

## **HIV/AIDS-RELATED STIGMA AND DISCRIMINATION IN THE COMMONWEALTH OF DOMINICA: ANALYSIS OF SURVEY RESULTS**

Roger McLean  
roger.mclean@sta.uwi.edu

Vyjanti Beharry  
vyjanti.Beharry@sta.uwi.edu

Christine Laptiste  
christine.laptiste@sta.uwi.edu

Patricia Edwards-Wescott  
patricia.edwards-wescott@sta.uwi.edu

Kimberly-Ann Gittens-Baynes  
kimberly-ann.gittens-baynes@sta.uwi.edu

Charmaine Metivier  
charmaine.metivier@sta.uwi.edu

*Health Economic Unit, Centre for Health Economics, University of the West Indies, St Augustine, Trinidad and Tobago*

The objective of this paper is to ascertain the pervasiveness of HIV/AIDS-related Stigma and Discrimination (HSAD) in the Commonwealth of Dominica. Since HSAD is manifested at different levels – individual, group and societal, the paper focuses on the indicators that measure the socio-cognitive aspects of HSAD from the perspective of the different age groups within the general population based on the results from a Knowledge, Attitudes, Beliefs and Practices (KABP) survey.

Indicative data on perceived and experienced stigma are presented through the responses given to questions about reactions to and perceptions of persons whose HIV positive status is known. Other survey data collected were based on questions concerning the individual's willingness to have casual interactions with persons living with HIV/AIDS (PLWHA). Results show that the level of perceived or anticipated stigma is higher among persons in the youngest age cohort of 15 to 19 years compared to members in older age groups. This age group also displayed more discriminating attitudes when questioned about various possible interactions with PLWHA, than respondents in the other age categories.

The social and economic implications of HSAD, which include loss of jobs, higher health care and social costs, increased levels of depression and other mental health

effects are discussed within the socioeconomic context of the Commonwealth of Dominica.

**Keywords:** HIV/AIDS, KABP, perceived stigma, experienced stigma, socioeconomic implications

## **Introduction**

HIV/AIDS was first diagnosed in the Commonwealth of Dominica, a Small Island Developing State (SIDS) located in the Caribbean, in 1987. The country has an estimated population of 71,293 (Central Statistical Office, 2011) and up to the end of 2009, there was a cumulative figure of 350 reported cases, of which 70% were male. The prevalence rate was 0.75% and the epidemic is described as a concentrated one that is driven mainly by the risk factors associated with men who have sex with men. However, epidemiological bridging or the mixing of high-risk individuals with the general population has resulted in an epidemic that is becoming more generalized as seen by a decline in the male to female ratio of new infections (UNGASS 2010).

An emerging, generalized HIV/AIDS epidemic affects the social and economic situation of a country through four main channels—Production, Allocation, Distribution and Regeneration. Through the production channel, it is manifested by decreases in the availability and productivity of labour and the accumulation of human capital which encompasses education, training, experience and knowledge embedded in individuals (Kwon, 2009). Secondly, as resources are allocated to HIV/AIDS related programmes, they become unavailable for alternative, production activities, the opportunity cost being the value of the lost output of goods or services. With respect to the distribution channel, HIV/AIDS widens the gap between the high and low income groups as persons in the poorer quintiles are made worse off due to job loss and increased health care costs (Casale and Whiteside, 2006). Finally, the regeneration channel, which determines a country's sustainable growth and development over time relates to investment in human and physical capital and new technology. As countries and individuals are required to increase spending on HIV/AIDS services, savings and investment eventually decrease thus undermining an economy's ability to expand.

The fact that an important component of the nation's future and current stock of human capital is resident in the age groups 15 to 49 years suggests that HIV/AIDS and HSAD may negatively impact on the production and regeneration ability of an economy, thereby decreasing the returns on current investments in education and training. In a country that is highly susceptible to exogenous shocks (Easter 1999) and with 29% of its population living in poverty (Kairi Consultants Ltd, 2010) there is little room for error when it comes to the efficient allocation and utilization of resources.

The recognition of HIV/AIDS as an almost predictable shock to a country's sustainable economic growth and development has led to the implementation of initiatives and programmes that aim primarily to prevent new infections and increase the life expectancy of PLWHA. However, availability of such services does not imply access and one of the major impediments to effective HIV/AIDS programme uptake continues to be stigma and discrimination (Parker and Aggleton, 2003). HIV/AIDS-related Stigma and Discrimination (HSAD) is defined by UNAIDS

(2007,9) as a *'process of devaluation of people either living with or associated with HIV and AIDS...Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status'*. Stigma, which tends to manifest itself as homophobia in Jamaica, has resulted in more than two-thirds of newly diagnosed cases of AIDS in 2002 arising from delayed testing in the progression of the disease. It also meant death for the remaining one-third as patients failed to seek care for their disease (UNAIDS, 2007).

Whilst the prevalence of HIV/AIDS has socioeconomic implications, this is compounded by the existence of HSAD since the resources spent on HIV/AIDS prevention and treatment programmes may reap little return if these services are not utilized. As Dominica, like other countries, adopts a knowledge-based approach to the HIV/AIDS response initiative there is a need for information on the various types of stigma and discrimination that exists. This will guide the development of programmes that remove HSAD as a barrier to access as well as improve access even in the presence of HSAD.

### **Methodology**

The attitudes, beliefs and practices towards persons infected with or thought to be infected with HIV/AIDS are presented, based on the results from a Knowledge, Attitudes, Beliefs and Practices (KABP) survey conducted in Dominica in 2011. This paper focuses on the indicators that measure the socio-cognitive aspects of HSAD from the perspective of the different age groups in the Commonwealth of Dominica and discusses the socioeconomic implications.

A two-stage, stratified sampling process was employed to select the sample population for this survey. In order to ensure that the sample was representative of the population, a list of all Enumeration Districts (ED) which included the total numbers of households, buildings, dwellings and persons (male and female) was developed for each parish in Dominica based on the most recent census data. Each ED was measured in terms of clusters of households and had a probability of selection that was proportional to its size which ensured the sample would be self-weighting. A sample of households from the selected EDs was then generated followed by the selection of one person per household using the Kish grid to reduce bias.

The survey enumerated 1,177 persons between the ages of 15 to 49 years. Approximately 57% of the respondents (n=669) were female and 43% (n=509) were male. The largest age group was the 25 to 39 year olds which represented 38% of the sample (n=449). The second largest age group was the 40 to 49 year olds which accounted for 27% (n=318) followed by persons in the 15 to 19 years group which made up almost 18% of the sample (n=211). The remaining 13% were persons who fell within the 20 to 24 years group (n=158).

In order to ensure confidentiality, completed questionnaires were placed in sealed envelopes and signed across the seal by the enumerator in the presence of the respondent. Intelligent Character Recognition (ICR) scanning and VBA programming were used to capture the data electronically. This minimised data entry time and errors. Data cleaning, variable construction, cross-tabulations and other statistical analyses were done in Microsoft SQL Server 2005.



The three top modes of HIV transmission identified from a given list by respondents were

- i) having unprotected sex with an HIV positive person (n=1,087; 92%),
- ii) sharing needles with an HIV positive person (n=1,056; 90%) and
- iii) giving blood (n= 706; 60%).

The majority (n=1139; 97%) of respondents knew that HIV could be transmitted from one person to another through sexual intercourse. Other modes of HIV transmission identified were

- i) blood transfusions (n=711; 60%),
- ii) injecting drugs (n=501; 43%) and
- iii) mother to child transmission (n=294; 25%).

### **Stigma and Discrimination**

#### *Friend or Relative with HIV/AIDS*

Approximately 32% of the sample population surveyed (n=374), knew someone who was infected with HIV. Another 4% (n=45) were not sure if they knew someone infected with HIV, while about 64% of the respondents (n=759) did not know anyone who had been infected with HIV. Thirty six percent of those (n=152) who knew a PLWHA, stated that this person was a relative/friend. When cross-tabulated by age, the data shows that more than twice the number of persons between the ages 40 to 49 (n=109; 53%) knew a PLWHA or someone who had died from AIDS-related causes than persons in the 15 to 19 age group (n=54; 24%).

When asked the question, 'Should HIV/AIDS Status of Family Members be Kept a Secret?', 57% (n=674) said yes. Of those who responded yes, 26% of these respondents (n=307) indicated fear, 28% (n=331) indicated shame and 21% stated ostracism/discrimination (n=240) as the reasons for not disclosing the HIV status of a family member.

An average of 68% (n=143) of persons in the age group 15 to 19 years and 20 to 24 years (n=109) said that the HIV status of a family member should be kept a secrets compared to an average of about 51% of persons in the age groups 25 to 39 (n=248) and 40 to 49 (n=155). This is indicative of the level of perceived stigma by the younger age groups compared to those in the older age categories.

Almost 70% of the sample (n=823) indicated that they would care for a male relative of their household, if he was infected with HIV. On the other hand, 16% (n=187) indicated they would not do so. The trend is repeated with reference to a female relative that is a member of the household with 73% (n=855) in favour of caring for a female relative and 14% (n=165) not being in favour of doing so.

#### *HIV Services at Health Facilities*

Perceived or anticipated stigma reflects the respondents' views on the level of HIV-related stigma in a particular community or country based on their willing or unwillingness to access HIV-related services at generally or at particular sites. With respect to HIV testing, 46% of the respondents (n=547) were able to name an HIV testing site, of which 46% (n=242) named a

hospital, 32% (n=164) named the health centre and 13% (n=69) identified the community health clinic as testing sites.

Seventy-nine percent (n=433) stated that they would go to one of these sites for an HIV test whilst 16% (n=88) said they would not. The main reasons identified for not going to these sites for an HIV test were lack of confidentiality (n=41; 35%) and knowing someone who worked there (n=17; 15%).

Sites for treatment and care services were identified by 68% of persons surveyed (n=805), of which 90% (n=723) identified the hospital. However, when asked if they would choose public or private care if given an option, 84% (n= 993) opted for private care.

Overall, 68% of the respondents (n=800) were willing to have the same medical personnel who treat PLWHA address their medical needs, while 23% (n=271) did not support it. With respect to the different age groups, a lower percentage, 56% (n=116;) of respondents in the 15 to 19 age group were willing to receive treatment from the same medical personnel that treated PLWHA when compared to 73% (n=327) of persons in the age group 25 to 39 year and 71% (n=226) of the 40 to 49 year olds.

In terms of willingness to stay in the same Primary Health Care (PHC) facilities with PLWHA, roughly 61% (n=718) were in favour or doing so, while 30% (n=353) were not. On the basis of age, 43% the respondents (n=91) in the younger age groups of 15 to 19 years and 49% (n=77) of those 20 to 24 years were willing to share PHC facilities with PLWHA compared to 68% (n=305) and 66% (n=210) of the persons in the age groups 25 to 39 years and 40 to 49 years respectively.

Sixty eight percent of the respondents (n=800) expressed willingness in having PLWHA accessing their medications at PHC facilities and 23% (n=271) did not support this suggestion. Again, persons in the younger age groups were less supportive of this than the older age cohorts. For the 15 to 19 year olds, 61% (n=129) stated their willingness compared to 72% (n=229) of respondents in the age group 40 to 49 years.

On the topic of children of PLWHA being treated at the same clinics as other children, 47% (n=553) were in favour of this and 43% (n=506) were not. The younger respondents once more displayed less willingness to support such an initiative with 59% of the 15 to 19 year olds (n=124) compared to 35% of the 40 to 49 year olds (n=112).

**Table 2: Attitudes With Respect to Sharing Health Care Personnel and Facilities with PLWHA**

		Age Groups					
		15-19	20-24	25-39	40-49	Not Stated	Total
		%					
<b>Number of Respondents</b>	<b>N</b>	<b>211</b>	<b>158</b>	<b>449</b>	<b>318</b>	<b>41</b>	<b>1177</b>
Willing To Have Same Medical Personnel Treat You and PLWHA At Clinic	Yes	56.1	61.7	72.9	71.0	78.1	68.0
	No	34.1	29.7	18.2	21.8	7.3	23.2
	Don't know	4.7	7.2	6.1	3.7	0	5.2
	Not stated	5.1	1.4	2.8	3.5	14.6	3.6
	Total	100.0	100.0	100.0	100.0	100.0	100.0
Agree PLWHA Can Get Tests Done At Primary Health Care Facilities	Yes	41.7	42.3	61.8	60.0	56.2	54.9
	No	46.1	41.6	30.5	30.9	7.3	34.1
	Don't know	8.3	14.7	3.9	6.9	14.6	7.3
	Not stated	4.0	1.4	3.7	2.2	21.9	3.7
	Total	100.0	100.0	100.0	100.0	100.0	100.0
Support PLWHA Getting Medications From Primary Health Care Facilities	Yes	60.7	65.8	70.7	71.6	56.2	68.0
	No	27.2	24.7	23.9	18.6	7.3	22.6
	Don't know	8.1	5.3	2.9	6.9	21.9	5.9
	Not stated	4.0	4.1	2.5	2.9	14.6	3.5
	Total	100.0	100.0	100.0	100.0	100.0	100.0
Willing To Have PLWHA Children and Your Children Treated At Same Clinic	Yes	30.4	39.8	52.2	55.1	52.4	47.4
	No	58.6	54.6	38.4	34.8	25.7	42.8
	Don't know	5.8	4.2	6.7	7.9	7.3	6.5
	Not stated	5.3	1.4	2.6	2.2	14.6	3.2
	Total	100.0	100.0	100.0	100.0	100.0	100.0

*Casual Contact with PLWHA*

HSAD was also assessed by the sample population's responses to questions about social interactions with PLWHA as the unwillingness to interact with PLWHA is a primary area used to measure stigma (Nyblade and MacQuarrie, 2006).

In Dominica, 59% of the sample (n=699) reported that they would be willing to share meals with a PLWHA while about 33% of the sample (n=386) indicated that they would not be willing to do so. Twenty-five percent (n=294; 25%) of the sample indicated that they would purchase food from a food seller or shop keeper that they knew to be infected with HIV. Of the remainder of the sample, 64% (n=748) indicated that they would not do so while about 9% (n=102) and 3% (n=34) respectively either did not know or did not state their view.

**Table 3: Attitudes With Respect to Casual Contact with PLWHA**

		Age Groups					Total
		15-19	20-24	25-39	40-49	Not Stated	
		%					
<b>Number of Respondents</b>	<b>N</b>	<b>211</b>	<b>158</b>	<b>449</b>	<b>318</b>	<b>41</b>	<b>1177</b>
Willing to Share a Meal with an HIV/AIDS Infected Person	Yes	50.7	54.8	65.9	56.8	70.8	59.4
	No	39.1	35.5	27.6	35.7	21.9	32.7
	Don't Know	10.2	8.2	4.0	4.8	7.3	6.0
	Not Stated	0	1.4	2.5	2.7	0	1.9
	Total	100.0	100.0	100.0	100.0	100.0	100.0
Would Buy Food from HIV Infected Food Seller/Shopkeeper	Yes	19.0	24.8	28.7	23.0	30.5	24.9
	No	69.5	64.0	59.4	67.9	40.3	63.5
	Don't know	10.2	9.8	7.3	8.2	14.6	8.6
	Not stated	1.3	1.4	4.7	0.8	14.6	2.9
	Total	100	100	100	100	100	100

When it came to working with an infected co-worker, 75% of the sample (n=883) indicated that they would be willing to do so while 16% (n=189) stated they would not want to work with a PLWHA. The respondents in the group 15 to 19 years were less comfortable working with someone with HIV – 57% (n=120), compared to persons on the older age groups of 20 to 24 years, 25 to 39 years and 40 to 49 years – 79% (n=125), 81% (n=364) and 75% (n=238), respectively indicated they would work with a PLWHA.

The majority of the sample (n=963; 82%) indicated that students infected with the virus should be allowed to continue in school. Those who disagreed amounted to 13% of the respondents (n=157). Just less than 5% (n=58) indicated that they did not know or did not state their views. Notably, a higher proportion of respondents in the youngest and oldest age groups, 15 to 19 years and 40 to 49 years were opposed than persons in the other age groups.

Just under eighty percent of the respondents (n=936) believed that a male teacher infected with HIV should be allowed to continue teaching while 17% (n=195) indicated that such teachers should not be allowed to continue teaching. Similarly, 80% of the respondents (n=942) believed that a female teacher should be allowed to continue teaching while and roughly 16% (n=185) did not think that this should be allowed. Again, a higher percentage of the 15 to 19 year olds (n=45; 21%) and the 40 to 49 year olds (n=64; 20%) displayed negative attitudes with respect to allowing a PLWHA to continue as a teacher than those in the other age categories.



**Table 4: Attitudes With Respect to Casual Contact with PLWHA in School**

		Age Groups					Total
		15-19	20-24	25-39	40-49	Not Stated	
		%					
<b>Number of Respondents</b>	<b>N</b>	<b>211</b>	<b>158</b>	<b>449</b>	<b>318</b>	<b>41</b>	<b>1177</b>
Should HIV Infected Student be Allowed to Continue Attending School	Yes	73.2	84.9	88.7	77.5	70.8	81.8
	No	19.8	8.2	9.0	18.4	7.3	13.3
	Don't know	3.7	5.4	1.3	4.0	7.3	3.2
	Not stated	3.4	1.4	1.1	.0	14.6	1.7
	Total	100.0	100.0	100.0	100.0	100.0	100.0
Should HIV Infected Male Teacher be Allowed to Continue Teaching	Yes	70.8	81.8	85.7	76.6	70.8	79.5
	No	23.1	14.0	11.4	21.7	7.3	16.5
	Don't know	5.2	2.8	1.9	1.7	7.3	2.7
	Not stated	1.0	1.4	1.1	.0	14.6	1.3
	Total	100.0	100.0	100.0	100.0	100.0	100.0
Should HIV Infected Female Teacher be Allowed to Continue Teaching	Yes	72.7	81.8	86.1	76.6	70.8	80.0
	No	21.4	14.0	10.9	20.3	7.3	15.7
	Don't know	3.8	2.8	1.9	3.1	7.3	2.8
	Not stated	2.0	1.4	1.1	.0	14.6	1.4
	Total	100.0	100.0	100.0	100.0	100.0	100.0

## **Discussion**

More persons in the younger age group of 15 to 19 years displayed attitudes of HIV/AIDS-related stigma and discrimination in Dominica than the other groups and as such a higher percentage of respondents in this groups (68%) were inclined to keep the HIV status of a family member a secret compared to about 51% of the 40 to 49 year olds. This may result in persons in the former age cohort to delay getting tested for HIV or not access treatment and care if needed, all of which contribute to higher morbidity and mortality rates.

On the issue of sharing health care facilities with PLWHA, 61% of the sample indicated their agreement with a lower percentage of respondents in the 15 to 19 age group (43%) willing to do so than those in the 40 to 49 year age group (66%). Whilst HIV testing and counselling is available in the seven health districts in Dominica (UNGASS 2010), programmes which address the issue of HSAD at the general population level and targeted to the 15 to 19 years age group is needed to improve access.

The fear of casual transmission of HIV has been linked to the unwillingness of person to interact casually with PLWHA in the community, at the workplace or in school. The data in Dominica indicates that only a minimal amount of persons (<10%) believe that HIV can be transmitted by casual contact such as sharing food and drink, mosquito bites or sharing a toilet. However, despite this, a relatively small proportion of the sample was willing to purchase food from a PLWHA (25%) and an even smaller percentage of those in the 15 to 19 years age group (19%).

With respect to interaction with PLWHA in schools, an interesting coincidence in the data suggests a pattern with the 15 to 19 year olds and the 40 to 49 year olds. A higher percentage of persons in these age groups (20%; 18% respectively) indicated that a student who has HIV/AIDS should not be allowed to attend school. This trend was repeated when asked if an infected teacher should continue teaching. Persons in these two age groups, 15 to 19 years and 40 to 49 years, represent a subset of the school age population and parents. The fact that 100% of schools in Dominica provide life skills-based HIV education (UNGASS, 2010) implies that a review of this programme is needed. Additionally, the feasibility of HIV/AIDS education and information programmes that target parents should be investigated.

## **Conclusion**

The findings of the KABP provided insightful information on perceived HIV- related stigma in Dominica by the various age groups. However, data on actual incidences and acts of discrimination experienced by PLWHA or perceived to be living with HIV/AIDS were not collected. The data from this survey can provide the baseline data for the evaluation of programmes aimed at reducing HSAD in Dominica as well as guide the design of these programmes as Dominica continues to roll out activities that meet the objectives of its 2010 to 2014 HIV/AIDS Strategic Response Plan. The opportunity cost of the resources required to develop and implement these programmes should also be reviewed as it may mean a reduction of resources available for activities such as training of staff, research in technology, infrastructure development and other investment spending that has a direct impact on economic growth.

**Author bios:** Roger Mc Lean is a Research Fellow/Lecturer at the HEU, Centre for Health Economics, University of the West Indies, St. Augustine Campus, Trinidad and Tobago. Mr. Mc Lean has been researching and working in the area of Development and Social Economics in general and Health Economics for the past sixteen years. Among the areas covered in his research are Health Sector Reform and Sexual and Reproductive Health issues focusing on such conditions as Cervical Cancer and HIV/AIDS, as well as Drug Abuse, Poverty and population ageing. Mr. Mc Lean is presently a member of The PAHO/WHO Technical Advisory Group on HIV/AIDS, the International AIDS Economics Network (IAEN), and a founding member of The University of the West Indies HIV/AIDS Response Programme (UWIHARP). He also serves as a member of the Board of Directors of the Family Planning Association of Trinidad and Tobago and the Caribbean HIV/AIDS Alliance.

Christine Laptiste is a Research Fellow at the HEU, Centre for Health Economics at The University of the West Indies, St. Augustine, Trinidad and Tobago. Her areas of research include health care financing, poverty and the costing of health and social sector programmes.

Patricia Edwards-Wescott is a Research Fellow at the HEU, Centre for Health Economics at The University of the West Indies, St. Augustine, Trinidad and Tobago. She holds a B.A. History and Social Sciences and a M.Sc. Economics from The University of the West Indies, St. Augustine. Her research interests lie primarily in the area of development economics with a focus on migration, government expenditure and health care issues.

Kimberly-Ann Gittens-Baynes is a Junior Research Fellow at the HEU, Centre for Health Economics, The University of the West Indies, St. Augustine, Trinidad. She is also a PhD candidate in the Department of Economics at UWI. Her areas of research include child rights and child protection issues, health issues and social policy with specific reference to women and children and other vulnerable groups and non-communicable diseases and poverty.

Charmaine Metivier is a Junior Research Fellow with the HEU, Centre for Health Economics of The University of the West Indies, St. Augustine, Trinidad and Tobago. She supports the research, training and outreach agenda of the HEU and has been involved in various projects in the areas of Health Financing, HIV/AIDS, Sexual Abuse and Domestic Violence in Trinidad and Tobago, as well throughout the Caribbean. Ms. Metivier is a member of the Trinidad and Tobago Economics Association and a director and founding member of Ray of Hope, a non-profit organization that works to improve the lives of underprivileged children in Trinidad and Tobago.

Vyjanti Beharry currently holds a Bachelor of Sciences (BSc) degree in Economic and Management, a Masters of Sciences (MSc) degree in Economics and a Masters of Philosophy (MPhil) degree in Economics. Her professional career began as a Research Technician in the Department of Economics, University of the West Indies (UWI) in 2001 and is currently a Junior Research Fellow at the HEU, Centre for Health Economics. She has also held the position of Senior Health Economist at the Ministry of Health, Trinidad and Tobago. Her areas of research include health financing, costing of health services and socioeconomic issues as it pertains to women and children.

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