual muestra los cambios en las familias debido a la enfermedad. La familia es la principal responsable por las prácticas de cuidado, pero la Enfermería debe actuar en el cambio y compartimiento de conocimientos.*

**Descriptorios:** *Enfermería. Familia. Salud de la familia. Infarto del miocardio. Enfermedad crónica.*

**Título:** *Experiencias de la familia después de infarto agudo del miocario.*

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## INTRODUCTION

Chronic diseases are currently characterized as a public health problem, since they are the leading causes of death worldwide<sup>(1)</sup>. They occur, mainly, due to increased longevity and most of them corresponds to cardiovascular diseases. The statistics project that the total number of deaths from these diseases will increase from 17 million in 2008 to 25 million in 2030<sup>(2)</sup>.

Among cardiovascular events, the Acute Myocardial Infarction (AMI), is an ischemia resulting from lack of blood supply to the coronary arteries, which can cause necrosis of the heart muscle. It originates from a complication of chronic atherosclerotic disease<sup>(3)</sup>. Its consequences are perpetuated throughout life, causing people to need permanent care.

Thus, the illness of the heart can trigger the patient and family emotional distress by fear of death, disability and the unknown<sup>(4)</sup>. It is necessary that the family system organize itself through internal negotiations, which aim to redefine and change roles to ensure the care, maintenance and structural functionality. These changes may be influenced by the type of disease, how it manifests itself and the meaning patient and family attribute to this chronic condition<sup>(5)</sup>.

In this sense, family care<sup>(6)</sup> is performed in the actions and interactions in the family and how it directs each of its members individually, or the whole group. It is defined from the meanings of each family, aiming at growth, development, health and well-being<sup>(6)</sup>.

Recent studies with chronically ill patients highlight specific aspects of family care, such as hospitalization<sup>(4,7)</sup>, spirituality and psychological distress<sup>(8-9)</sup>, situations related to care givers<sup>(10-11)</sup>, among others. However, it is noted that the family is a group permeated by several issues, therefore, it is relevant to show their real experiences through a vision of the factors that may emerge after the chronic condition, which can be viewed with application of this research.

Given these considerations, it becomes possible to deepen the knowledge about the family and their care strategies in the post-infarction, which may contribute to Nursing more precisely understanding of the issues that pervade the family and thus, practices can be developed that meet

the needs of those who experience this disease. So the guiding question was: How are families experiences of patients who had AMI? To answer this question we aimed to describe family experiences in the post-infarction.

## METHODOLOGICAL PATHWAY

This is a qualitative field research, descriptive and exploratory, originated from a Masters dissertation<sup>(12)</sup>. We carried out the research with six patients' families in post-infarction, totaling 18 people. Family members were nominated by the person who had the myocardial infarction and could exceed ties of consanguinity, adoption or marriage<sup>(13)</sup>.

Initially, the selection of families occurred from the post-AMI patients who were being followed-up at the Cardiology Ambulatory (CA) of a hospital in the south of Brazil, reading the medical records to detect those who were in post-AMI and who could fit the inclusion criteria of the study, characterizing an intentional sample.

As inclusion criteria, the family should have a person with a medical diagnosis of AMI caused by atherosclerosis in a minimum of six and maximum of 24 months and be under medical follow up at the CA. We included family members who were suggested by the patient during a casual conversation at the CA, or invited by him/her on the first visit at home. It should be noted that to set up a family representation, it was necessary the presence of at least two people, and the patient could be one of them<sup>(13)</sup>. We delimited as exclusion criteria: family members that presented significant cognitive limitations, such as attention, reasoning, speech, among others.

Data collection occurred from February to May 2012 and it was held by observation in CA and at home, as well as interviews with the family. This was comprised of two stages: initially we built a genogram<sup>(13)</sup> and subsequently, we conducted open questions organized by a script. We observed behaviors and care of family members, one to each other, as well as expressive aspects of family functioning.

The interviews were transcribed and saved in a computer file for data analysis and field diary entries were recorded after observation at the CA and at home. The data collection stage ended when

the research questions were answered and the study objectives were achieved. In order to assist coding the interviews we used the software Atlas Ti 6.2 (Qualitative Data Analysis). The data were explored with the thematic analysis<sup>(14)</sup>, consisting of three steps: Pre-analysis, content exploration and processing of results and interpretation.

The individuals who agreed to participate were informed about the research and signed a Consent Form. Secrecy was preserved through the adoption of fictitious names determined by the researcher. In order to identify the family as a group, we used the letter F, which means “family” and sequential numbers that correspond to the order in which the data collection was performed.

The research was registered by the Ethics Committee of the university linked to the project,

under no 0372.0.243.000-11, in agreement with ethical guidance in research with humans.

## RESULTS

Initially, we show the characterization of families and later the emerged categories that raised through data analysis, namely: “Difficult Times”: immediate consequence of AMI for families, and “We reeducate we can adapt ourselves”: current families experience.

### Characterization of families

The following data, presented in Figure 1, were extracted from genograms of participating families.

Family	Interviewed	Gender	Age	Occupation	Time of AMI	House residents
F1	People that had AMI (João)	M	54 a	Retired	9 months	Daughter in law and son live in the back.
	Wife (Cleusa)	F	46 a	Cook		
	Daughter (Mariana)	F	14 a	Student		
	Daughter in law (Daiane)	F	28 a	Housewife		
F2	People that had AMI (Jorge)	M	60 a	Retired	7 months	All live in the same house
	Wife (Vera)	F	51 a	Housekeeper		
	Daughter (Jéssica)	F	22 a	Nanny		
	Daughter (Fernanda)	F	16 a	Student		
F3	People that had AMI (Paulo)	M	65 a	Retired/Musician	14 months	Live by themselves
	Wife (Regina)	F	58 a	Seamstress		
F4	People that had AMI (Carmen)	F	59 a	Retired/ Housewife and Independent Cook	11 months	Live by themselves
	Partner/friend (Renato)	M	54 a	Self-employment and Law student		
F5	People that had AMI (Luiz)	M	57 a	Retired Machinist	10 months	Live by themselves
	Wife (Ana)	F	56 a	Caregiver for elderly		
F6	People that had AMI (Angelina)	F	58 a	Housemaker	6 months	In the house live the couple and the younger daughter
	Husband (José)	M	65 a	Driver Retired		
	Daughter (Luana)	F	31 a	Housemaker		
	Daughter (Juliana)	F	26 a	Military police officer		

**Figure 1** – Characterization of interviewed families. City in the South of Brazil, RS. Data collected between February and May 2012.

## “Difficult Times”: immediate consequence of acute myocardial infarction for families

Families reported that shortly after the infarction episode many emotions emerged such as anxiety and uncertainty.

[...] *I use to work all day [...] I was strict to myself, I cried at work, I use to cook and cry. [...] This is a difficult situation, you know, it was very difficult for me (F1-Cleusa).*

[...] *the impact was great in the first couple of days, especially, because there is uncertainty... it was horrible [...] We went there [the hospital] to see him, he came home, he was in such anguish that we did not know if he would recover, if he would not recover, those function (F5-Ana).*

As showed in the statements, one might observe that AMI has affected the dynamics of the family, even if there had been reports of signs and symptoms earlier, these were disregarded, causing feelings of anxiety, fear and distress after the event, permeating the family routine. These feelings generated impacts on family dynamics, since the activities of its members were impaired, since all thoughts were turned into the patient.

However, this initial suffering allows the family to find resources to face the problems and make sense of what is going on<sup>(8)</sup>. Feelings are responsible for, in a way, assisting in restoring the family equilibrium, allowing its members to leave the comfort area and become motivated to adapt the difficulties to their internal possibilities. It is noteworthy, however, that continuous exposure to the stress of the disease can deplete family resources, hindering the development of ways to face the circumstances that are presented<sup>(9)</sup>.

These issues affect the work of health professionals, making it a challenge, so these professionals must act in an attempt to include the family in their practices and thus contribute to new possibilities that are developed facing the illness<sup>(7)</sup>. This challenge can be related to the complexity of the structure and functionality of the family.

Death, as a possible event and feeling of despair emerged to the voice of family:

[...] *I thought, God, I thought he would die (F1-Cleusa).*

*It was horrible, I was working in São Lourenço [...] my brother in law called and said [what the doctor said] [...] to my sister: there is no use, it will not take much longer, there is no way to save him. [...] I came from there [from my job] to here crying, you know, it was like I didn't feel my legs, I thought I was going to die, it is too horrible (F6-Juliana).*

As we read the statements, we detect the prospect of death pervaded the moments after the episode of the disease, which occurred due to the symbolism of the heart as the center of life<sup>(15)</sup>. With the imminent possibility of the end of life, there was a family reorganization, removing family members from their daily routines, mobilizing them to attempt to control the situation and get close to the loved one. Even more than that, it triggered anguish and despair to close family members due to the inability to resolve the situation, leading them to believe that they would not be able to live well if the family member died.

The possibility of loss of a family member causes fear to be the focus of the family experience<sup>(7)</sup>, this malfunction of the heart, due to the disease, triggers psychological distress<sup>(4)</sup>. The feeling of anguish is common in individuals with cardiovascular problems, and health education interventions that aims to reduce anxiety have been effective<sup>(16)</sup>. These can be performed by nurses in order to develop clarifying actions with the families what would perpetuate the well-being of everyone.

Families also reported concerns caused by the absence of the patient at the home environment.

[...] *He was operated, his children missed him, for us, for me, because he is a wonderful father, good for my children, I have no complains (F1-Cleusa).*

*We used to spend our days together, our kids are already married, each one in a different place, they don't follow what is going on, so you get more apprehensive [...] Of course I was more concerned (F3- Regina).*

Regardless of family configuration, the absence of the ill patient, affects all family members, developing a sense of needy in the family environment. Therefore, at this time, conflicts are forgotten and the family strength is focused on assisting and restoring the patient so that he/she may return home, through family care. It is noteworthy that, although this is directed to the whole family, in some situations it may take specific actions to ensure that

the individual needs of the family member going through adversities is fulfilled<sup>(6)</sup>.

The union allows preservation of the family, affecting everyone involved<sup>(17)</sup>. It is worth noting that, in families where they had already had strong ties among its members, the union becomes easier, which was observed by affinities exposed during interviews.

In this context, the structure and dynamics of the family may resemble a puzzle, because, in the absence of a piece or of a member, they are modified by the absence of the person and the role he/she occupies or performs in the group. It was observed then, a movement towards patient recovery, facilitating him/her return as soon as possible to the heart of the family and reestablishing equilibrium with the fitting of the missing piece of the puzzle.

Seeing the suffering of those who had a myocardium infarction, the family sought help, organizing their homes, so somehow it could bring comfort and ease for that situation.

*It's like I said, I went there to my daughter's home, for seven days, she did the dressing [...] I Felt a lot of pain [...] then my daughter gave me her daughter's bed (F4-Carmen).*

Adjustments were made at home in order to provide better stabilization of the patient and family. In the statement, the daughter took her mother to her home, a fact that required some environment adjusts, also from other members to facilitate care, and promote tranquility by having the family member closer.

In the period of illness there is a commitment of the family to be close to the sick person and share their problems<sup>(17)</sup>, even if it takes a temporary change in their routine. It was noticed that there was a deepening in the living way of the family because of concerns that emerged and also by seeking to resolve the situation in the shortest time, because everyone needed to restore their lives again. Thus, a movement of coping is done to meet existing needs and ensure the functioning of the family system<sup>(17)</sup>.

Families referred to the division of tasks needed among its members in the immediate period post-AMI, demonstrating care in an attempt to ensure the well-being of everyone.

*We took turns [...] when one wasn't there, the other always was. Never leaving him alone, we were always with him (F1-Cleusa).*

*He always had one or the other there, he was not alone and he sometimes had lunch there with my daughter, during the period of recovery. However, being really careful (F3-Regina).*

It was noticed in the statements, a consistent family unity, in which members sought to provide better care to the sick person. However, it took a different dynamic, as well as a redefinition of roles and good relationship between everyone, so the family care could occur effectively.

The role of the family is essential for facing the disease, facilitating its management, as well as promoting adaptation to changes and difficulties<sup>(18)</sup>. In order for this to occur, its members should establish internal articulations that aim to guarantee care to maintain harmony of everyone and functionality of family structure<sup>(6)</sup>.

Even if the roles are modified due to illness, the attempt is to make the changes to be partial and the continuity of life routine reestablished with satisfactory adaptation. A study with family members of patients with chronic-degenerative disease also shows that there was a good adaptation to the changes that occurred in the family after the onset of the disease<sup>(18)</sup>.

Nevertheless, there are family conflicts, which may create new demands for the people who mostly experience chronic disease. This confirms that roles are not static<sup>(13)</sup>, so they are developed in specific situations, in this case the cardiovascular involvement, and the relationships between individuals<sup>(13)</sup> in the family environment. In this context, nurses should be alert, recommending interactive practices between family members, which may mitigate the confrontation and encourage a suitable environment that provides quality of life. These practices may be exemplified by conducting collective meetings between nurse and family members, both in the home environment, as in health care, articulating the needs of each and stimulating the exchange of experiences so that conflicts are best resolved.

### **“We reeducate – we can adapt ourselves”: families’ current experiences**

It was observed in the statement that after some time of the event, families had reconfigured their daily lives, showing sometimes, potential changes that emerged after the episode of the disease.

*Now God has given us joy, peace. [...] We are more united [...] That pain that we had been through is gone, you know? We divide better (F1-Cleusa).*

*[...] But now I do everything, all you need to do inside of a house (F2-Jorge).*

Changes in habits of some people who had AMI affect the whole family group, assisting in the promotion of a healthier life. The attitudes developed by families happen from their beliefs and values<sup>(13)</sup>, that are built through solidified communication processes in the family environment and influence the actions of health/disease of its members<sup>(19)</sup>.

Still as potential experienced by families, we highlight the changes in habits, whether food or life changes.

*I didn't use to take care of myself, I'll be very honest, I use to work day and night without stopping [...] I use to stay awake all night and day making dough [...]* (F4-Carmen).

*[...] Our eating habits have changed, it is different now, we had a very large transformation, at least we were reeducated to eat (F5-Luiz).*

The nutrition appears as the main modifiable item, highlighted by the families, and in contrast to results from a research<sup>(18)</sup> related to the cultural aspects of the chronically ill, these healthy habits remained over time, they were not limited only to the period of immediate care. This data leads to reflection of the representativeness of the heart for people, therefore, an organ that must be protected, because once it fails, it may not have viable recovery, confirming the cultural belief that the heart is the center of life<sup>(20)</sup>.

On the other hand, we can reflect the average time post-infarction of the participants in this study was 9.5 months, which is considered small compared to the time of another study<sup>(17)</sup> developed with chronically ill patients. Thus, it can be inferred that families could still maintain healthy practices due to the recent impact of the disease.

In addition, changes that occurred compromised the leisure activities, which were previously carried out by the AMI family:

*Before, we use to go out more often, now we don't go out anymore (F5-Ana).*

*Traveling, for example, by car; now, it has been a year. I do not know, I have not got that confidence to drive away (F5-Luiz).*

*What we did not do for a long time [...] was going to a dance (F3-Regina).*

According to the statements, the illness interfered with the leisure practice and social inclusion, making interactions among family members and the rest of their social network difficult.

The disease imposes restrictions that impair the resumption of life routine, which requires a process of adaptation of the patient and family<sup>(20)</sup>. It is like the heart, physically shaken by the disease, and the patient and family, emotionally affected by its effects; it would prevent people from pursuing their lives. Thus, Nursing can stimulate the resumption of social relations, enabling the (re)inclusion of the individual in society activities, as well as strengthening of bonds that may help promote the health of everyone.

In another moment, a daughter referred to the difficulties in her relationship with her father after the onset of the disease.

*Yeah, a little [changed], he [father] was more ... Now he is a little annoying. [...] Every little thing that I ask for example: has mom arrived? and he [replies]: are you seeing her here? (F1-Mariana).*

Having a sick person at home triggered stressful situations in the family environment, generating conflicts that had not occurred before, because the convalescent person, prior to the infarction, had a work routine. Now, due to the limitations of the disease, he saw himself away from his work or work activities and subjected to a lot of care, including rest, which demanded him to remain at home. A study conducted with family caregivers of chronically ill patients revealed that patients exhibit irritability and complain more often, mainly due to the impositions of the disease<sup>(11)</sup>.

Another situation caused by AMI in the family is the ongoing concern with the effects of the disease, even after some time of the acute episode.

*Of course, we started to worry [...] carefully [...] we always have a concern that we didn't have before. And with children the same thing, they worry, everybody is concerned [...]* (F3-Regina).

The family suffered modifications, as the statements show, because the cardiovascular problem appeared as something scary. The situation tends to return to equilibrium; however, some memories, mainly due to the impositions of the health/disease process, will be present in the family environment, generating new behaviors and adaptations.

In this context, Nursing, being close to the family, should seek to meet their demands, assisting in the particular process of adaptation.

## FINAL CONSIDERATIONS

The family, regardless of their settings, is characterized as a source of care for people and, at the time of acute exacerbation of a chronic disease, various strategies are developed in order to seek to restore equilibrium. Thus, in the immediate period post-AMI, we noticed a strong family union, which were presented with the fear of death, as well as feelings of anguish and distress facing the adversities imposed by the disease.

At this time, the family seeks to reestablish soon the living experience with patient, facing the issue and using tactics of management, both at home, and in the hospital. It is noteworthy that bonds are strengthened facing the illness in order to provide the assistance necessary for the situation to be normalized.

On the other hand, the families lives whose had one of their members suffering with AMI had demonstrated, from the episode of illness, some relationships became confusions because of the constant presence of the patient at home. In addition, the activities of daily living were impaired, turning interactions and social relationships difficult.

It is suggested that Nursing acts as a mediator of professional and family knowledge, aiming at providing an approximation and mutual exchange of knowledge so that the family can readjust facing the chronic opposite situation that are present. Furthermore, it is necessary that nurses plan the care congruently with the limitations and capabilities of each family, so that they are able to face and develop autonomously care to their family at home.

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