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Outcome and reasons for loss of follow-up among people living with HIV followed in Parakou from 2018 to 2022

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Abstract

Introduction: Among the challenges facing the monitoring of people living with HIV (PLHIV) are chronic diseases and loss to follow-up. This study focused on the reasons for loss to follow-up and outcome of PLHIV lost to follow-up.

Setting and Methods: This was a cross-sectional and descriptive study. The study population consisted of PLHIV lost to follow-up. PLHIV of both sexes, aged over 15, followed from January 1, 2018, to December 31, 2022, in Parakou were included in the study. The variables studied related to the reasons for loss to follow-up and the outcome of PLHIV lost to follow-up. Data analysis was performed using Epi Info version 7.2 software.

Results: The study population consisted of 293 PLHIV. The mean age was 37.72 ± 12.24 years, with a range of 21 to 78 years. A female predominance was observed, with a sex ratio of 0.65. The outcome of PLHIV lost to follow-up was characterized by death (9.90%), 11.94% were not found and 78.16% in alive. Among living PLHIV, the majority had either changed treatment site or were not treated. The reasons for loss to follow-up were dominated by stigma/self-stigmatization (60.26%).

Conclusion: The majority of PLHIV lost to follow-up were alive and had either changed treatment site or were not treated. The main reason for loss to follow-up was stigma/self-stigmatization.

Keywords: Outcome; Reasons for loss to follow-up; PLHIV; Parakou

1. Introduction

Antiretroviral triple therapy has revolutionized the management of people living with HIV (PLHIV), in whom improvements in quality of life, reductions in the incidence of opportunistic diseases, decreased mortality, and a lower risk of transmission have been observed [1]. Initially, this triple therapy was available only in developed countries; however, with the reduction in drug costs granted by pharmaceutical companies and the commitment of the highest authorities in African countries, antiretroviral access initiatives were launched in several African countries starting in 1998. In Benin, antiretroviral therapy has been used since 2002 and is provided free of charge to PLHIV. Prior to treatment initiation, care teams are required to inform, educate, and support patients in order to ensure good adherence and optimal effectiveness of antiretroviral therapy [2–3]. However, despite the measures implemented by healthcare providers and the benefits of antiretroviral therapy, loss to follow-up among PLHIV remains frequent. According to studies, the prevalence of loss to follow-up varies by region and level of national development, ranging from 30% to

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80% [4–6]. The consequences of loss to follow-up are numerous, including failure to achieve the UNAIDS targets [7]—namely, diagnosing 95% of PLHIV, initiating antiretroviral therapy in 95% of those diagnosed, and achieving viral suppression in 95% of those on treatment—as well as the emergence of HIV drug resistance, occurrence of opportunistic infections, and increased mortality. Several factors are associated with loss to follow-up among PLHIV, including sociodemographic conditions, healthcare-related factors, comorbidities, and treatment-related issues [8–9]. Therefore, active tracing of PLHIV lost to follow-up is essential. It would help identify the reasons for loss to follow-up and describe patient outcomes. Studies focusing on PLHIV lost to follow-up have been conducted in several countries. In Benin, however, existing studies have only addressed the prevalence and associated factors of loss to follow-up. To our knowledge, no study has investigated the outcomes of PLHIV lost to follow-up, nor the determinants of this phenomenon in Benin. To address this gap, we conducted this study in the northern part of the country. Identifying the reasons for loss to follow-up and addressing them will improve the management of PLHIV and facilitate the achievement of UNAIDS targets.

2. Methods

This was a cross-sectional and descriptive study.

The study population consisted of people living with HIV (PLHIV) lost to follow-up, of both sexes, aged at least 15 years, and followed in the Department of Internal Medicine at the Borgou Departmental University Teaching Hospital (CHUD/B) from January 1, 2018 to December 31, 2022.

Data collection was conducted from July 1 to November 30, 2023. Data were collected through face-to-face interviews with PLHIV lost to follow-up who were successfully traced either by telephone contact or by home visits based on the address provided in their medical records. For PLHIV lost to follow-up who could not be traced, interviews were conducted with relatives or cohabitants.

The variables studied included the outcomes of PLHIV lost to follow-up as well as the reasons for loss to follow-up. Reasons for loss to follow-up were specifically investigated among PLHIV who were alive.

The collected data were recorded, processed, and analyzed using EpiData version 3.1 and Epi Info version 7.2.0.1, respectively.

From an ethical standpoint, authorization was obtained from the Director General of CHUD/B. Anonymity and confidentiality of the data were strictly maintained.

Table 1 General characteristics of PLHIV lost to follow-up followed in Parakou from 2018 to 2022 (n = 293)

Variables	n	%
Age		
> 40 years	119	40.61
≤ 40 years	174	59.39
Sex		
Female	177	60.41
Male	116	39.59
Marital status		
Married	183	62.46
Single	110	37.54
Monthly income		
> 100,000 CFA francs	65	22.18
≤ 100,000 CFA francs	228	77.82
Distance from home to hospital		

> 10 km	72	24.57
≤ 10 km	221	75.43
Educated patients		
Yes	143	48.80
No	150	51.20
Serostatus disclosure		
Yes	65	22.18
No	228	77.82
Partner's HIV serostatus		
Positive	23	7.84
Negative	26	8.87
Unknown	244	83.29
Therapeutic adherence		
Yes	46	15.70
No	247	84.30

Table 2 Outcomes of PLHIV lost to follow-up followed in Parakou from 2018 to 2022 (n = 293)

Outcome	n	%
Alive	229	78.16
Transfer to another site	115	39.25
Without treatment	97	33.11
Traditional healer	17	5.80
Deceased	29	9.90
Not traced	35	11.94

Table 3 Reasons for loss to follow-up among PLHIV followed in Parakou from 2018 to 2022 (n = 229)

Reasons	n	%
General health deterioration	3	1.31
Family or occupational burden	21	9.17
Antiretroviral side effects	5	2.18
Poor reception at health facility	7	3.06
Financial problems	11	4.80
Stigma and self-stigma	138	60.26
Travel	15	6.55
Refusal of HIV status	12	5.24
Use of traditional medicine	17	7.41

3. Results

3.1. General characteristics of the study population

The study population consisted of 293 people living with HIV (PLHIV). The mean age was 37.72 ± 12.24 years, ranging from 21 to 78 years. A female predominance was observed, with a sex ratio of 0.65. Single individuals and those with a monthly income $>100,000$ CFA francs accounted for 66.46% and 22.18% of the population, respectively. Approximately one-quarter (24.57%) of the participants lived more than 10 km from the care center, and nearly half (48.80%) had received formal education. Serostatus disclosure was reported in only 22.18% of cases. The HIV serostatus of the partner was unknown in the majority of cases (83.29%). Good adherence to antiretroviral therapy was observed in only 15.70% of participants (Table 1).

3.2. Outcomes of PLHIV lost to follow-up

The outcomes of PLHIV lost to follow-up showed a mortality rate of 9.90%, 11.94% of patients not traced, and 78.16% alive. Among those alive, the majority had either transferred to another care facility or were no longer receiving treatment (Table 2).

3.3. Reasons for loss to follow-up

Among the 293 PLHIV lost to follow-up, 229 (78.16%) were successfully traced. The main reason for loss to follow-up was stigma/self-stigma (60.26%). Other reported reasons included family or occupational constraints (9.17%), use of traditional medicine (7.41%), travel (6.55%), financial difficulties (4.80%), and poor reception by healthcare providers (3.06%) (Table 3).

4. Discussion

The present study is one of the first in Benin to focus on people living with HIV (PLHIV) lost to follow-up. The study population consisted mainly of young adults (mean age: 37.72 ± 12.24 years) with a female predominance (60.41%). Our findings are consistent with those reported by Argaw et al. [10] in Ethiopia, who found a mean age of 35 years and a female proportion of 54%.

The outcomes of PLHIV lost to follow-up in this study were characterized by a mortality rate of 9.90%, 11.94% of patients not traced, and 78.16% alive. Similar findings have been reported by several authors. In the study by Samba et al. [11] in Kenya, the mortality rate among PLHIV lost to follow-up was 8%. Argaw et al. [10] reported that 14.49% of PLHIV lost to follow-up were not traced, while Assemie et al. [12] found that 77.1% of these patients were alive. In a multicenter study conducted in six African countries (Mozambique, Malawi, Lesotho, Zimbabwe, Zambia, and South Africa), 66% of PLHIV lost to follow-up had transferred to another treatment site, while 34% were not receiving treatment [13].

In the present study, the main reason for loss to follow-up was stigma/self-stigma. In contrast, Noukoubri et al. [14] reported stigma as a reason in only 16.5% of cases. In several other studies, long distance between home and healthcare facilities, lack of transportation, and the perception of being in good health were identified as major reasons for loss to follow-up [6,15–16]. Denial of HIV-positive status and religious beliefs were reported by Matimbwa et al. [17] in Tanzania and Bogenya et al. [18] in the Democratic Republic of the Congo.

A non-negligible proportion of PLHIV lost to follow-up could not be traced, making it difficult to assess their outcomes and the reasons for their loss to follow-up. This constitutes a limitation of the study, as the findings may not fully reflect the true situation of loss to follow-up among PLHIV.

Measures should be implemented to ensure regular follow-up of HIV-infected patients receiving treatment. It is also essential to strengthen therapeutic education, bring healthcare services closer to patients' homes, and improve patient reception in healthcare settings. HIV consultations should not be conducted in separate units in order to reduce stigma. HIV care should be integrated with the management of other diseases within the same clinical setting. In addition, psychological support is necessary and should be incorporated into the comprehensive care of PLHIV.

5. Conclusion

The majority of people living with HIV (PLHIV) lost to follow-up were alive and had either transferred to another treatment site or were no longer receiving treatment. Stigma and self-stigma were the main reasons for loss to follow-up. Strengthening therapeutic education, combating stigma, and ensuring a welcoming and supportive environment for PLHIV attending consultations are essential.

Compliance with ethical standards

Disclosure of conflict of interest

No conflict of interest to be disclosed.

Statement of informed consent

Informed consent was obtained from all individual participants included in the study.

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