Factors associated with the social participation of individuals hospitalized with HIV/AIDS

Fatores associados à participação social de indivíduos hospitalizados com HIV/AIDS

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Abstract

Introduction: HIV/AIDS imposes both physical and mental burdens that may hinder the social participation of affected individuals. Understanding the factors associated with social participation in this population enables the development of effective preventive and rehabilitative strategies. **Objective**: To assess social participation among people living with HIV/AIDS who were hospitalized and to examine whether demographic, clinical, psychological, and functionality-related characteristics are associated with their social participation. **Methods:** This was a cross-sectional study evaluating individuals diagnosed with HIV/AIDS upon hospital admission. The following aspects were assessed: clinical characteristics (time since diagnosis and CD4+ T-cell count), demographic data (age, physical activity level), social participation (LIFE-HABITS 3.1), cognitive function (Mini-Mental State Examination), psychological status (Hospital Anxiety and Depression Scale), handgrip strength (Handgrip Test), respiratory muscle strength (manovacuometry), and postural balance (Mini-BESTest). Pearson or Spearman correlation tests were used ($p < 0.05$). **Results:** Ten participants were included (90% female; mean age 42.3 years). Significant restrictions in social participation were observed in the domains of recreation and education. Additionally, respiratory muscle strength was associated ($p < 0.05$) with the mobility subdomain ($R = 0.68$); cognitive function was associated with the responsibilities subdomain and total score ($R = 0.62$ and $R = 0.63$, respectively); anxiety was negatively associated with the employment subdomain ($R = -0.73$); and age was negatively associated with the employment subdomain ($R = -0.65$). **Conclusion:** Social participation was found to be restricted in this population, and factors such as cognitive impairment, increased anxiety, and decreased inspiratory muscle strength were associated with lower levels of social participation.

Keywords: Social participation. HIV. International Classification of Functioning, Disability and Health.

Resumo

Introdução: *O HIV/AIDS impõe repercussões físicas e mentais que podem prejudicar a participação social de pessoas vivendo com HIV. Conhecer os fatores associados à participação social desta população permite desenvolver estratégias de prevenção e reabilitadoras efetivas.* ***Objetivo:*** *Avaliar a participação social de pessoas hospitalizadas com HIV/AIDS e a sua associação com características demográficas, clínicas, psicológicas e de funcionalidade.* ***Métodos:*** *Trata-se de um estudo transversal, em que avaliaram-se pessoas diagnosticadas com HIV/AIDS na admissão hospitalar quanto às características clínicas (tempo de diagnóstico e LT-CD4+), demográficas (idade, nível de atividade física), participação social (LIFE-HABITS 3,1), função cognitiva (Mini Exame do Estado Mental), aspectos psicológicos (Escala Hospitalar de Ansiedade e Depressão), força muscular de preensão palmar (Handgrip Test) e respiratória (manovacuometria) e equilíbrio postural (Mini-BESTest). Utilizou-se o teste de correlação de Pearson ou Spearman (p < 0,05).* ***Resultados:*** *Foram incluídas dez pessoas vivendo com HIV (90% mulheres; 42,3 anos). Observou-se restrição importante da participação social nas áreas de recreação e educação. Ademais, observou-se associação (p < 0,05) entre força muscular respiratória e subdomínio mobilidade (R = 0,68); função cognitiva e subdomínio responsabilidades e escore total (R = 0,62 e R = 0,63, respectivamente); ansiedade e subdomínio emprego (R = -0,73); e idade e subdomínio emprego (R = -0,65).* ***Conclusão:*** *Verificou-se restrição na participação social e que aspectos relacionados ao comprometimento cognitivo, aumento da ansiedade e redução da força muscular inspiratória estão associados à menor participação social destes indivíduos.*

Palavras-chave: *Participação social. HIV. Classificação Internacional de Funcionalidade, Incapacidade e Saúde.*

Introduction

The human immunodeficiency virus (HIV) is a retrovirus that causes chronic immune dysfunction through depletion of CD4+ lymphocytes. Moreover, CD4+ counts below 200 cells/mm³ or the presence of opportunistic infections define acquired immunodeficiency syndrome (AIDS).[1] First described in 1980, AIDS has undergone important epidemiological changes, with higher prevalence in vulnerable populations and reduced mortality due to antiretroviral therapy.[1-3] It is estimated that, by 2025, approximately 1,679,622 people will be living with HIV/AIDS in Brazil (since 1980), with an incidence of 18.4 cases per 100,000 habitants. The annual average of new cases is approximately 38,000, with about 80% of individuals being followed by healthcare services, including monitoring of CD4+ cell counts and viral load.[4,5]

Despite the alarming epidemiological data, a reduction in mortality was observed between 2015 and 2020 (from 5.5 to 4.5 deaths per 100,000 habitants), mainly due to the use of antiretroviral therapy (ART) among people living with HIV.[4,5] Consequently, a progressive aging of this population has been observed, along with an increased occurrence of comorbidities, particularly cardiovascular, neurological, and pulmonary complications, as well as metabolic and musculoskeletal disorders, which directly compromise functional capacity.[6,7] Finally, impairments in musculoskeletal structures and cardiovascular and cognitive functions, for example, may hinder the performance of activities such as mobility and, consequently, restrict social participation.

According to the International Classification of Functioning, Disability and Health (ICF), social participation refers to individuals' involvement in real-life situations, encompassing mobility, communication, interpersonal relationships, and community activities. Indeed, studies have shown that people living with HIV/AIDS frequently experience restrictions in these domains, negatively affecting autonomy, functional independence, and, consequently, quality of life.[8,9] In one study, nineteen individuals with HIV/AIDS followed in an outpatient clinic in South Africa verbally reported cognitive and physical limitations that affected their social participation.[10] However, no objective methods for assessing functioning were applied in that study. Moreover, no studies were identified that evaluated this population during hospitalization due to acute clinical exacerbation. Thus, the objective of the present study was to assess social participation among hospitalized people living with HIV/AIDS and to investigate its association with demographic, clinical, psychological, and functional characteristics.

Methods

The present study was approved by the Research Ethics Committee of the University Hospital of the Federal University of Juiz de Fora (HU-UFJF) under approval number 2,979,088. All participants were fully informed about the study procedures and, after agreeing to participate, provided written informed consent.

This was a cross-sectional observational study conducted with people living with a diagnosis of HIV/AIDS who were hospitalized due to disease-related impairments at HU-UFJF. Data collection was carried out through interviews, application of functional assessments, and review of medical records between September 2018 and January 2019. Assessments were performed within a maximum of seven days after hospital admission. Inclusion criteria were age ≥18 years and a medical diagnosis of HIV/AIDS, regardless of viral load, with follow-up in the hospital's infectious disease service for at least three months. Exclusion criteria included cognitive impairment, hemodynamic clinical instability (systolic and diastolic blood pressure >180×120 mmHg and/or <70×30 mmHg, respectively; oxygen saturation <88%; heart rate >140 bpm and/or <50 bpm), and osteomuscular limitations that precluded the performance of functional assessments.

Seventeen patients were recruited. After the initial assessment, seven were excluded for not meeting the eligibility criteria. Therefore, ten patients participated in the study.

Participants initially underwent an interview to collect information on demographic characteristics, duration of disease diagnosis, medication use, family situation, and physical activity practice. Subsequently, three questionnaires were administered to assess cognitive deficits and levels of anxiety, depression, and social participation. Functional assessments were then performed to evaluate peripheral muscle strength, respiratory muscle strength, dynamic balance, and mobility. All assessments were conducted by the same evaluator.

Procedures

Assessment of demographic and clinical characteristics: Data on demographic and clinical variables (age, sex, length of hospital stay, time since diagnosis, correct medication use, self-reported physical activity level, associated comorbidities, and family situation) were obtained through interviews. Additional laboratory and clinical data (complete blood count, CD4+ cell count, viral load, and medications in use) were collected from electronic medical records.

Assessment of cognitive function: Cognitive function was assessed using the Mini-Mental State Examination (MMSE), which consists of questions grouped into categories designed to evaluate specific cognitive domains: temporal orientation, spatial orientation, attention and calculation, memory, language, and visuoconstructive ability. Cutoff scores for participant exclusion were ≤13 for illiterate individuals, ≤18 for those with low to medium educational level, and ≤26 for those with high educational level.[11]

Assessment of anxiety and depression: Anxiety and depression were assessed using the Hospital Anxiety and Depression Scale (HADS), which comprises 14 items, seven related to anxiety (HADS-A) and seven to depression (HADS-D). Each item is scored from 0 to 3, yielding a maximum score of 21 for each subscale. For both subscales, the following cutoff points were adopted: no anxiety/depression (0–8) and presence of anxiety/depression (≥9).[12]

Assessment of social participation: Social participation was measured using the adapted Brazilian version of the Assessment of Life Habits 3.1 (LIFE-H 3.1–Brazil). This questionnaire consists of 77 items grouped into two subscales: daily activities, which include nutrition, physical fitness, personal care, communication, housing, and mobility; and social roles, which include responsibility, interpersonal relationships, community life, education, employment, and recreation. For each item, the level of accomplishment (no difficulty; with difficulty; performed by a caregiver; not performed; not applicable) and the type of assistance required (no assistance; assistive device; adaptation; human assistance) are identified. Participants were instructed to consider the two weeks preceding the assessment when answering the questionnaire. Based on the combination of accomplishment level and type of assistance, performance is classified on a scale from 0 to 9, where 0 indicates total restriction and 9 indicates no restriction in social participation, with activities or social roles performed without difficulty or assistance. Total scores for each subscale and domain are calculated using the formula: Σ scores × 10/number of applicable items × 9, where 0 indicates total restriction and 10 indicates no restriction in social participation.[3] Scores ≤5 were considered indicative of significant restriction in social participation.[13]

Assessment of peripheral muscle strength: Handgrip strength was measured using a portable digital hand dynamometer (Instutherm® Instrumentos de Medição Ltda., São Paulo, SP, Brazil). Measurements were performed on the dominant upper limb. Participants were seated with an upright posture, knees flexed at 90°, shoulder in a neutral position for flexion, adduction, and rotation,

elbow flexed at 90°, and forearm and wrist in a neutral position, with corrections provided by the examiner when necessary. The highest value of three measurements was recorded.[14]

Assessment of respiratory muscle strength: Maximal inspiratory pressure (MIP) and maximal expiratory pressure (MEP) were measured using an analog manovacuometer (Ger-Ar Famabras®). MIP was obtained from residual volume and MEP from total lung capacity, with participants using a nose clip and a rigid plastic mouthpiece. The pressure was sustained for at least one second. Participants performed three to six acceptable and reproducible maneuvers, defined as differences of 10% or less between values. An interval of approximately one minute was allowed between attempts, and the highest value was recorded.[15] Values were expressed as percentages of predicted values according to age and sex.

Assessment of dynamic balance: Dynamic balance was assessed using the Mini-BESTest. This instrument evaluates balance through the performance of 14 tasks divided into four sections corresponding to the subsystems of anticipatory postural adjustments, reactive postural control, sensory orientation, and dynamic gait. The test comprises 17 items scored from 0 (worst performance) to 2 (best performance), with a maximum total score of 28 points. Participants were instructed and assessed according to standardized test guidelines.[16,17]

Data analysis

Data are presented as median (interquartile range) or mean ± standard deviation, depending on data distribution. Normality was assessed through histogram visualization and the Shapiro–Wilk test. Pearson or Spearman correlation tests were applied, as appropriate, to evaluate associations between variables of interest. Statistical significance was set at $p < 0.05$ for all analyses. The strength of association between variables was considered.[18] Statistical analyses were performed using the STATISTICA 8.0 software package.

Results

Table 1 presents the demographic, clinical, and functional characteristics of the participants. A predominance of female participants was observed (90%), with a mean time since diagnosis of 11.5 ± 6.0 years. In addition, 50% of the sample received the HIV diagnosis before the age of 30 years, and only approximately half of the participants had viral load and CD4+ T-lymphocyte values documented in their medical records. The entire sample was classified as sedentary. Regarding family situation, nine out of ten participants lived with family members and/or partners.

Table 1 - Demographic, clinical, psychological, cognitive, and functional characteristics of the participants

Characteristics	n = 10
Age (years)	42.3 ± 9.8
Sex, female (%)	90
Primary education (%)	80
Secondary education (%)	20
Higher education (%)	0
Time since diagnosis (years)	11.5 ± 6.0
Viral load (copies/ml)	2,501 ± 409.9
CD4+ T lymphocytes (mm^3)	284.4 ± 428.2
Physical activity level: active (%)	0
Physical activity level: sedentary (%)	100
Lives alone (%)	10
Lives with others (%)	90
Mini-Mental State Examination	25.9 ± 3.6
Hospital Anxiety and Depression Scale-A	8.9 ± 4.6
Hospital Anxiety and Depression Scale-D	5.8 ± 3.2
MINI-BESTest	18.1 ± 8.7
Maximal inspiratory pressure (cmH_2O)	-55.8 ± 13.3
Maximal expiratory pressure (cmH_2O)	56.6 ± 18.7
Handgrip strength (kg)	18.0 ± 6.0

Note: Data are presented as mean ± standard deviation or proportion (%). CD4+ T lymphocytes = CD4+ helper T lymphocytes.

The level of social participation of the total sample, presented by domain and total score of the LIFE-H 3.1–Brazil, is described in Table 2. Significant restrictions were observed in the recreation and education domains. Notably, in the physical fitness domain, 90% of participants had scores ≤5. In the nutrition and personal care domains, only 10% of the sample presented any deficit in social participation.

When assessing the associations between social participation and the demographic, clinical, and functional characteristics of the participants, strong positive associations were observed between MIP and the mobility

subscale, as well as between MMSE scores and both the responsibility subscale and the total social participation score. These findings indicate that greater inspiratory muscle strength and better cognitive function are associated with improved social participation related to mobility, responsibilities, and overall participation. Additionally, strong negative associations were found between HADS-anxiety scores and the employment subscale, and between age and the employment subscale. Thus, higher levels of anxiety and older age were associated with lower social participation related to employment (Table 3).

Table 2 - Level of social participation

LIFE-H 3.1-Brazil (subscales)	n = 10
Nutrition	9.3 ± 1.4
Physical fitness	5.2 ± 0.8
Personal care	9.6 ± 0.7
Communication	8.4 ± 2.0
Housing	9.2 ± 1.2
Mobility	7.1 ± 1.9
Responsabilities	9.4 ± 1.0
Interpersonal relationships	9.1 ± 1.2
Community life	8.0 ± 2.1
Education	0.0 ± 0.0
Employment	7.9 ± 2.2
Recreation	1.8 ± 1.7
Total	7.6 ± 1.0

Note: Data are presented as mean ± standard deviation. Significant restriction was defined as a score ≤ 5.

Table 3 - Association between social participation and demographic, clinical, and functional characteristics

	NU	PF	PC	CM	CO	HO	MO	RE	IR	EM	RC	TS
HG	-0.29	0.06	-0.29	-0.21	-0.22	-0.55	-0.51	0.03	-0.46	-0.50	-0.37	-0.36
HG pred	0.17	-0.17	0.17	-0.01	0.01	-0.31	-0.12	-0.01	-0.24	-0.29	-0.28	-0.08
MEP	-0.55	0.52	-0.55	0.13	-0.59	-0.47	-0.09	-0.05	0.20	0.14	-0.24	-0.22
MEP pred	0.27	-0.06	0.27	0.45	-0.01	-0.09	0.59	-0.34	0.41	0.32	0.31	0.28
MIP	0.41	-0.51	0.41	0.13	-0.10	**0.68**	0.48	-0.50	0.23	0.24	0.25	0.34
MIP pred	0.60	-0.26	0.60	0.31	0.50	0.33	0.30	0.18	0.15	0.11	-0.01	0.59
MINI-BESTest	0.17	-0.20	0.17	0.45	0.57	0.04	0.49	0.31	0.49	0.05	0.21	0.21
MMSE	0.53	-0.54	0.53	0.40	0.30	0.46	**0.62**	-0.39	0.30	0.13	0.49	**0.63**
HADS-a	-0.29	-0.27	-0.29	-0.31	-0.30	0.04	0.11	-0.52	-0.40	**-0.73**	-0.16	-0.55
HADS-d	0.46	-0.11	0.46	0.09	-0.09	0.21	0.69	-0.50	0.17	0.23	-0.08	0.29
CD4+ T	0.35	-0.44	0.35	-0.15	0.15	0.44	0.35	-0.60	-0.26	-0.41	0.10	-0.10
Age	-0.11	-0.33	-0.11	-0.41	0.09	0.16	0.17	-0.37	-0.45	**-0.65**	-0.36	-0.33
Time since diagnosis	0.05	-0.42	0.05	0.06	0.49	0.18	0.28	0.13	0.08	-0.31	-0.24	-0.04

Note: Data are presented as correlation coefficients (R). *p < 0.05. NU = nutrition; PF = physical fitness; PC = personal care; CO = communication; HO = housing; MO = mobility; RE = responsibilities; IR = interpersonal relationships; CL = community life; EM = employment; RC = recreation; TS = total score. HG = handgrip strength; MEP = maximal expiratory pressure; MIP = maximal inspiratory pressure; ; MMSE = Mini-Mental State Examination; HADS = Hospital Anxiety and Depression Scale. Bold values indicate statistically significant differences (p < 0.05).

Discussion

Social restrictions experienced by people living with HIV/AIDS have been highlighted in the literature. However, quantitative studies evaluating which domains of social participation are affected and the factors associated with social participation in hospitalized individuals remain scarce. Thus, the main findings of the present study indicate that hospitalized people living with HIV/AIDS present restrictions in social participation related to recreation, education, and physical fitness. In addition, poorer cognitive function, higher levels of anxiety, and older age were associated with worse social participation.

Indeed, the use of the LIFE-H 3.1–Brazil questionnaire, translated and cross-culturally adapted for use in Brazil, identified marked restrictions in recreation, education, and physical fitness (90% with scores ≤5), in contrast to the preservation of nutrition and personal care (deficits observed in only 10% of participants). This distribution highlights impairments in the performance of "activities" within the ICF framework, particularly those requiring mobility and community interaction, even when basic functions remain intact. These findings suggest the need to prioritize targeted leisure, educational, and exercise programs.[13] Social participation is an essential determinant of health and quality of life among people living with HIV/AIDS, as it facilitates access to social support networks, community resources, and opportunities for work and leisure.[19,20] Restrictions in this domain may exacerbate social isolation, stigma, and poor treatment adherence, reinforcing the importance of assessing and addressing factors that limit social engagement in this population. In this study, we sought to quantify these restrictions and identify factors associated with social participation among hospitalized people living with HIV/AIDS.

Adopting the ICF framework, we aimed to understand health conditions, personal and environmental factors, body structures/functions, and activities that could be associated with participants' social participation. Regarding health conditions, the hospitalized sample presented a mean time since diagnosis of 11.5 years, with half of the participants diagnosed before the age of 30, a pattern consistent with data from the Brazilian Ministry of Health HIV/AIDS Epidemiological Bulletin.[21] Additionally, incomplete laboratory records were observed (50% without documented viral load or CD4+ T-lymphocyte monitoring), indicating gaps in clinical care. Among environmental factors, 90% of participants lived with family members or partners, which may function either as support (facilitator) or as a source of stigma (barrier) within the home environment.[22] Environmental factors, including stigma, accessibility, and inclusion policies, can substantially modulate social participation. Interventions aimed at stigma reduction and strengthening community networks have been shown to be effective in increasing social engagement among people living with HIV in different contexts.[23,24] Sedentary behavior, observed universally in the present sample, emerged as an important personal factor, indicating compromised health-related behaviors. This finding is particularly concerning given the established role of physical activity in maintaining functionality and promoting social participation among people living with HIV.[25] Furthermore, restrictions in social participation related to education may be discussed in light of other participant characteristics, such as mean age and prior educational level (80% reported completion of primary education), which likely influenced the reported non-participation in educational activities during the assessment period.

Considering the assessment of "body structures and functions," associations were observed between social participation restrictions and physical, cognitive, and psychological functions. Respiratory muscle strength showed a strong association with the "mobility" subdomain of social participation, indicating that better respiratory muscle performance appears to be linked to greater autonomy in mobility.[26] Moreover, poorer cognitive function was associated with the "responsibilities" subdomain and the total social participation score, which reflect engagement in social roles and overall participation, underscoring the multifactorial nature of barriers to social participation.[27]

Higher levels of anxiety were also associated with greater restrictions related to reintegration into employment. Age, as a personal factor, was likewise associated with employment-related social participation, with older age linked to poorer occupational participation. These findings emphasize the importance of psychosocial support and tailored vocational rehabilitation and support programs.[28,29] These results highlight that impairments in respiratory and mental functions ("body functions and structures") negatively affect the performance of "activities" and, consequently, restrict social participation. Personal factors (such as age) and environmental factors (such as stigma and community support) further shape these outcomes. Multidimensional interventions addressing physical aspects (e.g., muscle strength and physical activity), as well as psychosocial and environmental factors, are therefore essential to improve social participa-

tion among hospitalized people living with HIV. The development of communities of practice involving people living with HIV, clinicians, and researchers also represents a promising strategy to foster physical and psychosocial rehabilitation interventions aimed at promoting social participation. Physical rehabilitation, physical activity promotion, and psychosocial care emerge as crucial components to mitigate these restrictions and enhance well-being.[30]

Some limitations of the present study should be considered when interpreting the results. The small sample size, resulting from operational difficulties in recruiting hospitalized individuals living with HIV/AIDS, limits the generalizability of the findings and reinforces the need for future studies with larger samples. In addition, the cross-sectional design precludes the establishment of causal relationships between the evaluated factors and social participation. Another limitation relates to the sample composition, characterized by a predominance of women and sedentary individuals, which may not reflect the heterogeneity of the broader population of people living with HIV/AIDS in other contexts. The lack of complete clinical information for some participants, such as laboratory data (viral load and CD4+ T-lymphocyte count), also limits the analysis of clinical variables.

Despite these limitations, the study provides important preliminary contributions to the understanding of factors influencing social participation among hospitalized people living with HIV/AIDS. Future studies with larger and more diverse samples and longitudinal designs are recommended to examine changes in social participation over time and following hospital discharge. Additionally, studies incorporating multivariate statistical models that control potential confounding factors may further elucidate predictors of social participation in this population.

Finally, the findings of this study reinforce the importance of multidimensional interventions during hospitalization, focusing not only on clinical recovery but also on the preservation of cognitive function, management of anxiety, and physical rehabilitation, with the aim of maintaining and promoting social participation among people living with HIV/AIDS.

Conclusion

The results of the present study demonstrate that people living with HIV/AIDS experience restrictions in social participation, with particularly significant limitations observed in the domains of recreation and education. In addition, factors related to cognitive impairment, increased anxiety, and reduced inspiratory muscle strength appear to be associated with lower levels of social participation in this population. These aspects should be considered when planning physiotherapeutic and rehabilitation interventions, multiprofessional care during hospitalization, and the development of public policies aimed at improving social participation among individuals living with HIV/AIDS.

Authors' contributions

RAS and LBA were responsible for the conceptualization. RAS and PNA, for the visualization. RAS, for the investigation. LBA, for the formal analysis, methodology, writing of the original draft, and supervision. PNA, DGM, CM, and LBA contributed to the writing, review and editing. All authors approved the final version.

Data availability statement

Research data are available from the corresponding author upon reasonable request.

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