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Pilot Intervention Outcomes of an Educational Program for Biospecimen Research Participation

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Introduction

A growing body of cancer research studies demonstrate that biological and tumor variations may impact disparities in survival [1, 2]. Molecular epidemiological investigations are exploring multiple biomarkers and variables that may account for these differences. Such investigations require large cohorts of participants with available DNA samples given the necessary statistical power to address questions of relation of biological and tumor

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variations to outcomes. This is particularly true for studies that examine variation by race/ethnicity or Ancestry Informative Markers (AIMs) [3].

This need for large participant populations has led to the creation of biospecimen and databanks with existing samples that can be accessed for studies. A biospecimen and data storage and retrieval bank generally collects biological specimens such as blood or saliva from participants in order to extract DNA, and often includes collection of survey data on lifestyle and behaviors. The goal is to provide large cohorts of participants, typically both cancer cases and healthy controls, whose de-identified specimens and questionnaire data can be made readily available to investigators for research.

The success of a biospecimen databank is critically dependent on successfully recruiting participants who are willing to provide the required biological specimens (blood, saliva, etc.) and to complete standard lifestyle survey measures [4]. Thus, the success of studies to examine biomarker differences and potential variations in populations can be limited by hesitancy and resistance to participate in research, especially among minorities, vulnerable populations and healthy non-patient participants. Few studies [5–7] have explored the issues of recruitment and accrual of cases and controls to biospecimen and databanks and how to improve this process, and many of those studies have either simply documented rates of refusal [8] or focused specifically about issues around informed consent to participate [5, 9, 10].

The study reported here is a community-based, pilot test of educational intervention methods to encourage participation of African American adults, specifically, as well as lower income urban white adults in a biospecimen and data banking program at a regional National Cancer Institute (NCI) - designated cancer center. An educational intervention was developed, guided by both research on affective and cognitive determinants of decision making (described below) and a community-based participatory research process assessing factors associated with willingness to participate (this project is described in the linked accompanying article). The outcome goals were: a) “yield” or completion of both biospecimen donation and a standard epidemiologic questionnaire (i.e., “lifestyle survey”) following the intervention, and b) pre-post change in potential participants' feelings about research participation. In this paper we report pilot results for both outcome goals for the educational intervention. In addition, we report additional data on participation completion goal based on a community event/health care recruiting method that did not involve an educational intervention.

Making the Decision to Participate in Research

Traditional approaches to examining decision-making factors influencing research participation have typically focused on perceived benefits and costs and barriers to participation [11, 12], based on the assumption that decisions to engage in the behavior involve a cost-benefit analysis. Relatively little attention has been paid to the role that affectively-based factors, such as the feelings and emotions one associates with research, might play in the decision making process (this lack of attention to affective factors mirrors a relative paucity of affective research in other areas of health decision making) [13, 14]. Recent empirical work in other areas of decision making has shown that affective associations, the affective states or specific emotions one associates with a behavioral choice, can play a central role in decisions about whether or not to engage in a behavior [14, 15].

Affective associations may guide behavior related to biobanking. Obtaining genetic and cellular material involves interaction with blood and other bodily fluids, which may make the procedures themselves associated with emotions of fear and/or disgust [16]. For research

participants from minority groups, research may be associated with fear and anger due to the substantial and highly salient historical legacy of unethical research involving minority group members [17]. Thus, in the intervention study reported here we examined whether the intervention was associated with changes in both the expected utility (perceived benefits versus perceived costs) of participating and the affective associations (e.g., fear, anxiety) associated with research participation.

Overview of the Current Study

Given the importance of large and diverse samples for successful biobanking projects and the issue of low participation of race/ethnic minorities in biobanking and other cancer research, it is important to develop ways to increase minority participation in biobanking. The interventions tested in the current study were developed based on both the understanding of cognitive and affective factors involved in decision making described above and in response to an ongoing community-based research project conducted as a partnership between racially diverse community members in Niagara Falls, NY, and a local cancer center to increase mutual understanding of genetic research recruitment and biobanking.

The biobanking program is a critical tool within the cancer center for developing a foundation for molecular and genetic studies of cancer prevention, diagnosis and treatment [18]. As a data and sample bank, each consented participant responds to a 36-page lifestyle and behavioral questionnaire, and donates a blood sample or saliva. On the cancer center campus, the blood is processed within an hour of obtaining it with blood components of plasma, serum, red blood and white blood cells, aliquoted and stored in liquid nitrogen for long-term storage. This is not possible when samples are collected off-site, so a community cohort was created in which all samples are processed within 24 hours. All specimens and the survey data are de-identified and coded with a barcode and numerical identification; specimens are stored indefinitely. The focus for recruitment to this biobank has been primarily cancer patients and their friends and family members. When this study began, there was limited experience recruiting healthy people (controls) from the community.

In this pilot project, we examined two strategies for increasing research participation. First, we developed a group educational intervention. This program was developed collaboratively by a community leadership group (CLG) made up of health professionals, political and community leaders, and lay community members and by cancer center researchers and health educators, was centered around increasing knowledge about cancer research and the role of biobanking, addressing cognitive and affective factors influencing decision making about participation, and ultimately increasing participation in the cancer center's biobanking program. Second, in response to the community partners desires to explore the ability to collect biospecimens at larger, community-based health fair events, a less intensive, "tabling" display with printed materials and media presentation on a laptop computer were created to take to community events. In this pilot study, we examined the ability of both the educational program and the less intensive health care program to encourage research participation. In addition, for the educational program, we examined how participation in the program changed participants' feelings associated with research participation.

Methods

This study was approved by the cancer center's Human Subjects Institutional Review Board and all participants in the one-hour educational programs were appropriately consented for the survey study. Participants from either the educational programs or the community events who agreed to participate in the biospecimen and data banking program were separately

informed and consented into the biobanking research program. There was no financial cost to participants for taking part in either the educational programs or health fair events.

Participant Recruitment

Participants for the one-hour educational programs were recruited from Niagara Falls by the Co-Investigator (Walker), staff (Clark), and CLG members. Recruitment methods included organizing sessions at local community centers, churches and hospitals. The programs were promoted as educational sessions about cancer research in general, not specifically biobanking donation. Community-event programs were held in partnership with local health fair sponsors from health care foundations and community organizations. Efforts were made to promote both programs and attract participants from all areas of urban Niagara Falls. Participants attending the educational interventions were offered a gift card (\$10) to a local retailer to attend the educational programs. Consistent with the biobanking program's standard protocol, participants were not provided any incentive for participating in the biospecimen banking study. The CLG and staff collaborated with local artists and students to create a logo and promotional materials for project recruitment.

Procedures and Educational Intervention

Prior to delivery of the group educational intervention, participants completed pre-intervention measures of expected utility about research, affective associations with research, behavioral intentions to participate in research, and demographics items (see *Measures*). Both pre- and post-intervention measures were presented one question at a time on PowerPoint slides; participants responded using Audience Response System (ARS) [19] electronic remote keypads. After completing the pre-intervention measure, the intervention was delivered. Based upon the formative findings reported in the companion paper, educational materials and an intervention program were developed to specifically address the primary concerns, barriers and issues described in the companion paper results, as well as the cognitive and affective decision making influences described in the introduction.

The educational program lasted approximately one hour and included an overview of the historical legacy issues of research (e.g. Tuskegee), current ethical conduct with humans, the nature and use of biospecimens banks, and concepts about cancer genetics and why genetic materials are needed. This educational intervention was tailored for multiple learning styles [20] and to include interactive use of Power Points.

At the conclusion of four of the seven educational intervention programs in the community, participants had the opportunity to immediately sign consents to participate in the biobank. For three programs, phlebotomists and immediate donation was not available on site. This was due to the fact that the study team responded to a community request for a program to be held on a Saturday (which precluded specimen processing within 24 hours because biobanking laboratory technologists do not routinely work on Saturdays or Sundays). For these three programs, collections were offered at a later date or saliva samples alone were requested, and participants could donate blood specimens at the cancer center. Although this methodological variation could be expected to impact participation, it did not impact the ability to collect all of the affective and behavioral measures for the educational intervention, and the study team considered this an important opportunity to explore and document whether or not participants would follow-up and donate at a later time or go to the cancer center to donate specimens. In addition, it was essential to the CBPR partnership to respond to the community requests for programs regardless of the laboratory scheduling, and as a pilot study, this was all part of our investigation of research participation patterns of what was effective in what setting.

Likewise, the CLG wanted to explore a less intensive recruitment process for educating community members and offering biobanking participation during health fairs sponsored by local health care foundations. This intervention involved a much briefer description of the biobanking program and a printed brochure and the opportunity to evaluate the level of participation by community members who receive a minimum of information about research and the biobank. No affective association or utility measures were collected from these settings. In addition to printed and media materials, a phlebotomist was available on-site to collect blood for these programs, or saliva alone was collected. There was no specific recruitment about biobanking for these events other than general information for people to attend the health fair by public announcement sponsored by the health care foundation.

Educational Intervention Effectiveness Measures

The effectiveness of the educational intervention was assessed by examining changes in both expected utility beliefs and affective associations about research participation from pre- to post-intervention. For each construct, separate questions were asked about participating in a study that involved completing a lifestyle survey and participating in a study that involved drawing blood. Expected utility beliefs were assessed with a single item asking participants to report their perceptions of expected utility (i.e., the degree to which perceived benefits of participating outweigh the perceived barriers/costs of participating). Participants responded using a 5-point Likert scale response with endpoints of 1="disadvantages greatly outweigh advantages" to 5="advantages greatly outweigh disadvantages".

Affective associations were assessed with modified versions of a standard affectively-based attitudes measure [21]. Participants reported to what degree they felt each of five affective states (annoyed, pleased, anxious, fearful, nervous) when considering participating in research (5-point Likert scale; 1="not at all" to 5="extremely"). Responses to the "pleased" item were reverse coded and the mean of the five responses served as the measure of affective associations.

Finally, for those sessions where subsequent participation in the biobanking program was available, we recorded whether the participant: a) provided a blood sample; b) took a questionnaire to complete; and c) subsequently successfully completed the questionnaire and returned it to the biobanking program.

Statistical Analysis

Pearson's Chi-square tests were used to test associations among participants' participation in biobanking and type of program (educational session vs. health fairs) by demographic variables. To examine intervention effectiveness, a within-participants *t* test was conducted on each outcome variable. The degree to which responses following the intervention were more favorable towards research (i.e., greater perception of advantages relative to disadvantages and lower negative affective associations with research participation) relative to responses before the intervention was examined for evidence of effectiveness. Statistical analyses were performed using SPSS v.20 (SPSS Inc., Chicago, IL).

Results

A total of 148 individuals participated in either the one-hour educational program (n=88) or at a health fair/event (n=60); those participating in a health care event had higher educational attainment ($\chi^2(4)13.42, p < .01$)—aside from educational attainment, participants in the two program types did not differ on any demographic characteristics.

Data from both program types is used in reports of participation in the biobanking process. For reports of educational intervention effectiveness, pre-post effectiveness data were

available for 76 of the 88 participants. There was one educational session where a technical malfunction prevented capture of the ARS questionnaire data (n=7). The remaining unavailable data (n=5) were from participants who completed the pretest questionnaire and educational session but did not complete the post-test questionnaire.

Demographic data for all participants are shown in Table 1. The overall participation rate was 74%; 114 of the 148 individuals consented to participate in some aspect of the biobanking process (i.e., donated a blood sample and/or completed a questionnaire). Of those, 107 (73%) donated blood and 77 (52%) people completed the extensive surveys. Seventy five individuals (51%) completed both parts of the biobanking process. In addition, 13 individuals donated saliva for DNA extraction.

Of the 88 educational program participants, 52 (59%) participated in some aspect of the program (50% questionnaire; 57% blood draw). The participation rate was significantly higher for community fairs versus educational programs; $\chi^2(1)=9.44, p < .05$. Notably, when a phlebotomist was on-site at either the educational or health fair program, 87% of individuals educated or asked, agreed to donate blood for the biospecimen and data banking program. This participation rate was significantly higher than when no phlebotomist was present (i.e., participants had to return to donate blood at a later time; $\chi^2(1)=5.52, p < .05$). Chi-square analyses of participation in biobanking of blood by racial and ethnic categories (collapsed to African American, White, and Other due to small and irregular cell size for some categories) showed no significant differences.

Pre- and post-intervention responses to the affective association questions about feelings associated with donating blood and answering an extensive lifestyle survey were used to answer the research question, “Does the educational program influence affective associations and/or expected utility beliefs about research participation?” Table 2 presents the means for each study type (lifestyle survey, blood draw) for pre- and post-intervention. As can be seen in the table, for both study types, affective associations became less negative following the intervention for the lifestyle survey $t(74) = 5.91, p < .001$ and/or blood draw $t(74) = 3.06, p < .01$. In neither case did expected utility beliefs change as a result of the intervention; both $t_s < 1.2, ns$.

Discussion

The results reported here on this exploratory pilot study of intervention effectiveness reveal several important (although preliminary) findings. First, the educational intervention resulted in relatively high levels of participation in the biobanking process; 74% of participants took part in at least one part of the process (i.e., provided blood, saliva, or lifestyle survey responses); this rate was even higher for programs where a phlebotomist was available to allow for immediate participation. Although the study design does not provide a control group, these rates are a high participation level for a research study, especially considering that racial/ethnic minorities and lower income adults may be less likely to participate in health research (treatment or prevention)[16]. These rates were higher than the 33% predicted in the community survey conducted in Niagara Falls (See results reported in the companion manuscript).

Second, the educational program significantly impacted a known influence on behavioral decision making; following the educational program, there was a significant reduction in the negative feelings participants associated with research participation. This reduction in negative feelings, combined with the overall behavioral outcomes discussed above, suggests that affective associations might be an important influence on the decisions individuals make to participate (or not participate) in research. As discussed in the introduction, this

may be particularly true for race/ethnic minority participants, for whom knowledge of historical mistreatment of race/ethnic minorities in research may impact affective associations with participation.

Lessons Learned

Finally, from a practicality of conducting biobanking studies standpoint, it is important to note that participation rates were substantially higher for providing blood/saliva samples than for completing the epidemiologic lifestyle questionnaire. This may reflect the significant time commitment necessary to complete extensive pen and paper surveys, especially by community residents who may have limited health literacy [22]. By contrast, providing blood and/or saliva samples can be accomplished relatively quickly, potentially reducing the “cost” (i.e., time, inconvenience, reading level challenges) of participation.

On a related note, although not specifically examined empirically, the CLG and study staff found it was significantly more difficult to recruit community members to attend the research-oriented, one-hour educational programs versus previous experiences with education sessions focusing on cancer-site/screening style education program (e.g., community programs focused on breast cancer/screening, colorectal cancer/screening, or prostate cancer/screening). The staff and CLG members reported that many community partners did not want to host a program “about research” and asked for presentations about screening or prevention services, or scheduled programs were cancelled at the last minute. We suggest that individuals are more likely to want and attend community-based programs about screening and prevention of cancer because the perceived benefit to the individual and their own health is much higher and the participant is likely to gain information that can be directly applied to their access to health care services. Attending an educational program about cancer research may be a more difficult “sell” to community members because the average “healthy” (i.e., no diagnosis of cancer) lay person does not perceive a direct benefit to his/her health or access to health care services by attending this program, as it may be perceived as too erudite and therefore, irrelevant. Moreover, the underlying nature and objectives of these educational programs are different as cancer site-specific programs serve the individual because they are focused on educating individuals to change behavior to improve the health and survival of that attendee. On the other hand, our research-specific programs are more self-serving for the cancer center biobank and the overall science of oncology because they were focused on changing behavior that directly benefits the representation of minority controls in the biospecimen bank..

Implications

Although limited in scope, these pilot study results are important contributions to the development of effective recruitment methods for biospecimen banking. They demonstrate the potential for effective intervention development through the productive collaboration of community members and cancer center staff. Important CBPR and capacity building process outcomes between the cancer center and Community Leadership Group relevant to intervention development are reported in our companion article).

The intervention effectiveness results reported here demonstrate the positive influence of conducting a focused, culturally appropriate educational program for lay community members about the nature, methods, and process of research and biobanking as specific research technique. These results demonstrated that educational programming can reduce negative associations with research participation. We know that affective associations with a behavior are associated with willingness to engage in that behavior [14, 15]. It is possible that a group presentation such as this intervention may serve as an enhanced consent process for promoting biobanking participation. This evidence for effectiveness is very promising.

The evidence is even more promising in light of the fact that a higher proportion of people educated about the study (75%) actually participated in biobanking compared to the reported willingness to participate as reported by the community survey findings (33% to 61%) (see Companion manuscript). Thus, this pilot examination of intervention effectiveness suggests that education programming about research participation may have great promise to influence decision making mechanisms and thus increase willingness to take part in research studies.

Limitations

As mentioned in our formative research report (see companion manuscript) a limitation as well as important caveat to this study is the fact that at least some of the results from this formative research reflect issues that may be specific to Niagara Falls and Western New York (e.g., Love Canal and concerns of toxic exposure and cancer risk) increased interest in research like the biospecimen and data banking program because of these exposures; long-standing, positive reputation of the cancer center as a focus for research). The industrial toxin history and scientific cancer environment in this region may be unique or reflect issues inherent in the Great Lakes and northeastern U.S.. Scientists and community members need to document the *local* variation of known factors, such as medical mistrust and fear of being a “guinea pig,” and other perceptions and beliefs that impact vulnerable individuals' decisions to interact with the local clinical and research community.

A second limitation may be a self-selection bias related to the educational program. Because it was somewhat challenging to recruit community members to education programs not focused on specific cancers and screening information, those individuals who did attend may have more inherent interest and proclivity for research; although this bias would not account for the effect of the intervention on affective associations or for the differential willingness to participate in parts of the biobanking process, it may lead to a greater overall participation effect than would be found in the general population. Future investigations of this intervention through a randomized controlled study design would strengthen the results and limit any potential self-selection bias.

Conclusions

This style of CBPR, although relatively new for interventions to recruit to clinical studies or data banks, has the potential to forge important links between scientific mission and the individual needs and problems of vulnerable communities by creating working, power-neutral collaborations with the community. The significance for the cancer control scientist is that these links can lead to the development of multiple types of community-based studies and greatly enhance the applicability and social representation in cancer research. As the proportion of the minority patient and at-risk populations in the U.S. increases, the challenges for cancer care and clinical research recruitment require the application of science *with* community partners. This study supports the existing literature that demonstrates increasing awareness and involvement within the community [23], incorporating community members in the process and directly addressing issues of social justice have been shown to increase participation and decrease resistance to clinical research[24, 25].

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Table 1

Pilot Intervention Study Participants & Outcomes

<i>Variables</i>	Type of Program			
		Educational Sessions (7 programs)	Health Fair/Event (7 events)	Total
<i>Attendees</i>		88	60	148
<i>Gender</i>	<i>Male</i>	23	13	36
	<i>Female</i>	65	47	112
	Total	88	60	148
<i>Race/Ethnicity</i>	<i>White</i>	24	30	54
	<i>AA</i>	15	22	37
	<i>Native American</i>	12	.	12
	<i>Mixed/Other</i>	4	1	5
	<i>Not collected</i>	33	3	40
	Total	88	60	148
<i>Age</i>	<i>18– 29</i>	14	1	15
	<i>30– 39</i>	5	8	13
	<i>40– 49</i>	3	11	14
	<i>50– 59</i>	16	12	28
	<i>60– 69</i>	13	7	20
	<i>70+</i>	13	9	22
	<i>Not collected</i>	24	12	36
	Total	88	60	148
<i>Participated in Biobanking^a</i>	<i>Yes</i>	52	57	114
	<i>No</i>	36	3	34
		88	60	148
<i>Surveys Completed</i>	<i>Yes</i>	44	33	77
	<i>No</i>	44	27	71
	Total	88	60	148
<i>Blood samples collected</i>	<i>Yes</i>	50	57	107
	<i>No</i>	38	3	41
	Total	88	60	148
<i>Spit Sample Given</i>	<i>Yes</i>	13	.	13
	<i>No</i>	6	.	6
	Total	19	.	19

Table 2

Pre- and Post-Intervention Expected Utility of and Affective Associations with Research Participation

Study Type	Pre-Intervention Mean (SD)	Post-Intervention Mean (SD)
Questionnaire		
Affective Associations	2.51 (0.67)	2.15 (0.69)*
Expected Utility	3.81 (1.21)	3.70 (1.23)
Blood Draw		
Affective Associations	2.38 (0.95)	2.18 (0.90)*
Expected Utility	3.82 (1.14)	3.60 (1.32)

* Rows marked with a indicate a pre-post difference at $p < .001$.