Sales, Catarina Aparecida; Araujo da Silva, Vladimir; Pilger, Calíope; Silva Marcon, Sonia
A música na terminalidade humana: concepções dos familiares
Universidade de São Paulo
São Paulo, Brasil

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Music in human terminality: the family members' conceptions

Catarina Aparecida Sales1, Vladimir Araujo da Silva2, Caliope Pilger3, Sonia Silva Marcon4

ABSTRACT
This qualitative study was performed using the multiple case study method and Heidegger’s existential phenomenology for data analysis. The objective was to understand how family members perceive the influence of musical experiences on the physical and mental health of a relative living with a terminal illness. Participants were seven individuals belonging to two families. Data collection was performed through interviews and observation from May to June 2009. Results showed that using music while providing care to beings living with cancer can provide well-being to patients as well as their caregivers. Considering the deficit of leisure and the monotony of the home environment, using music complements the philosophical and humanitarian precepts of palliative care, thus being characterized as a complementary resource to nursing care, as besides being a communication resource, it improves the interpersonal relationship between patients and their families.

KEY WORDS

RESUMO
Estudo qualitativo que utilizou a estratégia metodológica do estudo de casos múltiplos e a fenomenologia existencial heideggeriana para analisar os dados. O objetivo foi compreender como os familiares percebem a influência das vivências musicais na saúde física e mental de um familiar que experimenta a terminalidade. Os dados foram coletados junto a sete indivíduos pertencentes a duas famílias por meio de entrevista e observação em maio e junho de 2009. Os resultados mostraram que a utilização da música no cuidado dos seres que vivenciam o câncer pode proporcionar bem-estar aos pacientes e cuidadores. Considerando-se o déficit de lazer e a monotonia do ambiente domiciliar, a utilização da música contempla os preceitos filosóficos e humanitários dos cuidados paliativos, caracterizando-se como um recurso complementar no cuidado de enfermagem, pois além de constituir um recurso de comunicação, promove melhor relacionamento interpessoal entre o doente e sua família.

DESCRITORES

RESUMEN
Estudio cualitativo que utilizó la estrategia metodológica del estudio de casos múltiple y la fenomenología existencial heideggeriana para analizar los datos. El objetivo fue comprender el modo en que los familiares perciben la influencia de las experiencias musicales en la salud física y mental de un familiar en estado terminal. Los datos fueron recolectados en mayo y junio de 2009, junto a siete individuos pertenecientes a dos familias, a través de entrevistas y observación. Los resultados mostraron que la utilización de música en el cuidado de los pacientes de cáncer puede proporcionarles bienestar, tanto a los pacientes como a sus cuidadores. Considerándose el déficit de placer y la monotonia del ámbito domiciliario, la utilización de la música contempla los preceptos filosóficos y humanitarios de los cuidados paliativos, caracterizándose como un recurso complementario en el cuidado de enfermería, pues más allá de constituir un recurso de comunicación, promueve una mejor relación interpersonal entre el enfermo y su familia.

DESCRIPTORES

1 Nurse. PhD. in Nursing. Professor of the Master in Nursing Program at Maringá State University. Member of Núcleo de Estudos, Pesquisa, Assistência, Apoio à Família (Center for Family Studies, Research, Carre and Support). Maringá, Paraná, Brazil. casales@uem.br 2 Nurse. Student of the Master in Nursing Program at Maringá State University. Maringá, Paraná, Brazil. vladimir_araujo_silva@hotmail.com 3 Nurse. Student of the Master in Nursing Program at Maringá State University. Maringá, Paraná, Brazil. caliopepilger@hotmail.com 4 Nurse. PhD. in Nursing Philosophy. Professor of the Nursing Undergraduate and Graduate Program at Maringá State University. Member of Núcleo de Estudos, Pesquisa, Assistência, Apoio à Família. Maringá, Paraná, Brazil. ssmarcon@uem.br
INTRODUCTION

The transformations that occur in the economy, politics, and culture of societies over time change the way individuals and groups organize their lives, thus establishing different lifestyles. These changes affect or impose difficulties in the accessibilities to health-favoring life conditions, and, therefore, change the patterns of how individuals fall ill. Among the illnesses currently referred to as epidemics, non-transmissible chronic diseases (NTCD) are a serious health problem in every country, regardless of their economic situation. Nevertheless, it is clear that poorer countries suffer more, as their chances of having public policies that could improve the social determiners of health are smaller.

According to the World Health Organization (WHO), chronic diseases include cerebrovascular, cardiovascular, and renovascular disorders, neoplasms, respiratory diseases and diabetes mellitus, because these diseases require continuous care and efforts from a set of equipment, public policies and people in general. The WHO also states that these diseases have a common risk factor, and, therefore, the same approach may be used in their prevention and care.

Regarding malignant neoplasms, the Ministry of Health estimates that for the year 2010/2011, there will be 236,240 new cases among men, and 253,030 among women. It is estimated that nonmelanoma skin cancer will be the most common type cancer among the Brazilian population (114,000 new cases), followed by prostate tumors (52,000), female breast cancer (49,000), lung (28,000), colon (28,000), stomach (21,000) and uterine cervical neoplasms (18,000).

Though the advancements in science and technology make early diagnosis possible, and despite an adequate therapy often permits to control the evolution of the disease and its cure, neoplasms trigger organic, emotional, psychological and social changes that demand constant care and adaptations from the patient as well as their family.

Taking into consideration the progressive increase in the number of cancer cases in Brazil, taking care of a relative with a malignant neoplasm is becoming a common reality for many families. This mission requires great dedication from the caregiver, causing physical and emotional burden, because of the time invested in this care and the difficulties involved. In such situations, the family experiences vicissitudes that have a serious effect on their psychological and emotional aspects, and it is perhaps the first time they have to deal with a situation of death at home.

In cases like these in the family environment, relatives and patients experience distress, which is associated with the evolution of the disease and the coping strategies, in which the caregiver is susceptible to having a more significant experience of facticities such as depression, fear, isolation and mood changes.

Palliative care is among the forms of end-of-life care strategies used by health professionals. According to the WHO, palliative care refers to “An approach that improves the quality of life of patients and families facing problems associated with life-threatening diseases, by preventing and relieving their suffering through early detection, making a correct evaluation and treatment of pain and other physical, psychosocial and spiritual problems”.

From this perspective, palliative care is becoming a highly specialized approach to help not only cancer patients, but especially their families, to cope with their everyday life as well as possible, as today it is necessary to reflect about their conditions in order to understand and interpret their attitudes and the reality they have to face. Every day, cancer patient relatives have to deal with several distressful issues related to the fear of losing their loved one, which are often difficult to be quickly understood; hence they need some time to work out their emotions and trace new perspectives in their lives.

Nursing care in this approach should respect the singularity and complexity of each individual. Furthermore, to provide humanized and holistic care, it is necessary to use several means of communication (verbal and non-verbal) so it is possible to obtain a comprehensive perception and understanding of the individual.

Following this line of thought, in Brazil, music has been gradually used as a strategy in nursing care, and may be used as a tool to provide comfort, relieve pain, facilitate communication and the patient-professional relationship...

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The difficulties inherent to the communication process, often permeated by feelings of helplessness and frustration, are changed to feelings of happiness, affectivity and gratitude by the performing musicians, as they recognize that their meeting mediated by music promotes their personal development, adds value to their life and results in the conscious search for interpersonal relationship and their professional, social and human commitment.

Using music could strengthen the individual’s expressiveness, making communication and interpersonal relationship easier. Furthermore, because of its particularities, music is present in the different life cycles, from the conception to the end of life, and its use in nursing care, idealized by Florence Nightingale, is recommended for the humanization of the health care environment.

On the other hand, the National Policy of Integrative and Complementary Practices (Política Nacional de Práticas...
In this sense, it was identified that there is a need to associate music to nursing care, because the “musical visit” presents a cross-disciplinary view inserted in a complex conception of health and disease that comprises the interpersonal relationship, the emotional and affective expressiveness and the historical-cultural aspects of the individuals and groups\(^{11}\).

This resource welcomes and establishes bonds and relationships aimed at humanized nursing care; reduces the feeling of depersonalization; increases self-esteem and promotes comfort and well-being. It is emphasized that in this process the patients’ participation in choosing the songs, stimulates their development of autonomy\(^{12}\).

Considering the information presented and the awareness that cancer patients, because of their physical, social, and mental limitations, require differentiated care, which would promote their well-being as well as of their family caregiver, the present study used music with the purpose of humanizing the care delivered to these individuals. Therefore, the aim of the present study was to understand how family members perceive the influence of music in the physical and mental health of a relative experiencing terminality of life.

**METHOD**

The present study is associated with the research project *O cuidado humanizado a pessoa portadora de câncer e sua família* (Humanized care to individuals with cancer and their family), which was funded by Fundação Araucária. This qualitative study was performed using the multiple case study method. In this specific type of study, although the analysis units are the same (the families), it is admitted for each unit to present specific experiences that deserve a deep investigation, and the results obtained from the analysis of each family case are added to reach the understanding of the addressed phenomenon\(^{13}\).

Data analysis was performed based on Heideggerian existential phenomenology, which establishes that to understand the studied phenomenon it is necessary to submerge into the everyday life of the individual and unveil their essence through the analysis of their discourse and their experiences\(^{14}\).

Participants were seven family members of two families of patients with terminal malignant neoplasm, assisted by the extension project *Cuidados paliativos à pessoa com câncer e sua família* (Palliative care to people with cancer and their family), conducted by professors and students of the Nursing Department at Maringá State University. The purpose of this project is to promote pain relief and create a support system to help patients lead an active and creative life, thus promoting their autonomy, personal integrity and self-esteem, whenever possible. As to the families, the aim is to prepare them to face the illness in the best possible way, and to prepare them to say goodbye to their loved ones.

Both of the studied families lived in the region covered by the Mandacaru health center in Maringá (Paraná) and had received assistance from the project for approximately a year. Because of the time dealing with the disease, the family already presented some physical and emotional weariness, which affected the patient as well as their relatives. This fact is the main reason why the families were included in the present study.

The description of the language of the deponents comprised significant data for developing this study, because it represents not only the feelings that were expressed, but their way of seeing, thinking, and feeling the events in their worldliness of the world. Therefore, the region being investigated, or the ontological region, was the situation in which the phenomenon to be unveiled occurred, i.e., the perception that each family member had about using music as a therapeutic resource at home.

After receiving permission from the caregivers, the visits were initiated, which were filled with music and care and took place on a weekly basis in May and June 2009. A total of eight visits were made to each family, which were followed by the patient and any relatives who were present. During the visits, voices and guitars interpreted classic of Brazilian country and folk music, as well as some gospel music.

Two techniques were used for data collection: recorded interviews using one open question and observation. The subjective data were collected informally during the visits through non systematic observation of the individuals in their worldliness of the world, i.e., in their home environment. These observations were registered on a field journal shortly after completing the musical visits. The open interview, on the other hand, took place at the same place of the meetings after the study had been completed. Subjects were interviewed one by one and the interview was based on the following guiding question: *Tell us what these musical meetings represented in your family environment*. These interviews were transcribed in full by the authors soon after their completion.

To capture the completeness of what was expressed by the subjects through their languages, we chose to perform an individual analysis of each discourse. Hence, *a priori*, we performed careful readings of each statement, extracting the excerpts or meaning units (mu) which appeared to us as fundamental structures of existence. *A posteriori*, we analyzed the meaning units of each statement, making a phenomenological selection of each subject’s language.
because one meaning unit, in general, consists of the feelings revealed by the deponents which contemplate the ontological question(15). The discourses that emerged in the interviews were transcribed by the researchers and interpreted under the light of some Heideggerian ideas, of authors who research this theme, also articulated with the subjectivity expressed by the patients during our visits.

The present study involved human beings and was thus performed in accordance with all the ethical aspects determined by Resolution 196/96 of the National Health Council – Ministry of Health. The study proposal was reviewed and approved by the Permanent Committee for Ethics in Research Involving Human Beings at Maringá State University (Document number 333/2008). The invitations to participate in the study were sent along with two copies of the Free and Informed Consent Form. The invitation informed participants about the purposes of the study, the anticipated participation time and the expected duration of the interview. Participants were assured there was no connection between the study and the service provided by the health centers and the extension project in which they already participated, as well as their free consent and the liberty to withdraw from the study at any time. We also ensured them any information they provided would remain confidential as well as their anonymity whenever any results were published. Hence, to keep the anonymity of the patients and their respective relatives, and avoiding the use of a generic form of reference, as subject 1, subject 2 … pseudonyms were used.

**RESULTS AND DISCUSSION**

**Getting to know the patients and their families**

Rose is divorced, she is 56 years old, has three daughters, who all live in Maringá; two of them actually live in the same backyard and the other lives in the same neighborhood. Though Rose lives alone in her house, she can count on the company and support from her daughters and grandchildren who live in the same backyard. She had colorectal cancer, and uses a colostomy bag. She is currently undergoing chemotherapy, and, because of the pulmonary metastasis that appeared, she is being followed by the project since 2008. Before the cancer appeared, she was very active and really enjoyed dancing, which she did every week at an association of aged individuals. The respondents from Rose’s family were her three daughters (Viola, Electric Guitar and Flute) and one granddaughter (Drums).

Camellia is a widow. She is 78 years old and has two children. They all live in the same house; her daughter is 56 years only and her son, which has special needs and is completely dependent, is 51. A brother of hers, who is 88 years old, lives close by. He lives alone, is completely lucid, hence being an important source of support for the family and is an active participant of our musical meetings. Her daughter is responsible for the care to those in the family who fall ill. Camellia has colorectal cancer and also uses a colostomy bag. She has been followed by the project since her diagnosis and surgery, which occurred in June, 2008. The respondents from Camellia’s family were one daughter (Harp), one niece (Trumpet) and one brother (Acoustic Guitar).

**Interpreting the subjects’ language**

Language is one of the forms of the being to be-in-the-world and se-him/herself absorbed by it. This way, through their words, the subjects expressed their perceptions about the music in the care they provided to their relative, which emerged from their thinking and living in the world, within a time and space in which they are included as informal caregivers.

In this sense, to listen is not only hearing, but also remain in silence, through gestures of solicitude that express acceptance and encourage others to free their feelings through non-verbal language, because being-with-the-other occurs not only in looking, but also in paying attention and identifying the different dimensions of the other, through their experiences, behaviors, emotions and spirituality(15).

Oh, I think it was really great when, really good, and the music is also great entertainment […] and my mother doesn’t stay in bed so much, she gets up, she stands here a little bit, then when you leave she runs back into bed and immediately goes to sleep. […] So she has to move around a bit. That’s why I appreciate it. Or else the person will stay in bed the whole time. That can’t happen, right? (Harp).

In the Heideggerian concept, disposition or mood is one of the three fundamental behaviors that the being-in-the-world uses to revel him or herself to the world. Through disposition, the individual opens up to him or herself and to the world, and permits other beings to come closer and meet with him or her(15). It is the condition of touching and being touched, of being able to share one’s feelings and, mostly, of experiencing manifestations of happiness or sadness.

Nevertheless, mood is not a mere psychological phenomenon that colors things and people; rather it is a constitutive determination of our being, i.e., a fundamental existence, which the Being-there uses to express him or herself to the world. Mood reveals how someone is and becomes. It is in this ‘how someone is’ that the tuning of the mood leads the being towards his/her pre(15). In mere mood, presence occurs in the most truthful way, and we thus realize in Harp’s language that music, besides awakening in her pleasant sensations, contributes with the well-being of her relative, thus assigning meaning to her days. It represents that she feels good. […] It helps her to feel more motivated, because she talks more […] I think this way we feel more relieved, because she isn’t crying all the time… She has more things to talk about. […] Things changed a lot. Because now she communicates more. There is more for her to listen to, for her to talk about. She used to be only with me… me and her, you remember. My grandmother didn’t live here, everyone would go out, it was just me and her, so we… we didn’t have anything else to talk about (Viola).
According Heideggerian analytics, transcendence is closely connected with factuality, i.e., there is no transcendence without factuality[14]. Human beings can only overcome themselves when some unplanned, unexpected event comes afore them. In this rationale, the supereminence of music, for Viola, brings about in her relative a feeling of happiness, thus making him more communicative, as if the disease had stopped in time and in the space in which they live.

To illustrate this interpretation, we refer to an episode. In our first meeting, as requested by Rose, we opened with a gospel song, The Boat (A Barca), because she is Catholic and said she enjoys this genre. We invited her to join us in the singing if she knew the words, and without hesitating she started to sing. We noticed her emotions in her eyes and during the song she kept her hand over her abdomen as if she were trying to be blessed and cured.

[...] it is very interesting, good, good for the person's health. I think it's good. [...] the person who is sick here, sometimes we don't even know if she is sick. She walks you see... yesterday she bought an electric oven, because she wants to bake bread. She wants to bake, can you figure that? [...] There are times when we know there is nothing we can do to save her. But she is living, living well and enjoying her life. (Acoustic Guitar).

Suffering does not represent a mere colloquial feeling experienced by humans in their everyday lives, as it occurs to so many others; rather, it is the only feeling that can pull humans away from their everyday life decadence, transcend their condition of being-thrown-in-the-world and assume the factuality of their existence[14]. In this line of thought, we observed in Acoustic Guitar's discourse that the musical meetings give Camellia the strength and courage she needs to transcend her own suffering of being-in-the-world with a stoma, and she even recovers her wish of baking bread for her family and herself. We reinforce that after her stoma surgery, Camellia emphasized at each meeting that she would never cook again, because what they had put on her belly made her sick, that is, the stoma.

In our first musical meeting, aiming to meet Camellia's request when she accepted the invitation to participate in the study, we took the song O Baile da Saudade (The Longing Dance) on MP3 on a cell phone. Although the quality of the song was poor, we meant to show our interest in seeing to her request. Camellia, in that meeting, took the risk of singing a few sentences and smiled. Even though she switched a few words, we considered that the fact was a positive result from our work. Each meeting we noticed she was happier and wearing a dress instead of her pajamas, as she used to in the beginning. Also, although she had reported she had some difficulty to learn things, at each new meeting she would sing the song O Baile da Saudade better that in the meeting before even though she did not have the lyrics, which shows the importance that music has in this moment of her life.

Considering this issue, we found in international literature that giving people the opportunity to choose the song for the meeting reflects that person's identity. In other words, it is a way to unveil their own meaning, the meaning of their uniqueness, and is related to the fact that music, being present in their existential temporality, creates a memory of feelings attached to important life events, thus originating a musical biography connected to each person's biography[14].

In this sense, it was very important to us to be with Camellia, because, as we presented the names of the songs and the singers, she recovered her memory and started making comments about the beauty of the songs and the lives of the singers. We cannot ignore the changes that occur in the family nucleus during our meetings, because we are convinced that nursing, considering the diversity of its actions in health promotion, has being searching for more and more ways of making care more human and alive, hence, more effective[16].

Oh! Mom gets really happy after you visit... it calms her soul, it's good! It was good for me. Because I saw mom a lot better. [...] I think it's beautiful! She feels a lot more excited. It makes her stronger. [...] Ah! I think it's really nice, it helps a lot, I think these meetings are important. Because if it helps her, it also helps us. And she doesn't cry all the time, she isn't depressed (Electric Guitar).

Understanding human existence does not happen at once, it grows with time and through the articulations of the meanings that the Being-in-the-world expresses to the world, because, while a Being-there, individuals assign meanings to things with which they related in the horizon of their existence[14].

Hence, the Being-in-the-world lives his or her everyday ontic life each moment, and in that existential experience comes across feelings of sadness and happiness, which expose them to the close ones around them through language. By analyzing Electric Guitar's discourse, we observed that she emphasizes the importance of music as the producer of strength and courage for Rose (her mother), because it transforms the crying and depression into happiness. Courage takes us away from the hesitating and empty circle of our subjectivity and casts us outside, closer to what is real[17]. Courage is not immediately present in success, in victory or in overcoming what is making us suffer! It is mainly inside ourselves as a feeling of what is possible: it opens us to the attempt, the effort and the work; it frees us to create the right way of living[17].

Understanding indicates one of the bonds between the world and the Being-in-the-world. By understanding, the Being-there discovers where he or she is with him or herself. Understanding holds the essential structure of the project; i.e., by understanding, the Being-there projects not only the world as a horizon of his or her everyday worries, but also their authentic can-be. In Drums' discourse (Rose's granddaughter), we noticed that, for her, not only did these musical meetings fill in the emptiness that Rose felt because other relatives were not there, it also brought about positive thoughts that gave life to happy memories of the strength she used to have. We emphasize that when the O Baile da Saudade (The Longing Dance) was performed, Rose had a longing look in her eyes, and she followed the beat...
by tapping her foot. She then went on to tell us about how many times she had danced to that song and won trophies in dances she participated in, which makes us believe that each person, consciously or unconsciously, brings inside their Being a personal and untransferable taste in music(18).

[...] it is cool because people come over, because she is there the whole day, alone mostly, almost no one comes here, so it’s good for her... In my opinion it cheers her up, because of the words... It gives her strength... She thinks about too many things she shouldn’t think about... Then the lyrics change her thoughts completely... Then people arrive, she starts talking about what it was like... and starts singing (Drums).

Watching closely at the end of the unit, when Drums (Rose’s granddaughter) stated: ... Then people arrive, she starts talking about what it was like... and starts singing, we see in her face how important it is for her to see her grandmother happy, eager and forgetful, for a while, about her existential condition. This message also showed us that music has the power to change our spirit, hence being a therapy for physical and psychic disorders (19).

I think it is really valuable, you know? You look at her, and she’s happy, she’s excited, asking for songs from her time. I think it’s marvelous! I think it’s fundamental. What you did, it’s worth millions. I think. Really great. I think it would be, if it were my mom I’d like it. Do you understand? She spends a pleasant afternoon, and we do, too. I think it’s really nice. Of course it is positive, surely. A person can’t be isolated and just stay in silence, sitting on the couch, she needs something different. And this is really helpful for patients. I think it’s really great (Trumpet).

The discourse or language defines another feature that the being-there uses to express in the world. Te being-there is a discursive being, not only because of his or her ability to speak, but also of articulating what they understand. However, in Heideggerian meditation, language is not only an of the many existential traits, but the foremost existential aspect, in which all forms of being-in-the-world are connected; i.e., through discourse it is possible to understand the situation of humans in the world(14). In this line of thought, we observe in Trumpet’s language that music, in addition to providing healthy memories, brings moments of joy and companionship in the family context. Therefore, care in end-of-life may be under-
motes moments of happiness and emotion. In these be-
tration of the disease and the imminent end of life of the be-
ning two daughters and their children live in the same back-
yard; rather, it concerns the absence of life in her soul. In
this context, we understand that in the dimension of mate-
rial life and contemporary language the discourse repre-
sents part of what one is and does, just as it is represented by what one is and does, and its repercussion on human life and on society has different meanings(9). In addition, the subjects’ language showed that a discourse does not aim only at expressing a certain point of view of one spe-
cific subject or social group. The discourse is immersed in human life as a production of society and as an act of the language activity in the everyday life of the Being(20).

CONCLUSION

Using music when providing care to beings living with cancer can promote well-being among patients and therefore also bring comfort to their caregivers. To participate in choosing the repertoire increases their enthusiasm, as it satisfies their personal taste. In the uniqueness of their preference, gospel songs may represent psycho-spiritual sup-
port in view of their worries about what is to come. How-
ever, we emphasize that their autonomy and disposition to participate in the visits should be preserved.

For some time the suffering associated with the evolu-
tion of the disease and the imminent end of life of the be-
ing-there gives space to entertainment, in which music pro-
motes moments of happiness and emotion. In these be-
ings’ worldliness of the world, in which social isolation per-
meates their existence, music, as a communication re-
source, may promote an interpersonal relationship and opening of the being-there to the discourse, making it pos-
sible to meet his or her emergent needs.
In view of the significant experience, we reiterate the importance of music in providing care to end-of-life situations, as we believe that through music it is possible to humanize care, as it contemplates the philosophical and humanistic precepts of palliative care. Therefore, music is characterized as a valuable resource in nursing care, considering the leisure deficit and the monotony of the home environment.

By using its affective tone, nursing provides psycho-emotional support in the transcendence of these beings, sharing their suffering and helping them with coping strategies. Furthermore, the reflexive action of music permits the beings to change spaces and relive forgotten emotions and unveils the idiosyncratic essence and the subjectivity of their experiences and their existence in the world.

We also emphasize that besides the feelings expressed by the caregivers, what caught our attention the most were their patients’ manifestations of well-being. Hence, in view of their experiences we believe regarding care in end-of-life situations, music can represent psycho-emotional and spiritual support, thus helping to face the disease.

Finally, some study limitations should be considered, as this is a qualitative study contextualized in the time and space of the subjects’ experiences. The results do not permit generalizations, but we believe, however, that they may be used in similar situations, thus contributing to improve the knowledge and reflections on the theme. In this sense, although the results are of great relevance for nursing, we emphasize the need for further studies in this same line, involving more families, as well as the conceptions of patients themselves, as the present study focused exclusively on the feelings of the relatives.

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