

En sus propias palabras (in their own words): Eliciting Latina women's perspectives on enablers of HIV testing using freelisting

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Abstract:

Objective: Comprehensive information on the facilitators of HIV testing in Latino women (Latinas) in the Southeastern USA is lacking. Efforts to rectify this should include Latina perspectives on the issue. This study aimed to (1) solicit Latina perspectives using qualitative methodology and (2) characterise enablers of HIV testing follow-through. **Method:** The study used the freelisting interview approach to document the perspectives of Latinas (18 years and older). The purposive sample included HIV-tested ($n = 21$) and non-tested ($n = 10$) women. The setting was Non-Traditional Counseling, Testing and Referral Sites in five counties in Central North Carolina, USA. The protocol was guided by the PEN-3 framework, which aims to take culture into account as part of health education. The focus was on the enablers (i.e. social groups, networks, information channels, systems and environments) of health behaviours. **Results:** While participants listed 66 enablers, 37 met the criteria for analyses. The top 10 enablers were TV advertisements/commercials, friends, personal health, family wellbeing, children, TV shows, pamphlets, self-interest, knowing someone HIV positive and spouse/partner. The most salient enabler for HIV-tested Latinas was *children*. For non-tested Latinas, it was *friends*. **Conclusion:** Freelisting proved to be a simple and effective data collection strategy with literate and low-literate women, providing culturally relevant concepts for inclusion in subsequent quantitative survey instruments. Study participants identified a number of important enablers that could serve as supports or reinforcements for health education outreach and interventions to enhance HIV testing uptake.

Keywords: enablers | freelisting | HIV testing | Latina women | USA

Article:

Introduction

HIV prevalence rates among Hispanic/Latino women (otherwise referred to as Latinas) in the Southeastern State of North Carolina, USA, are four times higher than that of non-Latino White women (North Carolina Department of Health and Human Services [NCDHHS], 2012). Despite statewide campaigns to increase early HIV detection (e.g. 'Get Real, Get Tested' and Video

Opportunities for Innovative Condom Education and Safer [VOCES/VOICES]), Latinas continue to be late testers (North Carolina HIV/STD Prevention and Care Branch, 2006). The unfortunate consequences of this are late diagnoses and the likelihood of suffering AIDS-defining events upon entry into HIV care (Dennis et al., 2011).

Latinas are actually more likely to report higher rates of testing than their male counterparts, but this is largely due to current US Centers for Disease Control (CDC) recommendations and procedures that have institutionalised HIV testing as part of routine prenatal screening and gynaecological visits (CDC, 2006; National Center for Health Statistics, 2008). As a general rule, Latinas do not view voluntary testing as a central core of HIV prevention, nor do they perceive that it leads to sustained protective practices (Medina, 2009). With this in mind, health educators and other HIV service providers need to better target their outreach efforts to increase the likelihood of voluntary testing among Latinas.

HIV prevention research suggests that culture-centred and gender empowering interventions show promise in encouraging early and voluntary testing among Latino women (Hernandez et al., 2012). However, these interventions are best constructed with an understanding of cultural and other factors that support or enable preventive behaviours. In this paper, we focus on the use of freelisting, a data collection method used in cultural anthropology, to gather women's perspectives on what constitutes an 'enabler' in the context of HIV testing uptake. Enablers here refer to factors that facilitate women to take an HIV test. Most prior research has focused on identifying the barriers to testing among women and men of different communities.

Relatively few studies have examined enabling or supportive factors of HIV testing among Latino women (CDC, 2006; Royce et al., 2001). Medina (2009) examined HIV testing experiences and the contextual factors involved for women of colour, including women of Latino heritage/descent. Reasons given for testing included personal concern because of risky behaviours (i.e. fear stemming from being with an HIV-positive partner), wanting to remain healthy and 'taking care' as a means of taking charge of their health particularly where children were involved. Furthermore, the ability to communicate with and receive support from a partner within a coupled relationship is a key facilitator of HIV testing.

Craig et al. (2012) examined determinants of HIV testing among middle-aged and older Latinas in South Florida and found that access to a local community clinic was significantly related to voluntary counselling and testing uptake among this subgroup. Of particular interest and appeal was the anonymity provided by the clinic setting, a benefit that women feel is lacking with use of a private physician or hospital setting. These studies highlight key cultural and structural supports for HIV testing behaviour. Further research to elucidate other important 'enablers' would assist community health providers to differentiate among women who are more versus less ready to voluntarily test for HIV, and focus scarce resources on the latter.

Freelisting in HIV-related research

Freelisting is a method used in anthropological research to elicit key elements or perspectives on a cultural or structural domain. In freelisting, respondents are asked to list all components or attributes of a particular domain (Bernard, 2006). This kind of information can be derived from

open-ended interviews, but the data from these interviews tend to be about only the participants. A freelisting format moves away from this by allowing participants to first think about what is being asked and then list items that represent one or more specific domains of knowledge associated with the particular issue they are presented with (Borgatti, 1999; Fleisher and Harrington, 1998). Researchers can then systematically capture the perspectives of individuals who represent cultural experts, that is, individuals possessing insider or 'emic' knowledge (Borgatti, 1999). Their words can be used to construct questionnaires or educational materials that have particular saliency and meaning for the cultural group (Trotter and Schensul, 1998).

In HIV-related research, freelisting approaches have been used to collect population perspectives on disease occurrence, management and prevention. Bolton and Wilk (2004), for example, used freelisting to identify problems affecting residents of a Ugandan community as a result of the HIV epidemic. The residents cited a lack of able-bodied adults, lack of care for children and mental and social problems as the three major problems. Similarly, Betancourt et al. (2011) used freelisting as part of a discussion of the mental health problems of Rwandan children and youth who were affected by HIV. The researchers uncovered six syndromes and associated symptoms that contributed to poor mental health.

Otieno et al. (2010) asked women who had participated in a programme to prevent mother-to-child transmission (PMTCT) in Nairobi, Kenya, to freelist factors hindering or supporting access to HIV care. Hindering factors included lack of money, confidentiality issues and dislike of the facility. Supportive factors included provision of health education, free services and an atmosphere of compassion. Murray et al. (2009) used freelisting to investigate reasons for lack of acceptance and adherence to anti-HIV drugs by HIV-positive Zambian women. They identified several different reasons: hunger, stigma, lack of accurate information, unfamiliarity with the deadly disease, depression and hopelessness and the effect antiretroviral therapy (ART) had on relations between husband and wife.

Key advantages of the freelisting technique include the fact that it is an inexpensive way to collect perspectives on a sensitive or emotionally charged topic. Furthermore, it can function as a 'probe' during conversations with individuals, to encourage participants to more clearly describe and expand explanations of items in a particular cultural domain (Bernard, 2006). Also, researchers can verify the information presented by reviewing the list of items with each participant and seeking clarification on specific items. Finally, the technique can easily be used to gather rich cultural information from low literacy participants whose input would be excluded if only self-written lists were used.

This paper reports on our use of freelisting in the qualitative data collection phase of a larger federally funded study to identify and characterise social and environmental supports for HIV testing decisions and behaviours. The larger study goal was to develop a culturally grounded assessment tool that could be administered to Hispanic/Latino women in non-clinical and community-based settings by community health workers who were tasked with expanding HIV testing outreach to Latino communities. We used a community-based participatory research (CBPR) approach whereby community members work together with academic researchers to identify and address community health disparities (Wallerstein and Duran, 2006). This allowed the research to be (1) grounded in community member experiences and (2) informed by multiple

sources of knowledge especially during development and implementation of culturally appropriate data collection strategies (McQuiston et al., 2005). We conducted semi-structured interviews during the qualitative phase of the study. The overall interview was designed to gather information about the elements that constitute or define a particular domain when ascertaining what enables women to take up voluntary HIV testing. The goal was to get these informants to share experiences and express viewpoints – ‘*en sus propias palabras*’ (in their own words) – and summarise (in list format) the most salient items raised in discussion.

Guiding framework

The PEN-3 model developed by Collins Airhihenbuwa (1995) provided an overall framework for our study. This model was developed by and has been used to guide HIV prevention programming for African and African American populations and for anchoring health education interventions for Latino women (Erwin et al., 2010; Scarinci et al., 2012). The model is organised into three cultural domains: cultural identity (determines whether *Persons, Extended family or Neighbourhoods* should be the targets for health promotion), cultural relationships and expectations (identify how the target audience’s *Perceptions, Enablers, Nurturers* influence health behaviours) and cultural empowerment (examines the *Positive, Existential and Negative* aspects of cultural behaviours). This study gave particular attention to *enablers*, which are systems, networks and structures likely to be supportive of health behaviours. Our interest was in enablers as supportive agents for HIV testing behaviour in this population.

Methods

Setting

The study was conducted in five counties in Central North Carolina. This region is home to over 100,000 Latinos, with an HIV prevalence rate of 25.5 per 100,000 (Office of Minority Health and Health Disparities and State Center for Health Statistics, 2010; US Census Bureau, 2010). Each county has a County Public Health Department (CPHD) and at least one AIDS Service Organisation (ASO) that offers HIV testing services. HIV testing is also offered at Non-Traditional Sites (NTS) such as community events, public parks, nightclubs, drug treatment centres and correctional facilities. The Institutional Review Board of the University of North Carolina Greensboro approved the study procedures. The first author (S.D.M.) contacted public health and HIV service providers, explained the study and sought assistance with recruitment.

Sample

The research team was granted permission to be stationed at the CPHDs, ASOs and the NTS to recruit participants. Inclusion criteria were (1) self-identification as a woman from Mexico or from Central or South America or the Spanish-speaking Caribbean, (2) aged 18 years or older and (3) accessed health services in the region. Our target sample was six women per county (four who had previously tested and two who had never voluntarily tested) to make up a total of 30 women. This sample size accorded with Weller and Romney’s (1988) recommended sample size (20–30 key informants) to adequately define and characterise a cultural domain using freelist methods in data collection during ethnographic fieldwork. This minimum is sufficient to

distinguish similar versus dissimilar items within the culturally derived domains. For purposes of the project, research assistants (RAs) approached women at the designated recruitment sites and invited them to participate. The women who agreed were administered an initial screening interview to determine whether they met the inclusion criteria.

All who participated provided oral consent. In some cases, permission had to be negotiated with others accompanying the woman (partner, mother, etc.) in order to proceed with the screening interview. The RAs sought oral informed consent prior to interviewing all eligible participants. Our final sample included 31 Latinas (21 tested and 10 non-tested). Given the sensitive nature of the topic and concerns expressed by community members about comfort level and confidentiality of information shared, we collected basic demographic information (e.g. age, country of origin/birth) and refrained from asking more sensitive questions (e.g. household income/socio-economic status [SES]) in this phase of the study. Women ranged in age from 18 to 47 years. Of these, 67% (20) reported being less than 40 years old. Of these women, 75% (23) indicated they had migrated from Mexico. Others had migrated from Colombia, Dominican Republic and Guatemala. All had resided in their respective county for at least 1 year.

Data collection

We concluded interviews with a freelisting exercise to clarify and summarise key points shared during the interview process. Women who had previously voluntarily tested for HIV were asked to think about and then freelist all the persons, places, structures and circumstances that enabled them to voluntarily go through HIV testing. Those who had not been tested were asked to freelist their perspectives on things that might enable or support a woman from within their culture and community to voluntarily seek and follow-through with HIV testing. We surmised that both groups would have extensive and common cultural knowledge about support for health seeking in Latino communities. At the same time, this would allow us to capture cultural variations in perceptions and opinions associated with personal HIV testing encounters versus anecdotal accounts of other's HIV testing experiences.

To accommodate low literacy participants, the RAs orally solicited items and then wrote down the responses verbatim. The freelisting interviews lasted 30–60 minutes. These were conducted in either Spanish or English by the bilingual members of the research team based on participant preference. All interviews were audio-recorded with one exception (written notes made instead) and a written freelist was collected. All women were offered a US\$20 gift card for their participation.

Data analysis

We generated 31 freelists from a total of 21 previously tested women and 10 non-tested women from the five counties. Items expressed as compound phrases were collapsed into a 'cover term', in keeping with domain analysis procedures (Bernard and Ryan, 2010). For example, if a participant listed 'having a mobile clinic in convenient location', then the cover term for the enabler would be 'convenient mobile clinic'. The total number of enablers was recorded at the bottom of each freelist. Freelists were then re-reviewed by the RAs to verify the actual counts, and discrepancies or disagreements were identified, discussed and resolved. An item in question

was included only after consensus was reached about its fit as an ‘enabler’ rather than a ‘barrier’ for voluntary HIV testing.

The lists were then arranged by group – testers versus non-testers. An index card was created for every enabler, and the freelists were combined in a summary list of the distinct cover terms. Colour-coded ‘tally marks’ were placed by each cover term that specified the type of participant (tested/non-tested) responsible for identifying the enabler. Once this data cleaning process was complete, a working codebook was created. Univariate analysis using ANTHROPAC 4.98 included item counts, frequencies and mean positions in the lists (Borgatti, 1996). Additional analysis was conducted to determine Smith’s salience index (S) defined as a measure of the importance of a listed item in a participant’s freelist (Smith, 1993). Smith’s S ranges from 0 to 1, with the higher score indicating higher salience or higher importance for the item or term in question.

Results

A total of 31 women participated in the freelisting activity. We used the data from 30 freelists because items on one participant’s freelist were deemed ‘barriers’ rather than enablers and therefore were excluded. The total number of enablers (words and/or phrases) derived from all the freelists was 66. Adopting the strategy used by Hough and Ferraris (2010), enablers that were mentioned by either fewer than two or fewer than 10% of participants were excluded. The final list contained 37 enablers (Table 1).

The 10 most frequently mentioned enablers (arranged in decreasing order of frequency) were TV advertisements/commercials, friends, personal health, family wellbeing, children, TV shows, pamphlets/fliers, ‘Just for me’, someone HIV+ and spouse/partner. In all, 63% of participants designated TV advertisements/commercials as their top enabler; 53% and 47% mentioned friends and personal health as enablers. The average rank indicated that women were likely to mention spouse/partner and friends early in their listing of enablers (average rank 3.222 and 3.25). Family wellbeing and children were the earliest freelisted (average rank 3.273 and 3.55) among the ‘top 10’ most mentioned enablers.

The ranking of the 10 most salient enablers, as represented by the Smith’s Salience Index, was almost identical to the ‘top 10’ most frequently mentioned with the exception of one enabler. *Curiosity*, which was absent from the original ‘top 10’ most freelisted enablers, was the ninth most salient enabler (Smith’s Salience $S = .177$) which occurred early in the list of the 23% of Latinas who mentioned it. The Smith’s Salience Index suggested that *friends* was the most important enabler for Latinas, and it appeared earlier in the lists of the 53% of participants who mentioned it (Smith’s $S = .426$; average rank = 3.25).

Tables 2 and 3 illustrate the ‘top 10’ freelists for HIV-tested and non-tested Latinas. The list in Table 2 is sorted according to the most salient enablers. Women who had HIV testing experience identified *children* ($S = .343$; Average Rank = 3.4) as the most important enabler of HIV testing. In all, 48% of women included this on their list. For women who reported never being tested, *friends* ($S = .760$; average rank = 2.50) was the most important enabler of HIV testing and the earliest freelisted enabler. Of these women, 89% included this enabler on their

freelist. Four enablers were of specific importance tested Latinas: *children*, ‘*just for me*’, *curiosity* and *risky sex*. For non-tested women, these were *fear*, *mistrust*, *TV shows* and *doubt*. Finally, there were six commonly shared ‘top 10’ salient enablers noted between tested and non-tested Latinas. These were *personal health*, *friends*, *TV commercials*, *family wellbeing*, *spouse/partner* and *someone HIV positive*, which were important to both groups.

Table 1. Enablers of HIV testing from participant freelists ($n = 30$).

Rank	Enabler	Frequency	Percent	Average rank	Smith's <i>S</i>
1	TV ads/commercials ^a	19	63	7.368	.238
2	Friends ^a	16	53	3.25	.426
3	Personal health ^a	14	47	3.714	.332
4	Family wellbeing ^a	11	37	3.273	.286
5	Children ^a	11	37	3.455	.266
6	TV shows ^a	10	33	5.9	.156
7	Pamphlets/fliers	9	30	9.556	.079
8	‘Just for Me’ ^a	9	30	3.778	.216
9	Someone HIV+ ^a	9	30	4.444	.193
10	Spouse/partner ^a	9	30	3.222	.232
11	Curiosity ^a	7	23	3.571	.177
12	Health/sex education	6	20	7.167	.068
13	Radio ads	6	20	9.167	.061
14	Someone with STD	6	20	4.667	.124
15	Mistrust	6	20	4.167	.144
16	Fear	6	20	5.167	.112
17	Doubt	6	20	4.667	.135
18	Public health gatherings	6	20	8.167	.066
19	Transportation	6	20	8.333	.032
20	Clinic environment	6	20	7.833	.068
21	Risky sex	6	20	3.333	.15
22	Relationship with provider	5	17	3.4	.124
23	Infidelity	5	17	4.2	.118
24	Internet	5	17	7.6	.053
25	Community member	4	13	4.5	.093
26	Intergenerational openness	4	13	5.25	.08
27	Blood transfusion	4	13	6.25	.077
28	Feeling symptoms	4	13	6.5	.07
29	Print media	4	13	6.25	.07
30	Access to provider	4	13	6.5	.06
31	Street news	3	10	10.333	.016
32	General ads	3	10	7.667	.034
33	Family HIV+	3	10	2.333	.091
34	Work environment	3	10	7	.041
35	Church	3	10	9.667	.014
36	News	3	10	6	.05
37	Convenient test and fast results	3	10	4.667	.056

STD: sexually transmitted disease.

^a Top 10 salient enablers

Table 2. Top 10 salient enablers for HIV-tested versus non-tested women.

HIV tested					HIV non-tested				
Enabler	Frequency	%	Average rank	Smith's <i>S</i>	Enabler	Frequency	%	Average rank	Smith's <i>S</i>
Children	10	48	3.4	.343	Friends	8	89	2.50	.760
Personal health	8	38	3.375	.286	Personal health	6	67	4.167	.438
Friends	8	38	4.0	.283	Family wellbeing	5	56	3.0	.437
'Just for me'	8	38	3.5	.278	Fear	5	56	4.8	.359
TV commercials	12	57	6.667	.236	Mistrust	3	33	1.667	.309
Family wellbeing	6	29	3.5	.221	Spouse/partner	3	33	3.667	.262
Spouse/partner	6	29	3.0	.220	TV shows	4	44	5.00	.250
Curiosity	6	29	3.833	.209	TV commercials	7	78	8.571	.243
Someone HIV+	7	33	4.714	.207	Someone HIV+	2	22	3.5	.162
Risky sex	5	24	3.0	.186	Doubt	2	22	4.0	.160

Table 3. Group-specific and shared 'Top 10' salient enablers.

Tested	Both	Non-tested
Children	Personal health	Fear
Just for me	Friends	Mistrust
Curiosity	TV commercials	TV shows
Risky sex	Family wellbeing	Doubt
	Spouse/partner	
	Someone HIV+	

Discussion and conclusion

With the current rise in HIV prevalence among North Carolina's Latino population and continuing delays in testing among Latinas, HIV service providers and other providers must develop and implement culturally grounded and environmentally viable programmes to increase voluntary testing. Success will require tools or methods to assess and incorporate into programmes the perspectives and circumstances or cultural realities that support and empower Latinas in their decision-making. Using freelisting, we sought to identify factors that support or enable Latinas to get HIV tested and provide cultural wording or phrasing that can be used in quantitative research and evaluation with the population. This method allows us to identify a list of factors that distinguish women who appear more versus less ready to take a test.

While freelists provide us with inventories of specific domains of interest, they do have shortcomings. They may not be as extensive or exhaustive as those that could be gathered through lengthy key informant interviews. Also, freelisted terms often represent the immediate vocabulary of a participant rather than the actual lexicon used when describing or discussing a health-related issue. In this project, we attempted to compensate for this limitation by using focused prompts to allow participants (1) to further think through and distinguish the concept of enabler from barrier and (2) to include additional items from their vocabulary that they have deemed related, but were originally omitted. A further limitation is the analyses of freelists largely rely on measures of frequencies that limit the kinds of inferences that can be drawn from the findings. Finally, the study involved only a small sample of participants, and the data gathered through their freelists may not be representative of the larger population.

In this study, several of the enablers mentioned in both the composite and individual freelists are consistent with the literature on factors supporting or facilitating health behaviours and health

promotion among the Latino population. For example, *TV commercials* were the most frequently mentioned enabler of HIV testing in the freelists of the sample of Latinas. This finding accords with research findings that attribute mass media, including the television, as the most popular and influential source of health information for the Latino population when they are ill (Britigan et al., 2009). Other research has found that for low-income and less-educated Latino women whose English proficiency is low, aural and visual channels such as radio and television are more likely to be trusted venue for health messages, and this could include messages about HIV testing (Clayman et al., 2010).

Children (HIV-tested Latinas) and *friends* (non-tested Latinas) appear to be highly important enablers of HIV testing behaviour. These findings support previous research emphasising the importance of children and childcare in Latino families and also the central role of social support in Latino health promotion. Domenech Rodríguez et al. (2009) established child rearing and parenting as important priorities in Latino families. Furthermore, Hardway and Fuligni's (2006) research revealed a high level of connectedness between Latino parents and children. Social support plays a significant role in promoting health of Latinos (Mulvaney-Day et al., 2007). Social support, which included friend support, has been positively related to self-rated physical and mental health among Latinos. Chang et al. (2014) also demonstrated that friend support influences access and use of informal mental health services. They found that those with friendship networks were more likely to seek out professional services because these networks served as referral points for treatment seeking.

The trend in HIV testing research is to focus on the barriers to accomplishing voluntary uptake of HIV testing in populations identified as 'hard-to-reach' and 'at greatest risk' for late diagnosis. Health educators and other professionals are continuing to address these barriers through interventions that will change, limit or eradicate these barriers (Obermeyer and Osborn, 2007). This study builds on the body of knowledge about supportive factors for HIV testing which, in public health practice, could serve as reinforcements for health education outreach and interventions to enhance HIV testing uptake. These enablers of voluntary testing may lend insight into facilitators of treatment seeking and adherence behaviours once an HIV-positive diagnosis is known. Our findings call for increased awareness and understanding among health educators and other health professionals about the context in which women of Latino heritage make health-related decisions and the importance these women place on the cultural, social and environmental supports that surround them.

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Declaration of conflicting interests

The content is the sole responsibility of the authors and does not necessarily represent the official views of the National Institute for Minority Health and Health Disparities or the National Institutes of Health.

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