

Considerations for bio-specimen collection among black women residing in the rural Deep South participating in a cancer prevention study

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Introduction

Cancer is a leading cause of mortality and morbidity in the USA (Hoyert et al. 2012). Additionally, cancer health disparities (incidence, morbidity, mortality) exist in the USA despite notable progress in diagnosis and treatment (Ward et al. 2004).

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Racial/ethnic minorities, low socioeconomically disadvantaged populations, and persons living in rural areas experience the greatest cancer burden (Jemal et al. 2008). Bio-specimen collection is vital for the advancement of enhanced diagnostic, prevention, and treatment tools for cancer and other diseases. Bio-specimens, materials taken from the human body, provide valuable information about how to (1) identify and validate ways to deliver drugs or agents to specific cells, (2) identify how diseases progress and vary, (3) group patients, based on their genetic characteristics or biomarkers of their disease, to determine which treatment is most appropriate, and (4) develop screening tests to detect biomarkers that are associated with certain stages or subtypes of a disease (National Cancer Institute 2013b). Given the potential impact of personalized medicine to improve disease outcomes and eliminate health disparities, research on bio-specimens from samples of diverse populations of patients and healthy controls are critical. However, historically, racial/ethnic minorities are poorly represented in bio-specimen, bio-banking, and cancer research (Scott et al. 2010; Murthy et al. 2004; Rodriguez et al. 2013).

The 2010 American Society of Clinical Oncology (ASCO) Statement on Attributes of Exemplary Research Sites, a series designed to help clinical research sites exceed Good Clinical Practice guidelines, highlights the following as important considerations for engaging individuals in bio-specimen research: talking with patients, informed consent, and disclosing of research results (Baer et al. 2010). Though grounded in clinical practice and aimed at helping oncologists make clinical trials a key part of their practices, similar considerations are also relevant for community-based bio-specimen research. ASCO recommends that “communication about bio-specimen collection be thorough, open, and honest” and should include information about the rationale for collecting bio-specimens

along with risks and benefits (Baer et al. 2010). ASCO also endorses an informed consent process that includes specific information that is in regulatory compliance for bio-specimen research and also highlights that there may be a need for additional focus on the issue of custodianship (i.e., how specimens and privacy will be maintained) (Baer et al. 2010). Finally, ASCO highlights the patient's desire for wanting to receive results of tests performed on their sample and suggests that the ability to honor this request is dependent upon the nature of the trial (Baer et al. 2010).

Challenges for recruitment of racial/ethnic minorities and rural populations into bio-specimen research are similar to ongoing challenges of recruiting this population into clinical trials despite a greater burden of cancer-related morbidity and mortality among these groups relative to their white and urban counterparts. In an attempt to address the need for diversity in bio-specimen research, the National Cancer Institute (NCI) recently launched The National Bio-specimen Awareness and Collection Campaign (National Cancer Institute 2013a). The goal of this campaign is to advance the ability “to diagnose, treat, and prevent cancer among all people as well as reduce cancer disparities among high-risk population groups” (National Cancer Institute 2013a).

The Deep South Network for Cancer Control

Blacks living in the rural Deep South have a greater risk for cancer mortality than the national average (National Cancer Institute 2005–2009). In 2000, the Deep South Network for Cancer Control (DSN) funded by NCI was established to reduce or eliminate cancer disparities between whites and blacks (Lisovicz et al. 2006; Partridge et al. 2005). To accomplish this, an academic–community partnership spanning two states (Alabama and Mississippi) and up to 22 counties has been maintained over the past 13 years. Guided by Paulo Friere's empowerment theory (Freire 1970, 1983) and the community development theory (Butterfoss et al. 1993), our partnership has implemented a community-based participatory research (CBPR) approach (Lisovicz et al. 2006; Partridge et al. 2005) to decrease disparities in cancer screening rates (Partridge and Fouad 2010; Fouad et al. 2010; Castle et al. 2011) and reduce behavior risk factors for cancer (Baskin et al. 2011). Historically, the DSN has been successful in identifying and training “natural helpers” in the community to function as community health advisors that are trained as research partners (CHARPs) with a primary responsibility of conducting outreach and disseminating cancer prevention messages (Lisovicz et al. 2006; Partridge et al. 2005; Hardy et al. 2005). More recently, DSN efforts have expanded to include evidence-based programs for cancer prevention research in the community (Hardy et al. 2012). In an effort to address community interest in nutrition, physical activity, and weight control for

cancer risk reduction, a behavioral weight loss intervention is currently being implemented in eight rural DSN counties. Implementation of this program has offered us a unique opportunity to conduct a supplemental study to explore the feasibility of collecting a bio-specimen sample for research from a sample of black women living in the Deep South. The purpose of this paper is to describe lessons learned from collecting bio-specimens from a subsample of study participants and describe best practices and recommendations for increasing participation of underrepresented groups in bio-specimen research.

Conceptual framework

CBPR is the overarching framework for this research study. CBPR necessitates mutual partnership between academic researchers and the community to better understand the needs of the community and design programs that would maximally appeal to the targeted group (Savage et al. 2006). For both the main intervention and the supplemental study, we were guided by the nine principles of CBPR (Israel et al. 2003). Table 1 details how CBPR was applied specifically to the supplement study. This study was further directed by the Theory of Planned Behavior, which proposes that one's behavioral intention is the strongest predictor of her behavior (enrollment in bio-specimen research study) and that behavioral intention is influenced by one's attitude toward the behavior, subjective norms, and perceived behavioral control (Ajzen 1985). As such, several steps throughout the recruitment and enrollment processes that are described in this report were designed to elicit a positive attitude about the behavior, to demonstrate that the key community leaders and peers approved of the behavior, and to assure participants that of their personal control over the behavior.

Recruitment of participants

Participants for this supplemental study were recruited from the larger behavioral weight loss/cancer prevention intervention. To briefly describe recruitment, 338 black women residing in eight rural DSN counties (four in AL, four in MS) have currently been enrolled in the behavioral weight loss/cancer prevention intervention. Local county coordinators and local CHARPs assisted with recruitment by identifying potentially eligible women primarily through word-of-mouth and other personal contact like such as setting up tables/booths at common areas like local supermarkets or neighborhood stores that were frequented by large volumes of local women. Potential participants were initially screened for eligibility by the local Coordinator with follow-up via telephone by central office research staff. If the potential participant was eligible, she was invited to the baseline group assessment meeting at which

Table 1 Application of CBPR to the current research study

CBPR principle	Application in this study
Acknowledge the community	Community members were consulted about the feasibility and appropriateness of enrolling members of the local community into the study
Foster co-learning and capacity building	The team of investigators and DSN local coordinators brought diverse expertise to the development and implementation of the study protocol. Investigators learned about strategies to increase the likelihood of success, while community members learned more about the scientific process and the potential adverse effects of high stress
Build on community strengths and resources	Community networks and social interactions were leveraged to meet recruitment goal
Integrate and achieve a balance of all partners	Community members were engaged in the design of this research study and significantly influenced changes to the original recruitment approach. Community members recommended the in person orientation in lieu of a mailer to introduce the study
Facilitate collaborative, equitable partnership	Investigators and local coordinators were active in all aspects of the study. Investigators regularly consulted with local coordinators and study participants to ensure acceptability
Focus on local relevance	Initial round table discussions with local coordinators confirmed that the topic of stress was important and relevant to the members of the local community
Cyclical and iterative systems development	Investigators maintained regular communication with our local coordinators to determine whether modifications to the protocol were needed. Local coordinators provided information about how to more efficiently collect data at 6-months
Disseminate findings and involve partners	Initial results were presented to participants collaboratively by a study investigator and the local coordinators. Future dissemination of study findings such as manuscripts and presentations will be developed and presented collaboratively by investigators and community partners
Plan for a long-term process and commitment	Investigators and community members continue to engage in ongoing discussions about how to sustain relevant programs that may be warranted based on the findings of this study

time her eligibility was confirmed. Participants were eligible if they: (1) self-identified as black, (2) were age 30–70 years, (3) had BMI between 25 and 45 kg/m², (4) lived in one of the study communities, and (5) expressed a willingness to participate in the study for the entire duration. Exclusion criteria

included the following: (1) pregnancy or plans to become pregnant in the next year, (2) known major medical or psychological condition known to influence body weight loss (e.g., medicated or poorly controlled diabetes (HbA1c>8 %), uncontrolled hypertension (BP>160 mmHg systolic or BP>100 mmHg diastolic), cardiovascular event in the preceding 12 months, history of gastric bypass surgery, bariatric surgery, eating disorder), (3) history of psychiatric hospitalization in the past 2 years, (4) history of substance abuse or eating disorder, or (5) any other condition by which a medical professional has suggested diet modification, physical activity, and/or weight reduction would be contraindicated.

Main intervention

The intervention includes a 24-month weight loss randomized controlled trial in which eight rural DSN counties (four in AL, four in MS) have been randomized to either a culturally tailored, evidence-based weight loss program alone (Zunker et al. 2008; Diabetes Prevention Program Research Group 2002; Brantley et al. 2008; Ard et al. 2010) or the same culturally tailored, evidence-based weight loss program plus support for community strategies (Khan et al. 2009) to promote healthy eating and/or physical activity. Both treatment arms include 20 weekly face-to-face (FTF) weight loss meetings, 3 months of bimonthly FTF meetings, 3 months of monthly FTF meetings, and 12 months of monthly motivational interviewing telephone calls. FTF sessions are led by a trained full-time regional coordinator (who resides within the state-specific region) and a part-time county coordinator (who resides within the specific county) with assistance from CHARPs.

Supplemental study

As a supplement to the intervention study, we wanted to investigate the relationship between stress, measured by salivary cortisol and surveys, and weight/weight loss among a subsample of participants. Our recruitment goal was 50 women. Given the successful history of DSN and the desire to maintain a positive relationship with the communities with which we partner, it was very important that careful attention was given to the best way to approach our participants for additional collection of a bio-specimen sample such as saliva. Thus, we methodologically engaged in a multistep process to increase the likelihood of greater acceptance and willingness to provide bio-specimens for research among our study participants.

Implementation of systematic recruitment/enrollment strategy

Given our overarching CBPR approach, first, we conducted a round table meeting at which our research team proposed the

supplemental study to DSN regional and local coordinators. The coordinators provided feedback which included the following: (1) the subject area of stress is of interest and relevant to the participant population, (2) the supplemental study should not create too much additional burden on participants in the main study, (3) participants may be hesitant to provide saliva samples, (4) use of the word “saliva” or “spit” was equally appropriate, and (5) participants should be made keenly aware of their choice to opt out of the supplement study and be reassured that it would not affect participation in the main study.

Information collected from DSN coordinators at the round table discussion and the ASCO points of consideration guided our recruitment for the supplemental study (Table 2). First, for women enrolled in the main intervention study, we held a 60-min pre-intervention orientation session at which they were introduced to what should be expected as a participant in the main study. They were also then introduced to the supplemental stress study. Special attention was given to describing how the supplemental study was complimentary to the main study and was very relevant to the overall study objectives. Following the overview, survey data and saliva sample collection was explained to participants in detail. One key feature of this orientation session was a live demonstration of the saliva collection process by the DSN local coordinator. After fully describing the data collection process and demonstrating the saliva collection, participants were invited to indicate whether or not they wanted to enroll in the supplemental study. Interested persons were asked to remain after the orientation session to enroll in the study.

Enrollment, data collection, and follow-up

Fifty-seven out of a possible 75 participants (76 %) enrolled in the supplemental study (Table 3). Participants were middle-aged, obese black women from two rural Alabama counties. Approximately 40 % of participants were college graduates.

Table 2 ASCO recommendations for engaging patients in bio-specimen research and implementation strategies used for volunteer community participants

ASCO recommendations	Implementation strategy
Talking with patients	•Orientation session
Informed consent	•Verbal review of consent form by research staff •Verbal confirmation of understanding prior to signing •Opportunity to ask questions prior to signing
Disclosure of results	•Personal feedback reports describing results of stress evaluations

Table 3 Demographics of participants in the supplemental study ($n=57$)

	Mean \pm SD
Age	47.2 \pm 9.3
Weight (kg)	104.5 \pm 21.9
BMI (kg/m ²)	39.2 \pm 8.0
	<i>N</i> (%)
Highest level of education ^a	
Less than high school	3 (5.4)
High school graduate/GED	20 (35.7)
Some college	11 (19.6)
College graduate or more	22 (39.3)
Total annual household income ^a	
\leq \$19,999	24 (42.9)
\$20,000–39,999	18 (32.1)
\geq \$40,000	13 (23.2)
Don't know/unsure	1 (1.8)
Marital status	
Married	24 (42.1)
Not married but living with intimate partner	4 (7.0)
Separated	3 (5.3)
Divorced	8 (14.0)
Widowed	1 (1.8)
Never married/single	17 (29.8)

^a Missing for 1

Over half of the participants reported an annual total household income of less than \$40,000. Sensitivity analyses indicated that women who enrolled in the supplemental study were not statistically different from participants in the larger study who did not enroll (data not shown) based on the characteristics shown in Table 3. Participants completed the informed consent process during which they were given two copies of the consent form (one for signature and one for personal records) to read in addition to it being reviewed by the research staff to ensure comprehension. Subjective and objective measures of stress were collected. Participants were given two surveys (Weekly Stress Inventory Short Form (WSI-SF) (Brantley et al. 2007) and the Life Experiences Survey (LES) (Sarason et al. 1978)) to complete and saliva collection kits with written instructions to take home for bio-specimen collection. Compliance for return of baseline saliva samples was 100 %. Both surveys and saliva for cortisol analysis were captured at baseline for analysis of the relationship between stress and weight status. Additional collection at 6 months is planned to examine the relationship between stress and weight loss. After the analysis of baseline data and saliva samples was completed, a member of the investigative team attended a weekly session to provide a written personal feedback report which summarized the findings of the stress assessments including the salivary cortisol. Based on how participants scored on stress measures, they were

given written feedback that described their results as consistent with, higher, or lower than their peers. In addition, the report provided reminders of stress management strategies that were taught in the curriculum for the main weight loss intervention study.

Discussion

Using a systematic approach underpinned by CBPR methodology and leveraging the infrastructure of the DSN, we exceeded our recruitment goal for enrolling a sample of black women living in the rural Deep South in a research study that included bio-specimen collection. Given the aforementioned need for bio-specimen collection to enhance cancer research and better explain and address the dramatic cancer disparities experienced by blacks in the Deep South (National Cancer Institute 2005–2009), proper representation of this high-risk, underserved population is desperately needed in bio-specimen-related research. Our work demonstrates the feasibility of recruiting black women for bio-specimen research and highlights specific strategies that may help increase the likelihood of successful enrollment for future bio-specimen research. Though the collection of a bio-specimen for a specific research study as we have described may differ in theory from bio-banking, i.e., providing material to be banked for some future unknown research, efforts such as those described in this report help begin to demystify bio-specimen research for a population that is typically not engaged in biomedical research. These efforts and outcomes indicate first steps in the right direction toward increased participation of diverse populations in bio-specimen and, ultimately, bio-banking research.

Particular strengths of our systematic approach included the following:

1. Engagement of community leaders/members to learn more about norms and acceptability prior to starting recruitment

Pre-recruitment conversations with the DSN regional and county coordinators were highly informative and provided the layperson's perspective on our research aims. Members of the targeted communities were at the table to provide insight on local norms, appropriate verbiage, and anticipated challenges of recruitment and data collection. By collecting this information prior to recruitment, we were able to adapt our approach in an effort to mitigate many potential barriers. This round table discussion also played a key role in garnering initial support from the coordinators, whose endorsement was critical for participant recruitment and acceptance.

2. Full disclosure and opt out option

As with all research, full disclosure about the expectations of participation in the study and the freedom to opt out were important aspects of our recruitment process. After being fully informed of what data would be collected, how it would be collected, and what it would be used for as well as being reassured that refusal to participate was acceptable, some individuals at the orientation session chose to opt out. This “no pressure” approach to recruitment helped to make those who did choose to participate more at ease while also maintaining goodwill with those who chose not to participate and the community-at-large. In the context of historical research, atrocities that have occurred in the rural Deep South, such as the Tuskegee Syphilis Study (Brandt 1978; Freimuth et al. 2001), particular attention must be given to the disclosure process while also making individuals feel empowered to opt out of participating in a research study.

3. Live demonstration by a member of the local community

The live demonstration of sample collection by a member of the local community appeared to be the moment at which “buy-in” took place for participants. For example, when participants were first told that a saliva sample should be collected for three consecutive days, anecdotally, strange facial expressions or noises suggesting apprehension were observed. However, after the live demonstration, concerns seemed to instantly diminish and facial expressions suggested acceptance of the process. We propose that this shift was due, in part, to participants actually seeing a peer whom they trusted endorsing the collection and also seeing that it was very minimally invasive and sanitary. For rural blacks in the Deep South, trusted community leaders and peers are very influential. Therefore, the support of local community leaders and their demonstration of bio-specimen collection was a critical part of our plan for recruiting participants for the supplement study. Though all bio-specimen collection processes do not lend themselves as easily to on-site community demonstrations (e.g., fecal and biopsy), endorsement from a trusted person in the community, and some visual aids (e.g., video or diagram) are important steps to enhancing an individual's understanding and acceptance of the process.

4. Assurance that participants would receive some feedback

Based on the ASCO key points for consideration and subsequent support from the DSN coordinators, at the orientation, we informed participants that we would provide some direct feedback based on the data that they had provided to us. Thus, we provided participants with personal feedback reports summarizing the results of their individual baseline assessment. These reports were very well received by participants,

who expressed great appreciation for receiving written feedback illustrating their results through text and figures. We anticipate that the personal feedback report will be an important retention tool based on participants' expressed eagerness to see how their stress levels will change over time as they participate in the weight loss program of the larger study. Though in certain settings, it may not always be feasible to provide participants with the results of bio-specimen analyses due to logistical or ethical issues, we submit that providing participants with some feedback such as a follow-up letter or flyer, for example, generally discussing how the sample was used will also satisfy the participant's desire to receive information.

This study has limitations. First, for the women who declined participation in the supplement study, it is unclear whether this refusal was due to the bio-specimen collection component or for some other reason. When possible, future studies should include follow-up data collection to determine reasons for declining participation. Despite this limitation, our analysis of baseline data indicated that women who enrolled in the supplement study were not statistically different from participants in the larger study who did not enroll (data not shown) based on the characteristics shown in Table 3, suggesting that there was no systematic bias based on these measured variables. Also, this report was focused solely on black women living in the Deep South and, thus, may have limited generalizability; however, this population is an ideal target for increased representation in bio-specimen research given the disproportionate cancer burden experienced by this group and the need for additional research to better understand how to reduce cancer disparities of rural residents, Southerners, and blacks.

Conclusion

Our work highlights the feasibility of obtaining a specific bio-specimen sample, saliva, from black women who were community volunteers in a research study using the CBPR model. This approach has the potential to significantly impact bio-specimen research specifically among underrepresented groups for whom community-based approaches have been successful. Thus, it is feasible that community health advisors, patient navigators, and other community networks such as DSN can play an important role in engaging members of the community to provide bio-specimen samples. The participation of diverse populations in bio-specimen research is imperative for the prevention and treatment of cancer and other morbidities. This report demonstrates that blacks living in the rural Deep South can be successfully recruited into such trials. Community buy-in garnered through full disclosure and empowerment steps described in this report are vital parts of efforts to increase minority participation in research trials with a bio-specimen collection component.

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Conflict of interest Authors have no conflict of interest to report.

Compliance with ethics guidelines The experiments comply with the current laws of the USA, the country in which they were performed.

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