Original Article

Structure and functionality of the social support network for adults with cancer*

Estrutura e funcionalidade da rede de apoio social do adulto com câncer

Estructura y funcionalidad de la red de apoyo social del adulto con cáncer

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ABSTRACT

Objective: To characterize the social support network of adults with cancer. **Methods:** A quantitative, exploratory, descriptive, cross-sectional research study conducted with adults with cancer, between August-November 2010, in their homes, using the *Convoy of Social Support*, and analysis of data with Microsoft Excel 2003. **Results:** Sixty-nine patients were consulted and cited 506 members in their support networks, aged 1 to 89 years, the majority being female, residing within 30 minutes of the patient's home and who were encountered daily. Of the support contemplated in the diagram, patients perceived that they gave more support than they received, except "Caring in a situation of disease." The type of support provided and received most was "Respect" and the least was "Caring in a situation of disease." **Conclusion:** This study demonstrated the relevancy of affective bonds for patients and pointed out the limitation of families as unique supportive bonds.

Keywords: Social support; Neoplasms; Family

RESUMO

Objetivo: Caracterizar a rede de apoio social de adultos com câncer. **Métodos**: Pesquisa quantitativa, exploratório, descritiva, de corte transversal realizada com adultos com câncer, entre agosto-novembro de 2010, em seus domicílios, utilizando o Diagrama de Escolta e a análise dos dados com o Microsoft Excel 2003. **Resultados**: 69 doentes foram consultados e citaram 506 integrantes em suas redes de apoio, com idade entre 1 e 89 anos, sendo a maioria do gênero feminino, residindo a menos de 30 minutos do domicílio do doente que se encontrava diariamente. Do apoio contemplado no diagrama, os doentes perceberam que dão mais apoio do que recebem, exceto "Cuidar em situação de doença". O tipo de apoio mais recebido e fornecido foi "Respeitar" e o menos foi "Cuidar em situação de doença". **Conclusão**: Esta pesquisa evidenciou relevância do vínculo afetivo para doentes e apontou a limitação das famílias como únicos vínculos apoiadores.

Descritores: Apoio social; Neoplasias; Família

RESUMEN

Objetivo: Caracterizar la red de apoyo social de adultos con cáncer. **Métodos**: Se trata de una investigación cuantitativa, exploratoria, descriptiva, de corte transversal realizada con adultos con cáncer, entre agosto-noviembre de 2010, en sus domicilios, utilizando el Diagrama de Escolta y el análisis de los datos con el Microsoft Excel 2003. **Resultados**: Fueron consultados 69 enfermos los cuales citaron 506 integrantes en sus redes de apoyo, con edad entre 1 y 89? años, siendo la mayoría del género femenino, residiendo a menos de 30 minutos del domicilio del enfermo que se encontraba diariamente. Del apoyo contemplado en el diagrama, los enfermos percibieron que dan más apoyo de lo que reciben, excepto "Cuidar en situación de enfermedad". El tipo de apoyo más recibido y dado fue "Respetar" y el menos fue "Cuidar en situación de enfermedad". **Conclusión**: Esta investigación evidenció relevancia del vínculo afectivo para enfermos y señaló la limitación de las familias como únicos vínculos de apoyo.

Descriptores: Apoyo social; Neoplasias; Família

** Study taken from the master's thesis entitled, "Family of the patient with cancer: perceptions of social support" – presented to the Federal University of São Carlos, SP, Brazil.*

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INTRODUCTION

Social support and social network are strategies with the goal of improving the quality of life. Both are widely mentioned in the literature as they are extensions of individual resources and are correlated to preventing negative effects on health, in addition to potentiating the ability to face adverse situations, resulting in positive emotional and behavioral effects (1,2).

Although the concepts of social networks and support networks are frequently equated, and not rarely used as synonyms, there are conceptual differences between them. Social networking refers to persons, structures and/or institutions that follow-up the individual throughout the course of life and with whom he/she maintains a social bond, offering a network of relationships that favor mutual help and encourage giving and receiving various degrees of support(1). The benefits of the network depend on the possibility of providing the expected help and the perception of the support offered(3).

The concept of social support involves material and emotional aid, and a feeling of belonging in the context in which the individual is included. It also alludes to reciprocity, because both the one that receives and the one that offers support are benefited(1).

During the course of a chronic disease, loaded with negative stigmas, such as cancer, it is believed that social support networks are of extreme relevance, as they may offer the family and the invalid support to overcome the challenges inherent to the infirmity (4). Moreover, the availability of material, social and/or emotional resources has a direct influence on the determination of and adhesion to the proposed therapy, as well as on the effectiveness of the results. This is because the needs inherent to cancer may vary along the trajectory of the disease, according to the profile of each family(5). For this reason, the social support made available by the network of relationships needs to be individualized, integral and dynamic.

Due to the fact that the adult with cancer requires constant attention and in the majority of cases, the family is responsible for it, this responsibility may generate excessive overload on the family(1). In this sense, in order for the support to be effective it is fundamental to know the social networks and the resources available to the invalid. Therefore, the aim of this research was to characterize the social support network for adults with cancer, assisted at a specialized service.

METHODS

This was a qualitative, exploratory and descriptive cross-sectional research. This modality of investigation reveals the reality of a situation, in a systematic and objective manner(6), and by means of determined variables, generates numerical data that are the basis of hypotheses and direct actions.

The initial survey was conducted in a service that centralizes the follow-up of invalids with cancer, assisted by the Brazilian national health service – SUS ("Sistema Único de Saúde"), in a municipality in the interior of the State of São Paulo. The population met the following inclusion criteria: adults with diagnosis of cancer confirmed by biopsy;; and under treatment for over one year, therefore experiencing the difficulties inherent to the disease and therapy. Invalids with diagnosis of non melanoma skin cancer were excluded.

After a survey of the registration charts, 83 patients who met the inclusion criteria were identified, however, when they were contacted, five of them did not accept participating and nine had died, leaving a total of 69 invalids. The data were collected at their homes from August to November, 2010, respecting their availability, and after they had signed the Term of Free and Informed Consent. The Convoy Diagram was the instrument used, which graphically represent the Convoy Model of Social Support(7). The project was approved by CEPE/UFSCar (CAAE 00230135135-10 Protocol 208/2010).

It is important to point out that this model has been used in researches that seek to know and characterize the social support networks under the most diverse situations and in different stages of the life cycle: Children and adolescents(8-10), the elderly(11-15), drug users(8) and riverbank dwellers(16). In common, the researchers agree with the idea that the support network is fundamental in the maintenance of wellbeing and improves satisfaction with life, and they support more effective professional interventions. It is considered that the relevance of the interpersonal sphere in the adult with cancer justifies investigation based on the Convoy Model of Social Support because it brings descriptive, multidimensional results of the social support networks within the scope of oncology.

In the theoretical plane, the Convoy Social model may be understood from models that propose the development of relationship as a process that involves social, cultural, biological and emotional interactions, starting with the individual's conception and lasting until his/her death. The Convoy Social model considers the potential of these relationships, but does not discard the possibility of being both a source of protection and source of risk(7). The graphic representation of this model is made in the shape of a target, with three concentric and hierarchic circles, whose center is represented by the invalid. The persons considered important are distributed by the individual into each of the circles, according to the degree of proximity.

Application of the instrument took an average of one hour, and before beginning the interviewees were instructed about the instrument. They were asked to reflect about the persons important to their lives, thinking: (i) "of those persons to whom you feel so close that it would be difficult to imagine life without them". The persons mentioned by the interviewee were placed in circle 1, the most internal; (ii) "of those persons to whom you do not feel so close, but even so are very important to you" (circle 2, intermediate); (iii) "of those persons whom you have not mentioned yet, and believe are important enough to be put into your network" (circle 3, the most external).

The persons mentioned were listed, allowing the second stage to begin with questions referring to the network structure, which would be: name, age, gender, circle inserted, degree of relationship, how long he/she has known the invalid, frequency with which they meet and the distance between the invalid's residence and that of the person.

Finally, the third stage consisted of questions with regard to the functionality of the network, considering giving and receiving social support in six types of support: Confide important things; be calmed and encouraged at times of uncertainty; be respected; be cared for in a situation of illness; talk things over when one is sad, nervous or depressed; and talk about one's own health.

For data analyses, the descriptive statistics of *MicrosoftExcel 2003* were used.

RESULTS

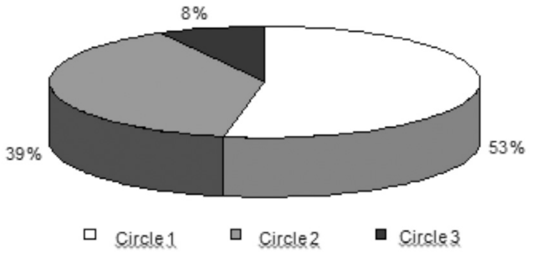
Of the 69 invalids, 65% were women and 35% men, with a minimum age of 28 years, maximum of 89 years, with a mean of 59.4 years and Standard Deviation (SD) of 13. There was concentration of 61% in the age range from 48 to 68 years. The highest incidence of cancer was of the breast (36%) followed by the prostate and esophagus (10%), intestine (9%), oral cavity (7%), lung (6%), ovary (4%), melanoma, neck of the uterus and non Hodgkin Lymphoma (4%), and Hodgkin Lymphoma, Burkitt's, Cancer of the pancreas, testicle, larynx and stomach (1%).

As regards time of diagnosis, the minimum was a year and the maximum 9 years ago, with a mean of three years and SD of 1.9, with the majority (60%) of invalids concentrated in the age-range between one and two years since diagnosis. With regard to therapy received by the invalids, there was prevalence of chemotherapy (91.3%), surgery (73.9%) and radiotherapy (51%), with hormone therapy (16%) and immunotherapy (1%) also being mentioned.

The results with reference to the application of the Convoy Diagram, for better visualization, are presented in two sessions as follows: (i) social support network structure; (ii) support network functionality.

Social Support Network Structure:

The 69 invalids mentioned 506 members in their social support network, comprising networks with a mean of seven members per person. In circle 1, the most internal, the largest number of people were placed (268), corresponding to 53% of the total, with a mean of four members of the network in this circle (Graph 1).



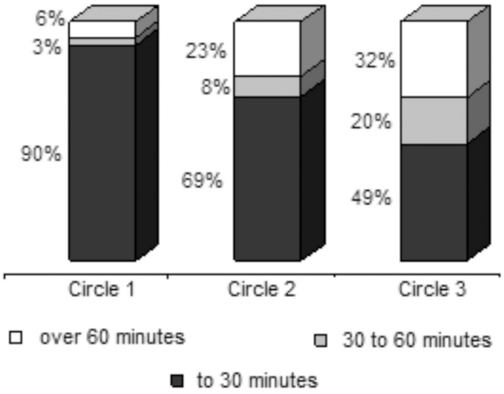
Graph 1 – Distribution of the percentage of persons per circle, in the graphic representation of the Convoy Social diagram. São Carlos, 2011.

The mean age of network members ranged from 1 to 89 years, with a mean (M) of 50 years and standard deviation (SD) of 14 years. In general, the members in the first circle (M = 48.5, SD = 14) were younger than those in the second (M = 51.2, SD = 15) and third (M = 48.9, SD = 14) circles.

As regards gender, of the 506 members, 368 were women (64.8%), predominance manifested in the first two circles, with circle 1 composed of 137 women, circle 2 of 113 women and circle 3 of 18 women.

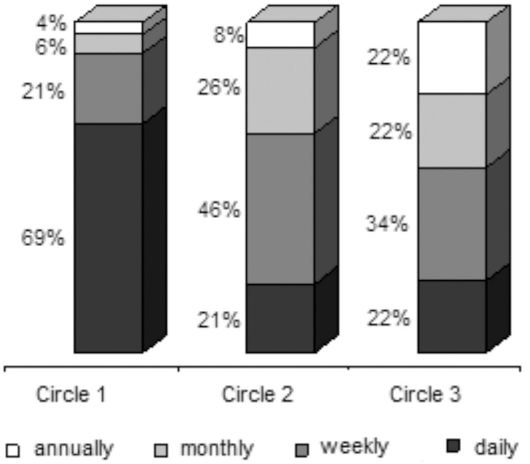
Due to the fact that the majority of the network members form part of the invalid's family, the time they had known the invalid was long, with M of 33 years and SD 16 years. In the first circle the mean time of knowing one another, between the invalid and the members in the network mentioned by him/her was 34.4 years (SD = 13), in the second the mean was 34.3 years (SD = 18), and in the third 27.1 years (SD = 17).

Moreover, of the 506 network members, 78.7% lived at a distance of less than 30 minutes travel time from the invalids. It is worth pointing out that the persons mentioned in circles 1 and 2 were predominantly closer, a fact expected by the trend of being those to whom the invalids most related, and who participated most actively in the care given. Thus, generally speaking, the persons of most significance to the invalid were those who were closest, participating in his/her context of disease (Graph 2).



Graph 2 – Incidence of persons mentioned in the Convoy Social diagram, per circle, according to they time it takes to travel between houses. São Carlos, 2011

There was also predominance of the daily meeting in circle 1 (186 persons) mentioned by 69% of the invalids, justified b the same statement as before (Graph 3).



Graph 3 – Incidence of persons mentioned in the Convoy Social diagram, per circle, according to the frequency of contact. São Carlos, 2010

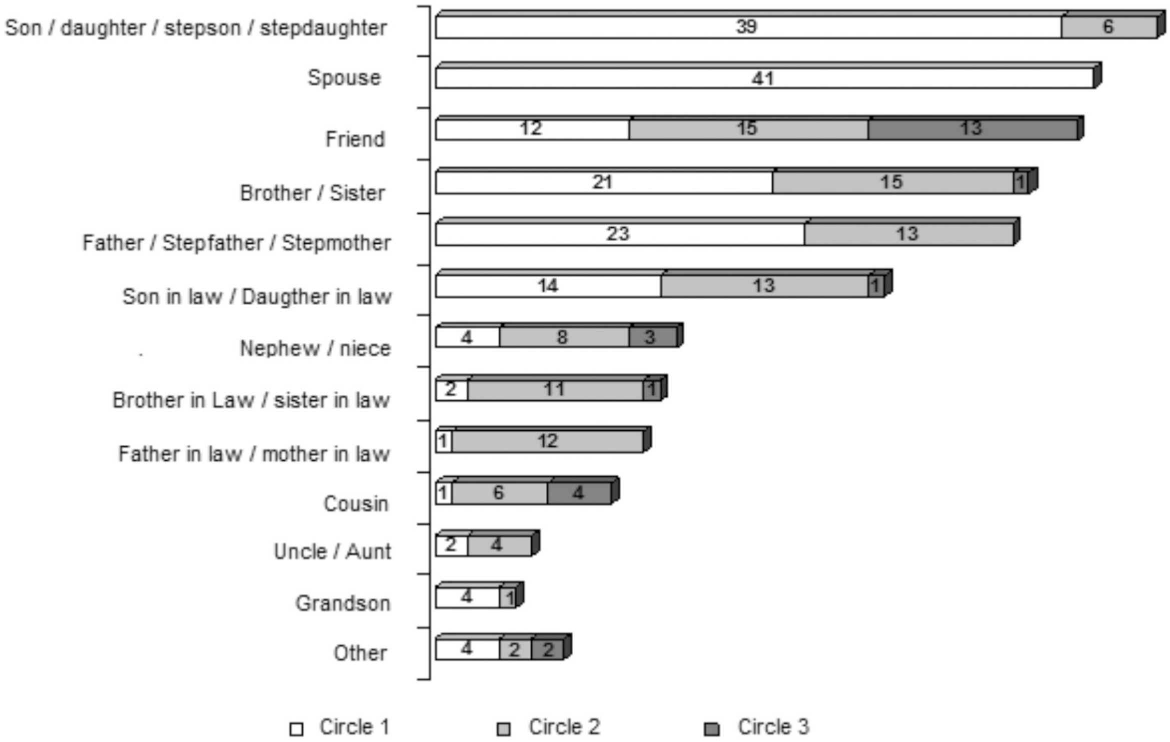
Finally, the question with reference to the type of relationship with the invalid demonstrated that the majority of network members were family members, spouses and children being most mentioned in circle 1, due to their greater proximity and bond. In circle 2, there was predominance of friends and siblings, and in circle 3 friends and cousins (Graph 4).

Social Support Network Functionality:

The item *Confide important things* demonstrated that of the 69 invalids, 66 (96%) informed that they received this support. Of the 506 members indicated by the respondents, 325 (64%) gave this support to the 66 invalids, of these, 62% belonged to circle 1 (most internal), 30%, to circle 2 and 8% to circle 3. When analyzing the aspect of providing this support, of the 69 invalids, 68 (99%) affirmed that they offered it, since of the 506 network members, 402 (80%) are those to whom the invalids give support. Of these, 64% belonged to the first circle, 29%, to the second and 7% to the third.

In the item *Calm and encourage in times of uncertainty,* 67 invalids (97%) informed that they received this type of support, from 396 network members (78%) and that they are the ones that give this support to the 67 invalids who affirmed that they received it. Of these, 54% belong to the first circle, 39%, to the second and 7% to the third. As regards offering this support, there were 68 invalids (99%) that said they offered it, and 447 network members (88%) were those to whom the invalids reported that they gave support. Of these, 58% belonged to circle 1, 36% to circle 2 and 6% to circle 3.

In the item *Respect,* 68 invalids (99%) informed that they received this support, 491 members (97%) were



Graph 4 – Incidence of the number of persons mentioned in Convoy Social diagram, per circle, according to the type of relationship with the invalid São Carlos, 2011 those that gave this support to the 68 invalids. Of these, 52% belonged to the first circle, 40%, to the second and 8% to the third. Moreover, all the invalids affirmed that they offered it, and 54% of the network members that received this support belonged to the first circle, 39%, to the second and 8%, to the third.

In the question *Provide care in a situation of illness,* 66 invalids (96%) informed that they received this type of support, 217 network members (43%) were those who gave this support to the 66 invalids who affirmed that they received it. Of these, 96% belonged to the first circle and 4% to the second. In addition, 66 invalids (96%) affirmed that they gave it, 300 network members (59%) were those to whom the invalids gave support. Of these, 83% belonged to the first circle (most internal), 15%, to the second and only 1% to the third.

With reference to the question *Talk things over when one is sad, nervous or depressed,* 67 invalids (97%) informed that they received this support, 352 members (70%) were those who gave this support to the 67 invalids. Of these, 60% belonged to the first circle, 33%, to the second and 7% to the third. In addition, 68 invalids (99%) affirmed that they offered it, 431 network members (85%) were those to whom the respondents gave support. Of these, 60% belong to the first circle, 34%, to the second and 6% to the third.

When asked about *Talking about their own health,* 67 invalids (97%) informed that they received this support, 348 members (69%) were those who gave this support to the 67 invalids. Of these, 59% belonged to the first circle (most internal), 34%, to the second and 7% to the third. Finally, 68 invalids (99%) affirmed that they gave it, 425 network members (84%) were those to whom the invalids gave support. Of these, 60% belonged to circle 1, 34% to circle 2 and 6% to circle 3. The synthesis of these results are represented in Graph 5.

DISCUSSION

There are indications in the literature of a statistically significant and positive correlation between the number of persons mentioned in a support network and the social support perceived [(17)]. However, the complexity of the aspects that permeate social relationships are not limited only to the quantity, and is necessary for the person to qualify the support, since there may also be stress generating relationships and interactions.

When analyzing the composition of the social support networks pointed out by the invalids, the predominance of women was observed, a fact in agreement with the literature(18,19), according to which women present greater interpersonal competence and tend to maintain more intimate and lasting relationships, in addition to culturally participating more actively in care, generating greater possibility of giving and receiving support(20).

Furthermore, within this context researchers have related that health care is predominantly offered by the family, and it is mentioned as the invalid's main support(17,21). Children and spouses are described in the literature as the main persons responsible for assistance in times of illness(22). The studious have also related that in the process of dealing with an oncological invalid , there is frequent disharmony in this context and in the family decisions, a fact that may interfere in the strategies for facing the disease(21). It is also imperative to emphasize the value of friendship within the context of disease. Research with oncological invalids have revealed friends present, not only in the support network, but considered members of the family(5,23).

It is worth pointing out here that there are distinct concepts about what is understood by family, not limited only to consanguinity or having housing in common/living together, but highlighting the relationship, recognition

Graph 5 – Incidence of support received and given by the social support network to the invalids, obtained with the Convoy diagram. São Carlos, 2011 by the members of which it is composed, in addition to the feeling of commitment, belonging, protection and emotional involvement(24). These bonds help with facing diseases that cause instability(5). When recognizing the invalid's social support network, the extensive family, neighbors, work/school colleagues, community, health and educational services, when interconnected may complement the necessary support. In addition to the family and most intimate friends predominantly assuming the role of informal carers, the resources of the community and of religious institutions may be important sources of emotional, material and spiritual support (25,26).

Emotional support for the family is most important, as its members need to express their emotions, fears and doubts caused by the cancer(27). When the family members perceive the emotional support provided by their network, they tend to overcome the impact of the disease (28,29). Thus, when health professionals understand the feelings unleashed by cancer, they become apt to perform a more effective intervention with the family. When this does not occur, one may predict depressive symptoms, conflict of feelings and suffering during the process of therapy (30). The literature brings evidences of correlation between the perception of life in a less conflicting manner when there is someone with whom you can confide important things(17). The invalid benefits by perceiving that he/she is emotionally and physically supported, and it influences his/her habits and is beneficial to his/her health.

In stressful situations, the bond with persons on whom one can count calms and protects one from negative feelings, improving wellbeing and ameliorating suffering anguish and fear(30). The changes in daily life given the context of chronicity, treatments the majority of which are aggressive, are related to symptoms of depression, anxiety and stress(31). Moreover, the invalid needs constant care and all this demand is incumbent on the family. A study conducted with women with cancer showed that the family is not always able to assume all the care, and needs to count on the help of others. This support coming from a network of friends ins efficient, especially from the emotional aspect and in providing practical care (23).

These findings indicate that planning the care of the adult with cancer needs to go beyond the biological area. Appreciating emotions, respecting singularity and independence is fundamental for physical and mental wellbeing.

An overall analysis of the types of support contemplated in the Convoy Diagram reveals that except for "providing care in a situation of disease", the invalids perceived that they gave more support than they received. The support most received and provided was "Respect". "Providing care in a situation of illness" was the least received and provided by the invalids, however, it was the only one in balance between giving and receiving (96%). The majority of network members were situated in the first circle of the diagram: that is to say, support preferentially occurs with the closest and relatively most important persons.

Analysis of the data relative to functional aspects of the invalids' social support networks demonstrated balance between providing and receiving support, with a slight tendency to provide more than receive. This balance may indicate that there is reciprocity in social relationships. A person's action influence the person him/herself and reciprocally influences those with whom the person relates, with positive effects, encourages and mobilizes them to interact progressively more, contributing to deepening relationships(32).

The support offered by the support network needs to be apprehended as a unique and personal experience, not only as a set of interactions, but appreciating the intensity with which they occur(17). The networks in the life of the adult with cancer are beneficial when they provide support in a way that positively influences the adult's health. Researches on chronic diseases have demonstrated the importance of the role of nursing in intervening positively in health by fostering hope in invalids(33). In the same manner, the family who is mainly responsible for the care of these invalids, needs to strengthen its bonds with health and community and institutions, to find resources that help them in the experience with cancer. Health professionals become important agents in directing and finding support networks in order to promote and recover the invalids health and that of the family.

CONCLUSIONS

Characterization of the social support network of adults with cancer, obtained by means of the Convoy Diagram contemplated the structure and functionality of their networks, making it possible to analyze them in an integrated and dynamic manner, showing the relevance of affective bonds, and the need for and importance of the aspects of relationships.

A broad analysis of the situation allows one to conclude that the supportive bonds of these invalids are found to be restricted to the family nucleus and extension, neighbors and close friends, with whom the invalids have a long-standing relationship, and consequently have become important during their lives.

Through this study, the importance of the family as a priority member of the network of adults with cancer was found. This issues a warning to focus the attention of health professionals on this unit of care. Cancer is a disease that usually brings imbalances into the family context, and mutual support becomes a basic element in the complement of resources (physical and emotional) at a time when these are impoverished. Recognizing the family of the adult with cancer as an active subject in care is essential for the planning of assistance, in agreement with the real needs of both parties. The social network makes a significant contribution to the invalids, offering support, a fact which underlines the need for implementing public policies that facilitate the access of invalids to the social support network available in the community in which they live.

In terms of evaluation of the limits of this research, it was not possible to make comparisons of the findings with other populations, as no studies were found in the literature, which used the Convoy Diagram in adults with cancer.

It is considered that future researches may be able to characterize the social support networks of invalids with cancer, by means of the Convoy Social model, in various populations, cycles of life, socio-economic situations and cultural aspects.

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