

# Uptake of health care services and health status of HIV-infected women diagnosed through antenatal HIV screening in Barbados, 1996–2004

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## ABSTRACT

**Objectives.** To study utilization of HIV-related health care services and to describe the health status of HIV-infected women diagnosed through antenatal voluntary counseling and testing (VCT) for HIV infection in Barbados.

**Methods.** This is a descriptive study. The study population includes all HIV-infected women in Barbados diagnosed as HIV-infected through VCT for HIV infection during 1996–2004.

**Results.** The median duration of HIV infection from time of diagnosis to the time of this report for the 163 women diagnosed during the study period was 72 months (low range, 9 months; high range, 117 months). Of the 163 women, 102 (62.6%) had attended the centralized HIV/AIDS clinic for follow-up (care, treatment, and monitoring), whereas 61 (37.4%) had never attended the clinic. The median time lag between diagnosis of HIV infection and first presentation to the HIV/AIDS clinic was 36 months (low range, 1 month; high range, 114 months). Of the HIV-infected women who attended the HIV/AIDS clinic, more than one-fourth had severe immunodeficiency at the time of their first follow-up visit. Of the 53 women undergoing highly active anti-retroviral therapy (HAART) at the time of the study, 23 (43.4%) began the therapy within three months of their first follow-up visit.

**Conclusions.** Early HIV diagnosis through antenatal VCT is not enough to ensure that women with HIV will get adequate and timely HIV-related health care. These women suffer significant premature mortality, largely related to inadequate follow-up.

## Key words

HIV infections, pregnant women, health status, Barbados.

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Realizing the full potential benefits of antenatal voluntary counseling and testing (VCT) for HIV infection is both an economic compulsion and a necessary public health objective for any successful and viable HIV/AIDS prevention program (1–4). Antenatal testing is undertaken primarily to offer interventions for prevention of mother-

to-child transmission (PMTCT) of HIV. However, the HIV diagnosis has implications for the mother herself, which is often forgotten. Many, including the mothers themselves, wonder about the significance of the letter “M” in “PMTCT” programs, given the way such programs are implemented in developing countries. This is particularly

disturbing in the era of highly active anti-retroviral therapy (HAART), given that model-based estimates indicate identifying patients early through antenatal screening, rather than through case finding, and beginning therapy when the CD4 count<sup>3</sup> is 350 cells/ $\mu$ L, rather than waiting until values drop to less than 200 cells/ $\mu$ L, resulted in a survival advantage (5, 6). Equally troublesome is developing countries' tendency to advocate support for home care, community programs, and government services as effective responses to the global orphan tragedy (7) without addressing the cause, that is, preventing the creation of orphans by developing strategies to save the lives of parents.

Since 1996, more than four-fifths of pregnant women in Barbados have received VCT for HIV infection during antenatal care (8). In 2002, the national Mother-to-Child Transmission Plus (MTCT-Plus) initiative was established to meet the needs of every family member infected or affected by HIV/AIDS. Before that time, programs to prevent mother-to-child transmission of HIV did not provide care and treatment to HIV-infected pregnant women and mothers. To fill this gap, the MTCT-Plus initiative expanded PMTCT programs to include comprehensive treatment services for pregnant and postpartum women. Nevertheless, the question remains whether the full benefits of VCT are being realized in terms of making a difference in the health of HIV-infected women. To answer this question, this study analyzed the use of HIV-related follow-up health services (care, treatment, and monitoring) by postpartum HIV-infected women, and their health status at first follow-up visit after the delivery of their babies.

## MATERIALS AND METHODS

### Study population

This is a descriptive study. The study population includes all HIV-infected women in Barbados diagnosed through antenatal VCT for HIV infection from January 1996 through December 2004. The study participants, like all new mothers in Barbados diagnosed with HIV, and their newborns, are enrolled in the Pediatric HIV Surveillance Program provided through national public health care services.

Barbados has a well-organized antenatal care delivery system delivered through three main types of health care facilities: state-run polyclinics—national primary care facilities where most pregnant women receive their antenatal care; private offices of obstetricians and general practitioners; and The Queen Elizabeth Hospital (QEH) in Bridgetown, Barbados' tertiary care referral hospital. Both the polyclinics and private doctors' offices liaise closely with QEH, where most deliveries are carried out. Following delivery, most women return to their respective polyclinics for postnatal follow-up, while others receive follow-up at the private obstetrician or general practitioner's office where they received antenatal care. HIV-exposed newborns are followed up at the QEH Pediatric Clinic, whereas HIV-infected mothers are referred to the centralized HIV/AIDS clinic run by the Ministry of Health (MOH). Established in the early 1990s for the sole purpose of providing continuous follow-up to all HIV-infected persons in the country, the clinic was located at the QEH Respiratory Unit (RU) until 2002, when it was moved to its current location at the Ladymeade Reference Unit (LRU) at MOH facilities in Bridgetown.

Follow-up of HIV-infected women involves monitoring their general health; conducting CD4 cell counts; and providing prophylaxis, as well as treatment of opportunistic infections. Since 2001, HAART (highly active anti-retroviral therapy) has been provided for all HIV-infected persons in

Barbados; the therapy is provided free of cost at the point of delivery, based on U.S. Department of Health and Human Services (DHHS) guidelines modified for the Caribbean. A CD4 cell count of less than 200 cells/ $\mu$ L is an absolute indication for commencing HAART. Some persons with a CD4 cell count between 200 and 350 cells/ $\mu$ L are also treated, based on their clinical stage and/or viral load level.

### Study ethics

All HIV-infected women who delivered from 1996 through 2004 were identified from the Pediatric HIV Surveillance Program database. The women were contacted, and informed consent for the study was obtained. Study participants were assured of the complete confidentiality of all information provided for the purpose of the study. They were also assured that their information would in no way influence their ongoing HIV/AIDS care or future medical care. The study method was approved by the Institutional Review Board for ethical issues in research at The University of the West Indies (Cave Hill) School of Clinical Medicine and Research in Barbados.

### Data collection methodology

Information on study participants' demographic data, including age, employment status, living arrangements, and marital status, was collected from records of their antenatal care maintained at the QEH. Information on their use of HIV-related health services and the status of their health with respect to HIV/AIDS-related illness, including time and year of diagnosis and admission, and outcome, at the QEH; follow-up at the HIV/AIDS clinic at the QEH RU (before 2002) or the LRU (after 2002); treatment, and adherence to treatment (if any); and deaths (if any) was collected from LRU and QEH medical records. For women who received follow-up at the HIV/AIDS clinic at RU/LRU, information on their first

3 CD4 cell count is a marker of the degree of immunodeficiency in persons infected with HIV. Normal CD4 cell count is usually greater than 750 cells/ $\mu$ L. Values less than 200 cells/ $\mu$ L are considered to represent severe immunodeficiency.

presentation at the clinic, their health status at the time, and their CD4 counts was collected from records maintained at the LRU.

### Outcome measures and statistical methods

Outcome measures included proportion of study participants attending the RU/LRU for HIV/AIDS-related illness, time interval between HIV diagnosis and first visit to the RU/LRU, CD4 cell counts at first visit to the RU/LRU, proportion of study participants on HAART, time interval between first presentation to the RU/LRU and initiation of HAART, compliance with follow-up, and mortality.

All data collected for the study were stored in a pre-designed Microsoft Access database and analyzed using SPSS statistical software package, version 11. The 9-year study period was further divided, based on the availability of HAART, into three 3-year sub-periods: 1996–1998, 1999–2001, and 2002–2004. For the purpose of comparison, the 1996–1998 period, when no antiviral therapy was available for treatment of HIV-infected persons in the country, was selected as a baseline and compared with the 2002–2004 period, when HAART was available for treatment. Antiretroviral therapy (mostly dual therapy) was also available during the 1999–2001 period, but only for a few HIV-infected individuals. The 95% confidence interval (CI) was corrected for continuity. Chi-square tests were used to analyze proportional data, and a *p* value  $\leq 0.05$  was considered statistically significant. Graphs were prepared with Microsoft Excel for Windows XP, version 7.0.

## RESULTS

### Socio-demographic profile of study population

During the study period, 163 HIV-infected women were diagnosed for

the first time through antenatal screening. Table 1 shows the relevant socio-demographic profile of these women. Most of them were in the 21–30 age group (56.4%), single (80.4%), and unemployed (42.3%); 151 (92.6%, 95% CI = 87.2%, 95.9%) were asymptomatic at the time of their diagnosis. Twenty-four (14.7%, 95% CI = 9.8%, 21.3%) women were deceased, and the whereabouts and status of 5 (3.1%, 95% CI = 1.3%, 6.9%) were unknown. The remaining 134 (82.2%, 95% CI = 75.6%, 87.3%) were alive at the time of the study (Table 2). The median duration of HIV infection from the time of diagnosis up to the time of this study was 72 months (low range, 9 months; high range, 117 months). Sixty-eight (41.7%, 95% CI = 34.4%, 49.4%) women were diagnosed during the period 1996–1998, 58 (35.6%, 95% CI = 28.6%, 43.2%) were diagnosed during 1999–2001, and 37 (22.7%, 95% CI = 16.9%, 29.7%) were diagnosed during 2002–2004 (Table 3).

### Follow-up of women diagnosed through antenatal VCT as HIV-infected

As shown in Table 2, of the 163 women diagnosed as HIV-infected through antenatal screening, 102 (62.6%, 95% CI = 54.9%, 69.6%) had attended the centralized HIV/AIDS clinic (RU/LRU)—the only clinic for complete and comprehensive follow-up (care, treatment, and monitoring) of HIV-infected persons in Barbados—and 61 (37.4%, 95% CI = 30.0%, 45.3%) had never attended the clinic for follow-up. For the 102 HIV-infected women who had attended the centralized HIV/AIDS clinic, the median time interval between diagnosis of HIV infection and first presentation to the clinic for follow-up was 36 months (low range, 1 month; high range, 114 months).

### Health status of HIV-infected women at first follow-up visit

More than one-fourth (28.4%, 95% CI = 20.1%, 38.4%) of those who pre-

**TABLE 1. Socio-demographic profile of 163 HIV-infected women diagnosed through antenatal screening**

Characteristic	<i>n</i>	(%)
Age (years)		
$\leq 20$	43	26.4
21–30	92	56.4
31–40	27	16.6
$> 40$	1	0.6
Marital status		
Single	131	80.4
Married	32	19.6
Employment status		
Unemployed	69	42.3
Employed	94	57.7
Disease status at time of diagnosis		
Asymptomatic	151	92.6
Symptomatic	12	7.4
Time since diagnosis of HIV infection		
1–3 years	35	21.5
4–6 years	46	28.2
7–9 years	82	50.3

**TABLE 2. Follow-up and health status of 163 HIV-infected women diagnosed through antenatal screening**

Follow-up/health status	<i>n</i>	(%)
Attendance at HIV/AIDS clinic for care and treatment		
Attended	102	62.6
Never attended	61	37.4
Total	163	
Current status		
Living	134	82.2
Deceased	24	14.7
Unknown	5	3.1
Total	163	
CD4 cell count at time of first presentation to RU/LRU		
$< 200/\mu\text{L}$	29	28.4
200–499/ $\mu\text{L}$	43	42.2
$\geq 500/\mu\text{L}$	28	27.4
Unavailable	2	2.0
Total	102	
Health status at first follow-up visit		
Satisfactory	79	77.5
Poor	23	22.5
Total	102	
Antiretroviral therapy		
On HAART	53	52.0
Not on HAART	49	48.0
Total	102	
Adherence to HAART		
Good	43	81.1
Poor	10	18.9
Total	53	

**TABLE 3. Trends in uptake of health care services for 163 women diagnosed as HIV-infected during three sub-periods, 1996–2004**

	1996–1998		1999–2001		2002–2004	
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)
Number of women diagnosed as HIV-infected	68	41.7	58	35.6	37	22.7
Status at time of study						
Deceased	13	19.1	9	15.5	2	5.4
Alive	53	77.9	46	79.3	35	94.6
Unknown	2	3.0	3	5.2	0	0.0
Follow-up at LRU/RU						
Did not receive	30	44.1	23	39.7	8	21.6
Received	38	55.9	35	60.3	29	78.4
Quality of adherence to follow-up schedules by those who received services						
Good (attended at least once every 3 months)	19	50.0	23	65.7	21	72.4
Poor (lost to system or attended less than once every 3 months)	19	50.0	12	34.3	8	27.6
Treatment status of women with good adherence to follow-up at time of study						
Not on HAART	7	36.8	11	47.8	14	66.7
On HAART	12	63.2	12	52.2	7	33.3

sented for follow-up and had a CD4 cell count done at the time of their first presentation to the RU/LRU had severe immunodeficiency (CD4 cell counts <200/ $\mu$ L) (Table 2). Of the 102 women who attended the follow-up clinic, 53 (52.0%, 95% CI = 41.9%, 61.9%) were undergoing HAART up to the time of this study. Of those who received HAART, 23 (43.4%, 95% CI = 30.1%, 57.6%) had begun the therapy within three months of their first follow-up visit. Adherence to HAART was reported as good (taking more than or equal to 96% of their prescribed medicine) in over four-fifths (43, or 81.1%) of those receiving the therapy. Among the 102 study participants attending the follow-up clinic, adherence to follow-up schedules was considered good (attended the clinic at least once every three months after their initial visit) for 63 (61.8%) women and poor (lost to follow-up or presented for follow-up less frequently than once every three months) in the case of 39 (38.2%) women (Table 3).

### Trends in uptake of health care services and health status of HIV-infected women

Trends in accessing HIV-related (follow-up) health services by the 163 HIV-infected women diagnosed through antenatal screening, and their health status, are shown in Table 3. Of those diagnosed as HIV-infected during the 1996–1998 period, 55.9% had attended the centralized HIV/AIDS clinic (RU/LRU) at some point; the corresponding figure for 2002–2004 increased to 78.4% (chi-square tests for trend;  $p = 0.049$ ). Only 50% of HIV-infected women diagnosed during 1996–1998 who attended the centralized HIV/AIDS clinic for follow-up services had good adherence to follow-up schedules (at least once every three months), while the corresponding figure for 2002–2004 increased to 72.4% (chi-square tests for trend;  $p = 0.034$ ).

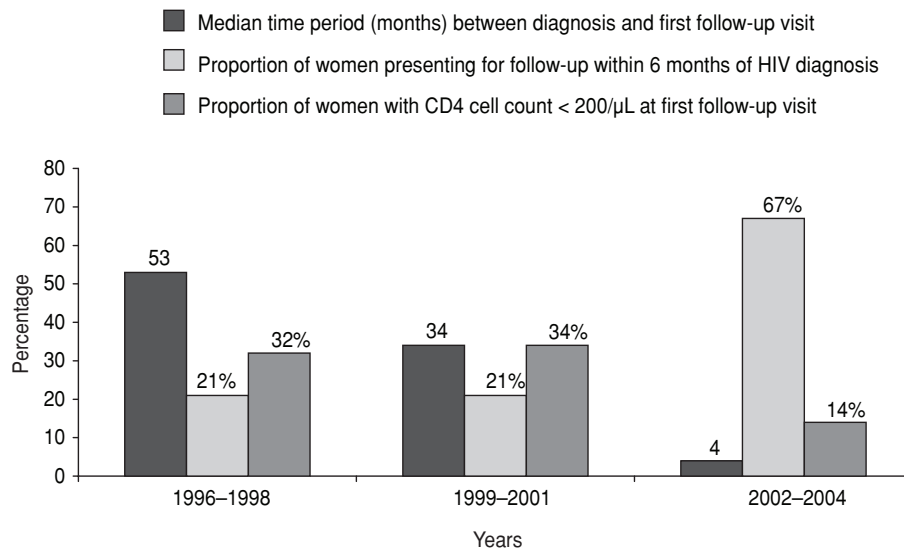
For HIV-infected women who presented for follow-up at the centralized HIV/AIDS care clinic, the median

time interval between diagnosis of HIV infection and first presentation to the follow-up clinic dropped from 53 months during 1996–1998 to 4 months during 2002–2004 (Figure 1). The proportion of all HIV-infected women attending the RU/LRU who presented for follow-up within six months of their diagnosis of HIV infection increased from 21% during 1996–1998 to 67% during 2002–2004 ( $p < 0.0001$ ). During 1996–1998, 32% of all HIV-infected women who presented for follow-up and underwent a CD4 cell count had values of less than 200/ $\mu$ L; this figure decreased to 14% during 2002–2004 ( $p = 0.048$ ).

### DISCUSSION

Barbados is one of the smaller countries in the English-speaking Caribbean, with an estimated 2001 population of 266,800 and a per capita gross national product of US\$ 18 200 (2006). The estimated (crude) mortality rate for Barbados for 2001 was 8.3 per 1000 population (9), and the adult prevalence rate of HIV in the country is estimated at 1.75%, with a male-to-female ratio of 2:1 (10). The Government of Barbados views health care as a fundamental right of all Barbadians and aims to provide comprehensive health care to all its citizens through its elaborate government-controlled health care system, free of cost at the point of delivery. Since the early 1990s, a number of interventions were targeted to reduce mother-to-child transmission of HIV in the country. These included the provision of free antenatal VCT (voluntary counseling and testing) for HIV infection since 1991 and free antiretroviral drugs for perinatal prophylaxis since 1996, resulting in a dramatic decline in the rate of perinatal transmission of HIV in the country (11). These measures were followed up by the provision of free antiretroviral treatment for all eligible HIV-infected individuals in the country since 2002, coupled with HIV/AIDS education interventions targeting the general public. All potential benefits of VCT must

**FIGURE 1. Trends in delay in seeking follow-up care by 163 HIV-positive women diagnosed through antenatal screening in Barbados during 1996–2004**



be realized in order for it to be a cost-effective and powerful tool in the fight against the spread of HIV/AIDS. Early detection of HIV infection in child-bearing women through antenatal screening following VCT is an important tool with huge potential benefits, especially when coupled with the provision of HAART (6, 7). The findings of this study are therefore relevant, and important, particularly in view of the lack of any other published reports on these types of studies from the Caribbean region.

### Delayed follow-up of HIV-infected women

The socio-demographic profile of the HIV-infected women in this study was consistent with those of the authors' earlier report, which described the socio-demographic profile of HIV-infected postpartum women in Barbados (12). It should be noted that more than 40 percent of the women under study had been diagnosed with HIV for 6 to 9 years, while the HIV status of more than four-fifths had been known

for more than 3 years. Keeping these figures in mind, it is a cause of great concern that more than one-third of the 163 women diagnosed through antenatal screening as HIV-infected after VCT had never attended the centralized HIV/AIDS clinic at the RU/LRU, which was designed to serve as a "one-stop shopping center" for persons affected by HIV/AIDS. Equally worrisome was the fact that entry into the follow-up system for those who did seek HIV-related care and treatment was significantly delayed (with a median time lag of 16 months between diagnosis of HIV infection and first presentation to follow-up clinic). This suggests the loss of much of the potential advantage gained through early diagnosis during the antenatal period following VCT. More than one-third of those who sought follow-up had poor adherence to it or were lost to the follow-up system altogether. Loss to follow-up, significantly long delays in seeking follow-up (following HIV diagnosis), and failure to comply with follow-up schedules are serious challenges to Barbados' MTCT-Plus initiative. The findings from this study rein-

force observations made in other studies from developing countries (13–15).

### The HAART factor

There are two interesting findings in regard to HAART and HIV-infected women diagnosed through antenatal screening. First, the unavailability of HAART during the initial (1996–2001) part of the study period could have been partly responsible for the reluctance on the part of these women to access health care services. It should be noted, however, that most of these women were asymptomatic at the time of their diagnosis and therefore would not have needed HAART until much later in the course of the disease. A second and somewhat troublesome finding is that even during the sub-periods when HAART was available, late presentation at advanced stage of the disease was reflected in a high percentage of women, most of whom were young (nearly three-fourths under 30) and asymptomatic (more than 90%) at the time of diagnosis. By the time most of these women made their first visit to the centralized HIV/AIDS clinic (RU/LRU), they had CD4 cell counts of less than 200/μL; therefore, most were started on HAART within three months of their first presentation. Given the evidence for poor outcome for HAART when initiated in patients with CD4 cell counts of less than 200/μL (16–19), these numbers indicate a failure to capitalize on early diagnosis of HIV infection in women who have willingly undergone HIV screening during antenatal VCT. They also imply the failure to prevent the orphaning of many of the infants born to these women, among whom HIV infection has been avoided through the use of perinatal ZDV/NVP<sup>4</sup> prophylaxis (11). This suggests that the un-

<sup>4</sup> St. John MA, Kumar A, Cave C, Carmichael K. Efficacy of nevirapine administration on the mother to child transmission of HIV using a modified HIVNET 012 regimen. [Conference presentation]. At: Caribbean Health Research Council 48th Annual Scientific Meeting, Nassau, Bahamas, 1–3 May 2003.

availability of HAART for the major part of the study period (1996–2001) may have been a major limitation of the MTCT-Plus initiative as well as a reason for delayed access of services for HIV follow-up by HIV-infected women in Barbados.

### Role of stigma and discrimination

Despite the provision of HAART free of cost, there has been a poor return on follow-up of HIV-infected women diagnosed through antenatal VCT. This could be an indicator of the high degree of HIV/AIDS-associated stigma and discrimination prevalent among this population; whether real, or perceived, or both, stigma and discrimination may be the biggest hurdle to the uptake of care and treatment services by HIV-infected women. A high prevalence of HIV/AIDS-associated stigma and discrimination associated with a low rate of self disclosure of HIV serostatus has been reported in previous studies of this population (20, 21). Until very recently, as in other parts of the developing world, HIV/AIDS-associated stigma and discrimination did not receive enough attention in Barbados.

### Trends and future outlook for the VCT program

In analyzing trends in HIV-related follow-up services and their uptake by women in the study, it is heartening to note that both the median time interval

between diagnosis and first follow-up visit and the proportion of women with a CD4 cell count less than 200/ $\mu$ L declined significantly during 2002–2004 compared to 1996–1998. These results should be viewed with caution, however, for even during 2002–2004 (when HAART was available free of cost for all HIV-infected persons in the country), more than one-fifth (21.6%) of HIV-infected women diagnosed through antenatal screening during this period never attended the centralized HIV/AIDS clinic for follow-up, and more than one-seventh (14%) of those who did eventually seek follow-up had a CD4 cell count less than 200/ $\mu$ L.

### CONCLUSIONS AND RECOMMENDATIONS

During the follow-up period, which ranged from one to nine years, there was a significant level of mortality among the HIV-infected women diagnosed through antenatal VCT. This was associated with inadequate adherence to follow-up, or delayed seeking of follow-up (until relatively advanced stages of the disease), in many cases compounded by the unavailability of HAART during most of the study period. This indicates that HIV diagnosis alone is not enough to ensure that all women with HIV will receive adequate and timely health care. One constraint may be the fragmented structure of the present system for postnatal follow-up of HIV-infected women and their exposed newborns. In this system, the mother receives her postnatal follow-

up at the clinic where she received antenatal care, but is referred to the centralized HIV/AIDS clinic for her HIV follow-up, while her baby receives follow-up at the QEH. This system of fragmented health care delivery, which requires visits to different health clinics located in different parts of the island, could have hampered study participants' follow-up.

Counseling and testing recommendations should highlight the intrinsic value of early diagnosis. Ongoing counseling from different members of the health care team involved in the care and treatment of these women, with frequent reinforcement and without stigmatization or discrimination, may increase the uptake of HIV-specific health care services by this population. Integrating antenatal and HIV/AIDS care for these women and their HIV-exposed infants in one clinic would add continuity and could thus strengthen the rapport between the HIV-infected women and their care provider. It may also improve adherence to and the quality of their follow-up. Conducting focus group discussions with these women to gain further insight into barriers to follow-up as perceived by these women may be useful in identifying system constraints as well as more appropriate and effective solutions.

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## RESUMEN

### Utilización de los servicios de atención sanitaria y estado de salud de las mujeres seropositivas al VIH diagnosticadas mediante el tamizaje prenatal para el VIH en Barbados, 1996–2004

**Objetivos.** Estudiar la utilización de los servicios de atención sanitaria relacionados con el VIH y describir el estado de salud de las mujeres infectadas con este virus, diagnosticadas mediante el asesoramiento y la prueba de detección del VIH de carácter voluntario (APDV) durante el período prenatal en Barbados.

**Métodos.** Este es un estudio descriptivo. La población de estudio abarcó a todas las mujeres infectadas por el VIH, diagnosticadas en Barbados mediante el APDV en 1996–2004.

**Resultados.** La mediana de la duración de la infección por el VIH —desde el diagnóstico hasta el momento de este informe— en las 163 mujeres diagnosticadas durante el período de estudio fue de 72 meses (nivel bajo: 9 meses; nivel alto: 117 meses). De las 163 mujeres, 102 (62,6%) asistieron a la clínica centralizada para el VIH/sida para su seguimiento (atención, tratamiento y monitoreo), mientras que 61 (37,4%) nunca asistieron a la clínica. La mediana del lapso entre el diagnóstico de la infección por el VIH y la primera presentación a la clínica para el VIH/sida fue de 36 meses (nivel bajo: 1 mes; nivel alto: 114 meses). Más de la cuarta parte de las mujeres infectadas que acudieron a la clínica presentaban inmunodeficiencia grave en el momento de su primera consulta de seguimiento. De las 53 mujeres que se sometieron al tratamiento antirretroviral de gran actividad (HAART) durante el estudio, 23 (43,4%) comenzaron el tratamiento en los tres meses siguientes a su primera visita de seguimiento.

**Conclusiones.** El diagnóstico temprano mediante el APDV no garantiza que las mujeres con VIH reciban una atención adecuada y oportuna para tratar esa infección. Estas mujeres sufren una mortalidad significativamente prematura, en gran parte debido al inadecuado seguimiento.

## Palabras clave

Infecciones por VIH, mujeres embarazadas, estado de salud, Barbados.