

## DIFFERENTIAL STUDY OF THE BELIEFS CONCERNING HOME CARE AND DEATH AMONG RELATIVES CARING FOR PATIENTS WITH HIV/AIDS AND CANCER

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**RESUMO:** Several forms of treatment have been developed regarding how AIDS and cancer are dealt with. Although these diseases have elicited prejudiced attitudes, the persons involved in patient care have permitted the advance of ideas and discussions towards the humanization of these diseases. The objective of the present study was to survey the beliefs of relatives of patients with HIV/AIDS and cancer regarding death and home care in an attempt to determine the characteristics of such beliefs. For this purpose we used Fishbein-Ajzen's affective-cognitive framework which conceives attitude as resulting from the association of beliefs and affects associated with a given phenomenon. Thirty-five relatives of patients with HIV/AIDS and 35 relatives of patients with cancer were studied. The attitudes of the relatives surveyed in this study revealed the lack of preparation and the difficulties of subjects in facing death and patient care. Although having pointed out that love and faith in God as important in family relations, day-to-day experiences of caregiving and of impending death, characteristics related to social exclusion and the vulnerability elicited by these diseases emerged.

*Palavras chave:* AIDS, Cancer, Death, Home care.

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### ESTUDO DIFERENCIAL DE CRENÇAS RELATIVAS AOS CUIDADOS DOMICILIARES E À MORTE ENTRE PORTADORES DE HIV/AIDS E CÂNCER

**ABSTRACT:** Ao longo do enfrentamento da sida e do Câncer, várias formas de tratamento foram desenvolvidas. Embora estas duas afecções tenham incitado atitudes preconceituosas, as pessoas envolvidas com os cuidados, possibilitaram o avanço de idéias e de discussões, em busca da humanização dessas doenças. Este estudo tem como objetivo, fazer um levantamento das crenças de familiares de portadores de HIV/SIDA e de câncer, relacionadas com a morte e cuidados domiciliares, procurando delinear as características dessas crenças. Para tal, utilizou-se o referencial afetivo-cognitivo de Fishbein-Ajzen, que concebe a atitude como resultante da conjugação entre crenças e afetos associados a um fenômeno qualquer. Foram estudados, 35 familiares de portadores de HIV/SIDA e 35 familiares de portadores de câncer. As atitudes dos familiares levantadas neste estudo mostram o despreparo e as dificuldades destes no enfrentamento da morte e no cuidar do doente. A orientação e o suporte emocional, tanto do doente quanto do familiar, seriam necessários, a fim de minimizar o sofrimento e oferecer subsídios para o enfrentamento dos diferentes estágios de doença, pelos quais o enfermo passará.

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*Key words:* AIDS e câncer, Atendimento domiciliar, Morte.

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Since the emergence of Immunodeficiency Virus (HIV), the scientific world has been waging a battle against it. Despite the efforts and interest of the international scientific community, a cure has not yet been found, although the therapeutic arsenal developed thus far raises hopes for the future (Martin, 1987).

Acquired Immunodeficiency Syndrome (AIDS) is not simply the relationship between HIV and the immunological system, but also the relationship between the carrier of the virus and the society that surrounds him. In addition to fighting the virus, the patient must fight discrimination, prejudice, fear of death, and the stigma and anxiety caused by the disease (Bennett, 1990), problems that are also faced by his family, friends and sex partners (Flaskerud, 1987). Both patient and relatives will be facing a new and complex situation which will completely change the family structure and the relationships with friends, sex partners and society.

Side by side with antiretroviral drugs, home care is a modality of assistance to HIV/AIDS patients. This care means the continuity of technical care for the patient, in addition to the feeling of safety provided by the company and presence of relatives (Leserman, Perkins, & Evans, 1992).

Like AIDS, cancer is being extensively studied and likewise researched by the international scientific community. Today, new anticancer medications combined with radiotherapy and surgery have significantly improved cure and survival rates of cancer patients (Fisher, Girgis, Boyes, Bonevski, Burton, & Cook, 2000). The diagnosis of cancer is poorly experienced by both patient and family because of the threat of impending death (Lewis, 1990). In addition to shock, feelings of insecurity, depression, guilt, stress, and pain are also experienced (Gilbar, 1991). This diagnosis will drastically change the family structure, causing a series of reactions and feelings to emerge in the patient-family relationship (Odling, Danielson, Christensen, & Norberg, 1998).

Home care for cancer patients, as an extension of hospital activities, is also an adopted practice. The patient will be home, sheltered by his family, receiving care, medications and love (Stetz & Brown, 1997). In addition, the family will have a chance to be with him in a close and supporting manner, sharing all of his moments (Hull, 1992).

In the present study, Fishbein-Ajzen's affective-cognitive reference framework was used, which defines attitude as the result of the of beliefs and affects associated with any kind of phenomenon (Fishbein & Ajzen, 1975).

The aims of the present study is to identify, to characterize, and to compare, the beliefs of HIV/AIDS and cancer patients regarding *death feeling* and *treatment provided at home*.

## METHOD

### Identification of prevalent modal beliefs

*Subjects:* Twenty-five subjects participated in the study: 15 relatives of patients with HIV/AIDS; 10 relatives of cancer patients.

*Procedures:* Individual interviews were held with each subject in order to survey the beliefs related to two categories: *death* and *home care*, based on the following procedures: (a) evocation – which consists of the activation in the subject of representations and beliefs about the phenomenon under study; (b) enunciation – which involves the expression in writing by the person interviewed of the beliefs and representations evoked in the first phase; (c) verification – based on a brief discussion of the contents in order to complement the information collected and to resolve possible doubts.

Statements were treated according to the method used in a previous study (Barbieri, Machado, & Figueiredo 2005), followed by the association of the Likert type scales “b” (true/false) and “e” (good/bad), of 7 points ranging from +3 to -3 with a median interval of zero, with emphasis on the final list of locutions.

Study of the propensities of relatives of patients with HIV/AIDS and of cancer patients regarding some categories of contents related to death and to home care.

### Subjects

The scales constructed in the previous phase were applied to 70 subjects, 35 of them relatives of patients with HIV/AIDS and 35 relatives of cancer patients.

### Procedures

*Differential studies:* Differential studies were performed using the *t* test and the Mann-Whitney test to determine within-group differences for the relatives of patients with HIV/AIDS and for the relatives of cancer patients, with the level of significance set at  $p < 0.05$ .

*Quadrant Analysis:* Quadrant analysis was performed as described by Fishbein e Ajzen (1975).

## RESULTS

Identification of the prevalent modal beliefs – Tables 1 and 2 present the statements selected.

Table 1

*Subcategories of the home care category*I – Basic Care (BC)

- 1) it is important to give the medication at the right time
- 2) it is important to provide a good diet

II – Affective Support (AS)

- 3) the affection, attention and support of the family are important
- 4) it is important to treat the patient in a normal manner

III – Care Barriers (CB)

- 5) it is difficult to care for the patient
- 7) caring for the patient involves much suffering

IV – Exclusive Dedication (EB)

- 6) it is normal to live for the patient and to stop worrying about oneself

Table 2

*Subcategories of the death category*I – Conformism/Rationalization (CR)

- 8) it is the rest of the patient who is suffering
- 11) everybody must die
- 16) it is important to accept death

II – Consequences/Effects (CE)

- 9) the deceased person is missed
- 10) it is difficult to deal with the loss of a loved one
- 12) the family becomes unstructured
- 15) people turn against God

III – Teleology (T)

- 13) it is God's will
- 17) it is a passage to another plane, a new life
- 18) it is inexplicable

IV – Coping Attitudes (CA)

- 14) it is important to fight against death

Differential studies using the *t* test and the Mann-Whitney test

Differential studies were carried out by comparing the group of relatives of HIV/AIDS patients (A) to the group of relatives of cancer patients (C). No significant differences were found in any of the eight subcategories (Tables 1 and 2), hence the two groups did not differ significantly in any subcategory.

Table 3

*Results of the Mann-Whitney test applied to the scores of relative attitude of the eight subcategories for the two groups (AIDS and cancer)*

Locutions	BC	AS	CB	ED	CR	CE	T	CA
<i>M/MeA</i>	1.00	1.00	-0.04	0.66	0.33	-0.50	0.33	1.00
<i>M/MeC</i>	1.00	1.00	0.15	1.00	0.33	-0.50	0.33	1.00
<i>T/Ut</i>	1225.0	1225.0	-1.20	1176.5	1244.5	1251.0	1238.5	1240.5
<i>p</i>	<b>0.84</b>	<b>0.84</b>	<b>0.25</b>	<b>0.44</b>	<b>0.98</b>	<b>0.92</b>	<b>0.96</b>	<b>0.98</b>

*Nota.* Ut/T=Mann-Whitney index; *p*=significance index; ME=median; M=mean; A=AIDS; C=cancer; BC=basic care; AS=affective support; CB=care barriers; ED=exclusive dedication; CR=conformism/rationalization; CE=consequences/effects; T=teleology; CA=coping attitudes.

### Quadrant analysis

Quadrant analysis of the results of the category *Home Care*, for both relatives of HIV/AIDS patients and cancer patients showed that the contents linked to basic care (medication at the right time and a good diet) and to affective support (affection, attention, family support, and treating the patient in a normal manner) are part of the beliefs of these relatives regarding the care they will provide to the patients at home and are positively valued by them. However, the contents linked to care barrier (difficulty in providing care and suffering a lot when providing it) and exclusive dedication (living as a function of the patients and not worrying about oneself) did not indicate a well-defined direction, as shown in the above tables.

Quadrant analysis of the two groups of relatives (AIDS and cancer) for the *Death* category showed that they strongly believe in death as rest for the suffering patient, as God's will and as the passage to another level. In addition, they also believe that it is important to accept death and to fight against it, assigning a positive value to these beliefs. On the other hand, death causing people to turn against God is valued negatively and with a low belief strength in both groups.

We also noted that these relatives have beliefs related to missing a person and to the destructuring of the family provoked by death, and also to the difficulty in coping with the loss of a loved one. These beliefs are valued in a negative manner.

Death as an inexplicable event and being part of everybody's life represented contents that did not find a well-defined direction for the relatives of patients with HIV/AIDS. However, for the relatives of cancer patients these statements tended to show a high belief strength and to be valued in a negative manner.

## DISCUSSION

It was possible to survey some aspects of the beliefs and representations of relatives of patients with HIV/AIDS and cancer patients regarding home care and death.

With respect to the contents linked to the *difficulty in caring for the patient* and to the fact that *it is a source of great suffering to care for him* (Barriers in Care), the present study did not identify a defined direction for the conjugation of beliefs *versus* values in this subcategory. This finding may be attributed to the difficulty faced by these relatives in contacting their own suffering and the suffering of the patient, choosing to deny the existence of this suffering in the caregiver-care recipient relation rather than facing it. The threat of impending death of the patient obliges the relative to live with the possibility of his own

death, causing anguish and fear in the family (Crockford, Holloway, & Walker, 1993). According to Kübler-Ross (1997), denial is one of the phases through which family and patient go through during the process of adaptation to the diagnosis of a disease considered fatal.

According to Odling, Danielson, Christensen, e Norberg (1998), to be able to perform the task of supporting the patient, the family needs to overcome its own fears, something that at times proves difficult in a society in which the denial of death is an imposition.

The subcategory *Exclusive Dedication*, which includes the statements *it is normal to live only for the patient and to stop worrying about oneself*, also did not present a definite direction for the association of beliefs *versus* values. However, a detailed analysis of the quadrants that present a higher concentration of subjects reveals that more than 70% have a high strength of belief in positive attributes and a low strength of belief in negative attributes. These quadrants indicate that most of the relatives who provide home care to patients have positive attitudes towards exclusive dedication, consider it normal to live for the patient with little or no concern for themselves.

According to Kübler-Ross (1997), relatives show ambivalent feelings of both solidarity and guilt. They overprotect the patients as a way of compensating for guilt feelings about the acquired disease. We almost always find out that the root of these guilt feelings is linked to real resentment regarding the patient (Kübler-Ross, 1997).

The meaning of the association of beliefs *versus* values for statement 11 (*everybody must die*) did not reveal a defined direction. However, a detailed analysis of the quadrant that presents a greater concentration of subjects reveals that more than 85% of subjects have a high strength of belief in positive and negative attributes. These quadrants indicate that most of the relatives strongly believe in their finitude, but are divided regarding the positive and negative nature of this item. The fact that some valued death in a negative manner as belonging to life may indicate the presence of fear of death and dying. However, those who attributed a positive value, coped better with death and dying.

On the basis of the present results, we were able to observe that relatives spend part of the day providing physical and emotional care to the patient, doing this with much love and affection. The fact that the caregiver-patient relationship becomes increasingly closer with time may raise at the time of separation (death) the most varied emotions in different stages, as accurately described by Kübler-Ross (1997) according to the stages mentioned in his book: denial and isolation, anger, bargaining, depression, and acceptance.

The attitudes of the relatives towards the categories studied revealed their lack of preparation and their difficulties in facing caregiving and the patient's death. Although they point out that affection, love, patience and faith in God are important for the family relationship, when faced with day-to-day experiences regarding caregiving and death, it can be seen that something more

is necessary. In this respect, more could be offered by health professionals, creating programs aimed at providing information, education, guidance and emotional support to both patients and relatives in order to minimize suffering and to provide ways to cope with the different stages of the disease through which the patient will go through.

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