

Association between the dimensions of family support and quality-of-life of people living with HIV

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Abstract

Family support is related to better quality-of-life parameters. However, the way in which the different facets of family support affect the dimensions of quality-of-life is not well established. Thus, the objective of the present study was to verify the association between family support and the quality-of-life of people living with the Human Immunodeficiency Virus (HIV), as well as to analyze the associations between the domains of each construct. The study had a cross-sectional design and was conducted with 296 people living with HIV from an HIV/AIDS referral clinic. The association between the quality-of-life domains and the perception of family support was verified by Binary Logistic Regression. The magnitude of the associations was presented using the odds ratio (95% confidence interval). People living with HIV who had a lower perception of family support showed a greater chance of having reduced quality-of-life, with the chances increasing from 2.10 (1.11; 3.97) to 6.20 (3.17; 12.12) times. The findings were consistent when analyzing the associations between dimensions, with the exception only of the association between family autonomy and the environmental dimension of the quality-of-life, as well as the association between the affectionate-consistent domain and the spirituality domain of quality-of-life. Therefore, the specificity of the associations between quality-of-life and family support must be considered in the care of people living with HIV, as some aspects of quality-of-life seem to benefit from specific aspects of family support.

Keywords: Family. Social support. Quality-of-life. HIV

INTRODUCTION

The inclusion of the Human Immunodeficiency Virus (HIV) in the Chronic Disease Care Model highlighted the need to understand the quality-of-life within the scope of public policies^{1,2}. Quality-of-life is defined as "the individual's perceptions from his position in life, in the context of the culture and value system in which he lives and in relation to his goals, expectations, standards and concerns"³. Therefore, looking at a person living with HIV must involve, in addition to the pathophysiological aspects,

a diversified and multiprofessional service network that addresses biopsychosocial demands, such as social, cultural and religious aspects, reinforcing comprehensive and holistic assistance compatible with individual needs⁴.

Several factors demonstrate influence on the quality-of-life of people living with HIV, such as symptoms⁵, age, income, time of diagnosis⁶, adherence to antiretroviral therapy, health status, maintaining safe sex practices, perception of social support⁷,

DOI: 10.15343/0104-7809.202044528538

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work, civil status, stigmas, among others⁸. Regarding social support networks, family support stands out, which is recurrently pointed out as an important aspect in the quality-of-life of people living with HIV^{9,10,11}. However, the association between these constructs is not well established, and it is possible that they are influenced by specific aspects of each of the constructs.

Family support is referred to as a point of great importance that serves as a divider between the extremes of overcoming and depression¹². A study carried out with 73 patients with HIV, of both sexes and undergoing treatment, pointed to the perception of family support as a facilitating factor in adherence to antiretroviral therapy and an attenuator in terms of mental disorders in the HIV context¹³, thus, it is a potential influencer of the quality-of-life. Previous studies indicate that greater social support is related to a higher quality-of-life, however they did not specifically investigate the family of people living with HIV and evaluated, in general, social support^{8,14,15}.

Therefore, it seems relevant that the family be included in health care, since the dynamics of the family system can be modified and, thus, generate a reorganization and redefinition of roles, which can contribute to meeting the needs of the person living with HIV and their families.

Understanding the association between quality-of-life and family support for people living with HIV can contribute to the establishment of protocols for health professionals, as well as the establishment of public policies to face HIV and support this population, which are of great importance due to the physical and psychosocial burden placed on these people. Thus, the present study aimed to verify the association between family support and the quality-of-life of people living with HIV, as well as to analyze the associations between the domains of each construct.

METHODOLOGY

This was a cross-sectional, descriptive study, with a quantitative approach, carried out in a referral outpatient clinic for HIV/AIDS, located in the municipality of Caruaru, PE, between March and July 2017. The service is a point of reference for Caruaru and surrounding cities, serving a population of 1281 people living with HIV according to LCSM-MH (Logistics Control System for Medication-Ministry of Health).

The study included people living with HIV of both sexes who were followed up at the outpatient clinic, diagnosed with HIV for at least one year, and 18 years or older. The sample was obtained intentionally, and was composed of patients who came to the clinic for medical consultations or to receive medication at the pharmacy. To calculate the sample size, the Epi Info 7 software (Centers for Disease Control and Prevention, Atlanta, Georgia) was used, using a frequency of 50% (unknown prevalence), significance of 5%, and a confidence interval of 95%, from a population of 1281 people living with HIV, resulting in a sample of 296 participants.

In data collection, instruments were used to obtain the following information: sociodemographic and clinical profile, quality-of-life (WHOQOL-HIV bref)¹⁶ and Perception Inventory of Family Support (PIFS)¹⁷. The WHOQOL-HIV bref was a cross-culturally developed and validated in Brazil¹⁶. It is specific for assessing the quality-of-life of people living with HIV. The WHOQOL-HIV bref consists of 31 questions, two of a general scope (which assess the general quality-of-life and general health perception), 24 representing the specific facets of the original instrument (WHOQOL 100), and five are specific to people living with HIV. The facets, minor manifestations of quality-of-life, are distributed between a component of overall perception and six domains,

namely: physical, psychological, level of independence, social relations, environment, spirituality/ religion/ personal beliefs¹⁸.

Quality-of-life was analyzed according to its domains and classified into three levels: low (from 4 to 9.9 points), intermediate (from 10 to 14.9), and high (from 15 to 20), according to other studies^{19,20}. The general score, as well as the domains of quality-of-life, were dichotomized as follows: reduced (low and intermediate) and elevated (high).

The PIFS was developed by Baptista¹⁷ in order to assess how much the individual perceives his family support and can be applied both to the core family members (father, mother, brothers and others), constituted family, and families with other conformations. For the purposes of this study, all family arrangements were considered. The inventory presents 42 questions that assess the individual in three dimensions: affectionate-consistent, family adaptation, and family autonomy²¹.

In order to correct possible typing errors, double data tabulation was performed and Epi-Info 7 software was used to validate the typing. The data referring to the sociodemographic and clinical profile, quality-of-life and PIFS scores were analyzed in a descriptive manner (minimum, maximum, average, standard deviation, and relative and absolute frequency). The association between the domains of quality-of-life and the perception of family support was verified by the Binary Logistic Regression. The magnitude of the associations was presented through the Odds Ratio and its 95% Confidence Intervals (95% CI). The models of Logistic Regression had their adjustments verified by the Hosmer-Lemeshow test. The analyses were performed using the IBM SPSS Statistics for Windows software, version 20 (IBM Corp., Armonk, N.Y., USA).

The project was submitted to the Research Ethics Committee of the University of Pernambuco and approved on March 7, 2017, under CAAE no. 65008117.8.0000.5207, protocol no. 1.951.880. In order to correct the sample calculation, an amendment was requested and approved under opinion No. 2.414.881.

RESULTS

296 people living with HIV over the age of 18 participated in the study. Of the total, 60.5% were male and, with regard to sexual orientation, the majority declared themselves to be heterosexual (70.3%). Age ranged from 18 to 71 years, with an average of 41 (standard deviation = 10.8) years. The age groups of 30 to 40 years old and 40 to 50 years old predominated, totaling 65.2% of the participants. As for education, 16.2% of the participants reached higher education and only 2.7% did not study. Regarding marital status, it was observed that 44.9% were single. Regarding religion, the majority reported being Catholic (56.4%). As for the occupational situation, 46.3% had employment and 56.4% had an income between 1 and 2 minimum wages (Table 1).

People with intermediate-low family support were about three times more likely to have reduced quality-of-life compared to people with high family support, whereas people with low family support were 5.83 times more likely to have reduced quality-of-life when compared to people with high family support. The same can be observed in the other domains of quality-of-life, showing that individuals with low

or intermediate-low family support have reduced quality-of-life (Table 2).

In the dimension of affectionate-consistent family support, it was demonstrated that people living with HIV who have low and intermediate-low family support had odds ratios of 2.10 and 4.42, respectively, for having reduced quality-of-life. Regarding the domain level of independence of quality-of-life, participants with low support were 2.57 times more likely to have reduced quality-of-life compared to those with high family support. Similar results were observed for the other domains, with the magnitude of the odds ratio reaching up to 4.48 when considering the environment domain. There was no significant association for the spirituality domain (Table 3).

With regard to the association between family adaptation and quality-of-life, both for the general score and in the social relationships domain, people with low and intermediate-low family support were more likely to have reduced quality-of-life, with

odds ratios ranging from 2.49 to 5.84. As for the physical, psychological, level of independence, environment, and spirituality, people with low family support were more likely to have reduced quality-of-life (Table 4).

In the analysis of family autonomy, people with an **intermediate-high**, intermediate-low, and low score were more likely to have a reduced overall quality-of-life score when compared to people with high family support. In the psychological domain and social relationships of quality-of-life, the odds ratios ranged from 2.11 to 4.07. People with intermediate-low and low family autonomy were more likely to have reduced quality-of-life in the domains of independence level and spirituality, with odds ratios ranging from 2.21 to 2.63. People with low family support were 5.38 times more likely to have reduced quality-of-life in the physical domain. There was no significant association between family autonomy and the environment domains (Table 5).

Table 1- Sociodemographic profile of people living with HIV treated at a Specialized Assistance Service. Caruaru, PE, 2017 (n = 296).

Variables	n	%
Sex		
Male	179	60.5
Female	117	39.5
Sexual orientation		
Heterosexual	208	70.2
Homosexual	73	24.7
Bisexual	15	5.1
Age years)		
≥ 18.0 to <30	46	15.5
≥ 30.0 to <40	95	32.1
≥ 40.0 to <50	90	30.4
≥ 50	65	22.0
Education		
None	8	2.7
Elementary School	159	53.7
High school	81	27.4
University education	48	16.2
Marital status		
Not married	133	44.9
Married/stable relationship	107	36.2
Divorced/separated	40	13.5
Widower	16	5.4
Religion		
Catholic	167	56.4
Evangelical	67	22.6
Spiritist	13	4.4
Another	20	6.8
None	29	9.8
Occupational situation		
Employee	137	46.3
Unemployed	61	20.6
Retired/Pensioner	74	25.0
On Leave/Away	2	0.7
Others	22	7.4
Income*		
No income / <1 MW	101	34.1
1-2 MW	167	56.4
>2 MW	28	9.5

Source: Research database.

*Minimum wage in effect at the time: R\$ 937.00

Table 2- Chance of having reduced quality-of-life according to the perception of overall family support. Caruaru, PE, 2017 (n=296).

Quality-of-life	Family Support			
	High (%)	Intermediate-High (%)	Intermediate-low (%)	Low (%)
Overall score				
Reduced (n = 142)	32.1	47.1	59.3	73.3
OR (95% CI)	Reference	1.88 (0.97; 3.65)	3.08 (1.60; 5.94)	5.83 (2.95; 11.50)
Physical Domain				
Reduced (n = 84)	18.3	25.5	38.9	43.3
OR (95% CI)	Reference	1.53 (0.71; 3.29)	2.84 (1.40; 5.74)	3.41 (1.73; 6.70)
Psychological Domain				
Reduced (n = 100)	22.1	33.3	42.6	51.7
OR (95% CI)	Reference	1.76 (0.86; 3.59)	2.61 (1.32; 5.15)	3.76 (1.96; 7.22)
Level of Independence				
Reduced (n = 135)	36.6	43.1	50.0	63.3
OR (95% CI)	Reference	1.31 (0.68; 2.53)	1.73 (0.91; 3.28)	2.99 (1.58; 5.63)
Social relationships				
Reduced (n = 109)	20.6	43.1	42.6	61.7
OR (95% CI)	Reference	2.92 (1.46; 5.87)	2.86 (1.44; 5.67)	6.20 (3.17; 12.12)
Environment				
Reduced (n = 187)	53.4	54.9	72.2	83.3
OR (95% CI)	Reference	1.06 (0.55; 2.03)	2.27 (1.14; 4.51)	4.36 (2.04; 9.32)
Spirituality				
Reduced (n = 76)	15.3	29.4	33.3	38.3
OR (95% CI)	Reference	2.31 (1.07; 4.98)	2.76 (1.33; 5.81)	3.45 (1.70; 6.99)

Source: Research database. OR = odds ratio, 95% CI = 95% confidence interval.

Table 3- Chance of having reduced quality-of-life according to the perception of affectionate-consistent family support. Caruaru, PE, 2017 (n = 296).

Quality-of-life	Family Support			
	High (%)	Intermediate-High (%)	Intermediate-low (%)	Low (%)
Overall score				
Reduced (n = 142)	38.4	44.2	56.6	73.3
OR (95% CI)	Reference	1.28 (0.67; 2.42)	2.10 (1.11; 3.97)	4.42 (2.11; 9.27)
Physical Domain				
Reduced (n = 84)	21.9	26.9	34.0	44.4
OR (95% CI)	Reference	1.31 (0.63; 2.72)	1.83 (0.92; 3.66)	2.85 (1.41; 5.78)
Psychological Domain				
Reduced (n = 100)	26.7	32.7	34.0	57.8
OR (95% CI)	Reference	1.33 (0.67; 2.65)	1.41 (0.72; 2.76)	3.75 (1.87; 7.53)
Level of independence				
Reduced (n = 135)	39.0	44.2	50.9	62.2
OR (95% CI)	Reference	1.24 (0.65; 2.35)	1.62 (0.86; 3.05)	2.57 (1.29; 5.12)
Social relationships				
Reduced (n = 109)	27.4	38.5	39.6	62.2
OR (95% CI)	Reference	1.66 (0.85; 3.23)	1.74 (0.90; 3.36)	4.37 (2.16; 8.82)
Environment				
Reduced (n = 187)	54.8	61.5	69.8	84.4
OR (95% CI)	Reference	1.32 (0.69; 2.52)	1.91 (0.98; 3.73)	4.48 (1.88; 10.69)
Spirituality				
Reduced (n = 76)	21.2	26.9	28.3	35.6
OR (95% CI)	Reference	1.37 (0.66; 2.84)	1.46 (0.72; 3.0)	2.05 (0.99; 4.24)

Source: Research database. OR = odds ratio, 95% CI = 95% confidence interval.

Table 4- Chance of having reduced quality-of-life according to the perception of family support - family adaptation. Caruaru, PE, 2017 (n = 296).

Quality-of-life	Family Support			
	High (%)	Intermediate-High (%)	Intermediate-low (%)	Low (%)
Overall score				
Reduced (n = 142)	32.7	34.3	55.0	67.0
OR (95% CI)	Reference	1.07 (0.48; 2.40)	2.51 (1.32; 4.79)	4.18 (2.31; 7.55)
Physical Domain				
Reduced (n = 84)	17.3	20.0	26.7	46.2
OR (95% CI)	Reference	1.20 (0.46; 3.14)	1.74 (0.82; 3.78)	4.11 (2.16; 7.81)
Psychological Domain				
Reduced (n = 100)	20.0	28.6	33.3	52.7
OR (95% CI)	Reference	1.60 (0.67; 3.82)	2.0 (0.98; 4.07)	4.47 (2.40; 8.32)
Level of Independence				
Reduced (n = 135)	38.2	37.1	46.7	57.1
OR (95% CI)	Reference	0.96 (0.44; 2.10)	1.42 (0.75; 2.68)	2.16 (1.23; 3.80)
Social relationships				
Reduced (n = 109)	20.0	28.6	38.3	59.3
OR (95% CI)	Reference	1.60 (0.67; 3.87)	2.49 (1.24; 5.0)	5.84 (3.12; 10.93)
Environment				
Reduced (n = 187)	50.0	71.4	58.3	79.1
OR (95% CI)	Reference	2.50 (1.10; 5.69)	1.40 (0.74; 2.64)	3.79 (2.02; 7.11)
Spirituality				
Reduced (n = 76)	16.4	14.3	26.7	40.7
OR (95% CI)	Reference	0.85 (0.29; 2.49)	1.86 (0.87; 3.99)	3.50 (1.82; 6.75)

Source: Research database. OR = odds ratio, 95% CI = 95% confidence interval.

Table 5- Chance of having reduced quality-of-life according to the perception of family support - family autonomy. Caruaru, PE, 2017 (n = 296).

Quality-of-life	Family Support			
	High (%)	Intermediate-High (%)	Intermediate-low (%)	Low (%)
Overall score				
Reduced (n = 142)	37.5	60.0	55.9	72.4
OR (95% CI)	Reference	2.50 (1.39; 4.49)	2.11 (1.0; 4.45)	4.38 (1.83; 10.47)
Physical Domain				
Reduced (n = 84)	20.8	32.3	32.4	58.6
OR (95% CI)	Reference	1.81 (0.96; 3.44)	1.82 (0.81; 4.08)	5.38 (2.35; 12.32)
Psychological Domain				
Reduced (n = 100)	23.2	43.1	50.0	52.2
OR (95% CI)	Reference	2.50 (1.36; 4.60)	3.31 (1.54; 7.09)	4.07 (1.80; 9.20)
Level of Independence				
Reduced (n = 135)	39.3	47.7	58.8	62.1
OR (95% CI)	Reference	1.41 (0.79; 2.51)	2.21 (1.04; 4.67)	2.53 (1.12; 5.69)
Social relationships				
Reduced (n = 109)	25.6	53.8	50.0	48.3
OR (95% CI)	Reference	3.39 (1.87; 6.17)	2.91 (1.37; 6.19)	2.71 (1.21; 6.08)
Environment				
Reduced (n = 187)	57.7	67.7	73.5	72.4
OR (95% CI)	Reference	1.53 (0.84; 2.80)	2.03 (0.90; 4.62)	1.92 (0.81; 4.59)
Spirituality				
Reduced (n = 76)	19.0	30.8	38.2	37.9
OR (95% CI)	Reference	1.89 (0.98; 3.63)	2.63 (1.19; 5.81)	2.60 (1.12; 6.04)

Source: Research database. OR = odds ratio, 95% CI = 95% confidence interval.

DISCUSSION

In this study, it was possible to observe that people living with HIV with less perception of family support were more likely to have a reduced quality-of-life. The findings were consistent for the associations between the three dimensions of family support with the domains of quality-of-life, except for the association between family autonomy and the environment dimension of quality-of-life, as well as the association between the affectionate-consistent dimension and spirituality dimension of quality-of-life. Therefore, the importance of interpersonal relationships for a better quality-of-life is highlighted, especially in the face of a chronic health condition, surrounded by stigma and prejudice^{22,23}.

The association between the affectionate-consistent dimension and the domains of quality-of-life indicates that the lack of affectionate interest in others, distance, perception that the environment does not allow for expressing affection, nor does assertive communication generate compromise in the physical domain, psychological domain, independence level, social relationships and the perception of inclusion in the environment of people living with HIV.

Therefore, the importance of strengthening affectionate bonds, coping strategies, and conflict resolution is emphasized, since it is in the family that primary health care is produced that permeates the emotional interactions necessary for psychosocial development, support for adherence to treatment, encouraging self-care, and emotional support²⁴.

Regarding the family adaptation dimension, it was observed that presenting negative feelings and behaviors in relation to the family, such as conflicts between

members, changes in routine, and adaptation to new demands are factors capable of compromising quality-of-life. This finding may be related to the fact that HIV generates stigma and prejudice, which can trigger negative feelings and behaviors towards the family, since confirmation of the diagnosis and/or its disclosure can cause family conflicts and socio-affectionate distance²⁵.

It is important to note that in cases where the diagnosis of HIV is not revealed to the family, the risk of abandoning treatment increases, as the person does not use the medication for fear of being recognized²⁶. Antiretroviral therapy requires changes in the routine of people living with HIV. In this process, family support seems to facilitate adherence to treatment, as it contributes to a greater commitment to maintaining care^{13,25}.

In addition, family support mitigates the presence of mental disorders, for example, perceived stress, and it is observed that the greater the support, the lower the stress experienced by the person living with HIV^{13,27}. These results show that the family promotes better health and, consequently, a better quality-of-life in the physical, independence level, and psychological domains. According to Baptista¹⁷, for family support to be considered a buffer for the effect of various stressors on people's lives, it is necessary that the individual be adapted to a family that is flexible to changes, through negotiations with discipline and assertiveness.

Regarding the family autonomy dimension, it was noted that the lower the individual's perception of autonomy, trust, privacy, and freedom, the greater the chance of having reduced quality-of-life in all domains, except the environment domain. The importance of relationships of trust, reciprocity, empathy, and strengthening of

autonomy in the family context have been demonstrated as promoters of health care, because the good relationship between the family comes through relationships of trust, and consequently provides these people with the freedom and privacy necessary in the family context²⁸.

The presence of low family support is generally associated with less pleasure and satisfaction with life. On the other hand, when there are social networks of support and family involvement, there is a reduction in stigma and prejudice and, consequently, an improvement in the quality-of-life²⁹. This is because people living with HIV feel more welcomed, protected, and included in the social environment.

Health professionals and managers need to be aware of the importance of reinforcing positive family support strategies³⁰. Therefore, it is necessary to bring the family into health services and, using specific strategies, provide the necessary information so that they understand the importance of their role, without stigmas and prejudices. In addition, the family also needs to receive health care, as the diagnosis and living with HIV also have significant repercussions on family relationships, causing fear and suffering.

Given this context, public policies directed at people living with HIV and their families are extremely important, since they must direct the necessary interventions for the fulfillment of health care that considers the family as a preponderant part of this care. The family makes the person living with HIV feel accepted, establish affective bonds, provides financial support, and, consequently, generates esteem of belonging to a social network, in which they enjoy common rights and duties. It is in the family that health care is produced and involves the affectionate interactions necessary to maintain the

mental health and mature personality of the members, as well as learn about hygiene and food culture, and is related to adhering to the prescribed treatment by health services²⁴.

According to Braathen *et al.*³¹, health services that serve this clientele need to be organized in a more familiar and community perspective, with a view not only to the immediate patient, but also to their broader care system. Therefore, it is important to recognize the barriers that individuals and families face in an attempt to seek health services in order to guarantee holistic health care.

In this sense, health professionals, in addition to providing care for people living with HIV, must establish relationships with family members and/or other social support networks, in order to provide guidance and identify weaknesses. Therefore, they can use consultations and systematize care to identify weaknesses and intervene effectively and individually. In addition, they can use a variety of strategies such as support groups and conversation circles that are considered important spaces for exchanging knowledge and mutual support.

The present study has some limitations that must be considered; among them is the impossibility of establishing a causal relationship due to the cross-sectional design. However, prospective studies that analyzed associations of indicators related to quality-of-life and social support in other populations obtained similar findings^{8,14,15}. Another aspect to be considered is the possibility of the information obtained being representative only in the context in which it was investigated. However, in general, investigations carried out in other contexts have shown that family support is an important factor in maintaining quality-of-life^{7,11,32}.

CONCLUSION

This study showed the existence of a significant association between family support and quality-of-life. People living with HIV who had a lower perception of family support were more likely to have reduced quality-of-life. Such findings were consistent when analyzing the associations between the different dimensions of family support and quality-of-life. The only exceptions were the associations between the family autonomy dimension of family support and the environment dimension of quality-of-life, as well as the association of affectionate-consistent family support with the spirituality dimension of quality-of-life.

The specificity of the associations between quality-of-life and family support must be considered in the care of people living with HIV, as some dimensions of quality-of-life seem to benefit from specific aspects of

family support. Thus, the inclusion of families in the health care of the person living with HIV is a factor to be considered in care, but always respecting the ethical precepts about professional secrecy and the patient's decision. In addition, the different individual and family beliefs and value systems must also be taken into account.

The family of the person living with HIV lacks care, support, and guidance, therefore, it is essential that the specialized services of care for the person living with HIV assist in the process of reintegration into the family environment, as well as in the strategies for inserting the family into the health care of this population. The evidence obtained can contribute to the planning of public policies aimed at people living with HIV and their families, as well as in the operationalization of professional intervention strategies.

ACKNOWLEDGEMENTS: To Programa Associado de Pós-graduação em Enfermagem UPE/UEPB - PAPGenf

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Received in may 2020.
Accepted in november 2020.