

PACIFIC JOURNAL OF MEDICAL SCIENCES
{Formerly: Medical Sciences Bulletin}
ISSN: 2072 – 1625



Pac. J. Med. Sci. (PJMS)

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**HIV/AIDS STIGMA: MAIN BARRIER TO VCT AND OTHER HEALTH SERVICES IN FOUR
SUBURBAN VILLAGES IN NATIONAL CAPITAL DISTRICT, PAPUA NEW GUINEA**

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ABSTRACT:

The HIV/AIDS stigma, fear and discrimination have been linked with poor participation in Voluntary Counselling and Testing (VCT) programs. Cultural factors, attitudes and behaviours strongly influence the spread of HIV/AIDS and these have been extensively studied in several sub-Saharan African countries. Similar studies in Papua New Guinea are scanty. This study investigates the extents of HIV/AIDS-Stigma, fear, discrimination and other psychological factors as barriers to the access of VCT and other services in four suburban villages in the National Capital District, Papua New Guinea.

The study sites were Baruni, Hanuabada, Pari and Kilakila villages. A semi-structured questionnaire comprising of closed and open ended questions was administered to respondents selected randomly. Groups were selected for focus group discussions. Gender stratification was used to ensure that views of both men and women were equally represented. A total of 333 respondents comprising of 166 (49.8%) males, and 167 (50.2 %) females participated in the survey. Self-stigmatization as a major barrier to VCT was indicated by 90.7% of all the respondents. Gender based differences were not statistically significant. Discrimination by relatives and friends was indicated by 74.8% respondents; 79.0% of respondents would discriminate HIV/AIDS-infected people. A total of 42.0% respondents indicated the possibility of rejection from close relationships. The likelihood of dismissal from workplace was indicated by 68.5% of respondents. Lack of support from health providers (67.0%) and fear of HIV test result (61.6%) were other barriers to VCT indicated by respondents. This study recommends the need to heighten awareness of VCT and to eliminate stigma and fear in order to control the HIV/AIDS pandemic.

Key words: HIV/AIDS, stigma, voluntary counseling, testing, VCT, Papua New Guinea.

Received November 2011, Accepted February 2012

INTRODUCTION:

The Joint United Nations Program on HIV/AIDS (UNAIDS) defines HIV-related stigma & discrimination as, the process of devaluation of people either living with or associated with HIV & AIDS [1]. Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status [1]. Withdrawal which is a self isolation and / or detachment from the immediate community due to fear of been stigmatized or perceived self stigmatization may also follow. Similarly rejection of people infected with, or perceived by others to be infected or associated with the HIV/AIDS virus is likely. Rating stigma among different epidemics at Hong Kong University it was found that people strongly expressed negative feelings about individuals with HIV/AIDS and tuberculosis (TB), with Severe Acute Respiratory Syndrome (SARS), a lesser-known threat, at a lower level [2]. They also found that respondents feared HIV/AIDS the most, followed by TB and SARS, in that order [2]. According to the UN Secretary General, Ban Ki Moon [3] "Stigma remains the single most important barrier to public action; It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies

around the world." HIV/AIDS - stigma and discrimination have the greatest impact on all aspects of a country's HIV response. The greater the level of stigma, the further HIV spreads [4]. According to Valdiserri [5], "To underestimate the insidious power of stigma is to risk the very success of effective HIV prevention and care programs".

In Papua New Guinea (PNG), HIV rates have continued to rise almost exponentially to about 32,005 cases since the first report in 1987 [6]. Through various HIV- awareness projects, the National AIDS Council Secretariat (NACS) has been working relentlessly in partnership with many organizations such as: the WHO [7], Australian Agency for International Development (AusAID) [8], UNICEF [9], The Joint United Nations Program on HIV/AIDS (UNAIDS) [10], National Institutions such as the Institute of Medical Research (IMR), the University of Papua New Guinea (UPNG), Non Government Organizations (NGOs) and Faith Organizations within and outside the country to reverse this trend. The concerted efforts have been in response to the Millennium Development Goal 6 (MDG 6) on the combat of HIV/AIDS, Malaria and other diseases, that specifically aims to halt and begin to reverse the global HIV epidemic by year 2015 [11]. To reduce HIV and realise the MDG 6, people need to know their sero-status through voluntary counseling and testing (VCT). In PNG, some studies on the awareness and

attitudes towards HIV among pregnant women were carried out at the Port Moresby Antenatal Clinic in 2003 [12]. This study revealed a large number of patients who knew that transmission of HIV was by sexual contacts (97%), and through Mother to Child Transmission (MTCT) 96%. However, misconceptions that could lead to stigma existed with patients who believed that HIV could be transmitted by mosquitoes (36%), and with those (17%) who thought care for AIDS patients was a risk [12]. Fear of stigma and discrimination had also been reported as a primary barrier to accessing VCT of HIV and other health related services in PNG [13]. A recent preliminary study on the Impact of HIV/AIDS- Stigma and discrimination on the access to VCT in two suburban areas of the National Capital District (NCD), PNG revealed the existence of high levels of stigma (88.2 – 95.8 %), discrimination (85-91.8%) and fear (74.2%) [14]. The findings from the study did not fully reflect the Motu and Koita ethnic groups which together constitute a major proportion of the NCD population. These ethnic groups possess strongly established cultural norms and the majority of them are Christians. Nevertheless, the reported rapid spread of HIV/AIDS among the population constitutes one of the recognized threats to the current Motu and Koitabu generation [15].

The aim of this study was to investigate the extent of HIV/AIDS-Stigma, discrimination, fear and other psychological factors as barriers to

the access of VCT and other services in four suburban villages in the NCD, with focus on the Motu-Koita population.

SUBJECTS AND METHODS:

The Motu and Koitabu are a group of people indigenous to areas in and around NCD. They number about 30,000 of the 250,000 NCD population [15]. The study sites included nine Motu-Koitabu villages: Baruni, Tatana, Elevala, Poreporena (Hanuabada) Lahara & Laurabada, Taurama including Tutu and Daugolata, Pari, Kilakila/Mahuru, Korobosea and Vabukori. Two villages from each of the ethnically stratified Motu or Koita groups were randomly selected for sampling. These were Pari & Hanuabada (Motu), and Baruni & Kila Kila (Koita) villages. Both males and females within the age range 15 – 24 years were eligible to participate in this study. A standard questionnaire and interviews were administered to volunteers from the four villages. Pretested, semi-structured questionnaire comprising of closed and open ended questions was used. The three major languages, English, Pidgin and Motu were used in the questionnaire. Information request in the questionnaire included gender, age, occupation, education level, language(s) spoken, current knowledge of the respondent about HIV/AIDS including knowledge on preventive lifestyle skills and behavioural change in the NCD. It also included questions about the existence of HIV/AIDS related fear, discrimination due to a casual contact with

HIV/AIDS infected person. Qualitative questions included in the questionnaire were aimed at exposing fear and discrimination or perceived discrimination that could occur when close relatives and / or people of the immediate community and work place would know about the HIV/AIDS status of individuals. The assessment of negative attitudes of respondents towards persons with HIV/AIDS was used to measure stigma and discrimination. Questions related to what respondents knew about VCT services, and whether they would be willing to make use of the services were also included. The associations between levels of stigma, discrimination versus knowledge of VCT services and VCT utilization was examined through appropriate tabulations and chi square analysis. Before the study was carried out, its objectives were explained to the Chairman of Motu Koitabu, to Counsellors, elders and religious leaders of the selected villages. They in turn, explained the objectives and benefits of the research, to the residents, and sought their cooperation. From each of the four villages, two research assistants (a female and a male) were recruited and trained in order to acquire strong familiarity with the objectives of the study, the research questions and the methods. Selection of research assistants, who also served as interviewers, from the study villages, was aimed at facilitating community ownership of the project and its outcomes. The training emphasized the need to maintain

confidentiality, neutrality and high ethical conducts during and after the study period. Interviews were carried out in secluded areas to ensure confidentiality. The interviewers always introduced themselves and explained the objectives and benefits of the study to the consented respondents.

The sample size of 400 subjects of the Motu Koita population was estimated based on the year 2000 census and its extrapolation to the year 2009. The Motu-Koitabu ethnic groups' population of 30,000 people mainly in the suburban areas of Port Moresby constituted about 10% of the NCD population [15, 17]. Given a growth rate of about 3.6%, this population was estimated to have increased to about 44,300 in the year 2009. Simple random sampling was used to select four villages (2 Motu and 2 Koita) from stratified Motu and Koita groups of 5 and 4 villages respectively. Male and female residents in the age group 15 – 24 years were randomly selected from each of the four villages. Table 1 shows the population, number of households, estimated number of subjects extrapolated from the year 2000 census, the actual number of subjects in the four villages, the number of focus groups in each village.

Exclusion criteria included the following, all residents outside the 15-24year age group, non Motu-Koita immigrants to the villages, Motuan living in a Koitabuan village and Koitabuan living in a Motuan village.

During the interviews, four focus groups (FG 1-4) each comprising 7 - 9 respondents were carefully identified. The selection process was as follows: Every 12th female and every 12th male respondents in the various sections indicated in the questionnaire were recruited to form the four focus groups. The groups were separated by villages and gender as indicated in Table 2. Focus group meetings were convened in the School of Medicine and Health Sciences (SMHS), UPNG about two weeks after completion of the interviews. A separate questionnaire was designed and used for the focus group discussions. Questions were

posed; answers and related discussions were audio-recorded, while a rapporteur took notes. Ethical clearance and permission for this study were obtained from the SMHS, UPNG ethical committee, the PNG National AIDS Council (NACS), appropriate Motu-Koitabu authorities and each respondent.

Collected data were coded, collated, classified, matched with key research questions and analysed with the SPSS software.

Table 1: Population, number of households, estimated and actual number of subjects in the villages selected

Villages	Population	No of households	Estimated sample size of subjects	Actual sample size of subjects	Focus groups recruits
Baruni	1629	210	90	88	6
Kila Kila	327	46	20	31	12
Hanuabada	2628	233	150	100	12

Table 2: Distribution of respondents in the four focus group

Villages	Males	Females
Pari & Baruni	Focus Group 1 (9)	Focus Group 2 (9)
Hanuabada & Kila Kila	Focus Group 3 (7)	Focus Group 4 (7)

RESULTS AND DISCUSSION:

A total of 342 questionnaires were administered to respondents in the four study villages. Of these questionnaires 333 were properly completed while 9 questionnaires were deficient in many sections and hence excluded from the analysis. Thus the response rate was considered as 97.4%. The 333 respondents were made up of 166 (49.8%) males and 167 (51.2%) females. The basic characteristics of the respondents are presented in Table 3. Of the 333 respondents, a total of 15 (4.5%),

which include 6 (3.6%) females and 9 (5.4%) males did not have the minimum primary school education. Respondents with primary and secondary education were the majority tallying jointly to totals of 130 (39.0%) and 166 (49.9%) respectively. Only 18 (5.4%) of all the respondents had completed either college or university education. Unemployment was prevalent among 101 (30.3%) of all the respondents, which include 43 (25.9%) males and 58 (34.7%) females.

Table 3: Basic characteristics of respondents

Characteristics	Males		Females		Total	
	n	(%)	n	(%)	N	(%)
Education Status						
None	9	(5.4)	6	(3.6)	15	(4.5)
Primary	69	(41.6)	61	(36.5)	130	(39.0)
Secondary	77	(46.4)	89	(53.3)	166	(49.9)
College or University	10	(6.0)	8	(4.8)	18	(5.4)
Unanswered	1	(0.6)	3	(1.8)	4	(1.2)
Total	166	(100.0)	167	(100.0)	333	(100.0)
Occupation						
Student	52	(31.3)	59	(35.3)	111	(33.3)
Employed	39	(23.5)	28	(16.8)	67	(20.1)
Self employed	15	(9.0)	5	(3.0)	20	(6.0)
Unemployed	43	(25.9)	58	(34.7)	101	(30.3)
Unanswered	17	(10.2)	17	(10.2)	34	(10.2)
Total	166	(100.0)	167	(100.0)	333	(100.0)

(Figures in parenthesis are percentages)

Table 4:

Distribution of respondents according to responses to questions on stigma and discrimination

Questions	Males 166 (%)	Females 167 (%)	Total 333 (%)	p-value
<i>Self Stigmatization</i>				
YES	154 (92.2)	148 (89.2)	302 (90.7)	p > 0.05
NO	10 (6.0)	14 (8.4)	24 (7.2)	
Uncertain	3 (1.8)	4 (2.4)	7 (2.1)	
$X^2=0.93; df=2; p=0.629$				
<i>Perceived Stigmatization by others</i>				
YES	116 (69.9)	114 (68.3)	230 (69.1)	p > 0.05
NO	36 (21.7)	33 (19.8)	69 (20.7)	
Uncertain	14 (8.4)	20 (12.0)	34 (10.2)	
$X^2=1.20; df=2; p=0.5478$				
<i>Perceived Discrimination from others</i>				
YES	119 (71.7)	130 (77.8)	249 (74.8)	p > 0.05
NO	44 (26.5)	34 (20.4)	78 (23.4)	
Uncertain	3 (1.8)	3 (1.8)	6 (1.8)	
$X^2=77; df=2; p=0.4137$				
<i>Possibility of respondents Discriminating others</i>				
YES	128 (77.1)	135 (80.8)	263 (79.0)	p > 0.05
NO	31 (18.7)	25 (15.0)	56 (16.8)	
Uncertain	7 (4.2)	7 (4.2)	14 (4.2)	
$X^2=0.83; df=2; p= 0.4137$				

[Figures in parenthesis are percentages]

Table 5:

Distribution of respondents according to responses to questions on rejection, dismissal and self withdrawal

Questions	Males 166 (%)	Females 167 (%)	Total 333 (%)	p-value
<i>Rejection by family or Immediate relationship</i>				
YES	68 (41.0)	72 (43.1)	140 (42.0)	p > 0.05
NO	74 (44.6)	73 (43.7)	147 (44.2)	
Uncertain	24 (14.5)	22 (13.2)	46 (13.8)	
$X^2=0.21; df=2; p=0.9025$				
<i>Dismissal from work place</i>				
YES	120 (72.3)	108 (64.7)	228 (68.5)	p > 0.05
NO	19 (11.5)	24 (14.4)	43 (12.9)	
Uncertain	27 (16.3)	35 (21.0)	62 (18.6)	
$X^2=2.24; df=2; p=0.03259$				
<i>Self- withdrawal from duties</i>				
YES	78 (47.0)	65 (38.9)	143 (42.9)	p > 0.05
NO	85 (51.2)	97 (58.1)	182 (54.7)	
Uncertain	3 (1.8)	5 (3.0)	8 (2.4)	
$X^2=2.47; df=2; p=0.2908$				

[Figures in parenthesis are percentages]

The fundamental issues that surround people with HIV/AIDS are stigma, discrimination and fear. The results of the respondents' responses to questions on self stigmatization, perceived stigma, perceived discrimination from others and possibility of the respondents discriminating others is presented in Table 4. Of the 333 respondents interviewed, 302 (90.7%) gave responses that indicated self-stigmatization as a major barrier to VCT.

Prevalence of perceived stigmatization by others was also high (69.1%) as a limiting factor to VCT and related services. Perceived discrimination of others, and the possibility of the respondents discriminating others or people infected with HIV/AIDS were high with positive responses of 74.8% and 79.0% respectively. The data indicated that the levels of stigma and discrimination were very high and well above 2/3 (66.7%) of the respondents in this study.

The high number of youths with only primary education (39%) coupled with those without basic education (4.5%) could have contributed to the relatively high levels of stigma and discrimination obtained in this study.

Table 5 shows the results of the respondents' responses to questions on rejection by close family members, dismissal from work place and self withdrawal from duties following disclosure of HIV status. Of all the respondents 147 (44.2%) indicated that they will not be rejected by their love ones, but 140 (42.0%) believed they would be rejected by relatives and close family members, while 46 (13.8%) of them were either uncertain or did not respond to the question. There were no statistically significant ($p > 0.05$) differences in the responses of the male and female respondents to this question, suggesting that their views are similar. This study recommends a successful intervention program that should target and capture about 55.8 % of the 15-24 years age group constituting those who would be rejected by their love ones (42%) and the ones uncertain (13.8%) and subject them to a more rigorous awareness that should reverse the perceived rejection by close relatives and consequently promote VCT.

A total of 228 (68.5%) of all the respondents indicated that they would be dismissed from work place subsequent to positive HIV test results. This suggests that the fear of dismissal

from work place for those employed or schooling in institutions constitutes a great obstacle that would discourage individuals from going to the VCT. The data indicates that HIV infected people are most likely to be discriminated at the work place than in the families. This finding should be of concern to the NACS authorities, because the PNG-HIV/AIDS Management and Prevention Act (PNG- HAMP Act") prohibits requiring or coercing a person to be tested for HIV in relation to employment or contract work [18].

It is important that all HIV/AIDS awareness campaign should also stress the government's policy of non discrimination of individuals with HIV/AIDS in the workplace, which is an important human right issue [18]. For the question on self withdrawal from duties, 143 (42.9%) of all the respondents, constituting of 78 (47.0%) males and 65 (38.9%) females indicated that they would withdraw from duties because of HIV +ve test. However, a total of 182 (54.7%) respondents made up of 85 (51.2%) males and 97 (58.1%) females indicated that they will not withdraw from duties; they intend to show self encouragement to continue with their normal duties. People should be educated and be encouraged to use the appropriate laws and legislations in PNG to challenge the HIV/AIDS related discrimination, stigma and denial that still exist in the society.

Table 6: Distribution of respondents according to responses to Lack of support from Health providers after HIV +ve results, fear of HIV +ve test and suicide elements

Questions	Male (%)	Female (%)	Total (%)	p-value
<i>Lack of support after HIV + results</i>				
YES	110 (66.3)	113 (67.7)	223 (67.0)	p > 0.05
NO	50 (30.1)	51 (30.5)	101 (30.3)	
Uncertain	6 (3.6)	3 (1.8)	8 (2.4)	
$X^2=1.05; df=2; p=0.5924$				
<i>Fear of HIV + ve test</i>				
YES	100 (60.2)	105 (62.9)	205 (61.6)	p > 0.05
NO	54 (32.5)	58 (34.7)	112 (33.6)	
Uncertain	12 (7.2)	4 (2.4)	16 (4.8)	
$X^2=4.26; df=2; p=0.1187$				
<i>Suicide elements after HIV + test</i>				
YES	3 (1.8)	6 (3.6)	9 (2.7)	p > 0.05
NO	158 (95.2)	157 (94.0)	315 (94.6)	
Uncertain	5 (3.0)	4 (2.4)	9 (2.7)	
$X^2=1.11; df=2; p=0.5737$				
[Figures in parenthesis are percentages]				

In Table 6, the results of respondents' responses on the lack of support from health providers after HIV +ve results are presented. The majority of respondents, 223 (67.0%) with an almost an equal distribution by gender, 110 (66.3%) males and 113 (67.7%) females indicated that they will not get support from health providers following an HIV +ve test results. Support from health workers is crucial in ensuring acceptance and improvement in

HIV testing. Special training should be made available for health workers to prepare them to be more receptive to VCT clients and to equip them with the required counselling and professional skills. Chi square tests of our data indicated that there were no statistically significant ($p>0.05$) differences between the responses of the male and female respondents, thus eliminating gender bias in the fear of HIV/AIDS stigma.

Table: 7 Distribution of respondents according to response on Knowledge of VCT centers & willingness to utilize their services

	Male 166 (%)	Female 167 (%)	Total 333 (%)	p-value
<i>Knowledge of Places With VCT</i>				
YES	127 (76.5)	130 (77.8)	257 (77.2)	p > 0.05
NO	39 (23.5)	36 (21.6)	75 (22.5)	
Uncertain	0 (0.0)	1 (0.6)	1 (0.3)	
<i>Willingness to utilize VCT Services</i>				
YES	148 (89.2)	153 (91.6)	301 (90.4)	p > 0.05
NO	18 (10.8)	11 (6.6)	29 (8.7)	
Uncertain	0 (0.0)	3 (1.8)	3 (0.9)	

$X^2=1.15; df=2; p=0.5621$

$X^2=5.07; p=0.0794$

[Figures in parenthesis are percentages]

Elements of suicide after HIV +ve test were indicated by few respondents (2.7%), with the breakdown of 5 (3.0%) males and 4 (2.4%) females.

Table 7 shows the results of respondents' responses to knowledge about VCT centers, and their willingness to utilize services offered in the centers. A total of 257 (77.2%) respondents knew the locations of the VCTs. Only 8.7% of all the respondents were unwilling to utilize VCT services.

Summary of the views from the focus group:

People are careless and don't care about this sickness; we can reduce large numbers of infections just like malaria cases if we raise awareness among the communities in the remote areas.

VCT has to be somewhere so that not everyone can see it.

We must arrange time such as midnight when nobody can see those infected visiting VCT.

It is our responsibility to get the VCT test because we don't know whether we have the

virus or not; VCT test is a good thing. We must not disgrace infected people or gossip about them. We must encourage them.

Our pastor has not done much on HIV awareness and needs to talk to the youths about it.

Everybody must be involved in working together so as to raise awareness in the community.

When a family member wants to go to a VCT site the others should all go with him or her as to give confidence and support.

Visiting each house is the best form of awareness in the village.

Active involvement of community leaders, the religious leaders in the campaigns against HIV/AIDS stigma & discrimination is recommended.

CONCLUSION:

Data obtained in the present study show that HIV/AIDS – Stigma & discrimination prevails in the areas surveyed and the influencing factors and barriers were identified. Awareness should be carried out carefully targeting the specific barriers identified in this study, with the aim of eliminating them. Active involvement of community leaders and religious leaders in the campaigns against HIV/AIDS stigma & discrimination is recommended. People who may suffer discrimination or dismissal from institutions or work place due to HIV +ve status need to be reminded of their rights to legally challenge such discriminatory actions.

ACKNOWLEDGEMENT:

Thanks to Mr Isu Aluvula, NCD HIV/AIDS Response Coordinator and to Mary Vagi, Secretary to Chairman, Motu-Koita Assembly for facilitating linkage with elders, religious leaders and counsellors of the study areas; to Dr Ripa for assisting with statistical analysis.

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