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Closing the Loop: An interactive action-research conference format for delivering updated medical information while eliciting Latina patient/family experiences and psychosocial needs post-genetic cancer risk assessment

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Abstract

Objective—A patient/family-centered conference was conducted at an underserved community hospital to address Latinas' post-genetic cancer risk assessment (GCRA) medical information and psychosocial support needs, and determine the utility of the action research format.

Methods—Latinas seen for GCRA were recruited to a half-day conference conducted in Spanish. Content was partly determined from follow-up survey feedback. Written surveys, interactive discussions, and Audience Response System (ARS) queries facilitated the participant-healthcare professional action research process. Analyses included descriptive statistics and thematic analysis.

Results—The 71 attendees (41 patients and 27 relatives/friends) were primarily non-U.S. born Spanish-speaking females, mean age 43 years. Among patients, 73% had a breast cancer history; 85% had *BRCA* testing (49% *BRCA*+). Nearly all (96%) attendees completed the conference surveys and ARS queries; 48% participated in interactive discussions. Most (95%) agreed that the format met their personal interests and expectations and provided useful information and resources. Gaps/challenges identified in the GCRA process included pre-consult anxiety, uncertainty about reason for referral and expected outcomes, and psychosocial needs post-GCRA,

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Ethical Standards

All human studies have been approved by the appropriate ethics committee and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. All persons gave their informed consent prior to their inclusion in the study.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

such as absorbing and disseminating risk information to relatives and concurrently coping with a recent cancer diagnosis.

Conclusions—The combined action research and educational conference format was innovative and effective for responding to continued patient information needs and addressing an important data gap about support needs of Latina patients and family members following genetic cancer risk assessment. Findings informed GCRA process improvements and provide a basis for theory-driven cancer control research.

Keywords

Latinas; cancer; genetics; oncology; patient conference; psychosocial

Introduction

Breast cancer is the most commonly diagnosed cancer among Latinas^a [1]. Although the overall incidence is lower compared to non-Latinas, Latinas are more often diagnosed at a younger age with more locally advanced disease [2]. Younger age at onset, high risk breast cancer, and a family history of breast or ovarian cancers are associated with inherited *BRCA* gene mutations. We previously demonstrated that *BRCA* mutations account for a significant proportion of these cancers in Latinas [3–4]. As in other healthcare services, Latinas experience disparities in access to genetic cancer risk assessment (GCRA), a standard-of-care medical service for persons/families suggestive of increased cancer risk. Within GCRA, personal and family medical history are used along with rapidly evolving genetic technologies and/or empiric cancer risk models to direct risk-tailored strategies to prevent an initial or subsequent cancer[5–12].

The City of Hope *Cancer Screening & Prevention Program Network (CSPPN)*sm cancer genetics team previously conducted a needs assessment of predominantly uninsured Spanish-speaking Latinas in Southern California [13]. Demonstrated interest, and commitment of the referring institution to provide GCRA patients with free follow-up cancer screening and prevention cares, led to extending the Network to this indigent healthcare system [14]. A decade later, GCRA uptake remains high, with a higher than initially expected rate of *BRCA* mutations identified [4].

We found that in our economically and educationally disadvantaged population, Latinas presenting for GCRA possess relatively high levels of social support and self-efficacy in feeling prepared for GCRA, and low levels of cancer-specific fatalism [15]. However, little is known about the extent to which underserved Latinas comprehend, retain, and process GCRA-related information. Open-ended comments in follow-up surveys identified that Latinas desire updated cancer genetics information and follow-up care, and revealed ongoing psychosocial support needs [16]. Consequently, we held a patient/family-centered conference at our primary underserved clinic to: 1) inform our Latina patients and their family members about medical advances in cancer screening and prevention, 2) further assess their GCRA-related experiences and psychosocial needs, and 3) determine the utility of the interactive action research conference format.

^a‘Latino’ is the most common consensus term for individuals of Spanish, Mexican, Central and South American, Cuban or Puerto Rican origin and is generally considered a more ethnically/culturally based term for individuals of the aforementioned groups.

Methods

Design

As successful in our prior patient conference [17], we employed a multimodal mixed methods design integrating action research principles [18–19]. Action research uses a cyclical process of iterative reflection, inquiry, and informed action [20–21] to co-generate knowledge and enable problem solving through the direct engagement of stakeholders in the research process.

Procedures

Study approval was obtained from the COH IRB. An interdisciplinary research team of Latino and non-Latino clinical cancer genetics staff, other healthcare professionals familiar with cancer genetics research, a Latina *BRCA* positive breast cancer survivor, and a local American Cancer Society [ACS] representative convened to develop the conference goals, agenda and format. The team selected two *BRCA* positive family patient-relative pairs for the patient-healthcare expert panel discussion, and three healthcare professionals for podium presentations, all bilingual Latino/a.

Eligible invitees were Latinos with a personal or family history of breast or ovarian cancers seen for GCRA between 2001–2009 within the COH's CSPPN in Southern California who previously enrolled in the COH IRB-approved prospective registry. The conference brochure and all other conference materials were professionally translated into Spanish. The brochure was mailed to the 167 eligible Latinos and indicated that adult family members were also welcome to attend.

The free half-day conference was held entirely in Spanish on Saturday May 9th, 2009, at Olive View Medical Center (OVMC), a Southern California community-based health services network participating in the COH CSPPN. Attendees chose the syllabus, surveys and video-recording notice in Spanish or English. Index cards and pens were distributed to allow anonymous questions and/or comments about any aspect of the GCRA process or podium presentations. The cards were collected after each presentation and selected content was addressed. An evaluation survey was distributed at the conference conclusion. Six community patient resource/support organizations provided materials in booth exhibits and representatives who were available to speak with attendees. Complimentary amenities included food and beverages, an ice cream social and raffles (grocery cards, gift baskets, etc.).

The 3 podium presentations by providers (manuscript authors) experienced in genetic counseling, surgical oncology, or clinical psychology addressed: 1) advances in risk assessment and cancer screening recommendations for high-risk patients (CR), 2) options and techniques to reduce risk for breast and ovarian cancers (BP), and 3) coping with psychological, social and cultural issues related to this risk (MP). Presentations were followed by a process of interactive discussion sessions mediated by Audience Response System (ARS; Audience Response Systems, Inc., Evansville, IN) items, index cards comments, and verbal exchange.

Measures

Data were collected using two written surveys, ARS items, index cards, and a transcript of the entire conference. Survey items and ARS questions (described below in English) were developed and revised by the multidisciplinary/multicultural clinical cancer genetics team.

The demographic characteristics (age, gender, marital status, number of children, education level, and place of birth) and clinical information (cancer history, *BRCA* status, etc.) survey consisted of check-box items and one open-ended item for comments or questions. The evaluation survey consisted of 5 Likert scale items ranging from “agree” to “disagree” and 4 open-ended items requesting feedback about the conference.

The ARS questions were: 1) Before the cancer genetics consultation, did you know why you were referred, 2) Was the time between being referred and seen stressful or challenging?, 3) Was your first consultation stressful or challenging?, 4) Was the test result visit stressful or challenging?, 5) Did you share the information obtained from the consultation and/or testing?, 6) Do you understand your cancer risk?, 7) Do you understand what needs to be done for cancer screening or prevention?, and 8) Are you able to obtain the recommended exams for cancer screening and detection? Between questions, aggregate group responses were displayed on a screen and the bilingual/bicultural moderator (MP) and the patient-pair facilitated interactive discussion among attendees. Attendees were again encouraged to actively participate in an iterative dialogue.

Analyses

Descriptive statistics were used to report survey items and participants’ demographic and clinical characteristics. T-tests and Chi-square statistics or Fisher’s exact tests were conducted to determine any significant differences between patient and non-patient responses. These analyses were conducted using SPSS v.16.0 (SPSS Inc, Chicago, IL). Index card comments were reviewed, assigned broad topic categories, and tallied. Open-ended data were transcribed verbatim. Data collected in Spanish was professionally translated into English. Bilingual/bicultural research team members reviewed the audio-recording and the Spanish and English transcripts to assure fidelity. Thematic analysis was used to review and independently analyze the Spanish and English transcripts [22–23].

Results

Sample

Sixty-eight (96%) of the 71 attendees, including 41 GCRA patients, completed the baseline survey. Of these, 96% completed the Spanish version. Responders’ demographic characteristics, subdivided by patients (n=41; all female) and non-patients (n=27), are presented in Table 1. The mean age of responders was 43 years (range, 18–71 years). Most were female (93%), completed at least high-school (70%), were married/cohabitating (56%), had children (76%), and were from Mexico (56%) or Central/South America (34%). Non-patient responders were more likely to be males and to have attended college. Utilizing the COH registry database demographic and clinical data, there were no significant differences between invited patient attendees and non-attendees.

Clinical characteristics of the patient attendees

Patients’ cancer history and *BRCA* status are depicted in Table 2. All patients were female, with a mean age of 40 (range, 29–48 years), 73% had a history of breast cancer, two also had ovarian cancer (7%), and three also had another non-*BRCA* related cancer (10%). Eighty-five percent had *BRCA1* and *BRCA2* gene sequencing free-of-charge through our undeserved outreach program, of which 49% were found to have a deleterious *BRCA* mutation.

Perceptions of the GCRA experience and access to care

On average, 93–95% of the 41 patient attendees responded to the ARS questions assessing perceptions of the GCRA experience and access to care (Table 3). Seventy percent understood why they were referred, while 30% did not, were uncertain, or did not remember. Most found the GCRA process to be stressful or challenging while awaiting their initial appointment (n=30; 81%) and during this visit (n=31; 89%) and the results disclosure visit (n=29; 76%). After GCRA, 95% of the patients shared the information (test results, implications) with at least one relative, with 81% doing so immediately, and 14% later. Two patients (5%) did not share the information, citing lack of access to pertinent family members.

Most patient and non-patient responders indicated that they understood their cancer risks (n=56; 80%), although 11 (20%) did not or desired more information, including information about cancer screening and prevention (7%–9%). Nearly all responders who indicated awareness of screening recommendations reported obtaining screening (96%), however 11 (17%) did not know what examinations were needed.

Post-GCRA-related knowledge needs

Participants' (n=31) most frequent topics of inquiry written on the index cards were related to cancer risks and risk reduction (41%), hormonal exposure (16%), breast reconstruction (12%), and age to initiate genetic testing of family members (9%).

Open-ended items and interactive discussion

Six main themes and several sub-themes emerged from the open-ended survey items and interactive discussions. Representative verbatim quotes are presented below in English to represent key points.

Personal challenges associated with the GCRA process-influence of preparedness and support: A dominant area of the interactive discussion revolved around being inadequately prepared for GCRA (not understanding the consultative process and/or necessity) and the subsequent implications for family members and the Latina community, both locally and in their country of origin. For some, fear and anxiety delayed presenting for risk assessment.

“I did not know how important this was.”

“I felt a lot of panic and postponed the appointment.”

For at least one other, anxiety set in when she received her positive result and was further exacerbated when the genetics team expressed surprise with the result since the prior probability that she carried a mutation was modest.

“I didn’t really feel much stress until we actually got my result. It was a big shock to everybody, my whole team, all my doctors...that’s when my stress started.”

Several participants discussed the need for more time to absorb the information provided and genetic test results before discussing healthcare implications. The amount and content of the information was often viewed as overwhelming.

“...many details... a lot of information...the whole thing was very stressful.”

Women also described the added burden of coping with a recent breast cancer diagnosis and treatment.

“Realizing that this disease would not allow me to be myself, do my chores, work, was a great depression...the physical change I suffered depressed me.”

The importance of having a support person present at each genetics visit was echoed by several patients.

“You should tell someone in your family about your first appointment...so that this person can process the information, understand or whatever and make sure they join you at the moment you are given the results, even if they have to take turns, because it’s a great help to rely on someone.”

Educating self in order to inform family and community: The need for ongoing education to facilitate medical/risk information sharing with family members was evident.

“I really wish to give them [relatives] more information, learn more about these genetic issues.”

“More than anything I am truly thankful for everything I have learned, everything I have been taught. What I actually really wanted to do [re learning more] was let my [relatives] know [of cancer risk].”

Sense of family and community responsibility: Patients also discussed their perceived responsibility to share information with, and motivate, others.

“I’d like to let the rest of you know that outside there are a lot of people who did not have the opportunity of attending this conference. I invite you to spread the information around, information we now have, so that we all help each other.”

Transitioning to survivorship: Several patients voiced how they advocated for and motivated each other:

“The most important think to bear in mind once you leave this room is that you have to keep going forward, you mustn’t let this disease overcome you.”

Information was seen as key to health promotion, self-efficacy.

“With the information you can gather, you can be very positive about the fact that we can all make it when it comes to cancer.”

Faith as an adaptive coping mechanism: Religious beliefs helped mobilize coping, as did being proactive.

“When I first heard the news, the first thing at the top of mind was, oh no, I’ll never be in love again, I’m going to die... but then I remembered that Jesus has worked a miracle for us, and I said to myself, no, where is the Christian in me? I must start praying right now.”

Need to educate the medical community: The final theme revealed was the importance of educating healthcare professionals, to reduce misguidance and enhance referral of patients for GCRA. This is illustrated by a *BRCA*-carrier participant reporting her physician’s advice:

“No, you are very young...don’t worry [about breast cancer risk], because you do not smoke, you don’t drink...”

Conference evaluation

Nearly all attendees (99%) completed the evaluation survey. At least 94% agreed or strongly agreed that the conference met their expectations, addressed issues of interest to them, provided information and resources that they would use in the future, and that they would attend a similar conference again. The most frequent topics suggested for future conferences pertained to psychosocial support for family members, cancer prevention and keeping current with cancer-related information. Attendees would bring family members, mostly

spouses and close female relatives, as well as friends to a similar conference. The only suggested change in conducting the conference was to allow even more time for questions.

Discussion

To our knowledge, our study represents the first time a conference format has been used to provide Latinas with updates in cancer genetics following GCRA and the first conference to explore Latinas' post-GCRA-related experiences and needs. We held the conference in response to the request for updated genetics information and on-going psychosocial support identified in long-term follow-up data from our underserved Latina patients [16]. We opted for a conference format because limited financial and staff resources preclude additional GCRA visits and disseminating information through a newsletter or other media would not permit personal interactions, psychosocial support, or additional needs exploration. Findings demonstrated feasibility, acceptability, and effectiveness of the action-research conference format for delivering updated medical information while directly eliciting ongoing post-GCRA issues/needs.

Attendees valued the information provided and were grateful for the opportunity to participate in a conference that was free, in their native language, and dedicated to their needs. Importantly, findings were immediately translatable into more responsive clinical care and are being used to expand our theory-driven research with this population.

Our prior work identified the desire for, and success of, providing cancer genetics services in this population [14]. Bilingual genetic counselors trained in culturally sensitive GCRA, a Latina clinic coordinator/patient navigator and a physician champion help prepare patients for their appointments [15]. Nevertheless, Latinas in our study discussed that the process was stressful or challenging. Several highlighted the importance of having a family member or friend present at their genetic appointments for psychosocial support as well as to assist with information comprehension and retention.

Poor understanding of, and distress associated with, the GCRA process at referral, while awaiting, and after risk level notification was also identified in free-text data from genetics patients responding to mailed questionnaires in Wales [24]. The authors suggested that means to better inform women of the process and timeline involved in GCRA may help prepare them for, and have more realistic expectations of, GCRA. The similarity to our findings is noteworthy despite ethnic and other demographic, clinical, risk level, and GCRA process delivery differences.

We identified the need to provide assistance with risk communications post-GCRA. Supporting our prior finding that Latinas and non-Latinas share similar beliefs regarding duty to inform relatives of hereditary cancer risk [25], Latinas expressed a responsibility and desire to personally share cancer risk information with relatives. Concomitant with this desire was their struggle to balance information dissemination without instilling anxiety or fear in relatives in countries with extremely limited GCRA resources. Avoiding potential harm has also hindered family cancer risk discussions in non-Latinas [26–27]. Of note, infrequent contact and geographical or emotional distance were not reported to censor risk communications. This is in contrast with our prior work and that of others in primarily non-Latina populations [28–29].

Being well-informed was valued as empowering not for one's personal healthcare but also for the sake of others. Consistent with the Latino concept of *familia*, in which 'family' may include non-biological others, the desire to take on the role of spokesperson extended to the community. "Spreading the word" to non-relative others appeared more ubiquitous for Latinas than in the literature or observed in our non-Latina patients. There was no evidence

of stigma, shame, or secrecy that might impair information flow as reported in a focus group study of Latinos queried about beliefs and attitudes towards cancer and *BRCA* testing [30]. However, only 3 of the 51 participants (57% female) were aware of *BRCA* testing prior to participation. Once informed, most viewed this testing favorably and thought that culturally sensitive educational efforts might lower barriers to information sharing.

Another finding was that faith in God, oneself, and genetics professionals instilled empowerment and catalyzed moving from fatalism to survivorship. This suggests that providers who cultivate positive attitudes about cancer genetics/risk reduction may improve patients' psychosocial well-being.

As we previously found in non-Latinas [31], some participants were dismayed that their physicians' did not recognize the need for a genetics referral. We expect that this care barrier will diminish over time given the current paradigm shift to personalized genetic/genomic medicine [9]. However, it is important to note that knowledge may not always translate into referral by practitioners in underserved settings.

Our study exemplifies one of few efforts to provide Latino/a patients with current health information while addressing and further exploring post-GCRA needs. Most studies to date investigating psychological or behavioral outcomes of genetic testing for hereditary breast and ovarian cancer (HBOC) risk have focused on non-Latina whites, such as the one-day retreat held in Vermont for persons seen at two local cancer genetics programs. The investigators provided updated medical management and addressed support needs for the 41 attendees from 22 families. Comparable to our study, most attendees were female (80%) and 50% had a prior cancer history; attendees appreciated the opportunity to discuss their experiences with others in similar circumstances and would attend a similar retreat again. In contrast to our study, the attendees were highly educated and the majority had healthcare insurance. Ethnicity was not reported, likely due to little diversity. Experiences and needs related to the GCRA process were not specifically assessed.

Our participants highly valued the opportunity to share their concerns with Latina breast cancer advocates and partake of the community resources provided. Few patient advocacy and community support resources specifically address the additional issues and needs of younger individuals and families with HBOC. Although genetics advances have catapulted the development of resources for this group by national organization such as FORCE (www.facingourrisk.org) and Bright Pink (www.bebrightpink.org), who have some Spanish resources, use by Latinas may be limited by access to and familiarity with the Internet.

FORCE has held an annual conference in Florida since 1996 to provide a forum targeted primarily to *BRCA* carriers and their families. Sessions discuss the latest advances in HBOC risk, provide an opportunity for networking and peer support, and may be available for viewing via the FORCE website. To our knowledge, data regarding the GCRA experience and ongoing needs of conference attendees are not formally collected. Similarly, the advocacy groups Living Beyond Breast Cancer and The Young Survival Coalition (www.C4YW.org) teamed in 2010 to hold annual conferences addressing medical and psychosocial issues faced by young women with breast cancer. While these organizations provide conference scholarships for some attendees, costs and distance as well as language barriers may prevent participation for others.

Finally, the Latinas in our study expressed understanding of genetic-related cancer risk but had questions about risks after risk reduction procedures or cancer treatment; hormone use; reconstructive surgery; and the appropriate age for genetic testing in their relatives. Similar post-GCRA information and psychosocial support needs were described in a review of studies reporting ongoing concerns among women with a *BRCA* mutation[32].

Given the above findings, we: 1) recently initiated a study of the impact of adapted motivational interviewing on GCRA preparedness for underserved, primarily Spanish-speaking Latinas; 2) are placing further emphasis on bringing a trusted person to all genetic appointments; and 3) have adapted the information content during genetic counseling to better address each counselee's individual needs and health status. We are also facilitating *BRCA* testing initiatives in Mexico through physician training and research collaborations.

Limitations

Generalizability is limited by the sample size, single geographical region, potential recall bias, and one-time event. Nonetheless, findings echo many of the experiences and needs expressed by our non-Latina patients [17, 28, 33] and other studies with high-risk non-Latina breast cancer patients [34–36]. Although attendees were demographically representative of Latinas in our clinics, they may represent a select group with on-going post-GCRA needs and may not be representative of Latinas elsewhere. Time in the U.S. and acculturation, not measured, may have influenced attendance and responses. Further, most participants are in a research program wherein a patient navigator facilitates obtaining risk management cares, thus the high rate of access to recommended post-GCRA healthcare may not be representative of other underserved Latinas.

Conclusions and Future Directions

Responding to and further exploring Latinas' post-GCRA information and psychosocial support needs using multimodal action research in a patient/family-centered conference was innovative, effective, and addresses a key disparity in cancer control research. Findings revealed post-GCRA needs similar to non-Latinas and allowed immediate translation to modify our risk assessment process. Findings also suggest support for Leventhal's Illness Representation Model [37–41], which will be used to guide future research to enhance evidence-based care for ethnically diverse families at high risk for cancer. Funding for similar conferences will be sought.

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Table 1

Sample Demographic and Clinical Characteristics

	Total* n (%)	Patients n (%)	“Non- patients”** n (%)	P value
	68 (95.6)	41 (60.3)	27 (39.7)	
Age				.379
Mean	43	44	42	
Range	18–71	27–65	18– 71	
Gender				.004
Female	63 (92.6)	41 (100)	22 (81.5)	
Male	5 (7.4)	0 (0)	5 (18.5)	
Marital status				.509
Married/living together	38 (55.9)	24 (58.5)	14 (51.9)	
Not married ¹	29 (42.6)	16 (33)	13 (48.1)	
Children				.360
Yes	52 (76.5)	33 (80.5)	19 (70.4)	
No	14 (20.5)	7 (17.1)	7 (25.9)	
Education Level				.020
Elementary	20 (29.4)	13 (31.7)	7 (25.9)	
High school	19 (27.9)	14 (34.1)	5 (18.5)	
Some college	22 (32.4)	10 (24.4)	12 (44.4)	
College graduate	7 (10.3)	4 (9.8)	3 (11.1)	
Country of Birth				.840
Mexico	38 (55.9)	24 (58.5)	14 (51.9)	
United States	6 (8.8)	4 (9.6)	2 (4.9)	
Other ²	23 (33.8)	13 (31.7)	10 (37.0)	
Preferred Language⁺				.654
Spanish	65 (95.6)	39 (95.1)	26 (96.3)	
English	3 (4.4)	2 (4.9)	1 (3.7)	
Cancer History				.000
Yes	30	30	0	
No	38	11	27	
Genetic Status				
BRCA-mutation positive		20 (29.4)		
BRCA-mutation negative		14 (20.6)		
BRCA-VUS ³		1 (1.8)		

	Total[*] n (%)	Patients n (%)	“Non- patients”^{**} n (%)	P value
No <i>BRCA</i> testing		6 (8.8)		

Percent totals may not equal 100% due to missing data.

^{*} Based on 68/71(96%) attendee voluntary survey completion.

^{**} Non-patients = family members/friends of patients.

⁺ Based on choice of survey completed

¹ Single, divorced, widowed.

² Columbia, El Salvador, Guatemala, Honduras, Peru, Venezuela.

³ VUS= variant of uncertain significance.

Table 2

Patient Clinical Characteristics (n=41)

Characteristics	n	%
Cancer History		
No	11	26.8
Yes	30	73.2
Breast only	25	83.3
Breast and ovarian	2	6.7
Breast and other ¹	3	10.0
Age at Breast Cancer Diagnosis		
Range	29–48	--
Mean	40	--
GCRA Status		
Genetic counseling and testing	35	85.4
Genetic counseling only	6	14.6
BRCA Status		
Positive	20	48.8
Negative	14	34.1
VUS ²	1	2.4

¹ Other reported cancers include thyroid, skin and stomach

² VUS = variant of uncertain significance

Table 3

Latina Conference Attendee ARS Responses

Q1. Did you know why you were referred for GCRA? n=61		
	n	%
No GCRA	15	24.5
Received GCRA	46	75.4
Yes	32	69.6
No	7	15.2
Had some idea, but confused	6	13.0
Do not remember	1	2.2

Q2. Was the time between referral and your GCRA appointment stressful or challenging? n=55		
	n	%
No GCRA	18	32.7
Received GCRA	37	67.3
Yes	30	81.1
No	5	13.5
Do not remember	2	5.4

Q3. Was your first GCRA consultation stressful or challenging? n=59		
	n	%
No GCRA	24	40.7
Received GCRA	35	59.3
Yes	31	88.6
No	3	8.6
Do not remember	1	2.8

Q4. Was the second visit for test results stressful or challenging? n=59		
	n	%
No GCRA	21	35.6
Received GCRA	38	64.4
Yes	29	76.3
No	8	21.1
Do not remember	1	2.6

Q5. Did you share the information that you obtained from the GCRA consultation and/or testing? n=62		
	n	%
No GCRA/testing	19	30.6
Received GCRA/testing	43	69.4

Q5. Did you share the information that you obtained from the GCRA consultation and/or testing? n=62		
	n	%
Yes: shared immediately	35	81.4
Yes: took time to share	6	13.9
No: thought it was irrelevant	0	0
No: no access to pertinent relatives	2	4.7

Q6. Do you understand your risk? n=64		
	n	%
No GCRA	8	12.5
Received GCRA	56	87.5
Yes	45	80.3
No	1	1.8
Have an idea, but need more info	10	17.9

Q7. Do you understand what needs to be done for cancer screening and prevention? n=66		
	n	%
No GCRA	7	10.6
Received GCRA	59	89.4
Yes	49	83.0
No	1	1.7
Need more info re: br ca	5	8.5
Need more info re: ov ca	4	6.8

Q8. Are you able to obtain the recommended exams for cancer screening and detection? n=66*		
	n	%
Yes	52	78.8
No	3	4.5
Do not know of needed exams	11	16.7

*"No GCRA" was not an option