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Experiencing cardiorespiratory arrest and death by relatives: a descriptive study

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ABSTRACT

Aim: understand the experience of relatives of people who suffered cardiac arrest and died. **Method:** this is a descriptive, qualitative study that used, respectively, symbolic interactionism and interpretive interactionism as a theoretical and methodological reference. Data were collected through a semi-structured interview at the household of 11 relatives, from November 2015 to June 2016. **Results:** the analysis of the narratives evidenced several feelings such as anger, anxiety and hope. Two epiphanies were identified. The first epiphany, discovering that the relative died, had as categories: experiencing the moment of the CRA and receiving the news. In the second epiphany, coexisting with the immediate changes, the following categories were evidenced: remembering and feeling the pain of loss and changes after the death of the relative. **Conclusion:** the interactionist perspective made it possible to better understand the experience of relatives in waiting for the attendance of cardiorespiratory arrest and the subsequent reception of the news of death of their loved one.

Descriptors: Heart Arrest; Family; Death.

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INTRODUCTION

The experience of cardiorespiratory arrest (CRA), followed by the death of a loved one is, most of the time, impacting for the family, due to the confrontation of CRA, the inexorable certainty that the physical body cannot live after death and the finding of the impossibility of going back or even changing the history of the event[1-2].

Western society understands death as a taboo, it is observed that death is absent from the everyday world of the family, since it was transferred to hospitals. Thus, death today is institutionalized and professionals are trained to attend the CRA from guidelines updated every four years; however, in these guidelines there is no description in terms of how to attend to the real needs of the family that is accompanying the dying; there is little interference from the family and lack of reflection on death and dying as a natural process of life[3-4].

Such logic permeates social thinking, which establishes rules so that death is preferentially recognized in the environment of the health service, either in the hospital or in Emergency Care Units (ECU), by trained professionals. Thus, even if the family does not want to, it must refer the dead family member to the health service and the way of facing and accompanying death will be influenced by the culture, history and daily life in which the person lives[3]. In the interactionist perspective, there is the sharing in society of the set of cultural and social meanings. These meanings guide the way mourning should be lived and the referrals to be followed before and after the finding of death[4].

Among the professions, nursing is the one that has the greatest contact with family and patients because it is present in the context of health services for most of the time. Nursing professionals should be communicative and prepared to serve the family, perceiving it as the focus of care[5]. The CRA situation is a moment when the family needs to obtain information and share their feelings. Thus, nurses must welcome, actively listen, and provide support to the family[6] and, for this, they must learn about the experiences of the family members accompanying the dying.

The choice of the problematic experience of relatives of people who suffered cardiorespiratory arrest and died is related to the concern to better understand this process, in order to better tailor care to the critically ill person and his/her family.

This research is important because it deals with an important theme and because there is a gap regarding this theme that is evidenced when carrying out a search in the literature, since only some publications about the family presence during cardiorespiratory resuscitation (CRR) in the children's parents' and health professionals' perspectives and other research associated with the benefits or disadvantages of the family being present during cardiorespiratory resuscitation.

In view of the above, the following questions arose: what is the family member's experience with the CRA of his or her loved one? What are the feelings aroused by the news of the death of this family member?

In order to answer them, understanding the experience of relatives of people who suffered cardiorespiratory arrest and died was set as the objective of this study.

METHOD

This is a descriptive, qualitative study that used, as theoretical and methodological reference, symbolic interactionism and interpretive interactionism, respectively. Symbolic interactionism starts from the perspective that the human being confers meaning to his

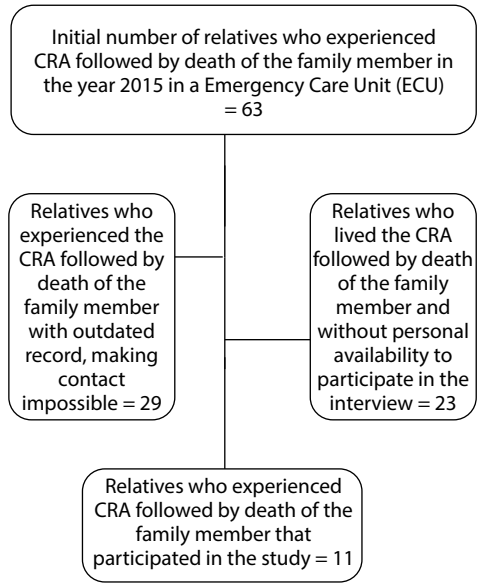
actions and creates meanings. This process directs individual behavior in specific situations. In this way, people interpret and adapt to circumstances, flexibly, according to the definition of the situation. Social life consists of interpretations of meanings shared by a group or community[7].

Meaning is an important element in understanding human behavior, its processes and interactions. These values are constantly revisited and transformed from the interactive process of individuals with the elements of their own universe. Thus, the meanings can be reformulated[7]. When researchers aim to fully understand the social process, they must seize the meanings experienced by the participants.

The data were collected from November 2015 to June 2016, at the home of family members, through a semi-structured interview, consisting of two parts. The first one consisted of general identification data (sex, age, kinship degree and reason for CRA) and the second was composed of guiding questions, based on the theoretical reference. The interviews were performed by at least two of the researchers, recorded and later transcribed in their entirety, with an average duration of 60 minutes.

Based on convenience sampling, the following selection criterion was adopted: family members over 18 years old who accompanied an adult loved one who underwent CRA and later death, assisted at an Emergency Care Unit, located in a municipality in the state of Minas Gerais General, Brazil, in the year 2015. The exclusion criteria were: family members who did not have personal availability to participate in the interview and inability to understand and/or respond to the proposed intellectual disability issues. Eleven participants were included in the study, as described in **Figure 1**.

Figure 1. Formation flowchart of the study participants: experiencing cardiorespiratory arrest (CRA) and death by relatives. Minas Gerais, Brazil. 2016.



Source: the authors, 2016.

Contact with the interviewees was carried out by telephone, which explained the purpose of the research, thus consulting the interest of the companion in participating in the interview. If so, the place and date of the meeting were set. It should be noted that all the interviews were held in a private place, at the participants' home.

The number of family members was not delimited a priori, it was determined by the analysis of the statements until the theoretical saturation was established. As the data analysis was performed, new data were sought in order for the categories to be better developed and densified.

Data analysis was performed according to the premises of interpretive interactionism. This approach was chosen by recognizing that the meanings of actions for the individual lie in the lived experience, and because they aim to generate dense and detailed descriptions of these biographically important experiences focusing on human interactions and how they

alter the behavior of people in the context to which they belong[8].

The phases of the analysis are constituted by capture, bracketing or reconstruction of the phenomenon and contextualization. These phases are preceded by the formulation of the research and deconstruction problem. In the deconstruction phase, the research problem was examined in the light of other existing research. The capture phase began with the collection of the stories of the people, told by the participants, about the phenomenon under study. In this phase we searched for moments experienced that marked the lives of people, positively or negatively. These moments are termed epiphanies and are directly involved with the research object[8].

The moment that the companion experienced the service of the CRA of a loved one left marks in its life. These brands have changed interactions and influenced future behavior. This was the moment of epiphany, which was captured by the collection of data seeking to rescue meanings and interpretations given by relatives to the events experienced. At the end of this phase, the researchers confronted the reports with the existing literature and the localization and isolation of the key phrases of the report occurred, so that they were interpreted. Thus, the reconstruction phase began. The objective of this phase was to relate the key phrases with other elements of the phenomenon under study, in order to reconstruct the phenomenon in its totality. In the reconstruction, the contextualization – when the analysis gives meaning to the phenomenon – began and it was put back in the context of the participant[8].

The development of the study was carried out in accordance with ethical precepts and the project was approved by the Ethics and Research Committee of the Federal University of São João del Rei, according to opinion number 1,286,336. The anonymity of the participants was maintained, using the letter E (of interviewee), followed by the sequential number of the participants of the research.

RESULTS

The study included 11 family members aged between 21 and 81 years (mean age 42 years). The majority was female (8 cases). The degree of kinship of those interviewed with the victims of CRA was first-degree consanguineous, that is, eight children and one parent; second--degree consanguineous relatives: grandson and grandmother e; finally wife and husband.

With respect to the diagnoses that led to the CRA of the loved one, it was verified that six were due to cardiovascular problems; three for oncological diseases and two for aggravation of chronic obstructive pulmonary disease.

The analysis of the narratives of the people who witnessed the CRA of their relatives showed the decisive moments. Two epiphanies were identified: discovering that the relative died and living with the immediate changes.

The first epiphany (discovering that the relative died) had as categories: experiencing the moment of the CRA and receiving the news. In the second epiphany (coexisting with the immediate changes), the categories were evidenced: remembering and feeling the pain of loss and changes after the death of the relative.

Finding out that the relative died

All participants received the news that their family member died after care by the health team. Eight participants knew that the person was dead before the care due to the fact they perceived the occurrence during the last moments of contact with the patient.

Experiencing the CRA moment

All participants realized that the relative was feeling badly at home and he or another person nearby called the emergency department. During this waiting period, the participant followed the patient and noticed all the changes. These changes were reported in detail by all participants, who brought their feelings to the surface. One of the main feelings was despair:

> Beth, I think mom died. I got there on the edge of her bed, I hugged and shook, called her and said: "Mom, forgive me, I asked God to take you, don't go, don't go mom, stay here, talk to me, mom, do something, but she did not react any more. (...) Wow! I wanted to die, I wanted to die at that moment, and then I said: my God. (...) I felt like I was choking, a desire to cry, cry, and cry, to scream and scream and ... Gosh, it was awful! She practically died in my arms. E2.

> Dad, wake up, get up, don't do this to me, don't. I cried, I screamed. (...)I was desperate, because I wanted him to wake up, but he wouldn't wake up. I climbed on him and said: Dad, don't do this to me, wake up! I did this on top of him (gestures) when the firemen arrived. E8.

Next, the attendance by the professionals occurred in the ECU and, during this period, the family member would wait, without news. At that moment, the relatives showed several feelings, such as anger, anxiety and hope:

> I was very angry because it seems like I was aware that she wasn't going to come home. E4.

> Oh, they had to give me a tranquilizer, because I wasn't quiet, I kept walking up and down. E6.

> I was quiet. I was quiet. Because I thought he wasn't going to die, I had hope. We knew about the severity, everyone knew, but in my head I thought he was going to leave the hospital. Because, everyone knew about the severity, but my father was a lively person. E7.

At the end of the care, the health team informed the family that accompanied the patient about the death.

Receiving the news

It is noteworthy that most of the participants reported that they had realized, before the emergency care team arrived, that the loved one was already dead, but when the death was confirmed, at first they had difficulty believing, as can be noticed in the following lines:

> I couldn't accept or believe it. I thought it was a dream, because he was not sick. It was all of a sudden. E3.

> I didn't believe it. You don't believe it, you think it's a lie. It seems like a bad joke. E10.

> I didn't believe it, I started calling my mother; my mother lives in São João del Rei: can you come here now because the worst has happened. As we've been fighting for five years, we knew this would happen, but we don't believe it. We get scared. E11.

It was observed that even the relatives of chronically ill people express difficulty in believing that the relative had passed away. Other feelings that arose immediately after the discovery that the person was dead were: sadness, anger, impotence, in addition to faith, bringing a sense of peace, despite the sadness.

> I felt impotent and useless. You see the person's life draining away. So you're useless, because life is gone. E5.

> At the moment it was a feeling of sadness, because I was never going to see her again and I had to give this news to the others, because I was the one who was there. On the other hand, I felt peace because I have fulfilled what the Lord had appointed for me to do. I had demanded to God that when he took her, none of my brothers and my father should be with her, for I wanted to be with her. It was when I was in peace, a feeling of peace. E9.

All the participants had never had the situation of witnessing CRA followed by the death of the relative, as we can see below:

> I had never been through this, I was the only one who lived with her, I followed her whole situation. I would take her to the hospital; I did everything! It was just me. I suffered a lot. E2.

> It was horrible. I never went through that, because when I lost my father I was little; then I lost my mother, but she got sick, it got very bad, and the doctor said there was no cure for her. (...) that makes us suffer more. It was a shock. When you wait for this, you get used to it little by little. Now suddenly, like this, it's crazy: it's too hard. E3.

> I've never seen a person die near me. This was the first time, and it keeps pounding in my head, you know? I saw him fall like this (gestures); I've never seen it, never. E8.

It was found that, even for the people who had passed through the death of other loved ones, the situation of CRA followed by death brought different elements that made the participant perceive it as a totally new event.

Living with the immediate changes

Remembering and feeling the pain of loss

Remembrance of the deceased relative and the situations lived next to him was in the report of all the participants.

> Her granddaughter is getting married. She won't be able to keep up with her first granddaughter's wedding. So that hurts a lot. I always remember her. E5.

> It's funny because, when I walk down the street, I think I'm going to see him, because I always used to walk in the street and meet him. He walked up and down that street. E7.

> The fact that we don't listen, don't see the person anymore and no longer have the person around to tell what happened or what is happening sometimes hurts. E9.

> We lived with her for 13 years in this house, so the memory of her is here (shows the heart) and wherever I go the memories are here, but at home the memories are bigger. E4.

> I always think: I have my sound, my records, CDs, DVDs and my radio at the head of the bed. I don't listen to any of them anymore. I even put the radio in the wardrobe. I don't feel like it anymore; it reminds me of him. E1.

Changes after the death of the relative

Besides living with the memories of the departed person and the mourning, it was necessary to make immediate adaptations so that the consequences of death did not become more serious and bring more suffering. It is observed that it was necessary to make some changes in the dwelling or in the daily routine that involved the deceased family member:

> We had to rent the house. She (the mother) went to an apartment. E8.

> (…) Because my father went to live with my sister after the funeral. He stayed there for a week, but she didn't adapt and asked to stay here and it worked. She adapted well. E9.

> We get adapted, the memories don't happen all the time, we meet other people, we make friends, we go out more often (...) I participate in a group of daily walk here in the neighborhood. E6.

> Today I have more freedom to go out, you know, to live my life. Because I didn't live my life, I lived for her. I didn't go out, I stayed home; I couldn't go to work calmly, because if I was in the street I had to come back fast. E2.

DISCUSSION

From the results obtained in this research, it was possible to perceive the presence of innumerable different feelings that characterize the experience of each interviewee before the CRA and subsequent death of the loved one. Such feelings were classified and inserted into epiphanies. The first epiphany - discovering that the relative died - revealed multiple feelings, such as despair, anger, anxiety, and hope. Studies indicate that the expression of feelings resulting from loss is part of mourning; the reactions to a loss can be of shock, desire, disorganization and organization; it is the time to learn that the death of the familiar happened; only from the experience of the mourning process will it be possible to establish new visions about the world, favoring personal investments[9-10].

Corroborating what was found in this study, research reveals that the initial shock of the news of the deceased can generate despair, anger, irritability, bitterness and isolation. Such feelings may emerge in intense emotional reactions[3,11]. Death is the final stage of man's development. People's reactions, feelings, and perceptions of life and death are entirely related to the society in which they live, the education they have received, and their previous experiences[12]. In the perspective of symbolic interactionism, individuals construct meaning in the face of the experiences and such experiences are the base of their actions and reactions[4]. In this way, the variation of the feelings reported by the participants occurs according to the meanings

constructed by them, in the interface of the interaction with the family member that died.

Therefore, in view of the detection of death, the professional should be prepared to give this news to relatives, because this moment will influence the confrontation of mourning[11,13]. The specific way in which death news was given and the way death occurred influenced the elaboration of mourning and the perception of death news[3,11]. The situation of abrupt and unexpected loss can lead to familiar disorganization, paralysis and impotence. In situations where there is a long period of care, as in cases of serious and progressively limiting diseases, relatives, especially the caregiver, may experience ambiguous feelings on the news of death[11], as demonstrated in this study.

There was also a sense of peace, coming from faith in divine power and prayer that helped reduce suffering and the search for courage to overcome difficulties. According to the literature, when spirituality, lived conscientiously, helps to experience troubled periods during life and in mourning events, because it collaborates in different ways to soften the process, bringing other perspectives to continue life, and, therefore, it is one of the resources used by families in coping with impotence and pain that arise in moments of loss[13].

Faith favors the elaboration of mourning. Mourning arouses diverse feelings, which fluctuate greatly during the process[13-14]. In this period, in fact, seeking for spiritual support helps in understanding grief, providing reflections that lead the bereaved to new perspectives, aiding in understanding about death and dying, loss, and, in most cases, providing changes that individuals drive to other aspects of daily life, and there is also an improvement in terms of quality of life[12,14-15], as pointed out in some interviews of this research.

Authors point out that recognizing faith, spirituality or religiosity as coping strategies and seeking the spiritual gaps of the person enables the health worker to plan and provide integral care to the individual assisted, emphasizing the importance of professionals to understand the beliefs and the values of each family member in mourning and perceive the influence of these factors on the quality of life of that person[14,16].

In relation to the suffering and pain of loss reported by relatives, these are natural reactions and they are present in all forms of mourning[11]. In this context, the health professional must accept the emotional expression of the family member, not considering the need to medicalize the event, the mourner should be free to express his feelings, even of anger, anguish and despair[9,12]. It is emphasized that the bereaved person only begins to perceive his new existence if the expression of his sadness and pain is allowed.

However, health professionals are taught to take care of life rather than death, and this can be observed due to the lack of a tanatological approach in health courses[13-14]. Death, as it is a daily reality of health workers, especially those working in a ECU, demonstrates the need to encourage the student, from all courses in the health area, to promote reflections on the life cycle of human beings, considering that they must be prepared to deal with the process of being born, living and dying[13].

In the second epiphany - living with the immediate changes - participants mentioned changes in routine and housing. These transformations had repercussions on the life of the accompanying family member and the family as a whole. Before the death of the loved one, the familiar interprets the meanings, the reactions of other people and the context. These meanings are socially shared and individuals constantly reflect on them by using them for action[4]. Even in the face of the process of mourning and all the accompanying feelings, such an interpretation

drives decisions related to changes in routine and housing.

Studies show that rites of passage in a family can be an opportunity for both psychological and spiritual changes, as well as changes in the routine of people[14-15].

The loss of a loved one leaves eternal marks; however, continuing is paramount, since life demands the bereaved to begin again, to build new routines and dreams, trying to experience a new stage of life[14,17]. Time causes despair to give way to reconstruction, suffering is softened, memories will always be present; however, grief is softened and the future becomes positively glimpsed, demonstrating that everything is believable[15].

The death of the beloved opens deep ruptures, requiring changes and adjustments in the way of understanding the world and making plans to continue living in it. However, the reactions to the process of loss are processed differently between individuals and depends on multiple situations that pervade death, such as: age, relationship that existed, chronic or not, faith, personality and culture[18].

The testimonies reported in this category of remembrance and feeling of pain and loss reveal that the familiar does not forget the memories of a meaningful relationship. Studies have stated that individuals in the process of mourning do not completely forget deceased loved ones. Humans cannot purge those who were dear and active participants in their history[15,18]. Remembering is a necessity of the mourner. The memories have the function of maintaining the relationship with the deceased.

As time goes by, the memories of the loved ones become companions of an existence, but instead of suffering, there is a thank you for the opportunity to have shared moments with this person. It is emphasized that this time varies from person to person, according to the degree of kinship and the affective connection with the deceased, that is, the duration of suffering can vary. Some mourners may show their grief for a longer period, reaching even more than a decade, such as those who experience a tragic death[18-19].

In the same way, some people can demonstrate their pain more naturally, while others are more collected and introspective[18]. In this study, many family members who experienced CRA followed by death of loved ones and who met the inclusion criteria of the research said they did not have personal availability to participate in the interview due to the absence of emotional conditions to talk about their experience.

The limitation of this study is related to the impossibility of interviewing all the family members who experienced the cardiorespiratory arrest followed by death of their loved one, in order to broaden their perception about the moment they lived. Another possible limitation was not to have approached how the news of the death was communicated to the companion.

CONCLUSION

The experience of relatives of people who suffered cardiorespiratory arrest and died was a defining moment for these individuals. The participants of this study had details of this event, according to their perception. Thus, it was an epiphany that brought changes.

The period that preceded the presence of the professionals was constituted by intense feelings and assumptions. The possibility of death was feared by the companions who were awaiting the completion of the CRA procedure. A whirlwind of feelings of fear, anxiety, despair, and anger plagued those who waited for information.

Upon receiving the news of the death, the relatives faced the mourning in different ways, and spirituality had a positive influence. However, this news needs to be communicated by health professionals with sensitivity and preparation, as it will have an impact on the grieving process of this relative.

The reception of the companions and the knowledge about tanatology will certainly help the health professional to deal with the people who have just received the news of the death of someone they love, so that they can give support and pertinent information at that moment permeated by pain.

Death is a theme that is not exhausted even with many studies in this field, since it is a natural event; however, this is painfully experienced in Western culture. Nonetheless, it needs to be widely discussed in universities, in homes, in workplaces, that is, in individuals' daily lives; in this way, it is believed, it will be a less overwhelming and more natural fact.

Considering the results of this study, it is suggested, for future research, that the impact of the death communication process and the support of the health team as a whole at this inexorable moment be evaluated.

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All authors participated in the phases of this publication in one or more of the following steps, in according to the recommendations of the International Committee of Medical Journal Editors (ICMJE, 2013): (a) substantial involvement in the planning or preparation of the manuscript or in the collection, analysis or interpretation of data; (b) preparation of the manuscript or conducting critical revision of intellectual content; (c) approval of the version submitted of this manuscript. All authors declare for the appropriate purposes that the responsibilities related to all aspects of the manuscript submitted to OBJN are yours. They ensure that issues related to the accuracy or integrity of any part of the article were properly investigated and resolved. Therefore, they exempt the OBJN of any participation whatsoever in any imbroglios concerning the content under consideration. All authors declare that they have no conflict of interest of financial or personal nature concerning this manuscript which may influence the writing and/or interpretation of the findings. This statement has been digitally signed by all authors as recommended by the ICMJE, whose model is available in http://www.objnursing.uff.br/normas/DUDE_eng_13-06-2013.pdf

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