ORIGINAL ARTICLE

Health care support to patients with AIDS: the convoy model and nursing *

SUPORTE RELACIONADO AO CUIDADO EM SAÚDE AO DOENTE COM AIDS: O MODELO DE COMBOIO E A ENFERMAGEM

SOPORTE RELACIONADO AL CUIDADO EN SALUD AL PORTADOR DE AIDS: EL MODELO DE CONVOY Y LA ENFERMERÍA

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ABSTRACT
The objective of the present study was to know the relationship and the exchange of support between patients with AIDS and the people around them. This study is based on the convoy model of social relations, which, as one of its features, presents the network as three concentric circles. Participants were people who were hospitalized and talked about the health care support their received from the people close to them, i.e., those belonging to the internal convoy circle. Most participants described the circle as being composed by a maximum of five members, with relatives being the most common. Health professionals must know patients and their convoy, and be able to recognize them in the pscychosocial and cultural context so as to favor the acceptance of being HIV-positive, the need to make changes to their lifestyle, help with health care and adhere to the treatment.

DESCRIPTORS
Acquired Immunodeficiency Syndrome
Interpersonal relations
Social support
Nursing, team
Nursing care

RESUMO
O presente estudo teve como objetivo conhecer a relação e a troca de suporte entre o doente com AIDS e pessoas à sua volta. O estudo está baseado no modelo de comboio das relações sociais que tem como uma de suas características a representação da rede em três círculos concêntricos. Os participantes eram pessoas que estavam internadas e que falaram sobre o suporte relacionado ao cuidado em saúde proporcionado por pessoas próximas, ou seja, que pertenciam ao círculo interno do comboio. A maioria dos participantes descreveu o círculo como sendo composto por no máximo cinco integrantes, sendo que pessoas da família foram as mais citadas. Os profissionais de saúde precisam conhecer o paciente e seu comboio, reconhecendo-os no contexto psicossocial e cultural de forma a favorecer a aceitação da soropositividade, mudanças no estilo de vida, ajuda nos cuidados de saúde e adesão ao tratamento.

DESCRITORES
Acquired Immunodeficiency Syndrome
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RESUMEN
El presente estudio objetivó conocer la relación y el intercambio de soporte entre el portador de AIDS y personas de su entorno. Estudio basado en modelo de convoy de las relaciones sociales que tiene como una de sus características la representación de la red en tres círculos concéntricos. Los participantes fueron personas internadas que hablaron sobre el soporte relacionado a cuidados de salud proporcionados por personas próximas, o sea, que pertenecían al círculo interno del convoy. La mayoría de los participantes describió el círculo como compuesto por un máximo de cinco personas, siendo los familiares las personas más citadas. Los profesionales de salud precisan conocer al paciente y a su convoy, reconociéndolos en el contexto psicosocial y cultural, para favorecer la aceptación de la seropositividad, cambios de estilo de vida, ayuda en cuidados de salud y adhesión al tratamiento.

DESCRIPTORES
Síndrome de Inmunodeficiencia Adquirida
Relaciones interpersonales
Apoyo social
Grupo de enfermería
Atención de enfermería

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INTRODUCTION

Human beings are born, grow and develop within groups and as a person develops, s/he starts to participate in different groups. In each group, one develops different roles, experiences events, influences and is influenced by other people, develops different types of relationships with people who participated in these varied groups, so that some people are closer and form a network of friends and relatives. This process goes on throughout the entire life of a person[1].

A network of relationships varies between close and more distant relationships according to intimacy. But the positive result of an HIV test changes the dynamic of a network of relationships because there is a probability that many changes and transformations will occur. There is loss, drawing close to and detachments from people to the patient due to stigma, psychological and physical changes that result from the disease and the discovery of secrets, such as a person's involvement with drugs and prostitution.

The dynamic of the network of relationships permeates issues regarding the health-disease continuum of HIV positive individuals. Whether a patient is treated as welcome or not, whether there is a greater or lesser degree of acceptance of seropositive individuals, whether there is a drawing closer to or distancing from people, depends on various factors that might be linked to situations that occurred before the disease.

Conflicts linked to problems that weaken family relationships such as involvement with the legal system, the use of illegal drugs, and also homosexual relationships may exist before the diagnosis is disclosed. These conflicts are aggravated after a person's HIV status is disclosed. In other cases, the hidden world of drug use, promiscuity, and other socially reprehensible behaviors come to light jointly with the discovery of the HIV infection[2]. Prejudice is twofold, both in relation to the HIV/AIDS and in relation to the reproachable behavior[3].

In addition to these issues, the reception and response of the family depend on other factors such as the form of contagion, feelings experienced at the moment of disclosure, socioeconomic conditions and quality of the relationship[2].

Disclosures interfere in the family context causing oscillations and transformations, as well as ruptures and sometimes even a time of drawing closer. There are families who are receptive and supportive after the initial shock, while others reaffirm prejudice, discrimination and total abandonment.

People in the network of relationships with the possibility of offering instrumental and/or affective support should be identified by the health team because they will probably be more participatory in the life of the patient and strongly influence this individual during the entire course of their disease, either collaborating with the patient's treatment and physical and emotional well-being or not.

The health service cares for patients while they are experiencing the disease's acute period. The health facility offers important help during the chronic period but people from the community and support network need to receive, support and care for the patient during the chronic portion of the health problem.

The relevance of this study bears on the fact that better understanding concerning the impact the disease has on the lives of patients and also how support networks and the dynamic of relationships affect these individuals can enable the nursing and health teams to identify the members of the support network who can better contribute to care and hence better heed the patient's primary needs. These people can provide important information concerning the progress of the disease and also encourage treatment adherence.

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OBJECTIVE

To identify the exchange of support related to health care among members of the inner circle of the *convoy* and the AIDS patient.

METHOD

Theoretical Framework

The term *convoy* was developed to describe the idea that a person is surrounded by other individuals who accompany her/him during life. The convoy model of social relations was adapted to include the concept of intra-individual vital development. It fills in the gap existing in the study of social networks and support. According to this concept, the individual develops him/herself in relationships with other people from his/her social milieu. This individual plays a specific role while a member of groups such as family, friends, and a given entity. In this role, the person experiences events as being part of a group or convoy. Negative or positive experiences that occur in the context of the convoy increase one's ability to understand the dynamics of each event[1].

The convoy is described as being composed of three concentric circles, which surround a person. Each circle represents a different level of proximity in relation to the individual in focus. Hence, the members of this inner circle are seen as the most important in providing support and also as recipients of support. These are the people with whom

the individual feels the closest. There are many exchanges and types of support at this level in which relationships go beyond the requirements of the role. Individuals in the second circle have greater affinity and a closer relationship than that required by their roles, but they are more distant than those in the first circle. Members of the third circle relate according to their role's prescription. People can change their places in these circles depending on the relationship they have with the individual and daily situations[4]. AIDS is one of these situations that have an impact on the network and can trigger changes in the location of people in this convoy.

Functional and structural characteristics among members vary according to the life cycle (age) and feeling of affinity (place in the convoy) in a significant and predictable manner[4]. Jointly with social support, the convoy is important in coping with different stressful daily situations and influences the mortality and morbidity of diseases such as AIDS[5]. Among the different designs or network analyses, we chose the convoy model as the theoretical framework for this study because it only investigates the relationship between the individual and each member of the convoy, and integrates support and intra-individual vital development and the concept of a network.

Participants

A total of 22 HIV positive individuals who were being cared for in the nursing ward of the Special Unit for Treatment of Infectious Diseases (UETDI) at the *Hospital das Clinicas*, Medical School at University of São Paulo were included in this study.

The following inclusion criteria were used:

- Being hospitalized in the nursing ward at UETDI
- Being older than 18 years of age
- Being cognitively competent to answer the questionnaire. Patients were evaluated through the Mini Mental State Examination.
- Consenting to participate in the study

Twenty-two out of the 25 individuals selected consented to participate in the study. The reasons provided by the three non-participating individuals for not participating were: being separated from family and friends networks, which caused them much pain and fear of being identified somehow even after confirmation that confidentially was ensured.

Setting

The study was conducted in the Special Unit of Treatment for Infections Diseases at the *Hospital das Clinicas*, Medical School at the University of São Paulo at Ribeirão Preto. This unit initiated operations in 1996 and since then has treated adult and pediatric infected patients or offspring of HIV positive mothers.

Data Collection

Data were collected between March and November 2007 in the nursing ward of UETDI at *Hospital das Clinicas* in Ribeirão Preto, after the Research Ethics Committee at the Hospital das Clinicas, Medical School at the University of São Paulo at Ribeirão Preto approved the project (process HCRP nº 11524/2006). The participants read and signed free and informed consent forms, in accordance with Resolution 196/96[6].

Participants were then presented a diagram composed of concentric cycles. The word "you" was written inside the smallest circle in the center to indicate the interviewee. In the outermost circle the interviewees indicated people who were close and important enough to be in their personal relationship circle. Then they would indicate in the second circle those who were not completely close but were still very important to them and in the interior circle they would note those who were close and so important to them that life would be unimaginable without these individuals. Then the participant would mention the first name or nickname of a member of the convoy and locate this individual in one of these circles according to degree of affinity.

Then the interviewee would answer questions about the ten closest people. It was not necessary to mention exactly ten people. However, in the event that more than ten were mentioned, the relationships with the closest people were analyzed.

An instrument based on the conception of the convoy model was composed of two parts in order to identify the relationship of each member who provided and received each type of support. The structural characteristics of the network are presented in the first part according to each member: gender, relationship to participant (ties), length of relationship, frequency of contact and distance between houses. The second part presents the functional characteristics divided into six types of support: confidentiality, respect, care in the event of illness, dialogue, dialogue concerning health and reassurance when there is uncertainty. Functional characteristics vary according to age and place in the convoy[4].

The interview was held after completing the representation of the convoy in the three concentric circles. The questions were related to the ten members of the inner circle, that is, to the closest people. Interviews were recorded and transcribed. Eleven out of the 22 participants agreed to have their interviews recorded. The remaining who did not consent to their interviews being recorded asserted that they were afraid their voices would be recognized. This fear persisted even after we explained the researchers were obliged through the informed and clarified consent form to keep the confidentiality of participants' identities. In these cases, notations were made in the data collection instrument. Interviews took about 30 minutes on average and were digitally recorded and then stored on a recordable CD.

This investigation focuses on support care in the case of disease; this is the object of this study.

Data analysis

Data analysis was carried out according to the functional characteristics of a convoy[4]. The testimonies of the participants related to support provided in the face of disease were categorized and analyzed according to its content in the light of the defining support categories according to the framework set out by Antonucci and Akiyama[1].

Excerpts of the interviews are presented throughout the manuscript. The names after each testimony are fictitious in order to protect the identity of the participants.

RESULTS AND DISCUSSION

Individuals grow up inside a convoy and participate in it during their entire life. The components of the inner circle receive and provide more types of support than the members from the middle and outermost circles[4]. People from the inner circle are those known for a longer period of time; members of this circle most frequently provided care during. The relationships within this circle are among the closest people, which are the most frequent and stable relationships[7]. Hence, we opted to better understand the support provided by the relationships that occur within this circle.

Among the 22 participants, 14 reported being white or of mixed racial ancestry; 15 were women. Age varied between 19 and 50 years of age, while 12 people were aged between 34 and 43 years old. Twelve individuals had completed primary school and nine were either unemployed or retired due to disability. Most were infected through sexual relationships and received their diagnosis between 1997 and 2007.

Most of the participants' inner circles were composed of five people at most. The first five to ten individuals who belong to the convoy are very significant individuals and people from the family occupy very important positions[8]. Oftentimes we found family and women as the closest people and with whom the participants have the most frequent contact[4]. Of the 235 people who compose the convoy of 22 participants, 165 before and after the disease belonged to the nuclear family. Support is one of the functions of the social network, while care is a specific type of support frequently exchanged within the family and which is influenced by the life cycle[8].

There are various concepts of family in the literature. In this paper we take the view that a family is a group composed of bonds of kinship, alliances, consensual unions, and may or not include biological offspring. It is socially constructed and influenced by cultural standards since depending on the point in life and society's expectations, domestic life may assume different forms[9].

The family is the first support to be activated in times of health crises. Only when the family cannot be activated do friends and formal services help[7]. The presence of family members in the inner circle directly and indirectly alleviates psychological stress and health problems. A social network influences the health of individuals and behavior related to health. Networks are also influenced by health[10]. The way the family represents the illness affects support.

At this point, an infected wife talks about the instrumental support received from her husband:

> He is the one who gives me medication at the right time, he gives me water, he puts me on the chair, helps me take a shower when I'm not well, you know. He does everything for me (Magdalena)

Families need to share health care with the health services as the level of physical and psychological impairment increases[11]. The greater the level of dependency, the greater the support and care required. The patient's level of satisfaction is a way to evaluate whether support is appropriate or not. Satisfaction with support influences the adaptation of individuals to chronic diseases and is assessed through an individual's expression of subjective aspects. The benefits such support provides to an HIV positive individual are taken into account in the assessment of satisfaction[12].

Direct and indirect effects of support are perceived. The direct effect of support is observed when self-care is encouraged and stimulated. Indirect effects of support occur when the negative interference of certain situations are mitigated[13]. Support also influences treatment adherence and reduces depressive signs. It is important to keep in mind that during periods of greater debility caused by the disease exacerbation, people in the convoy and particularly those in the inner circle provide emotional and instrumental support. However, stigma may distance significant people and impede the convoy in their provision of required support[14].

Functional limitations exert a negative impact on social relationships, especially when they limit one's flexibility and ability to keep in contact with other people[8-9]. Opportunistic diseases can limit this ability due to sequelae they may include. People in such conditions tend to reduce contact with convoy members. An individual with a given debility caused by some disease experiences a reduction in his/her ability to interact[15]. Hence, the level of dependency may lead to a reduced network in terms of extension and frequency of contact.

AIDS is a chronic disease that imposes physical and psychological limitations on relationships due to stigma and neurological changes it causes[16]. It is important to bear in mind that the interpretation of the disease has a temporal dimension, in which changes occur over the course of the disease, and through confrontation of diagnoses and situations constructed by the formal and informal support network. Hence, the meaning given to HIV/AIDS is continually

reformulated and reconstructed through interaction with a person's convoy[17].

Support provided by the family tends to be an obligation while support provided by friends is typically voluntary and based on mutual gratification[7]. Care provided by friends may reaffirm the importance of the person who receive care as the following excerpt indicates:

"This bosom friend was there when I needed" (Luzia).

The participants' testimonies show the expectation of support coming from a stepfather and a friend.

"... helped before and after I got sick. He never turned his back on me". "Not even before… when I used drugs, he never slammed the door in my face" (Aparecida).

"Joyce is an Angel in my life". "Because I can count on her anytime. She never let me down". "Whoa. She does groceries and a lot of house chores. She drives me to my medical appointments" (Marta).

However the decision to provide support or not to an HIV positive individual is linked to various factors such as relationship history, stigma, prejudice, and socially reproachable behavior. In relation to the last, when a person is affected through a blood transfusion or due to an accident, responses tend to be supportive. On the other hand, an HIV positive individual who is infected due to reproachable behavior, such as drug use, may receive a different response. Family members tend to reconstruct an individual biography based on the news of the HIV diagnosis[11].

The network provides informal care. The formal network is composed of professionals and health services, which provide emotional and instrumental support[9]. The components of formal and informal networks should work together. Health care provided by relatives and friends should be planned and guided by health professionals[18]. In addition, these professionals can provide general health information and information related to work issues to help relatives and friends provide the required support.

CONCLUSION

At the beginning of the epidemic, AIDS aroused the fear of imminent death. In many cases, people really had a realistic expectation of a brief time of survival right after the diagnosis was confirmed. Currently, given advancements in knowledge and an increased number of medications available, survival time and rates have increased considerably. Still, new issues are imposed on HIV positive individuals, their convoys and health professionals. These issues are related to the restructuring of life after the diagnosis in order to cope with the disease.

Additionally, the treatment itself seems to be influenced by psychosocial factors such as family support. Family support is important in treatment adherence because it requires a re-adaptation of daily life conforming to taking medication and even disclosing the diagnosis to those who are close to the patient and who can help in providing care.

The study was conduced with people who were infected with AIDS and were hospitalized in a hospital unit. Most of them included five people in their inner circle. These people were the closest ones and belong to the nuclear family in most of the cases.

Support is one of the functions of a social network while care is a specific type of support greatly favoring the well being of HIV positive individuals and influencing their mental and physical health. Support from friends and family related to health care is expected by patients. However, the meaning of care provided by relatives and by friends may be different. Care in this context, which is a type of support generally exchanged within the family, needs to be supervised and taught by nurses.

It is important that nurses are aware of who composes the inner circle of patients' convoys and who are potential caregivers and members of the informal support network. These people should be prepared to live with an HIV positive individual, with treatment and frequent contact with the team. A person with AIDS becomes sick at the same time her/his family has doubts and ambiguous feelings that emerge from the experience of living with a person infected by AIDS.

The involvement of people from the inner circle of convoys help patients cope with the disease, increasing the understanding of these people concerning issues related to HIV/AIDS. It may have positive results in the resolution of doubts and the maintenance of support from patients' social networks.

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