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ORIGINAL ARTICLE

Engaging diverse populations in biospecimen donation: results from the Hoy y Mañana study

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Abstract The disproportionately lower number of certain subpopulations participating in clinical and prevention research has a significant impact on the representativeness of scientific outcomes. The Hoy y Mañana program (Today and Tomorrow) was developed as a culturally and linguistically appropriate education program to engage diverse medically underserved populations without a cancer diagnosis in biospecimen donation for cancer genomic research. Participants were recruited to in-depth community-based educational programs (~45–60-min duration) or during open events in the community based on a convenience sampling. Programs were offered in English and Spanish. An on-site mobile lab along with phlebotomy services was provided at all programs and events to collect participant biospecimen (blood) samples to be stored at the cancer center's Data Bank and BioRepository (DBBR). The distributions for education, race/ethnicity, and gender were similar across the event types. Most of the participants were women. The analysis sample had a total of 311 participants, including 231 from the education programs and 80 participants from open events. Those with a higher education (college or more) were more likely to donate than those with a lower level of education (high school or less) (45 vs 28 %, $p = 0.007$). Actual donation status was not associated with age or race. Willingness to donate a biospecimen and biospecimen donation rates followed the same pattern with respect to participants with higher levels of education being more willing to donate and giving a blood donation. Prior to outreach efforts, less than 6 % of specimens donated to DBBR from healthy/non-cancer patients were from minority participants.

Keywords Biospecimen donation · Community outreach · Hispanic · African American · Education

Introduction

The collection of biospecimens in cancer research is increasingly more common; however, as with other types of biomedical research, ethnic and minority populations are often underrepresented in such studies. The availability of biospecimens is critical in moving cancer research forward and essential to the field of personalized medicine (Olson et al. 2014; Smith and Aufox 2013).

Several studies have shown low levels of awareness regarding biospecimen research among various racial/ethnic minority populations. However, community outreach that includes education on biospecimen research practices and efforts has resulted in a high level of interest in biospecimen donation (Dang et al. 2014; Dash et al. 2014; Hagiwara et al. 2014; Kiviniemi et al. 2013; Luque et al. 2012; Rodriguez et al. 2013; Tong et al. 2014). A commonly cited barrier to biomedical research participation among African Americans is "medical mistrust," but findings from Hagiwara et al. (2014) and

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Dash et al. (2014) both support that this is not the most reported barrier for biospecimen donation among this population. Common barriers to donation noted by African Americans relate to transparency with respect to how biospecimens will be used in research, a lack of knowledge of biospecimen collection, and not being approached or asked to participate in the research (Dash et al. 2014; Hagiwara et al. 2014). These barriers may explain the low participation of African Americans in biospecimen research, despite the cancer health disparities that exist in this population.

Hispanics, also underrepresented in biospecimen research, represent a diverse population with respect to the many countries of origin, cultural characteristics, and cancer rates. A study among a predominantly Puerto Rican population found low levels of awareness regarding biospecimen research (Rodriguez et al. 2013); however, in a study with participants from Central and South America, close to one half of respondents knew what biospecimens were and almost two thirds indicated they would donate a specimen upon receiving information regarding what the research involved (Loffredo et al. 2013). Both of these studies were conducted in Spanish language and included low-income medically underserved Hispanic populations, but medical mistrust was not reported as a barrier to intention to donate a biospecimen for research.

To date, no published studies have explored community-based strategies for engaging diverse disease-free (i.e., without a cancer diagnosis) ethnic minorities in the donation of biospecimens for broad use in research. Additionally, there is a lack of information on the participation rate of diverse ethnic minority populations who are asked to participate in biospecimen donation for cancer research. The purpose of this feasibility study was to test our ability to use community-based participatory research (CBPR) techniques to engage diverse medically underserved community members in biospecimen donation for cancer research through the use of a mobile laboratory .

The Hoy y Mañana (translated Today and Tomorrow) study was initially developed using a CBPR approach to understand the level of awareness and interest in biospecimen donation for cancer research among Hispanic community partners who were previously engaged in various cancer prevention programs and services. Results from previous pilot studies with Hispanics and African Americans, as well as the development of the education program with Hispanic and African American community partners, have been presented elsewhere (Erwin et al. 2013; Kiviniemi et al. 2013; Meade et al. 2015; Rodriguez et al. 2013).

In this community-based study, we tested the effectiveness of two different recruitment strategies to engage medically underserved African American and Hispanic community members without a cancer diagnosis in on-site biospecimen donation. Our objectives in testing these recruitment strategies were to identify predictors of participation and the best methods for engaging diverse medically underserved, underrepresented populations in biospecimen donation for cancer research.

Materials and methods

Study approval and consent

This study was approved by the Roswell Park Cancer Institute (RPCI) Institutional Review Board, and all participants who attended the educational programs were appropriately consented for the survey component of the study. Participants were then invited to participate in the RPCI Data Bank and BioRepository (DBBR), a Cancer Center Support Grant Shared Resource, with de-identified samples and data from cancer patients and community volunteers available for use by researchers (Ambrosone et al. 2006). Participants who agreed to participate in donating blood to the DBBR at either the educational programs or open community events were separately consented into the biobanking research program. There were no financial costs incurred to participants in either the educational programs or open community events.

Study design, setting, and participant recruitment

An in-depth description of the development process for the educational program and a comparative analysis of the tool have been previously described (Meade et al. 2015). Participants were recruited to in-depth community-based educational programs (~45–60-min duration) or during open events in the community based on a convenience sampling. All education programs and events took place within RPCI's primary catchment area of Buffalo and Niagara Falls, NY, which are predominantly urban regions. Engaging medically underserved African American and Hispanic adults from their respective communities was the focus of recruitment efforts for this study. All of the materials for the education programs and open events were available in both English and Spanish. The health educators who conducted both education programs and open events in the community were both race- and language-concordant for their respective target audiences. Individuals who participated in biospecimen donation were required to be adults (age 30+ years) with no personal history of cancer or cancer treatment.

Education program The educational programs, lasting about 1 h, including discussion and questions, covered information on genomic research and the need for representation from diverse populations as participants in biospecimen donation. An audience response system (ARS) was used to collect demographics and information to assess the impact of the program on willingness to donate to DBBR. Participants received a $10 gift card to a local grocery store. Following the education program, participants interested in donating a blood sample had the opportunity to do so, by way of on-site enrollment that included trained DBBR consenters and phlebotomy services, along with the mobile lab for processing and holding collected biospecimens.

Open events The open events typically lasted 3 to 4 h and included outreach activities at health fair type events in minority communities. They did not include the education program component. Staff at the outreach events engaged adults with a single pre-screen question to determine no personal history of cancer. Interested participants were directed to trained consenters from the DBBR who provided more detailed information and facilitated direct enrollment for biospecimen donation (i.e., blood).

Data sources

Survey data from education programs The education programs were designed in a PowerPoint format with embedded survey questions using the ARS to poll and record participant responses. The embedded survey included items about demographics, knowledge, and willingness to participate in biospecimen donation.

Participant sign-in sheets from open events Adults who were willing to speak with a trained consenter for the biobank completed a brief sign-in sheet that collected several demographic items: name, zip code, sex, age, race\ethnicity, and level of education (i.e., less than high school, high school grad\GED, some college\trade school, college graduate, and graduate school).

Process measures from education programs and open events were also assessed in terms of the number and type of programs delivered in the community.

Statistical analysis

Descriptive statistics were reported for the demographic characteristics by type of program (i.e., education program and open event) including the main outcome of biospecimen donation. Limited demographic data were collected during the open events due to the nature of this type of recruitment; the majority of the analyses were supported by data collected during the education programs. Pre- and post-education responses to a set of three items on intent to participate in a medical study were given specific conditions using the Bhapkar test for marginal homogeneity (Keefe 1982). Univariate descriptive statistics and χ^2 tests were used to explore associations of individual variables with intent to donate to DBBR after the education event. We also examined intention (post-education) versus actual participation in biospecimen donation by level of education using χ^2 tests.

Multivariable logistic regression was used to assess predictors of actual biobank donation status. Donation status was modeled as a dichotomous outcome (yes ref: no). The starting model was specified to include baseline characteristics having univariate p values <0.20. Gender, marital status, education, household income, and general health were included. The starting model was reduced by backward selection using a pre-specified type 3 retention threshold of $p < 0.20$. Only gender (male ref: female) and education (some college or more ref: high school or less) were retained in the final model. Multivariable results are described using estimated odds ratios (OR) and 95 % confidence intervals from this final model. All data analyses were generated using SAS/STAT software (version 9.4. Copyright 2012, SAS Institute Inc., Cary, NC, USA).

Results

A total of 370 participants were reached through 14 education programs ($n = 264$ participants) and 10 open events ($n = 106$) in the community from December 2012 through April 2014. Responses from 59 participants were excluded from the final analyses due to incomplete or missing data on race/ethnicity. The analysis sample had a total of 311 participants, including 231 from the education programs and 80 participants from open events.

Demographics

As shown in Table 1, the education programs engaged a greater proportion of adults aged 60+ years as compared to the open events (56 vs 11 %). The distributions for education, race/ethnicity, and gender were similar across the event types. Most of the participants were women. Open events yielded a higher biospecimen donation rate compared to the education events (55 vs 36 % respectively, $p = 0.003$).

Pre-/post-assessment of willingness to participate in a study

Generally, the education program induced a favorable increase in the proportion of participants willing to participate in a medical study. Before and after the education program, participants were asked three questions about participating in a medical study. These questions had three possible responses (yes/maybe/no). Question (1) was “Would you participate in a medical study that includes completing a questionnaire?” Responses showed a significant increase in the proportion of patients responding “yes” (45.2 % pre vs 51 % post) with a corresponding decrease in the

Table 1 Selected characteristics of participants without a cancer diagnosis in a community-based biospecimen donation study, by recruitment method ($N = 311$)

	Education program		Open event		
Characteristic	*n* (231)	(%)	*n* (80)	(%)	*p* value
Language of program					
English	146	(63)	40	(50)	0.038
Spanish	85	(37)	40	(50)	
Gender					
Female	176	(76)	69	(86)	0.066
Male	54	(23)	11	(14)	
Not reported	1	–	–	–	
Age (in years)					
18–39	27	(12)	17	(21)	0.000
40–59	70	(30)	50	(63)	
60+	130	(56)	9	(11)	
Not reported	4	(2)	4	(5)	
Race/ethnicity					
African American	139	(60)	39	(49)	0.075
Hispanic	92	(40)	41	(51)	
Education					
High school or less	112	(48)	34	(43)	0.682
Some college or higher	111	(48)	30	(38)	
Not reported	8	(4)	16	(19)	
Biospecimen donation					
Yes	83	(36)	44	(55)	0.003
No	148	(64)	36	(45)	

“maybe” responses (43 % pre vs 29 % post) (marginal homogeneity test $p < 0.01$). Question (2)"Would you participate in a medical study that involves giving a blood sample?" showed a similar pattern of increasing "yes" and decreasing "maybe" and "no" responses, but the changes were not statistically significant (marginal homogeneity test $p = 0.13$). Question (3) “Would you participate in a medical study that includes completing a questionnaire and giving a blood sample?” also showed a significant increase in “yes” responders (31 % pre vs 44 % post). Both the “maybe” and “no” responses declined (marginal homogeneity test $p < 0.001$).

Table 2 shows significant race differences in responses to two of the three pre-education responses and all three of the post-education questions about willingness to participate in a medical study. Generally, Hispanics were more inclined to participate than were African Americans. At baseline, Table 2 shows that Hispanics were more willing to participate across all three questions. When asked whether they would complete a questionnaire and provide a blood sample for a medical study, 55 % of Hispanics reported “yes” compared to 31 % of African Americans at post-education.

Post-education assessment of willingness to donate to the biobank

Table 3 shows the bivariate associations between participant demographics and willingness to donate to the biobank, as indicated on the post-education survey. Younger adults were considerably more willing to donate to the biobank than were older adults (omnibus $p < 0.001$). Hispanics were more willing to donate than African Americans were (answered “yes,” 66 vs 35 %, respectively, omnibus $p < 0.001$). Adults with some college or higher degree were also more likely to donate than were those with less formal education (answered “yes,” 57 vs 40 %, respectively, omnibus $p = 0.016$).

Rates of biospecimen donation

Overall, 41 % of participants ($n = 127/311$) in both education programs and open events donated a blood sample to DBBR. While almost 50 % of education program participants expressed willingness to donate a biospecimen ($n = 98/198$ in Table 3), only 36 % of participants ($n = 81/223$ in Table 4) actually donated a blood sample. Similarly, 57 % of participants with some college education or more expressed willingness to donate a biospecimen ($n = 56/98$ in Table 3), but only 45 % actually did donate. Those with some college education or more were more likely to donate than were those with high school education or less (45 vs 28 %, $p = 0.007$). Actual donation status was not associated with age ($p = 0.9$) or race ($p = 0.4$).

In multivariate analysis of participants in the education program, men were more likely than women to donate to the DBBR (OR 2.7 (1.3 to 5.4), $p < 0.01$) as shown in Table 5. Men were also more likely to have some college education, but the difference was not statistically significant (57 vs 48 %, $p = 0.27$ by χ^2tests). Participants with some college education had statistically higher donation rates than those with high school education or less (OR 2.1 (1.1 to 3.8), $p < 0.01$).

Discussion

Diverse medically underserved communities are less aware of opportunities to participate in biospecimen donation for cancer research as shown in our study and by others that have focused on recruiting underrepresented populations to cancer clinical trials (Ford et al. 2008); however, this lack of awareness did not translate to a lack of interest in participating in the research. As shown in similar studies, the use of a community-based education/outreach program facilitated engagement of diverse community participants and provided them with information on a novel opportunity to participate in cancer research through biospecimen donation (Dash et al. 2014; Gao et al. 2014; Hagiwara et al. 2014).

Table 2 Responses to biospecimen items, pre- versus post-educational program, by race and ethnicity

Questions		Pre							Post						
		Hispanic		AA		Total		*p*[a]	Hispanic		AA		Total		*p*[a]
		n (92)	(%)	*n* (139)	(%)	*n* (231)	(%)		*n* (92)	(%)	*n* (139)	(%)	*n* (231)	(%)	
Would you participate in a medical study that includes completing a questionnaire?	Yes	46	(50)	48	(38)	94	(43)	0.038	56	(64)	48	(40)	104	(50)	0.001
	Maybe	29	(32)	62	(49)	92	(42)		23	(26)	39	(33)	62	(30)	
	No	16	(18)	16	(13)	32	(15)		9	(10)	32	(27)	41	(20)	
Would you participate in a medical study that involves giving a blood sample?	Yes	41	(46)	43	(34)	84	(39)	0.196	48	(56)	46	(36)	94	(44)	0.015
	Maybe	23	(26)	37	(29)	60	(28)		18	(21)	33	(26)	51	(24)	
	No	25	(28)	46	(37)	71	(33)		20	(23)	48	(38)	68	(32)	
Would you participate in a medical study that includes completing a questionnaire and giving a blood sample?	Yes	37	(42)	27	(23)	64	(31)	0.007	46	(55)	36	(31)	82	(41)	0.003
	Maybe	31	(35)	46	(38)	77	(37)		17	(21)	38	(33)	55	(28)	
	No	21	(23)	47	(39)	68	(32)		20	(24)	42	(36)	62	(31)	

[a] A χ^2 test

An innovative and unique aspect of this study included the ability to offer on-site services (i.e., DBBR consenters, phlebotomists, and mobile lab for processing blood in real time) for donation at all of the community events. This effort significantly increased the proportion of non-white, non-patient controls in the biobank. The availability of control samples from minority populations for research projects is critical to successful, generalizable cancer genomic studies. Prior to outreach efforts, less than 6 % of specimens donated to DBBR from healthy/non-cancer patients were from minority participants. Results from our study can be used to refine approaches to increase enrollment in specimen banking, which are essential to enhance the utility of specimen banks so that they include samples that represent underserved communities. The mobile lab

Table 3 Univariate associations with post-education willingness to donate to the biobank (*n* = 231)

	Yes		Maybe		No		Total		
	n	Row %	*n*	Row %	*n*	Row %	*n*	Row %	*p* value
Gender									
Female	69	(46)	47	(31)	34	(23)	150	100 %	0.602
Male	27	(54)	14	(28)	9	(18)	50	100 %	
Age									
18–39	15	(65)	7	(30)	1	(4)	23	100 %	<0.001
40–59	37	(60)	20	(32)	5	(8)	62	100 %	
60+	43	(38)	34	(30)	37	(32)	114	100 %	
Race									
African American	41	(35)	40	(34)	37	(31)	118	100 %	<0.001
Hispanic	55	(66)	21	(25)	7	(8)	83	100 %	
Education									
High school or less	40	(40)	32	(32)	28	(28)	100	100 %	0.016
Some college or more	56	(57)	29	(30)	13	(13)	98	100 %	
General health									
Very good/excellent	25	(58)	13	(30)	5	(12)	43	100 %	0.021
Good	53	(53)	26	(26)	21	(21)	100	100 %	
Fair/poor	16	(30)	21	(39)	17	(31)	54	100 %	
Family/friend w/ cancer									
Yes	77	(50)	43	(28)	34	(22)	154	100 %	0.037
No	11	(29)	18	(47)	9	(24)	38	100 %	
Familiar with biobank									
Familiar	27	(68)	7	(18)	6	(15)	40	100 %	0.018
Not familiar	66	(43)	53	(34)	36	(23)	155	100 %	

Table 4 Comparison of biospecimen donation rates by participant level of education ($n = 223$)

Biospecimen donation	Level of education						p value
	High school or less		Some college or higher		Total		
	n	(%)	n	(%)	n	(%)	
Yes	31	(28)	50	(45)	81	(36)	0.007
No	81	(72)	61	(55)	142	(64)	

was well-received in the community and represents the first effort of this type to collect and process blood donations for cancer research in a community setting.

Participants' willingness to donate a biospecimen and biospecimen donation rates followed the same pattern with respect to those with higher levels of education being more willing to donate and giving a blood donation. Our findings are consistent with others which have reported that Latino participants with higher levels of education (i.e., beyond high school) are more willing to donate a biospecimen (Loffredo et al. 2013) and that older African Americans are more willing to provide biospecimens and personal information required for participating in medical research (Hagiwara et al. 2014). In addition, the donation rate for open events was significantly higher than for the educational programs (55 vs 36 %); this may reflect more of a methodological expediency difference than a choice by participants. Kiviniemi et al. (2013) also found a significantly higher participation rate for community fairs versus educational programs; $\chi^2(1) = 9.44$, $p < 0.05$. There is a time element involved with the number of participants waiting at any one time to donate blood and the maximum capacity for processing specimens per hour in the mobile laboratory. The people who attended open events were able to donate a biospecimen at their leisure over a period of time attending the event which results in a more gradual flow of participants as opposed to the education program format which requires all participants to wait in line to donate upon completion of the education session.

Table 5 Multivariable modeling for biobank donation status (yes (ref: no))

Covariate	Odds ratio (95 % CI) p value
Sex	
Women	Reference
Men	2.7 (1.3 to 5.4) $p < 0.01$
Education	
High school or less	Reference
Some college	2.1 (1.1 to 3.8) $p = 0.02$

Limitations/strengths

There are several limitations that should be considered with respect to our results, including issues related to sampling and feasibility of study processes. Our study sample was accrued through convenience sampling and yielded mostly female participants for both Hispanic and African American community recruitment efforts. Within the Hispanic population, participants were predominantly Puerto Rican. Cancer research involving the donation of biospecimens often involves a more complex process with respect to research participation and study recruitment efforts. In using a community-based approach, an intentional effort to build capacity among existing community partners is a required tenet of the research process but may also serve as a limitation in promoting non-randomized recruitment strategies for engaging participants from the community in the research opportunity. It is not possible for us to generalize our findings across all diverse medically underserved males or to all Hispanics and African Americans in the USA. Additionally, at some of our educational programs, especially those of groups greater than 15 people, we noted that either more participants were willing to donate specimens and the lab did not have the capacity to complete the blood draws and specimen processing in the time available or that participants were willing to donate, but unable or unwilling to wait until they could be consented and have their blood drawn. This demonstrates a limitation of this approach.

The application of a CBPR approach in the overall study design to engage ethnic minority populations in biospecimen donation for cancer research is an innovative use of CBPR and a unique strength. As shown in prior studies, being asked to participate is essential, and the convenience of participating at the community level is important, rather than having to seek out the opportunity at a research center (Hagiwara et al. 2014; Kiviniemi et al. 2013). Regardless of information transfer method (i.e., open event or structured group education), transparency in explaining the process and what is being asked of the participant, as well as providing examples of research that are relevant to the community or population of interest, is critical in engaging diverse disease-free (i.e., without a cancer diagnosis) adults in biospecimen donation (Dang et al. 2014; Tong et al. 2014).

Lastly, our data also included information from participants on knowing a family member or friend with cancer and how that factored into their willingness to donate to the DBBR. Participants that knew someone with cancer reported greater willingness to donate to the DBBR at post-education. This is an important factor to consider in both study design for specific research questions as well as in considering the influence of cancer on both friends and family of cancer patients that potentially may be more motivated to participate in research as a result of their personal connection. Through this work, we now have experience and understanding of a process template using a community-based approach that can be tailored to more specific cancer research questions that involve the collection of biospecimens from diverse and medically underserved populations to address cancer health disparities.

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Compliance with ethical standards

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Conflict of interest The authors declare that they have no conflict of interest.

Informed consent Informed consent was obtained from all individual participants included in the study.

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