Revista Brasileira de Enfermagem
REBEn

ORIGINAL ARTICLE

Meanings attributed by family and patients to family presence in emergency rooms

Significados atribuídos por familiares e pacientes à presença da família em emergências

Significados atribuidos por familiares y pacientes a la presencia de la familia en emergencias

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How to cite this article:
Barreto MS, Garcia-Vivar C, Santos JLG, Maciel DGS, Matsuda LM, Marcon SS. Meanings attributed by family and patients to family presence in emergency rooms. Rev Bras Enferm. 2019;72(6):1684-91. doi: http://dx.doi.org/10.1590/0034-7167-2018-0814

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Submission: 10-29-2018 **Approval:** 03-02-2019

ABSTRACT

Objective: to understand the process that leads adult and family patients to support family presence in emergency care. **Method:** a qualitative study that adopted Symbolic Interactionism as a theoretical reference and the Grounded Theory as a methodological framework. The theoretical sample consisted of 15 relatives and 15 patients assisted at two emergency units in the South of Brazil. Data were analyzed using open, axial and selective coding. **Results:** the central category "Convergence of ideas: family members and patients supporting family presence in emergency care" is supported by the categories: "Affectionate relationship among family members"; "Tacit obligation to care for the sick relative"; "Benefits for the family"; "Benefits for the patient"; and "Benefits for the health team". **Conclusion:** family presence in emergency care provides maintenance and strengthening of affectionate bonds among relatives and the experience of more sensitive and qualified care.
Descriptors: Patients; Family; Emergency; Family Relations; Family Nursing.

RESUMO

Objetivo: compreender o processo que leva pacientes adultos e familiares a apoiarem a presença da família no atendimento emergencial. **Método:** estudo qualitativo que adotou o Interacionismo Simbólico como referencial teórico e a Teoria Fundamentada nos Dados como referencial metodológico. A amostragem teórica foi composta por 15 familiares e 15 pacientes atendidos em duas unidades emergenciais no Sul do Brasil. Os dados foram analisados por meio de codificação aberta, axial e seletiva. **Resultados:** a categoria central "Convergência de ideias: familiares e pacientes apoiando a presença da família no atendimento emergencial" é sustentada pelas categorias: "Afetuosa relação entre os membros da família"; "Obrigação tácita de cuidar do familiar enfermo"; "Benefícios para a família"; "Benefícios para o paciente"; e "Benefícios para a equipe de saúde". **Conclusão:** a presença familiar no atendimento emergencial proporciona a manutenção e o fortalecimento dos laços afetivos entre os familiares e a vivência de cuidados mais sensíveis e qualificados.
Descritores: Pacientes; Família; Emergências; Relações Familiares; Enfermagem Familiar.

RESUMEN

Objetivo: comprender el proceso que lleva a pacientes adultos y familiares a apoyar la presencia de la familia en la atención de emergencia. **Método:** estudio cualitativo que adoptó el Interaccionismo Simbólico como referencial teórico y la Teoría Fundamentada en los Datos como referencial metodológico. El muestreo teórico fue compuesta por 15 familiares y 15 pacientes atendidos en dos unidades de emergencia en el sur de Brasil. Los datos fueron analizados por medio de codificación abierta, axial y selectiva. **Resultados:** la categoría central "Convergencia de ideas: familiares y pacientes apoyando la presencia de la familia en la atención de emergencia" es sostenida por las categorías: "Afetuosa relación entre los miembros de la familia"; "Obligación tácita de cuidar del familiar enfermo "; "Beneficios para la familia"; "Beneficios para el paciente"; y "Beneficios para el equipo de salud". **Conclusión:** la presencia familiar en la atención de emergencia proporciona el mantenimiento y el fortalecimiento de los lazos afectivos entre los familiares y la vivencia de cuidados más sensibles y calificados.
Descriptores: Pacientes; Familia; Urgencias Médicas; Relaciones Familiares; Enfermería Familiar.

INTRODUCTION

Family-centered care presupposes that patients' relatives are integrated into care and decision-making, including during hospitalization for acute and severe diseases[1]. Specifically, family presence during emergency care, defined as *the permanence of one or more relatives in a place that allows visual and/or physical contact with the patient during the performance of procedures in Emergency Rooms and Intensive Care Units,* is a recent and not yet fully established practice[2-3], but has over the years been increasingly endorsed by important international critical care organizations[4-6].

In Brazil, as far as is known, there are no reports in the literature of health institutions that systematically encourage and/or allow family members presence during emergency care. There is an exception in a hospital in Rio Grande do Sul State, in which some doctors, after initial evaluation of the patient's clinical picture, allow the entry of a family member into the Emergency Room (ER) to follow procedures[7].

Current evidence suggests that the presence and involvement of relatives can improve patient safety and comfort, reduce hospitalization time, enhance communication among family members and health professionals, and reduce medical and hospital costs and readmissions[5,8-10]. However, among health professionals, there is still controversy in the recognition of these benefits, which has triggered debates about its applicability, besides an inconsistent and sporadic practice[5].

Specifically in relation to family presence during care at ER, professionals should consider that, commonly, relatives seek these services through *unexpected events, grave, almost always surrounded by fanciful thoughts and that can definitively modify their lives*[11]. In this sense, relatives of patients in critical and emergency situations, when investigated, demonstrate a need for information, support, comfort and closeness to see and even touch their loved one, to say a final good-bye and to make sure that all possible is being done[9,12]. In addition, relatives and patients express not only a desire, but the perception that they have the right to experience emergency care with family presence[8,11,13]. Therefore, more and more, health services and their professionals must be prepared to receive and host relatives who experience acute and severe illness.

Compared to health professionals, patients and family members are more likely to support family presence during emergency care[10,14]. However, it is necessary to understand what motivates this support, because this can sensitize professionals and institutions to transform policies and routines, in order to favor the inclusion of relatives in care processes. Moreover, apprehending the Brazilian perspective on this topic can favor a more fruitful understanding of the phenomenon and contribute to the elaboration of international guidelines that boost discussion on family presence in ER and, therefore, its practice in a systematized way.

OBJECTIVE

To understand the process that leads adult and family patients to support family presence in emergency care.

METHOD

Ethical aspects

The study was approved by the Research Ethics Committee of the signatory institution. All individuals signed the Free and Informed Consent Form, were informed that participation was voluntary and guaranteed anonymity and confidentiality, as established in Resolution 466/12 of the National Health Council.

Theoretical-methodological frameworks and type of study

This is a qualitative research that used Symbolic Interactionism as a theoretical framework and Grounded Theory as a methodological framework.

Methodological procedures

Study setting

The data were collected in two ER located in two cities of Paraná State (Southern Brazil). These are public services funded by the Brazilian Unified Health System (*Sistema Único de Saúde*) and that serve emergency patients in an uninterrupted manner. These services, at the time of data collection, did not have institutional policies or systematic routines that allowed family presence in the care, being the standard of health services of the region.

Data source

The selected sample included patients under observation or hospitalized in emergency services and relatives of patients. The inclusion criteria for the participants were: to be over 18 years of age and not to present trauma, injury or illness that would impede interpretation and/or response to interview questions, which was considered from the clinical analysis of the patient by the multiprofessional team of service. Four patients and two relatives who were not psychologically or emotionally excluded from participating in the study were excluded.

Collection and organization of data

For data collection, non-participant observation and interview was used. Observations of the contextual setting and subjects constituted the initial stage, counted approximately sixty hours and were guided by the following guiding question: *how do adult and family patients behave during moments of interaction relatives them in the Emergency Room?* Observational data were recorded at the end of each shift, in field diary. Interviews, conducted by the main researcher, lasted between 16 and 52 minutes, were guided by the following generating question: *what is your opinion about family presence in the Emergency Room during care? Why?*

As recommended by the Grounded Theory[15], the theoretical sampling was used to guide the data collection. In total, 30 interviews with patients and relatives were carried out separately. The sample groups are shown in Chart 1.

Chart 1 - Presentation of the sample groups participating in the study, Maringá, Paraná, Brazil, 2017

Group	Patients	Family members
G1	Four elderly women	Four relatives of elderly people with chronic disease
G2	Two young women and four men	Six family members of patients with acute problems
G3	Three patients whose family members were able to follow up the care	Three family members who experienced the situation less than an hour ago
G4	Two patients validators	Two family validators

Data analysis

Data collection and analysis occurred simultaneously, being consistent with the constant comparative method[15]. The recorded interviews were transcribed in full for analysis, which began with the coding and comparison of each incident. Open coding was performed with the help of QDA Miner software®. This phase allowed the construction of memorandums, concepts and diagrams, which during investigation became more complex and explanatory, representing the link between codes, subcategories, categories and the central variable of the process.

Axial coding allowed codes to be grouped by similarities and conceptual differences, which began to identify conceptual properties of the categories, by establishing provisional concepts. Next, integration was carried out, which allowed the densification of the categories and the clear integration of the central category. The entire process of data collection and search for informants was guided by theoretical sampling, which occurred until data saturation was obtained[15]. At the end, the obtained understanding was validated with two patients and two relatives (one from each health unit), who did not participate in the data collection and composed the fourth sample group.

It should be highlighted that this study integrates a broad project aimed at exploring the perception of the actors involved in emergency care on family presence. All the research was guided by the paradigmatic model, whose objective is to identify the explanatory relationship between categories and subcategories, named as phenomenon, causal conditions, intervening conditions, context, strategies and consequences[15]. At this point, a central category will be presented concerning the causal, intervenient and contextual conditions, entitled: "Convergence of ideas: family members and patients supporting family presence in emergency care".

RESULTS

The 30 participants were equally divided between patients and family members. Eight patients were female; nine were between 19 and 59 years old and the other six were between 60 and 77 years old; nine had an employment relationship; eight had up to four years of study; and nine, low family income - up to a minimum wage per capita[1]. The reasons that triggered the search for the service involved neurological, cardiac, respiratory and automobile accidents.

The majority of family members were female (10), ranging in age from 22 to 69 years old and with a family income per capita of between two and a half minimum wages. Thirteen of them possessed up to eight years of study, and two, complete higher education. In relation to the degree of kinship, there were: spouses (05), children (04), aunts (02) and mother, niece, sister and sister-in-law (01 each).

Convergence of ideas: family members and patients supporting family presence in emergency care

In a convergent way, family and patients support family presence during emergency care. In the experience of both, emergency care is initiated by the arrival of health professionals at the place of occurrence, or by the patient's entry into the ER. Finalization, however, takes place only when the discharge occurs, the transfer to another sector/unit or the death. That is, the patient permanence in the ER, regardless the accomplishment of invasive procedures and/or the severity of the clinical picture is characterized as emergency care. The process that leads to the support of patients and relatives to family presence in emergency care is dynamic and different factors influence it, according to the categories presented below.

Affectionate relationship among family members

The main support and motivation for family members and patients to support family presence in emergency care is the need to maintain the affectionate relationship among their members. The strong link built over the years, based on proximity and coexistence, qualifies the relationship. The social interactions that individuals experience in the course of family life direct the type of relationship and the intensity of supporting family presence in emergency care. Relationships show that they are based on respect, love, affection and sharing.

> *I prefer that she* [wife] *is here with me, because we are married for 35 years, it's a long time, we have a relationship of years and years, it's a lot of love, a lot of affection involved. Do you know that person you trust? She is this person to me.* [...] *At home, I am a father dear to my children and they are mine. So we're very close, but I think if it was a beating, relaxed, inattentive parent, they would not want to be here with me. But it's the opposite, they call all the time, you saw that the two called me* [during the interview]*, it shows the concern, the desire to be here with me.* (G3, Patient 11)

Faced with the strong feeling of unity and belonging to a group, patients want to maintain closeness and complicity, albeit in a different environment and alien to their lives. The fact that family

1 Minimum monthly wage at the time of data collection: R$ 937.00 ≅ US$ 281.00.

members live daily and get to know each other in a profound way makes them mutually identify and understand one another's needs, as support to family presence in the ER does not suffer neither direct influence of the age nor patients gender.

> *Both men and women in illness should have this understanding. I speak for myself that it is always good to have someone in the family close to us, someone we know, trust* [...] *women should think the same way* [...] *after all, everyone wants to have someone close by to feel better.* (G2, Patient 07)

For family members, in the face of severe and / or unexpected illness in one of the family members, the relationship of closeness and affection is also responsible for triggering intense suffering. The experience of feelings, such as anguish, sadness, worry, regret and fear while the loved one is being cared for characterizes family suffering, which is extended to the whole family.

> *I'm touched, because we already think about the loss, will I lose* [the husband]*? Will the worst happen? The way it is there, lowering and rising* [blood glucose] *I am very worried, I am very afraid of losing it! He* [silence and cry] *is the father of my daughters, companion of a whole life.* (G1, Familiar 03 – wife)

Suffering sets in when the family is faced with the need for emergency care of one of its members. However, paradoxically, there is strengthening in the relationship and narrowing of family ties, since its members seek mutual support among themselves. Support does not come only from family members who are physically close, but also from those who are distant. In addition, family members resort to faith in a Higher Being and even profess it through prayers performed during the moments in which they are close to the patient, which minimizes suffering.

> *During visiting hours, the son of a patient who had suffered a cardiorespiratory arrest entered the Emergency Room. He did not ask anyone anything, just asked permission to enter and headed to his mother's bed. As he approached, he placed his hand on her forehead and intoned, almost silently, a few words, as if to say a prayer.* (Field note – 18th collection day)

Tacit obligation to care for the sick relative

Specifically for family members, supporting family presence in emergency care is also related to the perception of an implicit obligation to care. Relatives, who, prior to the emergency event, already play a formal caregiver role, feel more propelled to assume for themselves the responsibility of remaining with the patient. In addition, they believe that care is a way to give back to the loved one what has been done for the family.

> *I wanted to be with him* [the father] *because he lives with me and I cannot leave him alone, it is my daughter's duty. Although he has eight more brothers, he currently lives with me and I am responsible for him.* (G1, Relative 04 – daughter)

> *I have to stay with him, not that I feel obliged, in a bad way, but he is my husband, he was with me when I needed.* (G4, Relative 15 – wife)

Benefits for the family

Patients and family members perceive that family presence in emergency care results in benefits to family members, so they support their occurrence. Patients believe that families become calmer and safer by following the procedures and how the clinical picture of their entity evolves.

> *Professionals need to give the family a chance to stay here. She will be calmer, because she learns more information about the diagnosis, she sleeps more calmly, she is unconcerned. It only has benefits for the family, if you stay here.* (G2, Patient 10)

By staying away from care, family members become more stressed and anguished. This is a reflection of the lack of information provided by professionals to address the doubts of family members and / or the way in which such information is transmitted. Even the harrowing waiting for information leads family members to feel that time is passing more slowly.

> *From the time I arrived, it should already be over an hour* [looks at the clock and says:]. *No, actually, it's been 30 minutes, but it seems like it does more, so far no one has given me information, no one has come to say that they have received it, that they will be responsible for caring. I think they should give us more information and talk about how things are, this would give more peace and comfort to the family.* [...] *if I were in there this information would not be so necessary, because I would be following everything.* (G3, Relative 13 – son)

Benefits for the patient

Supporting family presence in emergency care is also related to the identification of benefits for patients. These include: fear reduction inherent in the situation of illness and staying in an acute care unit by maintaining visual and/or physical contact with the family and offering emotional support, calm, confidence and comfort; higher quality of care; and greater security due to the vigilance of the family, which is understood as something that goes beyond the company of family members.

> *I think it would be important* [family presence] *to have more support, less fear. If you think about my heart, I'd like you to have a family member here, because I think it would give me more strength. The family is safe haven, brings more confidence, more security.* (G2, Patient 06)

When present in emergency care, the family can exercise less complex activities and demonstrate to the patient that they have not abandoned them, providing care and emotional support. Health professionals cannot offer such emotional support in the same way as the family, however skilled and skilled they are to perform the technical care.

> *Now I was visiting, I kept talking to him quietly, I do not know if he was listening to me, but I said, "Father, I'm here," I took his hand, I caressed his face, I passed the positive energy he needs. As much as the professionals are caring and I see this, they will not comfort, give affection, positive strength, so the family is important.* (G1, Relative 04 – daughter)

Benefits for the health team

Support of family presence in emergency care also stems from the perceived potential benefits to the health team. Considering that the professionals have several functions, family presence can, in a certain way, individualize the care of the patient, when performing less complex activities and, therefore, reduce the workload of the team. Therefore, this would allow the professionals to take more attention and time to patients with greater needs or to those who did not have family members present.

> *A nurse is not willing to be with you all the time. Just like the nurse who is here* [in the Emergency Room] *she has to pay attention to all patients. If a patient arrives more serious than I, she has to attend, give priority to him, while my family would be with me only, all the time.* (G2, Patient 09)

Family presence can also provide professionals with better information about patients' chronic diseases and medicines used at home. In addition to the severity of the clinical picture, age, schooling or comprehension capacity can make it difficult for the patient to communicate with the team to provide information about their experiences of diseases and treatments, which makes key informants.

> *If she* [daughter] *could be here, she could help me remember things, because the moment I arrived, they asked me many questions about the medicines I take. As I am old and do not have much study, I forget things. If she were here, she could help me with that.* (G1, Patient 03)

In addition, when following up care, family members can also recognize and value the work performed by professionals, even if the outcome is the death of the loved one. Thus, they support family presence in care, because, if necessary, relatives can act as advocates for professionals and care provided.

> *When you say that the care is SUS, people are afraid, because the SUS is badly spoken, has a reputation that nothing works, nothing is well done. So if people came along, they would say, "No, they did what they had to do. All that could be done they did, if he died, it was time".* (G3, Relative 11 – wife)

Understanding synthesis

Figure 1 represents the *Convergence of ideas: family members and patients supporting family presence in emergency care*, which characterizes the process of supporting family presence in the ER during emergency care. This process represents causal, intervenient and contextual conditions of the identified phenomenon and has the same symbolic definition for family and patients. The main cause for the support is the *affectionate relationship among family members*, which constitutes a strong link built along the coexistence, social interactions and family closeness. Affection for the patient is also responsible for triggering the family suffering during emergency care, as the support to the family in this situation is the family itself (nuclear and extensive) and the belief in a Superior Being.

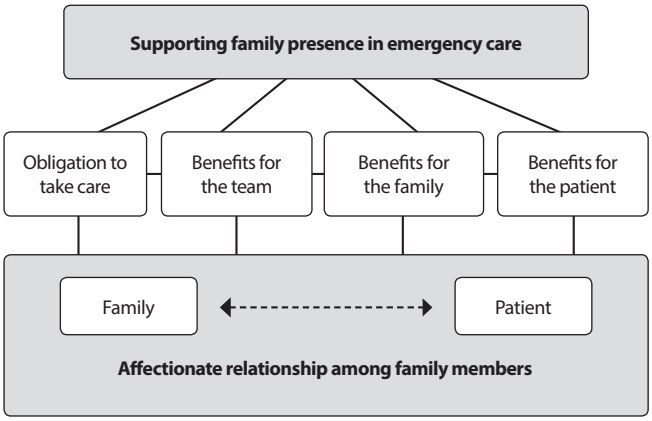

Figure 1 - Relationship between the central category: *Convergence of ideas: family members and patients supporting family presence in emergency care,* and its categories, Maringá, Paraná, Brazil, 2017

Specifically for relatives, there is an implicit obligation to care for the sick family member, who is in an emergency situation. Obligation to take care feeling comes from the context they are inserted, when they already carry out this activity, routinely, at home or because they aim to reciprocate the positive thing that the loved one has accomplished through the family throughout life.

Also, family presence participates in the perception of benefits, which reinforce support for this practice in emergency care. *Benefits for the family* are evidenced in the obtaining of bigger and faster information on the clinical picture and clinical evolution of the patient. In this way, it is possible, in addition to replicating the information for the other relatives, to understand the case severity and, therefore, to be better prepared to experience possible outcomes. *Benefits for the patient* come from the caring, comfort, safety and emotional support provided by the family members. Thus, professionals would care for the technical care and for the relatives the emotional care of support. *Benefits for the health care team* include receiving information about the patient's experiences with previous illnesses and treatments; assistance in less complex care; and even defended by unfounded accusations.

DISCUSSION

Results of this study allowed us to identify which relatives and patients, in a convergent way, support the family being allowed to follow the emergency care of the adult patient. The driver of the process leading to support is primarily the existence of a strong and affectionate relationship among family members and the desire to maintain it, even when experiencing acute and severe illness in one of its members.

The family's main characteristic is the ability to express affection through verbal and non-verbal communication, which promotes, through mutual coexistence and social interaction, the building of affectionate bonds among its members. The construction of relationships is never given. It starts from the first family interactions and needs to be sought and maintained in the family life. In addition, other aspects need to be present in family life in order to contribute positively to the relationship, such as mutual respect, dialogue, fellowship, ability to balance

differences and resolve conflicts[16]. In this way, when interacting socially, the family constructs realities, forms and ways of organizing and putting oneself in the world that allow the emergence of desires, beliefs and rites[17].

There is no doubt that the family relationship, derived from the group interaction pattern with the social environment and influenced by the setting in which they are inserted, should constitute a working tool in the clinical practice of health professionals in a wide variety of care contexts[18], including in emergency situations[19-20]. Adversities are known to interfere with the family balance, affecting the dynamics of all its members[18]. Emergency care is therefore a great challenge and a significant experience for the family, since the psycho-socio-emotional problems occasioned have repercussions and impact on the whole family system[19].

Experiencing acute and severe illness of an entity causes family disruption and changes its dynamics, causing it to reorganize itself to maintain balance. This reorganization is almost always accompanied by suffering and conflict, and tends to remain in the family for a long time[21]. In order to strengthen affectionate bonds, even during emergency care, an interactional and family-centered approach that can identify their desires and needs is indispensable in clinical practice. Thus, professionals can help the family reflect on their relationships, find alternative ways to understand the disease and accept the outcomes of the situation, which includes death. Evidently, this theoretical body emphasizes the relationship between professional and family, grounding their practice in an interactional territory.

It is also emphasized that the interaction among family members, which triggers and sustains the feeling of belonging and the strong affectionate relationship, may be responsible for evoking in the family members the feeling of "obligatory care". However, it is necessary to understand that the duty to care is not only expressed as an obligation, but also as a form of thanks and retribution. This possibly provides for the strengthening of affectionate bonds, ensuring and maintaining positive feelings within the family[16].

In addition to the affectionate relationship among family members, it was identified that the triggering of benefits for family members, patients and professionals from family presence in emergency care, acts as a propellant to support this practice. Specifically, benefits identified for relatives are related to the acquisition of greater information about patients and, therefore, a better understanding of the care and relief of suffering among relatives.

A study conducted in Australia with health professionals, family members and patients showed that for relatives the lack of professional support and information about the patient triggered fear and confusion[10]. On the other hand, studies with family members in France[9] and in the United States[22] found that allowing relatives to follow emergency care, including resuscitation maneuvers, made them aware of and value information received from professionals[21], triggering greater satisfaction with the assistance[9].

In addition, scientific evidence suggests that when family members are present during emergency care, they feel calmer and safer[2,9,22]. This is because they verify the high number of professionals who assist the patient[2]; the rapid intervention and cohesion that the team presents[22]; and the professionalism and psychomotor skills demonstrated by professionals[9,22].

In addition to acquiring better and earlier information through assistance, it was identified that in obtaining such information, family members consider it necessary to pass it on to other family members, who are also concerned about the ill loved one. Likewise, a study in five Australian critical care units revealed that, when the conditions of the adult patient worsened, the relatives, when present, accompanied care and, as soon as possible, distributed information about the patient's clinical picture and progression to other relatives, in particular with the aim of reassuring them[23].

Regarding benefits for patients, results of this study indicate that family presence functions as an important strategy for support. The understanding that family presence supports the patient by promoting maintenance of physical and emotional contact among the family-patient binomial has also been reported in other studies with family members[9,11,24] and patients[8,13]. Therefore, allowing family members to accompany them increases the chance of them supporting their loved ones, giving them security, comfort and calmness, reducing, consequently, fears, anguish and anxiety[8-9,11,13,24], common feelings in patients admitted to emergency units.

Finally, it was identified that family presence support is a reflection of the perception of benefits also for health professionals. Studies with family members demonstrated that they would like to feel involved in the patient care process because they understood that the provision of information on the initial clinical picture and the underlying diseases of the patient to health professionals was a necessary form of participation and that could assist them in their conduct[9,11]. Research carried out with professionals also pointed out that family members, when present during emergency care, function as team members and as "key informants"[25], being necessary to "provide useful information"[2]. Thus, potential benefits for the health team are perceived by all those involved in the process of emergency care.

Study limitations

This study has some limitations. One of them is related to the fact that the sample of relatives was constituted by women, in the majority, although it has been tried to insert more relatives of the masculine sort. Thus, results may reflect more the perception of female relatives. Another limitation is the fact that the participants were interviewed in health units themselves during the immediate experience of the emergency situation, without having time to reflect on the experience. In addition, because the recruitment of participants has been limited to two public services in the southern region of Brazil, results may not be generalizable to other geographic contexts or health services. Therefore, new studies are needed with broader sampling and in different care settings in the country, including services that present inclusive practices of family presence in emergency services.

Contributions to the field of Nursing

Findings are useful to awaken the attention of professionals working in emergency units, which has the potential to impact directly on care practice. By promoting awareness among those who, as a rule, have the power to decide whether or not relatives

can attend emergency care, one can stimulate the realization of this practice of care so that it becomes focused on the desires and needs of relatives and patients.

CONCLUSION

Results allowed identifying that family and patients define, symbolically, in a convergent way, the process of supporting family presence in emergency care. Support is motivated and sustained mainly by the affectionate relationship among family members, which is built along the coexistence and family life. Specifically for family members, support is also driven by the sense of obligation to care for the seriously ill entity. Secondarily, beneficial consequences for health staff, family members and patients direct support.

More studies on this topic are needed to solidify the knowledge produced and to reduce controversy between research and practice. Future studies should have an intervention design, in which the family members are inserted and followed up during emergency care of an entity. In this way, the need, adequacy and adaptability of the practice can be evaluated, as well as the impact on the team, patient and relatives.

ACKNOWLEDGMENT

A special thanks to the Coordination for Improvement of Higher Education Personnel (CAPES - *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior)* for granting the *Sanduíche* Doctorate scholarship to the main author of this study. Process number: 99999.n003873/2015-03.

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