REME • Rev Min Enferm. 2017;21:e-1001
DOI: 10.5935/1415-2762.20170011

RESEARCH

# INTERACTIONS AND THE ANTIRETROVIRAL THERAPY ADHERENCE AMONG PEOPLE LIVING WITH HIV/AIDS

## *INTERAÇÕES SOCIAIS E A ADESÃO À TERAPIA ANTIRRETROVIRAL DE PESSOAS VIVENDO COM HIV/AIDS*

## *INTERACCIÓN SOCIAL Y ADHESIÓN A LA TERAPIA ANTIRRETROVIRAL DE PERSONAS QUE VIVEN CON EL VIH/SIDA*

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Submitted on: 2016/08/02 Approved on: 2017/04/03

## RESUMO

Apesar do aumento de acessibilidade aos regimes de tratamento antirretrovirais, a adesão continua a ser um desafio para os sistemas de saúde no Brasil. Dificuldades relacionadas à baixa adesão entre os pacientes que vivem com HIV/ Aids incluem a adaptação ao tratamento e interações sociais mais pobres, devido, geralmente, ao estigma da doença. Esses e outros aspectos psicossociais dos indivíduos são expressos em suas interações sociais, objeto deste estudo qualitativo. Os participantes foram pacientes de serviços de referência para o tratamento do HIV. Realizaram-se 30 entrevistas, sendo definidas categorias empíricas a partir da análise de conteúdo realizada. Observou-se que os pacientes que se distanciaram de seus parceiros, família, amigos e vizinhos, em oposição a partilhar a sua experiência com a doença, experimentaram diminuição de apoio de sua rede social. Esses dados salientaram a necessidade de melhorar a educação do paciente e incentivar intervenções mais eficientes, favorecendo o trabalho multidisciplinar e uma abordagem integrada dos cuidados de saúde, para promover maior adesão ao tratamento.

**Palavras-chave:** Terapia Antirretroviral de Alta Atividade; Promoção à Saúde; Síndrome de Imunodeficiência Adquirida.

## ABSTRACT

*Despite increasing accessibility to antiretroviral treatment regimens, adherence remains a challenge for the health systems in Brazil. Difficulties related with low adherence among patients living with HIV/AIDS include adapting to treatment and poorer social interactions, usually due to the stigma of the disease. These and other psychosocial aspects of subjects are expressed in their social interactions. This is a qualitative study. The participants were patients of reference services for HIV treatment. It was reached on 30 interviews; we defined greater empirical categories using Content Analysis. We observed that patients distanced from their partners, family, friends and neighbors, as opposed to sharing their experience with the disease experienced decreased support from their social network. These data pointed out the need to improve patient education and encourage more effective interventions, favoring multidisciplinary work to promote greater treatment adherence, as well as a more integrated approach to healthcare.*

***Keywords:*** *Antiretroviral Therapy, Highly Active Adherence; Health Promotion; Acquired Immunodeficiency Syndrome.*

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*How to cite this article:*
Freitas MIF, Bonolo PF, Miranda WD, Guimarães MDC. Interactions and the antiretroviral therapy adherence among people living with HIV/AIDS. REME – Rev Min Enferm. 2017[cited _____ ___ ___];21:e-1001. Available from: _______________ DOI: 10.5935/1415-2762.20170011

## RESUMEN

*A pesar del aumento de accesibilidad a los regímenes de tratamiento antirretroviral, la adhesión sigue siendo un reto para los sistemas de salud en Brasil. Las dificultades relacionadas con la baja adhesión entre los pacientes que viven con el VIH / SIDA incluyen adaptación al tratamiento y disminución de la interacción social, en general debido a la estigmatización de la enfermedad. Estos y otros aspectos psicosociales de los sujetos se expresan en sus interacciones sociales. Se trata de un estudio cualitativo cuyos participantes eran pacientes de los servicios de referencia para el tratamiento del VIH. Se realizaron 30 entrevistas y, a partir del análisis de contenido, se definieron las categorías empíricas. Se observó que los pacientes, alejados de sus parejas, familiares, amigos y vecinos, al no compartir su experiencia con la enfermedad, sintieron que disminuía el apoyo de su red social. Estos datos señalan la necesidad de mejorar la educación del paciente y fomentar intervenciones más eficaces que favorezcan el trabajo multidisciplinario para promover una mayor adhesión al tratamiento, así como un enfoque más integrado de atención de la salud.*

***Palabras clave***: *Terapia Antirretroviral Altamente Activa; Promoción de la Salud; Síndrome de Inmunodeficiencia Adquirida.*

## INTRODUCTION

Adherence to antiretroviral therapy (ART) remains one of the largest challenges that health systems face in the control of the HIV epidemics, especially in countries where medication is given free of charge, such as in Brazil.[1-6]

To understand ART adherence researches need to clarify subjective, psychosocial and social dimension, as expressed in the ways that patients relate to the world. Comprehensive studies in this field indicate the need of new interventions for healthcare professionals to promote education.[7]

When patients facing difficulties they turn to people in their social circle creating a network that is indispensable for coping with their situation. In addition, healthcare personnel are favorable for treatment adherence within the context of a chronic disease. [8,9]

The social representations become the group's source of understanding the ways that patient relate to the world. Representations are "a set of concepts, propositions, and explanations originated in everyday life interpersonal communications and as shared knowledge between groups and societies".[10-13]

We assume that treatment adherence includes aspects of the individual's subjectivity and social interactions, deconstructed and reconstructed from the time of the infection.[10,11] Our main objective was to understand the influence of social interactions on antiretroviral therapy among patients initiating their treatment.

## METHODS

This qualitative analysis is part of the ATAR Project, a cohort study whose main objective was to evaluate the determinants of non-adherence to ART. Participants were adult patients initiating treatment at two public AIDS referral centers in Brazil. Written and informed consent was gathered from all research participants with the agreement that their identities would not be revealed. Pseudonyms have therefore been used throughout. The project was submitted and approved by the Ethics Research Committee of the Federal University of Minas Gerais.

Among 306 patients, 199 (65%) were male. The cumulative incidence of non-adherence was 36.9%. Unemployment, alcohol use, self-report of adverse reactions, number of pills, switch in antiretroviral regimen, and a longer time between the HIV test result and the first antiretroviral prescription were associated with an increased risk of non-adherence.[12]

We conducted 30 individual interviews with eight female and 22 male, aged 22 to 52 years. Data collection was conducted by experienced field workers and was audio recorded. The interview was open and with non-directive questions. After transcribing, we defined greater empirical categories relative to ART adherence using Content Analysis.[13]

The research was approved by the Ethics Committee on Human Research of the Federal University of Minas Gerais, following the ethical guidelines.[14]

The thematic analysis yielded categories related to ART adherence organized into two themes: the experience of ART and the social experience of AIDS. We aimed to understand better the social interactions of these individuals and healthcare delivery services and the importance of these interactions to adherence. Historical and social evolution of the AIDS shows that individuals have building representations about the HIV and its transmission, risk and prevention, and the disease. As result, we had the sub-headings for our findings which follow.

## RESULTS AND DISCUSSION

### INTERACTIONS WITH FAMILY

Respondents describe their relationship with family members as an integral part of antiretroviral treatment and realized families as a source of solidarity or conflict. Subjects always expected support from close relatives. Those who managed to reveal their illness recognized support within the family as a facilitating aspect for ART adherence.

> *My kids helped me the most. I want to live with them for a long while (I427, O287). When I feel like giving up, I remember I have a son, that I have my parents' support (I317, O410). My family supports me. They force me to keep going. (I327, O378)*

For some patients, however, the difficulties experienced in their nuclear family are a threat to treatment maintenance, causing subjects to feel alone in dealing with the disease. These feelings can lead them to abandon their treatments for long periods of time.

> *I am the only one who can really motivate me with the treatment. It's all me, all me. I just won't take anything. I think I'm alone. I got worse and they didn't see me, they didn't care for me at all (I112, O028).*

The interviewees perceived the family as psychosocial support when facing HIV infection. However, this support is not always present and this lack of love justifies non-adherence. For people who are not being able to count on their relatives is a source of frustration and reinforces the perception that we are all alone in life and that the treatment is not worthwhile.

The results found in this study corroborate other related studies. Family emerges as one of the strongest support networks in these patients' perspectives, perceived as an aid on the daily fight for life and a help in dealing with the medication.[3,8,15-17]

## RELATIONSHIP WITH THE PARTNER

The reports reveal that the ways interviewees live their relationships with partners can interfere with treatment adherence. Testimonies show that feeling that a partner is not caring enough is also a source of discontent, which can undermine the treatment. The partner is perceived as a companion and a source of cooperative and reciprocal support.

> *I'd rather not talk all the time about the disease. I'd rather not keep on commenting on the treatment. Sometimes my partner insists on it and I don't want to. He tells me not to worry about (I407, O239). My husband talks to me, and he reminds me when it's time to take the meds. He won't let me be without food. I don't know what I'd do without him. (I328, O377)*

These results are all in agreement with Murray *et al.*[18] who observed poorer adherence in those living alone. The almost direct relationship between desired support and support given by the partner confirms the importance of revealing the diagnosis as a means of socially coping with the situation.

## PRESENCE OF EVERYDAY FRIENDS

The presence of one or more trusted people who know of the diagnosis also helps in coping with AIDS. The patients choose a friend who subsequently becomes a confidante on subjects related to the disease and the treatment. However, there are few people with whom the interviewees can share.

> *He's really there for me. Every day, I pray to God for him because he really helps a lot (O109, I085). This friend of mine, who is with me until today, she asks how I'm doing, she worries about me, talks about life, asks me if I'm taking my meds, what the doctor said (O365, I320).*

In certain cases, patient strengthens old friendships, reestablishing relationships on affective bases without actually unveiling their situation. Trust is therefore relative and an attempt to protect oneself from the risk of exposure and be affirmed of friends' love. The interviewees expressed a fear of public exposure by a friend.

> *I want to forget, not to keep thinking, remembering it all the time. It's good to talk of other things, to talk to someone who doesn't know anything about it, without feeling pressured (O302, I468).*

The final expression of interactions among friends is related to a reorganization of living in society. On one hand few friends are selected as confidantes. On the other hand, subjects shy away from their friends.[15-17]

## THE RELATIONSHIP WITH HEALTH PERSONNEL

For the interviewees, the posture of the professionals caring and the availability of resources in health services are fundamental for the continuation of treatment.

> *What makes me continue the treatment is the encouragement that nurses and doctors give me. At the reception, everyone here really toughens me up (O324, I549). I thank God for the medication I can have here, and all for free. Another thing I am really happy with is the support I get here at the service. The doctor welcomed me so kindly. He gives me all the support I need. The most important thing I see is their satisfaction in just talking to us (O365, I320).*

Interviewees often can only open up with the professionals, and we can infer that treatment adherence is positively influenced by the interactions with the professionals caring for them, as supporters for their endurance.

This result reinforces the need to integral care, emphatic and shared such that patient can feel supported in their difficulties. Assistance offered by professionals is a predictive factor for adherence, especially at the onset of treatment when patients have to address a significant psychological impact.[12,19,20]

## CONCLUSIONS

The social interactions of subjects are presented as aspects that stimulate adherence but that can also be impediments. Family interactions, especially those between partners, parents and children, are most important for the process of accepting the treatment.

Our results show the need for past health personnel to understand the subjects' HIV / AIDS experience, especially regarding the importance of relationships with family members, friends and healthcare staff. The evidence is much clearer that fear of discrimination presents barriers to antiretroviral treatment.

This study was conducted in a context from patients initiating treatment and therefore generalization cannot be achieved. Furthermore, we did not intend to compare and seek for differences between gender and other socio-demographic characteristics.

## FINANCING

This research received financial support from the Pan-American Health Organization (OPAS/WHO) and the Brazilian National AIDS/STD/Hepatitis Department, UNESCO, Ministry of Health.

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