








Family members of children exposed to Human Immunodeficiency Virus: satisfaction with social support

Familiares de crianças expostas ao Vírus da Imunodeficiência Humana: satisfação com o suporte social

How to cite this article:

Hausen CF, Quadros JS, Bick MA, Ceretta PS, Langendorf TF, Padoin SMM, et al. Family members of children exposed to Human Immunodeficiency Virus: satisfaction with social support. Rev Rene. 2021;22:e61086. DOI: <https://doi.org/10.15253/2175-6783.20212261086>

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ABSTRACT

Objective: to analyze the satisfaction of family members with the social support received during the care of children exposed to human immunodeficiency virus. **Methods:** cross-sectional study with 87 relatives of these children, in a university hospital. The Satisfaction with Social Support Scale was used. Sociodemographic and clinical variables were analyzed using the Lilliefors, Kruskal-Wallis and Mann-Whitney tests. **Results:** the participants, mostly mothers, showed high satisfaction with the total social support (57 out of 75 points). The average indicated that the satisfaction was high for the support received from the family (80.46), followed by that provided by friendships (72.86) and intimacy (63.36) and low for social activities (55.65). The group classified with income up to R\$879.00 presented less satisfaction with social support (average=50,83) if compared with the group of income superior to R\$879.00 (average=58,78) ($p=0,014$). **Conclusion:** the satisfaction with the social support of the relatives is high and influenced by income. **Descriptors:** Infectious Disease Transmission, Vertical; HIV; Social Support; Caregivers; Child Health.

RESUMO

Objetivo: analisar a satisfação de familiares com o suporte social recebido na vigência do cuidado de crianças expostas ao vírus da imunodeficiência humana. **Métodos:** estudo transversal com 87 familiares dessas crianças, em um hospital universitário. Utilizou-se a Escala de Satisfação com o Suporte Social. Variáveis sociodemográficas e clínicas foram analisadas por meio dos testes Lilliefors, Kruskal-Wallis e Mann-Whitney. **Resultados:** as participantes, majoritariamente mães, demonstraram alta satisfação com o suporte social total (57 de 75 pontos). A média indicou que a satisfação foi alta para o suporte recebido da família (80,46), seguida do provido pelas amizades (72,86) e intimidade (63,36) e baixa para atividades sociais (55,65). O grupo classificado com renda até R\$ 879,00 apresentou menor satisfação com o suporte social (média=50,83) se comparado com o grupo de renda superior a R\$ 879,00 (média=58,78) ($p=0,014$). **Conclusão:** a satisfação com o suporte social dos familiares é alta e influenciada pela renda. **Descritores:** Transmissão Vertical de Doença Infecciosa; HIV; Apoio Social; Cuidadores; Saúde da Criança.

EDITOR IN CHIEF: Viviane Martins da Silva
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Introduction

The child exposed to the Human Immunodeficiency Virus (HIV) needs the usual childcare and also has specific demands arising from vertical exposure to the virus infection. These special cares begin immediately after delivery through the preparation and administration of antiretroviral drugs, immunizations, and specialized service follow-up. Thus, family caregivers need to modify and adapt their daily lives, according to the demands of care. The demands are assumed by one of the members of the family nucleus, mostly the mother of the children⁽¹⁻²⁾.

These women, who live with HIV, already present demands regarding their treatment and health follow-up. When they have children, they also assume the role of main caregiver. Since pregnancy, these mothers and their families face the fear of prejudice and sometimes choose to hide their serological condition and possibilities of exposure to the virus. Failure to talk about their diagnosis can negatively influence the self-care of themselves and the child and, consequently, their health and quality of life^(1,3).

The daily demands for care and the restriction of the caregivers' social network imply overload, including emotional⁽³⁾. Being able to count on social support may favor the performance of care at home, allowing women to structure and organize their routine from pregnancy, which will help in the adherence to prophylaxis of vertical HIV transmission⁽⁴⁾. Social support is defined by Cobb as the information that leads the individual to believe he has value and is part of a social network. It has been shown that adequate social support can protect the individual from a variety of pathological states, as well as accelerate recoveries and facilitate compliance with prescribed medical regimens⁽⁵⁾.

In view of the above, the importance of social support for the families of children exposed to HIV stands out, given its relevance to health and living with diseases in times of stress. Studies that allow to know and evaluate the satisfaction with the social support received from the family member responsible

for daily care can directly influence the well-being and quality of life of these individuals. Their results may contribute to the care dedicated to the child and the success of the prophylaxis of vertical transmission.

The knowledge about social support provides the professional conditions to perform the analysis of the context of family members of children exposed to HIV as well as meet the demands of daily care with themselves and with the child (children), so that they seek strategies to strengthen their networks. In this sense, the objective was to analyze the satisfaction of family members with the social support received during the care of children exposed to the human immunodeficiency virus.

Methods

This is a cross-sectional survey, conducted at a university hospital in southern Brazil that acts as a reference for outpatient follow-up of people living with HIV. The data collection period was from February 2015 to September 2017.

The study population was composed of family members responsible for the care of children exposed to HIV in outpatient care in the service. Inclusion criteria were to be a family member responsible for the care of children vertically exposed to HIV at up to 18 months of age, to follow the child's routine, and to be able to carry out daily care alone. Families who lost outpatient follow-up of children (more than one year without access to the service) and/or without telephone contact were excluded.

The list of possible participants was made by means of the individual notification forms of infected pregnant women and children exposed to HIV, computed in the Aggravated Notification Information System, in the period from 2014 to 2017. Thus, it was possible to access the appointments in the service. The sample was composed of 87 family members of children exposed to HIV, chosen by a non-probabilistic and intentional sampling process established to access the service during the collection period.

Family members were invited to participate in

the research before the consultation and the collection was carried out at that time, after the service. For those without a consultation schedule during the data collection period, the health service provided the telephone contact. In cases where it was not possible to collect in person, the telephone contact expanded the possibility of locating the participants and reduced losses. Previous experiences of the research team and the recognition of the difficult access to the population that tends to diminish the searches to the service with the child's age were determinant for the application of the collection by telephone.

The instrument used for data collection was composed of a form to characterize the family member and the Satisfaction with Social Support Scale. They were considered as sociodemographic variables: gender (male or female), age, marital status (with partner and without partner), schooling (no schooling, complete elementary school, incomplete elementary school, high school, college), municipality of residence, area (urban, rural, peri-urban), employment status (unemployed, with a signed work permit, employee without a signed work permit), monthly family income, considering the minimum wage of R\$ 879,00 (without income, salary, from 1 to 2, 3 or more), number of people living with the income (≤ 2 people to 5), relation of the responsible family member with the child (mother, father, sister/daughter, grandmother/grandfather, aunt/the, other), to have another child under their care (yes or no) and number of children (one child, between two and four children, more than five children). Clinical variables were also collected in the interview and included: having an HIV diagnosis (yes or no), route of infection (unknown, sexual, ignored), time of diagnosis (< 1 year, 1 to 5 years, 6 to 10 years, > 11, not applicable), treatment for HIV (yes or no), some health problem (yes or no), drinking alcohol (yes or no), and drug use (yes or no). The variables in relation to substance use were collected through the caregiver's sociodemographic-clinical form, without using a specific scale.

The Satisfaction with Social Support Scale aims to evaluate the individual's satisfaction with per-

ceived social support⁽⁶⁾, considering that it has been transculturally adapted to the Brazilian Portuguese language⁽⁷⁾. This scale was used with several populations even with relatives of children with chronic health conditions, for example, with Zika Congenital Syndrome⁽⁸⁾. However, this is the first study that applied such scale to family members of children with HIV infection. It is self-completed, and participants indicate how much they agree with each item based on a five-point *Likert* scale: totally agree (5); agree most (4), do not agree or disagree (3); disagree most (2); totally disagree (1).

The scale has 15 items, divided into four factors: satisfaction with friendships (SF), intimacy (IN), satisfaction with the family (SF) and social activities (SA)⁽⁷⁾, according to Figure 1.

Item	Factor
1r. My friends do not look for me as often as I'd like. 2. I am satisfied with the number of friends I have. 3. I am satisfied with the amount of time I spend with my friends. 4. I am satisfied with the activities and things I do with my group of friends. 5. I am satisfied with the kind of friends I have.	Satisfaction with Friendships (SF)
6r. Sometimes I feel alone in the world and without support. 7. When I need to vent with someone, I easily find friends to do it with 8. Even in the most embarrassing situations, if I need emergency support, I have several people I can turn to 9r. Sometimes I miss someone truly intimate who understands me and with whom I can vent about intimate things.	Intimacy (IN)
10. I am satisfied with the way I relate to my relatives. 11. I am satisfied with the amount of time I spend with my relatives. 12. I am satisfied with what I do together with my relatives.	Family Satisfaction (SF)
13r. I do not go out with friends as often as I would like to. 14r. I miss social activities that satisfy me. 15r. I would like to participate more in organizational activities (e.g., sports clubs, Scouts, political parties, etc.)	Social Activities (AS)

Legend: r = inverted items for the analysis

Figure 1 – Satisfaction with Social Support Scale. Santa Maria, RS, Brazil, 2020

The total score can vary between 15 and 75, and the higher the score, the higher is the favorable perception of social support, with no cutoff point ⁽⁷⁾. As for the individual factors score, Friendship Satisfaction varies between a minimum of 5 and a maximum of 25 points; Intimacy scores vary between 4 and 20; Family Satisfaction assumes values between 3 and 15 points; and Social Activity between 3 and 15. For the comparison between factors, the scores were converted, corresponding the value "0" to the minimum factor score and value 100 to the maximum.

The data entry was done in *Epi-info*[®] version 7.2 software in a double independent way. The descriptive analysis (percentage, absolute, mean and standard deviation - SD) was performed using the R 4.0 *software*. The descriptive statistics of the results were performed, and the Lilliefors test was applied to verify the normality of the variables. The non-parametric tests of Mann-Whitney and Kruskal Wallis were applied. The significance level adopted was 5% ($p \leq 0.05$).

The author of the scale has authorized its use. The ethical aspects of research with human beings were respected. Project approved by the Committee of Ethics in Research, Certificate of Presentation of Ethical Appreciation no. 50609615.1.0000.5346, opinion no. 1,348256/2015.

Results

Eighty-seven family members of children vertically exposed to HIV participated in this study. The average age of the children was 10.34 months (SD = 7.86) during the data collection period. Among the family members, 85 (97.7%) were mothers and 2 (2.3%) fathers. Of this total, 62 (71.3%) had no partner, and 47 (54.0%) were aged between 26 and 35 years. As for schooling, 69 (79.3%) of the family members had 5 to 12 years of study, 55 (63.2%) were unemployed, 38 (43.6%) lived with family income between 880 and 1760 reais and 61 (70.1%) had up to 2 people depending on that same income.

Regarding demographic characterization, 73 (83.9%) family members lived in the urban area; 52 (59.8%) had two to four children; 59 (67.8%) had another child under their care, of these 35 (59.3%) exposed children had at least one HIV-positive brother. Regarding the occupation, 36 (41.4%) reported being from home and 48 (55.2%) had another occupation. Regarding the use of psychoactive substances, 56 (65.1%) denied the use of alcohol and 84 (96.6%) of drugs. Regarding the clinical characteristics of the family members, 83 (97.6%) live with HIV, 48 (57.8%) were sexually infected, 33 (39.7%) found out the diagnosis within one to five years, and 77 (92.8%) perform the treatment.

The total scores of the scale varied between a minimum of 30 and a maximum of 75, with an average of 57 points (SD = 11.0); 73 (83.9%) participants are satisfied with the number of friends they have and 50 (57.5%) are satisfied with the time they spend with friends; 53 (60.9%) are satisfied with the activities they perform together and 68 (78.2%) are satisfied with the type of friends they live with. Most of them, 31 (35.0%), disagreed about being dissatisfied with the number of times their friends look for them.

Among the family members, 51 (58.6%) have friends to talk to and 48 (55.2%) in cases of emergency. Of these, 44 (50.6%) disagree about feeling without support and 33 (37.9%) about the lack of someone to vent intimate matters. For family support, 61 (70.1%) are satisfied with the amount of time they spend with their relatives, 62 (71.3%) with the way they relate to each other as a family, and 67 (77.0%) with family activities. As for social activities, 30 (34.5%) agree that they do not go out with friends as much as they would like, 33 (37.9%) do not miss social activities and 59 (67.8%) would not like more organization activities. The results, according to the average normalized by factors, indicate that family members are more satisfied with the support received from the family (80.46), followed by friendship (72.86), intimacy (63.36), and social activities (55.65) (Table 1).

In the perception of support received from the

family, 70 (81.4%) are satisfied with the time they live together, 70 (81.4%) with what they do together and 66 (76.5%) with the way they relate. With the support provided by friendship, 79 (91.9%) feel satisfied with the amount of friends, 76 (88.9%) with the type of friends, 62 (72.1%) with the activities they do together, 61 (70.9%) with the time they spend together, and 36 (41.9%) feel that friends seek them out as many times as they would like. With the support received from intimacy, 65 (75.6%) consider having support in cases of emergency, 58 (67.4%) count on intimate friends to vent, 50 (58.1%) feel alone and without support and 36 (41.9%) have someone to vent on intimate matters. And with social activities, 61 (70.9%) are satisfied with their participation in organizational activities, 38 (44.9%) do not miss social activities that satisfy them, and 31 (36.0%) go out with friends as many times as they would like.

Table 1 – Normalized values of the Social Support Satisfaction Scale factors. Santa Maria, RS, Brazil, 2017 (n=87)

Values	Factor 1 (SF) Satisfaction with Friend- ships	Factor 2 (IN) Intimacy	Factor 3 (SF) Family Satis- faction	Factor 4 (SA) Social Activities
Minimum	7.00	4.00	3.00	3.00
Maximum	25.00	20.00	15.00	15.00
Average	20.11	14.14	12.66	9.68
Median	21.00	15.00	15.00	10.00
Standard Deviation	4.38	4.99	3.60	3.82
Asymmetry	-0.76	-0.57	-1.55	-0.22
Kurtosis	-0.07	-0.77	1.32	-1.07
Standardized average	72.86	63.36	80.46	55.65
Lilliefors	0.132	0.140	0.306	0.108
p-value	0.001	0.000	0.000	0.014

Observing the values presented in Table 2, we find a statistically significant association between the income variable and the total Satisfaction with Social Support Scale flow ($p=0.014$). Thus, the group classified with income up to R\$ 879.00 presents lower satisfaction with social support (average = 50.83) if com-

pared with the group with income above R\$ 879.00 (average = 58.78).

Table 2 – Differences in the central tendency of the Satisfaction with Social Support Scale and characteristics of the family member of the child exposed to HIV. Santa Maria, RS, Brazil, 2017 (n=87)

Variables	n	Average	Average rank	Statistical test	p-value*
Income (Real)				-2.458	0.014
≤ 879,00	24	33.23	50.83		
> 879,00	63	48.10	58,78		
People/income				0.185	0.912
≤ 2	2	50.50	60.00		
3 a 5	61	43.47	56.49		
> 5	24	44.81	56.54		
Children				0.885	0.642
≤ 1	23	45.87	57.48		
2 a 4	52	42.05	55.73		
> 4	12	48.88	58.58		
Current job				0.790	0.674
Work and social security card	20	42.78	56.85		
Without professional license	12	50.00	59.08		
No	55	43.14	55.95		
Occupation				0.217	0.641
Housewife	36	41.07	55.61		
Other	48	43.57	57.38		

*Mann-Whitney (two samples) Kruskal Wallis (k samples)

Discussion

The limitations of the study are related to the fact that the collection was developed in a city in the central region of the state of Rio Grande do Sul, centered in a single health service, which is outpatient and located in a university hospital, which limits the generalization of the results described here. Furthermore, the fact that the participants are the family members responsible for the care of children, which may have limited the understanding in a more precise way about the satisfaction with the social support of other family members and its impact on the children's lives. Another weakness of this research is the lack of sample calculation. However, the results may positively

imply the clinical practice, given the importance of the team being attentive to the low satisfaction with the social activities of family members in order to observe, besides the health-disease process, the social and emotional issues.

It becomes evident that the social support benchmark is applicable by nursing, especially for its role with the team in reducing prejudice to favor the inclusion of women living with HIV in activities in society. It is suggested the promotion of opportunities for them to develop leisure activities, share their feelings and doubts, and expand their social network. These opportunities tend to positively influence the development of social support for the care of themselves and the child(ren) exposed to HIV.

Family members are satisfied with the perceived social support, since it resembles another research, also of a quantitative nature, with the population of women living with HIV⁽⁹⁾. In a quantitative study conducted in northeastern Brazil with an adult population living with HIV, in which a different instrument was used to evaluate social support, the results were also satisfactory⁽¹⁰⁾. Other qualitative researches in the Southeast of the country have also found results that converge with those of this research, which point out social support as a positive strategy to cope with the virus⁽¹¹⁾. Furthermore, in a quantitative study with a population of women with HIV, it was possible to observe that women who demonstrated greater satisfaction with social support presented less symptoms of fatigue and sadness, being support a protective factor⁽¹²⁾.

Regarding satisfaction with friendships, the findings differ from other qualitative investigations that interviewed HIV-infected women, whose reports describe the loss of social support by friends. They tend to omit their serological condition due to fear of abandonment, discrimination, and social exclusion^(1,12). In a study that uses a different scale to assess social support, less intimate friends such as neighbors and co-workers are cited as the least supportive⁽¹⁰⁾. Such difficulties may imply the support of friendships. In

the analysis of the on-screen study, this fact may be related to the lower average of the intimacy factor, if compared to friendship.

As for the results related to the intimacy factor, the findings corroborate other studies, in which the lack of intimate people to vent and count in case of emergencies can influence the disclosure of their diagnosis and, also, the child's exposure condition. However, it was observed that the exchange of experiences among mothers in waiting rooms made this place a relationship mediator for emotional support, information and appreciation⁽¹⁾. This can be a strategy aimed at strengthening bonds between peers.

Regarding family social support, the results corroborate a study with patients with schizophrenia, in which the aforementioned instrument was utilized, and whose results were of high satisfaction with family support⁽¹³⁾. Similar results indicate that the main sources of support cited by women with HIV and mothers of exposed children are family members, especially the partner and the child's grandmother^(1,9,14).

The family becomes a source of emotional and instrumental support and assists them in the difficulties of treatment and care required by the child. Moreover, it is a facilitating factor for the usual child care and specific for prophylaxis. Mothers, husbands and brothers of the main caregivers have organized themselves for the care of the child, even when facing access difficulties permeated by prejudice and stigma^(1,15). The support of the family also helps in the demands resulting from the woman's infection and favors her adherence to treatment⁽⁴⁾. There is need for investment in studies that value the performance of family members as participants and their homes as places for new research⁽¹⁶⁾.

Regarding the social activities performed, this was the factor with the lowest average found in this research, which resembles the results of another study with patients with schizophrenia, in which a low average was observed for satisfaction with social activities. The importance of providing greater participation in society is also highlighted, as it is associated

with quality of life and improvement in mental health⁽¹³⁾.

The result of this research shows that women do not perform social activities as often as they would like, a fact that may be related to the concealment of the diagnosis, due to the stigma and prejudice that still permeate social relations. This converges with the study in which the population composed of women living with HIV was neither satisfied nor dissatisfied with the support of the community, due to the fact that they felt insecure to disclose their serological condition in social spaces⁽⁹⁾.

Constantly, people with HIV go through embarrassing situations due to social stigma. Prejudice and the need to conceal the diagnosis are the main reasons for isolation, being considered difficult factors to care for a child with the virus⁽⁴⁵⁾. This isolation becomes common, initiated by the family circle, extending to the neighborhood, health services, and community. Caregivers claim to deprive themselves of close contacts with people for fear of stigma, and the lack of support is linked to the feeling of frustration and sadness, one that the individual becomes isolated and, in turn, isolates himself from the social environment⁽¹⁾.

The prejudice directed to parents and the difficulties faced in this process may extend to the child as much as to the school environment and may cause developmental delays and psychological problems^(4,17). The experience of the family member in facing difficulties in the treatment of the child in a solitary and silent manner causes overload⁽³⁾.

The correlation of income with Satisfaction with Social Support Scale was also found in a study that evaluated the role of informal and formal social support in mental health, parental self-efficacy and satisfaction with the life of 69 mothers of children with Zika Congenital Syndrome⁽⁸⁾. Income may imply conditions of social inequality, which tend to accentuate after the birth of a child with some chronic condition, especially those involving situations of prejudice. The on-screen study evidenced that most of the family members responsible for the daily care of the children

were unemployed. Mothers, especially those who are mostly the main caregivers, may lose/abandon their jobs due to the care needs and routine treatments of the children. This reinforces the importance of social support.

It is noteworthy that the average age of children aged 10.34 months may suggest that the loss of follow-up is high, considering the recommendation of 18 months to define the outcome, according to the Ministry of Health of Brazil. Discontinuation in follow-up of vertical exposure to HIV may even be evidenced in the occurrence of incompleteness of laboratory investigation data in the medical records of these children⁽¹⁸⁾.

Conclusion

In the course of care of children exposed to the human immunodeficiency virus, family members are more satisfied with the support received from the family, followed by friendship and intimacy. However, family members are not satisfied with the social activities performed. And income above a minimum wage favors the perception of the social support received.

Acknowledgements

To the National Council of Scientific and Technological Development, of the Ministry of Science, Technology, Innovation and Communications - Brazil, Universal Edict no. 01/2016; and the Foundation for Research Support of the State of Rio Grande do Sul, Edict of Research Program for the Unified Health System no. 03/2017.

Collaborations

Hausen CF, Quadros JS, Bick MA, Ceretta PS, Langedorf TF, Padoin SMM and Paula CC contributed to the conception and design or analysis and interpretation of the data, writing of the article, relevant critical review of the intellectual content and final approval of the version to be published.

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