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Implementation and outcomes of telephone disclosure of clinical BRCA1/2 test results★

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Abstract

Objectives: With an increasing demand for genetic services, effective and efficient delivery models for genetic testing are needed.

Methods: In this prospective single-arm communication study, participants received clinical BRCA1/2 results by telephone with a genetic counselor and completed surveys at baseline, after telephone disclosure (TD) and after in-person clinical follow-up.

Results: Sixty percent of women agreed to participate; 73% of decliners preferred in-person communication. Anxiety decreased from baseline to post-TD ($p = 0.03$) and satisfaction increased ($p < 0.01$). Knowledge did not change significantly from baseline to post-TD, but was higher post-clinical follow-up ($p = 0.04$). Cancer patients had greater declines in state anxiety and African-American participants reported less increase in satisfaction. 28% of participants did not return for in-person clinical follow-up, particularly those with less formal education, and higher post-disclosure anxiety and depression ($p < 0.01$).

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Conclusions: Telephone disclosure of BRCA1/2 test results may not be associated with negative cognitive and affective responses among willing patients, although some subgroups may experience less favorable responses. Some patients do not return for in-person clinical follow-up and longitudinal outcomes are unknown.

Practice implications: Further evaluation of longitudinal outcomes of telephone disclosure and differences among subgroups can inform how to best incorporate telephone communication into delivery of genetic services.

Keywords

Genetic testing; Cancer susceptibility; Cancer risk assessment; Communication

1. Introduction

Basic science advances in genomics have provided great promise for improving human health and reducing the burden of cancer in the United States [1]. Genetic testing provides opportunities to identify genetic changes associated with a variety of common diseases. The promise of personalized genomic medicine is the ability to tailor the treatment or screening of individual patients based on their genotype [2]. Genetic screening for cancer susceptibility is one application of “personalized medicine” that has become standard practice. Professional societies currently recommend that predictive genetic testing be paired with pre- and post-test counseling to optimize patients’ informed consent, understanding and processing of the implications of genetic test results [3,4]. Given these recommendations, the complexity of genetic information, the potential for false reassurance, the potential for psychological distress, communication of predictive genetic information has traditionally been conducted in-person by health professionals trained in clinical genetics [5]. With an increasing demand for genetic services and the anticipated increasing availability of genetic tests for disease susceptibility and clinical application, the two in-person visit delivery model presents barriers to widespread dissemination of genetic testing for disease susceptibility [6,7]. Innovative delivery models for effective, efficient genetic risk communication that result in behavior change are needed.

Telephone delivery of genetic services has the potential to expand services to diverse clinical systems and address the insufficient genetic workforce as increasing genetic applications enter clinical practice [7]. Telephone communication has the potential to improve access from distant geographic locations, decrease access and care burdens for patients in scheduling and traveling to a clinical center, increase patients’ perceived control and decrease intimacy, which could foster communication for some individuals [8–10]. While telephone communication might not be inherently innovative, it is widely available, relatively inexpensive and an accessible option for many populations [9,11]. Prenatal genetic counselors have incorporated telephone communication into standard counseling services [12] and surgeons and radiologists have utilized telephone to provide faster communication of breast biopsy results [13]. Telephone has also been used to reach underserved populations, motivate behavior change, reduce medical care burdens and provide support to patients and families [10]. Some genetic counselors, community health care providers and genetic research programs have already begun to incorporate telephone disclosure of genetic

test results for cancer susceptibility and incidental findings detected in genomic research for select or all patients [14–18]. Additionally, many direct-to-consumer companies have incorporated “streamlining” of pre- and post-test counseling protocols, offering *BRCA1/2* testing, entirely by telephone and the Internet [19], without evidence of outcomes of these delivery models.

Stakeholder interviews suggest that both patients and providers recognize potential advantages to telephone communication, including increased patient convenience and satisfaction, faster receipt of results and additional time to process information in advance of clinical visits [20,21]. Patients and providers also identify potential disadvantages to telephone communication, including loss of nonverbal communication cues, which could limit a provider’s ability to appreciate client needs and the lack of reimbursement models for telephone services [9,11,22]. Several small studies have suggested high satisfaction with telephone communication of *BRCA1/2* test results [6,16,17,23], fewer have suggested comparable knowledge [6,16,17], psychological adjustment [6] and risk reduction behaviors [16]. These studies have included highly select patient populations and have primarily been retrospective, not randomized and too small to meaningfully evaluate differences by genetic test result, a potential moderator of communication impact on psychosocial and behavioral outcomes [24,25]. While informative, the only published randomized study involved a highly select research population (few non-white patients) participating in a genetic counseling trial that provided genetic services at no cost [6]. Additionally, this study included a physician and genetic counselor in telephone disclosure sessions, which might not be a feasible delivery model in health care practice.

To contribute to our understanding of the risks and benefits of alternative innovative delivery models for genetic testing for disease predisposition in “real world” clinical service systems, we utilized preliminary data from patients and providers, our team’s multidisciplinary expertise, and existing literature of genetic counseling, health communication and health behavior to develop a delivery model and protocol for telephone disclosure of genetic test results [9,12,26,27]. In this study, we sought to evaluate the feasibility of this delivery model in patients undergoing clinical *BRCA1/2* testing, inform refinements to our initial protocol (reported separately), and evaluate immediate and delayed cognitive and affective responses to better understand the potential risks and benefits of telephone delivery of genetic test results.

2. Methods

2.1. Participants

Institutional Review Board approval was obtained before initiating this study. Participants were recruited through the Fox Chase Cancer Center Breast and Ovarian Cancer Risk Assessment Program between September 2009 and July 2010. Eligible participants included all patients presenting for clinical *BRCA1/2* testing who were over 18 years old, could communicate in English, completed pre-test counseling with a genetic counselor and elected to proceed with *BRCA1/2* testing. Consistent with professional guidelines from the National Society of Genetic Counselors, key components of pre-test counseling included ascertainment of targeted medical and family history as well as assessment of cancer risk,

cancer genetics education, discussion of appropriate genetic testing options, and informed consent for genetic testing [19,28]. Eligible participants were approached at completion of their pre-test counseling session provided informed consent. Participants completed baseline surveys within 72 h after their pre-test counseling session.

2.2. Telephone disclosure protocol

As above, we utilized our preliminary data, clinical expertise and existing literature to develop a protocol for telephone disclosure of genetic test results [9,12,27,29]. Telephone disclosure sessions were conducted by the genetic counselor who conducted the in-person pre-test counseling session and were scheduled in advance of the call (i.e. after enrollment and consent). Twelve standardized topics were developed to minimize differences between genetic counselors delivering results. These included: (1) confirmation of the recipient, (2) affirmation of the session purpose, (3) introduction of participants on the call, (4) confirmation of receipt of the visual aids, (5) confirmation of adequate hearing, (6) verification that the patients want to receive their test results, (7) disclosure of test results, (8) review of interpretation of the test results, (9) review of implications of the test results, (10) review of risk reduction options, (11) review of implications for family members and (12) inquiry if participant wants information provided to relatives or other health care providers. Other key components of the telephonedisclosure protocol included standardized visual aids, which were mailed to patients in advance of their telephone disclosure appointment, standardized provider probes to evaluate patient understanding and emotional responses, and situational probes to address patient distractions, distress, interruptions, silence and decreased attention. All genetic counselors (n = 4) completed telephone disclosure training, including a training manual and one or more mock telephone disclosure sessions with individualized feedback. Genetic counselors completed checklists of each session to ensure completion of 12 key components. Checklists revealed high fidelity to communication topics (mean 10.4, SE 3.6). Additionally, all telephone disclosure sessions were audiotaped and 20% were reviewed by research staff to assure that checklists reflected audiotaped sessions in standardization and completion of the protocol components. Audiotape reviews to evaluate fidelity revealed high consistency with completed check lists (93%). The majority of discrepancies were commissions (i.e. tape review revealed that the communication topic was covered but not marked on the checklist). All participants were asked to complete a post-telephone disclosure survey by telephone within 3–5 days of completing their telephone disclosure.

All participants who completed telephone disclosure were asked to return for an in-person follow-up appointment with a physician to address any remaining questions and to discuss and implement medical recommendations. Participants were asked to complete a post-clinical follow-up survey within 7 days of their clinical visit.

2.3. Measures

We employed the Self-Regulation Theory of Health Behavior [26,27,30] to inform the evaluation of the immediate (<72 h) and delayed responses to novel delivery models for genetic services. Patients completed quantitative assessments of knowledge [31,32],

psychological distress (state anxiety [33]), psychological adjustment [34] (general anxiety and depression), and satisfaction with genetic services [35,36] at each time point.

2.3.1. Knowledge of genetic disease

Participants completed 7 selected items consistent with the National Institute of Health National Center for Human Genome Research Cancer Genetics Consortium Knowledge scale and utilized in prior research [31]. This scale included items evaluating mechanism of cancer inheritance (1 item), the meaning of positive (3 items) and negative (3 items) result. Internal consistency in this study was good (Mean alpha 0.72).

2.3.2. Psychological distress

We measured psychological distress and adjustment with two instruments measuring distinct constructs. State anxiety was measured with the 20-item State Inventory of the State-Trait Anxiety Inventory (STAI). The state scale is a sensitive indicator of transient or situational changes in anxiety (test-retest reliability: $r = 16-0.62$) experienced by patients in response to stressful procedures or life events [33], and is frequently used to assess the short-term response to the receipt of a genetic test result [24]. Internal consistency in this study was high (Mean alpha 0.95). General anxiety and depression were assessed with the 7-item Hospital Anxiety and Depression Scale (HADS) anxiety and depression subscales, which have been utilized in the general population and a wide range of medical patients, including those with cancer [34,37]. Internal consistency in this study was good for both the anxiety and depression subscales (Mean alpha 0.88, 0.78 respectively).

2.3.3. Satisfaction with genetic services

Satisfaction with health communication was measured with a 9-item scale, reflective of constructs identified in prior qualitative, quantitative and comparative research evaluating participants' perceptions of their genetic counseling and testing experience, including cognitive, affective and time/attention items [35,36]. Internal consistency in this study was good (Mean alpha 0.73).

2.4. Statistical analyses

We used descriptive statistics to describe participant and non-participant characteristics. Straight-line distance was calculated using participant street address and the medical center street address[38]. Genetic test results were classified as positive (deleterious mutation or suspected deleterious variant of uncertain significance), true negative (negative with a known mutation in the family), uninformative negative (negative without a known mutation in the family) and variant of uncertain significance (VUS). We calculated means, standard deviations, and proportions for all constructs in the dataset and evaluated change from baseline to post-telephone disclosure and baseline to post-in person clinical follow-up. We used Fisher's Exact tests, *T*-tests, and simple linear regressions for hypothesis testing. *p*-Values of less than 0.05 based on two-sided hypothesis tests were considered statistically significant. As a sensitivity analysis, we confirmed our results for distance using non-parametric tests since there were some outlying values that could have unduly influenced the *T*-tests.

3. Results

3.1. Participant characteristics

A total of 167 consecutive eligible patients were approached for participation. Of the 167 eligible subjects, 100 (60%) agreed to participate, provided informed consent and completed the baseline assessment and 95 proceeded with *BRCA1/2* testing (Fig. 1). Participant characteristics are described in Table 1. All participants were women, 14% were non-white, 59% had a personal history of cancer and 47% had a college degree or graduate education. The majority of participants (84%) received an uninformative negative result (i.e. negative *BRCA1/2* result with no known clinically significant mutation in the family). Nine women received a positive result (i.e. clinically significant *BRCA1/2* mutation), 4 received a true negative result (i.e. negative for a known clinically significant mutation in the family) and 2 received a Variant of Uncertain Significance. This distribution of test results is reflective of results in clinical populations undergoing *BRCA1/2* testing [16,17,39,40].

All eligible participants received their genetic test results by telephone according to the telephone disclosure communication protocol within 8 weeks of their in-person pre-test counseling session. On average, participants completed their telephone disclosure within 20 days (SD 10.0, range 7–60). Eighty-six (91%) of the participants completed the post-telephone disclosure survey (Fig. 1). The majority (71%) of these completed their post-TD survey within 3 days (Mean 4 days, SD 6.5). Sixty-eight participants (71%) returned for their in-person clinical follow-up appointment. Clinical follow-up appointments took place on average 42 days (SD 28.8, range 1–90 days) from telephone disclosure. Fifty-seven participants completed a post-clinical follow-up survey. The majority of these (80%) were completed within 11 days (mean 10 days, SD 9.9).

3.2. Acceptability of telephone disclosure

Given preliminary data from stakeholder interviews with patients who have undergone genetic testing [20], we expected some patients would decline the option to receive their genetic test results by telephone. In this study, 67 (40%) participants declined participation (Fig. 1). The most frequently reported reason (73% of declining participants) for declining telephone communication of their *BRCA1/2* testing was a preference for in-person communication. Others reasons included no advantage to telephone disclosure given that in-person clinical follow-up was a required component of the study (27%), and no interest in participating in research (7%). As shown in Table 1, patients who declined participation did not differ significantly from participants in age, race, education, history of cancer or distance from the clinical site. Patients with a known mutation in the family were less likely to enroll ($p = 0.04$).

3.3. Cognitive and affective outcomes with telephone disclosure of genetic test results

As shown in Table 2 and Fig. 2, mean knowledge scores were high at baseline (i.e. after in-person pre-test counseling) and did not change significantly from baseline to post-TD. Knowledge scores were significantly higher post-clinical follow-up compared to baseline ($p = 0.04$). Mean state anxiety decreased significantly from baseline to post-TD ($p = 0.03$) but did not differ significantly from baseline to post-clinical follow-up. In contrast, mean

general anxiety (HADS) did not decrease significantly from baseline to post-TD but did decline from baseline to post-clinical follow-up. Mean depression scores (HADS) did not change significantly. Mean satisfaction with genetic services increased significantly both from baseline to post-TD ($p < 0.01$) and baseline to post-clinical follow-up ($p < 0.01$).

3.4. Subgroup analyses

The literature and our preliminary data support the hypothesis that both short-term cognitive and psychological responses to receipt of genetic test results will be moderated by biological (test result [14,20,24,25] and cancer history [24,41,42]) and socio-demographic factors [14,20,24,41,43]. Thus, we sought to evaluate participant factors associated with greater change in knowledge, higher anxiety and depression and lower satisfaction from pre- to post-telephone disclosure. In these exploratory analyses, African American participants reported significantly less increase in satisfaction from baseline to post-TD as compared to white participants (mean difference of -3.8 points, SE 1.74, $p = 0.03$). Having a history of cancer was associated with significantly greater declines in state anxiety from baseline to post-TD (mean difference of -4.8 points, SE 2.0, $p = 0.02$) compared to patients with no history of cancer. While not statistically significant, participants receiving a positive result had greater increases in state anxiety from baseline to post-telephone disclosure (baseline 34.5, SD 16.5; post-disclosure 37.1, SD 17.1) compared to participants receiving an uninformative negative result (baseline 35.8, SD 12.5; post-disclosure 33.2, SD 15.8). They also had reported declines in satisfaction (baseline 36.6, SD 3.9; post-disclosure 35.3, SD 3.5) compared to participants who received an uninformative negative result who reported increases (baseline 36.9, SD 3.5; post-disclosure 39.2, SD 4.0).

3.5. In-person follow-up

As described above (Fig. 1), 26 of the 94 participants who received results by telephone (28%) did not return for in-person clinical follow-up. Characteristics of those who returned for follow-up and those who did not are shown in Table 3. In exploratory analyses it appears that women with less formal education were more likely to not return for in-person clinical follow-up. The majority of patients with uninformative, positive and VUS results returned for clinical follow-up, although approximately one-third of women with positive results did not return. There were no differences in baseline knowledge, anxiety or depression among women who returned and did not return for clinical follow-up. Women who did not return were more likely to have higher general anxiety and depression scores post-telephone disclosure.

4. Discussion and conclusion

4.1. Discussion

In this study, we evaluated the feasibility, uptake and outcomes of telephone delivery of clinical *BRCA1/2* test results by genetic counselors. While other studies have explored telephone disclosure of *BRCA1/2* test results, the majority have been retrospective, not randomized and included select patient populations [16,17]. Additionally, the only published prospective and randomized study by Jenkins et al. included a physician in the telephone disclosure and recruited a highly select research population in contrast to a clinical patient

population [6]. In preliminary stakeholder interviews with genetic counselors, we found that the majority (86%) of early adopters of telephone disclosure do not include a physician in disclosures [14]. Additionally, both provider and patient stakeholders suggested potential benefits to learning of their test result by telephone, providing an opportunity to identify questions and be better prepared for a subsequent follow-up visit with a physician to discuss medical management recommendations [14,20]. Thus, in our study, we elected to evaluate telephone disclosure with genetic counselors followed by follow-up with a physician for medical recommendations.

Similar to the published studies to date, we found no significant change in knowledge and no significant increase in anxiety or depression with telephone disclosure of *BRCA1/2* test results by genetic counselors [6,16,17]. Similar to Jenkins et al., we found declines in state anxiety after telephone disclosure, but no change from baseline at subsequent follow-up. Additionally, patients reported significant increases in satisfaction with genetic services after both telephone disclosure and subsequent in-person clinical follow-up after telephone disclosure. These outcomes are reflective of previously published outcomes with in-person genetic counseling [44]. Multiple studies have shown similar decreases in anxiety immediately post-disclosure, with return to baseline with later follow-up [25,44]. Nonetheless, our study did not include a comparison arm. Thus, how affective and cognitive responses after telephone disclosure with a genetic counselor might differ from traditional in-person delivery of genetic services in current delivery systems and clinical populations remains unknown. Our ongoing multisite study is designed to address this gap [45].

Interestingly, while knowledge did not change significantly from pre-disclosure to post-telephone disclosure, knowledge did increase significantly after the in-person clinical follow-up visit. Again, this increase may be no different among patients who receive their results in-person and follow-up with a physician for medical management several weeks or months later [46]. As suggested in our preliminary interviews with patients and providers [14,20], it is possible that receiving results by phone in advance of clinical follow-up provides patients an opportunity to reflect on the results, seek additional information and ask additional questions at follow-up and subsequently enhance understanding of genetic test results. We expect that our ongoing randomized study to evaluate short-term and longitudinal changes in cognitive and affective responses to receipt of *BRCA1/2* results by telephone versus in-person will provide a better understanding of how knowledge and other outcomes may differ with telephone delivery by genetic counselors in “real life” clinical settings [45].

Of note, 29% of patients did not return for in-person clinical follow-up. This is consistent with our preliminary data where genetic counselors reported concerns that some patients do not return for in-person follow-up when requested [14]. We do not have longitudinal data among those who did not return, and therefore do not know if understanding of their genetic test results, the implications for their health and family members and options for risk reduction among this group differed from those who returned for clinical follow-up. It is interesting to note that in exploratory analyses women who did not return had greater general anxiety and depression than women who returned, although again, we do not know if these differences persisted. While it is possible that understanding of their test results

could be inferior to those who receive in-person communication or return for in-person clinical follow-up in high-risk screening clinics, these patients might follow-up and have additional discussions regarding their genetic test results and risk reduction options with other health care providers, such as their primary care physician or gynecologist. Similarly, women might seek and receive psychosocial support. Thus, while noncompliance with in-person clinical follow-up with a physician has been recognized as a perceived potential risk of telephone disclosure with a genetic counselor [14,16], we do not know that cognitive, affective or behavioral outcomes differ in the subset who do not return for clinical follow-up in specialized high-risk or cancer genetics clinics. In our ongoing study, we seek to obtain longitudinal data in both women who return and those who do not return for clinical follow-up after telephone disclosure, which we hope inform the risks and benefits of telephone disclosure with a genetic counselor in clinical settings.

The literature and our preliminary data support the hypothesis that both short-term cognitive and psychological responses to receipt of genetic test results will be moderated by biological (test result [14,24,25] cancer history [24,42,47,48]) and sociodemo-graphic [24,43,48,49] factors. Both patients and providers have suggested the potential for differential affective responses to telephone disclosure based on test result (i.e. positive test result) or pre-existing cancer worry or distress [14,20]. Our exploratory analyses suggest the potential for differences in cognitive and affective outcomes among subgroups based on test results, cancer history and race/ethnicity, which could be clinically relevant as cancer genetics and personalized medicine is disseminated and implemented more broadly into clinical care and more diverse clinical populations. While these exploratory findings are interesting, it remains possible that these subgroup differences are similar with in-person delivery of genetic test results. Thus, subgroups may fare no worse with telephone communication, but additional interventions may be useful to address difference in understanding or psychological responses to genetic information. Many of the studies evaluating outcomes with *BRCA1/2* testing, either in-person or by phone, have been conducted in relatively select populations and there is limited data on outcomes among more diverse populations [6,16,17]. These exploratory findings have informed our ongoing multi-center randomized study, where we seek to recruit a socioeconomically and geographically diverse population and a sufficient number of women to evaluate differences by race/ethnicity and genetic test result [45].

While other studies in select populations have suggested high uptake of telephone disclosure when offered to study participants [6,23], in this study in a clinical population, 40% of patients declined telephone disclosure and the majority indicated a preference for in-person communication of their genetic test results. This is consistent with our stakeholder data where patients reported both potential advantages and disadvantages to telephone communication and mixed interest in the opportunity to receive results by telephone [20]. In some programs and settings, telephone disclosure of genetic test results is being adopted and in some cases patients are not given the option to receive their results in-person [15,19]. Thus, uniform adoption of telephone delivery of genetic test results may not be consistent with the preferences of some patients. Patients with a known mutation in the family were less likely to enroll and might represent a potentially vulnerable population who experience

greater risks with telephone communication or other modifications to genetic delivery models.

We acknowledge several limitations to our study. Although we recruited a clinical population, we still had relatively low representation of several subgroups and our findings might not be generalizable to more diverse populations. As described above, this is a goal of our ongoing multi-center randomized study. This was not a randomized study and therefore how cognitive and affective responses may differ in patients receiving in-person communication remains unknown and is the goal of our ongoing study. Our outcomes at 3 months could be impacted by retention. Additionally, given relatively small numbers of positive and VUS results, our findings might primarily reflect the outcomes of patients with uninformative negative results. Similarly, the comparison between patients who returned after telephone disclosure and those who did not represent relatively small sample sizes and are exploratory. Confirmation in future studies would be beneficial. Our ongoing study will seek to recruit sufficient numbers of patients receiving VUS and positive results to improve our understanding our outcomes in the clinically relevant and potentially vulnerable subgroups.

4.2. Conclusion

In conclusion, some patients are willing to receive *BRCA1/2* test results by telephone with a genetic counselor after in-person genetic counseling. Overall, knowledge and satisfaction were high after pre-test counseling and after telephone disclosure, and anxiety and depression decreased after telephone disclosure, although some subgroups appear to experience more anxiety and less satisfaction. Some patients do not return for in-person clinical follow-up after telephone disclosure and longitudinal cognitive and affective outcomes are unknown.

4.3. Practice implications

Further research evaluating cognitive, behavioral and affective outcomes of telephone disclosure compared to in-person communication, differences among subgroups and outcomes over time can inform how to best incorporate telephone communication into delivery of genetic services, particularly as genetic testing becomes utilized increasingly in medical care across a wide range of medical settings.

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Fig. 1.
 Study schema highlighting consenting and study completion information.

ab, ac indicate $p < 0.05$ for change in scores

Fig. 2.

Change in mean cognitive and affection outcomes in Knowledge, State anxiety, HADS anxiety and depression and Satisfaction among individuals who received their genetic test results by telephone.

Table 1

Participant and non-participant characteristics.

	Participants (<i>n</i> = 94)	Non-participants (<i>n</i> = 67)	<i>p</i>
	No. (%)	No. (%)	
AGE, years			
Mean	48.9 (10.2)	48.0 (12.3)	NSS
Median	49	45	
Range	24–77	23–86	
Race			
White	81 (86)	58 (87)	NSS
African-American	9 (10)	7 (11)	
Asian	3 (3)	1 (1)	
Hispanic/Latino	1 (1)	1 (1)	
Education			
High school or less	17 (18)	15 (22)	NSS
Some college/vocational	33 (35)	17 (25)	
College degree or more	44 (47)	25 (37)	
Marital status			
Married ^a	62 (65)	49 (73)	NSS
Single	22 (23)	14 (21)	
Divorced/separated	6 (7)	3 (5)	
Widowed	4 (5)	1 (1)	
Marital status			
Married ^a	62 (66)	49 (73)	NSS
Single	32 (34)	18 (27)	
History of cancer			
Yes	55 (59)	39 (58)	NSS
No	39 (41)	28 (42)	
Treatment decision ^b			
Yes	19 (20)	7 (11)	NSS
No	75 (80)	60 (89)	
Known mutation in family			
Yes	6 (7)	12 (18)	0.04
No	88 (93)	55 (82)	
BRCA1/2 test result			
Uninformative negative	79 (84)		
Positive	9 (9)		
True negative	4 (5)		
VUS	2 (2)		
Distance from clinical site			
Mean (SD)	26.9 (51.6)	48.8 (251.0)	NSS

	Participants (n = 94)	Non-participants (n = 67)	p
	No. (%)	No. (%)	
Median	14.3	11.6	
Range	0.3–470.2	1.6–2065.4	

VUS, variant of uncertain significance.

^aIncludes domestic partnership.

^bDefined as individuals who had not received definitive surgical treatment for their breast cancer at the time of initial counseling.

Table 2

Change in cognitive and affective outcomes with telephone disclosure.

	Baseline and post-TD (<i>n</i> = 86)	<i>p</i>	Baseline and post-IP clinical f/u (<i>n</i> = 57)	<i>p</i>
Knowledge (range 6–33)				
Baseline	26.5 (3.0)	0.25	26.3 (3.0)	0.04
Post-TD	26.9 (3.2)			
Post-IP clinical follow-up			27.2 (2.7)	
STATE anxiety (range 20–80)				
Baseline	35.2 (13.1)	0.03	34.2 (11.7)	0.90
Post-TD	33.0 (12.6)			
Post-IP clinical follow-up			34.1 (10.0)	
HADS anxiety (range 0–21)				
Baseline	6.6 (4.2)	0.60	6.1 (3.9)	0.01
Post-TD	6.4 (5.0)			
Post-IP clinical follow-up			5.0 (4.3)	
HADS depression (range 0–21)				
Baseline	3.1 (3.0)	0.15	3.0 (2.7)	0.09
Post-TD	3.7 (4.2)			
Post-IP clinical follow-up			2.6 (2.0)	
Satisfaction (range 9–45)				
Baseline	36.8 (4.1)	<0.01	36.6 (3.1)	<0.01
Post-TD	38.7 (4.1)			
Post-IP clinical follow-up			38.5 (3.0)	

Table 3

Characteristics of participants who returned for in-person clinical follow-up and those who did not return.

	Returned (n = 68)	Did not return (n = 26)	p
	No. (%)	No. (%)	
AGE, years			
Mean (SD)	49.6 (9.7)	47.1 (11.5)	0.34
Median	48	47	
Range	30–73	24–77	
Race			
White	61 (75)	20 (25)	0.11
African-American	6 (67)	3 (33)	
Asian	1 (33)	2 (67)	
Hispanic/Latino	0 (0)	1 (100)	
Education			
High School or less	7 (41)	10 (59)	0.01
Some college/vocational	25 (76)	8 (24)	
College degree or more	36 (82)	8 (18)	
Marital status			
Married ^a	45 (66)	17 (65)	0.39
Not married	23 (34)	9 (35)	
History of cancer			
Yes	40 (73)	15 (27)	1.00
No	28 (72)	11 (28)	
Treatment decision ^b			
Yes	15 (79)	4 (21)	0.58
No	53 (71)	22 (29)	
Known mutation in family			
Yes	3 (50)	3 (50)	0.34
No	65 (74)	23 (26)	
BRCA1/2 test result			
Uninformative negative	59 (75)	20 (25)	0.17
Positive	6 (67)	3 (33)	
True negative	1 (25)	3 (75)	
VUS	2 (100)	0 (0)	
Distance from clinical site (mean miles, SD)			
Mean (SD)	21.7 (21.1)	40.6 (91.9)	0.11
Median	15.1	13.3	
Range	0.3–99.3	2.1–470.2	
Knowledge			
Baseline	26.7 (2.8)	25.6 (3.7)	0.11
Post-TD com	27.0 (3.2)	26.4 (3.1)	0.50

	Returned (n = 68)	Did not return (n = 26)	p
	No. (%)	No. (%)	
State anxiety			
Baseline	34.3 (11.7)	36.3 (15.7)	0.51
Post-TD	32.5 (11.4)	34.8 (16.6)	0.48
Satisfaction			
Baseline	36.9 (3.3)	36.2 (4.1)	0.40
Post-TD	38.7 (4.2)	38.4 (3.8)	0.81
General anxiety (HADS-a)			
Baseline	6.4 (4.0)	6.5 (4.2)	0.95
Post-TD	5.6 (4.0)	9.3 (7.3)	<0.01
General depression (HADS-d)			
Baseline	3.0 (2.7)	3.1 (3.3)	0.86
Post-TD	2.9 (3.4)	6.5 (5.8)	<0.01

VUS, variant of uncertain significance.

^a Includes domestic partnership.

^b Defined as individuals who had not received definitive surgical treatment for their breast cancer at the time of initial counseling.