SOCIAL SUPPORT FOR THE FAMILIES OF PATIENTS WITH CANCER LIVING IN POVERTY[1]

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ABSTRACT: This study aimed to understand the meaning that the family in social vulnerability attributes to the social support and social network, in their experience with cancer. This is a qualitative study guided by the Symbolic Interactionism as a theoretical framework and the Grounded Theory as a methodological reference. Data was collected, between 2008 and 2009, through interviews with six families that had one member diagnosed with cancer, and referred by a Family Health Care Unit in a country town, in São Paulo. Results from data continuous comparative analysis showed two dynamically interreled phenomena: Realizing they were vulnerable and Supporting each other for care. The meaning of social network and support, for these people, has been constructed during care, in a context of poverty, suffering from vulnerability and social exclusion. This study highlights the need for nursing interventions appropriate to the real necessities of families with cancer patients, in a situation of social vulnerability.

DESCRIPTORS: Neoplasm. Family. Social support. Social vulnerability. Family nursing.

O APOIO SOCIAL PARA A FAMÍLIA DO DOENTE COM CÂNCER EM SITUAÇÃO DE POBREZA

RESUMO: Este estudo objetivou compreender o significado que a família em situação de vulnerabilidade social atribui ao apoio social e à rede social em sua vivência com o câncer. Trata-se de um estudo qualitativo, orientado pelo Interacionismo Simbólico, como referencial teórico, e a Teoria Fundamentada nos Dados, como referencial metodológico. Os dados foram coletados de 2008 a 2009, mediante entrevistas com seis famílias que possuíam um de seus membros com diagnóstico de câncer, referenciados por uma Unidade de Saúde da Família, em uma cidade do interior paulista. Os resultados da análise comparativa constante dos dados apontaram dois fenômenos dinamicamente interligados: Percebendo-se vulnerável e Apoiando-se para cuidar. O significado de rede e apoio social, para estas pessoas, vem sendo construído durante o cuidado, em um contexto de pobreza, sofrimento, vulnerabilidade e exclusão social. O estudo evidencia a necessidade de intervenções de enfermagem adequadas a real necessidade das famílias de doentes com câncer em situação de vulnerabilidade social.

DESCRITORES: Neoplasias. Família. Apoio social. Vulnerabilidade social. Enfermagem familiar.

EL APOYO SOCIAL PARA LA FAMILIA DEL ENFERMO CON CÁNCER EN SITUACIÓN DE POBREZA

RESUMÉN: Este estudio objetivó comprender el significado que la familia en situación de vulnerabilidad social atribuye al apoyo social y a la red social en su vivencia con el cáncer. Se trata de un estudio cualitativo, orientado por el Interaccionismo Simbólico, como referencial teórico y la Teoría Fundamentada en los Datos, como referencial metodológico. Los datos fueron recolectados entre 2008 y 2009 mediante entrevistas con seis familias que poseen uno de sus miembros con diagnóstico de cáncer, indicados por una Unidad de Salud de la Familia, en una ciudad del interior del estado de São Paulo. Los resultados del análisis comparativo constante de los datos apuntaron dos fenómenos dinámicamente interrelacionados: Percibiéndose vulnerable y Apoyándose para cuidar. El significado de red y apoyo social, para estas personas, se viene construyendo durante el cuidado, en un contexto de pobreza, sufrimiento, vulnerabilidad y exclusión social. El estudio pone en evidencia la necesidad de intervenciones de enfermería adecuadas a las reales necesidades de las familias de enfermos con cáncer en situación de vulnerabilidad social.

DESCRIPTORES: Neoplasias. Familia. Apoyo social. Vulnerabilidad social. Enfermería de la familia.

INTRODUCTION

According to the World Health Organization, cancer is considered the most feared, chronic and degenerative disease and it has been contextualized as major public health problem, in developed and underdeveloped countries.[2] Long treatment, the need for external and family help lead to home care, which is a strategy for health care. In recent decades, family care has tried to meet the growing demand of patients with chronic, disabling or terminal diseases. In general, when a family member gets ill, inside the family concentrates the source of care and attention to alleviate the suffering caused by the disease.[3] The disease is characterized as a situation that leads to vulnerability[4], whose concept is related to a context that generates uncertainty and imbalance in the family's capability to function. It also generates disrupts, distance, changes and conflicts within the family.[5] To the context of greater or lesser social vulnerability, it is associated the quality and quantity of the social support needed.[6]

The concepts of social support and social network are different, but interrelated.[7] Social Network is a web of relationships that links individuals who have social ties among them, and it allows support resources to flow through these links. On the other hand, social support owns the informational dimension or resources provided by the network members generating physical effects, emotional and behavioral benefits.[8]

When analyzing the social support, it must be taken into account the population studied, and especially the factors characterizing the life of popular classes in underdeveloped countries, such as unemployed people, underemployment, family breakdown and violence. Yet, they are part of the everyday life of the impoverished social class.[9] There is knowledge gaps in relation to social support and social networks that are necessary for this population. Therefore, the present study aimed to understand the meaning that the family in a situation of social vulnerability attributes to the social support and social network on their experience with cancer.

METHODS

This study fits into the theoretical and methodological assumptions of qualitative approach, in light of Symbolic Interactionism (SI)[10-11] as theoretical reference, and the Grounded Theory (GT) as methodological reference.[12] The SI develops an analytical framework of society and human behavior, which involves basic ideas related to human groups or societies, social interaction, objects, human being as an actor, human action and interconnections of action lines.[10]

GT is a systematic technique that allows capturing subjective aspects of people´s social experiences, providing trajectories to the aspects of life that derive from the social interaction the participant establishes. When the researcher assumes the participant´s perspective, it is possible to understand the experience allowing the development of a theory.[13]

Research data were collected at the houses of patients with cancer. They were referenced by a Family Health Unit (USF) located in an area classified as having a population of social vulnerability 5, according to the Paulista Index for Social Vulnerability (PISV) of the State System Foundation for Data Analysis (SSFDA).[14] This index corresponds to a high vulnerability that includes census sectors with the worst conditions in the socioeconomic dimension (low), and standing between the two groups in which the households heads present, in average, the lowest levels of income and education. It includes older families with lower presence of small children.[14]

In this study, it was adopted the concept of family that considers two or more persons related through intimate associations, resources, values and recognized when members consider the elements that constitute it as a family.[15]

In order to collect and analyze data using the GT principles, in its initial steps, without being employed any sample groups. All of the families identified by the USF were interviewed, except for one that refused to participate. So, there were six families with six patients and eight family members.

In this work, the families are identified by numbers, and the subjects through fictitious names. Semistructured interviews were recorded with active participation of the family members in response to the guiding question: Who the family counts on that moment of disease / who helps the family? It was considered minimal family dyads as inclusion criterion, and it was not stipulated the maximum number of participants during the interviews.

It was respected every care for research involving human beings, and the project was approved by the Ethics Committee of the Federal University of São Carlos, under the number 438/2008, after approval of the Health Municipal

Secretary to the project development. Data collection was performed from the second semester 2008 to the second semester 2009.

Data analysis occurred concurrently with the interviews, which were transcribed verbatim, analyzed line by line and the conversations turned into codes. The grouping and organization of codes regarding similarities and differences provided the initial categories. The most dense and large categories allowed its processing in the so called axial codification, which links the initial categories, compares them with each other, and also group, rearranges and reduces them.[13]

This methodology allows the researcher to stop at any level of data analysis and report what he has found, because there is a constant construction.[16] Therefore, this study reached to the axial codification that allowed the identification of two representing phenomena from the significance of support and social network to the family of the patient with cancer, in a situation of high social vulnerability, without elaborating the theoretical model.

RESULTS AND DISCUSSION

From the constant and comparative data analysis emerged two phenomena dynamically interrelated: Realizing they were vulnerable, which reveals the situation of the family before the adversities imposed by the disease and Supporting each other for care, which shows the family´s movement searching for support in order to care for the family member with cancer, and trying to maintain the family balance.

Realizing they were vulnerable is a phenomenon that adds the categories dealing with the unknown; having problems beyond the disease; having difficulties with the institutions and having nobody to count on.

At the stage of diagnosis, the family with a cancer member faces the harsh reality of having to deal with the unknown. It feels frightened, anxious, afraid and with difficulty to accept the disease. Especially about cancer, people face the stigma brought by the disease and treatment difficulties that often require mobility and relocating. There are many obstacles to overcome until getting the cancer diagnosis and staging. Many referrals are made and there is long waiting time for appointments and tests. This delay forces the family to pay for expedite service and supply the lack of information.

[...] *I was the one who found the lump. Then, I went to the doctor and he performed the biopsy, those liquids that he takes away, and after, he fooled me during four years [...]. So, one day, the lump grew up [...]. Thus, I went back to see him. And he performed the biopsy again [...]. He did not let me get the biopsy, get the result there; he called me here at home. I had to go there, to get the referral to go to [...]. Then, I asked why and he said the result was bad. After four years! [...]* (Family 5 – Emilia - patient).

The obstacles mentioned by other authors[17] in relation to the clinical examination inaccuracy, delay of complementary diagnostic methods or even the bureaucracy of the Health Unique System (SUS), in the transfer of patients from one municipality to another are also experienced by the families interviewed. Even in the situation of financial shortage, these obstacles are solved with the payment of tests, in an attempt to expedite diagnosis and treatment.

This situation reveals lack of commitment, accessibility and solution proposed by the SUS. Since cancer treatment success is related, in most cases, to early diagnosis; so, the delay to get the correct diagnosis results in loss of time, advancement of the disease and family worries. The families´ stories highlight, once again, the need for better staff training, policy changes on primary care, greater speed and efficiency in the attendance.

The problems experienced by families go beyond the disease; they encompass financial, emotional and other health problems, difficulty in getting away from the job, bureaucracy of health services and even family conflicts. The Family 2 suffered modifications in its original structure, consisting of the patient, his wife and two children. After the family rejection, the patient was welcomed by his sister, and he began to consider this new constitution as his family.

[...] *she sent* [sister-in-law] *him* [sick brother] *here. She put him out to take his money [...]. Then, he came here because she sent him away from there. She used to beat him, there. Also, the way he left [...]. Because it is impossible, right? She is realizing the poor guy has got this stuff, and yet, she beats him. I had no conditions, right? She was sick to care for him [...] his insurance card, everything, she gave nothing to him, he spent two months here at home without being able to buy food for him, he could not get his money, and she refused to give it to him [...]* (Family 2 – Lea - sister).

Another problem is caused by the necessary removal of the work, causing income decrease and forcing the patient to request his return to the

job, even before being able to do that. As a result, the person is dismissed and the only way out for the families is gathering and selling recyclable material.

[...] *and during ten months my husband did not work* [...]. *He asked to return to his job and after three months the boss sent him away* [...]. *He was working because he was doing nothing* [...] *and could not survive; he had to go back to his work* [...]. *Sometimes I sell something, a little bit there* [...] *I am not ashamed, sometimes I sell cans, sometimes I sell cardboard* [...] *no, I am not ashamed* [...] (Family 6 – Dalva - wife).

In Brazil, the economic policy has been undergoing several changes in recent years, generating high levels of social inequality, affecting the living conditions of families, undermining the possibilities of overcoming poverty and enhancing their submission to the existing public services.[18] This situation of social vulnerability of poor families is directly linked to the structural poverty, aggravated by the economic crisis that casts the human being to the unemployment or underemployment.

Mostly, the family members consulted had no formal employment and those who had it were hampered by the removal from their services, followed by dismissal and loss of financial support. If they remained at work they would have a new role, inducing them to poor performance and subsequent dismissal. According to these findings, a study shows that workers under the Consolidation of Labor Laws, without formal stability, become vulnerable before a removal by illness, particularly those diseases of medium and long duration. Thus, it is common the permanent replacement that materializes in the dismissal right after returning from medical license, a fact that contributes to continue working even if they are sick.[19]

As for the medical examination of the Social Security to get financial support from the state, it is considered as great mobilizer of feelings, difficulties and obstacles for workers, since the relationship with the medical experts is a point of tension. The reports reveal situations in which people are treated with suspicion, in rude, authoritative, aggressive and offensive manners, and having their examinations and reports ignored in a demonstration of disbelief about their status.[20]

The family mentions lack of material support from health institutions, as it is exemplified through the statements of family members 2 and 6. They point out shortage of medication and disposable supplies, lack of medical, psychological, dental and social services care, failure to provide transport at certain times and treatment delays.

[...] *oh, I thought it should help more, right?* [referring to the FHU] *Give more support. Look for the family. I wish someone could look for the family, right? Sometimes, we were going there to talk to them. They answered 'oh, we will go there* [...]'. *But, they did not do that, right?* [...] (Family 6 - Thais - daughter).

[...] *because there, in the people's pharmacy; there, since we went there, so far, it has not arrived yet. They tell us to call, so we call them and it does not arrive* [...] (Family 2 – Lea - sister).

In addition, families evaluate the professional care received as below expectations and highlight the lack of home visits. The personal relationships established with the professional, through home visits, were especially valued by the families consulted. The valued prospect is the right to be heard, respected and considered in their needs, emphasizing relational aspects in order to change health practices.

The research with users indicates critics related to the fact that families do not receive home visits and they hope to receive those visits more frequently.[21] Surely, it is not possible to neglect rights, especially considering health-illness conditions and difficulties to access care in the SUS and Family Health Program (PSF).

The families report they do not know where to seek for support. The public service provides only basic medication; the most expensive remedies are not available to be requested by this population. It is realized the need to adequate support offering and its demand, in the studied population. A study indicates that the principles of universal care, which are fair and resolute to the population, may be compromised by the lack of free medicine supply. Many medicines are often purchased by patients, resulting in high costs and even compromising basic needs.[22]

The burden of the relative caregiver was identified by families, because it is causing illness and generating conflicts. In relation to the support for home care, a wife recalls her anguish to identify she had nobody to count on, feeling abandoned and vulnerable. Having three family patients under her care, she feels overwhelmed and ill.

[...] *I looked to one side, the other and I was not able to give attention by myself* [...], *to get medicine, transportation vouchers* [...]. *I did not know what I was doing. I just washed the clothes of my sister. I washed every day, I washed twice a day. My washtub*

had broken, and the house was getting [...] (Family 6 – Dalva - wife).

Similarly, the patient of another family who experiences family conflicts says that after her mother died, nobody else cares about her in the family. Families point out that when they realize a family member helps in a non-spontaneous way, such help is disregarded.

[...] *you can count on my family like this, you have just spoken and there is nobody there. Now, like that one over there, right* [...] [another sister]. *Until then, when my mother was alive, she was here at home, thank you, got it? Thank you! To help me, to bathe my mother, to help with my mother´s bandages* [...] *and after my mother died she did not come here anymore. So, people* [...] (Family 1 – Marta - patient).

In the interactionist perspective, human beings are social actors that take into account the others when they act. We communicate symbolically in our actions and we interpret the actions of each other. The interaction occurs in a continuous stream of actions among actors, becoming the basis for what we decide to do in different situations.[11]

When families realize their vulnerability, they mobilize in search for social support in order to care for the patient with cancer. This movement is represented by the phenomenon "Supporting each other for care", which aggregates the categories: Seeking people's support, Receiving professional support and Relying on beliefs.

The family looks for support to achieve its ultimate goal and function, which is caring for its members. It appreciates all the support received, because the family knows its importance. It counts on the support of family members and other people, such as neighbors, friends, co-workers and acquaintances.

[...] *oh, I washed her clothes* [patient], *I cooked food* [...]. *I swept the house for her, I cleaned up her house. And that is how we live every day* [...] (Family 5 – Cida - neighbor).

[...] they *gave clothes for her, here, to help* [radio listeners]. *She received food from the government, which helped my sister.* [...] *We received everything we needed in the house, they helped me. Then, they came, people I had never seen before, they brought food* [...]. *My gosh! There was a lady that came with the car, with diapers; there were lots of diapers.* [...] *Then, the radio, a friend offered for me, and they brought me a washtub* [...] (Family 6 – Dalva - wife).

Oh, I asked for help to the pharmacy, the grocery store, you know, people who knows her [patient], *who knows her problems, and my neighbor, too. Therefore, each one of them helped a little until I paid the total bill.* (Family 1 – Neide - neighbor).

In a way to overcome difficulties, families are driven to look for supporting ways in order to care, because the support offered by the closest people encourages and help families to find strategies for adapting to the new conditions of life.[23] In the search for understanding illness and treatment, there is an integration between social and family support network like friends and neighbors who seek solutions in the context of knowledge and beliefs.[24] Since the concept of network allows multiple approaches to produce family health care, namely: the consideration of the extended family as a network, neighborhood participation and elements of other contexts, such as work and school, various community resources and health services.[25]

The family also needs professional support to care for its loved ones, and it feels relieved when searching and getting good attendance. The support offered by health and social public services are all mentioned and valued.

[...] *and the van, it used to pick me up in the supporting house* [...]. *It is from here, the City Hall* [...]. *No, it is from the Specialty Center* [...]. *It was good because I did not pay, right? When I had to go there, it used to take me and when I had to come back, it was the same... and on Fridays, we used to call* [...] [employee], *it is part of the transportation. So, I used to go to the hospital social worker and she called here and asked them to pick me up* [...] (Family 1 – Marta - patient).

[...] *I had the card from the Government Family Help, right? I got it* [through social workers from the Community Center] [...] [she points to her son] (Family 3 – Leticia - patient).

[...] *the doctor taught him, there* [...] [self-care with the nasogastric tube and tracheotomy] *So, the nurses spoke there, the doctors said 'oh, keep on taking care of him that he is going to make it* [...] (Family 2 – Lea - sister).

By receiving information and encouragement, the family gets stronger and provides quality care, with less physical and emotional exhaustion. The authors recommend encouraging the caregiver with positive reinforcements and humanized care.[23] Demonstration of affection, concern, attention, willingness to listen, care and advices are appointed by the families as a source of emotional support offered by health professionals. They can also indicate other possible sources of support, which can be used by the families.

The informational support may come from different professionals and directed to care or clarifying family doubts. The families consulted, despite appreciating this support a lot, pointed lack of information before so many doubts. It is known that more humble families need to be informed clearly, with an accessible language and according to the educational level. The technical language prevents a simplified communication, to which the understanding of symbols used by the actors in the social interaction is necessary. The authors identified that pieces of information for families have occurred in a subtle way, using technical content, forbidding care autonomy and provoking uncertainties.[26] The most important symbols in the interactionist perspective are the words. Therefore, they should be used with clarity in order to achieve their goal.[11]

It is expected health professionals take care of the families by meeting and listening their real needs. Many times, the family is not prepared to provide such care, requiring information about the disease, treatment and technical instruction for attendance.[27] The absence of effective and documented strategies to guide family members for caring the patient with cancer persists, despite the matter has been studied since 1980.

The exercise of religious belief was placed in a privileged position by the families. Relying on spirituality, keeping the faith and receiving religious support, the family feels strong enough to take care of the sick and the rest of the family. Realizing the patient´s improvement, the family feels hope for a future with no disease.

[...] *then I guess, that in the first place, who helps me to stand up with courage and all, to endure everything is God. After that, it is the family, and God help the family, too. Provide support for the family, and the family will support me, right? [...]. Oh, when I feel like this on every Saturday, the Mass is performed here. But, when I am at home, I go to the Mass, so I feel that peace inside, you know? I feel that peace; I feel that hope inside and [...]. And I also started to overcome everything. I started to change my mind, getting calmer and everything, you know? [...]* (Family 3 – Leticia - patient).

Spirituality is mentioned by the families as a form of support with great value, in all circumstances of life. The family that participates in a religious community informs feeling more supported. The support offered through the celebrations and participation in the sacraments, spiritual care from the pastor and believers´ prayers are perceived by the families as help to overcome the disease,

accept it, and live with hope for a better future. Often, it is possible to mistake spiritual support with religious support, but we must understand that when referring to spiritual support, we are meaning to support the inner aspect of the person, his "soul", and this might occur regardless the religious aspect.[28] Even if the person does not belong to any religion, he may and should receive this support, which could bring comfort before the situation he is experiencing.

CONSIDERATIONS

The analysis of the research results takes us to the experience of these families, through the phenomena that were closely interconnected and influencing to each other, through a continuous stream of actions. Revealing the meaning assigned by the families to the social support and social network in their ongoing social interaction, showing how the symbolic elements are constantly influencing the family dynamics in coping with cancer, and how these families interact before the illness.

The availability of social networks and social support offered by various social actors, in different situations, allowed families to care for their relatives in less painful and more dignified manners.

This study allowed us to understand the meanings attributed to the social network and social support of the families in situations of high social vulnerability, and having a member diagnosed with cancer. This understanding is essential to subsidize interventions of the nursing professionals in order to care for the families. Considering that, the nurse works with individuals, society and his performance may increase the population health level.

This study evidences the need for nursing interventions appropriate to the real needs of families with cancer patients, in a situation of social vulnerability. However, the required action will become effective only to the extent that professionals receive training focused on families' care in their education, along with governmental and institutional incentives that encourage them to act with expertise in the assistance of the families.

Similarly, it is needed to expand the scope of services offered by the Health System, in other words, types of support offered by the network in order to facilitate the access of families to the resources required by them. By dealing with families in social vulnerability, the social network

and offered support are even more essential. It is necessary a proper planning to the offering of instrumental, informational, reinforcement or encouragement, spiritual, religious and emotional support, as well as a multidisciplinary team prepared to work in a cohesive manner, and guided by the principles recommended through the Health Unique System (SUS).

Although other authors demonstrate many findings, there is no Brazilian studies regarding interventions that might solve several problems listed here, while the foreign literature points out models of programs and interventions to help families, which can be considered as references to the improvement of our interventions.

Being aware of the scope and complexity of this topic, the present study did not intend to exhaust the subject, but cooperate to deepen and stimulate further researches, and provoke questions on health professionals, especially nurses, in their work with families. Above all, we hope to contribute to the reflection on the experiences lived by the family with a cancer patient, in a situation of social vulnerability, and also, to discuss ways of transforming this harsh reality.

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