Use of self-help groups by people living with HIV in Central America

Uso de grupos de autoayuda por personas que viven con el VIH en América Central

Uso de grupos de autoajuda por pessoas vivendo com HIV na América Central

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Abstract

Self-help groups (SHGs) for people living with HIV (PLHIV) are organizations created by the community to provide individuals with security, affection, improved self-esteem, and a sense of belonging. However, SHGs have also been used by the government to help implement HIV control policies. This study aimed to identify the characteristics associated with the use of SHGs by PLHIV and the routes and displacement patterns adopted by users. An analytical cross-sectional study was conducted based on data collected in six Central American countries during 2012. Using a list of SHGs, a random sampling was conducted in two stages. Firstly, the SHGs were selected. Then, the selected SHGs were visited and every third user who attended the SHG was surveyed. Logistic regression models were used to identify the characteristics associated with the use of SHGs and with attending the nearest SHGs. A spatial analysis was performed to identify the routes followed by users to reach the SHGs from their home communities. We found that the characteristics significantly associated with higher odds of SHG usage were country of residence and schooling level. The average and median distances traveled by users to attend SHGs were 20 and 5 kilometers, respectively. PLHIV do not use the SHGs closest to their locality, perhaps for fear of stigma and discrimination. We recommend that research on this topic use a mixed qualitative-quantitative methodology to better understand utilization decisions, user expectations, and the degree to which these are being met.

HIV; Self-Help Groups; Geographic Information Systems

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Introduction

Self-help groups (SHGs) hosted by health services are a form of association [1] in which individuals strengthen their self-help capacity while encouraging others to do the same. SHG participants gather around a common interest, such as sharing experiences on what it is like to live with a disease such as HIV.

SHGs are established by the community to provide individuals with association, safety, affection, improved self-esteem, and a sense of belonging [2]. They are a space where participants exchange information, knowledge, and experiences. Moreover, health services use these groups as instruments for psychological support [3].

In Central America, civil society organizations (CSOs) have adopted a strategy based on secondary prevention to improve the quality of life of people living with HIV (PLHIV), including collaborating directly with SHGs formed by PLHIV and health professionals. In these environments, PLHIV are assisted by services free from stigma and discrimination, such as consultations, medical follow-up, antiretroviral therapy (ART), and counseling in behavioral changes for safer sex practices and secondary prevention measures such as ART adherence.

According to reports, interventions offered as part of SHGs, such as psychological support [4], counseling, and medical services contribute to therapeutic adherence and lower high-risk behavior [5]. This, in turn, can improve the quality of life of PLHIV [6] and lower rates of HIV transmission [7,8].

Systematic reviews have reported on the causes and factors associated with the use of health services [8,9,10]. Findings indicate that use is related to individual characteristics such as sex, gender, age, family structure, social class, schooling level, ethnicity, social support, the geographical distance of health facilities from the place of residence, specific health needs, and the characteristics of the health care provided.

The information available on PLHIV who participate in SHGs is incipient and mainly based on research in Africa. According to studies, PLHIV who use SHGs are motivated mainly by: obtaining information on how to live with HIV; exchanging knowledge with other individuals living with HIV; belonging to a social support network [11,12]; becoming more empowered; receiving information on job opportunities; and actively participating in education programs on HIV prevention [4,11].

Evidence shows that PLHIV who use SHGs are mostly women [13] of reproductive age – mostly between 30 and 40 years [9] – who are unemployed [9,13], have a low schooling level [11,14], and were referred to the groups by health personnel [4,13,15].

Moreover, barriers to SHG usage include: unawareness of the existence and function of the groups; lack of time to attend; failure to perceive benefits; insufficient resources (money and transportation); fear of stigmatization and discrimination; and language restrictions. Women who wish to participate in SHGs often need authorization from their husbands or partners to attend [11].

Studies on the HIV epidemic show that geographic distance [16,17,18] should be considered to help explain the use of SHGs and other services offered to PLHIV. Considering health service availability, PLHIV were expected to seek the services nearest to them [8]. However, studies in North America have reported that PLHIV will travel longer distances for specialized medical services, better equipment, ensured availability of pharmaceutical supplies, and serostatus anonymity [17,19,20,21].

Despite the positive impact of SHGs on the secondary prevention of HIV, not all PLHIV use them. This study thus sought to identify the characteristics associated with the use of SHGs by PLHIV and the routes and displacement patterns adopted by users. Our analysis was based on the characteristics reported by studies on the use of health services and SHGs. A geospatial analysis was also performed to identify the geographic location of SHGs and the characteristics of their use.

Methods

An analytical cross-sectional study was conducted to identify the characteristics associated with the use of SHGs by PLHIV. Data were collected in six Central American countries (El Salvador, Belize, Costa Rica, Guatemala, Honduras, and Panama) under the project *Developing and Strengthening the Technical and Professional Capacities of PLHA for Effectively Impacting HIV-AIDS, Quality of Life, and*

Poverty Reduction [22]. Our study aimed to describe the risk profile of people with HIV who attend self-help groups and identify characteristics associated with the adoption of preventive measures (report of condom use in last sexual intercourse) and therapeutic adherence to antiretroviral treatment in people with HIV in Central America.

A survey was applied to PLHIV from June to October of 2012. The questionnaire was designed based on the *Behavioral Surveillance Surveys: Guidelines for Repeated Behavioral Surveys in Populations at Risk for HIV* [23], seeking to explore the sociodemographic characteristics, prevalence of condom use, ART adherence, sexual practices, predominance of HIV-related stigma and discrimination, and AIDS-related morbidity in this population. Our analysis focused on the sociodemographic characteristics associated with the use (or not) of SHGs by PLHIV.

The sampling frame was based on a sample drawn from a list of SHGs provided by the Ministries of Health in the participating countries. The groups on the list were subjected to a two-stage random sampling process. In the first stage, the listed SHGs were pre-selected using simple random sampling. In the second, the selected SHGs were visited and every third user who attended the SHG was surveyed. Data collection in each country lasted 66 days on average; that is, until reaching the required size. The sample size was estimated considering the proportion of people diagnosed with HIV who had used a condom during their last sexual encounter, which was assumed to range from 40 to 70% regardless of country. The sampling strategy resulted in a design effect (DEFF) of 1.74. For the aim of our work, the population of SHG users was defined as PLHIV who had been surveyed at SHGs. Moreover, based on the records of local health services and references from PLHIV who used SHGs, non-SHGs users were identified and contacted by the research team, who explained the purpose of the study and obtained permission to visit their home – where pollsters later applied the questionnaires.

The final sample size for the six countries analyzed totaled 4,190 PLHIV: 3,024 users of 88 SHGs and 1,166 non-users. All participants were informed regarding the survey and its purpose. Oral consent was obtained from each participant before engagement in the study. Participation was optional, did not risk the health of interviewees, and was not conditioned on SHG support or delivery of SHG services. To process the information, a folio number was used as the unique identifier so all participants remained anonymous. The Research Ethics Committee of the Center for Research and Health Studies, Nicaraguan National Autonomous University (CIES-UNAN) approved the protocol of the original study.

Considering that income was reported using whole numbers and 29% of interviewees reported a monthly income of zero dollars, a zero-inflated Poisson regression model was used to estimate the missing values. Our model considered sex, age, schooling level, type of employment, and country of residence. Pearson's correlation between the reported and estimated values equaled 0.65.

Based on available information and evidence on the characteristics of the use of health services and SHGs, a multivariate logistic regression model adjusted for sample weights was used to identify the variables associated with the use of SHGs. The dependent variable, use of SHGs, was obtained from the groups of SHG users and non-users.

The independent variables analyzed were: country of residence (El Salvador, Belize, Costa Rica, Guatemala, Honduras, and Panama); age (18-24, 25-44, 45-59 and ≥ 60 years); schooling level (no schooling, literate, six years of schooling, 12 years of schooling, and ≥ 16 years of schooling); sex (male and female); sexual orientation (heterosexual, bisexual, and homosexual); currently in a stable relationship (yes or no); average monthly income in American dollars – USD (grouped into quintiles); receives family support to cope with HIV disease (yes or no); has economic dependents (yes or no); has been diagnosed with tuberculosis (yes or no); has received counseling since HIV diagnosis (yes or no); and has engaged in illicit drug use (yes or no).

Future Time Perspective (FTP) was considered in the model and measured with the instrument *Consideration of Future Consequences* proposed by Strathman et al. [24] and validated in 2003 by Petrocelli [25]. Since FTP is regarded as a protective factor that promotes resilience, individuals with high FTP scores were expected to be more likely to use SHGs.

In total, 578 places of residence and 89 SHGs from our sample of PLHIV were geolocated, resulting in 864 estimated Euclidean distances [26] between the places of residence of PLHIV and SHGs. The distance values (in kilometers) were included in our model to identify their association with SHG usage. Non-users were assigned the distances of the SHGs closest to their places of residence. Dis-

tances were included in the model in squared function to identify a possible non-linear association. To verify the model fit, the goodness-of-fit test for logistic regression models was used, adjusted with data from the Hosmer-Lemeshow survey sample [27].

Considering that other studies have indicated that PLHIV will travel long distances to preserve their anonymity or to receive specialized health services, a second model was developed in this study to analyze the likelihood of PLHIV using the SHGs closest to their places of residence. Only information provided by SHG users (n = 3,024) was used.

A dichotomous variable was created using Euclidean distances for people who: (1) used the nearest SHG and (2) used a more distant SHG (with users traveling further). This variable was employed as a dependent variable in a logistic regression model that considered variables similar to those in the SHG model.

The variable "has been discriminated against at a healthcare facility (yes or no)" was also included since evidence shows that discrimination hinders the use of secondary prevention services [4,28]. This variable could then help identify potential reasons for using more distant SHGs. The type of SHG used was also considered, including: (1) installed in a CSO facility, (2) installed in a primary care facility, (3) installed in a secondary care facility, and (4) installed in a tertiary care facility. This variable could allow us to identify PLHIV's preferences for attending SHGs located in facilities associated with CSOs rather than healthcare facilities of different levels. To verify model fit, the goodness-of-fit test for logistic regression models was used, adjusted with data from the Hosmer-Lemeshow survey sample [27].

The estimated Euclidean distances were used to conduct a spatial analysis to identify the routes followed by PLHIV from their places of residence to the SHGs. The geolocation of places of residence and SHGs was obtained using Google Earth Pro 7.1.1 (https://www.google.com/earth) whereas distances were estimated using QGis 2.18 (https://qgis.org/en/site/). Statistical modeling was performed using the Stata 13.0 (https://www.stata.com) package and route projections using RStudio 1.0.143 (https://www.rstudio.com/).

Results

Our study population included 4,190 PLHIV, of whom 3,024 (72%) used SHGs and 1,166 (28%) did not. The population was composed of 55% men and 45% women, with an average age of 38 years. Schooling level ranged from 6 to 12 years, with 38% of men and 39% of women having attended school; the average monthly income was USD 198 (Table 1).

Eight out of ten PLHIV stated that they had neither been sick nor had an infection in the last three months, and nine out of ten denied having been discriminated against by health services because of their HIV diagnosis. Three out of four could count on family support in case of hospitalization and 88% were receiving ART at the time of the survey.

The characteristics significantly associated with the use of SHGs were country of residence, schooling level, sex, and family support. Those living in countries other than El Salvador showed greater odds for SHG use. The odds ratio (OR) for those living in Belize was 9.3 (p < 0.001), in Guatemala 12.6 (p < 0.001), in Honduras 3.2 (p < 0.001), and in Panama 13.8 (p < 0.001) (Table 2).

Schooling level was associated with a decreased OR for SHG use. The OR was 0.53 (p = 0.001) in those with 6-12 years of schooling, 0.42 (p < 0.001) in those with 12-16 years, and 0.50 (p = 0.005) in those with 16 years or more compared to those with no schooling. Men had higher odds of using SHGs (1.26, p = 0.035) than women. The goodness-of-fit value (Hosmer-Lemeshow) for this model was Prob > F = 0.988.

A marginally significant (0.05 ≤ p < 0.1) association was estimated for those in stable relationships relative to those who were not (OR = 1.19, p = 0.068). Similarly, each additional kilometer of distance from SHGs reduced the odds of SHG use by 1% (0.99, p = 0.059).

Analysis of the subsample of SHG users at the regional level showed that SHGs were most commonly located in public secondary care facilities (34%), followed by tertiary care facilities (23%), primary care facilities (27%), and less often by those located in CSO facilities (16%). This differed by country. As an example, SHGs were most frequently found in secondary and tertiary care facilities in El Salvador but were most associated with CSO facilities in Costa Rica (57%).

Table 1

General characteristics of the study population.

Characteristics	Total general (n = 4,190)		Users of SHGs (n = 3,024)		Non-users of SHGs (n = 1,166)		Paired difference test
	n	%	n	%	n	%	p-value *
Sex							
Female	1,894	45	1,347	45	547	47	0.061
Male	2,286	55	1,671	55	615	53	
Age groups (years)							
Young (18-24)	484	12	373	12	111	10	0.026
Young adults (25-44)	2,601	62	1,866	62	735	63	0.597
Mature adults (45-59)	899	21	627	21	272	23	0.109
Older adults (≥ 60)	206	5	158	5	48	4	0.297
Schooling level							
No schooling	402	10	330	11	72	6	< 0.001
Literate	142	4	101	3	41	4	0.778
6 years	1,540	37	1,053	35	487	43	< 0.001
12 years	1,611	39	1,176	40	435	38	0.453
≥ 16 years	417	10	312	11	105	9	0.011
Country of residence							
El Salvador	797	19	375	12	422	36	< 0.001
Belize	398	9	347	11	51	5	< 0.001
Costa Rica	624	15	294	10	330	28	< 0.001
Guatemala	792	19	722	24	70	6	< 0.001
Honduras	799	19	574	19	225	19	0.203
Panama	780	19	712	24	68	6	< 0.001
Received counseling after HIV diagnosis							
Yes	3,533	84	2,560	85	973	83	0.060
Receives family support to cope with HIV disease							
Yes	3,068	79	2,182	75	886	79	0.121
Has been ill in the last three months							
Yes	812	20	613	21	199	18	0.465
Has undergone viral load testing							
Yes	3,106	77	2,265	78	841	75	0.812
Is currently taking ARVs							
Yes	3,685	88	3,724	90	961	82	< 0.001
Has consumed alcohol in the last month							
Yes	907	22	681	23	226	20	0.655
	Mean	SD	Mean	SD	Mean	SD	p-value *
Average monthly income (USD)	197	230	150	234	176	218	0.002

ARVs: antiretrovirals; SD: standard deviation; SHGs: self-help groups; USD: American dollars.

Source: prepared by the authors based on data from REDCA+ [22].

* Variables of interest were estimated at sample level. Paired difference testing was performed between the SHG user and non-user groups. Standard errors are presented for income.

Table 2

Factors associated with use of self-help groups (SHGs).

Characteristics	OR	p-value	95%CI
Country			
El Salvador	1.000		
Belize	9.361	< 0.001 *	6.484-13.516
Costa Rica	1.027	0.849	0.779-1.352
Guatemala	12.615	< 0.001 *	9.092-17.503
Honduras	3.204	< 0.001 *	2.538-4.046
Panama	13.879	< 0.001 *	9.826-19.603
Age (years)			
18-24	1.000		
25-44	0.822	0.224	0.600-1.126
45-59	0.792	0.198	0.555-1.129
≥ 60	0.909	0.728	0.531-1.554
Schooling level			
No schooling	1.000		
Literate	0.704	0.211	0.406-1.219
6 years	0.530	0.001 *	0.369-0.760
12 years	0.420	< 0.001 *	0.291-0.606
≥ 16 years	0.507	0.005 *	0.314-0.818
Sex			
Female	1.000		
Male	1.261	0.035 *	1.016-1.565
Sexual orientation			
Heterosexual	1.000		
Bisexual	1.077	0.725	0.711-1.631
Homosexual	1.007	0.961	0.748-1.355
Is currently in a stable relationship			
No	1.000		
Yes	1.195	0.068 **	0.986-1.449
Monthly income			
Quintile 1	1.000		
Quintile 2	0.919	0.586	0.680-1.243
Quintile 3	0.927	0.584	0.708-1.214
Quintile 4	0.879	0.354	0.671-1.153
Quintile 5	0.872	0.407	0.632-1.204
Receives family support to cope with HIV disease			
No	1.000		
Yes	1.249	0.043 *	1.007-1.550
Has economic dependents			
No	1.000		
Yes	0.996	0.975	0.808-1.228
Has been diagnosed with tuberculosis			
No	1.000		
Yes	1.210	0.196	0.906-1.616
Received counseling after HIV diagnosis			
No	1.000		
Yes	0.863	0.262	0.668-1.115

(continues)

Table 2 (continued)

Characteristics	OR	p-value	95%CI
Has engaged in illicit drug use			
No	1.000		
Yes	0.983	0.909	0.740-1.307
Future Time Perspective			
Continuous 0-10	0.969	0.378	0.906-1.038
Distance to SHG			
Km (Euclidean)	0.992	0.059 **	0.985-1.000
Distance to SHG squared			
Km (Euclidean)	1.000	0.137	0.999-1.000

95%CI: 95% confidence interval; OR: odds ratio.

Source: prepared by the authors based on data from REDCA+ [22].

Note: estimates obtained using a multiple logistic regression model (n = 4,084). Hosmer-Lemeshow goodness-of-fit (Prob > F = 0.988).

* $p < 0.05$;

** $p < 0.1$.

PLHIV traveled an average of 20 kilometers to attend SHGs and the median distance was 5 kilometers. This also differed among countries, with Guatemala yielding the longest average distance traveled (32 kilometers) and El Salvador the shortest (8 kilometers) ($p < 0.05$) (Figure 1).

The maps of distances traveled show assorted figures (Figure 2) indicating that Guatemala and Panama presented the longest distances traveled. El Salvador, in turn, presented a web-like image indicating a relatively uniform pattern of distribution. The concentration of long journeys to SHGs in Belize stood out, more specifically in the coastal region corresponding to Belize City (Figure 2).

The average proportion of PLHIV using the nearest SHGs was 48% for all participating countries. Analyzed by country, El Salvador had the largest proportion of PLHIV using the nearest SHG (68%) whereas Panama had the smallest (37%) ($p < 0.001$).

The characteristics associated with the likelihood of using the nearest SHG were country of residence, sexual orientation, prior use of illicit drugs, and type of SHG (Table 3).

All countries had greater odds of PLHIV using the nearest SHG than El Salvador. The ORs by country were 1.49 ($p = 0.034$) for Belize, 1.55 ($p = 0.037$) for Costa Rica, 2.62 ($p = 0.001$) for Guatemala, 2.03 ($p = 0.001$) for Honduras, and 2.39 ($p = 0.001$) for Panama.
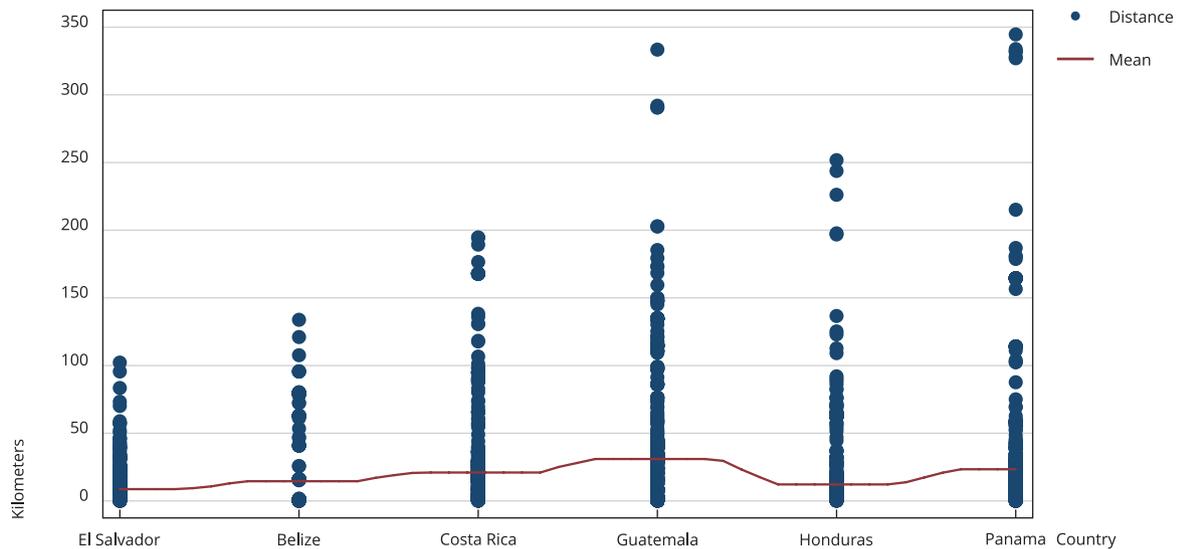
PLHIV identifying as homosexual had higher odds (1.43, $p = 0.015$) of using the nearest SHG than heterosexuals, and those reporting prior use of illicit drugs had lower odds (0.59, $p < 0.001$) of attending the nearest SHG. Regarding the type of SHG, those who used SHGs located in or near a tertiary care facility had higher odds (1.43, $p = 0.034$) of attending the nearest SHG than PLHIV who used a SHG located in or near a secondary care facility (0.51, $p < 0.001$). The value of the (Hosmer-Lemeshow) goodness-of-fit test for this sample was > F = 0.424.

Discussion

Our results differ from those of studies conducted in Africa, where young adult women [12] are the primary users of SHGs. In our study population, we observed no differences by age, but found that men were more likely to attend SHGs than women. Our results are similar to those of other studies conducted in North America [29], possibly since in the region of the countries in our study, the HIV epidemic affects mainly male groups [28]. In short, our results, obtained from Central America, are more similar to those from North American countries (with similar epidemics) than from African countries.

Figure 1

Distance between locations and self-help groups (SHGs).

Note: kernel = Epanechnikov, degree = 0, bandwidth = 0.29.

The foregoing can direct SHGs and their activities to focus more on providing care to men. Evidence shows that SHGs of this type are unprepared to respond to the needs of women [20], which may discourage these patients from attending SHGs. Accordingly, the observed association between having family support and using SHGs may correspond to the importance that PLHIV attach to the emotional support of social networks, reported in other studies [12,30].

Importantly, our study found that PLHIV with a higher schooling level had a lower OR for attending SHGs than those without schooling. This result is particularly relevant before other studies indicating a positive correlation between schooling level and the use of health services [9]. However, the evidence presented in previous studies has not been conclusive. Some systematic reviews have found as many positive as negative associations, as well as no association [8]. Moreover, another study reported that SHG users are mainly people with low schooling level, low income, and who are unemployed [15]. This could help explain our results.

Considering that PLHIV attend SHGs mainly to be part of a social network, receive emotional support, and find job opportunities [11,12], those who use these groups are more likely to be unemployed and therefore have more available time. We thus recommend conducting research with a mixed quali-quantitative framework to better understand the socioeconomic characteristics of users, their expectations concerning SHGs, and how much these expectations correspond to services received.
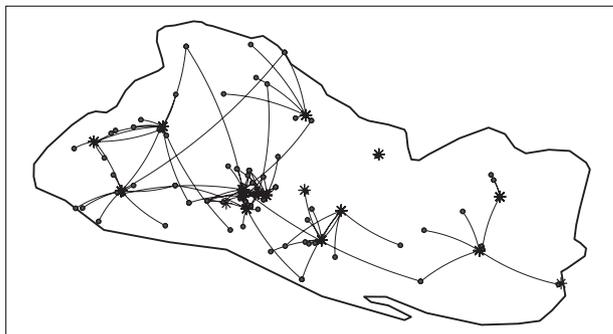
Importantly, although SHGs are frequently located in healthcare facilities, these groups have a fundamentally different purpose from health services. While SHGs are formed to satisfy a need for association, safety, affection, improved self-esteem, and a sense of belonging, health services are part of the institutional response to HIV. Accordingly, health services have used SHGs to implement actions aimed at harm reduction and secondary prevention; however, users might ultimately go to healthcare facilities for the very reasons for the creation of SHGs in the first place.

Regarding SHG users, the association observed between attending the nearest SHG and the level of care could be due to the preference for receiving care from facilities offering specialized services and an adequate pharmaceutical supply, which can be tertiary care facilities, as other studies have described [18,26,31]. A more detailed spatial analysis including mapping of routes and SHG typology

Figure 2

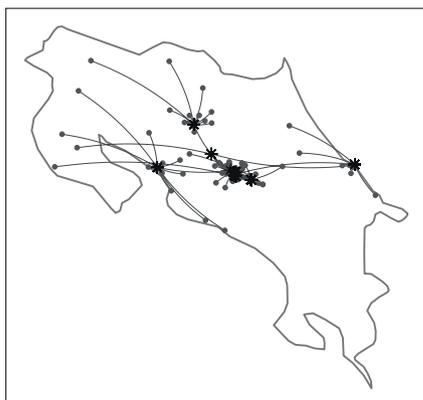Routes followed from places of residence to self-help groups (SHGs).
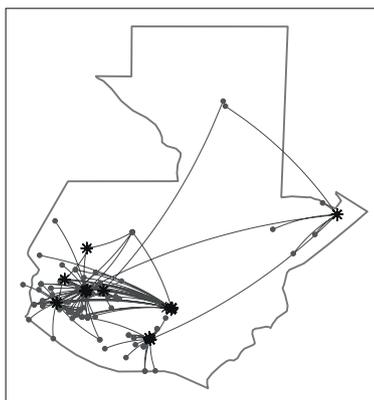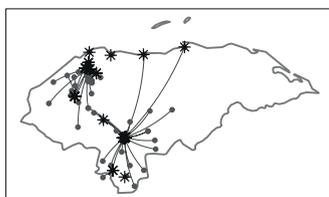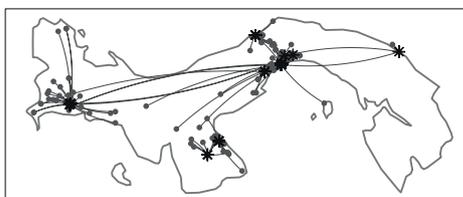

2a) El Salvador

2b) Belize

2c) Costa Rica

2d) Guatemala

2e) Honduras

2f) Panama

Central America

Source: prepared by the authors based on data from REDCA+ [22].

Table 3

Factors associated with use of the nearest self-help group (SHG).

Characteristics	OR	p-value	95%CI
Country			
El Salvador	1.000		
Belize	1.493	0.034 *	1.030-2.164
Costa Rica	1.554	0.037 *	1.026-2.354
Guatemala	2.622	< 0.001 *	1.931-3.561
Honduras	2.036	< 0.001 *	1.470-2.822
Panama	2.393	< 0.001 *	1.646-3.479
Age (years)			
18-24	1.000		
25-44	0.977	0.872	0.735-1.296
45-59	0.986	0.934	0.707-1.374
≥ 60	0.925	0.755	0.571-1.499
Schooling level			
No schooling	1.000		
Literate	0.944	0.824	0.573-1.557
6 years	0.871	0.351	0.652-1.163
12 years	0.839	0.265	0.617-1.141
≥ 16 years	0.742	0.143	0.497-1.105
Sex			
Female	1.000		
Male	1.072	0.498	0.876-1.312
Sexual orientation			
Heterosexual	1.000		
Bisexual	1.027	0.897	0.685-1.540
Homosexual	1.435	0.015 *	1.074-1.919
Is currently in a stable relationship			
No	1.000		
Yes	1.091	0.355	0.906-1.313
Monthly income			
Quintile 1	1.000		
Quintile 2	0.767	0.106	0.556-1.058
Quintile 3	0.842	0.206	0.645-1.099
Quintile 4	1.162	0.268	0.890-1.518
Quintile 5	1.187	0.266	0.877-1.607
Receives family support to cope with HIV disease			
No	1.000		
Yes	0.850	0.113	0.697-1.038
Has economic dependents			
No	1.000		
Yes	0.940	0.564	0.764-1.157
Has engaged in illicit drug use			
No	1.000		
Yes	0.598	< 0.001 *	0.456-0.784
Has been discriminated against			
No	1.000		
Yes	1.299	0.074	0.975-1.731

(continues)

Table 3 (continued)

Characteristics	OR	p-value	95%CI
Type of SHG			
CSO	1.000		
Primary care	1.197	0.344	0.824-1.740
Secondary care	0.518	< 0.001 *	0.375-0.716
Tertiary care	1.434	0.034 *	1.027-2.002

95%CI: 95% confidence interval; CSO: civil society organizations; OR: odds ratio.

Source: prepared by the authors based on data from REDCA+ [22].

Note: estimates obtained using a multiple logistic regression model (n = 2,939). Hosmer-Lemeshow goodness-of-fit (Prob > F = 0.424).

* p < 0.05.

could help evidence that those who live nearby a SHG located at a tertiary care facility will choose to attend this group, while those lacking this option will tend to travel to a neighboring SHG located in a secondary care facility.

The use of more distant SHGs by the heterosexual population, in turn, likely occurs since stigmatization and discrimination regarding HIV persist in the region studied, which – together with the epidemic prevalence in the gay community and among men who have sex with men (MSM) – may motivate many heterosexuals to seek safeguarding their anonymity.

The routes traveled by PLHIV to reach SHGs show a heterogeneous pattern, corroborated by analyzing the distances traveled in the different countries. The average distance traveled by our study population was 19.5 kilometers, longer than distances reported in other studies [17,18,27].

Analysis of the differences between countries showed that the average distance can be reduced by half, as in the case of El Salvador, which presented an average distance of 8.5 kilometers traveled. This might occur since El Salvador shows a more homogeneous pattern of spatial distribution, possibly translating into a greater availability of services [32]. It could also indicate that the population centers are spread throughout the country, unlike in other countries where the population is concentrated in fewer areas.

The longest routes and greatest movement occurred in Belize, Guatemala, and Panama, correlating with a higher concentration of SHGs in the capital cities of these countries and with a greater average distance between these cities and the places of residence of PLHIV.

The main limitation of this study was a lack of additional information on the SHGs in each country, such as the type of services offered and the days and hours of operation. To correct for this, we identified and employed the types of SHGs, allowing us to analyze these differences at least partially. However, we recognize that this is insufficient to consider the possible heterogeneity of the various services.

The study also lacked information on the places of residence of PLHIV – for example, whether these places were rural or urban, how densely populated they were, and what services were available. Having this information could have allowed for a better adjustment of the models.

Because of data confidentiality, we did not obtain detailed information on the addresses of PLHIV, including street and house number. To estimate distances, we assumed that all inhabitants of a given locality departed from the same point, located in the town centers.

Euclidean distances were used assuming a straight line between the two points of interest (in our case, places of residence and SHGs), without considering geographic characteristics, access roads, or means of transport. We recognize that this may lead to less precise estimates of distances traveled. However, this is a basic method which has been validated for identifying differences dictated by geographical proximity before limited information [26].

Despite the mentioned limitations, the results of this first regional analysis can be used as reference to design services intended for PLHIV, especially considering that until this point information was available exclusively from studies in other countries.

Performing spatial analysis provides new information on the study of displacements and the mobility patterns of PLHIV in search of care. Though we identified no clear displacement pattern, we observed that participants did not always attend the nearest SHGs and often preferred to travel further, possibly seeking for anonymity and confidentiality or more specialized services.

Finally, the data were collected in 2012 and might seem unqualified. However, the object of this study (variables associated with the use of SHGs) is expected to remain equal for some time since it relates to personal criteria for selecting services. PLHIV may prefer anonymity to, for example, avoid experiencing stigma and discrimination. Therefore, we hypothesize that although the number, location, and name of the SHGs in the region and within the countries might change, the relationship between variables, such as the conditions that motivate or discourage use of SHGs, should not change.

Contributors

M. Sanchez-Dominguez contributed to the study design, data analysis and interpretation, and writing. R. Leyva-Flores and C. Infante-Xibille contributed to the data interpretation and writing. J. L. Texcalac-Sangrador contributed to the data analysis, interpretation of results, and writing. H. Lamadrid-Figueroa contributed to the study design, data interpretation, and writing. All the authors approved the final version of the manuscript.

Additional informations

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References

1. Arribas Rubio FJ. Espacios sociales de participación: las asociaciones y los grupos de autoayuda. Nómadas 2008; 18:307-14.
2. Seebohm P, Chaudhary S, Boyce M, Elkan R, Avis M, Munn-Giddings C. The contribution of self-help/mutual aid groups to mental well-being. Health Soc Care Community 2013; 21:391-401.
3. Bonet R, Ferrer M, Vilajoana J. Estrategias de grupo y sida: ayuda mutua. Revista de Psicología General y Aplicada 1994; 47:193-200.
4. Bateganya MH, Amanyeiwe U, Roxo U, Dong M. The impact of support groups for people living with HIV on clinical outcomes: a systematic review of the literature. J Acquir Immune Defic Syndr 2015; 68 Suppl 3:S368-74.
5. Holstad MM, Essien JE, Ekong E, Higgins M, Teplinskiy I, Adewuyi MF. Motivational groups support adherence to antiretroviral therapy and use of risk reduction behaviors in HIV positive Nigerian women: a pilot study. Afr J Reprod Health 2012; 16:14-27.
6. Cardona-Arias JA, Higuita-Gutiérrez LF. Impacto del VIH/SIDA sobre la calidad de vida: metaanálisis 2002-2012. Rev Esp Salud Pública 2014; 88:87-101.
7. Janssen RS, Holtgrave DR, Valdiserri RO, Shepherd M, Gayle HD, De Cock KM. The serostatus approach to fighting the HIV epidemic: prevention strategies for infected individuals. Am J Public Health 2001; 91:1019-24.

8. Mendoza-Sassi R, Béria JU. Utilización de los servicios de salud: una revisión sistemática sobre los factores relacionados. Cad Saúde Pública 2001; 17:819-32.

9. Brennan A, Morley D, O'Leary AC, Bergin CJ, Horgan M. Determinants of HIV outpatient service utilization: a systematic review. AIDS Behav 2015; 19:104-19.

10. Uphold CR, Mkanta WN. Use of health care services among persons living with HIV infection: state of the science and future directions. AIDS Patient Care STDS 2005; 19:473-85.

11. Dageid W. Support groups for HIV-positive people in South Africa: who joins, who does not, and why? Afr J AIDS Res 2014; 13:1-11.

12. Heyer A, Mabuza LH, Couper ID, Ogunbanjo GA. Understanding participation in a hospital-based HIV support group in Limpopo Province, South Africa. S Afr Fam Pract (2004) 2010; 52:234-9.

13. Madiba S, Canti-Sigaqa V. Barriers to participate in support groups for people living with HIV: a qualitative study with men receiving antiretroviral treatment in a HIV clinic in Mthatha, South Africa. Glob J Health Sci 2012; 4:119-28.

14. Cummings B, Mengistu M, Negash W, Bekele A, Ghile T. Barriers to and facilitators for female participation in an HIV prevention project in rural Ethiopia: findings from a qualitative evaluation. Cult Health Sex 2006; 8:251-66.

15. Walch SE, Roetzer LM, Minnett TA. Support group participation among persons with HIV: demographic characteristics and perceived barriers. AIDS Care 2006; 18:284-9.

16. Kirby RS, Delmelle E, Eberth JM. Advances in spatial epidemiology and geographic information systems. Ann Epidemiol 2017; 27:1-9.

17. Akullian AN, Mukose A, Levine GA, Babigumira JB. People living with HIV travel farther to access healthcare: a population-based geographic analysis from rural Uganda. J Int AIDS Soc 2016; 19:20171.

18. Cook PA, Downing J, Wheater CP, Bellis MA, Tocque K, Syed Q, et al. Influence of sociodemographic factors on distances travelled to access HIV services: enhanced surveillance of HIV patients in north west England. BMC Public Health 2009; 9:78.

19. Bezabhe WM, Chalmers L, Bereznicki LR, Peterson GM, Bimirew MA, Kassie DM. Barriers and facilitators of adherence to antiretroviral drug therapy and retention in care among adult HIV-positive patients: a qualitative study from Ethiopia. PLoS One 2014; 9:e97353.

20. Fulcher C, Kaukinen C. Mapping and visualizing the location HIV service providers: an exploratory spatial analysis of Toronto neighborhoods. AIDS Care 2005; 17:386-96.

21. Simms I, Gibin M, Petersen J. Location, location, location: what can geographic information science (GIS) offer sexual health research? Sex Transm Infect 2014; 90:442-3.

22. REDCA+. Perfil de riesgo de personas con VIH de los países beneficiarios del Programa Regional REDCA+. Informe regional. https://1library.co/document/y4mwkmry-perfil-de-riesgo-de-personas-con-vih-de-los-paises-beneficiarios-del-programa-regional-redca-plus-informe-regional.html (accessed on 27/Jun/2022).

23. Family Health International. Behavioral Surveillance Surveys: guidelines for repeated behavioral surveys in populations at risk of HIV. Arlington: United States Agency for International Development; 2000.

24. Strathman A, Gleicher F, Boninger DS, Edwards CS. The consideration of future consequences: weighing immediate and distant outcomes of behavior. J Pers Soc Psychol 1994; 66:742-52.

25. Petrocelli J V. Factor validation of the Consideration of Future Consequences Scale: evidence for a short version. J Soc Psychol 2003; 143:405-13.

26. Eberhart MG, Voytek CD, Hillier A, Metzger DS, Blank MB, Brady KA. Travel distance to HIV medical care: a geographic analysis of weighted survey data from the Medical Monitoring Project in Philadelphia, PA. AIDS Behav 2014; 18:776-82.

27. Archer KJ, Lemeshow S. Goodness-of-fit test for a logistic regression model fitted using survey sample data. Stata J 2006; 6:97-105.

28. Joint United Nations Programme on HIV/AIDS. The gap report. Geneva: Joint United Nations Programme on HIV/AIDS; 2014.

29. Crook J, Browne G, Roberts J, Gafni A. Impact of support services provided by a community-based AIDS service organization on persons living with HIV/AIDS. J Assoc Nurses AIDS Care 2005; 16:39-49.

30. Li L, Wu S, Wu Z, Sun S, Cui H, Jia M. Understanding family support for people living with HIV/AIDS in Yunnan, China. AIDS Behav 2006; 10:509-17.

31. Taylor BS, Reyes E, Levine EA, Khan SZ, Garduño LS, Donastorg Y, et al. Patterns of geographic mobility predict barriers to engagement in HIV care and antiretroviral treatment adherence. AIDS Patient Care STDS 2014; 28:284-95.

32. Tanahashi T. Health service coverage and its evaluation. Bull World Health Organ 1978; 56:295-303.

Resumen

Los grupos de autoayuda (GAA) para personas que viven con el VIH (PVVIH) son organizaciones creadas por la comunidad para proporcionarles seguridad, afecto, mejor autoestima y un sentido de pertenencia. Sin embargo, el gobierno también ha utilizado los GAA para ayudar a implementar políticas de control del VIH. Se buscó identificar las características asociadas con el uso de GAA por PVVIH y las rutas y patrones de desplazamiento adoptados por los usuarios. Este es un estudio analítico transversal basado en datos recogidos en seis países centroamericanos en 2012. A través de una lista de GAA, se construyó un muestreo aleatorio de dos etapas. Primero, se seleccionaron los GAA. Luego, los participantes recibieron una visita, y se evaluó cada tercio de ellos. Se utilizaron modelos de regresión logística para identificar las características asociadas al uso y visitas a los GAA más cercanos a los usuarios. Se realizó un análisis espacial para identificar las rutas que los voluntarios tomaron para llegar a los GAA en sus comunidades de origen. Se constató que las características significativamente asociadas con mayores probabilidades de uso de los GAA fueron el país de residencia y la escolaridad. Las distancias medias y medianas recorridas por los usuarios para visitar los GAA fueron de 20 kilómetros y 5 kilómetros, respectivamente. Las PVVIH no utilizan los GAA más cercanos a su casa, tal vez por miedo al estigma y a la discriminación. Se necesitan investigaciones sobre este tema que utilicen una metodología mixta cualitativa-cuantitativa para comprender mejor las decisiones de uso, las expectativas de los usuarios y el grado en que se están atendiendo.

VIH; Grupos de Autoayuda; Sistemas de Información Geográfica

Resumo

Grupos de autoajuda (GAAs) para pessoas vivendo com HIV (PVHIV) são organizações criadas pela comunidade para proporcioná-los segurança, afeto, melhor autoestima e senso de pertencimento. No entanto, o governo também tem usado os GAAs para ajudar a implementar políticas de controle do HIV. Buscamos identificar as características associadas ao uso de GAAs por PVHIV e as rotas e padrões de deslocamento adotados pelos usuários. Este é um estudo analítico transversal realizado com base em dados coletados em seis países da América Central em 2012. Através de uma lista de GAAs, uma amostragem aleatória em dois estágios foi construída. Em primeiro lugar, os GAAs foram selecionados. Em seguida, eles foram visitados e cada terceiro de seus participantes foi avaliado. Foram utilizados modelos de regressão logística para identificar as características associadas ao uso e às visitas aos GAAs mais próximos aos usuários. Foi realizada uma análise espacial para identificar as rotas que voluntários tomavam para chegar aos GAAs em suas comunidades de origem. Verificamos que as características significativamente associadas com maiores chances de uso dos GAAs foram país de residência e escolaridade. As distâncias médias e medianas percorridas por usuários para visitar os GAAs foram de 20 quilômetros e 5 quilômetros, respectivamente. As PVHIV não utilizam os GAAs mais próximos de onde moram, talvez por medo de estigma e discriminação. Recomendamos que as pesquisas sobre este tema utilizem uma metodologia qualitativa-quantitativa mista para entender melhor as decisões de utilização, as expectativas dos usuários e o grau em que eles estão sendo atendidos.

HIV; Grupos de Autoajuda; Sistemas de Informação Geográfica