

○ | **Quality of Life, Positive Prevention,
and Social Inclusion for People Living
with HIV and Aids Program**

Baseline Study Report

December 2008

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Baseline Study Report
Study on Quality of Life - WHOQOL-Abbreviated, World Health Organization

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EXECUTIVE SUMMARY

The objective of this study was to construct a baseline for monitoring the results of the Quality of Life, Positive Prevention, and Social Inclusion Program for People Living with HIV and AIDS. As part of the study, the Abbreviated version of the World Health Organization Quality of Life (WHOQOL-Bref) survey was applied with 121 PLHIV, including 39 men and 82 women who participated in the pilot projects implemented by the Civil Society Organizations (CSOs) linked to the Program in Salvador, Sao Paulo and the Federal District. The data was analyzed using SPSS 16.0 and in accordance with the instructions provided by the WHOQOL Group for the coding, verification, and cleaning. The sample included more women (67.8%) and a higher concentration of PLHIV between the ages of 30 and 49. Of all of the respondents, 36% self defined themselves as black, which was the same percentage of people who declared themselves to be brown. In combining the two categories, 73% of the people self defined themselves as what in Brazil would be considered as “black”. The majority of PLHIV interviewed reported being unemployed. In the self-evaluation of their quality of life, 42.1% of PLHIV defined it as “neither poor nor bad” and 30.6% as “good”, 3% of the PLHIV reported that their quality of life was “very poor”. Only 5% of the PLHIV interviewed are “very unsatisfied” with their

health, 37.5% defined themselves as “satisfied” and 22.5% “unsatisfied”. In terms of work, the majority reported being satisfied with their ability to work (29.8%) or very satisfied (28.1%). Through the results of the study, it is possible to define the profile of the people reached through the CSO activities and services: older age bracket; strong presence of blacks and women; high level of satisfaction with oneself; high level of satisfaction with ability to work coupled with a high percentage of people who are not employed.

Recommendations for activities and Program strategies based on the results include: (I) identify and implement strategies to expand access to Program activities for the younger population; (II) incorporate topics to attract the male population into the income generation and employability activities; (III) implement awareness raising activities with the private sector to address the question of the employability of PLHIV; (IV) conduct in-depth interviews and focus groups as part of the comparison study to explore the themes of quality of life, capacity and interest in working, and the influence of stigma and discrimination on PLHIV’s ability to procure and secure employment.

Key words: HIV/AIDS, Quality of Life, WHOQOL, Program monitoring

INTRODUCTION

In 2007, Pact Brasil, in partnership with the National STD/AIDS Program (NAP), the United States Agency for International Development (USAID) and the Centers for Disease Control (CDC) began the implementation of the *Quality of Life, Positive Prevention, and Social Inclusion for People Living with HIV and AIDS Program*. The main objective of the Program is to contribute to increasing the quality of life of PLHIV in situations of social vulnerability through the implementation of activities with CSOs. The specific objectives of the Program are:

- ✦ Strengthen health promotion and HIV transmission prevention activities that target PLHIV;
- ✦ Promote the social inclusion of PLHIV through professional development activities;
- ✦ Stimulate the social responsibility of businesses in relation to the cross-cutting themes of the Program (quality of life, income generation, employability, and combating stigma and discrimination of PLHIV).

In 2008, Pact Brasil announced a request for projects to identify CSO partners for the Program. Three projects were selected for support:

- ✦ The “Extension of Income Generation and Support workshops” implemented by the Movement for Support of AIDS Patients (MAPA) in Sao Paulo.
- ✦ “Emancipation and Adherence: Pathways to a Positive Life” from the Support and AIDS Prevention Group (GAPA) in Salvador.
- ✦ “Positive Inclusion” Implemented by the Brazilian Association for Combating AIDS (Grupo Arco Iris) in Brasilia.

All of the projects seek to increase the quality of life of PLHIV, conducting positive pre-

vention activities (including the themes of human rights, adherence and treatment, physical exercises and nutrition), professional development and income generation.

To monitor the results of the activities of this Program, a Monitoring and Evaluation Plan (M&E Plan) was developed and the following outcome indicators were identified:

- ✦ Level of satisfaction with one’s quality of life.
- ✦ Level of satisfaction with one’s health.
- ✦ Level of satisfaction with one’s current level of energy.
- ✦ Level of satisfaction with oneself.
- ✦ Level of satisfaction with one’s capacity for work.
- ✦ Level of satisfaction with the availability of information that one needs.

To measure these indicators, the Program chose the World Health Organization Quality of Life Survey Abbreviated Version (WHOQOL - Bref).

Developed in 1991, the WHOQOL was designed to evaluate the quality of life of PLHIV with an international perspective. Quality of life was defined as a “individual’s perceptions in the context of their culture and value systems, and their personal goals, standards and concerns” (WHOQOL Group 1994). To design and validate this instrument, the WHO organized a multi-center research study that included 15 countries in a rigorous process. The final result of the process was the WHOQOL-100, an auto-evaluation instrument with 100 questions that take 6 domains into account including physical health, psychological health, level of independence, social relationships, environment, and personal beliefs. The abbreviated version of this instrument to be used by Pact Brasil was developed in 1998 and contemplates the four domains of the physical, psychological, environmental

and social relationships. The Portuguese versions were validated and tested by the WHOQOL Center in Brazil located at the Psychiatric and Legal Medical Department at the Federal University of Brazil in Rio Grande do Sul between 1996 and 1997 with patients at the Clinical Hospital of Porto Alegre (Fleck et al 1999)

This report describes the main results of the implementation of the WHOQOL-Bref with the PLHIV who participate in the activities supported by the Program. The analysis of the data collected as part of the WHOQOL-Bref privileged the information relative to the six indicators described above.

METHODOLOGY

This cross-sectional study was implemented with 121 PLHIV, including 39 men and 82 women reached through the CSOs. The participants fit the following three criteria for inclusion: be 18 or older, be HIV positive and receive services from the CSO. The questionnaire was applied in the CSOs during a five-week period in September and October of 2008. During this time period, all people who fit the inclusion criteria were invited to collaborate with the study.

The instrument was applied according to the procedures validated by the WHOQOL Center in Brazil (Centro WHOQOL 2008). Before responding to the questionnaire participants signed an informed Consent Form (Attachment II) and a trained interviewer applied a short questionnaire with socio-demographic variables. The WHOQOL-Bref is self-applied and was

filled out in a private location reserved specifically for this purpose.

The WHOQOL-Bref was analyzed by an external consultant using SPSS 16.0. The consultant followed the instructions elaborated by the WHOQOL Group in Brazil regarding how to code, verify, clean, and input the final data from the questionnaires. A stratified analysis by city will also be conducted to evaluate differences between the participants in the three cities in terms of the Program indicators and their socio-demographic profiles.

The study protocol, data collection instruments and consent forms were analyzed and approved by the Ethics Review Board of the Municipal Health Department of Sao Paulo and the National Research Ethics Board (CONEP) before they were implemented (Attachment III).

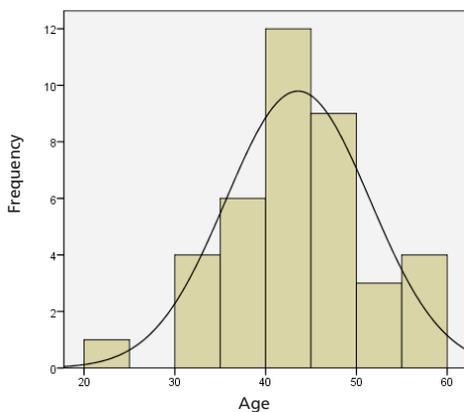
RESULTS

Socio-demographic Profile of Study Participants

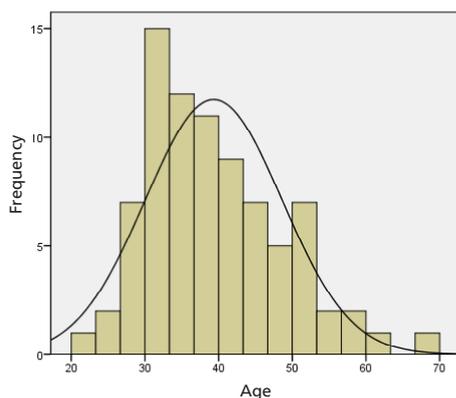
Of the total participants (N=121), 40.5% came from Sao Paulo, 31.4% from Brasilia and 28.1% from Salvador. The majority of the participants were female (67%).

The average age of the people who access the CSO activities is 40, with 39 being the average age for the women and 43 for the men. In terms of age, among men the majority is between 35 and 49 and for women, between 30 and 45. Among both men and women, the largest concentration of PLHIV fell within the 30-49 age range (Graphs I and II).

Graph 1: Age of the Masculine Participants



Graph 2: Age of Female Participants



Of the total respondents, 36% of people self-defined themselves as black¹, the same percentage of people who identified themselves as brown. Combining the two percentages, approximately 73% of the people self defined themselves as black, a percent much higher than the Brazilian population.

In terms of civil status, the majority is single (54.5%), representing twice the percentage of people who are married (24%).

¹ In Brazil, the socio-demographic questions regarding race followed the example of the Brazilian Statistical Institute (IBGE) which literally asks people what color they consider themselves. In Portuguese, there are three different words to refer to people with darker skin color—pardo, negro, and preto (more negative connotations), yet the IBGE only includes “preto” and “pardo” and considers that “negro” is equivalent to the sum of the two previous categories.

Consolidated Socio-demographic Characteristics		
	N =121	%
Sex		
Male	39	32,2
Female	82	67,8
Color		
Black	44	36,4
Brown	44	36,4
White	29	24,0
Yellow	2	1,7
Indigenous	2	1,7
Level of Education		
Illiterate	5	4,2
Semi-illiterate	4	3,3
Primary school incomplete	51	42,5
Primary school complete	19	15,8
High school incomplete	10	8,3
High school complete	22	18,3
College incomplete	4	3,3
College complete	4	3,3
Graduate school	1	0,8
Civil Status		
Married	29	24,0
Single	66	54,5
Separated	13	10,7
Widowed	9	7,4
Other	4	3,3
Employed		
Yes	29	24,2
No	91	75,8
Market		
Formal	10	34,5
Informal	19	65,5
Income		
Yes	95	78,5
No	26	21,5

In terms of level of education, the highest percentages are among those who did not complete primary school (42.5%) and completed high school (18.3%). PLHIV with the lowest levels of education (illiterate and semiliterate) summed up 7.5% of the total of the study participants.

In terms of inclusion in the labor market, we found that the majority of PLHIV are unemployed (75.8%). Considering only the total of people who reported having a job, 65.5% of them are in the informal labor market and only 34.5% are in the formal sector. Women tended to be employed in the informal market, as nearly 20% more men than women reported holding jobs in the formal labor market.

The majority of the participants reported having income (78.5%), which was an interesting finding considering that 75.8% of those interviewed reported being unemployed. It is likely that the income reported is related to the social benefits that many PLHIV receive in Brazil.

Socio-demographic Profile of Participants, by Location

The table to the right illustrates the socio-demographic profile of PLHIV who responded to the WHOQOL-Bref by city (Sao Paulo, Salvador, Brasilia) and disaggregated by sex, color/race, level of education and civil status.

It can be observed that in Brasilia, there is a more equal distribution between men (44.2%) and women (55.3%), different from what can be observed in Salvador (32.4% – men and 67.6% – women) and Sao Paulo (22.4% men – 77.6% women) where women’s participation is much higher.

In relation to color, the high number of people in Brasilia and Salvador who self defined themselves as “preto” (black in Portuguese, but with a negative connotation)

is surprising given the racism and ideology of whitening that exists in Brazil: 42.1% in Brasilia and 55.9% in Salvador. In Sao Paulo, only 18.4% of the study participants self defined themselves as “preto”, as the majority of PLHIV defined themselves as white (40.8%). Those who defined themselves as “brown” are the majority in Brasilia (42.1%) and Sao Paulo (40.8%) and the whites were the minority in Salvador (11.8%) and Brasilia (13.2%).

In terms of level of education, it was possible to see that the majority of PLHIV did not complete primary school: 35.1% in Brasilia, 29.4% in Salvador, and 57.1% in Sao Paulo. PLHIV who reported being illiterate or semiliterate are the minority in each location, as well as PLHIV who completed college and entered into graduate work.

Socio-demographic Profile, by City						
	Brasília		Salvador		São Paulo	
	n = 38	%	n= 34	%	n= 49	%
Sex						
Male	17	44,7	11	32,4	11	22,4
Female	21	55,3	23	77,6	38	77,6
Color						
Black	16	42,1	19	55,9	9	18,4
Brown	16	42,1	8	23,5	20	40,8
White	5	13,2	4	11,8	20	40,8
Yellow	0	0	2	5,9	0	0
Indigenous	1	2,6	1	2,9	0	0
Level of Education						
Illiterate	2	5,4	1	2,9	2	4,1
Semi-illiterate	0	0	0	0	4	8,2
Primary school incomplete	13	35,1	10	29,4	28	57,1
Primary school complete	5	13,5	7	20,6	7	14,3
High school incomplete	1	2,7	5	14,7	4	8,2
High school complete	11	29,7	9	26,5	2	4,1
College incomplete	3	8,1	1	2,9	0	0
College complete	1	2,7	1	0	2	0
Graduate school	1	2,7	0	0	0	0
Civil Status						
Married	12	31,6	5	14,7	12	24,5
Single	19	50,0	26	76,5	21	42,9
Separated	3	7,9	1	2,9	9	18,4
Widowed	2	5,3	2	5,9	5	10,2
Other	2	5,3	0	0	2	4,1

In terms of civil status, it can be observed that single PLHIV are the majority in each city is single: 50% in Brasilia, 76.5% in Salvador and 42.9% in Sao Paulo. PLHIV who reported being married were 31.6% in Brasilia, 14.2% in Salvador and 24.5% in Sao Paulo.

As illustrated in the table, the percentage of PLHIV was high in each location, with the highest percentage being reported in Salvador (85.3%). On the other hand, for those PLHIV who are employed, their participation in the informal market is more expressive in Sao Paulo (81.3%). In Brasilia, the percentage of people employed in the informal or formal market was split equally. Sao Paulo had the highest percentage of PLHIV employed (32.7%) and in Salvador, the highest percentage of PLHIV was in the formal market (60%).

The majority of PLHIV reported having some form of income: 83.7% in Sao Paulo, 83.7% in Salvador and 64.7% in Brasilia. Salvador has the highest number of people without income (35.3%). The

most commonly reported age bracket in the three locations was R\$201-\$415 (approx. US\$100-\$200). The high percentage of PLHIV in the lowest bracket (R\$10-\$200) in Sao Paulo is interesting considering that Sao Paulo is the economic center of Brazil.

Employment Data by Location						
	Brasilia		Salvador		São Paulo	
	n	%	n	%	n	%
Employed						
Yes	8	21,6%	5	14,7%	16	32,7%
No	29	78,4%	29	85,3%	33	67,3%
Total	37	100,0%	34	100,0%	49	100,0%
Market						
Formal	4	50,0%	3	60,0%	3	18,7%
Informal	4	50,0%	2	40,0%	13	81,3%
Total	8	100,0%	5	100,0%	16	100,0%
Income						
Yes	32	84,2%	22	64,7%	41	83,7%
No	6	15,8%	12	35,3%	8	16,3%
Total	38	100,0%	34	100,0%	49	100,0%
Income Bracket						
R\$10-\$200	3	9,4%	4	18,2%	13	31,7%
R\$201-\$415	17	53,1%	14	63,6%	16	39,0%
R\$416-\$830	8	25,0%	3	13,6%	9	22,0%
R\$831+	4	12,5%	1	4,5%	3	7,3%
Total	32	100,0%	22	100,0%	41	100,0%

Indicators of the WHOQOL-Bref Regarding Quality of Life of PLHIV

Level of Satisfaction - Quality of Life

In the self-evaluation of quality of life, 42.1% of PLHIV chose “neither poor nor good” and 30.6% “good”. Only 3.3% of PLHIV identified their quality of life as “very poor”. An analysis per location had a similar tendency: the large part of PLHIV in Sao Paulo and Salvador identified their quality of life as “neither poor nor good” (50% and 49%, respectively); the people from Brasilia identified their quality of life as “good” (42.1%); and in the three locations the percentage ob-

tained for the category “very poor” was very low (2.6% in Brasilia, 2.9% in Salvador and 4% in Sao Paulo).

WHOQOL-Bref - Quality of life								
	Consolidated		Brasilia		Salvador		São Paulo	
	N	%	N	%	N	%	N	%
How would you rate your quality of life?								
Very poor	4	3,3%	1	2,6%	1	2,9%	2	4,1%
Poor	15	12,4%	4	10,5%	6	17,6%	5	10,2%
Neither poor nor good	51	42,1%	10	26,3%	17	50,0%	24	49,0%
Good	37	30,6%	16	42,1%	8	23,5%	13	26,5%
Very good	14	11,6%	7	18,4%	2	5,9%	5	10,2%

Level of Satisfaction with Health

Only 5% of PLHIV are “very unsatisfied” with their health, 37.5% are satisfied and 22.5% “unsatisfied,” as shown in the table to the right. PLHIV “neither satisfied or unsatisfied” with their health represent 21% of the total study participants. In the three cities, there is a higher percentage of people satisfied with their health: 38.8% in Sao Paulo, 43.2% in Brasilia and 29.4% in Salvador.

In the short questionnaire completed prior to the WHOQOL-Bref, participants included more information about their health: 36.4% of the participants consider their health good, 16.5% very good and only 3% consider it very poor. The highest percentages in each location are connected to the category of “good” (Sao Paulo 34.7%, Brasilia 41.7% and Salvador 35.3%), being that in Brasilia no one considered their health to be “very poor”, different from the register of Salvador (2.9%) and Sao Paulo (6.1%). The participants that considered their health nor poor nor good were 30.6% in Sao Paulo, 29.4% in Salvador and 25% in Brasilia, with important percentages for each one of the locations related to the participants who considered their health to be very good: 22.2% in Brasilia, 16.3% in Sao Paulo and 11.1% in Salvador.

Another interesting finding was the large percentage, 90.1%, who said that they were in treatment.

In Brasilia, 94.6% of the participants said that they were in treatment, in Salvador, it was 91.2% and in Sao Paulo, 87.8%.

WHOQOL-Bref – Satisfaction with Health								
	Consolidated		Brasilia		Salvador		São Paulo	
	N	%	N	%	N	%	N	%
How satisfied are you with your health?								
Very insatisfied	6	5,0%	1	2,7%	1	2,9%	4	8,2%
Insatisfied	27	22,5%	6	16,2%	9	26,5%	12	24,5%
Neither satisfied or unsatisfied	26	21,7%	7	18,9%	9	26,5%	10	20,4%
Satisfied	45	37,5%	16	43,2%	10	29,4%	19	38,8%
Very satisfied	16	13,3%	7	18,9%	5	14,7%	4	8,2%

Of the total sample, 49.1% said that they suffered from side effects from treatment representing 50% of the PLHIV in each location. The most commonly cited side effects were diarrhea, nausea, lipodistropia, mood changes, and muscle pains.

In addition, 44.2% of the participants reported a past hospital visit related to their serological status. The PLHIV in Salvador indicated a higher percentage of hospitalizations (58.8%) in comparison to Sao Paulo (34.7%) and Brasilia (43.3%).

WHOQOL-Bref - Self-Reported Health Data		
	N = 121	%
How would you consider your health?		
Very poor	4	3,3
Poor	17	14,0
Neither poor nor good	34	28,1
Good	44	36,4
Very good	20	16,5
Are you currently in treatment?		
Yes	109	90,8
No	11	9,2
Do you suffer from any side effects of the medication?		
Yes	52	49,1
No	54	50,9
Have you ever been hospitalized due to HIV?		
Yes	53	44,2
No	67	55,8

Level of Satisfaction with your Current Level of Energy

Only 0.8% of the participants are linked to the category of “not having enough energy for everyday life”, the others were

in the “moderately” (33,9%), “mostly” (28,9%), “completely” (21,5%). By location, it is important to point out the data

for the categories “a little” (20.4%) and “moderately” (38.8%) for Sao Paulo.

On the other hand, in both Brasilia and Salvador had high percentages for the categories “mostly” (36.8% in Brasilia) and “completely” (29.5% in Salvador).

WHOQOL-Bref - Sufficient Energy for Everyday Life								
	Consolidated		Brasilia		Salvador		São Paulo	
	N	%	N	%	N	%	N	%
Do you have enough energy for everyday life?								
Not at all	1	0,8%	0	0	1	2,9%	0	0
A little	18	14,9%	3	7,9%	5	14,7%	10	20,4%
Moderately	41	33,9%	12	31,6%	10	29,4%	19	38,8%
Mostly	35	28,9%	14	36,8%	8	23,5%	13	26,5%
Completely	26	21,5%	9	23,7%	10	29,4%	7	14,3%

Level of Satisfaction with Yourself

From the sum of the percentages for “satisfied” (38.0%) and “very satisfied” (29.8%), it is possible to identify the high percentage of participants who reported feeling satisfied with themselves. Few people reported not being satisfied with themselves: 4.1% said they were “very unsatisfied” and 9.1% said they were “unsatisfied.” Nineteen percent of the participants reported being “neither satisfied nor unsatisfied”. After analyzing this variable according to location, it is possible to see that the largest percentage of PLHIV who reported being satisfied with themselves is in Brasilia (44.7%), followed by Sao Paulo (36.7%) and Sal-

vador (32.4%). No one in Sao Paulo reported being “very satisfied” with themselves, as opposed to 5.9% of those in Salvador and 7.9% of those in Brasilia.

WHOQOL-Bref - Satisfaction with Yourself								
	Consolidated		Brasilia		Salvador		São Paulo	
	N	%	N	%	N	%	N	%
How satisfied are you with yourself?								
Very unsatisfied	5	4,1%	3	7,9%	2	5,9%	0	0
Unsatisfied	11	9,1%	3	7,9%	2	5,9%	6	12,2%
Neither satisfied nor unsatisfied	23	19,0%	4	10,5%	8	23,5%	11	22,4%
Satisfied	46	38,0%	17	44,7%	11	32,4%	18	36,7%
Very satisfied	36	29,8%	11	28,9%	11	32,4%	14	28,6%

Level of Satisfaction with your Capacity for Work

The majority of PLHIV refer to being “satisfied” (29.8%) with their capacity for work or “very satisfied” (28.1%). The quantity of PLHIV that self-defined themselves as “unsatisfied” was not small: 20% of those interviewed put themselves in this category. No one in Sao Paulo reported being “very unsatisfied” with their capacity for work, as compared to 2.6% of the people in Brasilia and 8.8% of those in Salvador. The most commonly reported response for Sao Paulo was “unsatisfied” (32.7%) as compared to Salva-

dor where the majority reported being “very satisfied” (41.2%).

WHOQOL-Bref - Satisfaction with Capacity for Work								
	Consolidated		Brasilia		Salvador		São Paulo	
	N	%	N	%	N	%	N	%
How satisfied are you with your capacity for work?								
Very unsatisfied	4	3,3%	1	2,6%	3	8,8%	0	0
Unsatisfied	25	20,7%	4	10,5%	5	14,7%	16	32,7%
Neither satisfied nor unsatisfied	22	18,2%	5	13,2%	6	17,6%	11	22,4%
Satisfied	36	29,8%	18	47,4%	6	17,6%	12	24,5%
Very Satisfied	34	28,1%	10	26,3%	14	41,2%	10	20,4%

In the analysis presented in the table below, it is interesting to note that most people who are not working are “satisfied” (30.8%) or “very satisfied” (26.4%) with their ca-

capacity for work. The table also illustrates that 57.2% of the people who are “satisfied” with their capacity for work are not currently employed.

WHOQOL - Bref - Capacity for work and employment												
Are you currently working?	How satisfied are you with your capacity for work?											
	Very unsatisfied		Unsatisfied		Neither satisfied nor unsatisfied		Satisfied		Very Satisfied		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
Yes	1	3,4%	5	17,2%	6	20,7%	8	27,6%	9	31,0%	29	100,00
No	3	3,3%	20	22%	16	17,6%	28	30,8%	24	26,4%	91	100,00

Level of Satisfaction with your Availability of Information in Day-to-Day Life

In the consolidated responses, there is a fairly equal distribution among the categories in terms of the level of satisfaction with the availability of information that participants needed in their day to day: the categories of “not at all” and “mostly” were each 25.0%; 23.3% for “moderately” and 22.5% for “completely satisfied”. Sao Paulo was the only city where people referred to not having access to the information that they needed (10.2%).

WHOQOL-Bref - Availability of Information in Day-to-Day Life								
	Consolidated		Brasilia		Salvador		São Paulo	
	N	%	N	%	N	%	N	%
How available to you is the information that you need in your day-to-day life?								
Not at all	5	4,2	0	0	0	0	5	10,2%
A little	30	25,0	5	13,5%	15	44,1%	10	20,4%
Moderately	28	23,3	9	24,3%	7	20,6%	12	24,5%
Mostly	30	25,0	14	37,8%	6	17,6%	10	20,4%
Completely	27	22,5	9	24,3%	6	17,6%	12	24,5%

DISCUSSION AND RECOMMENDATIONS

The objective of this study was to define a baseline for monitoring the results of the Quality of Life, Positive Prevention, and Social Inclusion Program for People Living with HIV and AIDS. The study sought to describe the socio-demographic profile of the people currently reached through the pilot projects and define the baseline indicators for the project.

Considering this premise, the discussion here will focus on the data and indicators that are directly relevant to the implementation of the pilot projects. In the comparative study (in July 2009), we will provide a more complete discussion, considering other contextual factors related to the quality of life of PLHIV in Brazil.

The study results describe the socio-demographic profile of the people who currently access the services and activities of the CSOs supported in the Program, which contributes to a greater understanding of the public that will be benefited through the project activities. The men and women living with HIV and AIDS who participated in the study represent a highly vulnerable population segment, due to their socio-demographic profile: they are predominantly female, black, with few years of formal education and over forty. All of these are qualities, combined with their serological status, make their inclusion in the formal labor market more difficult, made even more difficult.

The application of the WHOQOL-Bref also provided a better understanding of how the PLHIV accessed through the CSO services perceive their quality of life, thereby permitting an important reflection on the strategies planned for the Program and how they could be improved. As such, here we have identified five findings that are directly relevant to the Program objectives: 1) the older age of the participants; 2) the high percentage of women and blacks; 3) the high level of satisfaction with oneself; 4) high level of satisfaction with one's ability to work; and 5) high number of people who are not working but are satisfied with their capacity for work.

It is important to observe that the findings refer only to those people who are reached through the CSO services. The population participating in the pilot-projects sought out the CSOs because they were interested in improving their possibilities for employment, access to information, and/or health. It is important to interpret the data in light of this fact, understanding that the level of satisfaction with health, employment capacity, and level of energy are likely higher in this particular group than they would be for PLHIV who do not access services at CSOs.

The average age of the participants was around 40, with very few participants reporting being younger than 30. Considering the transformations in the AIDS epidemic in Brazil during this decade which included an increase in HIV infections among adolescents and young people, the first recommendation of this study is to implement strategies to expand the activities of the CSOs to young people who live with or are affected by HIV and AIDS in the three locations.

The high percentage of women participating in the study may be related to the type of activities promoted by the CSOs prior to Program implementation, which tended to focus on income generation activities such as sewing and crafts. As such, our second rec-

ommendation is that the pilot projects incorporate income generation activities more specific for the masculine population. The income generation activities traditionally directed towards the female population should also be revised to try and identify other areas that may better facilitate their insertion into the formal labor market.

Considering the physical activities planned as part of the Program, it is important to note that the majority of study participants reported having enough energy for their day-to-day activities, which would seem to indicate that there is space to incorporate physical activities into their daily routines.

There are limitations to the way in which the WHOQOL-Bref measures the capacity to work, as the definition of "capacity to work" could refer both to the question of feeling professionally qualified to work and/or physically able to work. The third recommendation of this study is that the CSOs look more into this issue through focus groups with the people currently accessing their services to make appropriate adjustments to their strategies.

Taken together, the high level of satisfaction with oneself along with the high level of satisfaction with their capacity for work suggest that the study participants feel that they are well positioned for the labor market.

The fact the majority is not working but is satisfied with the capacity of work indicates that not working may not be directly related to a perception of being unqualified for the labor market. This finding is important for the Program as it indicates that the activities focused on increasing possibilities for employment should not be focused exclusively on professional training, but rather also confront issues such as the stigma and discrimination faced by PLHIV in the job market. Awareness raising strategies with private sector partners is key to address the question of employment both from the perspective of the employer as the employee.

The role of the social security benefits provided to PLHIV by the government in terms of their decision to work or no is another important question that should be examined further in the comparative study. In addition, the relationship between the socio-demographic variables and the Program indicators should also be further analyzed as the initial descriptive data seems to indi-

cate a population that is highly vulnerable to unemployment and social exclusion. In the comparative study, qualitative methods, such as in-depth interviews and focus groups, will also be incorporated to explore the concept of quality of life, capacity and interest in work, and the influence of stigma and discrimination on one's decision both to procure and secure employment.

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ATTACHMENT I WHOQOL Questionnaire - Abbreviated

This assessment asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. For example, thinking about the last two weeks, a question might ask:

	Not at all	Not much	Moderately	A great deal	Completely
Do you get the kind of support from others that you need?	1	2	3	4	5

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

	Very poor	Poor	Neither poor nor good	Good	Very good
1 How would you rate your quality of life?	1	2	3	4	5

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last two weeks. The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

	Not at all	A little	A moderate amount	Very much	Extremely
3 To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4 How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5 How much do you enjoy life?	1	2	3	4	5
6 To what extent do you feel your life to be meaningful?	1	2	3	4	5
7 How well are you able to concentrate?	1	2	3	4	5
8 How safe do you feel in your daily life?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	Have you enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

How long did it take to fill this form out? _____

Do you have any comments about the assessment?

THANK YOU FOR YOUR HELP

ATTACHMENT II CONSENT FORM

Voluntary and Informed Consent Agreement

We are conducting a study about how people view their quality of life. As part of this, we would like to count on your collaboration to respond to this questionnaire. There are several different questions about different aspects of your life: physical health, emotional life, your relationships with family and friends, and your living environment. The objective of this study monitor the results of the Quality of Life, Positive Prevention, and Social Inclusion Program for People Living with HIV and AIDS implemented in Sao Paulo, Brasilia, and Salvador.

Participation in this study is voluntary and your refusal will not adversely affect you, or cause you any harm. Nevertheless, some personal questions may be a little uncomfortable. You may interrupt your participation at any time during the study, even after the interview has been concluded.

This study is confidential and you will not be identified at any time. Neither your name nor those of the people you mention in the interview will be released in the results of the study, thus ensuring your privacy and that of the people you may mention. All material related to you will be kept in locked cabinets at the Pact Brasil office.

The information you provide will be used only for purposes of the study. You are free to access the results of the study. You will be reimbursed for any transportation and food costs, provided that you have incurred in such expenses due to the study. You will receive no compensation for participating in this study.

Please do not hesitate to contact Laura Murray at the number 21 -3553-0511 to clarify any questions you may have with respect to this study. If you have any other questions related to the study, also feel free to contact the Sao Paulo Municipal Health Department Ethics Review Committee at 11 3214 4043.

Voluntarily and duly informed, I hereby agree to participate in the above-mentioned evaluation.

Data: ____/ ____/ 200_

Name of the participant in the study: _____

Signature: _____

Interviewer: _____

Contact: _____

ATTACHMENT III APPROVAL FROM THE BRAZILIAN NATIONAL RESEARCH ETHICS COMMISSION



MINISTÉRIO DA SAÚDE
Conselho Nacional de Saúde
Comissão Nacional de Ética em Pesquisa
Esplanada dos Ministérios, Bloco "G" – Ed. Anexo, Ala "B"
– 1º andar – sala 145 – CEP 70058-900- Brasília / DF
Tel. : (61) 3315-2951 / Fax : (61) 3226-6453
conep@saude.gov.br – <http://conselho.saude.gov.br>

OFÍCIO Nº. 1958 CONEP/ CNS/ MS

Brasília, 15 de agosto de 2008.

A Senhora
Iara Coelho Z. Guerriero
Coordenadora do Comitê de Ética em Pesquisa
Secretaria Municipal da Saúde de São Paulo
Rua General Jardim, 36 2º andar
Vila Buarque São Paulo SP
CEP: 01.223-010

Assunto: "Encaminhamento de Parecer ao CEP"

Senhora Coordenadora,

Encaminhamos em anexo, o (s) Parecer (es) nº. 504/2008, já enviado(s) por fax, referente ao Protocolo de Pesquisa Registro CONEP nº 14.883, da Comissão Nacional de Ética em Pesquisa – CONEP, referente(s) a(os) projeto(s) de pesquisa acompanhado(s) por esse Comitê.

Atenciosamente,

Aparecida de **Fátima Pianta F. Lino**
Secretária-Executiva

Comissão Nacional de Ética em Pesquisa - CONEP/CNS/MS

CEP/MS
ENTRADA
026/08/08
Quarantena

Cont. Parecer CONEP 504/2008

Todo o desenho, execução, acompanhamento e análise de dados oriundos deste estudo será de responsabilidade da Pact Brasil, no entanto, o estudo contará com colaboradores estrangeiros (pesquisadores e instituição que financiará a pesquisa).

Apresentação do Protocolo

A Folha de Rosto está preenchida corretamente.

A equipe de pesquisa demonstra experiência na área da pesquisa proposta (cópias dos currículos foram apresentadas para análise).

O orçamento financeiro foi apresentado de forma adequada (total R\$18.180,00), esclarecendo que será financiado pela USAID.

O cronograma foi apresentado e as atividades envolvendo sujeitos de pesquisa iniciarão somente após aprovação ética do projeto pelo sistema CEP/CONEP.

Os dados coletados serão adequadamente tratados, e há garantia de sigilo, privacidade e confidencialidade dos mesmos.

Estão anexados ao protocolo documentos indispensáveis para análise ética, inclusive o questionário de avaliação de qualidade de vida.

O Termo de Consentimento Livre e Esclarecido (TCLE) é completo, foi redigido de forma clara, é conciso e apresenta linguagem adequada.

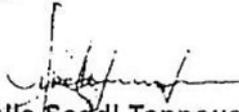
O projeto foi muito bem analisado pelo CEP da Prefeitura Municipal de São Paulo, com um parecer claro, detalhado e completo que aprova sem restrições.

Trata-se de um estudo relevante, bem estruturado, com objetivos claros e factíveis, com metodologia adequada. Poderá trazer contribuição importante sobre o impacto das ações de atenção à saúde relacionadas à infecção pelo HIV/AIDS e poderá ajudar no direcionamento de ações futuras nesta área.

Diante do exposto, a Comissão Nacional de Ética em Pesquisa – CONEP, de acordo com as atribuições definidas na Res. CNS 196/96, manifesta-se pela aprovação do projeto de pesquisa proposto.

Situação: Protocolo aprovado.

Brasília, 11 de Agosto de 2008.


Gyselle Saddi Tannous
Coordenadora da CONEP/CNS/MS

