Participant-Centered Strategies for Overcoming Barriers to Biospecimen Collection among Spanish-Speaking Latina Breast Cancer Survivors

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ABSTRACT

Background: Latinos are underrepresented in biomedical research, particularly biomarker research, yet they constitute the nation's largest ethnic/racial minority. Optimal methods for obtaining biospecimens for biomarker research among Latinos need to be identified. To minimize barriers and enhance participation, this study developed and tested tailored strategies for collecting biomarkers of chronic stress and premature aging among Spanish-speaking Latina breast cancer survivors.

Methods: This study used a community-based participatory approach and selected hair and saliva as noninvasive biospecimens to assess telomere length, the cortisol awakening response (CAR), and hair cortisol concentration. We developed bilingual multimedia instructional materials, and community health workers assisted in collections. Telephone surveys assessed willingness to participate in future studies, barriers to sample collection, and recommendations for improving the strategies.

Results: A total of 103 participants were recruited over 18 months from two rural sites in California, and 88 were retained at 6-month follow-up. At baseline, rates of donating salivary DNA for telomere length measurement, saliva for CAR analysis, and hair for cortisol concentration were 98%, 89%, and 52%, respectively. At follow-up, rates were 83%, 76%, and 55%, respectively. The majority of participants reported being very willing to provide hair (72%) or saliva (74%) for future studies.

Conclusions: Our results support the feasibility of including minorities in biomedical research. We report excellent rates of saliva collection when community partners are engaged in the process, and when patient-centered and culturally tailored recruitment methods are implemented.

Impact: The development of methods to facilitate the inclusion of minorities in biomedical research is critical to eliminate racial/ethnic health disparities.

Introduction

Latinos are underrepresented in biomedical research and biorepositories, yet they constitute the nation's largest ethnic or racial minority (18.3% of the U.S. population as of July 2018), numbering almost 60 million persons (1, 2). For example, as the Latino population ages, they will account for an increasing number of cancer cases, yet Latinos represent only 3% of patients who are genomically characterized in The Cancer Genome Atlas (TCGA; ref. 3). Although Latinos indicate a willingness to participate in biomedical research, most studies lack culturally and linguistically appropriate recruitment strategies to facilitate their participation, resulting in their underrepresentation (1, 4). More specifically, optimal methods for obtaining biospecimens for biomarkers research among Latinos need to be identified. Such methods will be critical to ensure equitable representation of Latinos in the NIH All of Us Research Program (5). The All of Us Research Program, formerly called the Precision Medicine Initiative, seeks to build a cohort of over one million persons in the United States from diverse backgrounds who will contribute their health data and biospecimens to a centralized national database to support research on precision medicine (6, 7). Failing to include Latinos and other diverse populations in precision medicine, and oncology specifically, could potentially widen health disparities (8).

Compared with their white counterparts, Latina breast cancer survivors experience a number of cancer health disparities. Despite the relatively low incidence of breast cancer among Latinas, their risk of mortality is higher than that of their white counterparts (9, 10). Latinas are more likely to be diagnosed with later stage cancer and to receive a mastectomy rather than breast conserving surgery, which means they receive more aggressive treatments (11). Independent of stage at diagnosis, having comorbid conditions is associated with worse survival after a breast cancer diagnosis (12). Compared with African American breast cancer survivors, Spanish-speaking Latina breast cancer survivors were more likely to report having more than three comorbid conditions, with 77% of them reporting at least one comorbid condition (13).

These comorbidities include metabolic conditions that are influenced by cortisol and the hypothalamic-pituitary-adrenal (HPA) axis,

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such as diabetes, high blood pressure, and dyslipidemia (13, 14). A breast cancer diagnosis brings stressors related to the diagnosis, intrusive medical procedures, aversive treatment side effects, and psychologic distress, which can also disrupt HPA-axis function (15). Spanish-speaking Latina breast cancer survivors clearly experience particularly high levels of chronic stress due to factors related to low socioeconomic status, language, discrimination, and immigrant status (16). These conditions are alarming because of the strong evidence linking chronic stress and cancer (17–22). Latina breast cancer survivors have largely been ignored in such studies of stress among patients with cancer.

Complex collection protocols, collection of serum or tissue biopsies that require visits to health care facilities and use of health care personnel, time commitment, transportation, family considerations, and job constraints all pose unique challenges among Latino and other minority populations (4, 23–25). Effective recruitment and retention strategies for randomized controlled trials among low-income minority populations include maximizing study staff availability, strong rapport of staff with participants, attention to time constraints of participants, and participant's perceptions of the study as informative (26). A few large studies have had success in enrolling Latinos in studies that include biospecimen collection due to community-engaged and culturally centered recruitment approaches. Notable examples include the Hispanic Health Study/ Study of Latinos (HCHS/SOL), the largest and most comprehensive study of Latino health in the United States, which enrolled over 16,000 U.S. Latinos (27) and the Mano a Mano study of over 19,000 participants of Mexican descent (1). Effective recruitment and retention strategies used in these studies include those mentioned thus far, along with use of face-to-face recruitment, community-based researchers who were culturally and linguistically congruent with potential participants, home visits, field locations within close proximity to the targeted population, and targeted multistage sampling designs that make use of in-depth knowledge of the communities and U.S. census data on clustering of populations by race/ethnicity and socioeconomic status (1, 27). However, the SOL and Mano a Mano landmark studies were afforded extensive resources for recruitment of participants and collection of biospecimens that may not be available in many other studies. Feasible, cheaper, more practicable methods of biospecimen collection are needed for smaller, less resource-intensive community-based settings and studies.

The objective of this study was to develop and test strategies to increase participation and adherence of Spanish-speaking Latina breast cancer survivors in the collection of biospecimens. The Nuevo Amanecer-II Biospecimen Study, henceforth referred to as the biospecimen study, was an ancillary study to a randomized controlled trial (RCT) of a stress management intervention (The Nuevo Amanecer-II Study; ClinicalTrials.gov Identifier NCT02931552). The parent study used community-based participatory research (CBPR) approaches to adapt and test a culturally tailored evidence-based stress management program among Spanish-speaking Latina breast cancer survivors from three rural communities in California (28). The biospecimen study evaluated the feasibility of biospecimen collection among Spanish-speaking Latina breast cancer survivors participating in the RCT, and the effects of the intervention on biomarkers of stress and aging. Here, we report on our innovative methods to overcome barriers to collecting hair and saliva samples and donation rates over time, for researchers to consider for future biospecimen collection studies.

Materials and Methods

Participants were rural Spanish-speaking Latina women with non-metastatic breast cancer living in two California communities with a high concentration of Latinos and agribusiness: El Centro and Visalia (and surrounding Imperial and San Joaquin Valleys). Three Institutional Review Boards at the partner institutions approved the study protocol: San Francisco State University (SFSU IRB #E13-169), University of California San Francisco (UCSF IRB #16-18737) and Kaweah Delta Health Care District Institutional Review Board (IRB #201604006). Written informed consent was obtained from participants.

The biospecimen study benefitted from the academic–community partnerships developed with three community organizations for the parent study. A detailed description of a community-engaged translational model that was applied throughout the study and how its seven-step process was implemented are described elsewhere (28). The academic partners in this study were almost all Latinas with extensive community-engaged cancer research experience in Latino communities. Community partners were agencies or health plans that had in-depth knowledge of and experience with delivering health education or cancer support services to Latino patients. Community partner organizations selected identified the community health workers (CHW) who were then trained by academic partners and community organization leadership. Academic and community partners all participated in planning the grant application, project, protocol development, and full implementation of the parent and biospecimen studies. Iterative academic–community consultations occurred throughout the study to define the roles of the CHWs and academic staff and develop the protocol and materials for the biospecimen study described next.

Three community organizations were invited to collaborate on the biospecimen study, but only two agreed: Cancer Resource Center of the Desert (CRCD), El Centro, CA, and Kaweah Delta Health Care District, Visalia, CA. The third site, a provider of mental health services, opted out because "physical health" was not under their organizational purview. Women from that site were not invited to participate in the biospecimen study.

Community and academic partners first identified barriers to biospecimen collection based on their experience working with this vulnerable population. Many barriers were the same as those to recruiting Latinas into any research study; others were specific to collecting biospecimens. We then identified participant-centered methods and materials (summarized in **Table 1**) to overcome these barriers.

Participant-centered methods

Methods, described in detail below, included selecting biomarkers that required minimally invasive and practical procedures, employing parent study CHWs to collect some of the biospecimens, and addressing privacy concerns.

Selection of minimally invasive biomarkers

Measures of stress and premature aging usually involve collecting blood, urine, and a midday saliva sample, which need to be kept on ice or refrigerated. Such measures can discourage individuals from participating. For studies conducted in rural settings, collection of these biomarkers is cumbersome due to the lack of clinical laboratories in proximity, complexity of shipping biological samples, environmental factors such as hot temperatures, lack of access to refrigeration at work,

Table 1. Facilitators/barriers and strategies used to enhance biospecimen donation among rural Spanish-speaking breast cancer survivors (some strategies address more than one barrier).

Facilitator (F) or barrier (B)	Strategies to address facilitator or barrier
Beliefs/attitudes/knowledge	
Altruism (F): Latino culture emphasizes collectivism, which instills a desire to give back to improve the health of their communities and future generations (52)	• General: explained lack of Latina representation in research • Biospecimen-specific: explained benefits of biospecimens for advancing scientific discovery
Mistrust (B): Mistrust of researchers due to historical ethical violations and experimentation; general mistrust of health care institutions (53)	• General: collaborated with trusted community organizations, CHWs served as recruiters • Biospecimen-specific: CHWs served as biospecimen collection assistants
Lack of information about biomarkers (B): Purpose of biospecimens and contributions to advancing science (25, 53)	• Biospecimen-specific: explained rationale for and purpose of biospecimens
Cultural/linguistic factors	
Fear of loss of privacy (B): Providing personal information can result in loss of privacy, fear of deportation (54, 55)	• General: eliminated use of social security numbers for tracking cash incentives • Biospecimen-specific: informed participants that samples would be de-identified
Cultural sensitivity (F): Staff members of the same ethnicity and community share cultural values and practices (56)	• Biospecimen-specific: CHWs shared similar values and lived in the community, multimedia instructional materials used peer models
Limited English proficiency and literacy (B): English-only materials not understood, use of jargon impedes comprehension; complex instructions difficult to understand (57)	• General: all materials and communication in Spanish • Biospecimen-specific: developed easily accessible instructional videos, pretested illustrated bilingual instructions with community members
Intrusiveness (time, routine, family) of biospecimen collection	
Invasive biospecimens (B): Collecting tumor biopsies and blood/serum is invasive and requires medical personnel (25)	• Biospecimen-specific: selected hair and saliva, which are relatively non-invasive and do not require medical personnel
Inconvenience of providing samples (B): Need to visit a laboratory to donate sample; need transportation (58)	• Biospecimen-specific: selected biospecimens that can be easily self-collected and stored at home, samples picked up by CHWs
Intrusiveness on daily routine (B): Collecting biospecimens may require planning, time, and effort over multiple days (59, 60)	• Biospecimen-specific: explained significance of biospecimen donation, cash incentives ($20 at baseline and $20 at 6 months)
Complexity of biospecimen collection	
Lack of confidence in meeting biospecimen collection requirements (B): Believe they are not capable of following protocol (44)	• Biospecimen-specific: CHWs provided assistance and placed reminder calls for collecting saliva samples
Complexity of collection protocol (B): Multiple steps, special storage conditions, need to provide/record written details (61, 62)	• Biospecimen-specific: used step-by-step instructions, color-coded collections materials, collection kit contained all necessary materials

and employers who may not approve of breaks to donate specimens during work hours.

To measure chronic stress and premature aging, we selected biomarkers that could be obtained from minimally invasive biospecimens of saliva and hair. The selection of these less invasive biospecimens was based on the prior experience of the researchers, input from the CHWs and organizational leaders, and the scientific literature (29–32). CHWs were not licensed phlebotomists so could not collect blood samples. In addition, CHWs felt that drawing blood would serve as a barrier to participation; this is supported by a study that found that Mexican American communities reported greater resistance to collection of blood for biobanking due to a fear of needles or being infected (25). Thus, two biomarkers of chronic stress were used in this study, cortisol awakening response (CAR) and hair cortisol concentration (HCC). Here we describe the rationale for each biospecimen.

HPA dysregulation: CAR via repeated saliva samples: Saliva collection is noninvasive and can be used for reliable cortisol quantification that reflect cortisol levels in the blood (31), and if measured repeatedly are indicative of HPA-axis function. Cortisol is normally released in a tightly regulated pattern that peaks concentration 30 minutes post-awakening and is lowest at bedtime (33). While HPA-axis function can be measured in a few ways, respondent burden varies across methods. Measurement of Diurnal Cortisol Rhythm (DCR) usually includes a midday sample that poses timing and storage challenges, while CAR assessments involve a sample taken 30 minutes postawakening that is

collected at home. For these reasons, the CAR method of assessing HPA-axis function was chosen for this population, as it would avoid the need for coordination, storage, and transportation of a midday sample, which poses a significant hardship for working women.

Chronic stress: HCC from one hair sample: Cortisol in hair quantifies cumulative cortisol production incorporated into the hair over time, serving as a unique biomarker of chronic stress and long-term HPA-axis activity. Hair grows at a rate of 1 cm per month, thus, it is possible to determine hair cortisol concentrations over several months by obtaining hair cut near the scalp (34), providing an excellent source for cortisol analysis (35). Hair collection is painless, does not require special collection materials or storage, and can be obtained from a discreet area of the scalp. Although the impact of hair dying, chemical processing, and shampooing frequency on HCC remains inconclusive, it is best to avoid chemically treated hair (36).

Premature aging: telomere length via DNA from cheek cells found in saliva: A noninvasive method to assess telomere length (TL) is through the measurement of DNA extracted from cheek cells in saliva (37). This is a particularly useful method to enable studies of the relationship of TL to cancer outcomes in populations with reservations regarding biospecimen donation. Collection is simple, requiring spitting saliva into a tube. Thus, cheek cells from saliva can be collected rapidly and preserved easily, eliminating the need for special storage conditions.

Table 2. Description of procedures for biospecimen collection for measurement of CAR, HCC, and TL.

Biomarker	Biospecimen	Number of samples	Time of day	Preparation instructions	Materials	Procedure	Storage
CAR, a measure of HPA dysregulation	Saliva	Nine samples (3 per day, for 3 consecutive days)	On awakening, 30 minutes postawakening, bedtime	Collect at least 30 min after drinking, eating, or brushing teeth	Tube, straw-like aide to collect saliva, box	Using straw-like aide, passively drool saliva into tube to fill line (2 mL)	Place tube in box, immediately store in refrigerator
HCC, a measure chronic stress	Hair	One sample	Any time	Avoid coloring hair for at least 2 weeks before sample is taken	Small rubber band, index card, tape, envelope	From back of head, separate 100 strands from rest of hair using small rubber band, cut close to scalp. Tape hair to index card, denoting end closest to scalp	Place card in envelope, store at room temperature
TL, a measure of premature aging	Saliva (DNA is extracted from cheek cells found in saliva)	One sample	Any time	No drinking, smoking, brushing teeth 1 hour before; rinse mouth two times before	Funnel, tube (stabilization agent in tube cap), storage bag, prepared label	Gently rub inside of mouth using teeth, allow saliva to pool, spit saliva into funnel, fill tube to fill line (2 mL)	Apply label to tube, place tube in storage bag, store at room temperature

Practicable protocol for biospecimen collection

In **Table 2**, we provide the detailed protocol for each biospecimen, including the biomarker, biospecimen, number of samples, time of day, preparation instructions, materials, procedure, and storage. The protocol is described for the three biomarkers:

(i) Chronic stress: CAR via 3 daily saliva samples collected over 3 days;
(ii) Chronic stress: using HCC via a single hair sample;
(iii) Premature aging: TL via DNA extracted from cheek cells obtained from a single saliva sample.

Detailed descriptions of the selection, hiring and training of CHWs are described in another publication (28). CHWs from the partner community organizations, who also conducted the baseline assessment, provided collection assistance at the baseline visit for the two biospecimens requiring a single sample (HCC and TL). CHWs' responsibilities included to obtain consent and enroll participants. Through webinars, recruiters were trained by a cancer biologist on consistent and reliable biospecimen collection methods.

CHWs' procedures for assisting with collecting hair for HCC and saliva for TL at baseline: Upon completion of the baseline survey and randomization, CHWs guided participants in the collection of two of the biospecimens: saliva for TL and hair for HCC. They reviewed instructional materials with participants and assisted them in collecting these biospecimens.

CHWs' procedures for training participants on self-collection of saliva for CAR at baseline: CHWs then instructed participants in the more complex protocol of collecting 3 saliva samples a day for 3 days

(9 samples). At the conclusion of the baseline visit, the CHW gave the participant the CAR saliva collection materials and reviewed a video and written instructions for at-home self-collection of CAR saliva samples. The 9 samples were stored in a box in the refrigerator at home until the CHW picked them up. For the next three days, recruiters placed reminder calls to participants in the evening to remind them of collection of CAR samples for the next day, and on the final day, arranged for picking up the sample (approximately the 4th day after the baseline visit).

Portable insulated coolers and reusable ice packs were provided to CHWs to transport samples between participants' homes and the CHWs' organization where they were stored under refrigeration. Community organizations were provided with a refrigerator if one was not available for sample storage. To coordinate sample pickup by a member of the research team, CHWs telephoned the team when samples were ready for pickup. On average, samples were transported from the community site to the University's laboratory by a member of the research team using portable insulated coolers every 3 weeks via ground or air transportation.

Six-month biospecimen collection protocol: The protocol for the 6-month biospecimen collection was similar. Upon completing the 6-month telephone survey (administered by a staff person), the interviewer reminded the participant that 6-month samples needed to be collected. If the participant agreed, the staff person contacted the CHW who would then conduct a home visit to pick up CAR saliva samples and collect the 6-month hair sample for HCC and saliva sample for TL. The CHW once again reviewed with the participant a video and written instructions for at-home self-collection of CAR saliva samples and gave the participant the CAR saliva collection materials. Daily reminder calls were made for the CAR samples, as at baseline. The procedures for collecting the samples from the

participant, transporting them to the organization, and then to the research lab were the same as at baseline.

Incentives and protection of privacy

Participation in the biospecimen study was voluntary and did not affect eligibility to participate in the main RCT study. Additional incentives for participating in the biospecimen study were provided for any biospecimen at each timepoint ($20 at baseline; $20 at 6-month follow-up). Most research institutions require collection of social security numbers (SSN) for study participants who receive financial remuneration. Although collection of SSNs can be a barrier to research among the general population due to views that this is among the most sensitive types of data that can be collected (38), hypervigilance regarding providing SSNs is especially present among Latino immigrants due to the nation's current anti-immigrant climate and Latinos' long-standing fears of deportation. CHWs strongly urged against collection of SSNs because of similar local concerns so we were able to obtain institutional approvals to use participants' study ID numbers for tracking of payments in lieu of SSNs. This way, participant privacy was maintained. Samples were deidentified and coded using the participant ID for processing and biological analysis in the Health Equity Research Lab at San Francisco State University (San Francisco, CA).

Patient-centered materials

Both academic and community partners (CHWs, leaders of the organizations, and community members) contributed their in-depth knowledge of the Latino community's values, literacy levels, and preferences to help develop written and video instructions for collection of biospecimens. Development of the materials was informed also by studies that had extensive involvement of CHWs and community members in the development of materials to reduce disparities in cancer screening among minority communities (39, 40). For this study, a bilingual and bicultural Latina molecular biologist developed low-literacy drafts of the materials, which were then reviewed by the study team (academic staff, CHWs, and community leadership). Written and video materials featured a middle-aged Latina modeling the collection and minimal and simple text that was provided in both English and Spanish. The goal was to increase the self-efficacy of CHWs and study participants for collecting biospecimens.

Patient-centered biospecimen collection materials

Biospecimen collection kits containing all necessary materials were assembled and placed in a quart-sized Ziploc bag, with illustrated and written instructions for participants for each type of biospecimen. For hair collection for HCC, we included an envelope with client ID label, rubber band, gloves, notecard and adhesive to indicate location of the roots from the hair provided. For saliva collection for TL, we included an Oragene saliva kit (DNA Genotek OG-500) and a small Ziploc bag labeled with the client ID number. Lastly, for self-collection of saliva samples for CAR, we included color-coded and numbered tubes in a storage box, color-coded straw-like aides to transfer saliva to tubes, and a log to record time of collection and notes regarding any unusual activity.

Multimedia instructional materials for self-collection of saliva for CAR

Bilingual-bicultural multimedia instructions for saliva self-collection for CAR were provided to participants. Low-literacy bilin-

gual (English and Spanish) written instructions were developed by the researcher. Written instructions were illustrated with photographic demonstrations of each step of collection, using a middle-aged Latina model to instill confidence that collection would not be difficult. YouTube videos (3–7 minutes duration) demonstrating CAR biospecimen collection were produced in English and Spanish. Videos were pre-loaded onto CHWs' tablets, eliminating the need for internet connectivity. Each CHW received a tablet and played the video for participants during the baseline and 6-month visits to teach them how to collect samples at home. Participants were given a copy of the illustrated written instructions and a YouTube link to the videos for viewing on their personal devices if needed.

Feasibility assessment
Biospecimen collection rates

We counted the number of each type of biospecimen provided and tracked the collection of each type of biospecimen at baseline and 6-month timepoints by site.

Assessment of participant's experiences with CAR sample collection

Because biospecimen collection for CAR measurement was complicated and required self-collection, we assessed their experiences in collecting these samples. At baseline, CHWs administered a 7-item survey when picking up the CAR samples from participants' home that asked about the difficulty of collecting CAR samples and helpfulness of instructional materials and aids. A single question asked participants to rate the difficulty of collecting saliva samples three times a day for three days, using a 4-point response scale ranging from 1 = not at all difficult to 4 = very difficult. Three items asked about the helpfulness of telephone reminders, illustrated written instructions, and YouTube video, using a 4-point response scale ranging from 1 = not at all helpful to 4 = very helpful and 5 = did not use. If the participant was unable to collect one of the nine samples or indicated they were unable to refrain from eating or drinking for 30 minutes for the morning saliva samples, open-ended questions asked about reasons for this. All participants were asked if they had suggestions for simplifying saliva collection procedures.

Willingness to participate in future studies and provide biospecimens

At the 6-month final telephone assessment, participants were asked about their willingness to be contacted for future studies (of any kind), willingness to provide hair samples in future studies, and willingness to provide saliva samples for any type of analysis in future studies. Response options were 1 = not at all willing, 2 = somewhat willing, 3 = very willing.

Demographic characteristics

Demographic measures obtained in the baseline assessment for the parent study included self-reported age, years residing in the United States, language read and spoken, education, employment, and experience with financial hardship. Breast cancer characteristics were confirmed by medical record review and included years since diagnosis, breast cancer stage and type, and treatment received.

Statistical analysis

Descriptive statistics (mean, percent) were used to describe sample characteristics; Fisher exact test was used to test for site differences on sample characteristics. Descriptive statistics were used to report overall and site-specific rates of donation by biospecimen type and the number

and percent donating none, one, two or all three types of biospecimens. Bivariate χ^2 comparisons were conducted by financial hardship, employment, and education level on measures of donating CAR, hair and saliva for TL, as well as for donating all three types of biospecimens. Descriptive characteristics were used to describe participants' ratings of the difficulty of CAR sample collection and the usefulness of aids. Two study staff members performed content analysis, reconciled, and summarized responses to open-ended items on reasons for not being able to follow the CAR biospecimen collection protocol and suggestions for simplifying the process.

Results

Sample characteristics

At baseline, all women who were asked, agreed to participate in the biospecimen study ($n = 103$, 100%). Mean age was 56.1 years (SD = 10.6; range 28–88) and 97% were of Mexican origin (**Table 3**). The majority spoke Spanish only and 67% had less than a high-school

education. About one quarter were employed and over one-third (37%) reported financial hardship. Mean time since the most recent breast cancer diagnosis was 2.7 years (SD = 3.1; range 0–16) and almost 60% received both chemotherapy and radiation. Women from the El Centro site reported greater financial hardship and shorter time since diagnosis than Visalia women.

Feasibility assessment

Biospecimen collection rates

At baseline, all women ($n = 103$) provided some type of biospecimen; half of women provided all three types of samples, 41% provided only 2 types and 10% provided only 1 type. At 6 months, 88 of 103 (85%) women provided some type of biospecimen; 51% provided all three types of samples, 25% provided 2 types, 9% provided 1 type, and 15% did not provide any. Women form Visalia were more likely than those from El Centro to provide all three types of samples at baseline (79% vs. 18%) and 6-month follow-up (75% vs. 26%).

Table 3. Demographic and clinical characteristics of rural Latina breast cancer survivors ($N = 103$), California, 2016–2018.

Characteristics	Total ($N = 103$) n (%)	El Centro, CA ($n = 50$) n (%)	Visalia, CA ($n = 53$) n (%)	P^a
Age in years (mean ± SD)	56.1 ± 10.6	56.1 ± 9.7	56.1 ± 11.4	0.980
Years in the United States (mean ± SD)	27.6 ± 13.7	25.0 ± 14.7	30.3 ± 12.0	0.063
Language read and spoken				0.195
Spanish only	60 (58)	30 (60)	30 (57)	
Spanish better than English	22 (21)	12 (24)	10 (19)	
Both equally	13 (13)	7 (14)	6 (11)	
English better than Spanish	8 (8)	1 (2)	7 (13)	
Education				0.116
Elementary or less	36 (35)	13 (26)	23 (43)	
> Elementary < high school	33 (32)	15 (30)	18 (34)	
High school graduate	11 (11)	7 (14)	4 (8)	
> High school	23 (22)	15 (30)	8 (15)	
Employment				0.556
Part-time or full-time	23 (22)	8 (16)	15 (28)	
Homemaker/caregiver/student	34 (33)	18 (36)	16 (30)	
Retired	13 (13)	6 (12)	7 (13)	
Unemployed	5 (5)	2 (4)	3 (6)	
Unable to work due to poor health or disability	28 (27)	16 (32)	12 (23)	
Any financial hardship	38 (37)	27 (54)	11 (21)	<0.001
Breast cancer characteristics				
Years since most recent diagnosis	2.7 ± 3.1	1.8 ± 2.1	3.5 ± 3.6	<0.01
Breast cancer diagnosis				0.468
Ductal carcinoma *in situ*	9 (9)	6 (12)	3 (6)	
Invasive	78 (76)	38 (76)	40 (75)	
Inflammatory	11 (11)	5 (10)	6 (11)	
Missing	5 (5)	1 (2)	4 (8)	
Breast cancer stage				0.693
0	4 (4)	3 (6)	1 (2)	
1	27 (26)	14 (28)	13 (25)	
2	38 (37)	17 (34)	21 (40)	
3	23 (22)	12 (24)	11 (21)	
Missing	11 (11)	4 (8)	7 (13)	
Breast cancer treatment				0.060
Chemotherapy only	14 (14)	9 (18)	5 (9)	
Radiation only	21 (20)	14 (28)	7 (13)	
Chemotherapy and radiation	61 (59)	23 (46)	38 (72)	
No treatment	7 (7)	4 (8)	3 (6)	

[a]Fisher exact test of differences between sites at baseline.

Table 4. Number of biospecimens provided and rates of donation by biospecimen type at baseline and follow-up among rural Latina breast cancer survivors (N = 103), California, 2016–2018.

	Baseline			Six-month follow-up		
	Total	El Centro, CA	Visalia, CA	Total	El Centro, CA	Visalia, CA
Number of biospecimens provided	N (%)	n (%)	n (%)	N (%)	n (%)	n (%)
0 of the 3 types of biospecimens	0 (0)	0 (0)	0 (0)	15 (15)	7 (14)	8 (15)
Only 1 of 3 types of biospecimens	10 (10)	9 (18)	1 (2)	9 (9)	8 (16)	1 (2)
Only 2 of 3 types of biospecimens	42 (41)	32 (64)	10 (19)	26 (25)	22 (44)	4 (8)
All 3 of 3 types of biospecimens	51 (50)	9 (18)	42 (79)	53 (51)	13 (26)	40 (75)
Total	103 (100)	50 (100)	53 (100)	103 (100)	50 (100)	53 (100)
Rate of donation by type of biospecimen	N (%[a])	n (%[a])	n (%[a])	N (%[a])	n (%[a])	n (%[a])
Saliva for CAR[b]	92 (89)	41 (82)	51 (96)	78 (76)	34 (68)	44 (83)
Hair for HCC	54 (52)	11 (22)	43 (81)	57 (55)	15 (30)	42 (79)
Saliva for TL via DNA from cheek cells	101 (98)	48 (96)	53 (100)	85 (83)	42 (84)	43 (81)

[a]Percentage of total sample (N = 103) or site subsample (n = 50 for El Centro and 53 for Visalia) at baseline.
[b]Requires 3 samples per day for 3 days (9 samples total).

Donation rates were highest for the saliva for TL samples at both baseline and 6 months, followed by the 9 saliva samples for CAR; rates for the hair samples for HCC were lowest (**Table 4**). Rates of donation tended to be higher for Visalia than El Centro for all three types of biospecimens. At baseline, 98% (101/103) donated saliva for TL measurement versus 89% for the 9 saliva samples for CAR assessment and 52% for hair samples for HCC analysis. At 6 months, 83% (85/103) donated saliva for TL versus 76% for the 9 saliva samples for CAR, and 55% for hair for HCC. Overall, donations of any biospecimen decreased from 100% (n = 103) at baseline to 85% at 6 months (88/103).

At baseline (results not tabled), there were no differences by financial hardship (yes vs. no) or employment (vs. unemployed) on rates of donation of CAR samples, hair samples, saliva for TL, and all 3 types of samples. Education (elementary or less/ > elementary and < high school/high school/ > high school) was associated with hair sample donation only (P < 0.04), whereby women with higher education appeared to be less likely to donate.

At 6 months (results not tabled), financial hardship was associated with a lower likelihood of donation of all three types of samples (P < 0.02) and hair donation (P < 0.01); higher education was also associated with a lower likelihood of donating all three types of samples (P < 0.04) and hair donation (P < 0.01). Employment status was not related to any of the donation measures.

Participants' experiences with CAR sample collection

Eighty-nine of 103 women completed the survey asking about difficulty collecting the CAR samples, usefulness of aids, and open-ended items on barriers and suggestions for simplifying the protocol (**Table 5**). Fourteen women did not respond: 11 did not provide the CAR samples, and 3 were inadvertently not administered the survey. Of 89 women completing the survey, 72% indicated that collecting the CAR samples over the 3 days was a little or not at all difficult (vs. somewhat or very). Regarding the instructional aids, 75% found the written instructions to be very or somewhat helpful (vs. a little or not at all) and 82% found the telephone reminders to be very or somewhat helpful. YouTube videos were used on their own when the recruiter was not present by only 6% of the sample.

The most common reasons for not being able to collect the CAR samples were forgetting to collect the sample at the right time (n = 12) or having a competing demand at the time the collection was due (n = 7). The most frequent suggestion for simplifying CAR sample collection was elimination of the second daily (30-minute postawakening)

collection (n = 5). Women also suggested modifying the straw-like collection aide by making containers bigger or using a straw with a bigger spout (n = 3) as well as providing tips to increase saliva production (n = 4).

Willingness to participate and/or provide biospecimens in the future

At 6 months, 95 of 103 women provided responses regarding their willingness to participate in future studies and willingness provide biospecimens in the future (**Table 6**). Eighty-eight percent indicated they would like to be contacted for future studies, 72% would be very

Table 5. Self-collection of saliva samples for CAR measurement: difficulty collecting samples and helpfulness of multimedia instructional materials, rural Latina breast cancer survivors at baseline.

Difficulty of collection of CAR samples	n (%)		
Very difficult	5 (6)		
Somewhat difficult	12 (13)		
A little difficult	26 (29)		
Not at all difficult	46 (52)		
Total	89 (100)		
Missing[a]	11		

Helpfulness of multimedia instructional materials	Written instructions, n (%)	Telephone reminder, n (%)	YouTube video, n (%)
Very helpful	53 (59)	51 (58)	5 (6)
Somewhat helpful	14 (16)	21 (24)	1 (1)
A little bit helpful	—	2 (2)	—
Not at all helpful	—	1 (1)	—
Did not use	22 (25)	13 (15)	83 (93)
Missing survey item	0	1	0
Total	89 (100)	89 (100)	89 (100)

[a]Did not provide baseline CAR samples or were not administered the brief survey.

Table 6. Willingness to participate in future biospecimen studies, rural Latina breast cancer survivors at 6-month assessment.

	Total ($N = 103$) n (%)	El Centro, CA ($n = 50$) n (%)	Visalia, CA ($n = 53$) n (%)
Can be contacted for future studies			
Yes	91 (88)	45 (90)	46 (87)
No	2 (2)	1 (2)	1 (2)
Missing survey response	2 (2)	1 (2)	1 (2)
Did not complete 6-month interview	8 (8)	3 (6)	5 (9)
Willingness to provide hair in future studies			
Very willing	74 (72)	37 (74)	37 (70)
Somewhat willing	17 (17)	8 (16)	9 (17)
Not at all willing	—	—	—
Missing survey response	4 (4)	2 (4)	2 (4)
Did not complete 6-month interview	8 (8)	3 (6)	5 (9)
Willingness to provide saliva in future studies (for any analysis)			
Very willing	76 (74)	38 (76)	38 (72)
Somewhat willing	14 (14)	6 (12)	8 (15)
Not at all willing	1 (1)	1 (2)	—
Missing	4 (4)	2 (4)	2 (4)
Did not complete 6-month interview	8 (8)	3 (6)	5 (9)

willing to provide hair, and 74% would be very willing to provide saliva for any type of analysis. There were no differences by site in willingness to participate in future studies.

Discussion

We developed and tested tailored strategies for collecting biospecimens to measure biomarkers of stress (HCC and CAR) and premature aging (TL) among Spanish-speaking Latina breast cancer survivors, a population not well represented in research studies. Our study demonstrated that employing participant-centered strategies leads to successful rates of biospecimen donation for these biospecimens and willingness to be contacted for future studies, including those requiring hair and saliva donation.

Overall, our participant-centered strategies resulted in high rates of collection of salivary DNA for TL measurement at baseline (98%) and follow-up (83%). We saw a lower rate of biospecimen donation for the nine saliva samples for CAR assessment; 89% at baseline and 78% at 6-month follow-up. However, these rates compare favorably to prior saliva donation rates (either 6 or 9 samples) for CAR assessment of 70%–98% (41, 42). For hair samples used for HCC analysis, we saw the lowest rates of biospecimen donation (52% at baseline and 55% at 6 months), with differences by site that were most likely due to differences in time since diagnosis and chemotherapy treatment-related hair loss/thinning.

Our excellent rates of collection of salivary DNA and nine saliva samples are comparable to biospecimen collection rates in studies that included principles of CBPR to specifically address the issue of low minority representation in research studies (1, 27, 43, 44). Similar to others, our use of CBPR methods and in-depth knowledge of the community were effective recruitment strategies for biomedical research (45, 46). On the basis of our results and those of other studies conducted among Latinos, including the HCHS/SOL study (41, 47), recommendations for overcoming challenges with enrollment of participants and collection of biospecimens include collaboration with trusted community-based organizations, use of CHWs, and use of culturally-tailored instructional and collection materials. Also, in the Latino community, altruism, trust, and loss of privacy are common beliefs and concerns that need to be addressed when developing recruitment strategies (25, 44). These community-engaged and participant-centered strategies can be adapted to meet the specific needs of diverse minority groups in different settings (48). Use of such strategies allows researchers to leverage the altruism of minority participants who perceive one of the benefits of research participation as an ability to help others through their contribution (49).

Implementation of these strategies will be particularly important for the success of the NIH All of Us Precision Medicine Initiative in achieving its goal of establishing a cohort of over one million diverse participants who will contribute biospecimens.

This study has limitations. It describes strategies for overcoming barriers to biospecimen collection in a relatively small sample that may not be generalizable beyond this population. The barriers and facilitators, and strategies to overcome them that we describe in this article could be used as a guide by researchers seeking to recruit members from other vulnerable communities, as these barriers may be similar across groups (50). Seeking community input can help with assessing the relevance of strategies for other marginalized populations (51).

In conclusion, recruitment for future biomarker research among Latinas should integrate principles of CBPR, highlight the potential benefits of study findings on future generations, and include research staff that is bilingual and bicultural with in-depth knowledge of the community. These more practical methods of biospecimen collection are pertinent to large studies, as well as smaller and less resource-intensive community-based research studies. Together, these participant-centered strategies can increase Latino participation in research studies, a critical step in addressing health disparities and achieving health equity.

Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

Authors' Contributions

Conception and design: C. Samayoa, A.L. Stewart, C. Ortiz, L. Márquez-Magaña, A.M. Nápoles
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References

1. Lopez DS, Fernandez ME, Cano MA, Mendez C, Tsai CL, Wetter DW, et al. Association of acculturation, nativity, and years living in the United States with biobanking among individuals of Mexican descent. Cancer Epidemiol Biomarkers Prev 2014;23:402–8.
2. Hispanic heritage month 2019. United States Census Bureau. 2019 Aug 20;CB19-FF.07. Available from: https://www.census.gov/newsroom/facts-for-features/2019/hispanic-heritage-month.html.
3. Spratt DE, Chan T, Waldron L, Speers C, Feng FY, Ogunwobi OO, et al. Racial/ethnic disparities in genomic sequencing. JAMA Oncol 2016;2:1070–4.
4. Dash C, Wallington SF, Muthra S, Dodson E, Mandelblatt J, Adams-Campbell LL. Disparities in knowledge and willingness to donate research biospecimens: a mixed-methods study in an underserved urban community. J Community Genet 2014;5:329–36.
5. National Institutes of Health All of Us Research Program [homepage on the Internet]. Washington (DC): U.S. Department of Health & Human Services; 2020. Available from: https://allofus.nih.gov/.
6. Fitzgibbons S, Treston C. Understanding the All of Us Research Program: a dialogue with Dara Richardson-Heron, MD. J Assoc Nurses AIDS Care 2018;29:949–52.
7. Sankar PL, Parker LS. The precision medicine initiative's All of Us Research Program: an agenda for research on its ethical, legal, and social issues. Genet Med 2017;19:743–50.
8. Huey RW, Hawk E, Offodile AC 2nd. Mind the gap: precision oncology and its potential to widen disparities. J Oncol Pract 2019;15:301–4.
9. Jemal A, Center MM, DeSantis C, Ward EM. Global patterns of cancer incidence and mortality rates and trends. Cancer Epidemiol Biomarkers Prev 2010;19:1893–907.
10. Ooi SL, Martinez ME, Li CI. Disparities in breast cancer characteristics and outcomes by race/ethnicity. Breast Cancer Res Treat 2011;127:729–38.
11. Yanez B, Thompson EH, Stanton AL. Quality of life among Latina breast cancer patients: a systematic review of the literature. J Cancer Surviv 2011;5:191–207.
12. Satariano WA, Ragland DR. The effect of comorbidity on 3-year survival of women with primary breast cancer. Ann Intern Med 1994;120:104–10.
13. Ashing K, Rosales M, Lai L, Hurria A. Occurrence of comorbidities among African-American and Latina breast cancer survivors. J Cancer Surviv 2014;8:312–8.
14. Walker BR. Glucocorticoids and cardiovascular disease. Eur J Endocrinol 2007;157:545–59.
15. Antoni MH. Psychosocial intervention effects on adaptation, disease course and biobehavioral processes in cancer. Brain Behav Immun 2013;30 Suppl:S88–98.
16. Finch BK, Vega WA. Acculturation stress, social support, and self-rated health among Latinos in California. J Immigr Health 2003;5:109–17.
17. McEwen BS. Protective and damaging effects of stress mediators. N Engl J Med 1998;338:171–9.
18. Antonova L, Aronson K, Mueller CR. Stress and breast cancer: from epidemiology to molecular biology. Breast Cancer Res 2011;13:208.
19. Antoni MH, Lutgendorf SK, Cole SW, Dhabhar FS, Sephton SE, McDonald PG, et al. The influence of bio-behavioural factors on tumour biology: pathways and mechanisms. Nat Rev Cancer 2006;6:240–8.
20. von Zglinicki T. Oxidative stress shortens telomeres. Trends Biochem Sci 2002;27:339–44.
21. Shammas MA. Telomeres, lifestyle, cancer, and aging. Curr Opin Clin Nutr Metab Care 2011;14:28–34.
22. Maciejowski J, de Lange T. Telomeres in cancer: tumour suppression and genome instability. Nat Rev Mol Cell Biol 2017;18:175–86.
23. Dang JH, Rodriguez EM, Luque JS, Erwin DO, Meade CD, Chen MS Jr. Engaging diverse populations about biospecimen donation for cancer research. J Community Genet 2014;5:313–27.
24. Erwin DO, Moysich K, Kiviniemi MT, Saad-Harfouche FG, Davis W, Clark-Hargrave N, et al. Community-based partnership to identify keys to biospecimen research participation. J Cancer Educ 2013;28:43–51.
25. Heredia NI, Krasny S, Strong LL, Von Hatten L, Nguyen L, Reininger BM, et al. Community perceptions of biobanking participation: a qualitative study among Mexican-Americans in three texas cities. Public Health Genomics 2017;20:46–57.
26. Barnett J, Aguilar S, Brittner M, Bonuck K. Recruiting and retaining low-income, multi-ethnic women into randomized controlled trials: successful strategies and staffing. Contemp Clin Trials 2012;33:925–32.
27. Lavange LM, Kalsbeek WD, Sorlie PD, Aviles-Santa LM, Kaplan RC, Barnhart J, et al. Sample design and cohort selection in the Hispanic community health study/study of Latinos. Ann Epidemiol 2010;20:642–9.
28. Santoyo-Olsson J, Stewart AL, Samayoa C, Palomino H, Urias A, Gonzalez N, et al. Translating a stress management intervention for rural Latina breast cancer survivors: the Nuevo Amanecer-ii. PLoS One 2019;14:e0224068.
29. Ramirez J, Elmofty M, Castillo E, DeRouen M, Shariff-Marco S, Allen L, et al. Evaluation of cortisol and telomere length measurements in ethnically diverse women with breast cancer using culturally sensitive methods. J Community Genet 2017;8:75–86.
30. Stalder T, Kirschbaum C, Kudielka BM, Adam EK, Pruessner JC, Wust S, et al. Assessment of the cortisol awakening response: Expert consensus guidelines. Psychoneuroendocrinology 2016;63:414–32.
31. Kirschbaum C, Hellhammer DH. Salivary cortisol in psychoneuroendocrine research: recent developments and applications. Psychoneuroendocrinology 1994;19:313–33.
32. Drury SS, Theall K, Gleason MM, Smyke AT, De Vivo I, Wong JY, et al. Telomere length and early severe social deprivation: linking early adversity and cellular aging. Mol Psychiatry 2012;17:719–27.
33. Ice GH, James GD, editors. Measuring stress in humans: a practical guide for the field. Cambridge (UK): Cambridge University Press; 2007.
34. Raul JS, Cirimele V, Ludes B, Kintz P. Detection of physiological concentrations of cortisol and cortisone in human hair. Clin Biochem 2004;37:1105–11.
35. Sauve B, Koren G, Walsh G, Tokmakejian S, Van Uum SH. Measurement of cortisol in human hair as a biomarker of systemic exposure. Clin Invest Med 2007;30:E183–91.
36. Hoffman MC, Karban LV, Benitez P, Goodteacher A, Laudenslager ML. Chemical processing and shampooing impact cortisol measured in human hair. Clin Invest Med 2014;37:E252–7.
37. Hewakapuge S, van Oorschot RA, Lewandowski P, Baindur-Hudson S. Investigation of telomere lengths measurement by quantitative real-time PCR to predict age. Leg Med (Tokyo) 2008;10:236–42.

38. The state of privacy in post-Snowden America. Pew Research Center. 2016 Sep 21. Available from: https://www.pewresearch.org/fact-tank/2016/09/21/the-state-of-privacy-in-america/.

39. Brown DR, Fouad MN, Basen-Engquist K, Tortolero-Luna G. Recruitment and retention of minority women in cancer screening, prevention, and treatment trials. Ann Epidemiol 2000;10:S13–21.

40. Nguyen BH, Stewart SL, Nguyen TT, Bui-Tong N, McPhee SJ. Effectiveness of lay health worker outreach in reducing disparities in colorectal cancer screening in vietnamese Americans. Am J Public Health 2015;105:2083–9.

41. Squires EC, McClure HH, Martinez CR Jr, Eddy JM, Jimenez RA, Isiordia LE, et al. Diurnal cortisol rhythms among Latino immigrants in Oregon, USA. J Physiol Anthropol 2012;31:19.

42. Adam EK, Kumari M. Assessing salivary cortisol in large-scale, epidemiological research. Psychoneuroendocrinology 2009;34:1423–36.

43. John EM, Sangaramoorthy M, Koo J, Whittemore AS, West DW. Enrollment and biospecimen collection in a multiethnic family cohort: the Northern California site of the Breast Cancer Family Registry. Cancer Causes Control 2019;30:395–408.

44. Hohl SD, Gonzalez C, Carosso E, Ibarra G, Thompson B. "I did it for us and I would do it again": perspectives of rural Latinos on providing biospecimens for research. Am J Public Health 2014;104:911–6.

45. Greiner KA, Friedman DB, Adams SA, Gwede CK, Cupertino P, Engelman KK, et al. Effective recruitment strategies and community-based participatory research: community networks program centers' recruitment in cancer prevention studies. Cancer Epidemiol Biomarkers Prev 2014;23:416–23.

46. Rodriguez EM, Saad-Harfouche FG, Miller A, Mahoney MC, Ambrosone CB, Morrison CD, et al. Engaging diverse populations in biospecimen donation: results from the Hoy y Mañana study. J Community Genet 2016;7:271–7.

47. Sorlie PD, Aviles-Santa LM, Wassertheil-Smoller S, Kaplan RC, Daviglus ML, Giachello AL, et al. Design and implementation of the Hispanic community health study/study of Latinos. Ann Epidemiol 2010;20:629–41.

48. Brooks SE, Muller CY, Robinson W, Walker EM, Yeager K, Cook ED, et al. Increasing minority enrollment onto clinical trials: practical strategies and challenges emerge from the NRG Oncology accrual workshop. J Oncol Pract 2015;11:486–90.

49. Castillo AG, Jandorf L, Thelemaque LD, King S, Duhamel K. Reported benefits of participation in a research study. J Community Health 2012;37:59–64.

50. Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. Attitudes and beliefs of African Americans toward participation in medical research. J Gen Intern Med 1999;14:537–46.

51. Ford JL, Boch SJ, McCarthy DO. Feasibility of hair collection for cortisol measurement in population research on adolescent health. Nurs Res 2016;65:249–55.

52. George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. Am J Public Health 2014;104:e16–31.

53. Clark LT, Watkins L, Pina IL, Elmer M, Akinboboye O, Gorham M, et al. Increasing diversity in clinical trials: overcoming critical barriers. Curr Probl Cardiol 2019;44:148–72.

54. Kaufman DJ, Murphy-Bollinger J, Scott J, Hudson KL. Public opinion about the importance of privacy in biobank research. Am J Hum Genet 2009;85:643–54.

55. Sabri AA, Qayyum MA. Increasing the participation: another factor. PLoS Med 2006;3:e250.

56. Hussain-Gambles M, Atkin K, Leese B. Why ethnic minority groups are under-represented in clinical trials: a review of the literature. Health Soc Care Community 2004;12:382–8.

57. Hunt S, Bhopal R. Self reports in research with non-English speakers. BMJ 2003;327:352–3.

58. Wendler D, Kington R, Madans J, Van Wye G, Christ-Schmidt H, Pratt LA, et al. Are racial and ethnic minorities less willing to participate in health research? PLoS Med 2006;3:e19.

59. Sanderson SC, Diefenbach MA, Zinberg R, Horowitz CR, Smirnoff M, Zweig M, et al. Willingness to participate in genomics research and desire for personal results among underrepresented minority patients: a structured interview study. J Community Genet 2013;4:469–82.

60. Ross S, Grant A, Counsell C, Gillespie W, Russell I, Prescott R. Barriers to participation in randomised controlled trials: a systematic review. J Clin Epidemiol 1999;52:1143–56.

61. Rockett JC, Buck GM, Lynch CD, Perreault SD. The value of home-based collection of biospecimens in reproductive epidemiology. Environ Health Perspect 2004;112:94–104.

62. Rodriguez EM, Torres ET, Erwin DO. Awareness and interest in biospecimen donation for cancer research: views from gatekeepers and prospective participants in the Latino community. J Community Genet 2013;4:461–8.

Participant-Centered Strategies for Overcoming Barriers to Biospecimen Collection among Spanish-Speaking Latina Breast Cancer Survivors

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