Genetic counseling communication with an African American BRCA1 kindred

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Ellington, L., Maxwel, A., Baty, B. J., Roter, D., Dudley, W. N., & Kinney, A. Y. (2007). Genetic counseling communication with an African American BRCA1 kindred. Social Science & Medicine, 64(3), 724-734. doi:10.1016/j.socscimed.2006.09.017

Abstract:

We studied communication in genetic counseling sessions conducted with an African American, Breast Cancer 1, Early Onset (BRCA1) kindred in the USA. The Roter Interaction Analysis System (RIAS) was used to code and compare two sessions of 46 participants (26 females and 20 males) before and after they underwent genetic testing. Three certified genetic counselors and one medical geneticist conducted the sessions. When compared to pre-test communication, most of the providers' post-test communication was devoted to the provision of biomedical information (including screening recommendations) with fewer questions and psychosocial statements. Clients contributed a similar proportion to the total session dialogue in pre- and post-test sessions (40%). A larger proportion of their post-test session was devoted to indicating receptiveness to provider information than in the pre-test session. We found when providers were informing clients that they were BRCA1 mutation carriers, they provided more biomedical and psychosocial information and asked more psychosocial questions than when talking with non-carriers. This study provides the first description of genetic counseling communication for pre- and post-test BRCA1 sessions with African American individuals.
Keywords: BRCA1; Communication; African American; Genetic counseling; Roter interaction analysis system; USA

Article:

Introduction

Although the majority of individuals currently seeking cancer genetic counseling and testing services in the US are non-Latino Caucasian women of middle to upper middle class socioeconomic status (Armstrong, Carney, Stopfer, & Putt (2005) K.M. Armstrong, A. Carney, J. Stopfer and M. Putt, Racial differences in the use of brca1/2 testing among women with a family history of breast or ovarian cancer, Journal of the American Medical Association 293 (2005) (14), pp. 1729–1736. (79)Armstrong, Carney, Stopfer, & Putt, 2005; Hall & Olopade, 2005; Hughes et al., 1997), this may not be true in the future. BRCA1/2 mutations have been identified in African and African American families, but more research is needed to understand dispersion patterns (Olopade et al., 2003). African American women under 40 years of age have a proportionally higher incidence of early-onset breast cancer than non-Latino Caucasian women (Johnson, 2002; Nanda et al., 2005). It is likely that a proportion of the African American breast cancer incidence is associated with high penetrance genes such as BRCA1/2 (Pal, Permuth-Wey, Holtje, & Sutphen, 2004). This statistic, coupled with data indicating that African American individuals may be less knowledgeable about genetic testing and are less likely to have access to genetic services than non-Latino Caucasians, highlights the importance of studying the dynamics of patient-provider communication with African Americans in such genetic settings (Halbert, Kessler, & Mitchell, 2005).

The communication between genetic counselors and clients is an understudied area. A charge from leaders in the field to open the "black box" of genetic counseling communication has led to a small but growing body of research, particularly in the area of cancer genetic counseling (Biesecker & Peters, 2001). Various research teams have described the communication associated with counseling sessions just prior to BRCA1 testing

(Butow & Lobb, 2004; Ellington et al. (2006) and Ellington et al. (2005); Lobb, Butow, Barratt, Meiser, & Tucker, 2005; Lobb et al., 2004; Pieterse, van Dulmen, Ausems, Beemer, & Bensing, 2005). Although these studies varied in method and design, multiple similarities in communication were found: genetics service providers talked more than clients, sessions were largely focused on biomedical as opposed to psychosocial topics, and providers asked significantly more questions than clients. All of these projects were conducted with individuals of European descent and examine pre-testing sessions only, and thus significant questions remain about the nature of the genetic counseling process with underserved ethnic minorities.

This study was undertaken to explore cancer genetic counseling with African Americans who were known to be part of a BRCA1 kindred (Olopade et al., 2003) We applied the Roter Interaction Analysis System (RIAS) (Roter, 2002) to cancer genetic counseling sessions. RIAS is the most widely used system of interaction analysis with demonstrated levels of sensitivity and concurrent validity, and has been used in over 100 studies of patient–physician communication (Roter & Larson, 2002). The feasibility and validity of using RIAS with genetic counseling sessions has been documented (Ellington et al., 2005). Findings from the application of the RIAS offer the potential to develop improved counseling strategies as well as to educate genetic counseling students and practitioners (Roter, Ellington, Erby, Larson, & Dudley, in press). Using the RIAS, we characterized the nature of communication during sessions both before and after genetic testing and with carriers versus non-carriers, in an attempt to highlight variations associated with these variables.

Methods

Study population

Study participants were part of a larger investigation of the psychosocial and behavioral effects of BRCA1 counseling in the US. Participants were members of an African American kindred (K2099), which was previously identified as having the BRCA1 mutation during a genetic epidemiologic study conducted to localize the BRCA1 gene (Miki et al., 1994). Carrier status was not revealed as part of the original linkage study, as the testing was done in a research setting prior to identification of the BRCA1 gene. The parent project and current communication study were approved by the Institutional Review Boards at University of Utah and at Louisiana State University.

Procedure

Recruitment for the parent project began in 2001 and long-term follow up continued. Recruitment procedures, eligibility criteria, and research protocol have been described in detail elsewhere (Kinney et al., 2005) but are summarized here. Using the pedigree from the original linkage study, those individuals who agreed to be contacted for possible participation in future studies were sent a letter inviting them to participate in a genetic testing and counseling research study. Kindred members were asked to return a form if interested, and were then contacted by telephone to complete a screening survey to determine participant eligibility. After consenting to the genetic counseling study, participants completed a baseline interview. One hundred and sixty kindred members expressed initial interest to participate in the study; of those 105 (65%) completed the baseline interview. The baseline-structured interview was conducted by trained study staff and consisted of a large battery of questionnaires (e.g., questions targeted sociodemographics, access to clinical genetic services, perceived risk, cancer worry, and social support; Kinney et al., 2006b). Following the baseline interview, participants were invited to take part in a genetic education session followed by a testing and counseling session. These sessions took place within a two- to four-week period following the baseline interview. Participants chose either a group education session and private counseling session or private education followed by a private counseling session. The genetic counseling medical information was tailored and materials were designed with input from African American focus groups as well as from kindred members (Baty, Kinney, & Ellis, 2003). Ninety-nine of those completing the baseline interview participated in an education and counseling session. Following the counseling session, 87 participants underwent genetic testing, while the remaining 12 counseled subjects declined genetic testing.

Three certified female genetic counselors and one female doctorally prepared medical geneticist conducted the counseling sessions (henceforth called “genetic service providers”). All providers were non-Latino Caucasians.

Assignment of clients to a particular counselor was based on scheduling availability.

The protocols for the pre- and post-test sessions followed current practice standards (Baty et al., 1997). The outline for the pre-test education session included information about cancer genes and BRCA1 in general, discussion of general population and carrier cancer risks, education about screening and preventive behaviors, description of available testing, and an examination of the benefits and disadvantages of genetic testing and genotype knowledge. The pre-test counseling session included family and medical histories, screening for untreated mental health diagnoses, discussion of current and past personal cancer screening practices, screening education, discussion of prior risk and how testing might change risk, explanation of availability of oncology consultation, discussion of the testing decision, opportunity for questions and discussion of personal issues (e.g., impact of personal and familial cancer experiences), and informed consent if testing was chosen. Participants were given a family-specific pamphlet developed for the study and were sent a short follow-up letter. Approximately one month after the blood test, a second session was scheduled. Post-test sessions involved revealing test results, discussion of immediate reactions to test results, information about personal risk of cancer based on the test result, a review of options for surveillance and preventive measures, an explanation of altered risks for relatives, referral recommendations, arrangement for a follow-up phone call, and the offer of additional counseling sessions by request. A written results letter was sent after the session. Both pre- and post-test sessions were audio-taped with permission from the participant. These 1–2 h sessions were scheduled at locations convenient to the participants (e.g., local community center, private area in participant's home) and were provided at no cost to the participant (Kinney et al., 2006a).

Of the 87 participants that underwent genetic testing, 85 participated in the post-test session and 46 participants' pre- and post-test sessions were coded for use in this study. Because of the restraints of our grant funding dedicated to trained coders, we were able to record and code only sessions through the summer of 2003 (n=46) The 46 participants included in this study did not differ on any demographic characteristics from the 39 participants whose sessions were not coded.

Measures

RIAS coding of genetic counseling sessions: Trained coders applied the RIAS directly from audiotapes, without transcription, using direct entry software (Roter, 2002). The unit of analysis for RIAS coding is defined as the smallest speech segment that expresses a complete thought. This may be a statement, a phrase, a clause, or a single word. Each complete thought is assigned to a mutually exclusive and exhaustive category. Thus, the RIAS codes provide a comprehensive accounting of every thought expressed during an interaction by each speaker.

For purposes of the current study, coding focused on the following composite categories (example statements are presented in Table 1) reflecting dialogue by the genetic service provider and by the client: (1) Biomedical information, which includes statements of medical history, information related to breast cancer risk, and information regarding the test for the BRCA1 gene mutation; (2) Psychosocial communication, which includes the discussion of emotional reactions to genetic testing and self-care information; (3) Question asking, which includes all open and closed questions; (4) statements that reflect social chit-chat (e.g., comments about the weather); (5) Positive talk, including laughter (statements of approval are counselor only); (6) statements showing agreement and/or understanding are labeled as Receptive communication (e.g., uh-huh, right; agreement code only). Two more composite categories represent provider-only dialogue. The first is called Emotional talk in which the provider makes statements of reassurance, empathy, and concern. Emotional talk differs from Psychosocial communication in that the former reflects the affective process inherent in a statement and the latter reflects a topic of a psychosocial nature (without an emotional or affective overtone). If a statement reflects both psychosocial information and is affectively charged then it would reside in the Emotional talk category. The remaining provider composite category is dialogue that reflects the provider's attempt to Activate and partner with the client. This composite category includes paraphrasing, orienting statements, and back channeling.

Table 1. Examples of session dialogue reflecting RIAS categories

RIAS composite categories	Statement examples
Biomedical information	GC: The population risk is …; Smoking has been associated with increased risk; If you have what we call a mutation, a change in the DNA, then you may have a higher chance of having a tumor start to form.
	CT: My sister was diagnosed with cancer last year; I have a mammogram about once a year.
Psychosocial/lifestyle communication	GC: Families often find it helpful to discuss testing; My mother and I were very close.
	CT: I don't want to burden my family; My husband is very supportive.
Question asking	GC: Has anyone else in your family been diagnosed with cancer?; How worried are you about your sister?; Do you exercise regularly?
	CT: Can my daughters get cancer?; What do other people in this situation do?; Do I increase my risk by eating fatty foods?
Social chit-chat	GC: Parking here can be a headache; The weather has been chilly lately.
	CT: We are avid fans of professional hockey.
Positive talk	GC: You are absolutely right!; (laughter).
	CT: You have been very helpful; How interesting!
Receptive communication (agreement code only)	GC: Yes, that's right.
	CT: Uh-huh; yes; okay.
Emotional talk	GC: I think you will feel better as time passes; So you are really worried.
Activating and partnering	GC: Let me make sure I've got what you said right…; I would like to review your family history first; uh-huh, go-on.

Note. GC=genetic services provider; CT=client.

Intercoder reliability was calculated between coders based on a set of nine tapes (20%), including both pre- and post-sessions. Reliability for the RIAS individual codes was assessed separately for genetic provider and client codes. Pearson correlation coefficients for high-frequency categories (codes with a mean frequency of >2 statements per visit; (Roter & Ewart, 1992; Roter & Larson, 2002) averaged 0.80 (range=0.77−0.99) for genetic counselor talk (with a few exceptions) and 0.96 (range=0.77−0.99) for client talk. Two provider codes related to Emotional talk (empathy, r=0.43; M=2.58 (2.86) and reassurance, r=−0.08; M=2.88 (2.91)) had low reliability coefficients. When these codes were combined with the concern code to create the composite category of Emotional talk, the coefficient for the category was acceptable at r=0.71. The low intercoder reliabilities for empathy and reassurance likely reflect their low frequency of occurrence (albeit acceptable) and the difficulty coders have in differentiating them from the concern code, as they all represent emotionally responsive communication. Additionally, the intercoder reliability for approval was low r=0.26; M=5.86 (4.85); however, once examined within the composite category of Positive talk, the coefficient was acceptable. Reliabilities for all composite code variables averaged over 0.90 (range=0.71–0.99). The composite categories account for the majority of session communications and are used in subsequent analyses, but those that consist of codes with low intercoder reliability have been interpreted with caution.

Analysis

All analyses were conducted using SPSS version 13.0 (SPSS, 2005). Descriptive statistics were used to examine

the communication within the genetic sessions along the coding categories present in Table 1. Differences between the communication of pre- versus post-test sessions and post-test sessions for carriers versus non-carriers were assessed by t-tests. Two-tailed p values <0.05 were considered statistically significant.

Results

Characteristics of study population

Forty-six individuals (n=26 females; n=20 males) from the parent project make up the participants in the present study. All participants self-identified as African American and 89.1% (n=41) also identified themselves as Black Creole (Dubois & Melancon, 2000). Most participants were married or living as married (82.6%; n=38) and were high school graduates or had completed a higher level of education (82.6%; n=38). Nearly two thirds of the participants (60.9%; n=28) had an annual income greater than $30,000 per year, and 69.6% (n=32) had private health insurance. Seventeen percent (17.4%; n=8) of the participants were found to be BRCA1 mutation carriers.

Pre-test communication

As seen in Table 2, a large portion of the communication in the pre-test session was biomedically focused with fewer statements or questions of a psychosocial nature. Genetic service providers contributed 59% of the total talk at the pre-test sessions. Also, a relatively large proportion of genetic provider dialogue was devoted to question asking. These questions were predominantly of a biomedical nature. Roughly the same proportion of provider talk was devoted to Activating and partnering and statements showing understanding and agreement. Emotional talk comprised a small portion of provider talk.

Table 2. Comparison of pre- and post-test communication

		Pre-test		Post-test	
		Genetic counselor	Client	Genetic counselor	Client
Biomedical information	%	0.2447	0.4880	0.5106 *	0.2624 *
	Mean frequency (SD)	106.91 (123.00)	134.46 (73.51)	150.33 (132.74)	48.59 (33.06)
	Range	8–742	23–321	17–675	5–143
Psychosocial/lifestyle communication	%	0.014	0.1680	0.0236	0.0831 *
	Mean frequency (SD)	8.89 (9.63)	46.63 (44.96)	7.67 (9.94)	17.26 (26.93)
	Range	0–35	0–290	0–41	0–155
Question asking (total)	%	0.2601		0.0622 *	
	Mean frequency (SD)	81.63 (30.82)	—	15.67 (11.11)	—
	Range	23–160	0.0106	2–52	.0175
Biomedical questions	%	0.1925	3.43 (3.87)	0.0449 *	3.57 (4.81)
	Mean frequency (SD)	62.52 (28.27)	0–17	11.46 (10.33)	0–20
	Range	15–139	—	1–52	—
Psychosocial questions	%	0.0542		0.0188 *	
	Mean frequency (SD)	16.35 (7.70)		4.96 (4.65)	

		Pre-test		Post-test	
		Genetic counselor	Client	Genetic counselor	Client
	Range	0–40		0–19	
Social chit-chat	%	0.0140	0.0157	0.0281	0.0455 *
	Mean frequency (SD)	4.96 (8.43)	5.93 (13.26)	7.46 (12.34)	10.43 (24.94)
	Range	0–38	0–78	0–58	0–120
Positive talk	%	0.0567	0.0625	0.0657	0.0683
	Mean frequency (SD)	20.87 (17.76)	18.80 (16.96)	18.59 (13.72)	14.15 (13.76)
	Range	1–80	0–81	0–53	0–54
Receptive communication (agreements)	%	0.1466	0.1806	0.0840 *	0.4643 *
	Mean frequency (SD)	51.76 (30.21)	55.96 (52.74)	22.04 (13.56)	97.46 (94.48)
	Range	8–121	2–208	2–62	3–458
Emotional talk	%	0.0243		0.0496 *	
	Mean frequency (SD)	8.49 (5.95)	—	10.30 (5.53)	—
	Range	0–30		1–30	
Activating and partnering	%	0.1630		0.0941 *	
	Mean frequency (SD)	54.41 (33.89)	—	24.41 (28.07)	—
	Range	7–152		4–185	

Note. A single dash indicates that the mean frequency of respective RIAS code was< 2. A double dash indicates that it is not a coded category for the speaker. The percent symbol (%) indicates the average composite statements as a percent of the total speaker statements. Mean frequency represents the mean number of statements by the speaker.
* p<.05.

Clients contributed 41% of the total talk at the pre-test session. Similar to the provider, a majority of client communication was devoted to the provision of Biomedical information with less devoted to the provision of psychosocial information. Clients asked relatively few questions during the pre-test session. Nearly a fifth of client talk was statements such as “yes” and “uh-huh”.

Post-test communication

Post-test communication is also presented in Table 2. Note that most of genetic service providers’ communication was biomedical in nature with relatively fewer psychosocial statements. A similar proportion of genetic provider post-test communication was devoted to each of the following categories: Emotional talk, Activating and partnering, question asking, and statements reflecting agreement and understanding.
Similar to the pre-test ratio, clients contributed 40% of the total post-test session talk. Nearly half of client participation reflects statements of agreement and understanding. Client statements related to Biomedical information comprised a quarter of their post-test dialogue, with fewer psychosocial statements. As with the

pre-test sessions, client post-test session communication showed minimal question asking.

Comparison of pre-/post-test communication

We found that pre- and post-test communication differed significantly for both client and provider. Providers asked proportionally more questions in the pre-test session than in the post-test session, $t(90)=14.30$, $p<0.05$ and they expressed more Activating and partnering statements than in the post-test session, $t(90)=4.67$, $p<0.05$. Providers devoted a greater proportion of their post-test session dialogue to Biomedical information than in pre-test sessions, $t(90)=10.23$, $p<0.05$. Moreover, they exhibited proportionally more Emotional talk in post-test sessions than in pre-test sessions, $t(90)=4.79$, $p<0.05$.

In contrast to the genetic service provider findings, we found proportionally less client Biomedical information in post-test sessions than in pre-test sessions, $t(90)=8.96$, $p<0.05$, and less psychosocial talk, $t(90)=4.59$, $p<0.05$. Clients also expressed more Receptive communication in the post-test sessions when compared with pre-test sessions, $t(90)=9.66$, $p<0.05$.

Post-test communication by carrier status

As can be seen in Table 3, in post-test sessions with BRCA1 mutation carriers, providers dedicated significantly more of their talk to both Biomedical information and Psychosocial communication, $t(44)=3.07$, $p<0.05$, than in post-test session with non-carriers. Providers also asked more psychosocial questions of carriers than non-carriers, $t(44)=3.30$, $p<0.05$ and expressed more Activating and partnering statements to non-carriers than carriers. Providers dedicated more of their communication to positive talk and statements of agreement and understanding to non-carriers than carriers. There were no differences in client post-test communication by carrier status.

Table 3. Comparison of communication for carriers and non-carries during the session after genetic testing

		BRCA1 carriers N=8		Not Carriers N=38	
		Genetic counselor	Client	Genetic counselor	Client
Biomedical information	%	0.6187 *	0.1981	0.4879	0.2759
	Mean frequency (SD)	272.50 (176.04)	46.88 (30.97)	124.61 (107.98)	48.95 (33.86)
	Range	83–576	10–87	17–675	5–143
Psychosocial/lifestyle communication	%	0.0472 *	0.1195	0.0186	.0755
	Mean frequency (SD)	19.00 (11.88)	18.63 (7.69)	5.29 (7.75)	16.97 (29.50)
	Range	3–34	6–32	0–41	0–155
Question asking (total)	%	0.0579	—	0.0630	—
	Mean frequency (SD)	22.13 (10.45)	0.0215	14.32 (10.89)	0.0166
	Range	8–43	6.75 (7.74)	2–52	2.89 (3.75)
Biomedical questions	%	0.0356	0–20	0.0468	0–16
	Mean frequency (SD)	14.38 (8.47)	—	10.84 (10.68)	—
	Range	4–32		1–52	
Psychosocial questions	%	0.0365 *		0.0150	
	Mean frequency	12.50 (4.14)		3.37 (2.86)	

		BRCA1 carriers N=8		Not Carriers N=38	
		Genetic counselor	Client	Genetic counselor	Client
	(SD)				
	Range	6–19		0–12	
Social chit-chat	%	0.0058 *	0.0096	0.0328	0.0531
	Mean frequency (SD)	1.75 (4.17)	2.75 (5.75)	8.66 (13.17)	12.05 (27.10)
	Range	0–12	0–16	0–58	0–120
Positive talk	%	0.0392 *	0.0588	0.0712	0.0702
	Mean frequency (SD)	17.50 (12.93)	14.63 (12.88)	18.82 (14.04)	14.05 (14.10)
	Range	0–36	1–33	0–53	0–54
Receptive statements (agreements)	%	0.0541 *	0.5566	0.0903	0.4448
	Mean frequency (SD)	20.75 (11.15)	190.88 (173.31)	22.32 (14.13)	77.79 (53.76)
	Range	10–43	3–458	2–62	8–232
Emotional talk	%	.0394	—	0.0518	—
	Mean frequency (SD)	13.38 (7.44)		9.66 (4.93)	
	Range	5–30		1–23	
Activating and partnering	%	0.0536 *	—	0.1026	—
	Mean frequency (SD)	20.75 (10.11)		25.18 (30.59)	
	Range	8–33		4–185	

Note. A single dash indicates that the mean frequency of respective RIAS code was <2. A double dash indicates that it is not a coded category for the speaker The percent symbol (%) indicates the average composite statements as a percent of the total speaker statements. Mean frequency represents the mean number of statements by the speaker.

* $p<.05$

Discussion

There is a small but growing body of literature on genetic counseling communication, particularly in cancer genetics (Butow & Lobb 2004; Roter et al., in press; Ellington et al. (2006) and Ellington et al. (2005); Lobb, Butow, Barratt, Meiser, & Tucker (2005) and Lobb et al. (2004); Pieterse, van Dulmen, Ausems et al., 2005; Pieterse, van Dulmen, Beemer, Ausems, & Bensing, 2005). These initial projects have examined the communication of clients of European descent and have assessed only pre-test sessions. The current study offers two novel contributions to this body of literature. First, we describe cancer genetic counseling communication for sessions with African American individuals at familial risk. Second, we provide an examination of post-test communication and how the dialogue may vary from pre- to post-sessions and for carriers and non-carriers.

Consistent with previous research conducted on non-Latino Caucasians, we found that the communication in cancer genetic counseling pre-test sessions tends to be largely biomedical in nature with significantly less talk devoted to psychosocial issues (Ellington et al., 2005; Lobb et al., 2004; Pieterse, van Dulmen, Ausems et al., 2005). Some differences from previous findings are evident, such as more provider talk of an emotional nature. When compared to Pieterse et al.'s work (Pieterse, van Dulmen, Beemer et al., 2005), the participants in the

present study asked fewer questions, but discussed more psychosocial issues. These findings may reflect the fact that these sessions were part of a larger study with frequent communication concerning the project as a whole, and a pre-test education session (Kinney et al. (2005), Kinney et al. (2006a) and Kinney et al. (2006b)). Thus, one explanation for fewer questions is that clients already felt well informed. An alternative explanation is the racial and socio-economic power asymmetry between the providers and the clients (Cooper et al., 2003). A key purpose of the pre-test session is to promote informed decision making about testing and thus the predominant focus of previous research has been on the communication during these initial sessions. As one reviewer of this manuscript noted, the pre-test sessions tended to have more of routine format involving biomedical information than post-test sessions. For example, a large portion of the pre-test session is devoted to family and medical history taking and the dialogue structure is turn taking (i.e., the genetics services providers asks a question about family history and the client provides an answer). The post-test session is equally important, complex and delicate, particularly for individuals at familial risk for cancer. Counselors must convey test results including lay explanations of test specificity and sensitivity, discuss screening recommendations based on carrier status, discuss subsequent results disclosure with family members, and assess the potential emotional reactions of clients (e.g., relief, guilt, disappointment, fear, and anxiety). Our findings suggest that providers are equally emotionally responsive in the pre-test and in the post-test sessions.

We found that post-test communication was more consistent with some aspects of a provider-driven educational approach than the pre-test sessions. More of the genetic services providers' post-test communication was devoted to the provision of Biomedical information (including screening recommendations) with fewer questions and psychosocial statements than in the pre-test. The pre- and post-test differences in proportion of talk devoted to Biomedical information may be explained in part by the separate educational session held prior to the pre-test counseling session. A combined education and counseling pre-test session is the most common mode of practice and thus the generalizability of our findings are limited somewhat by this "extra" session. The benefits of a combined versus separate pre-testing session remain a relevant empirical and clinical question.

As one would expect, the clients devoted a significant portion of the pre-test session providing Biomedical information (including family history). Conversely, the majority of what the client said in the post-test sessions were comments indicating that they were receiving a large amount of information and agreeing with what was being said (e.g., "uh-huh, yes"). Among a Caucasian population, this client verbal behavior has been interpreted by investigators as a sign of passive listening or passive learning which may result in reduced understanding for the counselee as compared to a more interactive discussion (Butow & Lobb, 2004). Another explanation for a large percentage of client post-session agreement-type statements may be specific to this ethnic group. The consistent, almost rhythmic murmuring of "uh-huh," "yeah," "hmm," is common in African American interpersonal exchanges and is referred to as back channeling (Green, 2002). Back channeling indicates that the listener is encouraging the speaker to continue and is "in tune" with what the speaker is saying. The specific RIAS back channel code reflects attentiveness and is a "provider-only" code which has been the topic of some controversy in the literature (see Roter & Larson, 2002; Sandvik et al., 2002). Thus, in the present study the RIAS code for agreement was used for client utterances such as "uh-huh" and to some extent may reflect active engagement rather than passive listening.

Of additional note, in contrast to the pre-test sessions, there was a significant reduction in the post-test session of counselor statements reflecting partnership and activation. These communication skills are important in trust building with clients and helping them make informed decisions (Jenkins, Fallowfield, Souhami, & Sawtell, 1999). Research from Hall and colleagues (Hall, Roter, & Katz, 1988) suggests that these skills are equally important in promoting adherence to provider recommendations. The post-test session provides a critical opportunity for counselors to introduce and/or reinforce breast and ovarian cancer screening practices among carriers and non-carriers alike. Using communication strategies that are known to increase adherence is important in the clinical setting, particularly with African American clients who as a group tend to have low cancer screening practices (Crump, Mayberry, Taylor, Barefield, & Thomas, 2000).

Another verbal strategy to promote screening among clients besides Activate and partner statements may be

what Sarangi and colleagues (Sarangi et al., 2004) call a “reflective frame.” According to these investigators, reflective frames are provider questions that elicit client introspection about a decision-making process and subsequent consequences. The RIAS does not include this code, so we were unable to ascertain if a subset of provider psychosocial questions are consistent with reflective frames.

We found when providers were informing clients that they were BRCA1 mutation carriers, they provided more Biomedical information (which includes screening recommendations), Psychosocial communication (which includes discussion of results with family members) and asked more psychosocial questions than when they talking with non-carriers. Additionally, as one would expect, providers appeared to be using a more “down to business” communication approach with carriers than non-carriers (e.g., less laughter and social chit-chat). Our findings for post-test communication with carriers are consistent with sociolinguistic investigations of genetic counseling (Benkendorf, Prince, Rose, DeFina, & Hamilton, 2001). Genetic service providers are likely to feel most comfortable coming from a position of “medical expert” when delivering information that is likely to invoke fear and a feeling of vulnerability among clients. This is reflected in provider style focused on imparting biomedical information in an educational-type format, which reflects sociolinguistic concepts of differential power and social distance in interpersonal encounters (Brown & Levinson, 1987). Further research is warranted to understand how this interpersonal positioning influences genetic counseling client outcomes, particularly when the provider is from the dominant culture and the client is from a minority culture. More research is also needed to determine why clients with carrier status did not differ in their communication compared to those with non-carrier status.

Limitations

A limitation of this study is our small sample size, which resulted in limited power. Thus, we were precluded from statistically examining linkages between the communication variables and client characteristics and outcomes. Second, with only four genetic service providers, we cannot be certain that the communication behaviors are generalizable in nature. Third, the African American kindred participating in this study may not be representative of African Americans in the US (Kinney et al., 2005). Many members of this kindred resided in rural Louisiana and most family members described themselves as Creole. Fourth, all genetic service providers were of European Caucasian ancestry, while all study participants were of African ancestry. Since there are known to be differences in communication depending on whether the provider is of the same ethnicity as the consumer (Cooper et al., 2003), this also limits the generalizability of our findings. Finally, because the counseling sessions were part of a research study, aspects of the research protocol (e.g., baseline interview) may have affected the genetic counseling exchange.

Despite these limitations, the current study found important pre-post testing differences in provider communication with carrier and non carrier clients that will be useful in designing protocols for counseling of African American.

Acknowledgments

We are grateful to Renn Upchurch and Ryan Beveridge for their coding of the audiotapes. We would like to acknowledge Bonnie Baty, Regan Challinor, Kelly Jackson, and Mary Kay Pelias for conducting the genetic counseling sessions and Kate Seggar for data management. We are especially grateful to all the individuals who participated in the study. This project was funded by the National Human Genome Research Institute, the National Cancer Institute, and the National Institute of Nursing Research (1 R03HG002359-01; 1 R01 HG02241 and 1 R01 HG02241-02S1).

References

Armstrong, Carney, Stopfer, & Putt (2005) K.M. Armstrong, A. Carney, J. Stopfer and M. Putt, Racial differences in the use of brca1/2 testing among women with a family history of breast or ovarian cancer, Journal of the American Medical Association 293 (2005) (14), pp. 1729–1736.
Baty, Kinney, & Ellis (2003) B.J. Baty, A.Y. Kinney and S.M. Ellis, Developing culturally sensitive cancer genetics communication aids for African Americans, American Journal of Medical Genetics. Part A. 118 (2003)

(2), pp. 146–155.
Baty et al. (1997) B.J. Baty, V.L. Venne, J. McDonald, R.T. Croyle, C. Halls and J.E. Nash et al., Genetic counseling protocol development and counseling issues, Journal of Genetic Counseling 6 (1997), pp. 223–244.
Benkendorf, Prince, Rose, DeFina, & Hamilton (2001) J.L. Benkendorf, M.B. Prince, M.A. Rose, A. DeFina and H.E. Hamilton, Does indirect speech promote non-directive genetic counseling? Results of a sociolinguistic investigation, American Journal of Medical Genetics (Semin. Med. Genet.) 106 (2001) (3), pp. 199–207.
Biesecker & Peters (2001) B.B. Biesecker and K.F. Peters, Process studies in genetic counseling: Peering into the black box, American Journal of Medical Genetics 106 (2001) (3), pp. 191–198.
Brown & Levinson (1987) P. Brown and S. Levinson, Universals in language usage: Politeness phenomena, Cambridge University Press, Cambridge, UK (1987).
Butow & Lobb (2004) P.N. Butow and E.A. Lobb, Analyzing the process and content of genetic counseling in familial breast cancer consultations, Journal of Genetic Counseling 13 (2004) (5), pp. 403–424.
Cooper et al. (2003) L.A. Cooper, D.L. Roter, R.L. Johnson, D.E. Ford, D.M. Steinwachs and N.R. Powe, Patient-centered communication, ratings of care, and concordance of patient and physician race, Annals of Internal Medicine 139 (2003) (11), pp. 907–915.
Crump, Mayberry, Taylor, Barefield, & Thomas (2000) S.R. Crump, R.M. Mayberry, B.D. Taylor, K.P. Barefield and P.E. Thomas, Factors related to noncompliance with screening mammogram appointments among low-income African-American women, Journal of the National Medical Association 92 (2000) (5), pp. 237–246.
Dubois & Melancon (2000) S. Dubois and M. Melancon, Creole is, Creole ain't: Diachronic and synchronic attitudes toward Creole identity in southern Louisiana, Language in Society 29 (2000), pp. 237–258.
Ellington et al. (2005) L. Ellington, D. Roter, W.N. Dudley, B.J. Baty, R. Upchurch and S. Larson et al., Communication analysis of BRCA1 genetic counseling, Journal of Genetic Counseling 14 (2005) (5), pp. 377–386.
Ellington et al. (2006) L. Ellington, B.J. Baty, J. McDonald, V. Venne, A. Musters and D. Roter et al., An exploration of BRCA1 genetic counseling communication patterns: The role of teaching and counseling approaches, Journal of Genetic Counseling 15 (2006), pp. 179–190.
Green (2002) L.J. Green, African American English: A linguistic introduction, Cambridge University Press, Cambridge, UK (2002).
Halbert, Kessler, & Mitchell (2005) C.H. Halbert, L.J. Kessler and E. Mitchell, Genetic testing for inherited breast cancer risk in African Americans, Cancer Investigation 23 (2005) (4), pp. 285–295.
Hall, Roter, & Katz (1988) J.A. Hall, D.L. Roter and N.R. Katz, Meta-analysis of correlates of provider behavior in medical encounters, Medical Care 26 (1988) (7), pp. 657–675.
Hall & Olopade (2005) M.O. Hall and I. Olopade, Confronting genetic testing disparities: Knowledge is power, Journal of the American Medical Association 293 (2005) (14), pp. 1783–1785.
Hughes et al. (1997) C. Hughes, A. Gomez-Caminero, J. Benkendorf, J. Kerner, C. Isaacs and J. Barter et al., Ethnic differences in knowledge and attitudes about brca1 testing in women at increased risk, Patient Education and Counseling 32 (1997) (1–2), pp. 51–62.
Jenkins, Fallowfield, Souhami, & Sawtell (1999) V.A. Jenkins, L.J. Fallowfield, A. Souhami and M. Sawtell, How do doctors explain randomized clinical trials to their patients?, European Journal of Cancer 35 (1999) (8), pp. 1187–1193.
Johnson (2002) E.T. Johnson, Breast cancer racial differences before age 40—implications for screening, Journal of the National Medical Association 94 (2002) (3), pp. 149–156.
Kinney et al. (2005) A.Y. Kinney, L.E. Bloor, D. Mandal, S.E. Simonsen, B.J. Baty and R. Holubkov et al., The impact of receiving genetic test results on general and cancer-specific psychological distress among members of an African-American kindred with a BRCA1 mutation, Cancer 104 (2005) (11), pp. 2508–2516.
Kinney et al. (2006a) A.Y. Kinney, S.E. Simonsen, B.J. Baty, D. Mandal, S.L. Neuhausen and K. Seggar et al., Risk reduction behaviors and provider communication following genetic counseling and BRCA1 mutation testing in an African American kindred, Journal of Genetic Counseling 15 (2006) (4), pp. 293–305.
Kinney et al. (2006b) A.Y. Kinney, S.E. Simonsen, B.J. Baty, D. Mandal, S.L. Neuhausen and K. Seggar et al., Acceptance of genetic testing for hereditary breast ovarian cancer among study enrollees from an African American kindred, American Journal of Medical Genetics. Part A 140 (2006) (8), pp. 813–826.

Lobb et al. (2004) E.A. Lobb, P.N. Butow, A. Barratt, B. Meiser, C. Gaff and M.A. Young et al., Communication and information-giving in high-risk breast cancer consultations: Influence on patient outcomes, British Journal of Cancer 90 (2004) (2), pp. 321–327.
Lobb, Butow, Barratt, Meiser, & Tucker (2005) E.A. Lobb, P. Butow, A. Barratt, B. Meiser and K. Tucker, Differences in individual approaches: Communication in the familial breast cancer consultation and the effect on patient outcomes, Journal of Genetic Counseling 14 (2005) (1), pp. 43–53.
Miki et al. (1994) Y. Miki, J. Swensen, D. Shattuck-Eidens, P.A. Futreal, K. Harshman and S. Tavtigian et al., A strong candidate for the breast and ovarian cancer susceptibility gene BRCA1, Science 266 (1994) (5182), pp. 66–71.
Nanda et al. (2005) R. Nanda, L.P. Shumm, S. Cummings, J.D. Fackenthal, L. Svenn and F. Ademuyiwa et al., Genetic testing in an ethnically diverse cohort of high-risk women, Journal of the American Medical Association 294 (2005) (15), pp. 1925–1933.
Olopade et al. (2003) O.I. Olopade, J.D. Fackenthal, G. Dunston, M.A. Tainsky, F. Collins and C. Whitfield-Broome, Breast cancer genetics in African Americans, Cancer 97 (2003) (Suppl. 1), pp. 236–245.
Pal, Permuth-Wey, Holtje, & Sutphen (2004) T. Pal, J. Permuth-Wey, T. Holtje and R. Sutphen, BRCA1 and BRCA2 mutations in a study of African American breast cancer patients, Cancer epidemiology, biomarkers & prevention: A publication of the American Association of for Cancer Research, cosponsored by the American Society of Preventive Oncology 13 (2004) (11 Pt 1), pp. 1794–1799.
Pieterse, van Dulmen, Ausems, Beemer, & Bensing (2005) A.H. Pieterse, A.M. van Dulmen, M.G. Ausems, F.A. Beemer and J.M. Bensing, Communication in cancer genetic counselling: Does it reflect counselees' previsit needs and preferences?, British Journal of Cancer 92 (2005) (9), pp. 1671–1678.
Pieterse, van Dulmen, Beemer, Ausems, & Bensing (2005) Pieterse, A. H., van Dulmen, A. M., Beemer, F. A., Ausems, M. G., & Bensing, J. M. (2005). Tailoring communication in cancer genetic counseling through individual video-supported feedback: A controlled pretest-posttest design. Patient Education and Counseling.
Roter (2002) Roter, D. (2002). The Roter method of interaction process analysis. ⟨http://www.rias.org/manual.html⟩.
Roter, Ellington, Erby, Larson, & Dudley (in press) Roter, D., Ellington, L., Erby, L., Larson, S., & Dudley, W. N. (in press). The genetic counseling video project (GCVP): Models of practice. American Journal of Medical Genetics.
Roter & Larson (2002) D. Roter and S. Larson, The Roter interaction analysis system (RIAS): Utility and flexibility for analysis of medical interactions, Patient Education and Counseling 46 (2002) (4), pp. 243–251.
Roter & Ewart (1992) D.L. Roter and C.L. Ewart, Emotional inhibition in essential hypertension: Obstacle to communication during medical visits?, Health Psychology 11 (1992) (3), pp. 163–169.
Sandvik (2002) M. Sandvik, H. Eide, M. Lind, P.K. Graugaard, J. Torper and A. Finset, Analyzing medical dialogues: Strengths and weaknesses of Roter's interaction analysis system (RIAS), Patient Education and Counseling 46 (2002) (4), pp. 235–241. (100 KSarangi et al. (2004) S. Sarangi, K. Bennert, L. Howell, A. Clarke, P. Harper and J. Gray, Initiation of reflective frames in counseling for Huntington's Disease predictive testing, Journal of Genetic Counseling 13 (2004), pp. 135–155.
SPSS (2005) SPSS, SPSS version 13, SPSS Inc, Chicago (2005).