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SOCIAL SUPPORT FOR PEOPLE LIVING WITH ACQUIRED IMMUNODEFICIENCY SYNDROME

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ABSTRACT: The aim of this study was to evaluate the social support for people with AIDS. It was a cross-sectional study, with 215 outpatients at a University Hospital in Northeastern Brazil. Data were collected from August to December 2012, through interviews, using a Socio-demographic and Clinical Form and a Social Support Scale for People Living with HIV/AIDS. Statistical Package for the Social Science was used for data analysis. Results showed that average scores of social emotional and instrumental support were satisfactory and not influenced by sex ($p=0.954$; $p=0.508$), education ($p=0.756$; $p=0.194$), marital status ($p=0.076$; $p=0.446$) and length of antiretroviral therapy ($p=0.480$; $p=0.120$). People diagnosed for less than three years had more instrumental support ($p=0.048$) than those diagnosed over three years ($p=0.370$). Neighbors, employers and health professionals provided less support. The conclusion was that people with AIDS have satisfactory social support, especially from friends and family not living in the same household.

DESCRIPTORS: Acquired Immune Deficiency Syndrome. HIV. Social support.

SUPORTE SOCIAL DE PESSOAS QUE VIVEM COM A SÍNDROME DA IMUNODEFICIÊNCIA ADQUIRIDA

RESUMO: Teve-se como objetivo avaliar o suporte social de pessoas com aids. Estudo transversal, com amostra de 215 pacientes ambulatoriais de um hospital universitário do Nordeste brasileiro. Dados coletados de agosto a dezembro de 2012, por meio de entrevista, utilizando formulário sociodemográfico e clínico e Escala de Suporte Social para Pessoas Vivendo com HIV/aids. O *Statistical Package for the Social Science* foi utilizado para análise de dados. Resultados mostraram que médias de escores de suporte social emocional e instrumental foram satisfatórias e não influenciadas pelo sexo ($p=0,954$; $p=0,508$), escolaridade ($p=0,756$; $p=0,194$), situação conjugal ($p=0,076$; $p=0,446$) e tempo de terapia antirretroviral ($p=0,480$; $p=0,120$). Pessoas diagnosticadas há menos de três anos tiveram mais suporte instrumental ($p=0,048$) que os diagnosticados há mais de três anos ($p=0,370$). Vizinhos, chefe e profissionais da saúde forneceram menos apoio. Concluiu-se que pessoas com aids possuem suporte social satisfatório, principalmente, de amigos e familiares que não moram no mesmo domicílio.

DESCRIPTORIOS: Síndrome da imunodeficiência adquirida. HIV. Apoio social.

APOYO SOCIAL DE LAS PERSONAS QUE VIVEN CON SÍNDROME DE INMUNODEFICIENCIA ADQUIRIDA

RESUMEN: Este estudio objetivó evaluar el apoyo social a personas con SIDA. Estudio transversal con muestra de 215 pacientes ambulatorios de un hospital universitario del nordeste de Brasil. Los datos recolectados entre agosto y diciembre de 2012, a través de entrevistas utilizando el formulario sociodemográfico y clínico y la Escala de Apoyo Social para las Personas que Viven con VIH/SIDA. El *Statistical Package for the Social Science* fue utilizado para análisis de datos. Los resultados evidenciaron que las puntuaciones medias de apoyo social emocionales e instrumentales fueron satisfactorios, y no influenciados por el sexo ($p=0,954$; $p=0,508$), educación ($p=0,756$; $p=0,194$), estado civil ($p=0,076$; $p=0,446$) y tiempo de terapia antirretroviral ($p=0,480$; $p=0,120$). Las personas diagnosticadas en menos de tres años tenían más apoyo instrumental ($p=0,048$) que los diagnosticados hace más de tres años ($p=0,370$). Los vecinos, jefe y profesionales de salud proporcionaban menos apoyo. Se concluyó que personas con SIDA tienen un apoyo social satisfactorio, principalmente por parte de amigos y familiares que no viven en el mismo hogar.

DESCRIPTORIOS: Síndrome de inmunodeficiencia adquirida. VIH. Apoyo social.

INTRODUCTION

Social support has a positive influence on people living with acquired immunodeficiency Syndrome (AIDS), concerning the ability to face the stress related health-disease process, contributing towards the treatment against the HIV virus and dealing with aspects related to the fear of death.¹ Two categories of social support are noteworthy - the emotional-affective and the instrumental or operational.

The emotional-affective support includes activities related to attention, presence and listening, so that the person feels cared for or appreciated; whereas the instrumental or operational support regards household chores or practical aspects of the treatment itself, like accompanying the person in a medical visit, fetching medicines in the health unit, taking care of the children during medical visits, amongst other activities.²

Moreover, social support is an important variable in the prevention of diseases, promotion of health, therapeutic compliance and in the process of recovery from illness.³ When available in an appropriate manner, it has a protective effect during crisis, such as mourning, retirement, unemployment, illness recovery, and hospitalization, as well as the HIV infection.²

Living with a stigmatizing disease like AIDS represents a source of stress, as people affected by it feel rejected and are, often, victims of prejudice and discrimination.⁴ In these cases, social support can play an important role and should be taken into consideration, in addition to the subject's social integration, as a fundamental issue on behavior related to therapy compliance.³

Nursing assistance offers the appropriate social support to help people living with AIDS in the fight against the disease, as well as in the promotion of positive health care. Integration involving individuals with AIDS, health professionals and social support network, establishes the actions of each sphere in health-disease process and promotes self-care.⁵

The lack of social support affects people's psychological state in a negative way. Hospitalized patients with clinical depression reported greater lack of social support and higher levels of pain.⁶ In addition, factors such as lack of social support, unsatisfying affective relationship of the customer with the multidisciplinary team, inadequate information about the disease, along with the large amount of

drugs, can hinder the compliance to Antiretroviral Therapy (*Terapia Antirretroviral* - TARV). This would interfere in the adjustment on the requirements of treatment and daily routines.⁷ Social support benefits, however, allow for better treatment compliance, less stress and mental problems, and it provides improved self-esteem and psychological well-being.⁸

Therefore, this research was presented as a social support for people living with AIDS. This study is important within the HIV/AIDS context, since patients suffer privations of different orders, where social care is a support that may affect positively on these individuals' life quality.⁶⁻⁸

Information from this study can contribute towards understanding the health-disease process. In addition, the use of social support assessment measures can be incorporated into the monitoring of people living with AIDS, in order to implement more effective health interventions directed to the patient's context, considering the entirety and interdisciplinarity of care.

Thus, the objectives of this study were to assess this social support of people living with AIDS, as well as to analyze the sources of instrumental and emotional support of the participants.

METHOD

This is a descriptive study of cross-transversal line, with quantitative approach, developed from August to December 2012. The survey was conducted at the infectious diseases clinic of a hospital linked to a public University in the Northeastern region of Brazil, which is reference to human resources training and research development in the health area.

A sample calculation was applied to estimate the number of participants. The number of people taking TARV, which were in outpatient monitoring during the year 2011 (n=358) was used as a basis. Confidence level adopted of 95% ($\alpha=0,05$), and a sampling error of 5% ($d=0,05$), representing the difference between the resulting ratio in the sample and the true population ratio. A sample of 215 patients was estimated out of all people living with AIDS taking TARV.

Inclusion criteria were: adults with AIDS, taking TARV for at least three months, and under monitoring. Exclusion criteria were: pregnancy, mental illness or any other condition that interfered with the responses of the study instruments.

Participants were selected through the technique of convenience sampling. Patients were invited to participate in the study as they attended the service for routine consultations. Data collection took place in a private environment, through an interview with a trained researcher, with an average length of 40 minutes, using the Socio-demographic and Clinical Form for People with HIV/AIDS and the Social Support Scale for people living with HIV/AIDS as instruments. Prior to data collection, a pilot test was conducted with 20 patients who were not part of the sample.

The Socio-demographic and Clinical Form for People with HIV/AIDS has already been validated in prior research⁹ and it presented the following variables: sex, education, religion, income, marital status, viral load, lymphocyte count T CD4+, length of diagnostic and length of TARV use.

The Social Support Scale for People living with AIDS (*Escala de Suporte Social para Pessoas Vivendo com HIV/AIDS*) is a derivation of the Social Support Inventory Scale for People Who are Positive or Have AIDS, already validated in Brazil.² The instrument has 22 items, which are divided into two factors: Factor 1, instrumental social support (10 items), refers to the perception and satisfaction regarding the availability of support in the management or resolution of operational issues in the treatment or health care, practical activities of daily life, material or financial aid. Factor 2 relates to the emotional social support (12 items), represented by the perception and satisfaction concerning the availability of listening, attention, information, appreciation, company and emotional support in relation to HIV seropositivity.²

For each of the items of the scale, the person indicated only one answer. Each question offered options of responses following a Likert-type scale, ranging from one to five points. For the interpretation of the results, higher values indicated greater perceived availability and satisfaction with social support. Furthermore, the scale also questioned about people providing both types of support.²

Data were typed using Microsoft Access software and were exported to the software Statistical Package for the Social Science (SPSS), version 18.0, for the processing and analysis of results. Descriptive analyses were performed in order to characterize study's population and to respond to proposed objectives, through the distribution of frequency and descriptive measures (average and standard deviation).

Cronbach's alpha coefficient was used in order to evaluate the internal agreement of the items in the Social Support Scale for people living with HIV/AIDS. The use of this coefficient was suitable for measuring the degree of correlation between answers and items in a scale. Its values range from zero to one, so that the closer to 1, the stronger and more consistent it is the correlation between items. The following ranking was adopted: below 0.70, weak internal consistency; between 0.70 and 0.90, good internal consistency; and above 0.90, high agreement among items.¹⁰

A T-test was used for Student to analyze associations between the average scores on two types of social support related to sex, education, marital status, length of diagnosis and length of TARV use. The choice of association of the support and the studied variables was consistent with previous studies.^{6,11} The statistical significance level adopted was 5%, considering $p < 0.05$ as statistically significant value.

The study followed norms about ethics in human research, and was approved by the Hospital's Ethics Committee under protocol N. 040.06.12. All participants signed an informed consent form and research data were used only for scientific purposes.

RESULTS

Out of the total number of participants, 144 were male (67.0%). Age ranged from 18 to 78 years old (average 39.5 years; standard deviation 10.6). There was a predominance of single subjects (119; 55.4%), and a large proportion of people with 12 or more years of study (169; 78.6%; average 11 years; standard deviation 4,9). Of all participants, 123 individuals had *per capita* income lower than a minimum wage (57.2%). The effective minimum wage at the time of the study was R\$ 545.00, which was equivalent to U\$ 286.00. Regarding religious belief, 148 reported being Catholic (68.9%).

Most of the subjects took TARV for more than 12 months (181; 84.2%); 152 knew the diagnosis of HIV infection for over three years (70.7%); 120 (55.8%) had values lower than 50 copies of RNA viral/ml (average 6.300; standard deviation 21,434.9) and 120 (55.8%) had lymphocytes count T CD4+ greater than 500 cells/mm³ (average 663,8; standard deviation 2,333.7).

Concerning social support, the variability of scores showed the diversity of results in the studied

population. Participants ranged from those who perceived high availability and were satisfied with the two types of social support, to those who indicated null or precarious perceived social support, coupled to a lot of dissatisfaction.

Indicators and scores distribution showed an average of 3.69 for the instrumental dimension (standard deviation 0.72; range from 1 to 5) and average of 3.74 for the emotional dimension (standard deviation 0,67; range from 1,42 to 5). There was a slight asymmetry to the right in both supports, indicating that most participants reported availability and satisfaction with these support mechanisms. Cronbach's Alpha for instrumental and emotional support were 0.86 and 0.83, respectively, which meant good internal consistency of the scale to the studied population (Table 1).

Table 1 - Assessment of the factors of the Social Support Scale for People Living with AIDS. (n=215)

Descriptive measures	Social Support Scale factors	
	Instrumental support 1 - 5	Emotional support 1,42 - 5
Resulting range		
Average \pm standard deviation	3.69 \pm 0.72	3.74 \pm 0.67
Cronbach's alpha	0,83	0,86

In face of the social support sources mentioned by participants, a reduced percentage difference was observed between the sources of social instrumental and emotional support. The main sources of social instrumental support were family members outside the domestic environment (121; 56.3%), friends (112; 52.1%), family members living in the same household (77; 35.8%) and the spouse/partner (75; 34.9%). As for the main sources of emotional support, friends (137; 63.7%), spouse/partner (72; 33.5%), family members living in the same household (72; 33.5%) or people not living in the same household (111; 51.6%) (Table 2).

For both dimensions of social support, trust and bonding, established by the person living with

AIDS, seem to determine the availability and satisfaction with the received support. The availability of people geographically closer was referred as third and fourth option.

From the descriptive data of the scale, it was noted that low frequency of support was received from neighbors, employers, coworkers and health-care professionals. One of the questions was how the person was receiving support from anyone who could offer information and improve the level of knowledge about the health problems being experienced, however, health professionals were barely mentioned.

Table 2 - Sources of instrumental social and emotional support mentioned by people living with AIDS. (n = 215)

Source of Support*	Types of Social Support	
	Instrumental n (%)	Emotional n (%)
Spouse/partner	75 (34.9)	72 (33,5)
Family member living in the same household	77 (35.8)	72 (33,5)
Family member not living in the same household	121 (56.3)	111 (51,6)
Friend(s)	112 (52.1)	137 (63,7)
Employer/co-worker	12 (5,6)	9 (4,2)
Neighbor(s)	10 (4,7)	12 (5,6)
Health professionals	23 (10,7)	30 (14,0)
Others	6 (2,8)	6 (2,8)

*A person may have indicated one or more sources of support.

Statistically significant associations between measures of social, emotional and instrumental support were not observed in the analysis in regard to gender ($p=0.954$; $p=0.508$), education ($p=0.756$; $p=0.194$), marital status ($p=0.076$; $p=0.446$) and length of TARV use ($p=0.480$; $p=0.120$), showing that these variables did not interfere with the social support of the sample studied (Table 3). However, in relation to the time of HIV positive serology diagnosis, it was found that people diagnosed for less than three years had greater instrumental support ($p=0.048$) than individuals diagnosed over three years ago ($p=0.370$).

Table 3 - Description of averages of instrumental social and emotional support according to sex, educational level and marital status of people with AIDS. (n = 215)

Variables	Types of Social Support					
	Instrumental			Emotional		
	Average	DP*	p**	Average	DP	p**
Gender						
Male	3,68	0,72	0,954	3,72	0,66	0,508
Female	3,69	0,76		3,79	0,68	
Level of education						
Illiterate/primary/ incomplete secondary education	3,67	0,70	0,756	3,68	0,60	0,194
Completed secondary education /higher education	3,70	0,74		3,80	0,72	
Marital status						
Living with partner	3,80	0,64	0,076	3,79	0,56	0,446
Living without partner	3,62	0,77		3,72	0,72	
Length of diagnosis						
< 3 years old	3,83	0,80	0,048	3,81	0,70	0,370
≥ 3 years old	3,62	0,68		3,72	0,65	
Length of antiretroviral therapy						
< 12 months	3,78	0,92	0,480	3,91	0,64	0,120
≥ 12 months	3,67	0,69		3,71	0,67	

DP: standard deviation; **Student T.

DISCUSSION

The majority of people living with AIDS and taking TARV consisted of young, single, male adults, with education level and low income. Such information is consistent with the findings of studies carried out with people living with AIDS in different regions of Brazil, such as in the Northeast,¹² Midwest¹³ and Southeast.^{5,14}

Low educational level is a risk factor for the treatment of people living with AIDS, as individuals with less years of schooling present difficulties in following the prescribed therapeutic recommendations.⁷ Despite the small illiteracy rate identified in this study, it should be noted that these people lack prevention interventions and health promotion, and require social support to live well and positively face the results from HIV infection.

As in this study, another research showed that a significant portion of participants were under social vulnerability conditions, living in extreme poverty conditions and low income *per capita*.¹⁵ Poverty is one of greatest challenges faced by people living with HIV/AIDS, considering that the financial deficit is a barrier to meet essential needs, such as eating. It is also a factor for poor treatment compliance, since the shortage of financial resources can hamper the access to health service, especially transportation means.¹⁶

Religious belief constitutes an important part of culture, principles and values carried by patients

to judge and to process information. People with HIV/AIDS perceive religious search as a source of support. In this perspective, the sense of help from religion can be considered as a contributing factor towards physical, mental and spiritual health, considering the hardships imposed by HIV.⁴

Concerning social support, a study carried out with the elderly¹⁷ indicated high measures of emotional and instrumental social support. High satisfaction and availability regarding the received support were noted, as participants were satisfied or very satisfied with the support received. Similarly, in the present study, people living with AIDS showed satisfaction about the social support received. This result is important because both emotional and instrumental support are significant variables to achieve better quality of life.¹⁸

The averages on emotional social support were slightly higher than the ones from the instrumental social support. A similar fact was observed in a research with caregivers of children and adolescents living with HIV/AIDS, which indicated satisfaction with the social support received, especially emotional, as opposed to the instrumental support, which covered financial aid and help in practical and operational aspects of everyday life.¹⁹

The main sources of social support were friends and family not living in the same household. Spouses/partners were not the most mentioned people, probably as a result of AIDS, often occurring

amongst couples with different HIV status, where there is a tendency of the not revealing the diagnosis to the spouse, due to stigma and fear of abandonment.²⁰ Another possibility would be that infection was contracted by the partner him/herself, which can weaken the bond and hinder the availability of social support available.

The lack of social support by family and partners, which were reported by some patients, could result from the omission of HIV seropositivity. This situation shows the difficulty faced by people living with AIDS, fighting against both discrimination and prejudice. The partner or spouse is an important source of emotional support, with a positive impact in several areas of life quality,²¹ which evidenced the need of care directed to the couple and not only to the HIV seropositive individual.

The patient's fear of rejection, the fear of people turning away from them and the fear of being victims of prejudice in society, make them choose to rather not reveal the HIV positive serology diagnosis and to seek ways to hide the diagnosis from other people.²² That fear may be the reason why neighbors and employers/coworkers were less mentioned as a source of social support.

Employers and coworkers were less mentioned, both from instrumental and emotional social support, showing sources of inexpressive support. In working environments, weaknesses were highlighted with specific issues related to HIV, such as the fear of disease transmission at the workplace.²³ Contradictorily, research developed with teachers that were evaluating the social support received at work, showed high appreciation of emotional support.²⁴ This difference is probably due to the fact the study was conducted in an environment that did not involve people with HIV.

This research data reproduced the results of a study with elderly patients with cardiac failure,¹⁷ showing that social support towards emotional aspects were received from family and friends, with little expression from health professionals and incipient amongst employers and/or coworkers. Doctors and other health professionals assisting this population should be aware about factors affecting the quality of life of people living with AIDS, as not realizing that social support related to their HIV condition is associated with low quality of life, perceived social isolation, discrimination and marginalization, which reinforces the importance of creating a social network to support patients.¹¹

The relationship with the health professional and the support perceived by the patient interferes

with treatment compliance. By ensuring that an effective doctor-patient relationship affects the evolution of the disease is to fully endorse that, which is associated with better health and higher level of TARV compliance.²⁴

No significant differences were related to social support received in regard to gender, marital status, education level and length of TARV use. These findings are contrary to what was expected. It was imagined that the males would present greater social support, since females are generally the main family carers.⁹ In addition, another research carried out with people with AIDS indicated that low schooling was related with poor social relations.¹³

However, concerning the length of diagnosis it was clear that patients diagnosed for less than three years showed better instrumental social support. This kind of support refers to the support received on operational issues of treatment or health care, practical activities of daily life and financial aid. This finding could mean that patients receive more instrumental social support at the beginning of the disease. This may result from people's awareness regarding the discovery of the diagnosis.

Research shows that social support received from friends, public network or other people, causes patients to better understand the meaning of events, and to increase their ability to understand doubtful events at the initial moment of the HIV positive serology diagnosis.²⁵

In another investigation, people with higher education were more fulfilled and realized greater availability of emotional support, making it easier to share the diagnosis and doubts about the illness and, as a result, achieve social support. These differences were not attributed to gender or clinical conditions.²

More conflicts have been noted by people living with AIDS, in view of the relationship difficulties with the partner, especially concerning sexual relationships, resulting in sexual abstinence.²¹ These conflicts between partners may be the reason why they were not mentioned more often on social support. There was no significant relationship between received support and marital status.

Studies show that the partner's presence positively affects the illness treatment process, as the partner is a significant source of social support.⁷ This is also observed in diseases that do not have prejudice and are not communicable, such as breast cancer, in which the social support offered by partners is significant, with caring and understanding of the situation being experienced,²⁶ as opposed to the HIV infection, which is full of stigma,²⁷ and is still

related to the initial characteristics of the epidemic, where risk groups predominated with behaviors that were considered inappropriate by society.

CONCLUSION

This study evidenced that people living with AIDS have available and satisfactory social support to help them live and cope with the infection, especially from family members and friends not living in the same household. However, support from neighbors, employers, coworkers and the health team, which are the main professionals to offer full and proper care during health monitoring, is scarce.

In the sample considered for this study, gender, education, marital status and the use of TARV did not interfere in the social support received, evidencing the need to expand studies with other social and clinical characteristics of people living with AIDS. The length of positive HIV serology diagnosis was the only fact influencing the instrumental social support.

This study was limited by the fact that it was carried out in a single collection. If conducted analyzing social support change over time, more important information could have resulted. Thus, the need for more research on this subject is emphasized.

Finally, we reinforce the importance of social support. It can contribute towards self-care, which is needed for treatment; it improves the life quality and it reduces feelings of incapacity in face of the disease. We highlight the need for health professionals' knowledge about social support, in order to contribute towards the maintenance of positive behaviors for TARV compliance, such as attending all consultations and taking medication at the prescribed time. Furthermore, a social support network allows for the reduction of stigma and discrimination resulting from the disease.

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