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

RESUMO

A pesar 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 sua experiência com a doença, experimentaram diminuição do 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, experimentally diminished their social support. 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.
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.

Introducción
Adherencia a antirretroviral (ART) es una de los desafíos más importantes que los sistemas de salud enfrentan en el control de la epidemia del VIH, especialmente en países donde la medicación es gratuita, como en Brasil.1-6

Para entender la adherencia a ART, se requiere clarificar aspectos subjetivos, psicosociales y dimensiones sociales, como expresado en lo que pacientes perciben al mundo. Estudios de campo han indicado la necesidad de nuevas intervenciones para mejorar la adherencia.7

Cuando pacientes enfrentan dificultades, se dirigen a personas de su grupo social, creando un redete que es indispensable para el control de la enfermedad. En esta situación, el personal de cuidados de salud se convierte en una fuente de tratamiento para la adherencia, en el contexto de una enfermedad crónica.4,9

Las representaciones sociales se convierten en el grupo de referencia de las formas en que los pacientes relacionan al mundo. Las representaciones son "un conjunto de conceptos, proposiciones, y explicaciones originadas en el día a día de la vida inter-personal, y compartida entre grupos y sociedades".10-13

Asumimos que la adherencia a ART es un reflejo de aspectos subjetivos y dimensiones sociales, construidas y reconstruidas desde el momento del contagio.10,11 Nuestro objetivo fue entender cómo las interacciones sociales afectan la adherencia a ART en pacientes que inician su tratamiento.

Métodos
Este análisis cualitativo es parte del Proyecto ATAR, un estudio cohorte cuyo objetivo principal era evaluar los determinantes de la no-adherencia a ART. Los participantes eran adultos que iniciaban tratamiento en dos centros de referencia de VIH en Brasil. Se obtuvo el consentimiento informado de todos los participantes con el acuerdo de que sus identidades no serían reveladas. Se utilizaron pseudónimos para garantizar la privacidad de los participantes. El estudio fue aprobado por el Comité de Ética de la Universidad Federal de Minas Gerais.

Entre los 306 pacientes, 199 (65%) eran varones. La adherencia acumulada fue del 71%. No se registraron muertes durante el estudio. La adherencia de ART sigue siendo un reto para los sistemas de salud en Brasil. La falta de adherencia a ART está asociada con un aumento en la transmisión del VIH y con una mayor morbilidad y mortalidad.12

Resultados y discusión
Interacciones con la familia
Respondieron describir su relación con sus familiares como un elemento integral del tratamiento antirretroviral. Los sujetos siempre expresaron que sus familias eran importantes para su tratamiento y para promover su adherencia.22

My kids helped me the most. I want to live with them for a long while (I427, O378). 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, O578)
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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 (1112, 0028).

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.14,15-17

**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 (1407, 0239). 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 (1328, 0377)

These results are all in agreement with Murray et al.16 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 (0109, 1085). 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 (0365, 1320).

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 (0302, 1468).

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 (0324, 1549). 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 (0365, 1320).

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.

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