

## WOMEN WITH AIDS: AVAILABILITY AND SATISFACTION WITH SOCIAL SUPPORT<sup>1</sup>

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### ABSTRACT

This study measured the availability and perceived satisfaction about social support and identified the sources of support for women with aids in treatment with antiretrovirals. This was a quantitative and descriptive study that included 83 users of the Drug Dispensing Unit (UDM) from a public hospital in Santa Maria, Rio Grande do Sul. A demographic and health questionnaire and the Evaluation of Social Support Scale were used between February and April of 2011. The results were presented through measures of central tendency and dispersion. The study revealed that the most received social support was the emotional and that the women are neither satisfied nor dissatisfied with the support received. The main source of support was from family members, especially partners. The importance of this study is highlighted with the recognition of the different needs women with this infection have and the importance of social support as a mediator to maintain positive relationships and health promotion.

**Keywords:** Social support. Acquired immunodeficiency syndrome. Nursing. Women.

### INTRODUCTION

In the 70 decade, investigations on social support were relevant in the literature especially pointing out the influence of social interactions in the well-being and health of people. During that time, the studies seek to understand the vulnerabilities of people to diseases in the face of their instability or absence of social support<sup>(1)</sup>.

Social support is understood as information that leads the person to believe that he is loved, cared for, that people are concerned about them, and that their social network has mutual obligations<sup>(1-2)</sup>.

This issue has raised interest to the extent that availability and satisfaction with social support seems to protect people with chronic diseases<sup>(1)</sup>. Social support has a mediating role during stressful events for the maintenance of health and embracing individuals who are facing the possibility of illness in certain situations of life<sup>(3)</sup>.

For this reason, this construct has been investigated in people with Aids, which is a stigmatizing disease from the social point of view that causes physiological debilitation due

to decreased immunity.

In addition to these aspects, people living with aids, especially women, have been shown to be vulnerable because of difficulties in negotiating prevention measures such as the use of condoms during intercourse and the non-disclosure of their serological condition to their close and significant people<sup>(4)</sup>. Often these women experience situations of discrimination and prejudice as the result of seropositivity, partly because of ignorance and lack of information about the disease, or for being associated with risk groups and engaged in transgressing behaviors<sup>(4)</sup>.

Upon diagnosis, women experience feelings of insecurity and uncertainty, especially those who felt protected or invulnerable because they were in stable and monogamous relationships<sup>(5)</sup>.

Furthermore, the profiles of reported Aids cases in the Southern region<sup>(6)</sup> show that some situations indicate increased vulnerability for women resulting from low level of education and increasing numbers of HIV-infected people at reproductive age. This aspect requires special attention in health services because it represents real possibilities for vertical transmission (from mother to child) at the time of delivery and/or

<sup>1</sup>Study extracted from the Master's degree Dissertation. It will be published in the research paper section.

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breast-feeding in addition to the possibility of transmitting the infection to others<sup>(7)</sup>.

Aids reveals the importance of discussing and questioning syndrome related themes such as sexuality, social vulnerability, diagnosis disclosure, imminence of death, prejudice, wish to motherhood, and gender relations among others<sup>(7)</sup>.

Therefore, the relevance of positive social relationships to face the problems arising from the disease is coupled with the importance of revealing the implications of this infection in women with possibilities to increase personal trust among those involved, both in the social, physical, and biological stand point<sup>(1,3)</sup>.

Thus, the present study, which is part of a master's degree dissertation<sup>(8)</sup>, had the objective of identifying the perceived dimension of support social, the users' satisfaction about this support, and the sources of social support for women with Aids in anti-retroviral treatment (HAART) in a public hospital in the countryside of Rio Grande do Sul, Brazil.

## METHODOLOGY

This was a quantitative, descriptive, and exploratory transversal study developed in the Drug Dispensing Unit (UDM) in HIV/Aids, at a public hospital in the countryside of RS.

A total of 177 users participated in the study, of these, 83 were women between 19 and 70 years old, residents in the cities in the Midwestern region of the State, in use of HAART, and systematically registered in the UDM. Those with cognitive limitations that prevented the understanding of the study and users' relatives/friends who have accessed the service only to pick up medicines were excluded.

The data were collected using a questionnaire for the socio-demographic and health characterization of users and the Evaluation of Social Support Scale for people living with HIV/Aids. The first instrument was developed for the study and contained questions for the social and medical-clinical characterization of the users. The second was developed by Canadian researchers to measure social support and perceived satisfaction by HIV positive people and Aids patients; this instrument has

been translated and adapted to the Portuguese by Seidl<sup>(1)</sup>.

The instrumental dimension of social support shows 12 items (six about availability and six about satisfaction) and assesses the perception and satisfaction of individuals about availability of support to resolve practical issues in the everyday life. The emotional dimension also shows 12 items (six about availability and six about satisfaction) and assesses the perception and satisfaction regarding availability of listening, attention, information, self-esteem, and emotional support regarding the individual's health condition and treatment. The answers were scored in the five-point Likert scale in regard to frequency and satisfaction with the support sources; the scores ranged between (1) never to (5) always for support availability, and from (1) very satisfied to (5) very dissatisfied for satisfaction with the support. The average values assigned to the items marked for each factor (perception and satisfaction) was calculated for the composition of scores; therefore, the scores varied from one to five, for both emotional and instrumental support. Higher values indicate greater perceived availability and greater satisfaction with social support.

The data were collected between February and April of 2011, during the hours of operation of the service, i.e. two days a week in the morning (Tuesday and Thursday) and afternoons (Monday to Friday).

The invitation to participate in the study was presented to users when they came to the UDM to pick up their medication. The participants received assistance through the application of the instruments, which were filled individually in the room next to the service; the average fill time was sixty minutes.

The number of people who met the inclusion criteria (700 people) and the percentage of treatment adherence (60 percent) were considered for sample size calculation. From a real population of 420 subjects, the study sample was composed of 177 users, of which 83 were women selected by simple random sampling.

Those who did not attend the service for a period equal or longer than 90 days since the last prescription filing, according to recommendations from the Ministry of Health<sup>(9)</sup>, were considered as

abandoning the treatment or non-adherent members.

The data collected were saved in a database by independently double input in Excel worksheets and analyzed statistically with the aid of the *Statistical Package for the Social Science software*. The internal consistency of the Evaluation of Social Support Scale was evaluated by the Alpha Coefficient of Cronbach. The results were analyzed and presented through measures of central and dispersion trends.

The study was submitted to and approved by the Research Ethics Committee from the institution (CEP-Dean/UFSM) under the number CAAE 0377.0.243.000-11.

## RESULTS AND DISCUSSION

Eighty-three women with aids, from Santa Maria (47.9%), married (28.4%) and separated (24%), at ages ranging between 19 and 70 years old, with an average age of 40 years old (SD = 10.04) were interviewed.

The socio-demographic characteristics of the participants were similar to those reported in other investigations<sup>(10-12)</sup> and in accordance with the data from the Brazilian epidemiological bulletin<sup>(6)</sup>, showing stability in the gender ratio since 2006 (1.7 new cases in men for each case in women), which sustains the feminization profile of the epidemic.

In this study, the women were at an economically productive age, however 32% faced difficulties to enter the labor market and 65% had two or more children, in addition to the low educational and income level; these data resemble those from the Ministry of Health<sup>(6)</sup>.

Twenty percent of the participants were professionally active in stable jobs (with labor rights) or temporary jobs (self-employment), and 19.2% were unemployed, 12% never worked, and 10% were retired.

The predominant occupation was related to domestic services (69%) referred to as a maid, cook, housekeeper, and those who were homemakers.

The schooling profiles were distributed as 48% with incomplete elementary school, 12% with complete high school, and 4.8% with complete higher education; none held a graduate degree. Sixty-four percent declared an income of up to one minimum wage (national minimum

wage of R\$ 545.00, which is equivalent to approximately US\$230.00) and 4.8% between one and three national minimum wages.

The results show that, from the onset of the disease, the changes in the epidemiological profile are strongly associated with vulnerability, particularly in women, both by the conditions of poverty, devaluation in the labor market, gender issues that lead to reproductive and sexual submission, and biological factors that favor increased chances of HIV infection among women<sup>(11-13)</sup>.

The schooling profiles in this study match the Brazilian profile, which highlights that, between 1980 and 2011, the numbers of women with complete elementary school increased and the predominance of men beyond this level is observed. The epidemiological data<sup>(6)</sup> also showed that women with Aids who have more than 12 years of schooling are also outnumbered when compared to men. Other studies<sup>(5,11-12)</sup> have also identified the low educational and income levels in women, which according to the authors, can be a vulnerability factor because it influences the absorption of information and cognitive abilities needed to deal with treatment difficulties and demands.

Therefore, schooling can compromise adherence to treatment because users might have difficulties remembering the names of medicines; however, this situation can be generally bypassed by familiarity with the therapy related to characteristic of tablets or containers such as size, color, or printed number<sup>(11-12)</sup>. This observation underscores the importance of the attention required by health teams when providing guidance to users<sup>(9-10)</sup>.

Just as the low levels of education, minimum household incomes can hamper the everyday treatment of users with HIV/Aids because the frequent visits to health services imposed by the disease can be prevented by the lack of financial resources<sup>(5,11)</sup>.

Sexuality is also an anxiety factor and is closely intertwined to the disease because it is the most frequent cause of transmission, it is related to issues pertaining to marriage, maternity, gender relations, and other aspects of feminine nature associated to the prevention of aids<sup>(14,5,13)</sup>.

Motherhood is reported as a source of concern in women with Aids because of the fear of transmitting HIV to their children this fact often implies the decision to not experience motherhood. In other instances, they are not prepared to face the situations arising from the decision to take the pregnancy forward resulting from prejudice and need to hide their serologic status at work, with family, socially, and sometimes with their sexual partner<sup>(13-14)</sup>.

Conversely, the idea of motherhood as a biological attribute, often justifies the need of the experience of motherhood, leading these women to believe that they will not be complete if they do not have children<sup>(5,11)</sup>. This explains the predominance of women in the present study with two or more children (65%).

The health characteristics showed that the number of hospitalizations ranged from one to twenty with an average of 2.41 times. The time from diagnosis ranged from one to twenty-two years, and the time under HAART ranged from one to twenty years.

The number of hospitalizations can be associated with late diagnosis awareness, when the disease is already in advanced stages and the patient shows characteristic symptoms of the syndrome such as immunodeficiency and severe clinical complications. Some authors<sup>(5,13)</sup> report that certain people require longer times to assimilate the HIV/Aids positive result and take a more active stance in the face of infection. By denying the result, they fail to get help for their physical and emotional health and do not reveal their condition to their closest people.

There is a need to approach women with HIV/Aids beyond the drug treatment or clinical control of symptoms, by enabling the dialogue between actors considering the woman as someone who needs care and aimed at not only the prevention of complications arising from HIV infection but also to help them to see themselves as women, daughters, professionals, and in many cases mothers and wives<sup>(13,15)</sup>.

The Cronbach's alpha coefficient of 0.93 indicated the adequate internal consistency and reliability of the Evaluation of Social Support Scale in this study.

The available social support perceived by the women showed the emotional support with slightly higher average, both in availability of emotional

support ( $\bar{x}=3.33$ ;  $DP=1.105$ ) and satisfaction ( $\bar{x}=3.39$ ;  $DP=1.074$ ), when compared with the instrumental support in which the availability average was 3.04 ( $DP = 1.409$ ) and 3.38 ( $DP = 1.045$ ) for satisfaction.

The perception of receiving greater emotional support than other support types corroborate the results presented in other studies<sup>(1,13)</sup> explaining these results based on the peculiarities of living with the disease and the negative impact of this experience in social relations. The awareness of contamination is devastating to women, especially among those who believed to be distant from the risk of transmission by maintaining stable relationships, with fixed and unique partners<sup>(4-5,13)</sup>. The discovery about the disease causes an impact on the lives of these people, which can result in a prolonged state of stress in addition to the fear and anguish about what the infection mean in their lives. The emotional support received from close people provide subsidies to assist in the difficulties experienced<sup>(13-14)</sup> and constitute important factors of protection to those who must face the disease and receive the diagnosis. The feeling that they are cared for and cherished, that others are interested in them, and are available in case of need leads to satisfaction for the relations they have<sup>(16)</sup>.

In the emotional support, the highest availability average was in valuing people ( $\bar{x}=3.70$ ;  $DP=1.237$ ) and satisfaction ( $\bar{x}=3.71$ ;  $DP=0.918$ ). The lowest availability average ( $\bar{x}=2.96$ ;  $DP=1.374$ ) and satisfaction ( $\bar{x}= 3.34$ ;  $DP=1.074$ ) was in the support to feel part of someone's family (neighbors, colleagues), which means that women are "rarely" supported in this situation, however, they expressed being "not satisfied, nor dissatisfied" with this support. The quest for personal valuation assumes the need from people to feel loved and respected regardless of the diagnosis of a disease that causes rejection and discrimination in society.

The study revealed that women are "neither satisfied nor dissatisfied" with the support of people from the community because they do feel integrated into their families or insecure in the revelation of their diagnosis in these environments. Similarly, other studies<sup>(4,13,15)</sup> showed that fear and prejudice are factors that prevent women from talking about their illnesses

in different social spaces, which can negatively affect social and affective relationships.

Table 1 shows the data from availability and satisfaction in emotional support perceived by the studied women.

The results from the instrumental support showed that the women "sometimes" receive support ( $\bar{x}=3.48$ ;  $DP= 1.409$ ) and were

"neither satisfied nor dissatisfied" ( $\bar{x}=3.61$ ;  $DP=1.057$ ) in concrete situations that would facilitate the achievement of health treatment. Nevertheless, it was identified that this was the situation that aroused greater availability and perceived instrumental satisfaction by the users.

**Table 1** - Availability and satisfaction on social emotional support for women with Aids, Santa Maria/RS, 2011.

SOCIAL EMOTIONAL SUPPORT	AVAILABILITY	SATISFACTION
	Average (SD)	Average (SD)
Have you received support that makes you feel valued as a person?	3.70 (1.237)	3.71 (0.918)
Have you received support from someone with whom you can vent or talk about issues related to your illness?	3.20 (1.421)	3.39 (1.124)
Have you received support from someone who provides information, improving your knowledge about your health problems?	3.46 (1.252)	3.58 (1.049)
Have you received support from someone who makes you feel part of your family, neighborhood, and work?	2.96 (1.374)	3.34 (1.074)
Have you received support that helps you improve your mood, emotional state, and state of mind?	3.45 (1.232)	3.61 (0.998)
Have you received support when you need company for fun and leisure activities?	3.01 (1.401)	3.36 (1.215)

Table 2 shows data from availability and satisfaction in instrumental support perceived by the studied women.

Support appears in some studies<sup>(1,5,16)</sup> as fundamental in established relationships because it can prevent isolation and loneliness and facilitate the clinical monitoring of the disease

for infected women. Authors<sup>(4-5)</sup> report in their studies that women change their lives after the diagnosis, they fail to do what once was routine, avoid social activities and work, and feel abandoned by the people of their conviviality.

**Table 2** - Availability and satisfaction in instrumental social support for women with Aids, Santa Maria/RS, 2011.

SOCIAL EMOTIONAL SUPPORT	AVAILABILITY	SATISFACTION
	Average (SD)	Average (SD)
Have you received support in concrete situations that facilitate the completion of your health treatment?	3.48 (1.409)	3.61 (1.057)
Have you received support in financial issues, such as sharing the costs of the household, or donated or borrowed money?	2.71 (1.410)	3.22 (1.105)
Have you received support in practical activities in your daily life?	2.96 (1.477)	3.47 (0.992)
Have you received support in relation to your own health care?	3.10 (1.470)	3.54 (0.954)
Have you received support from person (s) with whom you can count in case of need?	3.12 (1.443)	3.36 (1.089)
Have you received support from people who give you things that you need in your everyday life?	2.81 (1.329)	3.30 (1.045)

On the other hand, women seem to adopt different strategies of adaptation to the illness and treatment such as performing household chores on the evening before appointments or

requesting time off work claiming other reasons to go to the hospital. The double shift workday is sometimes perceived by these patients as natural

because, according to them, it is up to women to take more burden than men<sup>(5,10,13)</sup>.

In situations of financial support they "rarely" receive support ( $\bar{x}=2.71$ ;  $DP=1.410$ ) and are "neither satisfied nor dissatisfied" with this support ( $\bar{x}=3.22$ ;  $DP=1.105$ ). The perception of insufficient support in financial situations was identified by other authors<sup>(5,17)</sup> who consider the existence of additional problems after the diagnosis, which normally are not presented to healthy people. Among them, the need for healthy eating, frequent visits to health services, clinical control, and systematic laboratory tests are cited<sup>(5,17)</sup>.

The difference between users in their adaptation to the infection may be related to the social and family support available to them. In the studied group, the major sources of support that provided instrumental support were from husbands/partners/boyfriends, cited by 50% of the users, followed by relatives who do not reside with the user (35%), and friends (32%). In the emotional support, a predominance of husbands/partners/boyfriends (51%) was observed, friends (49.3%), and family members who do not reside with the user (38.9%). Health professionals were mentioned by 37.3% of the users as a source of emotional support, whereas in the instrumental support family members who reside with the user showed a slightly higher percentage (28.7%) than health professionals (26%).

Similarly, studies<sup>(1,10,12)</sup> performed with HIV + people observed greater adherence to treatment in individuals with a consistent social network, which helped them in solving problems, especially church friends and spouses.

The family can also become an important ally in this process, protecting the person in the everyday life because it acts as an agent for help and referral, interferes with self-esteem, accelerates the healing and recovery processes<sup>(12,16)</sup>, and plays a fundamental role in the well-being of its members<sup>(1,14)</sup>.

Conversely, the family may find it difficult to provide support in the presence of an unexpected and serious illness such as Aids<sup>(5,15)</sup>. The support can be incipient or even ambivalent, depending on the clinical conditions in which the individual finds himself and the family dynamic, which can make the family a source of support or stress<sup>(16)</sup>. The

existence of a stigma regarding poverty and women, which often are associated to carelessness and promiscuity, may lead to greater vulnerability in relation to HIV infection<sup>(10,13)</sup>.

Thus, studies underscore the need for a set of actions and concurrent care to HIV-positive women, not limited to therapeutic assistance, but covering the various aspects and the evolution of this disease, allowing the appreciation of life and quality of living with Aids<sup>(9,14)</sup>.

## CONCLUSION

Emotional support was considered by the studied group as the most available and the cause of the greatest satisfaction. In general, women "sometimes" received assistance, especially in relation to instrumental support and felt "neither satisfied nor dissatisfied" with social support in the two dimensions. Actions of support related to financial matters and feeling of being embraced by friends and relatives from known people were perceived as rarely available.

The impact on the lives of women facing the diagnosis, especially related to sexuality, maternity, gender, and social exclusion lead to the search for personal valuation, self-esteem, respect, and receipt of support from their families, especially spouses.

The importance of exploring the effects of Aids on the lives of women in the different health contexts stands out because it is believed that they have needs that are distinct than those in the male population; women present major disadvantages with regard to prevention, control and treatment of HIV infection, and subjective needs that go beyond the biological conditions.

It is up to the team, and in particular the nurse, to contribute to health education initiatives and development of adaptation strategies to this health condition. The stimulus to the collective or individual dialogue that takes into account the cognitive and education level of users is critical to ensure the knowledge necessary for them to have greater control over their health.

This study confirmed the importance of relationships of solidarity and help in the daily lives of women with Aids because the inclusion

of this referential goes beyond the biomedical rationality and approximate expanded care.

Therefore, it is suggested that health professionals from various fields of knowledge serve women living with Aids with an integral

perspective considering the social, family, individual, and programmatic dimensions and contemplate the stimulation to strengthened social support networks on their strategies.

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## MULHERES COM AIDS: DISPONIBILIDADE E SATISFAÇÃO DO SUPORTE SOCIAL

### RESUMO

Objetivou-se mensurar a disponibilidade e satisfação percebida do suporte social e identificar as fontes de suporte das mulheres com aids em tratamento com antirretrovirais. Pesquisa quantitativa, descritiva, com amostra de 83 usuárias da Unidade Dispensadora de Medicamentos de um hospital público em Santa Maria, no Rio Grande do Sul. Utilizou-se um questionário sociodemográfico e de saúde e a Escala de Avaliação do Suporte Social, no período de fevereiro a abril de 2011. Os resultados foram apresentados pelas medidas de tendência central e dispersão. O estudo revelou que o suporte social mais recebido foi o emocional e as mulheres estão nem satisfeitas, nem insatisfeitas com o suporte recebido. A principal fonte de suporte foi a dos familiares, especialmente, o companheiro. Destaca-se a importância deste estudo quando se reconhece as diferentes necessidades das mulheres com essa infecção e a importância do suporte social como mediador na manutenção de relacionamentos positivos e na promoção da saúde.

**Palavras-chave:** Apoio social. Síndrome da imunodeficiência adquirida. Enfermagem. Mulheres.

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## MUJERES CON SIDA: DISPONIBILIDAD Y SATISFACCIÓN DEL APOYO SOCIAL

### RESUMEN

Se objetivó medir la disponibilidad y satisfacción del apoyo social percibido e identificar fuentes de apoyo de las mujeres con la Sida en tratamiento antirretroviral. Es un estudio cuantitativo y descriptivo, con muestra de 83 usuarios de la Unidad Dispensadora de Medicamentos de un hospital público en Santa Maria de Rio Grande do Sul. Se utilizó un Cuestionario sociodemográfico y de salud y la Escala de evaluación del apoyo social de Febrero a Abril 2011. Los resultados fueron presentados por las medidas de tendencia central y de dispersión. El estudio reveló que el apoyo social más recibido fue el emocional y las mujeres no están satisfechas o insatisfechas con el apoyo recibido. La principal fuente de apoyo fue de los miembros de la familia, el compañero. Se destaca la importancia de este estudio cuando reconoce las diferentes necesidades de las mujeres con esta infección y la importancia del apoyo social como mediador en el mantenimiento de relaciones positivas y promoción de la salud.

**Palabras clave:** Apoyo social. Síndrome de inmunodeficiencia adquirida. Enfermería. Mujeres.

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