



Social welfare related to AIDS in Brazil: factors associated with social assistance and social security, 2004 – 2016

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ABSTRACT

Objective. To describe the occurrence of social welfare benefits related to AIDS in Brazil and to compare the characteristics of the beneficiaries of social assistance and social security in 2004 – 2016.

Methods. This was an observational, analytical study based on secondary data obtained from the Ministry of Social Security of Brazil. Sociodemographic and epidemiologic characteristics of the beneficiaries of AIDS-related social assistance and social security were analyzed.

Results. From 2004 – 2016, a total of 99 369 benefits were granted, the majority of which were sick pay (64%), followed by social assistance benefits (26.5%) and disability retirement (8.1%). At the time that benefits were initiated, 51% of the individuals were unemployed. Those living in urban areas, females, the young, the elderly, and residents of the North and Northeast received more social assistance benefits. Duration of social assistance benefits (average 4 589 days) was greater than that of social security benefits (302 days). Survival among women (578 months) was greater than among men (311 months).

Conclusions. In Brazil, the profile of social welfare beneficiaries living with AIDS reveals their social vulnerability. Controlling AIDS should be a priority on public agendas, aiming to minimize the disease's social and economic impact, especially on public health, social security, and social assistance.

Keywords

Acquired Immunodeficiency Syndrome; HIV; social welfare; social security; social assistance; Brazil.

Since its recognition in 1981, human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) has been a serious public health problem worldwide, especially in developing

countries. Globally, about 37 million people live with HIV/AIDS in 186 countries (1). The disease burden varies considerably among different regions and countries (1).

In Brazil, 842 710 cases of AIDS have been reported from 1980 (when the first case was recognized) to June 2016 (2). In the last 10 years, the average annual rate has stabilized at 20.7 cases per 100 000 inhabitants. The distribution in

the country is also heterogeneous, as the Southeast and South experience a greater portion, shouldering 53.0% and 20.1% of the cases, respectively (2).

Since the beginning of the epidemic in Brazil, 303 353 AIDS-related deaths have been identified (2). However, the country has seen a gradual increase in the survival rate. The median survival for cases diagnosed in the 1980s was 5 months (3). In a cohort of patients diagnosed in

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1995 – 1996 throughout Brazil, the survival rate had risen to 36 months (3). In another cohort initiated in 1998 – 1999 in just the South and Southeast, the survival rate had grown to 108 months (4). Currently, the life expectancy for young individuals without any opportunistic infections is > 50 years of age. The use of antiretroviral therapy has been the main cause of this increase (5).

In Brazil, public health is provided by the Unified Health System (SUS), along with social security and social assistance. These are the three pillars of its social welfare system. The pillars constitute rights guaranteed by the 1988 Federal Constitution of Brazil, in which social security is funded by contributions, while social assistance and public health are funded by the Government of Brazil (6).

Social welfare plays an important role in the history of AIDS in the country. Its policies regarding prevention, treatment, social security, and social assistance for patients were supported and implemented with the participation of state governments, researchers, and social movements (7, 8). Given the magnitude and the transcendence of AIDS in Brazil, this study aims to describe the country's AIDS-related social welfare benefits and to compare the characteristics of the beneficiaries of social assistance and social security in 2004 – 2016.

MATERIALS AND METHODS

This was an observational, analytical study conducted with secondary data obtained from the *Sistema Único de Informações de Benefícios* (Unified System of Benefits Information; SUIBE) maintained by the Ministry of Social Security and Assistance of Brazil. This information system is not freely accessible and is composed of the beneficiaries' sociodemographic and epidemiologic data. It is used to collect statistical data from the country's social security system. The data were obtained through express authorization from the National Institute of Social Security. SUIBE is an information system with a high degree of reliability; however, individualized data were again verified at the time of the research, guaranteeing greater consistency.

Analysis

This study analyzed the following variables: sex, current age, start of

benefits, age group, area of residence, geographic region, occupational situation (employed/unemployed), type of benefit received, duration of benefits (in days), duration of contributions to social security, salary range, date of disease onset, date of beginning of disability, and date of death. The specific age groups, in years, were: 0 – 14, 15 – 19, 20 – 39, 40 – 59, and 60 – 79. The dichotomous variable benefits (social security x social assistance benefits) was created for the bivariate analysis. The chi-square test and multiple logistic regression with dummy variable (for variables with more than two categories) were employed, considering the Odds Ratio with 95% Confidence Intervals as a measure of association. The Kruskal-Wallis test was used to compare numerical variables. The level of significance adopted was 5%. The curve of Kaplan Meier was employed for survival analysis, and the Log-Rank test was employed to compare the survival distributions.

The software, Epi Info™ version 7.1.5 (Centers for Disease Control and Prevention, Atlanta, Georgia, United States) was used for all the analyses. The Geographic Information System, QGIS version 2.18 (Open Source Geospatial Foundation, Chicago, Illinois, United States) was used for data spatialization, enabling the development of the mosaic map.

Ethics

This work was approved by the Research Ethics Committee of the Federal University of Uberlândia, Minas Gerais, Brazil (Register no. 1.427.726/ 2016). The Worker's Identification Number (NIT), a variable that identifies individuals in the SUIBE, was excluded from the database to ensure the anonymity of individuals.

RESULTS

During the study period (2004 – 2016), a total of 99 369 benefits were granted, predominantly to males (65%), in the age group 20 – 39 years (49.8%), living in urban areas (97.4%). The distribution of benefits across the country's geographic regions followed the same trend as the number of confirmed cases of AIDS (Figure 1). Sick pay was the main benefit granted (64%), followed by social assistance benefits (26.5%) and disability retirement (8.1%). Based on the time interval between the date of disease onset

(DDO) and the date of beginning of disability (DBI), 50% of the population studied was incapacitated up to 9 months after DDO; 23.7% was found incapacitated upon DDO.

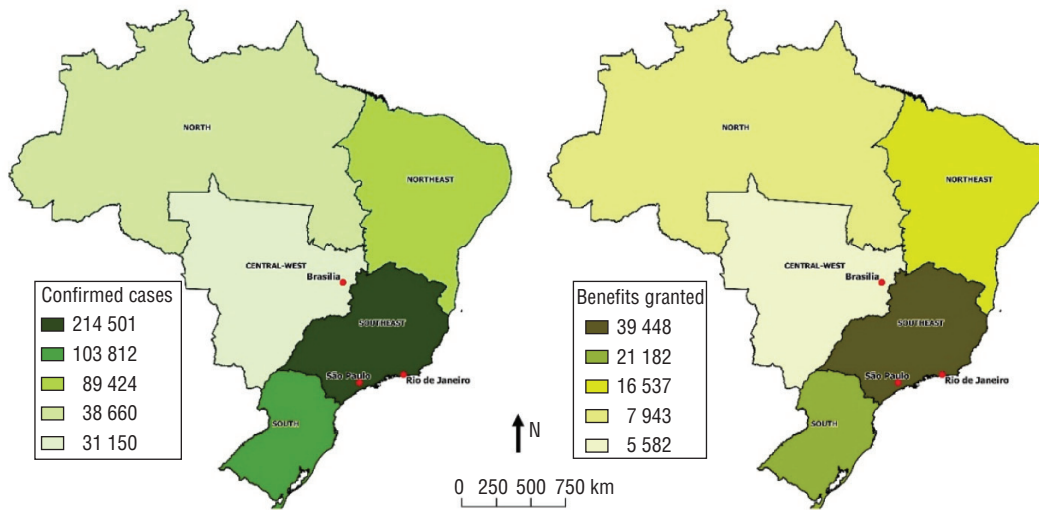
The average age of sick individuals was 36 ± 10 years. The average age of disabled individuals was 39 ± 9.0 years. A contribution time of ≤ 15 years was predominant (91%), with an average of 5.0 ± 6.0 years. At benefit initiation, 51% of the individuals were unemployed; of the employed individuals, 75% were working in commerce. Most beneficiaries were receiving 1 – 2 times the minimum wage (75%), with a mean of 1.5 ± 1.0. The geographic regions with the greatest incidence were the Southeast (43%) and the South (23%).

As shown in Table 1, women were more likely to receive social assistance benefits than men were (OR = 2.08). Individuals living in urban areas were 12 times more likely to receive benefits than those in rural areas. In the younger age groups, social assistance benefits were more frequent (0 – 14 years, 92.9%; 15 – 19 years, 68.5%) than in the older one (60 – 79 years, 33.5%). The age group 20 – 39 years, compared to the 0 – 14 year group, was 98% less likely to receive these benefits. The occurrence of social assistance benefits was also more frequent in the North (OR = 3.68) and Northeast (OR = 2.8). Recipients of AIDS-related social assistance benefits tended to be younger than those receiving social security benefits and had less monetary assistance; they also had less social security contribution time and their duration of benefits was significantly greater (Table 2).

The survival curve was calculated for the 67 495 cases for which DDO and/or date of death information was available. During the period analyzed, there were more deaths among men (13 658; 70.5%) than women (5 705; 29.5%). The general median survival was 331 months; for men, 311 months, and for women, 578 months. As shown in Figure 2, after 450 months of diagnosis, there were about 55% and 32% of surviving women and men, respectively ($P < 0.000001$).

The duration of benefits analysis found that social assistance benefits were being granted for a longer period (median of 4 589 days) than social security benefits (median of 302 days). As shown in Figure 3, after 3 600 days, social assistance benefits were still active in 57% of

FIGURE 1. Distribution of confirmed cases of AIDS and Social Welfare benefits (social assistance and social security) granted in Brazil, by geographic region, 2004 – 2015^a



^a Full details of confirmed cases unavailable for 2016.

Source: Prepared by the authors from the study results and data from the Brazilian Institute of Geography and Statistics.

Note: Map produced using QGIS version 2.18 (Open Source Geospatial Foundation, Chicago, Illinois, United States). Source of shapefile: Brazillian Institute of Geography and Statistics (Rio de Janeiro, Brazil).

TABLE 1. Characteristics of people with AIDS receiving social welfare benefits in Brazil, 2004 – 2016

Characteristics	Social Security benefits		Social Assistance benefits		Odds Ratio (95% Confidence Interval)	Chi-square value or Z-statistic ^a	P value
	n	%	n	%			
Sex							
Male	50 889	78.7	13 765	21.3	1		< 0.00001
Female	22 178	63.9	12 537	36.1	2.08 (2.03 – 2.15)	2 549.43	
Age range, ^a in years							
0 – 14	127	7.1	1 658	92.9	1		
15 – 19	150	31.5	327	68.5	0.17 (0.12 – 0.21)	13.27	< 0.00001
20 – 39	37 178	75.1	12 330	24.9	0.02 (0.02 – 0.03)	39.72	< 0.00001
40 – 59	33 933	75.3	11 144	24.7	0.03 (0.02 – 0.03)	39.64	< 0.00001
60 – 79	1 675	66.5	843	33.5	0.04 (0.02 – 0.05)	32.14	< 0.00001
Area of residence							
Rural	2 526	97.0	76	3.0	1		–
Urban	70 541	72.9	26 226	27.1	12.3 (9.8 – 15.7)	760.03	< 0.00001
Geographic region ^a							
South	18 660	81.0	4 365	19.0	1		–
North	4 787	53.8	4 115	46.2	3.68 (3.48 – 3.87)	48.02	< 0.00001
Northeast	11 247	60.0	7 386	40.0	2.8 (2.69 – 2.93)	45.84	< 0.00001
Southeast	33 965	80.0	8 680	20.0	1.09 (1.05 – 1.14)	4.28	< 0.00001
Midwest	4 408	71.5	1 756	28.5	1.70 (1.60 – 1.82)	16.20	< 0.00001

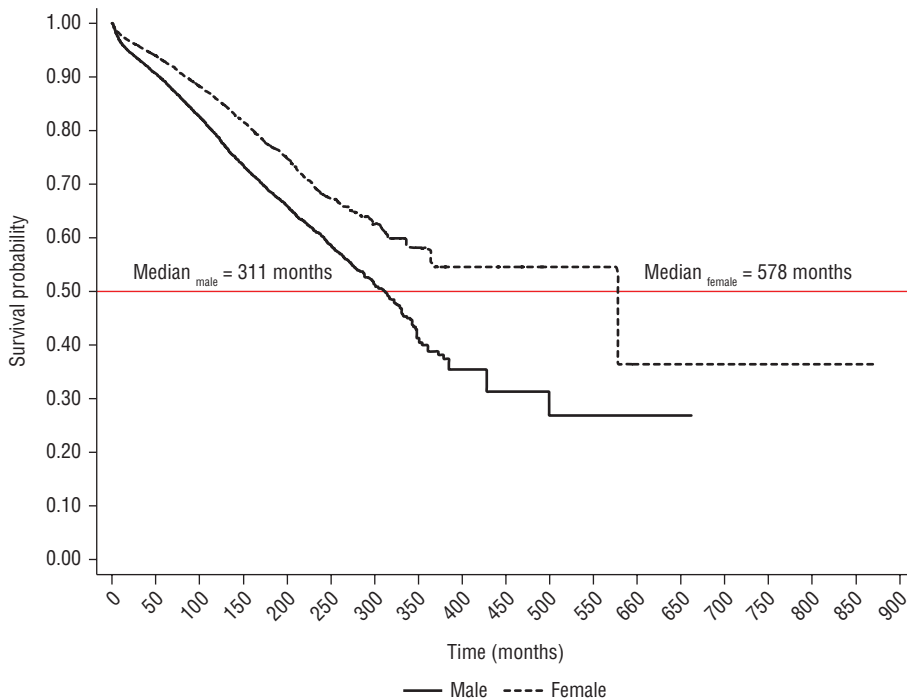
^a Z-statistic.

Source: Prepared by the authors from the study results.

TABLE 2. Sociodemographic variables for individuals with AIDS receiving social welfare benefits in Brazil, 2004 – 2016

Characteristics	Social Security Benefits	Social Assistance Benefits	Kruskal-Wallis H value	P value
	Median (min-max)	Median (min-max)		
Age at beginning of disability, in years	39 (0 – 81)	38 (0 – 71)	283.89	< 0.00001
Current age, in years	45 (0 – 88)	44 (1 – 82)	444.28	< 0.00001
Years of contribution	5 (0 – 38)	0 (0 – 28)	47602.74	< 0.00001
Initial monthly income (number of minimum wages)	1.21 (1 – 8.78)	1 (1 – 1)	28886.35	< 0.00001

Source: Prepared by the authors from the study results.

FIGURE 2. AIDS survival analysis, by sex, Brazil, 2004 – 2016

Source: Prepared by the authors from the study results.

cases, whereas social security benefits represented only 8% ($P < 0.000001$).

DISCUSSION

In Brazil, there were 493 435 AIDS cases reported from January 2004 – June 2016 (2). During the same period, a total of 99 369 AIDS-related social security and social assistance benefits were granted. There are a variety of reasons that explain the discrepancy between reported cases and benefits. The individuals might not have proven their need in terms of the poverty criteria required for social assistance benefits (9). As to social security benefits, the individual may not have met the insurance criteria. Or, because AIDS is a progressive disease, the individual's observable symptoms

may not have triggered a work disability (10). Another probable reason for the discrepancy is due to a lack of access to information regarding assistance available by law. Moreover, the great variability in types of work activities may result in individuals being able to retain employment despite the illness. The fact that an incapacity to work was confirmed in 23.7% of individuals at the time of diagnosis, and in 50% within 9 months, points to late diagnosis as well as non-adherence to antiretroviral therapy (11).

The short social security contribution time associated with a large proportion of unemployed individuals showed that a significant number of people living with AIDS in Brazil are socially vulnerable. Moreover, the benefit granted, on average

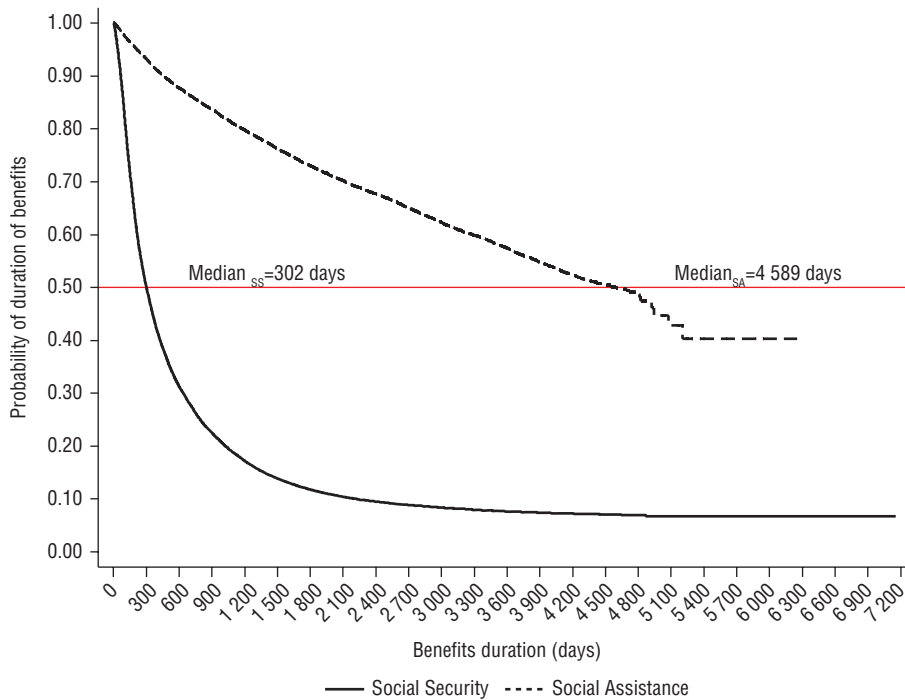
1.5 times the minimum wage, hardly guarantees a good quality of life (11).

The highest concentration of AIDS in Brazil, based on reported cases from January 1980 – June 2016 (2), was among those 25 – 39 years of age for both men (53.0%) and women (49.4%). The concentration of cases in this age group and the lengthy absences from work caused by AIDS heightens its social impact. In this study, 49.8% of beneficiaries belonged to this age group. By contrast, only 2.5% of the individuals were elderly; however, 45.4% were in the age group 40 – 59 years.

Brazil is undergoing a rapid demographic transition. Greater survival rates and an aging population are challenging the health and social welfare systems (12). In addition, the incidence of AIDS among the elderly has increased in recent years (13). In this context, the aging of patients with AIDS, as well as the emergence of new cases among the elderly, greatly impacts all three of Brazil's social welfare pillars—public health, social security, and social assistance.

In the early 1980s, the first cases of AIDS were identified in Brazil, namely in São Paulo and Rio de Janeiro. The epidemic hit all areas of the country, though in a heterogeneous way, with most cases concentrated in the Southeast, in the state capitals, and in coastal cities (14). According to the Brazilian Institute of Geography and Statistics, in 2010, the Southeast, Northeast, and South were the most populous areas (15). This study showed that in the Southeast and South, fewer social assistance benefits were granted than social security benefits, compared to other regions.

Furthermore, throughout the country, AIDS-related social assistance benefits were granted mostly to females. These findings support data from the Ministry of Labor and Employment that shows that in the Southeast and South, where there is the greatest number of formal jobs, most jobs are held by males (16). Overall, social

FIGURE 3. AIDS survival analysis according to duration of Social Welfare benefits (in days), Brazil, 2004 – 2016

Source: Prepared by the authors from the study results.

welfare in Brazil, and specifically, AIDS-related benefits, show persistent inequalities between men and women in the labor market, though at an increasingly lower proportion. Women still make up the majority of unpaid family workers. Such disparity in sex and quality of work leads to women's limited access to work-related social protections. Lower rates of formal remuneration and a reduced number of hours and years of work with social protections have negative consequences (17).

This study found that individuals residing in rural areas received less social assistance benefits than those in urban areas. According to Brazilian law, social assistance benefits are granted to individuals who can prove that they cannot provide for themselves or be supported by their families. Individuals living in rural areas can often subsist on crops, while those in urban areas do not have such options; thus, they seek and are granted social assistance benefits. Furthermore, the rural population often has a lower level of education and difficulty accessing social and health services due to isolation and lack of public transportation (18). Therefore, the reduced number of benefits claims in rural areas could be associated with a lack of knowledge about the law and the assistance to which the disabled are entitled.

The number of deaths was higher among men (70.5%). Men also had a shorter survival time (311 months) than women. This higher mortality rate among men is well reported in the literature in almost all age groups and for almost all causes, focusing attention on issues related to biological (sex) and behavioral (gender) factors (19). The overall median survival for beneficiaries was 331 months, considerably longer than that reported by previous studies in Brazil: in the 1980s, 5 months; 1995 – 1996, 36 months; and in 1998 – 1999, 108 months (3, 4). The public policies implemented in Brazil in this period, mainly the use of antiretroviral therapy, contributed substantially to these results (20).

Social assistance benefits, although less frequent, had a significantly longer duration. This can be explained, in part, by the continued precarious conditions of the beneficiaries, but also by the lack of biannual reviews that should be performed by the social welfare system to verify the continued need for benefits (9, 21).

Since 2013, as recommended by the World Health Organization (WHO), all individuals with HIV in Brazil, regardless of CD4 cell count, receive antiretroviral therapy. This strategy improves individuals' life expectancy and lowers the risk of viral

transmission (22). In addition, in 2017, Brazil became one of the first countries in the world to begin providing free access to Dolutegravir, a retroviral drug recommended by WHO for treating HIV/AIDS. Currently, the Government of Brazil has an annual drug expenditure of over US\$ 351 MM (23). With timely diagnosis, access to current medications, and adherence to treatment, those with recently-acquired HIV infections may have a life expectancy nearly equal to an HIV-negative individual, surpassing 50 years in some estimates (24, 25). Given the advances achieved in AIDS therapy in recent years, it is expected that there will be a decrease in the number of individuals who must leave work due to the illness.

Currently, Brazil faces two significant burdens: public health (spending on prophylaxis, medications, and hospitalizations of patients) and granting long-term benefits. However, besides improving the health and life expectancy of individuals with AIDS, there is a need to reduce the stigma of the disease, especially in relation to the work market. Since 2010, the Ministry of Labor and Employment has banned HIV testing of workers and prospective employees in order to avoid any work-related discriminatory or restrictive practices (26).

To legally assess an incapacity for work, the courts in Brazil also consider the social stigma of the disease, not just the individual's clinical status. The recommendation of the Federal Special Courts is as follows: "Proven that the benefit applicant is HIV positive, it is up to the judge to verify the claimant's personal, social, economic, and cultural conditions, in order to analyze the disability in a broad sense, given the high social stigmatization of the disease" (27).

In Brazil, there are different epidemiologic profiles of AIDS related to the geographic and structural diversity of the country. In general, the North and Northeast and medium-sized municipalities have growing epidemics and a low response capacity, while the Southeastern and South and the largest urban centers have brought epidemics under control (28). The great cultural, demographic, economic, and social diversity of the country can mask regional inequalities in both reporting of AIDS cases as well as access to social welfare services (14).

Limitations. An important study limitation was the absence of a variable for the underlying cause of "incapacity for

work” in the SUIBE database. In addition, although “education” exists in SUIBE, there was no data recorded for this socio-demographic variable. It is also worth noting that this study did not include the large number of workers who do not have formal employment contracts and/or do not contribute to social security. In 2011, 28.3% of employees were “informal” and 23.5% made no social security contribution. For employers and the self-employed, it was even higher, at 76.1% and 72%, respectively (16). Also excluded from this analysis were government and military personnel.

Conclusions

This study found that AIDS in Brazil is affecting an undue number of male workers at their most productive stage of life, mostly in urban areas of the Southeastern and Southern regions. The large number of unemployed people among the beneficiaries reveals their social vulnerability. Also shown was a high rate of social assistance benefits directed to urban dwellers, women, the young and elderly, and residents of the North and Northeast.

The social security system in Brazil faces its greatest crisis due to an aging

population, early retirement, and social security fraud, among others. The control of diseases that are debilitating due to physical, moral, and social incapacity should be a top priority for the social welfare system. Controlling AIDS will minimize the social impact to the country on all levels.

Conflict of interests. None declared.

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RESUMEN**El bienestar social relacionado con el sida en Brasil: factores asociados con la asistencia social y la seguridad social, 2004-2016**

Objetivo. Describir la distribución de las prestaciones en materia de bienestar social relacionadas con el sida en Brasil y comparar las características de los beneficiarios de la asistencia social y la seguridad social entre el 2004 y el 2016.

Métodos. Estudio de observación y analítico basado en datos secundarios obtenidos del Ministerio de Seguridad Social de Brasil. Se analizaron las características sociodemográficas y epidemiológicas de los beneficiarios de la asistencia social y la seguridad social relacionadas con el sida.

Resultados. Entre el 2004 y el 2016 se otorgó un total de 99 369 prestaciones, de las cuales 64% fueron pagos por enfermedad, seguidos de prestaciones de la asistencia social (26,5%) y pensiones por incapacidad (8,1%). En el momento que se iniciaron las prestaciones, 51% de las personas estaban desempleadas. Los residentes en zonas urbanas, las mujeres, los jóvenes, los adultos mayores y los residentes del norte y el nordeste recibieron más prestaciones de la asistencia social. La duración de las prestaciones de la asistencia social (en promedio, 4 589 días) fue mayor que la de las prestaciones de la seguridad social (302 días). La supervivencia en las mujeres (578 meses) fue mayor que en los hombres (311 meses).

Conclusiones. En el Brasil, el perfil de los beneficiarios de los programas de bienestar social que tienen sida muestra su vulnerabilidad social. Controlar el sida debe ser una prioridad entre los asuntos de interés público, a fin de reducir al mínimo sus repercusiones sociales y económicas, especialmente en materia de salud pública, seguridad social y asistencia social.

Palabras clave

Síndrome de Inmunodeficiencia Adquirida; VIH; bienestar social; seguridad social; Brasil.

RESUMO**Bem-estar social das pessoas com HIV/aids no Brasil: fatores associados à assistência social e previdência social, 2004–2016**

Objetivo. Descrever a concessão de benefícios do sistema de seguridade social a pessoas com HIV/aids no Brasil e comparar as características dos beneficiários assistenciais e previdenciários no período de 2004 a 2016.

Métodos. Estudo observacional analítico conduzido com dados secundários obtidos do Ministério da Previdência Social do Brasil. Foram analisadas as características sociodemográficas e epidemiológicas dos beneficiários assistenciais e previdenciários portadores de HIV/aids.

Resultados. Foram concedidos ao todo 99.369 benefícios no período 2004–2016, entre eles auxílio-doença (64%), benefícios de assistência social (26,5%) e aposentadoria por invalidez (8,1%). Ao início da vigência dos benefícios, 51% dos beneficiários estavam desempregados. Pessoas residentes em áreas urbanas, do sexo feminino, jovens, idosos e vivendo nas Regiões Norte e Nordeste foram os maiores beneficiários de benefícios assistenciais. A vigência dos benefícios assistenciais (média de 4.589 dias) foi maior que a dos benefícios previdenciários (302 dias). A sobrevida no sexo feminino (578 meses) foi superior à observada no sexo masculino (311 meses).

Conclusões. O perfil dos beneficiários do sistema de bem-estar social revela que as pessoas vivendo com HIV/aids no Brasil estão em estado de vulnerabilidade social. O controle do HIV/aids deve ser prioridade entre as questões de interesse público a fim de reduzir ao mínimo a repercussão socioeconômica da doença, sobretudo na saúde pública, assistência social e previdência social.

Palavras-chave

Síndrome de Imunodeficiência Adquirida; HIV; previdência social; seguridade social; Brasil.