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O olhar da enfermagem sobre as práticas de cuidado de famílias rurais à pessoa com câncer
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Nursing’s view of the care practices of rural families and the person with cancer*

O OLHAR DA ENFERMAGEM SOBRE AS PRÁTICAS DE CUIDADO DE FAMÍLIAS RURAIS À PESSOA COM CÂNCER

VISIÓN DE LA ENFERMERÍA SOBRE LAS PRÁCTICAS DE CUIDADO DE FAMILIAS RURALES A LA PERSONA CON CÁNCER

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ABSTRACT
The objective of this study is to identify the care practices of rural families who care for a person with cancer. This qualitative study used the Urie Bronfenbrenner’s Ecological Systems Theory as the theoretical and methodological framework. The participants were three families from a rural area who had a relative undergoing chemotherapy at an oncology service of a teaching hospital in southern Brazil. Data collection was performed between February and July of 2009. It was found that the care provided by the rural families is developed based on the family interactions across generations, and also on other community practices. The affection, love, protection, family unity, faith, togetherness and diet concerns describe the care and comprise the care practices of rural families who provide care to the person with cancer.

RESUMEN
Identificar las prácticas de cuidado de familias rurales que experimentan la necesidad de cuidar de un miembro con cáncer. Estudio cualitativo, utilizando como referencial teórico-metodológico el Modelo Bioecológico de Urie Bronfenbrenner y el método de inserción ecológica. Participaron tres familias de área rural, con un miembro en tratamiento quimioterápico en Servicio de Oncología de un Hospital Escuela de la Región Sur de Brasil. Datos recolectados de febrero a julio de 2009. Se constató que la familia rural cuida a partir de las prácticas construidas con base en las interacciones entre los familiares a lo largo de generaciones y en otras prácticas de la comunidad. El cariño, el amor, la protección, la unidad familiar, la fe, el estar junto, la preocupación por la alimentación, describen el cuidado y se constituyen como prácticas de cuidado familiares en las familias rurales con un integrante afectado por cáncer.

DESCRIPTORS
Family
Rural population
Neoplasms
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DESCRITORES
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INTRODUCTION

Every family has its shared stories. Narratives are impregnated with values, beliefs and traditions that are passed down from generation to generation, providing them with their own identity. These are stories of love, unity, respect, resilience, and care for one another, as well as the struggles they have overcome in search of a better quality of life. Each family, at some point in their history, experiences a crisis such as a serious disease affecting a family member, which results in the necessity of learning different and new care practices. This has been one of the major approaches in contemporary nursing(8).

As a chronic disease, cancer is one of the most feared diseases. It is much more than a biological disorder; it evokes a number of ambivalent feelings laden with meanings. In this regard, it is considered to be a symbolic disease in that it has different meaning for different individuals. Some may view it as a catastrophe, while others may view it as a punishment(2-3). Experiencing cancer continues to be a significant social event that triggers changes in the person’s social relationships and in family dynamics(4-5). Although there are similarities in living with cancer, each person has his/her own strategies for coping with the disease that are based on his/her values, beliefs, and way of viewing the world(4-5).

We address the family as a system of health maintenance for its members, which includes a set of values, beliefs, knowledge and practices that guide their actions; within this process lies their own caring process. The family becomes responsible for overseeing the health of its members, making decisions about the paths that must be followed when complaints or signs of malaise arise, in addition to constantly monitoring and evaluating the health and illness status of family members(6).

In describing the family throughout history, we see that it occupies different spaces and functions. Since ancient times, the family has represented a welcoming, sheltering place among people, who maintain bonds of affinity, love and respect. It is within the family context that we build our identity, consolidate our values and principles, and share our first emotions(7). It is in the family that we learn about social roles, and it is from the family that, guided by the social culture, we join other groups that begin to integrate our life(8).

From the previous, one can see that it is important to know the reality of the life situation of the person with cancer and his/her family, as well as the context, the dynamics, the organization of care, the interactions, the social role of the person in the family and in the community, and the potential and the limits of those who are involved in the care. Moreover, looking at the social aspects, such as housing conditions, family income, work activities, and values, beliefs and habits of the family is also a factor that health professionals might consider when caring for families facing a crisis of illness, in order to meet the demands that illness generates.

By directing the focus onto the context of the families experiencing cancer, you realize that they inhabit different locales, one of which is the rural setting.

The way in which we conceptualize health, associated with the reality of this environment, has a significant effect on people’s behavior in seeking health services and accepting assistance in caring for the person and the family(9). Thus, it is indispensable to understand the family’s care practices because they differ from group to group, related to the history of each individual family and influencing how care is provided(7). Development of care practices requires an active participation in interacting with others, with objects and with symbols in their context, over the course of time(10).

There is lack of research in nursing that focus on rural families, which proves the need to expand the knowledge regarding lifestyle, illness and care processes of this population(9). The nurse, upon understanding how the family is organized and how they care for a relative with cancer, may develop a care plan in accordance with the context of each family. Thus, this study aims at describing the practices of care adopted by rural families in caring for individuals with cancer.

METHOD

This is an excerpt from a qualitative study, which used the Bioecological Model of Urie Bronfenbrenner as a theoretical reference methodology. Bronfenbrenner holds as the essential core the process, the person, the context and time, also known as the PPCT model. This model enables the investigation and analysis of the phenomenon in question through the identification of four interrelated cores. It promotes knowledge of how individuals or family groups experience a particular care practice (process), in terms of the different environments or contexts within which they are inserted. These physical, social or value contexts characterize and exert influence over the person and family through continuity and stability of the interaction system, the construction of its routines, its biography and the social history(10).

In the search for methodological tools to approach the people in the study, the method chosen was that of ecological inclusion, which aims at understanding the processes of interactions of individuals within the context in which they are living(11). Therefore, the environment...
in this type of investigation plays a key role, since it is in this environment that interactions and proximal processes occur, such as the emergence of supportive bonds\textsuperscript{(11)}. Proximal process occurs through the mutual and complex interaction of investigators, family members, the multidisciplinary team, the community and objects and symbols present in the immediate context, which make up the basis for all investigation that adopt the method of Ecological Inclusion\textsuperscript{(13)}.

Ecological Inclusion relies on five essential steps for the establishment of proximal processes: (a) researchers and participants interact and engage in a common task; (b) there is a need for many meetings over a considerable period of time; (c) informal conversations must evolve to address increasingly complex issues and shall last as long as or more than one hour; (d) proximal processes established during these meetings serve as a basis for the entire research process, and they are of utmost importance in shaping the informal posture and conversations with the subjects, enabling dialogue on issues not directly related to the study objective; and (e) themes included in the interviews are interesting and encouraging for researchers and participants as they tap into life stories and the way the development of the person involved in the study takes place \textsuperscript{(11)}.

For the performance of the study, we considered the following criteria for inclusion of families: dwell in a rural area, and have a family member with cancer aware of his/her diagnosis and treatment who is able to participate in the study (conscious and presenting no communication difficulties). We used simple observation\textsuperscript{(12)}, data collection techniques and in-depth interviews \textsuperscript{(13)}, as well as the development of genograms and eco-maps\textsuperscript{(14)}. With the participants’ consent, interviews were recorded and were subsequently transcribed in full and enriched with notes from the field journal, derived from observations and impressions from the investigators regarding the family’s behavior during the interview. We conducted five interviews with each of the families in their homes, with an average duration of 60 minutes, accounting for about 15 hours each; in total, there were 100 hours of observation, with 20 hours in the Oncology Service and 80 hours in the home context.

The study was conducted with three families in the rural area of the southern state of Rio Grande do Sul. The study took place during harvest time while one of their members was undergoing chemotherapy at the Department of Oncology, University Hospital, Federal University of Pelotas. Data collection occurred from February to July 2009, the period during which we followed persons with cancer and their families during treatment. The first meeting with the research subjects occurred in the Oncology Service, where they were invited to participate. For the analysis of the study data, we utilized the process of thematic analysis\textsuperscript{(13)}, identifying the core meaning contained in the speeches of the participants in the observation records. This study was developed from one core theme - care practices performed in the context of rural families, in caring for family members with cancer.

The development of the study complied with all ethical research precepts involving human beings under Resolution 196/96 of the Ministry of Health. This study is a subproject of the research entitled Patients with cancer and their families and the care systems in chronic conditions, which was submitted to and approved by the Ethics Committee in Research of the Catholic University of Pelotas, under Protocol No. 2008/23. All subjects signed the Term of Consent. The families were named according to their ethnicity, and to preserve the identities of the participants the degree of kinship was defined according to the age of the family member.

**RESULTS**

We will present the three rural households in the study who were followed at the Department of Oncology and their home, as well as their practices of care towards the members with cancer, within their contexts over time.

**Pomeranian family**

The Pomeranian family was characterized as an extended family; they were farmers, (tobacco, black beans and corn) residing in a community of individuals of mainly German and Pomeranian descent. The family was comprised of the person with cancer (aged 18), her mother (aged 44), her father (aged 42), a brother (aged 16), the patient’s husband (aged 22) and a grandmother (aged 66). The person diagnosed with cancer had non-Hodgkin lymphoma, was white, of Pomeranian ethnicity, married with a 10-month-old daughter, had finished elementary school, worked as a farmer and lived with her parents, husband and grandmother. The family members were Evangelical Lutherans.

Supporting bonds were present with neighbors and people in the community. Mutual assistance with daily rural activities and life in rural communities seems to provide a supporting bond for rural families who care for a family member with cancer. This way of living can be a culturally constructed value that reflects and extends into caring for one another, with individuals meeting their needs in the contexts in which people share and exchange experiences through interactions with other people/contexts/symbols/objects over a period of time.

The daily activities were divided between the different members of the family. Their main leisure activity was to participate in parties within the church community, which happened frequently on weekends. They attended religious services in the community, as well as couples, ladies and lay groups. All family members attended at least one community group. We observed that they felt the need to share, communicate, interact and promote their faith with...
other community members, i.e., the family interacted and participated actively in the mesosystem - the community. In this family, the work ethic appeared to be a cultural value passed from generation to generation (macrotime), also being a factor that defined whether the person was healthy or ill. In their opinion:

Health is not having a disease [Person with Cancer]. Health is almost everything; if you have health, you can work; without your health you have nothing. We are born in it, it comes with the family and it is what the family teaches. You are already born in it, seeing and learning. (Father).

Work is everything; it is what we do, it is all we know how to do (Person with cancer).

Regarding eating habits, they referred to the need to consume a healthy diet and their own traditional food culture. One can perceive this from their comments:

When we have a cold, we make tea, an orange tea (...) it is the culture of the person, my mother taught me to make bread, these things were all related to food when I was young; she taught me to cook and now I cook for my family (...) (Mother)

As for family care, the woman in this study was knowledgeable regarding care. She learned life skills while living with another woman, and relayed that knowledge to other women, particularly her daughters and granddaughters. She was the locus of care, whether providing care for her family or extended social network(15). The community priest visited the family often, a relationship which became closer with the onset of illness in the family. The need to express faith and harmony was evident, as well as the concerns and the unity that were present in the everyday life of this rural family. This is evident from the reports:

A lot of prayer, we pray a lot. Faith is in first place. I have to ask, I have faith that she will get better; faith is hope. Ah, we always had faith; you have to have faith and hope to achieve your dreams (Mother).

Yes, faith helps a lot to have hope of getting better. My father always taught me and encouraged me to have faith(Person with cancer).

One can see that the care provided by the Pomernanian family was also strengthened by the social network comprised of relatives, friends and neighbors. The social network is defined as a system of sequential interactions comprised of individuals who can support the developing person, even when this person is not present. The extensive social networks and more common ones are those that exceed the environments and thus constitute elements of a meso or exosystem(16).

The process of disease causes cancer patients and their families to seek support in the community, such as formal support groups. These groups are part of the context of the community, and through the interactions between people with cancer and their families in other contexts, and with the presence of objects and symbols, care is realized. The groups play an important role in dealing with the situation of suffering established by the disease and its treatment. Participation in a support group provides people with the opportunity to share experiences, maintaining self-esteem, hoping and overcoming difficulties and trying to understand the experience of being ill in the context of socialization of information(17-18).

In this family’s home, it was shown that family interactions and values were very strong and held great importance. The values of affection, respect, protection, unity, togetherness and faith were transmitted from generation to generation (macrotime) and moved the family in its context and process of care, even before the illness was diagnosed, and continued during treatment when the family sought strategies to perform care based on their beliefs.

German family

The family of German descent had lived less than a year in their home, which was 15 km outside the nearest urban area. The family was characterized as being a nuclear Catholic family, made up of the person with cancer, who was 63 years old, his wife (59 years old), and their children (33 and 21 years old). They made the decision to move closer to the city due to illness and the necessary treatment. Previously they lived in a district of the referred municipality, approximately 100 km away, which meant that they had farther to travel to the city. This was not feasible due to transportation difficulties.

The family member with cancer was 63 years old and had a medical diagnosis of bladder cancer; there was a past history of this type of cancer in the family. The patient had undergone initial treatment with radiotherapy and, at the time of data collection, was undergoing chemotherapy. When questioned regarding their health habits, they denied smoking and drinking. The family worked in agriculture, planting potatoes, beans, corn, and other products for consumption and sale.

One aspect highlighted was the supportive bond between the members of this rural family and former neighbors and friends, which remained strong and was present in everyday life, both before and after the illness and treatment. Besides relating intensely with nature, people in rural areas have a strong relationship with their neighbors. Social relationships are more intense and have an essential support background, including the exchange of favors and mutual aid. This is possible due to the nature of rural routines and the constant interaction among dwellers of rural areas, thus becoming an important social network. [9,10] In this network, reciprocity and interactions of the person within the context are crucial so that the person becomes strong and is present in the day to day life.
In the period when he became aware that he was ill, the person with cancer began to utilize alternative therapies, such as: the preparation of aloe, or Aveloz (Euphorbia tirucalli L.), tea from the bark of a tree (he did not know the name), and spiritual surgery. The family used to use various teas such as common plantain (Plantago major L.), not only when the person with cancer became sick, but also prior to the illness to maintain their health. We observed this tradition in the following reports from the person with cancer:

The Aveloz was recommended to me by a neighbor. I took it for over 14 days; in the first week I took one drop a day with half a cup of water, and every day I would add one more drop; so on the seventh day, I added seven drops. Then, you start over again, only in reverse. Afterwards, I started taking aloe; one meter of aloe with honey. The person who recommended it to me and stated that it was good was a person in the community who works with this. Regarding the use of bark tea, the person who recommended it was an agronomist. His family lives there [Amazon] and he said it was very good, a lot of people were taking it for cancer.

It was evident in the German family that the use of these therapies was combined with chemotherapy, and these alternative therapies represented an important factor in maintaining and restoring health. It is important that nurses, as health professionals, take ownership of these practices concerning local knowledge and broaden their knowledge to assist people with cancer and their families by providing appropriate guidance for their use.

Spanish family

This family had lived in a rural area for 30 years, 20 km away from the city of Pelotas. The person with cancer was a 66 year-old gentleman of Spanish ethnicity. He was white, Catholic, retired, and was born in the city of Pelotas. He was talkative, smiling, and active in the performance of his daily activities. The patient seemed to have lost a lot of weight due to the illness and its treatment. When he was asked about his health habits, he reported being a smoker for more than 45 years. He consumed alcohol on a daily basis and had a history of cancer in his family. He had received a medical diagnosis of lung cancer and was being treated with chemotherapy. The Spanish family was characterized as being a blended family, comprised by: the person with cancer (66 years old), his wife (72 years old), a stepdaughter (28 years old), a granddaughter (11 years old), another granddaughter (10 years old) and a grandson (7 years old). They lived on a property containing ten hectares of land, and lived economically from selling firewood and the retirement pensions of the person with cancer and his wife.

The work, from animal care to hauling and cutting the wood, was performed by the person with cancer, as well as the stepdaughter and grandchildren, with his wife being responsible for the housework. They depended on the assistance of friends to haul the wood, and in return they helped their friends as needed. In one of the meetings in the home, it was observed that the person with cancer was cutting firewood near the residence, and his granddaughter (10 years old) was with him. When asked what he was doing, he replied: I must work; I have to work (...). This was a remarkable feat as he had received chemotherapy the day before. For the person with cancer in this rural family, work was seen as a priority, with health needs receding into the background.

The family relaxed by participating in parties and lunches with family members, friends and neighbors. They also enjoyed going to town. At the first visit we made to the home, we observed that in the corners of the kitchen there were glasses of water which held a green branch. Asked about their meaning, they explained: It is to purify the environment (Wife).

Regarding the physical and emotional structure of the family, the family members interacted with other people, objects and symbols. Despite the poor conditions found in the home, we found that they used their home as a site of interaction, a source of income, for food preparation, for realization of care and also as a manifestation of spirituality. The person with cancer was experiencing a chronic illness and chemotherapy. It was observed that affection and love were present in everyday life, as both were witnessed at times among the people of this family. This was also confirmed from the reports:

We have great affection for him, and consideration because he stayed with us and helped me raise my family (...) it is only proper, he is our family. It is our heart that sends that affection; it is not taught by anyone, we are very attached to people. I am around him, I see what he wants to eat, prepare him what he wants, his soup. (...) which I also prepare for the kids, they like it (Wife).

All family members performed care for the person with cancer, each with his own activity but always together, as described in the report:

She [granddaughter, 11 years] gives the medication to him; she can read, knows the medications. He [grandson 7 years] is a good friend of his, he goes places with him. He hangs out with him, he jumps in the car and he is already inside. He says: You cannot go alone Grandpa, I’ll go with you to take care of you. She is the cook [granddaughter, 10 years], she likes to feed him. She makes the delicacies and takes them to him, bread with sauce; she takes it to him: Look, Grandpa, what I made for us to have with our coffee. Then she takes it to him, he gets mad and eats, he eats out of schedule. The [stepdaughter], when I cannot go, I ask her to go. She accompanies him to the hospital and when he works. Everyone cares for him in their own way (Wife).

Members of the Spanish family made use of alternative healing methods such as prayer and going to church in order to seek strength that would assist them in the care-
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ing process. The person with cancer and his wife claimed to be Catholic, but attended a Pentecostal church. In addition, the person with cancer said that before he became ill they did not attend church, and only returned to church after he fell ill and was persuaded to go by a friend. However, the wife reported:

We have great faith that he [person with cancer] will heal, he is already improving, is healing. We go to church, and we have seen many people healed. The children go [grandchildren] all around him, praying (Wife).

It is noted that faith seems to be one of the contributing factors to enhance the provided care, helping families to overcome problems and promote strength of the family. It is in the process of care that people seek support in faith, seeking strength to cope with the adversities imposed by the disease and its treatment.

DISCUSSION

Rural households in the study held values, beliefs and habits, which were constructed based on interactions between its members, friends, neighbors and others in the rural community. These values are shared between individuals depending on the context of each one and by which method they are shared. Care, love, protection, unity, faith, and togetherness describe care and are constituted as care practices provided by rural families to the person living with cancer. Being together in the realization of care, characterized in this study as a proximal process, is critical to mobilize people in the family to care for the person with cancer.

Food has established itself as an important cultural value and tradition in care practices. Rural families showed concern not only through nutritional care of the person with cancer, but also by sharing with others who belonged to the family system. Thus, food was part of the care plan for the person with cancer undergoing chemotherapy, and the family was included in this plan.

Food is not only a source of nutrition. In many societies, food is also considered to be a remedy with a full range of symbolic meanings. It must be added that, in addition having a symbolic meaning, food assumes a scientific character, which classifies foods as potential health risks in addition to natural remedies(20). Providing care with food to keep the body in balance while receiving chemotherapy is what has been described by the families as a demonstration of concern of the other participants toward the person with cancer. Therefore, we must investigate and understand the reality of families concerning their eating habits, valuing the symbolic dimension that they acquire in their life(21).

Medicinal plants continue to occupy a prominent place in the therapeutic arsenal of many communities and ethnic groups, and the family is the main source of supply and means of use. The adoption of alternative healthcare practices can facilitate the achievement of better results in terms of the medical treatment. This is justified by the belief in the therapeutic action because they avoid the adverse side effects of the medical treatment, instead seeking a treatment that maintains the integrity of the human body(21). Families have combined chemotherapy with popular alternative health practices. The scientific intervention - chemotherapy - accompanied by care practices guided by values, beliefs and traditions stems from the interactions - proximal processes - between people and various contexts, with their related objects and symbols. Thus, when dealing with experiences of health/illness, dispossessing people of concepts and beliefs rooted in cultural knowledge - individual and collective - is a process that can take a long time to change.

When cancer was diagnosed, the rural families in the study were faced with situations of suffering, experiencing a process of liminality. They sought to hold themselves to their values, beliefs and traditions in caring for the sick person, dealing with the disease and side effects of the treatment. Families influenced and were influenced by the people who comprised their social network. This has enhanced the care of people with cancer, at the time when it was performed, i.e., they had the necessary skills to deal with situations related to health and disease.

It was found that the performance of care practices was closely connected with the adverse effects of chemotherapy, varying from person to person irrespective of context, in accordance with the chemotherapeutic agents used for treatment. This was evidenced strongly in the Pomeranian family, which developed a ritual to care for its family member. During the three days that the person with cancer was suffering from the adverse effects of chemotherapy, the family ceased performing all of their routine activities, such as working in the fields and going out into the community, in order to care exclusively for the person. Each family member played a role, but all stood together beside the person.

Thus, in the rural households in the study, there were times when certain care practices were intensified and times when they were diminished. This was done according to the symptoms that the person with cancer was experiencing. The care practice performance was classified as follows: before each chemotherapy session, care practices focused on the microsystem and mesosystem; at the time the person with cancer was receiving chemotherapy at the Oncology Service, they were concentrated on the microsystem, and throughout the following three days after chemotherapy (defined by the family as a period of crisis), care practices were focused in the microsystem and mesosystem (interactions of other community people) and in the macrosystem, because they make use of support from non-governmental organizations and psychological assistance from the Oncology Service.
The moments of realization of care practices were associated with the adverse effects of treatment, which were aggressive and impacted everyone involved in the situation. Accordingly, in times of acute distress - “period of crisis” - the family was mobilized to perform care practices and meet the needs of its ill member. Caring existed and was characterized as bioecological care, because it made use of the social network, expanding the occurrence of interactions, improving bonds, and thus enhancing the process of caring for the person with cancer at that time. Moreover, in a situation of illness, both the person with cancer and the family members held on to their values, beliefs and traditions in order to move forward with life and overcome the difficulties imposed by the disease and treatment effects.

The rural family, as part of a larger system, provided care to individual members with cancer in the form of healthy relationships, forming important bonds of support. Thus, rural families take for granted that which occurs in the immediate family (microsystem), as opposed to the mesosystem, the exosystem and the macrosystem, and vice versa, maintaining reciprocity in the process of conducting care practices during the entire treatment period. Thus, care practices based on the experiences of family members throughout life are linked to the customs, values, and traditions of the family, influencing and being influenced from the sociocultural context of building a social network.

CONCLUSION

In presenting the families of this study, the intention of the researcher was: to demonstrate the characteristics of each of the rural families, according to their ethnicity, their context and their ways of performing care for family members with cancer; to understand the dynamics of healthcare practices during a period of intense suffering, which was represented by having a family member with cancer and experiencing the adverse events of chemotherapetry; and to confirm the need for follow-up and guidance by the nursing professional in the course of the therapy process.

It was found that rural families are strengthened by their experiences with cancer, showing much more potential for strength than weaknesses in providing care to loved ones. Although they were experiencing a situation of suffering, from diagnosis to treatment the families mobilized themselves to support the person, and they also reorganized and distributed functions so that they could perform care practices and their daily activities.

The beliefs and traditions embedded in the care practices of rural families who experienced cancer corresponded to a life involving all family members in caring for the person with cancer, regardless of their role in the family. Thus, by interacting and enhancing care in times of crisis, the family sought to preserve, adapt, take responsibility, maintain a healthy diet using herbs and maintain their faith, as means of providing practical care to the ill person. The family turned inward to meet the individual needs of its members and to strengthen itself as a system. At the same time, members felt the need to establish interactions with other people and institutions in the community to care for their family, as well as the person with cancer.

Therefore, it is relevant to consider the context of nursing care practices when performing care, keeping in mind the cultural ties and interactions that people establish over time within their environments. Thus, beliefs, traditions and values are transmitted in the family unit between the different generations, involving not only the transmission of knowledge but also social characteristics of rural context. This knowledge is part of everyday life for the rural families studied, who have a desire to preserve the interactions with people, objects, symbols, and context, and to care for their members and neighbors. It is noteworthy that these factors should be considered important by health professionals when they assess, prescribe and perform care practices.

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