

Awareness and interest in biospecimen donation for cancer research: views from gatekeepers and prospective participants in the Latino community

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Abstract Latinos are one of the fastest-growing population groups in the USA, and are underrepresented in scientific research and even more so in genetic research. The disproportionately lower number of certain subpopulations participating in biomedical research has a significant impact on the representativeness of scientific outcomes. We established a collaboration with scientists at a designated National Cancer Institute comprehensive cancer center to test the feasibility of community-based approaches for engaging Latinos in biospecimen donation for cancer genomic research. A methods triangulation approach was applied to gain a deeper understanding from the community, that included key informant interviews with Latino community leaders ($N=6$), four focus groups ($N=22$) with members of the Latino community, and the use of an audience response system within the focus groups to capture quantitative data. Overall, the majority of participants had never participated in biospecimen donation; however, despite being unaware of the biobank, they expressed willingness to participate as a way to help advance research. Themes included: Confusion on what biospecimen donation process entails; Barriers to and incentives for participation; Strategies and locations for reaching

the Latino community. Clear communication of the “public good” as it relates to biospecimen donation by healthy/non-patient participants is a less clearly conceptualized message; yet, the significance of delivering this message is important to gaining participation and increasing the diversity of samples available for cancer genomic studies from a broader community context.

Keywords Latino · Biobank · Biospecimen donation · Community-based · Cancer

Introduction

Cancer genetics, and more specifically the collection of biospecimen donations for the creation of biorepositories, continues to gain significant interest and attention as related to cancer research. The National Cancer Institute (NCI) dedicated resources to genetic research through the creation of The Cancer Genome Atlas which was established in 2005 (National Cancer Institute 2010) and continues to grow through additional multi-pronged research initiatives. The NCI/Center to Reduce Cancer Health Disparities (CRCHD) Community Networks Program Centers is one of the research initiatives that include a focus on racial/ethnic and/or underserved population’s participation in biobanking research studies (National Cancer Institute 2011). Increasingly, a large-scale recruitment effort at the community level to promote participation in biospecimen donation is a strategy for acquiring healthy control samples with greater contributor diversity. The development of biorepositories for a variety of research endeavors is of global interest yet there are many unknowns related to the ethics of biorepository collection procedures and specimen usage with respect to public health research interests (Lemke et al. 2012; Meslin and Garba 2011; Tutton 2009).

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Several studies have examined community perspectives of attitudes and beliefs about biobanking (Beskow and Dean 2008; Halverson and Ross 2012; Luque et al. 2011), and/or the development of a genetic biobank (Goldman et al. 2008; Tutton 2009). However, little is known about the feasibility of community-based approaches to engage racial/ethnic minority communities in biospecimen donation for cancer research.

We established a collaboration with scientists at a local NCI-designated comprehensive cancer center to test the feasibility of community-based approaches for engaging Latinos, who are currently underrepresented in biospecimen donation for cancer genomic research. The goal of this study was to build capacity around existing community research partnerships and initiate community engagement in cancer research efforts that include biospecimen donation as a form of research participation. The *Hoy y Mañana* (Translation: Today and Tomorrow) program was developed in partnership with previously established community partners from a cancer screening outreach study, (*Esperanza y Vida (EyV)*, (Translation: Hope and Life) (Erwin et al. 2005, 2010; Jandorf et al. 2008, 2012; Saad-Harfouche et al. 2011; Sudarsan et al. 2011) as the authors theorized that discussions with individuals with some prior experience with outreach staff from the cancer center would facilitate biobanking discussions among engaged community members. This approach is further supported by community-based participatory research (CBPR) such as the Healthy Black Family Project (Thomas and Quinn 2008) that suggests that community members should receive services/resources in order to build relationships prior to solicitation for institutional/research gain.

Through the *Hoy y Mañana* study we examined individual, social, and community level factors as described by research partners and study participants from the Latino community of Buffalo, NY in terms of: (1) factors that promote or act as barriers to community awareness and interest in biospecimen donation for cancer research; and in consideration of (2) how to design a pilot intervention with partners from the Latino community to promote biospecimen donation opportunities for cancer prevention research. In this manuscript, we examine and compare the Latino community's awareness of biospecimen donation for cancer genomic research from both the community leader and prospective participant perspectives. We focused on Latinos because they are one of the fastest-growing population groups in the USA, as well as in Buffalo, New York, and are underrepresented in medical research and even more so in genetic research (Lemke et al. 2012). They mirror African Americans in their negative perceptions about participating in research studies, specifically with regard to perceived high levels of risk for volunteering to become research participants in biomedical studies (Katz et al. 2008).

Nearly half of the Latino population of Western New York (WNY), (27,438 people) reside in the city of Buffalo

and constitutes 10.5 % of the city's population (U.S. Census Data 2010). Two thirds of the Latinos of WNY are of Puerto Rican birth or parentage, and the remaining Latino population is of Mexican origin and from other countries (U.S. Census Data 2010). Buffalo remains the third poorest city of its size in the U.S. with 30.3 % of the residents below the poverty level (Thomas 2009). Five percent of adults in WNY are without a regular source of health care; however, 11 % of adults living in the West Side of Buffalo (Latino neighborhoods) reported not having a usual source of care, compared to 16 % nationally (Western New York Public Health Alliance 2005). Buffalo, NY is designated as a medically underserved area/population (MUA) according to criteria established by the U.S. Department of Health and Human Services. Buffalo has an Index of Medical Underservice score of 52.30 out of 100 which qualifies for designation as an MUA (U.S. Department of Health and Human Services 1995). Overall, the Latino population that resides in Buffalo and represented in this research is predominantly Puerto Rican as well as medically underserved. Most are mono-lingual Spanish speakers and may move back and forth between Buffalo and family and homes in Puerto Rico.

Materials and methods

This feasibility study began in October 2010 and ended in August 2012. The focus of this paper is on qualitative and quantitative results obtained from the initial phases of formative research that were conducted in two waves, with the first wave consisting of key informant interviews with Latino community members during November and December 2010. The second wave of formative data collection included focus groups that were conducted from May through July 2011 with Latino participants, primarily of Puerto Rican ethnicity. Digital audio recordings of the focus group sessions were professionally transcribed. Responses to interviews were written. We applied a methods triangulation approach (Patton 2002) that included key informant interviews, qualitative and quantitative data (using an audience response system (ARS)) from focus group setting (Gamito et al. 2005). By using multiple methods of data collection, we are able to examine the consistency of findings and/or points of divergence generated by the multiple data sources.

Participant recruitment

We identified key informant interview (KII) participants through our established partnerships with key Latino community leaders (i.e., pastors, civic leaders, and clinicians who practice in a community clinic). Interview participants were recruited exclusively for key informant interviews and were not included in focus group recruitment. The goal of

the KIIs was to achieve a baseline of awareness and understanding from influential and trusted individuals with respect to the topic of biomedical research participation and more specifically biospecimen donation for cancer research. Results from these KIIs were used to inform the topics of discussion for the focus group protocol which included an additional level of formative inquiry with a broader segment of the Latino community.

Purposive sampling from an existing cohort of Latino men and women participants who had previous research participation experience in a breast and cervical cancer educational and screening intervention study (i.e., *Esperanza y Vida/EyV study*) was used to recruit focus group participants (Erwin et al. 2012). Based on responses from KIIs, it was determined that recruiting Latinos with at least a minimal, baseline experience with behavioral researchers from the cancer center would produce optimal focus group interactions and candid responses.

Interviews and focus groups

KII participants gave oral consent and each received a \$15 gift card for participating. Interviews lasted on average 30 min and were digitally recorded. The majority of interviews were conducted in person by one of two interviewers at a location convenient for the participant; however, telephone interviews were also completed to accommodate participant needs. We used an interview protocol to guide the process and ensure discussion of the research topics.

KIIs were analyzed using the immersion crystallization approach (Borkan 1999) to reveal patterns and themes in the data. Two of the authors (EMR and ETT) reviewed the responses and summarized them into themes by question topic (interview script is available upon request). Several items in the script that were included in the sections specific to beliefs on medical research treatment among Latinos and questions specific to biobanking used a Likert scale or yes/no response pattern, these items were quantified to determine an overall response rate.

Focus group participants also gave oral consent, received \$10 gift cards in addition to food and beverages during the session which lasted on average 64 min and were digitally audio-recorded. Two experienced bilingual facilitators conducted the sessions in Spanish; however, participants responded in both Spanish and English during the sessions. Each of the four focus groups had two sources of data including: (a) ARS polling results; and (b) focus group transcripts. The ARS was used during the focus groups to collect demographic data, and incorporated questions in PowerPoint format that were read aloud by the facilitator. The audience then selected their numeric answers by pressing individual anonymous keypads. This method has been found to be an excellent education and research tool,

especially for low literacy populations (Gamito et al. 2005). The first draft of the focus group guide was informed by themes derived from the KIIs in relation to relevant topics identified in the literature (Goldman et al. 2008; Katz et al. 2008). We used an iterative approach in finalizing the focus group guide in order to incorporate valuable feedback gained from participants and ensure clarity and accuracy of the topics explored which included the following sections: (1) consent; (2) practice questions to familiarize participants with ARS key pads; (3) sociodemographics; (4) biobank awareness probe, (5) education and promotion of biobank facility at the cancer center; (6) specific types of research participation; and (7) incentivizing and opportunities to participate in research.

Focus group recordings were professionally transcribed by a service that is certified in bilingual transcription as both Spanish and English were spoken in all of the sessions. One author (EMR) compared the transcripts to the audio for consistency and a second author (ETT) who facilitated the sessions verified the transcripts for accuracy. The two authors used the immersion crystallization approach as described above to analyze the focus group transcripts. A summary of themes for each focus group was created by one author (ETT) and was then compared to the second coder's analysis to verify agreement and detect any differences. The authors discussed their final analyses and agreed on the dominant themes. All responses collected by the ARS at the focus groups were tabulated and the sociodemographic information was summarized using descriptive statistics, including frequencies and percentages (Table 1). No individual identifiers were collected from any of the participants.

Results

Interview and focus group participant characteristics

We recruited six key informants who all self-identified as Latino and represented a diverse cross-section of roles (i.e., pastors, physician, cancer survivor) to participate in individual interviews. Saturation of the responses provided by participants was achieved by the fourth interview. Four of the six participants were female. Four focus groups ($N=22$) were conducted with self-identified Latino community members and all were at least 18 years old. The focus groups were not held concurrently but by the final group, saturation was achieved with no new information emerging. Sociodemographic characteristics of the focus group participants are described in Table 1.

Key informant interview participant perspectives on biomedical research

The initial question began with participants responding to the following item: *When I say the words "biomedical*

Table 1 Sociodemographic characteristics of focus group participants

Variables		n	%
Gender	Male	3	13.6
	Female	19	86.4
Birth place	Puerto Rico	19	86.4
	USA	2	9.1
	South America	1	4.5
Years living in the USA	<1 year	1	4.5
	1–14 years	2	9.1
	15–19 years	5	22.7
	20+ years	14	63.6
Age	18–39 years	5	22.7
	40–59 years	13	59.1
	60+ years	4	18.2
Marital Status	Married/partnered	9	40.9
	Divorced/widowed/ separated/single	13	59.1
Education	Less or equal to high school/GED	17	77.3
	>High school	5	22.7
Income	<\$5,000	8	36.4
	\$5,000–\$15,000	6	27.3
	\$15,001–\$30,000	7	31.8
	≥\$30,001	1	4.5
Employment	Full time	5	22.7
	Part-time	2	9.1
	Retired/disabled	7	31.8
	Unemployed	8	36.4
Insurance	Public (Medicare/Medicaid)	12	54.6
	Private	3	13.6
	Uninsured	7	31.8
Perceived health status	Very good	3	13.6
	Good	5	22.7
	Fair	12	54.5
	Poor	2	9.1
Had a friend/family member with cancer	Yes	19	86.4
	No	3	13.6
Familiarity with data bank and BioRepository (DBBR)	Very familiar	2	9.1
	Somewhat familiar	3	13.6
	Not at all familiar/presentation is the first time heard of DBBR	17	77.3

research,” what do you think of? In response to this general inquiry about “biomedical research,” participants discussed the purpose of biomedical research in terms of finding a cure and/or investigating strategies to prevent illness. Their impressions of medical research, as based on personal experiences or stories from other people, revolved around taking new medications for treatment and “fear” related to being experimented on and used as a “guinea pig” in order to sell medication. Altruistic reasons for their own participation in

medical research studies included advancing medicine and helping other people, who were often specified as relatives or family members. One interview participant did discuss compensation for participation as a motivation for those who have financial needs. Reasons not to participate in medical research were discussed in terms of, fear related to treatment side effects and receiving results regarding incidental findings (i.e., disease or illness diagnosis), as well as financial cost to the participant. Respondents discussed barriers to participation in terms of, lack of direct benefit and perception of research participation being “too risky.” Family responsibilities were also identified as a barrier to participation in research with respect to respondents’ perception that research participation might cause illness and impede their ability to take care of their family. In addition, four out of six interview participants believed doctors or the scientist conducting research benefit from these studies and cited the recognition received for finding a cure and profiting from the discovery as the reason for this belief.

Interview participants were also asked to respond to the following statement: *More white men and women participate in medical research studies. What does this mean?* Respondents cited Latinos as not being informed and marketed to effectively with respect to research study information. In addition, participants perceived white men and women to have more illnesses and more education, therefore having more interest and opportunities to participate in biomedical research. In terms of their perception of Latinos’ ethical treatment compared to white participants in biomedical research, four out of six participants believed rarely to never that Latinos in the USA are more likely to be “taken advantage of” when they participate in medical research. One participant did believe that Latino participants are more likely to be “taken advantage of” some of the time due to language barriers and another participant believed this to occur most of the time “because they are immigrants and they are less likely to get a lawyer.”

KII participant perspectives on biospecimen donation for medical research

Participants were asked to describe the following: *How is a medical treatment study for people with a specific disease different than a medical research study that may take blood samples or test for something on healthy people that don’t have any diseases yet?* This question was intended to prompt discussion about perceptions and differentiation by participants regarding clinical treatment studies versus biobanking and prevention studies. Five out of six participants described “sick people” as looking for results and having more distrust because they are concerned with an outcome related to their condition; in contrast to healthy people who were described as not looking for a cure to an

illness and believed to have less required of them. Based on respondents’ previous discussion of barriers to participation in medical research, there is indication that there is a lack of understanding among participants regarding the differences between clinical, prevention, and biobanking research.

Table 2 presents results from six KIIs that discussed more in-depth perceptions and beliefs about medical research and the biospecimen bank located at the cancer center. Overall, the majority of participants had not donated any type of biospecimen, and stated the reason for this was never being asked to do so. However, all participants stated they would be willing to donate a biospecimen, and they would do so in order to help advance research. Despite their willingness to donate, most participants were not aware of the biospecimen bank in their community, but believed it to be important for the community. Most did not have concerns about the biospecimen bank, and the one concern mentioned was due to lack of information about the purpose of the biospecimen bank.

Focus group analysis

The following results include dominant themes from the content analysis of the focus group transcripts as well as quantitative data collected using the ARS tool.

Medical diagnosis, medical research, and biobanking

One of the overarching themes in perceptions, knowledge and beliefs of focus group participants regarding research involving the biospecimen bank was the inability to conceptualize the difference between biomedical research and medical diagnostic services and results. The expectation of receiving individual cancer diagnoses or results was a recurrent topic described during the focus group discussions and is best represented by the following participant quote: *My baby has cancer, my aunt died of cancer, my sister has cancer, my mother died of cancer, so for example, if I donate, I would like to know the level of development of cancer in me, for example.* [Direct

translation from Spanish; Focus Group 1 quote] Many participants made reference to receiving some sort of diagnostic results after their donation and referred to it as a type of medical service available to the community.

The anonymity of donating to the biospecimen bank was an unfamiliar concept and statements about being contacted in case some illness was found was often mentioned by participants during the sessions and noted regularly in the transcripts. Participants were unclear about who could donate to the biospecimen bank, and had questions about eligibility criteria such as being healthy versus ill, having cancer versus having other illnesses, and being a patient at the cancer center. Barriers to interest in biospecimen donation identified by participants included not having medical insurance in order to pay for the donation process, and fear of not understanding how the donation will be used was connected to participants’ lack of experience in prevention research and the role of healthy research participants in cancer research studies. This was made clear by the perception of the cancer institute as exclusively functioning as a hospital for people with cancer and the common statement from participants: *When people think (cancer center name) they think cancer, and outreach is needed to educate the community and change this perception.* [Translation from Spanish to English; Focus Group 3 quote] Fear that their donation would be misused was discussed in terms of negative expectations as related to receiving individual medical diagnoses. Donating to the biobank was compared to taking an HIV test, and the fear associated with “knowing” the results. Lastly, when asked if they would participate in biospecimen donation if a health care provider (HCP) recommended it, many said they would because their HCP knows what would be in their best interest.

Strategies for community engagement

Participants were asked about outreach to the Latino community for the purpose of education about the biospecimen bank and increasing participation in donations for cancer prevention research. Monetary incentives were mentioned as a primary method of ensuring participation, but most stated they themselves would not need a monetary incentive to donate. In terms of health promotion efforts, having language appropriate material was key and making it available in a variety of locations throughout the community was seen as the best way to reach and include the Latino community. The identification of language as a barrier was consistently identified by participants and best described by this participant quote: *Language is a big barrier, and therefore we do not feel included in these opportunities because we speak Spanish* [Translation from Spanish to English; Focus Group 1 quote]. When asked about Latinos’ knowledge of research opportunities, the consensus across focus group participants

Table 2 Biobanking items: key informant responses (N=6)

Question	No/no answer	Yes
Have you donated saliva, blood, or other types of tissue for medical purposes?	4	2 ^a
Would you ever donate saliva, blood, or types of tissue for medical research?	0	6
Are you aware that there is a biospecimen bank located in Buffalo, NY?	5	1
Do you think having a biospecimen bank is important in the community?	1	5
Do you have any concerns about having a biospecimen bank in the community?	5	1 ^b

^a Blood only

^b Participant response: *What is it being used for?*

is that the Latino community is not well-informed. As part of the educational process, emphasizing the small amount of the biospecimen (e.g., blood) required for the actual donation was seen as positive and participants suggested that this be highlighted during recruitment. Focus group participants also discussed logistics in terms of making the donation process as convenient and accessible as possible which was viewed as an extremely important factor. Using medical practices as an opportunity to disseminate educational materials was mentioned by most participants, but many added the need for follow-up and having someone available for questions as a critical component of the educational outreach efforts. Locations suggested for outreach in the community included media outlets (e.g. radio, print, ads, and newspaper), community centers and health fairs, Latino churches, and businesses that cater to the Latino community (e.g. supermarkets, restaurants, bakery, beauty salons/barber shops, and bingo halls).

Biobanking responses: comparison of ARS items and focus group transcripts

Table 3 presents polling results from focus group participants regarding their knowledge and expectations of the biospecimen donation process. A brief background on the biospecimen bank was included in the focus group session and questions were asked during the post-assessment.

In contrast to the descriptive data analyzed in the transcripts which highlighted the lack of clarity in participant understanding regarding a medical diagnosis versus medical research, and more specifically the anonymity involved in the biospecimen donation process, participants overwhelmingly indicated that they understood the purpose of the biospecimen bank with 18 of 22 participants answering yes to this item included in the post-assessment. While the majority of participants did not expect to receive an incentive for their participation in a research study, the majority of

participants did indicate that an incentive would influence their decision to participate in a biospecimen donation which was consistent with qualitative findings. Participant polling results also indicated that a recommendation from the participant's doctor for the biospecimen bank would be trusted and that a brochure in the doctor's office was a good way to inform people about the biospecimen bank. An additional item regarding the biospecimen bank was included in the script after the first focus group; therefore, the response rate for this item reflects an $N=16$. Participants were asked to respond to the following: *Now that you know what the biospecimen bank is and what they do, would you participate?* The majority indicated that yes they would participate (13 of 16 responses) and the remaining three participants responded as maybe/do not know.

Discussion

These data demonstrated an overall willingness by Latino participants to donate to a biospecimen bank; however, barriers to their participation include lack of outreach and education about this type of resource and research participation opportunity.

The results from our key informant interviews provided a baseline of understanding with respect to the Latino community's lack of awareness regarding the biospecimen bank and similarly their lack of familiarity with the process/concept of biospecimen donation (Luque et al. 2011) as a form of research participation to be used for cancer research. Findings from the focus groups demonstrated expectations of individual diagnoses/results as related to cancer or other health conditions that may already exist in their family. The focus group facilitators reinforced that biospecimen donations collected from participants were not being linked to identifying information for that individual; and therefore, individual results would not be available as the specimens were not being tested for cancer or other diseases mentioned by participants. Explaining the intent for the collection of biospecimen donations is a critical step in the education/outreach component when engaging communities in voluntary donation to the biobank as their expectations are influenced by their interpretation of the information being provided.

Both interview and focus group data documented language as a major social level barrier with respect to participants' awareness of resources and opportunities at the cancer center; as well as their perception of inclusivity with regard to cancer research study participation involving the Latino community. The very fact that materials and information about the cancer center biobank and program had not been disseminated in the local Spanish media was perceived by participants as evidence that specimen donations from

Table 3 Biobanking items: focus group polling results using audience response system (ARS) ($N=22$)

Question	No/no answer	Yes
Do you understand the purpose of the biospecimen bank?	4	18
Do you expect to receive an incentive for your participation in a research study?	16	6
Would an incentive offer influence you to participate in a biospecimen donation?	8	14
Do you believe it will cost you money to participate in the biospecimen bank?	19	3
Would you trust a recommendation of the biospecimen bank from your doctor?	4	18
Would a brochure in the doctor's office be a good way to inform people about the biospecimen bank?	1	21

the Latino community were not a focus of the program. The *Hoy y Mañana* study made every effort to translate materials for this project and obtain feedback from the community on translated materials as a way to improve information delivery and access to Spanish language materials on biospecimen donation for cancer research; however, it was through these efforts that we were also able to realize some of the existing institutional limitations related to serving the needs of diverse populations. The process of translating research documents requires specific certifications of the document and the person performing the translation, and subsequent IRB approvals, which can require additional resources that are not always readily available and delay program implementation in the community. Interview and focus group data contributed to understanding the technical accommodations required of the cancer center to promote and conduct research that includes the collection of biospecimens from diverse communities, specifically the Latino community.

Ethical considerations regarding the collection of biospecimens for research are not uncommon in the literature (Beskow and Dean 2008; Haga and Beskow 2008; Tutton 2009), especially in consideration of genetic research as it relates to epidemiologic studies and public health research more broadly (Brand and Probst-Hensch 2007; Ford et al. 2006; Goldman et al. 2008; Katz et al. 2008; Meslin and Garba 2011). Participants in this study linked their altruistic intentions for participating in research as a way of helping others in the future, especially their family members who may become ill in the future. Clear communication of the “public good” as it relates to biospecimen donation by healthy/non-patient participants is a less clearly conceptualized message; yet, the significance of delivering this message is important to gaining participation and increasing the diversity of samples available for cancer genomic research studies from a broader community context.

Our findings are limited to the primarily Puerto Rican Latino community in Buffalo, NY, and may be further biased by this cohort’s previous participation in cancer screening research programs (i.e., *EyV* study cohort) with the cancer center which may influence socially desirable responses from this group. This limitation may be mitigated to some extent due to the intrinsic nature of capacity building as a key element of CBPR which strives to develop resources in the form of skills, material resources, and/or knowledge by building on existing partnerships. Hence, the purpose of recruiting from an existing cohort was to increase knowledge and skills specific to biospecimen donation for cancer research efforts among the already engaged Latino community. Our use of multiple data collection methods helped to facilitate a deeper understanding of community perspectives as related to biobanking awareness and interest. In addition, the majority of participants did report having a friend or family member with cancer which may influence a more positive response or

active interest toward research participation; however, it is likely that most people in the general population would also report having cancer in family or friends.

Important implications of this study include: the need for educational materials/programs that explain the *purpose* of community participation in biospecimen donation for cancer research efforts; explanation of potential *risks and benefits* of participation in biobanking research; and a clear statement of what if any *clinical information will or will not be returned to participants*, are all critical topics that need to be addressed in culturally appropriate education/outreach programs to engage communities in biospecimen donation for cancer research.

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

Ethical standards The research reported in this manuscript was approved by the Roswell Park Cancer Institute Institutional Review Board and is in compliance with the ethical standards and current laws in the USA where all of the research was conducted.

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