

Evaluation of AIDS-Related Disability in a General Hospital in Southern, Brazil

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The increase in survival rates of patients affected by AIDS is associated with physical disabilities that can compromise their functional independence. We examined the degree and types of disabilities in hospitalized AIDS patients, as well the clinical and immunological parameters associated with disability. The lowered functional status was associated with increased time since AIDS had been diagnosed, with complaints of weakness, and with the involvement of more than one set of systems in the definition of AIDS. The inability to perform daily living activities was associated with higher viral loads (log) c/mL, lower CD₄⁺/mL and CD₄⁺/CD₈⁺ ratios, and with involvement of the central nervous system, in the cause of hospitalization. Both the inability to perform daily living activities and low functional status were associated with muscle strength alteration and with being unemployed.

Key Words: AIDS, HIV, disability, functional status, functional assessment, functional independence measure.

The treatment of HIV infected patients in Brazil has been a great challenge for health professionals. Latin America holds third place in the epidemic of Acquired Immunodeficiency Syndrome (AIDS) [1], and Brazil is the country with the largest number of infected people, with nearly 600,000 infected individuals. By December 2002, 257,780 AIDS cases had been reported to the Health Ministry, with 185,061 males and 72,719 females [2].

Treatment has led to an increase in life expectancy in the patients who, in turn, have had to deal with a large number of complications and with physical disabilities resulting from infection [3,4]. When their functional abilities are limited, both their independence as well as their quality of life will be compromised [3].

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As the number of persons diagnosed with AIDS, as well as their life expectancy, rises, the assessment and treatment of the physical disabilities related to this disease have become increasingly important priorities [18,19]. The ability of HIV to involve multiple organ systems, especially the central nervous system, results in a great variety of disabling conditions that can manifest themselves at any time and through different factors associated with the evolution of the disease [20-22].

The effects of AIDS disease are not limited exclusively to a biological sphere. Social, political and economic factors are extremely important; treatment and an extended life expectancy of an AIDS patient depend, to a great extent, on the country in which he or she lives.

In a developing country, the need for assistance caused by the reduction of the functional ability of debilitated individuals places a considerable weight on the shoulders of society. In this functional context, assessment is necessary both for clinical research as well as for the definition of the kinds of services required. The knowledge of the normal progression of the disease through its course and the patterns of

transition in functional status can help in planning rehabilitation [5].

As the impaired ability to perform self-care tasks is the major determinant of need for formal or informal personal care services or other long-term care [6], it is very important for this assessment to take into account the degree of independence for daily-living activities [7]. On the other hand, scales that measure overall independence can provide a gross indication of the functional status and the burden of care [8].

We examined and quantified the various types of physical disability in hospitalized persons affected by AIDS, and we examined associations of disability with immunological and clinical data.

Material and Methods

Study population

The study population consisted of 120 inpatients admitted to the Federal University Hospital of Paraná, Brazil, in the city of Curitiba. They were under the care of the Infectious Disease, General and Neurological Clinics. All evaluations were performed by one of the authors (ZMB) in the period from May/2000 to July/2001, and each patient was examined once. All patients had proven HIV infection, and all met the Center for Disease Control's criteria for the diagnosis of AIDS [9]. All the patients invited to participate in this study gave their informed written consent.

Evaluation procedure

The evaluation consisted of an interview with the patient, administration of standard functional assessment instruments, a specific physical exam and retrospective examination of hospital records. During the interview, the patients were questioned about any kind of motor disability, when it started and what other factors could be related to it. They were asked to describe the degree of difficulty they had in the performance of daily activities and at their jobs. We measured functional independence by using the

Functional Independence Measure* (FIM) [10] in 85 patients and the Barthel Index [11,12] in 120 patients. Evaluation was completed by actual patient observation or by simulation of the functional activity. To measure the functional status of the 120 patients, we used the modified Rankin score [13] and the Karnofsky Performance Status [14,15]. Consulting with the patients' primary nurse or caregivers was also used and was especially helpful in completing the social cognition assessment. The physical exam consisted of measuring muscular strength in muscular groups or specific muscles (upper limbs: deltoid, biceps, triceps and palmar flexors; lower limbs: hip flexors, quadriceps, hamstrings and dorsal flexors). Strength was measured from 0 (absence of muscular contraction) to 5 (normal active movement) [16].

An examination of the hospital records provided the clinical and immunological data, including viral load (log) c/mL, CD₄⁺/μL counts and CD₄⁺/CD₈⁺ [17]; medical history, data on the AIDS-defining illness, admission cause, risk factors for HIV infection and neurological involvement.

Statistical approach

The patients were separated into two groups for the evaluation of the results of the Karnofsky scale and their correlations: up to 70% (dependent or partially dependent), and above 70% (independent). For analysis by the modified Rankin Score, the degrees of independence (0 and 1) were grouped, the same being done for the other group - 2 to 5 (dependent or partially dependent). Two groups were indicated for each specific item of the Barthel Index: one for independence and another for dependence and need of assistance. For the evaluation of the FIM scale, the independent (scores 6 and 7) and the dependent or partially dependent classifications were grouped (scores 1 to 5) for each item.

The Student-t test was used to compare quantitative variables of the two groups. The non-parametric Mann-Whitney test was adopted for the variable log viral load. For the qualitative variables, Fisher's Exact Test was adopted. A 0.05 significance level was adopted for all the tests.

Results

Patient demographics

Among the 120 patients evaluated in this study, 65% were male, 89% were white, 8% were black and 3% mixed, 39% were intravenous drug addicts and 62% reported contracting the disease through sexual contact. There was more than one risk factor involved in 17% of the patients, and in 36% there was no information in the records about the transmission of the virus.

The average age was 35 years (SD = 8.5), median of 34, varying from 20 to 57 years. Average duration of schooling was 6 years (SD = 3.3), median of 6, range 0-15 years; there was no information on this item for 28 patients.

Regarding the cause of admission, 52% of the patients had pulmonary disease; 44% had gastrointestinal disease, 35% had neurological complications, 20% had a blood deficiency, 12% had genitourinary disease, 10% mucocutaneous disease, 5% visual and vestibular disease, 2% cardiovascular disease, and 32% had systemic involvements. Among the 120 patients evaluated in our study, 72% had more than one set of systems involved as the cause of admission and 12 (10%) were admitted with exclusively neurological complications.

Regarding the AIDS-defining illness, 43% were related to pulmonary disease, 29% to a blood deficiency, of whom 16% had only immunosuppression characteristics, 28% had neurological complications, 23% gastrointestinal disease, 9% systemic involvement, 5% mucocutaneous disease, 3% visual and vestibular disease, 3% genitourinary disease and 1% cardiovascular disease. Among the 120 patients, 29% had an AIDS-defining illness with the involvement of more than one set of systems and 21% exclusively with neurological complications, 29% had their AIDS-defining illness during this hospitalization. The data on clinical and immunological assessment are shown in Table 1.

Among the 120 patients, 67% were not employed, and 52 (43%) had quit their jobs for infection-related reasons. Among the 52 who left their jobs, 44% mentioned weakness as the main cause that prevented them from maintaining their jobs.

Disability

Among the 120 patients, 85% reported impaired physical activity. Seventy percent of the patients complained about various degrees of weakness. When questioned about the type of weakness, 50% stated that they performed all of their regular activities, although at a slower pace, with pauses for resting; 42% admitted that they had difficulty making larger efforts and 8% felt like lying in bed. Besides weakness, other complaints were related to impaired physical activity (Figure 1).

Fifty-five (45%) of the patients reported disability related to neurological complications, which included: paresthesia in 44% of patients, headache in 22%, dizziness in 16%, balance impairment in 13%, convulsions in 11%, disorientation in 7% and mental confusion in 7%.

Muscular strength was altered in 52% of patients; among them, 68% reported weakness and 56% had complaints about disabling neurological involvement. The cause of admission was considered to be neurological complications in 34%, respiratory disease in 31%, gastrointestinal disease in 24%, wasting syndrome in 13%, and other reasons in 6%. Among the patients who had their muscular strength altered, 79% were unemployed when admitted.

Functional assessment and correlates of AIDS-caused disability

Hypothesized associations with disability included age, gender and race, time elapsed since the HIV diagnosis, time elapsed since the AIDS diagnosis, log viral load in c/mL, CD₄⁺ counts, CD₄/CD₈ ratios, involvement of more than one set of systems in the AIDS-defining illness, involvement of the central nervous system in the cause for admission, muscle strength alteration and employment.

The Karnofsky scale (n=120)

Based on this classification, 52% of the patients had normal activity with effort (score 80%). The mean situation of the patients was a score equivalent to caring

Table 1. Clinical and immunological characteristics of the assessment of AIDS patients

	Mean	Median	SD	N
Duration of HIV diagnosis (months)	36.90	24	41.40	120
Time since AIDS diagnosis (months)	11.60	1	19,70	120
Viral Load c/mL*	335.65	140.00	491.77	34
CD ₄ ⁺ /μL	74.57	51	84.90	119
CD ₈ ⁺ /μL	493.00	412	458;70	101
CD ₄ ⁺ /CD ₈ ⁺	0.20	0.1	0.31	102

SD = Standard deviation. * Viral load in the last three months.

Table 2. Disability frequency in AIDS patients

Item	Number Needing Human Assistance	
	N	%
Eating	18	21
Grooming	17	20
Bathing	20	24
Dressing – Upper body	19	22
Dressing – Lower body	21	25
Toileting	16	19
Bowel management	13	15
Bladder management	17	20
Transfers: bed, chair, wheelchair	19	22
Transfers: toilet	19	22
Transfers: tub or shower	20	24
Walk/wheelchair	24	28
Stairs	31	36
Comprehension	11	13
Expression	11	13
Social interaction	11	13
Problem Solving	11	13
Memory	11	13

for self, being unable to perform normal activities or an active job (score $70\% \pm 0.19$), with a median of 80%, varying from 10% to 90%. There was an association between a lower functional status with alteration in muscular strength ($p < 0.0001$), as well as with being unemployed ($p = 0.01$).

The rankin modified scale (n = 120)

There was an association between lower functional status and the length of time elapsed since AIDS was diagnosed (Figure 2), with the involvement of more than one set of systems and the AIDS-defining illness ($p = 0.01$), and with muscular strength alteration ($p = 0.001$) and with being unemployed ($p = 0.009$).

The Barthel index (n = 120)

Among the 120 patients, 56% were considered independent (score 100 BI), 34% were considered partially dependent (score between 50 and 100), and 10% were considered dependent (score lower than 50 BI). The activities requiring moderate or greater assistance were walking, ascending or descending stairs and transfers.

There was an association between the inability to perform the following actions: getting dressed ($p = 0.01$), getting on and off a toilet ($p = 0.1$) and bathing ($p = 0.04$), and high log viral load. There was an association between the inability to ascend and descend stairs ($p = 0.05$) and lower CD_4^+ counts, even though they were lower than the what is considered normal, they were higher in those considered as being independent. There was an association between the inability to use the toilet ($p = 0.01$) and lower CD_4^+ / CD_8^+ ratios. There was an association between the inability to perform the following: feeding oneself ($p = 0.008$), use of toilet ($p = 0.03$), controlling bowels ($p = 0.03$), getting dressed ($p = 0.02$), and getting on and off the toilet ($p = 0.04$), and the involvement of one or more sets of systems in the cause for admission. There was an association between muscular strength alteration and the inability to do the following: controlling the bladder ($p = 0.01$), getting dressed ($p = 0.002$), moving

from wheelchair to bed ($p = < 0.0001$), walking ($p = < 0.0001$), ascending and descending stairs ($p = 0.0001$) and bathing ($p = 0.003$). There was an association with the inability to move from wheelchair ($p = 0.04$) and walking ($p = 0.04$) and a complaint about more significant degrees of weakness. There was an association with the inability to perform the following: feeding oneself ($p = 0.04$), controlling bowel movements ($p = 0.006$), controlling bladder ($p = 0.003$), getting dressed ($p = 0.02$), getting on and off the toilet ($p = 0.02$), ascending and descending stairs ($p = 0.04$), with the fact of being unemployed.

FIM* (n = 85)

Among the 85 patients evaluated with the FIM instrument, 36 (42%) were dependent, requiring human assistance in at least one item of the scale, and 22 (26%) required assistance in four or more areas.

The frequency of the occurrence of specific disabilities as measured by the FIM, is summarized in Table 2. There was an association between the inability to control the bladder ($p = 0.01$) and a higher mean log viral load. The items bathing ($p = 0.06$), grooming ($p = 0.06$), transfers from bed to wheelchair ($p = 0.06$) and to toilet ($p = 0.06$) had values that were very close to significant. There was an association between the inability to perform the following: comprehension ($p = 0.03$), expression ($p = 0.03$), social interaction ($p = 0.03$), problem solving ($p = 0.03$) and lower CD_4^+ / CD_8^+ ratios. There was also an association between inability and the involvement of the central nervous system in the cause for admission (Figure 3). There was an association between the inability to perform the following: grooming ($p = 0.04$), bathing ($p = 0.003$) dressing - lower body ($p = 0.003$), using the toilet ($p = 0.003$), bladder management ($p = 0.003$), transfers to and from bed, chair, wheelchair ($p = 0.01$), ascending and descending stairs ($p = 0.001$) and alteration in muscular strength. There was likewise an association between the inability to do the following: dressing - upper body ($p = 0.03$) and lower body ($p = 0.01$); toileting ($p = 0.01$), bladder management ($p = 0.009$), transferring to and from bed, chair, wheelchair ($p =$

Figure 1. Complaints related to impaired physical activity in AIDS patients.

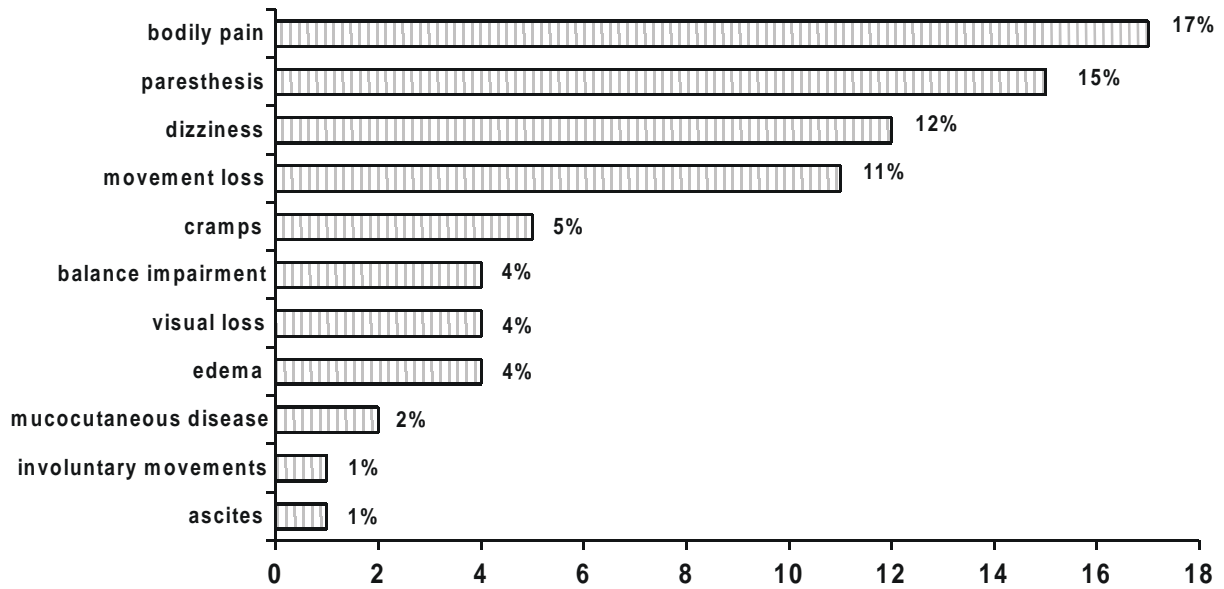


Figure 2. Association between lower functional status and the length of time elapsed since AIDS was diagnosed ($p = 0.0005$).

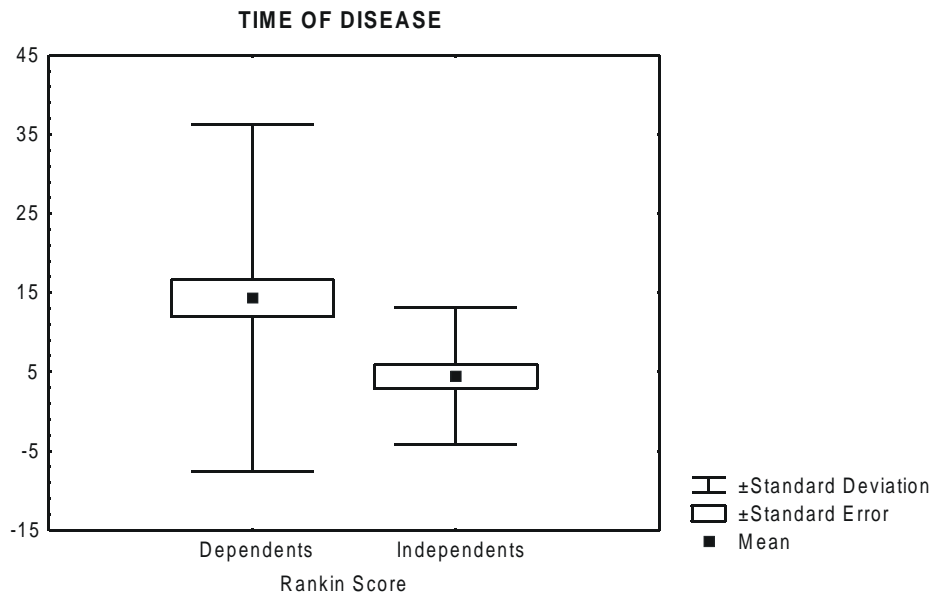
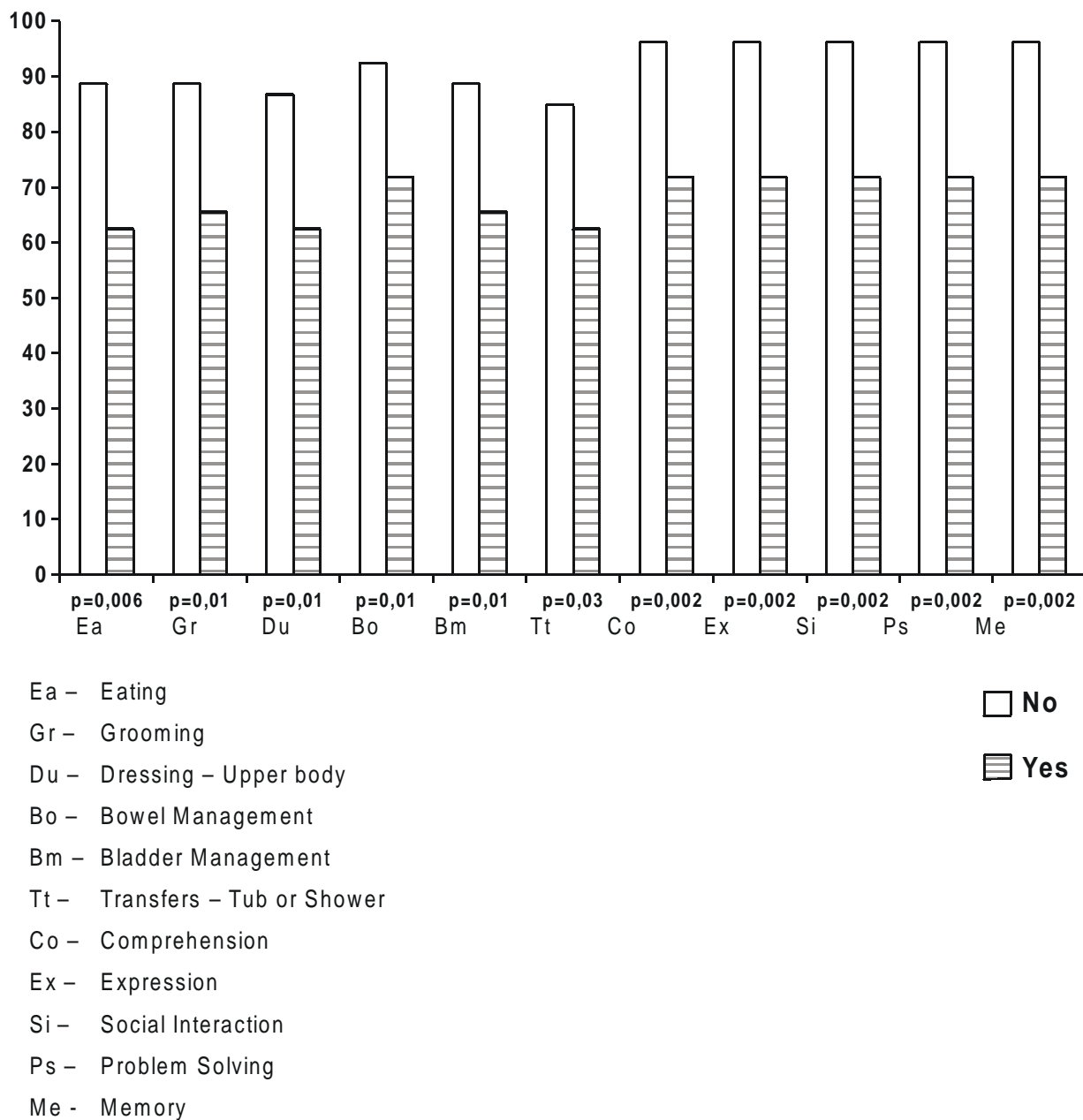


Figure 3. Association between disability with the involvement of the central nervous system in the cause for admission.



0.003), transferring to and from toilet and to and from tub or shower (0.03) and the fact of being unemployed. Seven other items showed values that were very close to significant.

Discussion

One of the ways to observe the consequences of infection by HIV is through an evaluation of the functional ability of the patients [5]. We found a significant incidence of disabilities in an AIDS-affected population, with 85% of the patients complaining of impaired physical activity, and 82% reporting different degrees of weakness.

The Karnofsky scale, although it did not provide detailed information on physical disability, showed that the need for effort to perform day-to-day activities compromised the independence and the quality of life of half of this population.

The modified Rankin scale [23] provided an even broader view of overall independence, which made it possible to associate the variables duration of disease and involvement of one or more systems in the AIDS picture.

The variety and quantity of motor deficits noted in this study through the evaluation by means of the FIM scale can be compared with a study [7] based on 37 discharge evaluations where the FIM scale was used. In both studies the items most often requiring human assistance were stair climbing and ambulation, as they are the items that require the greatest physical effort and balance.

The data of our study are based on a single evaluation, and the severity and frequency of the disabilities would probably be much greater if they were longitudinally assessed. Even so, high levels of disability were observed in the population, which raises several questions regarding the assessment of the disability, as well as with respect to the possible interventions in terms of rehabilitation [32,33].

Consistent with previous studies [3], no significant differences were found as regards age, sex and race in any of the four scales that were used. Neither did this study reveal any associations between inability and the time elapsed since infection by HIV.

In this sample, 29% of the patients were diagnosed with AIDS upon admission; this can partly explain the lower levels of inability and the lack of relationship with infection by HIV. Based on a study [3] which evaluated 391 individuals having AIDS by means of the AIDS Time-oriented Health Outcome Study (ATHOS), severe disability was relatively unusual, while mild and moderate disability were more common, as we also noted in our study.

A significant association between the functional status and the time elapsed since AIDS diagnosis ($p=0.0005$) was expected. As the immune compromise advances, patients will gradually lose their ability to recover functionally [7].

Even though we had few results on this factor, there was an association between lower functional status and higher average viral load ($\log c/mL$), which suggests a greater compromise brought about by the disease.

In a cohort study [24], which kept track of the progression to AIDS for three years, there was a strong association between progression and lower CD_4^+ counts. Both the lymphocyte counts and the CD_4^+/CD_8^+ ratio allow for an evaluation of the patient's cellular immunity compromise, and both were associated in this study.

Disorders affecting the central nervous system are among the most common causes of disability in patients with AIDS [25-27]. In our study, the association of inability with the involvement of the nervous system in the cause of admission was observed by using two scales. The social cognition and communication items were the most significant ones, which suggests that the application of the FIM scale may be indicated for patients with AIDS, due to the possibility of a minimal cognitive-motor disturbance being present, in addition to demential conditions that might be suggested by this evaluation.

Both the functional status and the disability evaluations were associated with alterations in muscular strength. This alteration, which was present in 43% of the

* With permission of the Research Committee of Uniform Data System for Medical Rehabilitation.

population, accompanied complaints about neurological involvement, weakness and a worsening of the overall status. Another study [28] mentioned that both the neurological and the constitutional symptoms were highly significantly correlated with physical function. Fatigue contributes to morbidity and inability, mainly in stage IV of the CDC classification, which corresponds to the AIDS-related complex and to AIDS itself [29], which was the diagnosis of the patients in our study.

Consistent with other studies, the work variable was also associated with disability [30] and with low functional status. The ability to work may involve the social function, but it mainly involves the physical function, ability that generally implies the prerequisites of mobility and self-care. Many AIDS factors may determine the need to give up one's job, and many AIDS patients mention fatigue as the main reason why they gave up their professional activities [19,29].

In our study, several reasons related to systemic complications and resulting from HIV infection caused 52 patients to give up their jobs. Among them, weakness was mentioned by 44% of these patients, but other factors such as incapacitating edemas, skin lesions, loss of sight, as well as prejudice, both on the part of the patient and of society, contributed to their giving up their jobs. This situation is consistent with the observations of another study [31], which warns about the care that must be taken in the interpretation of the relationship between functional disability and work, as many other factors, besides physical inability, affect the decision to give up one's job.

Due to the great variability of types and severity of the functional deficits, a single scale would rarely be adequate for this type of evaluation. This explains why among the studies that we mentioned, different scales and indices were used for the evaluation of patients with AIDS. The four functional scales used in our study have contributed to the literature related to physical disability resulting from AIDS; first because they show the efficacy of the use of a more simplified scale, like the Rankin one, which allows for important and significant relationships; on the other hand, the efficacy of the Karnofsky scale was confirmed, which, despite being generic, classifies the functional status in a more specific manner, as in the case of fatigue and physical effort of AIDS patients.

As far as functional ability is concerned, both scales assess in detail the degree of independence of patients, but in the case of an AIDS-infected population the FIM scale may be more useful, as it includes cognitive and communication items. The FIM scale grades in greater detail the amount of human assistance required by the patient, which would be useful in case it is used for selecting patients for specialized care. The FIM scale also differentiates modified independence, by detailing the need for some type of support. As far as our study is concerned, the most significant contribution has to do with the evaluation of the items of communication and social cognition.

A preventive program would have a greater possibility of significantly contributing to maintaining the patients as productive individuals in society for a longer period of time [18]. Whenever they are indicated, the techniques used in order to prevent disability are not going to alter the progress of the disease, but they often increase the patient's functional status [31].

Considering that, once they are infected by HIV, virtually all patients will be hospitalized at some point due to this disease [34], there is little reason to believe that our sample will be very different from other patients at the same stage of disease. On the other hand, even if they happen to be broadly representative of patients hospitalized with AIDS, it must be remembered that our study was limited to hospitalized patients from in and around the city of Curitiba. Hence, the results may not be generalized, as they do not contemplate outpatients and those who were not hospitalized by reason of infection.

The awareness of problems and subsequent disabilities seen in AIDS are indispensable for proper management, which includes prevention, basic care and rehabilitation services. Timely attention to physical and functional shortcomings is crucial if a better quality of life is to be ensured for these patients.

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