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Knowledge and Willingness to Provide Research Biospecimens Among Foreign-born Latinos Using Safety-net Clinics

Christopher A. Loffredo, PhD, Gheorghe Luta, PhD, Sherrie Wallington, PhD, Solomon B. Makgoeng, MS, Claire Selsky, MA, Jeanne S. Mandelblatt, MD, MPH*, and Lucile L. Adams-Campbell, PhD* for the Latin American Cancer Research Coalition and the Region 1 Biospecimen Management of Cancer Health Disparities Program

Cancer Prevention and Control Program, Lombardi Comprehensive Cancer Center, Georgetown University Medical Center, Washington, DC

Abstract

Background—Latinos tend to be under-represented in cancer research and in bio-repositories.

Send Correspondence to: Dr. Christopher Loffredo Lombardi Cancer Center Georgetown University 3800 Reservoir Road Washington, DC 20057 cal9@georgetown.edu Phone: 202-687-3758.

*dual senior authors

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The Latin American Cancer Research Coalition included:

Stacey Banks

Larisa Caicedo MA

Janet Cañar MD, MPH

Michael Dalious MA

Marguerite Duane MD, MHA

Jessika Duarte

Kirsten Edmiston MD

Karol Espejo

Ronald Greger MD

Margarita Gutierrez

Elmer E. Huerta MD, MPH

Anna Maria Izquierdo-Porrera, MD

Barbara Kreling PhD, MPH

Maria Lopez-Class PhD, MPH

Gheorghe Luta PhD

Jeanne Mandelblatt MD, MPH

Barbara Merritt RN

Guadalupe Mota

Noel Mueller MPH

Nancy Pallesen MSW

Margarita Paredes MD

Monique Perret-Gentil MD, MS

Jyl Pomeroy RN

Dino W. Ramzi MD, MPH

Christine Reesor MSN, FNP

Juan Romagoza, MD

Michael A. Sanchez MPH, CHES

Claire Selsky MA

Cherie Spencer MS

Alicia Wilson

Bin Yi MS

Members of the BMaP Initiative included:

Lucile Adams-Campbell, PhD

Shereida Muthra, MS

Sarah Reisinger, MS

Peter Shields, MD

Methods—We conducted a Spanish-language, interviewer-administered cross-sectional survey of 331 foreign-born Latinos from Central and South America attending safety-net clinics in order to describe factors associated with knowledge about and intention to provide bio-specimens for research purposes. We used logistic regression and multiple imputation methods to evaluate associations between socio-cultural measures, medical trust, demographics, as well as knowledge about and intentions to provide bio-specimens.

Results—Almost half (47%) of respondents knew what bio-specimens were, and 67% said that they would provide a specimen after being given information about what this involved; this increased to 72% among those with prior knowledge. Controlling for covariates, Latinos with a high school education and above were more likely to know what a bio-specimen was and to say they would provide bio-specimens than were those with lower levels of education (adjusted OR [aOR] 2.85, 95% CI 1.37-5.96; and 3.49, 95% CI 1.41-8.63, $p < .01$, respectively). Those with greater social integration were more likely to know about bio-specimens than those with less integration (aOR 2.54, 95% CI 1.45-4.46, $p = 0.001$). Higher endorsement of family values was independently associated with intent to give bio-specimens (aOR 1.11, 95% CI 1.02-1.20, $p = 0.017$ per five-point increase in “familism” score). Medical mistrust was not related to intentions to provide specimens.

Conclusions—Our results suggest that interventions to increase willingness to provide bio-specimens could leverage trusted clinics or social networks and should consider individuals’ education and socio-cultural perspectives.

Keywords

Biospecimens; Latinos; Culture; Research

Introduction

Rapid growth in the Latino population over the past decade has made this group the largest minority in the US [1, 2]. Currently numbering 50.5 million, Latinos make up 16.3% of the general population [2]. Cancer is the second leading cause of death among Latinos, and Latino cancer patients have higher overall case fatality rates than Whites [3]. Unfortunately, despite their large numbers and poor outcomes, Latinos tend to be under-represented in cancer research, [4] including bio-specimen repositories [5,6].

This under-representation of Latinos may be related to several factors, including limitations in language and health literacy as well as cultural norms about research, and this may hinder progress in personalizing care for the growing US Latino population [7,8]. Recently, the National Cancer Institute (NCI) increased efforts through the Office of Biorepositories and Biospecimen Research to develop infrastructure for collecting biospecimens from broad populations – the NCI defines biospecimens as a quantity of tissue, blood, urine, or other human-derived biological material [9].

These initiatives have been expanded to target Latinos and other under-served and minority populations in different geographic regions under the Geographical/Bio-specimen Management of Cancer Health Disparities Program (G/BMaP) [10]. However, these efforts are likely to be hampered by the relative paucity of quantitative data on the barriers to and promoters of donation of biospecimens by Latinos [11,12].

In this cross-sectional study, we evaluated knowledge about and intentions to provide bio-specimens for cancer research among a large sample of foreign-born Latinos from Central and South America attending urban safety-net clinics. Safety-net providers are defined by the Institute of Medicine as those who “...organize and deliver a significant level of health

care and other health-related services to the uninsured, Medicaid, and other vulnerable patients” [13]. Thus, these clinics represent an important avenue to engage Latinos and other minority and underserved populations in biospecimen research.

We used the socio-ecological model [14,15] as a theoretical framework to evaluate the unique factors that might impact biospecimen data collection in this population, since many cancer health-related behaviors of and disparities experienced by Latinos have been noted to be grounded in sociocultural realities and conditions [16-20]. The model includes intrapersonal level factors (education level and attitudes), interpersonal level/social environment processes whereby culture, social organizations, and role expectations affect health behaviors, and organizational, community, and physical environment influences, including provider accessibility, communication and trust and insurance status.

Using this theoretical framework, we hypothesized that higher education would be associated with knowledge about biospecimens among foreign-born Latinos but that those with a greater collectivist or familial orientation and those with greater involvement in social organizations would be more likely to have positive intentions to provide biospecimens. Finally, we expected that medical mistrust would decrease intentions to provide biospecimens. Our results are intended to inform future interventions designed to increase the provision of biospecimens by Latinos so that future research findings and therapeutic advances can benefit this group and improve their cancer outcomes.

Methods

This study was conducted by members of the Latin American Cancer Research Coalition (LACRC) and the Region I Biospecimen Management of Cancer Health Disparities Program (BMaP). The LACRC was an academic-community partnership with community safety-net clinics providing care to low-income, uninsured Latinos in the metropolitan Washington, DC area. The Region I BMaP was an effort to provide geographical coordination of biospecimen science in the DC, Maryland and Virginia area. All procedures were approved by the Institutional Review Board at Georgetown University.

Setting and Population

The study was conducted between June and August of 2010 in seven freestanding safety-net clinics that provide low- or no-cost services primarily to foreign-born Latinos. We recruited a convenience sample from each clinic. Eligible participants were self-identified as Latino and > 21 years old. We obtained informed consent (in Spanish), and each participant received a \$15 gift card for his/her time.

We approached 414 patients and 88% consented to participate. The most common reasons for refusal included not having time, not being interested, and having other commitments. Among the 364 who completed surveys, 24 were excluded post-hoc because they were missing more than 50% of their data due to interview interruption by clinical care or time conflicts. From the resulting sample of 340, we excluded nine who were not foreign-born and/or born outside of Central or South America. The remaining 331 individuals constituted the final analytic data set.

Data Collection

We developed a structured interview instrument using validated Spanish-language instruments. Trained bicultural and bilingual staff conducted face-to-face interviews in a private space; interviews lasted about 30 minutes; 99% were completed in Spanish.

Outcome Measures

We used knowledge of biospecimens and intentions to provide biospecimens for research as our outcome measures. Prior knowledge about biospecimens (an intrapersonal level variable) was ascertained first and was evaluated using a single item probing knowledge about the definition of a biospecimen in a multiple choice answer format. We present results for knowledge (yes vs. no) based on the correct vs. incorrect answers to the prompt.

Next, respondents were provided a short explanation of biospecimens and their use in research. We then assessed intentions to provide biospecimens using responses to a single item on a 4 point Likert scale, scoring 1 as “I would not consider it” and 4 as “Definitely would consider.” We dichotomized the variable to classify patients into high (“definitely would consider”) vs. low (“would not consider”, “might consider”, and “probably would consider”) intent categories.

Correlates of Outcomes

Based on our theoretical model, socio-cultural factors were our primary correlates of interest regarding biospecimen knowledge and intent to provide these specimens; prior knowledge of biospecimens was also used as a predictor of intentions. Latino culture was conceptualized as the beliefs, values, and customs within this group [21] and was assessed using several measures. The first was collectivism, measured using an 8-item validated Spanish-language instrument developed by Bagley, Dilworth and colleagues [22]. Responses ranged from 1 to 9 (Cronbach’s $\alpha=.61$). We also used the 18-item Familism Scale developed by Lugo to measure importance of family values (Cronbach’s $\alpha=.80$) [23]. Social network integration was measured using a Spanish-language item from the HINTs survey, probing the number of social organizations in which a respondent was a member [24]. Social and other aspects of acculturation were measured using the social (Cronbach’s $\alpha=.70$) and language (Cronbach’s $\alpha=.75$) acculturation items from the Marin and Marin scales [25].

Medical context was assessed via medical mistrust based on our prior research about health behaviors in this population; we used a Spanish translation of the 7-item LaVeist Medical Mistrust Scale (Cronbach’s $\alpha=.80$) [26,27]. Since all of the participants from these safety-net clinics were uninsured, we did not include insurance status in the analyses.

Controlling Variables

Controlling variables included sociodemographic characteristics, including age, region of birth (countries in Central vs. South America), clinic attended, length of time living in the US, educational level (>high school vs. < high school), and marital status (presently married or living as married vs. not).

Data Analysis

We used our theoretical model to guide evaluations of the associations between biospecimen knowledge and intention to provide bio-specimens and study variables using t-tests (or Wilcoxon rank sum tests if needed) and chi-square tests (or Fisher’s exact tests if needed). We used logistic regression to separately model knowledge and intentions. We began by including all variables that were associated with at least one outcome at the $p=.10$ level in bivariate analyses. We then removed variables from the models if they did not have a statistically significant association with either outcome. However, we specified retention of age, gender, education, region of birth, clinic, and years living in the US for face validity. We assessed the predictive ability of the models using the C-statistic. As a sensitivity analysis, we used multiple imputation methods to impute values for missing data. The R package “MI” was used to generate 10 imputed data sets [28]. Estimates from the logistic

regression models corresponding to the 10 imputed datasets were combined according to the method of Rubin [29,30] for comparison with those from models using observed data. Parameter estimates and confidence intervals from both methods were nearly identical for each outcome; therefore we provide results from observed data only. All analyses were performed using SAS 9.2 and R 2.13.0.

Results

Study Population

Characteristics of the overall study sample are shown in Table 1. The mean age of participants was 43 years, just over half were females, and approximately half were unmarried. Eighty percent had attained only a high school education or less. On average, this foreign-born Latino group had lived in the US for 12 years.

Knowledge and Intentions

Almost half (47%) of the participants knew the correct definition of a biospecimen. In bivariate analyses, correct knowledge was significantly associated with higher educational level or being a member of one or more social organizations and inversely associated with familism scores. Knowledge was not associated with age, gender, marital status, or social acculturation.

Overall, 67% of respondents intended to provide a biospecimen; this increased to 72% among those who had prior knowledge of biospecimens. In bivariate analyses, positive intentions were associated with older age and higher education, but not with other socio-demographic characteristics or medical mistrust. Intentions to provide biospecimens were also positively associated with membership in one or more social organizations.

Results of Multivariable Models

Taking into account the covariates related to knowledge about and intention to provide biospecimens, we observed that several factors were strong, independent predictors of these outcome measures (Table 2). Higher education level (> high school) was associated with nearly 3-fold increased odds of knowing about biospecimens (aOR 2.85, 95% CI 1.37-5.96, $p=0.005$), relative to those with less education. Those who belonged to one or more social organizations (vs. none) had more than 2-fold increased odds of having correct knowledge of biospecimens (aOR 2.54, 95% CI 1.45-4.46, $p=0.001$). Positive intention to provide a biospecimen for research was associated with increasing age (4% increased odds of intention per 5-year increase) and increasing levels of familism (11% increased odds of intention per 5-unit increase on this scale).

Discussion

To our knowledge, this is the first quantitative study to examine correlates of knowledge about and intentions to provide biospecimens for research purposes in a Latino sample from safety-net clinics. Our results indicate that nearly half of this population has knowledge of biospecimens, and a majority said they would provide biospecimens if asked. Consistent with the socio-ecological model framework, socio-cultural constructs and education were positively associated with both correct knowledge and intention to provide biospecimens for research. Of note, medical mistrust was not a barrier to intentions regarding provision of specimens in these safety-net clinics.

While 67% of Latinos in our sample intended to provide biospecimens, increasing to 72% among those with prior knowledge, these rates are lower than those reported in the general

US population. For example, almost 85% of individuals agreeing to complete a National Health and Nutrition Examination Survey stated that they would contribute biological samples for future research [6]. In a study of patients, their families and healthy volunteers coming to the National Institutes of Health Clinical Research Center, 85% authorized use of their biological samples. There were no Latinos included in the sample, but 75% of African-Americans in that study agreed to use of their biospecimens [5].

Our results support the hypothesis that socio-culturally-related beliefs are one explanation for the somewhat lower rates of participation of Latinos in biorepository initiatives [31]. For instance, we found that higher levels of social acculturation and affiliation with social networks were important in having knowledge about biospecimens, yet many foreign-born Latinos have limited social networks. Therefore, outreach to newer immigrants via Latino social networks using a community-based participatory research framework [32, 33] could increase participation in biospecimen research by Latinos with fewer social connections. For those who are more highly socially affiliated, Latino social networks could also be used as information channels. The observed positive association between family values and intentions to provide specimens suggests that messages conveyed through social networks might emphasize the benefit for future family generations [11]. These hypotheses will need to be tested in future research.

Low levels of education and related intrapersonal barriers such as limited English-language ability and poor health literacy also appear to play a role in the low rate of inclusion of Latinos in biorepositories [4, 7, 31]. Thus, information about medical research in general and biospecimens in particular may be “lost in translation” for Latinos. For instance, the materials currently available from the National Cancer Institute about biospecimens are only available in English and appear to be written at a much higher level than 8th grade, which inhibits their accessibility [34]. Thus, future efforts to increase knowledge about research biospecimens may need to be sensitive to language, health literacy barriers, and cultural perspectives [31]. Use of existing Spanish-language information channels could also enhance communication about research specimens, especially if they are targeted to appropriate health literacy and/or educational levels of diverse Latino audiences [32, 36].

Foreign-born Latinos may be unwilling to agree to the provision of biospecimens or research participation in general if they have fears about their immigration status, which raises potentially complex legal issues [36]. Latino-focused safety-net clinics, such as those in our study, may present a good venue for biospecimen research and community outreach since we observed that medical mistrust was not associated with lack of intentions to provide specimens. Others have found that therapeutic benefit could also override trust issues in minorities [11]. Moreover, similar to behavior in non-minority groups [37,38], among minorities already enrolled in a study, most would be willing to provide specimens [5, 11, 39]. Non-invasive methods of biospecimen collection may also favor the participation of Latinos (and others) in biomedical research. For example, recent advances in the development of user-friendly, non-invasive specimen collection tools, such as buccal swabs and oral rinses, could increase the acceptability of providing biological materials as part of survey and other research [40].

There are several caveats that should be considered in evaluating our results, including issues related to the study population, cross-sectional design, and measures. Our study sample was homogeneous with respect to insurance, immigration and broad countries of origin, so it is not possible to generalize the findings to all Latinos in the US or to directly compare data from other ethnic groups. Given the cross-sectional design of this study, we were unable to determine causal links or directionality of the observed associations. Next, we used intention as one outcome measure. While intentions correlate with many health

behaviors, we do not have information on how well intentions will predict actual behavior in providing biospecimens. Results from other research have been inconclusive [41]. We also do not know whether Latinos diagnosed with cancer would be more or less likely to provide biospecimens than Latinos from a healthy unaffected population [11]. In addition, our population was all foreign-born, low-income, and uninsured, therefore we could not test the impact of measures such as insurance and perceived health care access on biospecimen knowledge or intentions.

We included measures of culturally-related constructs, but it is difficult to capture the essence of an individual's or group's values and context with standardized survey items [42]. These values may be especially important in decisions to provide specimens to biobanks [43]. Additionally, there may be cultural differences between the Central and South American sub-groups included in our study that were not fully captured by considering country of origin in analyses. Finally, generalizations about Latino culture can also promote stereotypes that may not be true for specific individuals [42].

The findings of this study contribute to the limited base of knowledge regarding Latinos and biospecimen data collection, particularly since these groups are especially vulnerable to under-representation in cancer research. Our results suggest that increased education and having stronger social networks are correlates of correct knowledge about and intention to provide biospecimens. The findings also support the idea that collectivism, as embodied by strong family values, may lead to increased willingness to participate in donating biospecimens for research purposes. Trusted safety-net clinics, Latino social networks, churches, peer educators (*promotoras*), and Spanish language media [44-46] may provide natural leverage points for future research, including efforts such as the National Cancer Institute's Cancer Human Biobank (caHUB) initiative [47].

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Table 1

Unadjusted Associations between Knowledge and Intentions to Provide Biospecimens and Intrapersonal and Socio-Ecological Factors among Foreign-born Latinos in Safety-net Clinics

	Knowledge of Bio-specimens, n=323			Intent to Give Bio-specimen, n=325		
	Yes (47%)	No (53%)	P	Yes (67%)	No (33%)	P
Age, mean years (sd)	44 (±15)	42 (±14)	0.20	45 (±14)	38 (±14)	<.001
Gender, n (%)						
Male	62 (41)	86 (50)	0.11	107 (49)	44 (41)	0.20
Female	87 (58)	84 (49)		109 (50)	61 (56)	
Missing	2 (1)	2 (1)		1 (0)	3 (3)	
Marital Status, n (%)						
Married	71 (47)	81 (47)	0.99	100 (46)	53 (49)	0.61
Not Married	80 (53)	91 (53)		117 (54)	55 (51)	
Education, n (%)						
<=High School	105 (70)	155 (90)	<.001	163 (75)	98 (91)	<.001
>High School	46 (30)	17 (10)		54 (25)	10 (9)	
Number of Years in US, mean (sd)	12 (±10)	13 (±9)	0.56	12 (±9)	12 (±10)	0.60
Missing	1	0		1	0	
Collectivism ^I , mean (sd)	58 (±5)	59 (±7)	0.46	59 (±5)	58 (±8)	0.07
Missing	3	2		3	2	
Familism ^I , mean (sd)	157 (±18)	162 (±17)	0.02	160 (±17)	158 (±18)	0.24
Missing	12	11		16	7	
Medical Mistrust ^I , mean (sd)	22 (±5)	22 (±5)	0.31	22 (±5)	22 (±5)	0.33
Missing	36	44		48	33	
Social Acculturation ^I , mean (sd)	9 (±2)	8 (±2)	0.03	8 (±2)	8 (±3)	0.56
Missing	60	57		83	33	
Member of Social ^I Orgs, n (%)						
None	79 (52)	125 (73)	<.001	126 (58)	79 (73)	0.008
At least one	72 (48)	47 (27)		91 (42)	29 (27)	
Intend to Give Biospecimen, n (%)						
Yes	108 (72)	105 (61)	0.04	--	--	--
No	41 (27)	65 (38)		--	--	--
Missing	2 (1)	2 (1)		--	--	--

Significant associations shown in bold font

^I Higher scale scores indicate higher levels of the attribute measured. Scale and subscale scores had the following possible ranges: Collectivism, 8-72; Familism, 18-180; Medical Mistrust, 7-28; Social Acculturation, 4-20.

Table 2

Adjusted Odds Ratios for Associations between Knowledge of Biospecimens and Intent to Provide a Biospecimen and Intrapersonal and Socio-Ecological Factors among a Sample of Foreign-born Latinos in Safety-Net Clinics¹

	Correct Knowledge of Biospecimens n=292 (yes vs. no)		Intent to Give Biospecimen n=294 (yes vs. no)	
	OR (95% CI)	P-Value	OR (95% CI)	P-Value
<i>Intrapersonal/Demographic Factors</i>				
Age (per 5 yrs)	1.00 (0.98-1.02)	0.98	1.04 (1.02-1.07)	0.001
Gender (female vs. male)	1.67 (0.92-3.03)	0.09	0.88 (0.46-1.67)	0.70
Education (>high school vs. high school)	2.85 (1.37-5.96)	0.005	3.49 (1.41-8.63)	0.007
Number of years in the US	0.98 (0.95-1.01)	0.21	0.97 (0.94-1.00)	0.08
<i>Socio-Ecological /Cultural Factors</i>				
Familism ²	0.95 (0.88-1.02)	0.173	1.11 (1.02-1.20)	0.017
Member of social organizations (yes vs. no)	2.54 (1.45-4.46)	0.001	1.54 (0.83-2.86)	0.174

Significant associations shown in bold

¹Results for logistic regression models controlling for all variables in the table and clinic and region of birth (Central and South America). Some parameters were retained in both models for comparability and/or face validity (e.g., number of years in the US). Parameters were estimated from observed data. Point estimates (odds ratio [OR]) and confidence intervals (CI) for the complete observed data were comparable with those from models using imputed data. C statistics were 0.73 and 0.74 for the knowledge and intent models, respectively.

²Based on a scale score coded from low to high, where a high score on the familism scale reflects a high degree of familism. The odds ratio refers to the change in odds of observing the outcome for each five-point increase in the scale score.

³Higher scale scores indicate higher levels of the attribute measured. Scale and subscale scores had the following possible ranges: Collectivism, 8-72; Familism, 18-180; Medical Mistrust, 7-28; Social Acculturation, 4-20.