# PERCEPTION OF THE PERSON WHO LIVES WITH HIV / AIDS AND THEIR FAMILIES IN RELATION TO THE CARE IN THE HOSPITALIZATION, CONSIDERING THE INDEX OF ANXIETY AND DEPRESSION

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## Abstract

*The human immunodeficiency virus (HIV) was discovered in the 1980s, it affects the immune system and when not treated with appropriate medications it can lead the person to develop acquired immunodeficiency syndrome (AIDS). The antiretroviral therapy (ART) that makes HIV undetectable was discovered in 1990. However, despite the free ART in Brazil, there is still a challenge regarding the adherence of people (100%) living with HIV/AIDS (PLWHA), because the abandonment of the medication or the non-regular use reduces future treatment options which cause illness and death. The objective of this research was to understand the perception of the person living with HIV/AIDS and their family members, regarding the care offered in the infectious and parasitic diseases unit. In addition, the anxiety and depression rate that affects them during the hospitalization period will be considered. This study was carried out in the Infectious and Parasitic Inpatient Sector DIP Infirmary (Enf/DIP), which is part of the Infectious and Parasitic Diseases Unit (UNIDIP) of the Hospital Maria Aparecida Pedrossiam (HUMAP), in the municipality of Campo Grande - MS. The prospective collection of primary data was obtained through questionnaires that were replaced by words and expressions in the title and in the content. Changes were made and elaborated with the objective of improving the understanding of the sentences, which became a semantic evaluation of content by a committee of evaluators. Thus, before the final application of the questionnaire to the participants, all the steps cited constituted the methodological strategies for capturing data.*

**Keywords:** Patient-centered care; Family; HIV/AIDS; Anxiety; Depression.

## 1. Introduction

The family of the person living with HIV/AIDS (FPVHA) can assist in adhering to antiretroviral therapy (ART), which causes a decrease in illness, a decrease in hospitalizations and readmissions. Thus, there was a need for transformation in the way of caring and acting by health professionals, through partnerships and sharing of knowledge, inserting people living with HIV / AIDS (PLWHA) and FPVHA in care. The principles of the care model of Patient and Family Centered Care (CCPF) suggest planned actions that make PLWHA and FPVHA the protagonists of their own care through shared responsibility with health professionals. It is known that PLWHA and FPVHA can experience anxiety and depression during the care process, and for FPVHA, work overload and its repercussions on social life are evident. On the other hand, for PLWHA, the diagnosis of HIV/AIDS, the severity of the disease and social prejudice are the most relevant items.

## 2. Historic

### *2.1 Brief contextualization of HIV/ADS*

Since it appeared in 1980, the human immunodeficiency virus (HIV) is considered one of the biggest problems faced by humanity, because it affects the human immune system and when in the advanced stage it triggers the acquired immunodeficiency syndrome (AIDS), which when untreated can cause death (COSTA; ARRUDA; MENDONÇA; LUCAS, 2015; BRASIL, 2019 b).

The infection happens mainly through sexual and vertical routes (ABBAS; LICHTMAN; PILLAI, 2015), however, a person can live for years until the first symptoms and / or opportunistic infections appear (SAMPAIO, 2018).

According to a worldwide estimate, 36.9 million people are infected with HIV (JOINT UNITED NATIONS PROGRAMME ON HIV/AIDS, 2018). In 2019, the Brazilian Ministry of Health (MS) reported that there was an increase in the number of cases of HIV contamination, even after years of reduction mainly among young people aged 15 to 24 years (BRASIL, 2019a).

In 1986, after studies were carried out, the American drug regulatory agency approved mono-drug therapy for the treatment of AIDS, with the drug Zidovudine (AZT) as an antiretroviral (ARV) (STYRT; PIAZZA-HEPP; CHIKAMI, 1996). In the 90s, studies were developed on the combination of ARVs, which led to Antiretroviral Therapy (ART), being considered more effective in combating infection caused by HIV / AIDS, becoming in 1996 the world standard of treatment (CARVALHO, 2019), adopted for free distribution in Brazil, through the Law 9.313/96 (SARCINELLI, 2018; COLAÇO, 2016; VILLARINHO *et al.,* 2013; SOUZA; TIBÚRCIO; KOIKE, 2016).

It is said that this disease can be controlled when the infected are in regular treatment (MONTEIRO; VILLELA, 2009; VILLARINHO et al., 2013), for that purpose the goal “90-90-90” was established, whose objective is that infected people are being treated, and that 90% of those living with HIV are diagnosed, 90% receive ART and 90% have the virus undetectable (BRASIL, 2019a; WHO, 2017; MENEZES *et al.,* 2018).

In Brazil, according to the Ministry of Health, treatment adherence is a dynamic and multifactorial phenomenon related to the patient, treatment, illness, socioeconomic aspects and health systems (SILVA et al., 2017b; COSTA; MEIRELLES, 2019), therefore, it is not restricted to following prescriptions (BRASIL, 2008). The lack of adherence is considered a threat to the effectiveness of the treatment, which contributes to the spread of virus-resistance (COLAÇO, 2016; MIYADA et al., 2017).

It is also noticed that the correct use of ART can reduce the costs of future hospitalizations due to complications of the infection, as well as the need to exchange the medication for more complex and expensive ones (BANDEIRA et al., 2016; MENEZES et al ., 2018). Given the above, it is observed that adherence to treatment with ART requires more investigations to develop a care plan (VALE et al., 2018), in which the various factors involved are considered to better guide the multiprofessional and FPVHA team (FERREIRA *et al.*, 2020).

In a study carried out with families of premature infants during hospitalization in a neonatal ICU, the authors concluded that when the family is considered in the decision-making process, in the planning of care and empowered, it becomes coresponsible for the treatment process (BALBINO; BALIEIRO; MANDETTA, 2016). Although there are gaps in the scientific production on FPVHA, Silva et al. (2017) affirm that when it is inserted in the treatment of the disease, adherence to ART increases, and the number of abandonments to treatment decreases. However, social judgment, discrimination and stigma, silence FPVHA, this context leads to anxiety and depression (COUTINHO, O´DWYER, FROSSARD, 2018).

### *2.2 Depression and anxiety in people living with HIV / AIDS and their families*

Depression is a disease recognized as a priority public health problem. It is estimated that in the world more than 300 million people suffer from this condition and 800,000 die each year, while less than half of the affected people receive treatment due to lack of resources, lack of trained professionals and due to social stigma linked to mental disorders (ORGANIZAÇÃO PAN-AMERICANA DE SAÚDE, 2018; WHO, 2017).

According to the International Classification of Diseases (ICD-10), depression received the F-32 code, and people with this diagnosis have a sad, empty or irritable mood, accompanied by somatic and cognitive alterations that significantly affect the functional capacity of the individual who may have anhedonia - loss of interest or pleasure in activities - difficulty thinking or concentrating, and the constant presence of suicidal ideation (recurrent thoughts about death) (WHO, 2017).

Generalized anxiety disorder (F-41), presents itself as a basic human emotion, which alerts the organism when there is imminent danger through excitation of the Central Nervous System (CNS), it is part of the emotional and physiological state of the human being, it presents itself with an empty, unpleasant emotion, fear, restlessness and agitation in behavior (WHO, 2017).

Depending on the way that PLWHA react in relation to their HIV status, they may show feelings of inferiority due to the discrimination suffered, uncertainty about the future, fear of approaching death and changes in appearance (ANTELMAN et al., 2007; GONZALEZ et al., 2011), which results in an unfavorable prognosis, with a greater involvement of opportunistic diseases, which can lead to neurocognitive impairments (CHRISTO, 2010; SEIDL et al., 2007; AZEVEDO et al., 2014)

Anxiety and depression affect PLWHA twice or more than in the general population (PINTO et al., 2007), however, when both are treated, they show a high rate of improvement, reducing the use of health care, mortality and can prolong life (PINTO et al., 2007). According to Nanni et al. (2015), anxiety and depression can interfere in adherence to the treatment of PLWHA, triggering the progression of the disease and mortality, however there are few publications on the subject, which results in the professionals' lack of knowledge.

The support of the family can improve the self-esteem, self-confidence and self-image of PLWHA and bring benefits (BOTTI et al., 2009), which can assist in maintaining the treatment, in complying with medication schedules, being important even for acceptance diagnosis and protection against the risk of suicide (COUTINHO; O´DWYER; FROSSARD, 2018).

Studies have pointed out the presence of depressive and anxiety syndromes among FPVHA during the care process, mainly because of the burden triggered by care, differentiation of quality of life, decreased freedom in social and personal activities (DELALIBERA et al., 2015 ; QUEIROZ et al., 2013; CARDOSO; GALERA; VIEIRA, 2012; ISHII et al., 2012; BAPTISTA et al., 2012). In addition, the presence of prejudice in the workplace that can lead to job loss, financial problems, together with the increase in expenses with the sick family member (GARBELINI, 2014; KUO et al., 2012).

They may also experience sleep deprivation, hopelessness, feeling of shame, guilt, anger, denial, rejection, indifference, non-acceptance, lack of understanding, support, acceptance, and concerns about PLWHA in the course of the disease. These situations can affect the relationships between family members (DELALIBERA et al., 2015; QUEIROZ et al., 2013; CARDOSO; GALERA; VIEIRA, 2012; ISHII et al., 2012; BESSA et al., 2013), which is why social and psychological support is necessary for the success of the care process (KANG, et al., 2013; SILVA; BATISTA; CERQUEIRA, 2017).

Despite the emotional distress faced, some FPVHA see the care process positively, and report that it is a possibility to demonstrate love, satisfaction and feelings of accomplishment that bring the feeling of having participated in a rewarding, meaningful experience, which strengthens family relationships personal growth.

In view of the above, in the search for a reference that considers PLWHA and FPVHA during the hospitalization period, and the perception both of the care offered by health professionals, and of the level of anxiety and depression experienced in this phase, in this research, we opted for based on the Patient- and Family Centered Assistance (PFCC) model.

### *2.3. Approach to Patient-and family-centered care*

To carry out the family approach in the context of care, it is necessary to conceptualize the term, which has undergone changes over time (BRASILEIRO; RIBEIRO, 2016), in which Wright and Leahey (2012) define family as who their members say they are, and that was adopted in that study. For a long time, the family was kept as an expectant of hospital care for fear of spreading infections, in which the same occurred during the second world war (1939-1945), when the parents were removed from the hospital environment, causing a partial break the bond between children, parents and health teams (GOMES; MENDES JÚNIOR, 2017).

In the post-war period, there were changes in the health system, which changed from a hospital-centered view and linked to hard technologies to light technologies of interpersonal relationships (TANENBAUM, 2015). At the end of the 50s, in England and the United States of America (USA), there were movements by health consumers and parents for the assistance transformation of health care, with the inclusion of the family in the treatment process, which became a service centered not only on the patient (ROSENBAUM et al., 2009).

After the 1950 movement, the Platt Report was published in England in 1959 (MINISTRY OF HEALTH, 1959; LIGHTWOOD et al., 1959), which is a historic milestone and aimed at improving the care provided to hospitalized children, through some recommendations such as unrestricted visits, stay of mothers in the hospital, as well as training of the medical and nursing staff for an approach that meets the emotional needs of the child and the family (SHIELDS et al., 2007).

The CCPF recognizes that policies, hospital practices and outpatient care, must develop partnerships between the patient, family and caregiver triad (KUO et al., 2012; JOHNSON et al., 2008), includes patients with various levels of care and all phases of life, as well as those with chronic health conditions or not; shows the family in a positive perception, with a central and permanent role during the patient's period of vulnerability and suffering; proposes breaking the restriction of access in the participation of care and in the definition of problems, which leads to the planning of actions (MORADIAN, 2018) together with the health care provider who acquires with this interaction a broad view of the problems, leading to understand the priorities of those involved, developing a new way of caring with the beneficial collaboration between the triad for decision making (BARBOSA; BALIEIRO; PETTENGIL, 2012; BALBINO; BALIEIRO; MANDETTA, 2016; ROSENBERG *et al*., 2016; CRUZ; ÂNGELO, 2011).

The conceptual phrase “Nothing about me without me” has become a guiding principle of the CCPF, and it means that professionals should not make decisions without involving the patient and their family, consulting them on their perspectives, choices, knowledge, values, beliefs and cultural background (INSTITUTE FOR PATIENT AND FAMILY-CENTERED CARE, 2017). It must be considered that an individual experience has repercussions on the collective, therefore, it is important to know what is a problem for the family, to understand “what is the situation that causes suffering", which can be perceived differently by each member of the group (MARCHETI; MANDETTA, 2016).

In 1992, the Institute for Family Centered Care (ICCF) was founded in the USA, being essential for the advancement of the understanding and practice of the CCPF, it facilitated the change of approach in the environments where individuals and families receive care and support (JOHNSON, 2000).

In order to improve the quality of health services, the governments of some countries such as Australia, Canada, the United States of America and the United Kingdom have endeavored to change the care model to CCPF. For this purpose, strategies were created to reform the health system, encouraging partnership between patients, health professionals, managers and political authorities, as well as realigning the vision of care based on the results of research on satisfaction and expectation of patients (GOMES; MENDES JÚNIOR, 2017).

In Brazil, the CCPF approach continues to be insufficiently implemented in clinical practice, as it is not effectively incorporated into the care philosophy of national health systems, as is the case in some first world countries (CRUZ; ANGELO, 2011). According to Dokken et al. (2015), for this care model to be a prevalent practice, institutional commitment is required, a change in the ways of collaboration between health professionals, technical and paternalistic care models, and to implement the CCPF assumptions: dignity and respect, information sharing, collaboration and participation to induce everyone to rethink the way of caring (INSTITUTE FOR PATIENT AND FAMILY CENTERED CARE, 2017).

It is interesting to note that with the implantation of the CCPF, an improvement in the results was detected on the reduction of costs, more effective allocation of resources, reduction of errors and medical processes, with an increase in patient, family and professional satisfaction (KUO et al., 2012). However, implementation models and strategies for this practice are still lacking (CRUZ; ÂNGELO, 2011), which includes strong leaders and attentive employees who have time and patience for implementation (GARROUSTE-ORGEAS et al., 2010).

## 3 METHODOLOGY

The data presented are part of the doctoral thesis developed in the Postgraduate Program in Health and Development in the Midwest Region of the Federal University of Mato Grosso do Sul (UFMS). The project meets the ethical precepts of research with human beings of Resolution No. 466/2012 of the National Health Council. In addition, the project was approved by the Ethics Committee on Research with Human Beings at UFMS (No. 3,030,822).

It is a quantitative, evaluative and descriptive research, with prospective collection of primary data obtained through questionnaires. It was carried out in the Infectious and Parasitic Diseases inpatient sector DIP Infirmary (Enf/DIP), which is part of the Infectious and Parasitic Diseases Unit (UNIDIP), Hospital Maria Aparecida Pedrossiam (HUMAP), in the municipality of Campo Grande – MS

The research was carried out in the period from 2019 to 2021, and had as participants the PLWHA, FPVHA, and the health professionals of Enf/DIP. The questionnaires applied to PLWHA and FPVHA were: Hospital Anxiety and Depression Scale (HADS), which is divided into two subscales - one for anxiety and one for depression, composed of seven multiple-choice questions, with four possible answers, the which was given a score ranging from 0 to 3, with a total score of 0 to 21 points (from 0 to 21 for anxiety, and from 0 to 21 for depression), with a score of 0 to 8 meaning no symptoms , on the other hand, the score from 8 to 10 is interpreted as a mild case of depression or anxiety; 11 to 14 as a moderate case; and a score of 15 to 21 as a severe case (ZIGMOND; SNAITH, 1983), and the Perception of Care Questionnaire Centered on the Adult Person and his family - Family member and person living with HIV / AIDS (PCCPAF / F - Brazilian version).

The health professionals answered the questionnaire Perception of Care Centered on the Adult Person and his / her family / Professional - Brazilian version (PCCPAF / P - Brazilian version) in order to verify the comparison of the responses between the group of professionals, of PLWHA and FPVHA.

For the use of the PCCPAF / P - Brazilian version and PCCPAF / F - Brazilian version questionnaires in adults, it was necessary to substitute words and expressions in the title and content, such changes were thought and elaborated aiming at the understanding of the sentences, making it necessary an evaluation semantics of content, by a committee of evaluators. Such questionnaires are composed of two parts, the first with 20 socio-demographic questions, and the second with 20 statements regarding the care provided. Statements 1 to 6 belonging to the respect domain, which recognizes the family's rights in the hospital; from 7 to 15 are collaboration areas, reflecting the recognition of the role of family members in the partnership of care with their family members; 16 to 20 address the support domain, which includes items related to the way health team professionals offer support to the family. The interpretation of the responses for PCCPAF/F and PCCPAF/P - Brazilian version, were made through statistical analysis, using a score between the domains answered by mean, standard deviation and median.

# 4 RESULTS

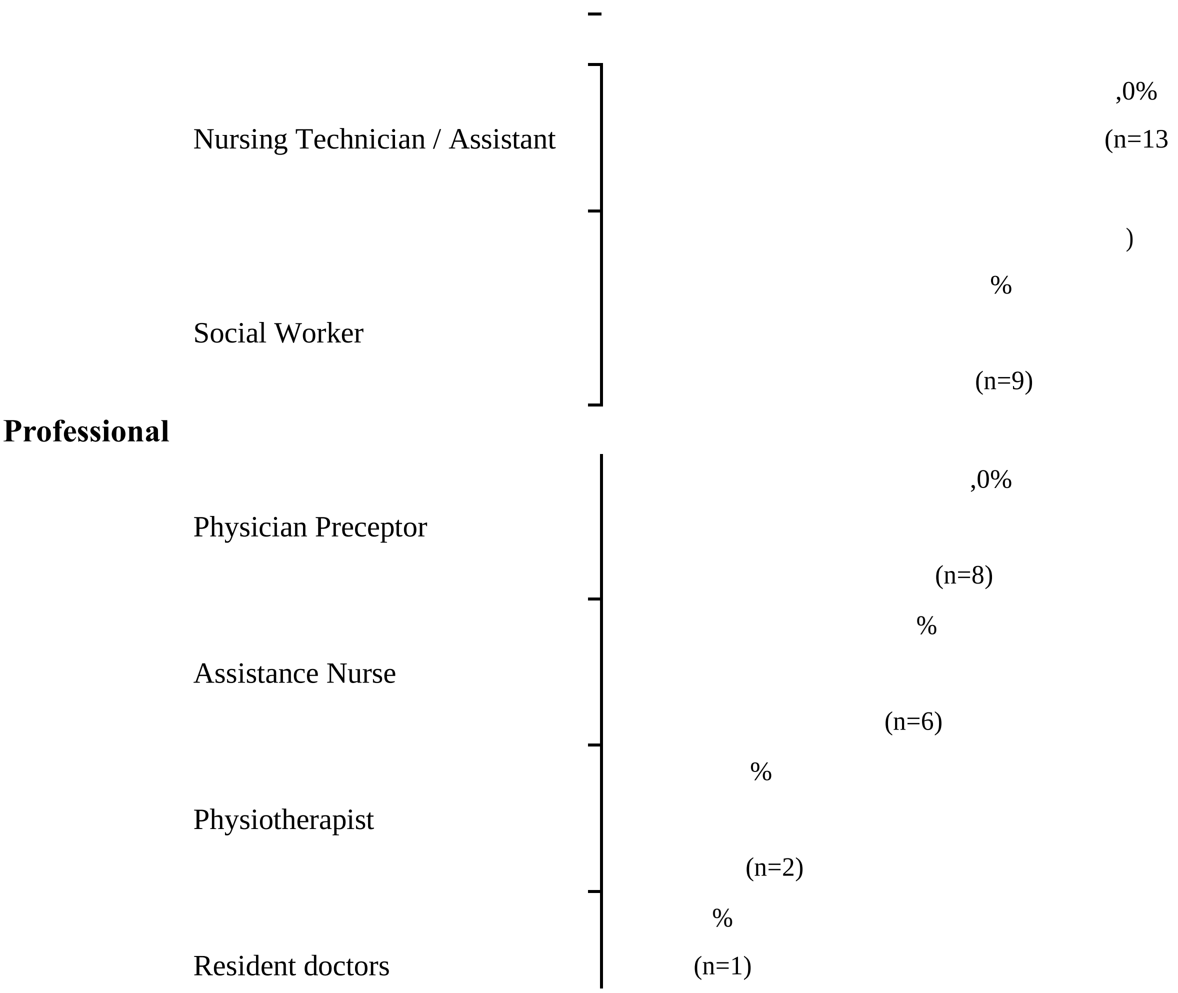
## *4.1 Results obtained among health professionals*

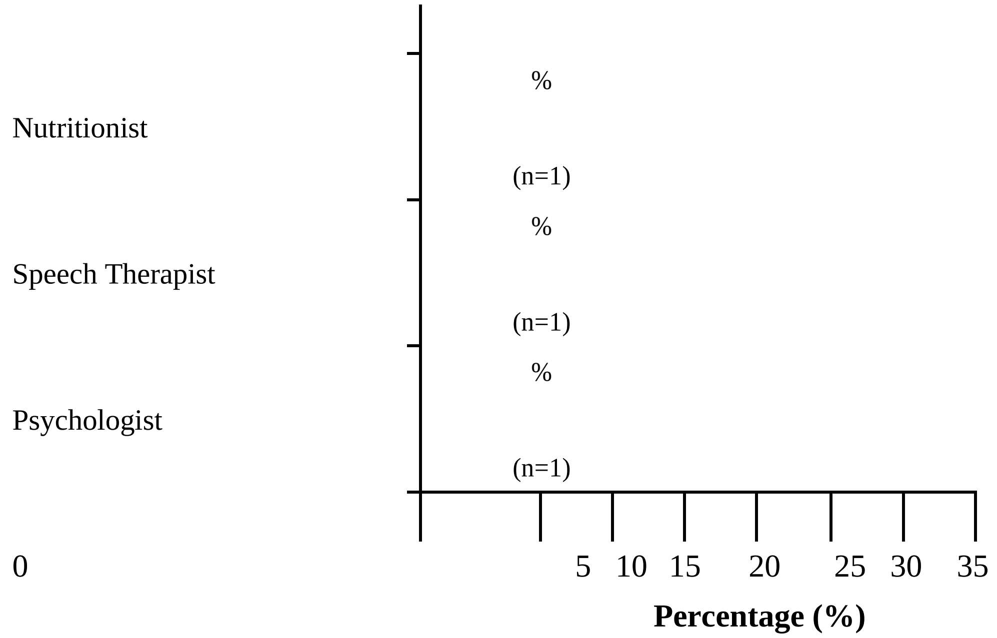
Of the total 42 questionnaires about PCCPAF/P - Brazilian version, 61.9% were female and aged between 31 and 61 years old, only 6 (14.3%) had high school education, 34 (80.9%) said have undergraduate, graduate, master's or doctoral degrees, 35 (83.3%) of whom reported that during technical or academic training they had no contact with the term CCPF, however, 38 (90.5%) said they had no training in this care model or to know about theories in this area.

From the group comparison analysis between the PCCPAF / P questionnaire - Brazilian version and the social profile of the professionals (Student's t test), it was found that there is no difference in the behavior of the scores in relation to the variables considered, that is, the response to the PCCPAF/P questionnaire - Brazilian version, did not interfere with the social profile of the participants.

Figure 1 shows the distribution of the professionals interviewed in this study, the most frequent being Nursing Technician / Assistant (31.0% - n = 13), Social Worker (21.4% - n = 9), Physician Preceptor (19, 0% - n = 8) and Assistance Nurse (14.3% - n = 6).

Figura 1 – Distribution of professionals interviewed in this study





***4.2 Results obtained in the questionnaires applied to the person living with HIV / AIDS***

Responded to the PCCPAF/F questionnaire - Brazilian version and HADS, 9 (100%) PLWHA, where it was found that upon admission all PLWHA had a diagnosis of secondary or associated diseases, which can lead to readmission and death. Of the participants, 7 (77.8%) were male aged 19 to 53 years old, and time of HIV/AIDS diagnosis from 1 to 13 years old, 6 (66.7%) reported having a fundamental level of schooling, 4 (44.5%) single, 5 (55.6%) said they were heterosexual, reporting sexual as a form of contamination 4 (44.4%), and the same number do not know how they got infected.

The same number of FPVHA responded to the PCCPAF/F - Brazilian version, with 7 (77.8%) female participants ranging in age from 21 to 51 or more years old, predominance 6 (66.6%) between 31 and 50 years old, 6 (66.7%) who report having a high school education, 4 (44.4%) claiming to be Catholic, in addition, most of the people who remained as companions were 3 (33.3%) mothers of PLWHA, 4 (44.4%) claimed to be a husband.

Based on the group comparison analysis, when the crossing between the HADS scores and the social profile of PLWHA is performed (considering the Student t test applied to the variable anxiety and depression - Mann-Whitney u test), there is no difference in the behavior of the scores in relation to these variables, that is, the response to the HADS questionnaire did not interfere according to the social profile of the participants.

According to the association between the social profile and the Classification of the HADS questionnaire, of PLWHA (Fisher's Exact Test), there is no difference in the behavior of the scores in relation to the variables under consideration, that is, no item of the social profile influenced the classification level of anxiety and depression of FPVHA.

***4.3 Results obtained among family members of people living with HIV/AIDS***

The PCCPAF/F questionnaire - Brazilian version and HADS was applied in 9 (100%) FPVHA, where 7 (77, 8%) were female aged 21 to 62 years old, 6 (66, 7%) had a average education level, 4 (44.4%) claimed to be the husband of PLWHA and 3 (33, 3%) were mothers, when questioned about their religion, only 8

(88.8%) mentioned to profess any faith.

Only 6 (66, 7%) of the FPVHA reported that they were not working, and had earnings ranging from 1 to 5 minimum wages, with up to 5 (55.6%) people who depend on that amount. They also mentioned that 6 (66.7%) do not have the help of others to take care of PLWHA, and that in addition to the hospitalized family member, there are more people who depend on their care 4 (44.5%).

The municipality of residence of the majority 6 (66.7%) was Campo Grande, and the average time of arrival at the hospital was 30 minutes to 1 h, however, 7 (77.8%) declared that there was no difficulty in reaching the hospital. , although 6 (66.7%) do not have their own car. When verified about the admission of PLWHA, 5 (55.6%) had been hospitalized other times, and in the current hospitalization it was less than 7 days, 5 (55.6%) and 6 (66.7%) more than 15 days, and regarding hospital discharge, 7 (77.8%) did not know the date.

From the comparison analysis made between the PCCPAF/F questionnaire - Brazilian version and the social profile of the FPVHA, the items age group p-value: 0.032, religion p-value: 0.021 and length of hospitalization of PLWHA p-value: 0.046, it was found that there was a significant difference (ANOVA test, $p \leq 0.05$), that is, there was a change in the responses to the PCCPAF / F questionnaire - Brazilian version, according to the social profile of the participating FPVHA.

### *4.4 Associations between participants (professional, family and person living with HIV / AIDS) and the HADS and PCCPAF / P or F scale questionnaires - Brazilian version*

In the PCCPAF - Domain Respect questionnaire, it was found that there was a significant association between the interviewees (professional, FPVHA or PLWHA) and the perception of the PLWFF considering the fact that they are welcome to be with the PLWHA in the hospital (chi-square test) , $p <0.001$), and 5 (55.6%) PLWHA “never” felt that FPVHA were welcome, an index higher than that reported by professionals 0 (0.0%) (Chi-square test with Bonferroni correction, $p <0.05$).

In addition, there was a significant association between the perception of FPVHA, if they could remain with PLWHA during the procedures performed ($p <0.001$), with the percentage of FPVHA and PLWHA who answered that “always” (FPVHA: 6 (66, 7%); PLWHA: 5 (55.6%) was higher than that reported by professionals 2 (4.8%) (Chi-square test with Bonferroni correction, $p < 0.05$).

As for the PCCPAF - Collaboration Domain, there was a significant association between the interviewees and the perception, considering that the FPVHA were included in the decision-making of care for PLWHA (chi-square test, $p = 0.004$), with the percentage of FPVHA and PLWHA who "always" felt included in the decision-making (FPVHA: 4 (44.4%); PLWHA: 9 (77.8%) was higher than that reported by professionals 8 (19.0%) (chi test) - square with Bonferroni correction, $p < 0.05$).

A significant association was still observed between the interviewee and the perception of whether FPVHA received information in relation to what they needed to know about care for PLWHA ($p = 0.008$), with the percentage of PLWHA responding that they “never” received information in relation to what they needed to know about their own care 3 (33.3%), it was higher than that reported by professionals 0 (0.0%) (chi-square test with Bonferroni correction, $p <0.05$).

There was also a significant association between the interviewee and the perception of whether FPVHA was able to understand the guidelines he received at the admission of PLWHA (chi-square test, $p <0.001$), with the percentage of both who "never" managed to understand the guidelines that received on admission (FPVHA: 4 (44.4%); PLWHA: 5 (55.6%) was higher than that reported by professionals 0 (0.0%) (Chi-square test with Bonferroni correction, $p < 0,05$).

In addition, there was a significant association between the respondent and perception if FPVHA was included in PLWHA care (chi-square test, $p = 0.003$), with the percentage of both who "never" felt that FPVHA was included in the study. care PLWHA (FPVHA: 3 (33.3%); PLWHA: 4 (44.4%) was higher than that reported by professionals 0 (0.0%) (Chi-square test with Bonferroni correction, $p <0, 05$).

Finally, there was also a significant association between the respondent and the perception of whether FPVHA was overloaded with information about PLWHA (chi-square test, $p <0.001$), with the percentage of FPVHA who "always" felt overwhelmed with information about PLWHA (FPVHA: 7 (77.8%); PLWHA: 5 (55.6%) was higher than that reported by professionals 1 (2.4%) (Chi-square test with Bonferroni correction, $p < 0.05$).

In the PCCPAF Questionnaire - Support Domain, there was a significant association between the interviewee and the perception that the team listened to the concerns of the FPVHA and PLWHA (chi-square test, $p = 0.015$), with the percentage of PLWHA who answered that "never "The team listened to their concerns 4 (44.4%), a higher value than that reported by professionals 1 (2.4%) (Chi-square test with Bonferroni correction, $p <0.05$).

Finally, there was a significant association between the interviewee and the perception that the team knew what FPVHA was going through (chi-square test, $p <0.001$), with the percentage of FPVHA and PLWHA who answered "never" (family members: 7 (77.8%); patients: 6 (66.7%)) was higher than that reported by professionals 1 (2.4%) (Chi-square test with Bonferroni correction, $p <0.05$). On the other hand, the percentage of professionals who answered "sometimes" to feel that they know what FPVHA was going through 29 (69.0%) was higher than that reported by PLWHA 0 (0.0%) (Chi-square test with Bonferroni correction, $p <0.05$).

A significant association was also observed between the interviewee and the perception that the team knew who the people who offered a support network to FPVHA were ($p <0.001$), with the percentage of FPVHA and PLWHA responding "never" feeling that the team knew who were the people who offered a support network to both was 7 (77.8%), a number higher than that reported by professionals 4 (9.5%) (Chi-square test with Bonferroni correction, $p < 0,05$).

In the HADS questionnaire for anxiety and depression, the question "I look forward to the good things to come" showed a significant association with the respondents' variable (FPVHA or PLWHA) (chi-square test, $p = 0.011$), however, there was a difference between respondents in relation to the percentage of responses to the question (chi-square test, with Bonferroni correction,> 0.05). In addition, there was no association between the respondent and the other questions in the HADS questionnaire (chi-square test, p-value ranging from 0.052 to 0.856).

When the comparison analysis between the scores of the HADS, FPVHA questionnaire and the socioeconomic profile was performed, it was found that the item age group p-value 0.021 (Student's t-test / ANOVA), influenced their level of anxiety, being the degree of depression influenced by the number of dependents on their care p-value 0.009, or some other family member has already been hospitalized before p value of 0.040 (Mann-Whitney u test / Kruskal-Wallis test).

In the classification of HADS (Table 1), it is identified that 4 (44.4%) of PLWHA and 8 (88.9%) of PLWHA have some level of anxiety, and the depression variable is verified in 5 (55.5%) of PLWHA and (77.8%) of FPVHA subdivided between classifications (mild, moderate and severe).

When assessing the association between respondents (FPVHA or PLWHA) and the degree of anxiety or depression in HADS, there was no significant difference between the participants regarding the degree of anxiety (Chi-square test p = 0.209) and the degree of depression (p = 0.613).

Based on the group comparison analysis, when the association between the HADS scores and the social profile of the FPVHA was carried out, in the anxiety classification, age group variable p-value 0.021 (Student's T test), for the depression classification of the items : number of dependents on their care p-value 0.009 and whether another family member has been hospitalized before (p-value 0.040) influenced the behavior of the scores in relation to these variables (Mann-Whitney u test and Kruskal-Wallis test), it was found from the answer to the HADS questionnaire, that there was interference according to the social profile of the participants only in the items mentioned above.

From the group comparison analysis, when the association between the classification scores of the HADS Scale - Anxiety (No Symptoms, Mild Anxiety, Moderate Anxiety, Severe Anxiety), and the social profile of FPVHA (Fisher's Exact Test) was performed, it was found that there is no difference in the behavior of the scores in relation to these variables, that is, no item of the social profile influenced the classification of the level of anxiety and depression of the FPVHA.

## 5. Conclusion

The data collected and results obtained in the scope of this research evidently show the importance of implementing Patient and Family Centered Care, with the objective of including PLWHA and their family members in decision-making and in the assistance provided making them protagonists of their own care, in which is obtained through shared responsibility with health professionals. Therefore, this constitutes a positive factor in adhering to the therapeutic dynamics adopted by PLWHA, through the continuous use of ART, reducing the rate of readmissions and consequently decreasing hospital expenses. During the responses to the PCCPAF questionnaires in the domains of respect, collaboration and support, discrepancies were perceived between the perceptions of the professionals, PLWHA and FPVHA. As an example, we have the perception of FPVHA and PLWHA regarding: not being seen and treated as such; do not feel welcome; unable to understand the guidelines they receive upon admission, they felt overwhelmed with information about PLWHA. However, they believed that they did not receive the information they need about their family members; not feeling included in the care provided to PLWHA; realize that the team did not listen to their concerns; and therefore, they did not know what they were going through; or who was part of your support network; and, not knowing when the PLWHA discharge would be given. Associating the HADS Scale with the socioeconomic elements of the FPVHA, the age group element influenced their level of anxiety; the degree of depression was influenced by participating in previous hospitalizations with other family members; and the number of dependents they had on their care during the hospitalization period. With these perceptions immersed during the study, and expressed during the hospitalization period, it was found that PLWHA and FPVHA had some level of anxiety and depression which were subdivided between the mild, moderate and severe classifications.

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