



Possibility of accompanying emergency care from a family perspective: a descriptive study

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ABSTRACT

Aim: to understand the perception of families regarding the possibility to accompany emergency care procedures of their beloved one. **Method:** this is a descriptive study, with a qualitative approach. The sample is composed by 16 accompanying families of people who were treated in emergency rooms of units located in three cities in the South of Brazil. The data was collected in August 2015, through audio recorded interviews, later transcribed, and sent to analysis of content based on the themes. **Results:** the relatives mentioned they would have liked to accompany their beloved ones during emergency care. They believed that they could have demonstrated support to the patient, and they would have understood better the clinical condition. Yet, the fact they were not present during emergency care demonstrated the presence of feelings, such as sadness, despair, impotence, and feelings of family abandonment. **Final considerations:** health professionals of emergency rooms need, according to the possibilities present in the units, allow that families are near to their beloved ones during care procedures.

Descriptors: Family; Emergency Medical Services; Perception; Nursing.

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INTRODUCTION

In Brazil, as a routine, the emergency units attend an elevate number of patients with different levels of severity. They also include those that could be treated in less complex services present in the health care network⁽¹⁾. This fact also affect such units, which constantly work overloaded, once the majority of them do not have enough infrastructure, human resources, and materials in necessary proportion to support the population, with quality and resoluteness⁽²⁻³⁾. Then, the daily unpredictability, the severity of the cases attended, the large number of patients, and the limitation of human, material, and structural resources are part of the work of the health professionals, and certainly influence directly in the quality of the care provided⁽¹⁾. Such factors are also described as inferring elements in inviting and accepting the presence of relatives in the care environment together with the severely ill patient⁽⁴⁾. The scenario repeats itself in various countries in Latin America, such as Chile⁽⁵⁾, and Colombia⁽⁶⁾.

The family – the first social group we are part of, and main source of health care – while experiencing a critical moment, such an acute and severe illness, or accident, of one of its members, share the suffering demonstrated through countless negative feelings, such as: frustrations, doubts, fears, and anxiety. Therefore, it is necessary to take into consideration that an emergency situation is an unexpected event in the life of the family, and then, many of the decisions it has to face does not have similar previous precedents in magnitude, despite they involve circumstances in which the members of the family do not have any sort of experience⁽⁷⁾.

During emergency care, the relatives are usually stressed and confused with the lack of

timely information, or with information that arrive from the care team full of technical, complex, and/or difficult terminologies that are far from understanding. Under this spectrum, when questioned, the families of the patients in emergency care classify the necessity of shared information, the communication in timely manner, the support, and the proximity with relatives as their main priorities⁽⁷⁻⁸⁾.

Hence, the presence of family members during care procedures in emergency units has called attention and motivated debates and studies by researches and health professionals from all over the world, such as Trinidad and Tobago⁽⁹⁾, Australia⁽¹⁰⁾, Saudi Arabia⁽¹¹⁾, and South Korea⁽¹²⁾. Yet, the majority of the researches are limited to investigate the perception of health professionals regarding the topic⁽⁹⁻¹²⁾, or if the care is to interview relatives, the data are originated from situations, in which the majority of the times, are hypothetical or collected months after experiencing the phenomenon^(2,5) As far as we know, there are no researches that analyze the perceptions of relatives after they experienced a situation of emergency care to an adult member, as it was seen studies in this topic in pediatric emergency care only⁽¹³⁾.

In Brazil, the presence of the family in emergency care environment is a recent practice, yet minimally instituted and little investigated⁽¹³⁻¹⁴⁾. Thus, studies are necessary to understand the manner in which relatives see and take a position over the topic in question. Based on such notes, the following research question arises: how relatives of patients in emergency units evaluate the possibility to be present in the emergency room during care? To answer to this query, the following objective was proposed: to understand the perception of the family about the possibility to accompany emergency care of their beloved one.

METHOD

This is a descriptive study, with a qualitative approach, with a sample composed by 16 families of people being treated in emergency rooms of public emergency units of three small cities in the South of Brazil. Such units were working non--stop, open-doors, and were reference units to all emergency cases in the surroundings. They had similar physical structure, working processes, and user demand, with an average of 150 care procedures/day. Most of the critical patients had clinical and/or traumatic injuries, who could be sent to the units by the civil defense, municipal ambulances, or by the relatives themselves. It was decided to perform the research in these three units in order to have more participants possible, besides a larger variation of experiences and opinions of the relatives regarding the investigated phenomena. In the end, it is important to mention that the units do not have institutional policies that allow the presence of the family during emergency care.

To select the subjects of the study, it was asked that the twelve nurses working in these units register the name of the accompanying relative, home address, and a contact phone number of all patients supported at the emergency room during the month of July 2015, and who were also classified as urgent (red color), according to the protocol service with risk classification, proposed by the Brazilian Ministry of Health, and adopted in these units. Furthermore, only the data from relatives who initially accepted to participate in the investigation was registered, after the explanation of the objectives of the research by the nurse present in the health care service.

Weekly, the researchers would visit the units and had access to the information registered. The contact with the relatives and the following interviews had an average of 30 days after the health care procedure. This difference generated a minimal period for the families to reflect upon the experience of emergency care given to their beloved one.

The data was collected in the month of August 2015. Initially, the researchers called the potential participants of the research, and based the observation of the criteria of inclusion proposed – being 18 years old or more, and had accompanied the relative that is severely ill to the health unit - and acceptance to participate in the study, which later a visit was scheduled, in day and time that better fit the family's schedule. In a total of 25 registered families, the researchers were able to contact 20 of them, but two did not return the calls, and other two changed their minds and refused to participate in the study. With the intention to bring more variability to the information collected, it was selected, based on the lists produced by the nurses, relatives with different degrees of kinship; and patients with various clinical diagnoses and outcomes.

The final number of participants in the research was determined by the criterion of data saturation, taking into consideration that the search for information continued until the moment that the discourses became repetitive, not bringing new information to understand the phenomenon⁽¹⁵⁾, and when the objective of the research was fulfilled. This effect was observed during the 14th interview. To confirm the saturation of data, other two relatives were interview.

The interviews took 45 minutes in average, and they were guided by the following question: would you like to be present in the emergency room with your relative during the care procedures he went through? What is your opinion about this topic? The information was recorded in a digital format, fully transcribed, preserving the discourses in a natural format in order to allow a greater reliability in the answers. Later, there was a process of edition of the discourses, so the language idioms and grammar errors are removed, in order to provide a better fluid reading of the testimonies, and to avoid embarrassments for the participant, but without changing the meaning and the content⁽¹⁵⁾.

During the analytic process, the following steps were pre-established by the methodological reference, which is: pre-analysis; exploration of material; and treatment of data. In the first phase, the empirical material was organized, transcribed, and separated, followed by an initial reading of the data to identify the emergent and relevant aspects that allow to fulfill the objective of the study. In the second phase, it was performed a process of classification and aggregation of data from a meticulous reading, using color coding, and a clipping of common and specific aspects, leading to the construction of the previous categories. And, in the end, the third phase permitted to deepen the categories through the articulation of empirical data with the theoretical material⁽¹⁵⁾.

Through this exhaustive process, based on the exercise of reflexivity – in which the pre-concept ideas of researchers regarding the topic were known and left in suspension –, data analysis and categorization was rigorous. Two thematic categories emerged: a) "I wanted to be there": understanding the position of the family; b) Family suffering while staying out of the emergency room.

The study was developed according to the directives described by the Resolution #466/12 of the Brazilian National Health Council (CNS), and the project was approved by the Permanent Committee of Ethics in Research with Human Beings of the signed institution (CAAE: 43765315.7.0000.0104). The participants signed the Free and Clear Consent Agreement in two ways, and identified by the degree of kinship, followed by a fictitious name, and diagnose of the patient under treatment in the emergency

unit, such as, for example: Sergio's mother, exogenous intoxication).

RESULTS

Characterization of the participants

Sixteen relatives were part of the study, with ages varying from 23 to 80 years old (an average of 44 years old). The majority was female (13 cases). The degree of kinship of the interviewees with the patients was first degree - four mothers, four sons/daughters, and two fathers - and first degree by affinity - five partners, and one daughter-in-law. In regards to the diagnoses that motivated the search of patients for emergency care support, it was seen that six were driven by cerebrovascular issues; three due external causes; two due oncological illnesses; one due to allergic process; one due to exogenous intoxication; one due to convulsion; one due to severe dehydration; and one due to escalation of chronic obstructive lung illness. As case outcomes, there were six patients progressed to death, five were transferred to other health units, and other five were discharged, from which only two on the same day they were admitted.

"I wanted to be there": understanding the position of the family

It was observed that all interviewees would like it was given the possibility to go inside the emergency room during the procedures of their relatives. This is justified because they believe it is a family right to be present during the many steps of care procedure, in order to accompany, to confirm, and also to evaluate the assistance offered.

> I wanted to go inside the emergency room [...] I needed to be inside the

room, he was my son and I have this right (Jesus's mother, traumatic brain injury).

I know they are working there inside and doing everything possible for him, but I only wanted to be there, I wanted he knew I was there too, and I was watching everything that was being done (Miguel's father, traumatic brain injury).

The relatives perceived as positive their presence in the emergency room, specially because they understand that they could represent a support for their beloved ones who was ill and needed support at that moment.

> If I could I would give him some support, going into the emergency room to hold his hand. He needed me (Antonio's wife, stroke).

The relatives understood that the support to the patient consisted in simple attitudes, suc as, holding the hand of their beloved one, and making them aware that the family was worried with their safety and comfort, even inside the emergency unit. Thus, relatives did not demonstrate in their testimonies to have a more active role in the process of care, or under therapeutic decisions, specially because they recognized that the health professionals were performing their roles in adequate manner. In fact, they were anxious to be present and support, through affection and care, their relative.

Another aspect that pushed the interviewees to continue to be present during emergency care procedures was the lack of information. Then, the testimonies demonstrated an afflictive and distressing experience in the wait for information. In this sense, some attempts were implemented, with the objective to request attention and information from the health professionals, being in eleven cases, this information arrived only after hours of the beginning of the procedures, reported as too quick, superficial, and not clarifying.

> How I wished to be inside the room to be close and see what was being done [...] they only came to me to talk after two hours. This is terrible! I was so distressed, waiting for answers, information, or something like that (Maria's daughter, acute myocardial infarction).

> It is hard to feel distressed, anguished, waiting for someone to come and tell what is going on, it is so sad (Pedro's father, allergic reaction).

Then, it was evident that one of the preponderant factors that drive families to manifest a desire do accompany the emergency care procedure was the necessity to be informed about their beloved one. Other interviewees also declared this information should be offered earlier, clearly, and objectively.

> [...] I didn't understand anything he said, despite he was talking too fast, he used some hard words, that neither my husband who was near the nurse was able to understand, nor I was able to grasp anything. If we could have stayed together, I think it would be easier [...] (Estevão's daughter-in-law, intestine cancer).

> The doctor almost didn't say a words, the only thing I understood is that he was alive and he said something about oxygen, but I didn't understand that. For us who don't know these things,

² Soares JR, Martin AR, Lopes APAT, Marcon SS, Barreto MS. Possibility of accompanying emergency care from a family perspective: a descriptive study. Online braz j nurs [internet] 2017 Jun [cited year month day]; 16 (1):188-198. Available from: http:// www.objnursing.uff.br/index.php/nursing/article/view/5585

it is complicated to understand, we can only get it if we see it, and if I was there near him, I would understand better [...] (Luiz's wife, acute myocardial infarction).

Altogether, thirteen interviewees made reference to the necessity to be early informed about the clinical status of their relative. When this information took time to arrive, or were filled with technical terminology, not so comprehensible for its understanding, the necessity to be with the relative in the emergency room wakes up. They believe they would better understand the situation.

In summary, it is possible to observe that the relatives would like to be with their beloved ones in the emergency room during the procedures, and they see that as a right as a family. The objective to be closer with the relative was to accompany the service provided, to offer some support, and to have more and better information, which would facilitate the understanding of the clinical condition.

Family suffering while staying out of the emergency room

Based on the impossibility to go inside the emergency room, and without any contact with their beloved ones who were under emergency procedures, all relatives reported to experience negative feelings, such as sadness, despair, impotency, and the sensation to have abandoned their relative in such a delicate moment of their lives.

> I really wanted to go in to be by her side. I was really said with the fact I was not there with her during that moment of suffering (Julia's daughter, stroke).

It seemed that I abandoned him there, that's how I felt (José's daughter, acute myocardial infarction).

One interviewee demonstrated she felt incapable for not being present with her son during care, as she knew he needed her presence. The experience of this situation of exclusion inside health services collaborated to the emergency, maintenance, and potentialization of negative feelings that were naturally being experimented and seen by the family based on the known outcome and perception by the family based on the fear of the unknown result and treatment in an emergency unit.

> I feel that I was weak because I couldn't do anything to help my son. How can I be outside while he needs me on his side? This would make me desperate and would destroy from inside out (Sergio's mother, exogenous intoxication).

The interviewees also called attention to the fact that, besides the possible awakening from a sensation of suffering and challenging in being in an emergency room during procedures, and yet, preferring to be near to their relatives. This occurs because they could see that the experiences of negative feelings wee maximized due to exclusion of the family from the emergency room.

> That day was suffering for all of us. Even though I was unable to do anything, and I was going to be there and I had to see the whole attendance, which may be hard, I would rather be inside there. On the outside, a million things went through my mind, as the fear of death, insecurity, some weight on the chest, all the bad things you can ima

gine (Manoela's daughter, congestive heart failure).

The testimonies of ten relatives demonstrated the necessity to be with their beloved one in the moment of emergency care, even recognizing that such experience can progress to a difficult situation. When being prohibited to stay with their relatives, the interviewees demonstrated the arrival of different negative feelings, such as sadness, insecurity, and impotency.

DISCUSSION

The results of the present study showed that the interviewees were anxious to be present in the emergency room while their relatives were under treatment. Different reasons pushed the necessity "to be with". For example, the need to understand the practice as a family right was one of them. Yet, to believe that their presence would give some support to the relative, or improve the understanding of the clinical condition from the accompany to the provided care practice and/ or acquisition of more information also moved the relative to manifest a desire to be present in the emergency room.

Today, in Brazil, as in other countries around the world, the possibility or not to have a relative present during the procedures is yet a decision to be taken exclusively by the health professionals, who are commonly against the presence of a foreign individual in the emergency ward, impeding the company of the relatives. The justifications to exclude these individuals are fundamentally centered in the fear that the relatives may lose their emotional control, interfering in the assistance provided and/or that the families suffer from psychologically stressing memories related to care, specially when the outcomes are unfavorable (death/sequels)^(14,16). However, it is important to consider that the families, when experiencing and acute and serious illness of one of their own, show the necessity to be present⁽¹⁷⁾. A phenomenological study performed in *Hong Kong, with 18 relatives* of patients who were seriously ill – relatives who never were present in any other life-sustaining intervention, showed that the majority indicated a strong preference to be present if the option was given to them. According to the interviewees, there was a strong emotional connection between the relatives; they knew the necessities of the patient; and they perceived as an advantage the possibility to accompany the procedures, observing possible inadequacies in the care provided⁽¹⁷⁾.

Corroborating with the previous discussion, the findings of this investigation demonstrate a desire and a necessity of the relative to be near to the beloved one in the moment of emergency care, giving support and consolation, being able to observe that all necessary resources were used by the team, guaranteeing a quality care. When these desires are not investigated, perceived, and answered by the health professionals, they cause higher stress levels and suffering to the relatives, as they wish to experience together with their beloved one the whole process of care, which includes from the moment the patient is assisted initially (pre-hospital care), running through the entry in the emergency unit, and the possible outcome (death/hospitalization/ discharge). In summary, they would like to feel as part of the care process, by showing their support.

A study performed in a Brazilian city with health professionals who have experienced the assistance to children in an emergency unit with the presence of the family demonstrated that, among the reasons to have a consent to have their presence, there was the fact to let the family to presence the efforts of the health team to save the life of the child. Furthermore, it was

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also demonstrated that, besides being a right to the family, it provides important information about the medical records of the patient, which helps in emergency assistance⁽¹⁴⁾.

In the present investigation, the relatives also emphasized the necessity to have access to clear and objective information, which includes a less technical and scientific language in the information provided by the health professionals. It is a consensus in literature that providing information to relatives is extremely important, specially to clarify the medical diagnose that motivated the search for the emergency unit, how the patient is being assisted by the unit professionals, and the clinical evolution of the present condition. Therefore, it will provide the family a better sensation of safety towards the quality of assistance their beloved one is receiving. At the same time, this procedure helps to facilitate family restructuring when facing the experience of an acute and serious illness⁽¹⁸⁾.

Furthermore, it is worth to mention that during the moment of emergency care, it is common that the families are stressed and confused with the lack of information⁽⁷⁾. It is known that both the patient and the relative, when well informed, help and support in the treatment of the illness⁽¹⁶⁾. Therefore, health professionals must inform about the illness, the signs and symptoms, the diagnose, the treatment, and the follow up to other health units. The previous knowledge can facilitate the process of acceptance of the illness, enabling the family to get organized again to overcome the stressing situation and to think in the rehabilitation of their beloved one⁽²⁾.

Besides that, it is important to take into consideration the indication from the relatives in which, by enabling the presence of the families in the emergency rooms, it will increase the chance they early and easily understand the medical condition of the patient. Thus, the health professionals must understand this desire from the families, and give opportunity that they accompany the procedures. In order to do so, the families also need to be assisted with caution and attention. Therefore, it is possible to avoid, or at least, to reduce, the feeling of inability that families declare they feel during the experience of an emergency situation^(14,16).

The results of the present study found sadness, inability, and the sensation to have abandoned the relative as feelings the interviewees reported they had when waiting for the end of the emergency procedures. Then, it is demonstrated the importance to include the family in the acute care to the seriously ill patient. This fact, added to other aspects, will provide a more helpful, safe, holistic care, focused on the aspirations of the other, not only from the patients to their families, thus reducing the suffering. From an analogy, the study performed with relatives of patients assisted in an emergency unit in the South of Brazil identified that they presented feelings of gratitude towards the health professionals, and the fulfillment of their role as family members in regards to the possibility to observe the improvement of the health condition of their beloved ones, and to have helped in the relief in the suffering and in care, specially the emotional one, to their ill relative⁽²⁾.

When considering the real possibility to insert the families in the emergency room, it is necessary to call attention to the way each person reacts in different manners when experiencing emergency care of a relative. Some can be less prepared to accompany their relatives. This fact occurs because each individual has his own singularity and particularity. However, those who are willing or feel self-educated, in special emotionally, should have the possibility to be with the beloved one, as evidences^(10,19) suggest it is beneficial both for patients and families, and besides that, ethic and humanly the relatives cannot be ignored or excluded during the therapeutic process, independently from where it takes place.

Even though, many health professionals justify their conducts as less receptive to the families due to the fact they consider emergency care as an intensive, invasive, critical treatment, and solely destined to save the life of the patient⁽¹⁴⁾. In these cases, the assistance must be quick, effective, and with technical quality. Thus, the focus of the professional is on the patient, which is important and necessary, however the family is placed on the side, which also shares and needs care^(14,20).

Therefore, the promotion of the presence of the family in emergency procedures can be possible and accepted by the health professionals if there is a program/training of awareness of the team to allow the access in this context, and to annul the improvements given by the family in emergency care^(8,19). This training can be performed by the managers and professionals of the health unit itself in other that further expensive formative demands are not generated, and above all, that the professionals are integral part of the process of construction of an institutional identity that valorizes the families.

Limitations of the study

It is important to highlight that this study has limitations. One comes from the fact that the record of potential participants was done by the nurses of the units, and for this step it was not produced any standardized model, besides the criteria of inclusion. This might have influenced in the selection and record of relatives. However, aiming to reduce such limitation, before starting data collection, the researchers observed the criteria of inclusion and of clinical records, and the outcomes of the cases of the patients, so then, include the relatives in the research. Another limitation is related to the fact that the interviews were performed in about one month after the experience, which implies a bias based on the forgetfulness. However it was given the option to allow families to reflect upon the situation experienced during emergency care, and then, with more time and understanding, the families could give signification and resignification for the phenomenon, so then it could be investigated. It was seen that, in general, the answers given were rich in details, constructive, and encouraging.

FINAL CONSIDERATIONS

The conclusion is that the relatives want and feel the necessity to be with their beloved one through the process in the emergency unit, and that presently this demand is ignored. Therefore, feelings of regret arise, such as sadness, feelings of abandonment of the ill relative, despair, and incapacity, many times originated by the lack of timely information, or the clear one.

It is believed that to a more humanized care to the relatives of patients under treatment in emergency units, the health professionals, and in special, the nurses, must consider the possibility to insert them in the physical space where patient care occurs. However, adequate nursing interventions can only occur if supported by institutional policies and directives towards the necessities of the relatives. Then, it is urgent to discuss and implement the learning of this topic in the formation of nurses and other health professionals, as well as to keep the discussions through activities of continuous education in health care units. That is the only way to slowly change the present paradigm of family exclusion in emergency services.

Based on the results of this study, which show that relatives demonstrate sadness, unsafety, uncertainty, and incapacity when staying outside the emergency rooms, it is suggested further studies of interventions who insert the relatives accompanying the patient in emergency care, and after, trying to understand the level of suffering of these individuals. This would amplify the results od the present investigation and better understand the phenomenon of family experience in emergency care.

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