

Comparing Outcomes of Genetic Counseling Options in Breast and Ovarian Cancer: An Integrative Review

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PROBLEM IDENTIFICATION: Genetic counseling is vital in helping people at high risk for hereditary breast and ovarian cancer (HBOC) make informed decisions to undergo *BRCA* testing. Many people, particularly those in rural locations, lack access to these services. This review examines evidence to determine if remotely delivered genetic counseling via telephone or telemedicine is an effective alternative to in-person counseling for people who are at high risk for HBOC.

LITERATURE SEARCH: A literature review was completed by searching PubMed, SCOPUS, and CINAHL® databases.

DATA EVALUATION: 151 articles were identified from the search, and 7 were included in the review.

SYNTHESIS: Patients' *BRCA* knowledge acquisition, cancer-specific distress, anxiety, depression, and satisfaction with mode of counseling delivery were equivalent between in-person and remotely delivered counseling groups. Genetic testing rates were significantly higher in participants receiving in-person counseling. Remotely delivered genetic counseling was more convenient and less expensive. Mixed outcomes existed regarding counselor–patient communication.

IMPLICATIONS FOR PRACTICE: The demand for genetic counseling will grow as advances in cancer genomics reveal genes that may contribute to cancer predisposition. Innovative delivery models are necessary to ensure that all people have access to care.

KEYWORDS genetic counseling; hereditary breast and ovarian cancer; *BRCA*; telegenetics

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When the tumor suppressor genes *BRCA1* and *BRCA2* (*BRCA1/2*) are mutated, they are strongly associated with the development of breast and ovarian cancer (Jacobs et al., 2016). Commercial testing for *BRCA1/2* mutations was first made available in 1996 and is now widely used for those at high risk (Ahn & Port, 2017). Within the United States, an estimated 350,000 women carry a *BRCA1/2* mutation; however, it is likely that only 15% of these cases have been identified (Schwartz et al., 2014). Identification of women with a *BRCA1/2* mutation is of important clinical significance because interventions can help reduce their risk of developing hereditary breast and ovarian cancer (HBOC), including early initiation of breast cancer screening, chemoprevention, and risk-reduction surgery, such as mastectomy or oophorectomy (Schwartz et al., 2014).

The U.S. Preventive Services Task Force supports genetic counseling and risk assessment for women at high risk for these mutations (Mette et al., 2016). Genetic counseling and risk assessment involves analysis of personal and family medical history, education regarding cancer risk and prevention, as well as discussion of genetic testing and interventions for people who test positive for a *BRCA* mutation (Mette et al., 2016). Cancer genetic services have traditionally included in-person counseling with pre- and post-testing counseling provided by a qualified health professional. However, the National Society of Genetic Counselors Service Delivery Model Task Force identifies four distinct methods for delivering genetic counseling services (Bradbury et al., 2016), which include in-person genetic counseling (IPGC), group genetic counseling, telegenetics, and telephone genetic counseling (TGC) (McDonald, Lamb, Grillo, Lucas, & Miesfeldt, 2014). Telegenetics encompasses counseling services provided remotely

by live videoconferencing with visual and audio access, whereas TGC is provided remotely via the telephone (Buchanan, Rahm, & Williams, 2016).

Genetic counseling may be delivered by genetic counselors, advanced practice nurses with a master's degree, and genetic clinicians or physicians. Counseling by a genetics counselor or clinician has been associated with improved adherence to cancer risk management, better informed surgical decision making, increased cancer genetics knowledge, improved family communication regarding cancer risk, high patient satisfaction, decreased anxiety, and improved cost savings (Buchanan et al., 2015).

A current barrier to genetic counseling services for women at high risk for HBOC is the availability of healthcare providers who can provide genetic counseling, most of whom reside at large academic medical centers (Bradbury et al., 2016). Women who do not live close to a medical institution offering these services may have to travel long distances for genetic counseling. Healthcare providers in the community often do not have the training to properly analyze a woman's risk for HBOC or to provide appropriate guidance and counseling, which can lead to misinformed decision making, test-related distress, and unnecessary testing (Bradbury et al., 2016; Kinney et al., 2016).

The demand for genetic counseling has increased as genetic information has been integrated into medical practice (Meropol et al., 2011). To meet the demand for genetic services, alternatives to IPGC must be explored (Platten et al., 2012). Telegenetics and TGC are potential remotely delivered alternatives to traditional IPGC that can expand the reach of these services, as well as help save time and costs (Zilliacus et al., 2011). In theory, remotely delivered genetic counseling provides patients with the same educational resources as in-person counseling but reduces travel time and travel burden for patients and providers (Bradbury et al., 2016). Although these methods are promising means to improve access to counseling for at-risk people, they may not be equivalent to traditional in-person counseling. This review examines if any evidence supports remotely delivered genetic counseling via telephone (TGC) or telemedicine as effective alternatives to IPGC for people who are at high risk for HBOC.

Methods

Eligibility Criteria

This review included publications that evaluated outcomes in people previously diagnosed with breast or ovarian cancer or who were considered to be at high risk for HBOC based on their family history.

Studies were included if they used a telephone or a telegenetics-delivered genetic counseling intervention. To be included, studies had to evaluate participant outcomes associated with genetic counseling or provide a cost analysis of genetic counseling. Study outcomes of interest included how IPGC compared to TGC in terms of HBOC knowledge, psychosocial outcomes (cancer-related distress, anxiety and depression), testing uptake, patient-counselor communication, patient satisfaction (convenience and satisfaction), and cost.

To ensure that the most current and relevant publications were used in the review, studies published prior to January 2011 were excluded. Results were limited to English publications. Feasibility studies, case studies, abstracts, and posters were excluded. Studies that evaluated outcomes of genetic counseling for hereditary cancer syndromes other than HBOC were also excluded. Studies that evaluated genetic counseling perceptions or outcomes are beyond the scope of this review and were not included.

Search Strategy

Using the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines, the authors conducted a systematic search of PubMed, Scopus, and CINAHL®. Studies were eligible for inclusion if they were published from January 2011 to November 2016. All three databases were searched on November 28, 2016, using the Medical Subject Heading (MeSH) terms *telemedicine*, *videoconferencing*, *genetic counseling*, and *neoplasms*. Additional search terms included *telephone**, *telehealth*, *telegenetic**, *telemedicine*, *videoconferen**, *genetic counseling*, *genetic*, *counsel**, *e-genetic**, and *cancer*. A research librarian assisted in the literature search.

In total, 151 records were identified across the three databases (see Figure 1). After duplicates were removed, 84 publications were available for review. Articles were initially screened by title and then by abstract content, with 17 articles remaining for full-text review. A secondary review of references for relevancy was included, and no additional studies were identified. Of the remaining 17 articles, a total of 10 articles were excluded for the following reasons: five studies included participants with high-risk genetic conditions other than HBOC, two publications were feasibility studies, and three studies surveyed genetic counselors and did not evaluate participant outcomes. Articles were evaluated using a rapid critical appraisal tool to determine each study's level of evidence, quality, and application to practice (Melnik & Fineout-Overholt, 2014).

Results

In examining the research articles included in this review, six themes emerged as common outcomes in the studies. Synthesis of the intervention results are organized by the following variables: HBOC knowledge, psychological outcomes, genetic testing uptake, patient–counselor communication, cost, and patient satisfaction (see Table 1).

Hereditary Breast and Ovarian Cancer Knowledge

Three studies evaluated HBOC knowledge. Schwartz et al. (2014) conducted a parallel-group, randomized, noninferiority trial ($n = 669$) comparing IPGC to TGC. *BRCA1/2* knowledge was assessed at baseline and two weeks following completion of the genetic counseling intervention (Schwartz et al., 2014). *BRCA1/2* knowledge was measured using the Breast Cancer Genetic Counseling Knowledge Questionnaire, a validated 27-item scale with a total score that is equivalent to the number of correct responses (Erblich et al., 2005). In Schwartz et al. (2014), knowledge attainment with

TGC was not inferior to that with IPGC, and the results were comparable (Schwartz et al., 2014). For IPGC, the mean knowledge score increased from 17 at baseline to 20.1 at two weeks after counseling; whereas with TGC, the mean knowledge score at baseline was 17.3 and increased to 20.2 postcounseling. The lower bound of the 97.5% confidence interval (CI) (-0.61) did not cross the noninferiority limit of -1 , supporting the noninferiority of TGC (Schwartz et al., 2014).

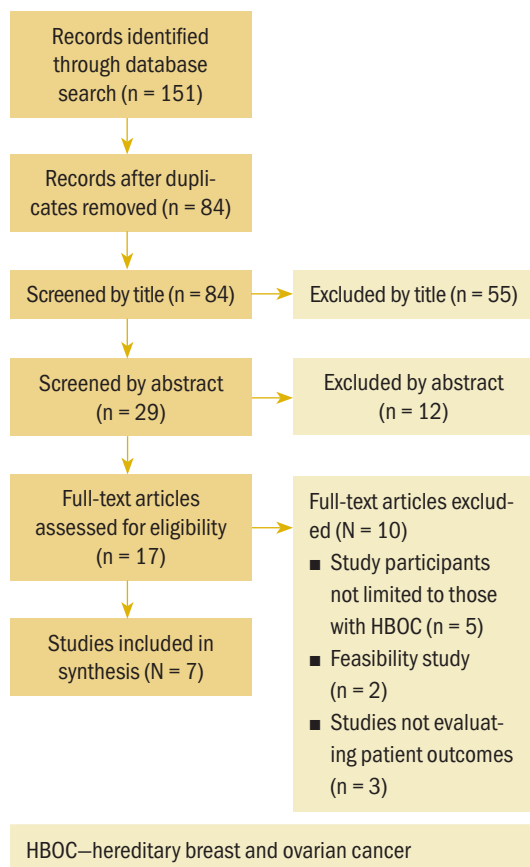
In a prospective cohort study of 195 high-risk women, Zilliaccus et al. (2011) evaluated whether telegenetics was as effective as IPGC in improving patient outcomes, one of which included breast cancer knowledge. The study measured knowledge about breast cancer genetics using a 12-item true/false scale, with one point given for each correct response (Zilliaccus et al., 2011). The mean score in the telegenetics group improved from 7.7 to 8.7, and the mean score in the IPGC group increased from 7.4 to 8.9. Paired sample t tests showed that HBOC knowledge increased from baseline to follow-up in the IPGC group ($t = -5.5$, $p < 0.001$) and telegenetics group ($t = -5.8$, $p < 0.001$) (Zilliaccus et al., 2011).

In a two-armed, parallel-cluster, randomized, noninferiority trial directly comparing TGC to IPGC, Kinney et al. (2014) evaluated *BRCA1/2* knowledge at baseline, one week after completion of pretest counseling, and one week after post-test counseling. The authors used a 10-item index that awarded one point for each correct response. The mean score in the TGC group improved from 6.9 at baseline to 8.3 after completing post-test counseling. Within the IPGC group, the mean score at baseline was 7 and increased to 8.3 after completion of post-test counseling (Kinney et al., 2014). The difference between the groups fell within a one-sided 97.5% CI and revealed that TGC was noninferior to IPGC for knowledge attainment.

Psychological Outcomes

Four studies addressed psychological outcomes. Kinney et al. (2014) evaluated two psychosocial patient outcomes as part of a randomized, controlled trial directly comparing IPGC to TGC ($n = 988$). They evaluated cancer-specific distress and patient anxiety at four time points in the genetic counseling and testing process. Outcomes were evaluated at baseline, one week after pretest counseling, one week after post-test counseling, and six months after completion of the last counseling session. Cancer-specific distress was evaluated with the validated 15-item Impact of Events Scale (IES), with scores ranging from 0–75 (Horowitz, Wilner, & Alvarez, 1979). The noninferiority margin for cancer-specific distress was set at 4 points

FIGURE 1. Studies Examining Remotely Delivered Genetic Counseling for HBOC



(as established in the literature for IES) (Kinney et al., 2014). The difference between groups was estimated using linear models in combination with a 97.5% clus-

ter bootstrap CI (Kinney et al., 2014). Cancer-specific distress scores in both intervention groups followed the same trajectory and decreased from baseline to

TABLE 1. Study Outcomes Comparing IPGC to TGC

Study	HBOC Knowledge and Psychological Outcomes	Genetic Testing Update and Cost	Patient–Counselor Communication and Patient Satisfaction
Butrick et al., 2015	–	Genetic testing update <ul style="list-style-type: none"> ■ Randomization to IPGC, higher HBOC knowledge, lower perceived stress, and non-Hispanic White race were predictors of testing. ■ Race predictive of testing in TGC arm ■ Race not predictive of testing in IPGC arm 	–
Chang et al., 2016	–	Cost <ul style="list-style-type: none"> ■ Pretest counseling: TGC (\$120) versus IPGC (\$270) ■ Counseling and genetic testing: TGC (\$3,680) versus IPGC (\$4,060) 	–
Kinney et al., 2014	HBOC knowledge <ul style="list-style-type: none"> ■ TGC equal to IPGC Psychological outcomes <ul style="list-style-type: none"> ■ Cancer-specific distress: TGC equal to IPGC ■ Anxiety: TGC equal to IPGC 	Genetic testing update <ul style="list-style-type: none"> ■ Testing uptake: IPGC greater than TGC at six months post-counseling 	Patient–counselor communication <ul style="list-style-type: none"> ■ Counselor informativeness: TGC equal to IPGC ■ Interpersonal sensitivity: TGC equal to IPGC ■ Partnership building: TGC equal to IPGC
Kinney et al., 2016	Psychological outcomes <ul style="list-style-type: none"> ■ Cancer-specific distress: TGC equal to IPGC ■ Anxiety: TGC equal to IPGC 	Genetic testing update <ul style="list-style-type: none"> ■ IPGC greater than TGC at one year post-counseling 	–
Peshkin et al., 2016	–	–	Patient–counselor communication <ul style="list-style-type: none"> ■ Perception of genetic counselor’s ability to recognize emotions: IPGC greater than TGC ■ Maintaining attention: IPGC greater than TGC ■ Counselor providing support: IPGC greater than TGC
Schwartz et al., 2014	HBOC knowledge <ul style="list-style-type: none"> ■ TGC equal to IPGC Psychological outcomes <ul style="list-style-type: none"> ■ Cancer-specific distress: TGC equal to IPGC at two weeks and three months post-counseling 	Cost <ul style="list-style-type: none"> ■ TGC: \$3,660 ■ IPGC: \$3,774 	Patient satisfaction <ul style="list-style-type: none"> ■ TGC equal to IPGC
Zilliacus et al., 2011	HBOC knowledge <ul style="list-style-type: none"> ■ Increased in TGC and IPGC groups Psychological outcomes <ul style="list-style-type: none"> ■ Cancer-specific anxiety: TGC equal to IPGC ■ Anxiety: TGC equal to IPGC ■ Depression: TGC equal to IPGC 	–	Patient–counselor communication <ul style="list-style-type: none"> ■ Perceived genetic clinician empathy: TGC equal to IPGC ■ Perceived genetic counselor empathy: TGC equal to IPGC Patient satisfaction <ul style="list-style-type: none"> ■ TGC equal to IPGC
HBOC—hereditary breast and ovarian cancer; IPGC—in-person genetic counseling; TGC—telephone genetic counseling			

one week after pretest counseling, with an additional decrease one week after post-test counseling. Although a slight rise in scores was observed at six months in both groups, they remained below baseline. Mean differences in the cancer-specific distress scores between IPGC and TGC at each time interval were not significant and endorsed noninferiority of TGC for this outcome.

Kinney et al. (2014) also evaluated participant anxiety using the Brief Symptom Inventory 18, a tool that contains a six-item anxiety subscale with scores ranging from 0–24 (Derogatis, 2001). The noninferiority margin for participant anxiety was set at 5 points, which was less than 0.5 standard deviations from the IPGC mean score (Kinney et al., 2014). The baseline score for the TGC and IPGC arms were similar (2.8 and 2.6, respectively), and both groups showed a decrease in anxiety scores at one week after pretest counseling (2.3 and 2.2, respectively). A further decrease in scores was observed at one week after post-test counseling (2.2 and 2, respectively). Participants in both arms had a slight increase in scores at six months (2.7 and 2.5, respectively) but, as with cancer-specific distress, they remained below their baseline levels. The mean difference between the TGC and IPGC arms remained within the noninferiority margin, supporting noninferiority of TGC to IPGC for participant anxiety.

Kinney et al. (2016) published a follow-up to their initial study in which they re-evaluated the same outcomes at the one-year mark ($N = 988$). As with the findings in the previous publication, the mean differences for both cancer-specific distress and anxiety between the two study arms at the one-year time point were within the noninferiority margins (five points as established in the previous study), supporting noninferiority of TGC to IPGC (Kinney et al., 2016). At one year, the mean cancer-specific distress score for participants who received TGC and IPGC was 11.19 and 10.06, respectively (Kinney et al., 2016). The mean anxiety score for participants who received TGC had almost returned to baseline (2.74) compared to the IPGC arm (2.37), which remained below baseline (Kinney et al., 2016).

Zilliacus et al. (2011) evaluated cancer-specific anxiety, as well as anxiety and depression, in participants receiving telegenetics counseling. As in the Kinney studies, cancer-specific anxiety was measured using the IES (Horowitz et al., 1979). Anxiety and depression were evaluated with the validated Hospital and Anxiety Depression Scale, a 14-item measure, with total scores ranging from 0–42. The mean cancer-specific anxiety score in the telegenetics and IPGC groups were comparable at baseline (20.8 and 20.7, respectively), and both groups saw a decrease

in this level at the one-month follow-up (17.5 and 20.5). The upper limit of the CI for the mean change score was less than the prespecified noninferiority margin of five, supporting noninferiority of telegenetics to IPGC for cancer-specific anxiety (Zilliacus et al., 2011). Both groups saw comparable decreases in the mean generalized anxiety ($\bar{X} = -0.53$, 95% CI $[-1.81, 0.75]$, $p = 0.42$) and depression scores ($\bar{X} = 0.03$, 95% CI $[-1.04, 1.1]$, $p = 0.96$) from baseline to one month, suggesting no difference between the telegenetics and IPGC arms (Zilliacus et al., 2011).

Schwartz et al. (2014) evaluated cancer-specific distress and compared this outcome in the IPGC and TGC intervention arms. As in the last two studies, cancer-specific distress was measured using the IES. In this study, measurements were made at baseline, after pretest counseling, and three months after result disclosure. After pretest counseling, participants receiving TGC had noninferior outcomes related to cancer-specific distress compared to participants who received IPGC ($d = -1.6$, upper-bound one-sided 97.5% CI $[0.27]$, noninferiority limit = 4) (Schwartz et al., 2014). Three months after result disclosure, cancer-specific distress outcomes in the TGC arm remained noninferior to the IPGC arm ($d = -0.79$, upper-bound one-sided 97.5% CI $[1.16]$, noninferiority limit = 4) (Schwartz et al., 2014).

Genetic Testing Uptake

Schwartz et al. (2014) evaluated genetic testing uptake ($N = 988$). Of the participants who completed pretest counseling, 272 receiving IPGC underwent genetic testing for *BRCA1/2* compared to 251 who received TGC (relative risk = 0.93, 95% CI $[0.88, 0.99]$). Statistical analysis was completed using two one-sided tests approach, and the lower bound of the 90% CI fell outside the equivalence range ($d = -5.9\%$, 90% CI $[-10.3, -0.01]$) (Schwartz et al., 2014).

Consistent with the results from Schwartz et al. (2014), Kinney et al. (2014) found that *BRCA1/2* testing uptake in the TGC arm was not equivalent to the IPGC arm. Within the TGC arm, 101 women went on to receive genetic testing, compared to 139 participants in the IPGC arm (Kinney et al., 2014). Of the women who chose to undergo testing in the IPGC arm, 132 completed testing the same day in the clinic (Kinney et al., 2014). In a subgroup analysis comparing genetic uptake in participants living in rural versus urban areas, genetic testing uptake was higher in participants who lived in rural areas in both arms of the study; however, the results were not statistically significant. In the rural setting, 31.9% (95% CI $[22.1, 43.6]$) of participants who received TGC underwent

testing as opposed to 38.5% (95% CI [27.6, 50.6]) of participants who received IPGC (Kinney et al., 2014). For urban-dwelling participants, 20% (95% CI [16.4, 24.2]) of participants who received TGC underwent testing compared to 30.6% (95% CI [26.2, 35.5]) of participants who received IPGC (Kinney et al., 2014).

In their follow-up publication, Kinney et al. (2016) re-evaluated genetic testing uptake one year after completion of genetic counseling (N = 988). At one year, 27.9% of participants receiving TGC and 37.3% of participants receiving IPGC had undergone genetic testing for BRCA1/2 (Kinney et al., 2016). A 95% CI in the difference of testing uptake was 2.2%–16.8%. Equivalence was set at –10% to 10%, and the results fell outside of this range, supporting nonequivalence of the two arms (Kinney et al., 2016). The authors also compared testing uptake in rural and urban populations. At the one-year mark, within the rural population, 38.7% (95% CI [26.2, 50]) of participants who received TGC had undergone genetic testing compared to 41.3% (95% CI [29.1, 53.9]) of participants who received IPGC. In the urban population, 25.9% (95% CI [21.1, 30.9]) of participants who received TGC underwent testing compared to 36.6% (95% CI [30.8, 42.8]) of participants in the IPGC arm (Kinney et al., 2014).

Butrick et al. (2015) evaluated factors that influenced genetic testing uptake. Using a logistic regression model, the authors found that predictors of completing genetic testing in the full sample of participants (N = 669) included randomization to IPGC, higher knowledge about HBOC, lower perceived stress, and non-Hispanic White race. For participants who received IPGC, race and ethnicity were not associated with likelihood of undergoing testing; 94.2% of minority participants who received IPGC underwent genetic testing compared to 89.4% of non-Hispanic White participants (odds ratio [OR] = 2.75, 95% CI [0.61, 12.5]). However, for participants who underwent TGC, race and ethnicity were significantly associated with the likelihood of getting genetic testing. In this arm, 68.4% of minority participants underwent genetic testing compared to 87% of non-Hispanic White participants (OR = 0.41, 95% CI [0.18, 0.92]) (Butrick et al., 2015).

Patient–Counselor Communication

Three studies compared communication outcomes for IPGC and TGC. Kinney et al. (2014) examined patient-centered communication one week after pretest counseling using a 13-item instrument adapted from a publication on physician–patient communication (Street, 1991). Higher scores indicated that patients had better perceptions of counselor infor-

mation, interpersonal sensitivity, and partnership building. TGC was found to be noninferior to IPGC for all three measures, as the scores for these measures in each arm fell within the study's established 10% noninferiority margin.

In a study of 554 women, Peshkin et al. (2016) evaluated several outcomes related to patient–counselor communication comparing IPGC to TGC, including patients' perceptions of the genetic counselors' ability to recognize their emotions, patients' ability to maintain attention during a counseling session, and perceived emotional support from genetic counselors. For all measures, TGC was statistically nonequivalent to IPGC. For participants receiving IPGC, 68.8% reported that their genetic counselor was extremely effective at recognizing their emotions, compared to only 55.5% of the participants receiving TGC (χ^2 [df = 1, n = 554] = 10.39, p = 0.001). Bivariate predictors of higher perceived emotional recognition included non-Hispanic White ethnicity, lower perceived stress, and higher physical quality of life (Peshkin et al., 2016). In the IPGC arm, 95% of participants reported that they had no difficulty maintaining attention during the session compared to 89.7% of patients receiving the TGC intervention (χ^2 [df = 1, n = 552] = 5.5, p = 0.019) (Peshkin et al., 2016). Of the participants in the IPGC arm, 66% of women reported that their genetic counselor was extremely effective at providing support in contrast to 52.9% of participants receiving TGC (χ^2 [df = 1, n = 554] = 9.74, p = 0.002) (Peshkin et al., 2016). Race moderated the association between the study arm and perceived supportiveness of the genetic counselor; non-Hispanic White study participants reported higher levels of counselor support in IPGC compared to TGC (Peshkin et al., 2016).

Zilliacus et al. (2011) evaluated perceived relational empathy of the healthcare provider (genetics counselors and clinicians) delivering genetic counseling in a trial comparing IPGC to a telegenetics intervention. Relational empathy was evaluated using a 10-item scale, with total scores ranging from 0–50 and with higher scores indicating higher levels of perceived practitioner empathy. In this study, no difference existed between the IPGC and telegenetics arms regarding perceived genetic clinician empathy (OR = –0.74, 95% CI [–0.22, 1.69], p = 0.13) or perceived genetic counselor empathy (OR = –0.76, 95% CI [–1.73, 0.2], p = 0.12) (Zilliacus et al., 2011).

Cost

In an economic evaluation conducted alongside a randomized, controlled trial comparing IPGC to TGC, Chang et al. (2016) used a microcosting approach

to itemize the value of each resource used in delivering genetic counseling to study participants. Cost estimates included staff travel and time, office space, overhead, patient time costs, and testing using national data for wage rates (Chang et al., 2016). For pretest counseling, the cost of delivery of TGC per participant counseled averaged \$120, compared to \$270 to deliver IPGC. The average total cost of counseling and genetic testing with TGC was \$3,680 versus \$4,060 for IPGC. When comparing the cost of counseling to detect one participant with a *BRCA1/2* mutation, based on detection rates of 10.1% for IPGC and 9.9% for TGC, the average cost for patients receiving TGC totaled \$37,160 compared to \$40,330 for IPGC.

Schwartz et al. (2014) also compared costs of TGC to traditional IPGC. To calculate costs, the authors considered time and travel expenses of staff and patients, the cost of genetic testing, and overhead needed to provide pretest counseling, testing, and posttest counseling (Schwartz et al., 2014). The average cost for IPGC was \$3,774, compared to \$3,660 for TGC. TGC costs were less because of shorter counseling sessions, less patient travel, and lower overhead costs. The greatest cost savings was for rural patients who completed telephone counseling with in-home buccal DNA testing, which equated to a cost savings of \$321.40 more than usual care (Schwartz et al., 2014).

Patient Satisfaction

Three studies evaluated outcomes related to participant satisfaction with the delivery modality of genetic counseling. Peshkin et al. (2016) evaluated both patient-rated convenience and satisfaction with TGC compared to traditional IPGC. As part of a parallel-group, randomized, noninferiority trial, 72.4% of participants in the TGC arm rated the genetic counseling and testing process as extremely convenient, compared to only 35% of participants in the IPGC arm ($\chi^2 = [df = 1, N = 552] = 77.7, p < 0.0001$) (Peshkin et al., 2016). The IPGC and TGC groups' satisfaction with the mode of genetic counseling did not differ; 83.1% of the participants in the TGC arm and 86.8% of the IPGC arm were very satisfied with their counseling ($\chi^2 = [df = 1, N = 552] = 1.48, p = 0.22$) (Peshkin et al., 2016).

Schwartz et al. (2014) evaluated participant satisfaction two weeks after completion of the genetic counseling intervention using the Genetic Counseling Satisfaction Scale, consisting of six questions. The items are scored on a five-point Likert-type scale summed to generate a final score with scores ranging from 6–30. Higher scores indicated higher satisfaction. The mean score for participants in the TGC arm was

26.8 compared to 27 in the IPGC arm. After adjusting for multiple comparisons using the Holm-Bonferroni correction, TGC was found to be noninferior to IPGC ($d = -0.16$, lower-bound one-sided 97.5% CI $[-0.7]$, noninferiority limit = -1) (Schwartz et al., 2014).

Zilliacus et al. (2011) surveyed all participants with the 18-item short form of the validated Medical Interview Satisfaction Scale, with scores ranging from 0–54 and with higher scores indicating greater satisfaction (Wolf, Putnam, James, & Stiles, 1978). In addition, participants in the telegenetics arm completed the validated Telemedicine Satisfaction Questionnaire, a 14-item tool in which the user rates a statement about his or her experience with telegenetics on a five-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree) (Yip, Chang, Chan, & MacKenzie, 2003). No difference existed between the IPGC and telegenetics arms for general counseling satisfaction (OR = -0.14 , 95% CI $[-1.06, 0.77]$, $p = 0.76$) (Zilliacus et al., 2011). The mean score for the Telegenetics Satisfaction Questionnaire was 32; however, this questionnaire was administered only to the telegenetics participants, which did not allow for comparison of the two counseling modalities used in the study (Zilliacus et al., 2011).

Discussion

As the randomized, controlled studies included in this review demonstrate, TGC is noninferior to IPGC in numerous participant outcomes. Both interventions resulted in similar *BRCA* knowledge acquisition, levels of cancer-specific distress, anxiety, depression, and satisfaction with mode of counseling delivery. In addition, participants were more likely to find TGC to be very convenient (Peshkin et al., 2016). Findings from the two studies that examined cost breakdown for genetic counseling and testing demonstrated cost savings of TGC compared to IPGC. Cost savings increased for rural people using TGC related to reduced travel costs for genetic counselors and participants (Chang et al., 2016; Schwartz et al., 2014).

Although the prospective cohort study by Zilliacus et al. (2011) comparing telegenetics to IPGC did not directly evaluate noninferiority of telegenetics, both arms of the study demonstrated similar results in knowledge gained, patient satisfaction, cancer-specific anxiety, anxiety, depression, and perceived empathy of the counselor, indicating that telegenetics is likely an acceptable alternative method of delivering counseling services.

IPGC outperformed TGC in genetic testing uptake. Several possible factors may have contributed to this disparity. Participants who received IPGC could

complete genetic testing immediately following their consultation, whereas participants receiving counseling delivered remotely could not complete testing immediately. The travel requirement for testing may have been an obstacle for some, preventing them from undergoing testing (Schwartz et al., 2014). This delay in testing may have also afforded TGC or tele-genetics participants more time to deliberate about their decision and, ultimately, opt against undergoing genetic testing (Schwartz et al., 2014).

Kinney et al. (2014) addressed the hypothesis that a delay in testing affects whether a person decides to undergo testing. In this study, participants receiving TGC were mailed buccal DNA testing kits to submit their samples via mail instead of traveling to a laboratory for blood testing. Despite testing kits being readily available, Kinney et al. (2014) found that uptake of *BRCA1/2* testing was higher in the IPGC arm of the study. Higher uptake of genetic testing in the IPGC arm may not represent better likelihood of *BRCA1/2* mutation detection. This discrepancy requires additional study. The researchers did not survey participants on their rationale for undergoing or forgoing genetic testing, which could have provided a better context for this disparity (Butrick et al., 2015).

Although participants receiving TGC had lower overall completion rates of genetic testing, when examining participant subgroups, Kinney et al. (2016) found that rural inhabitants had a higher uptake of genetic testing compared to participants residing in urban areas in the IPGC and TGC arms. This finding may suggest that the cancer genetic counseling and testing needs of rural-dwelling patients are unmet by the current healthcare system. High-risk people should be connected to these resources so that they can access services that may not have otherwise been available to them (Kinney et al., 2014). Expanding the availability of TGC may help fill this void.

Disparities in outcomes between non-Hispanic White participants and minority participants were observed within the reviewed studies, particularly in the setting of TGC. Minority participants reported lower levels of perceived emotional support from their genetic counselor. One hypothesis is that genetic counselors have more difficulty reading nonverbal language from minority participants because of differences in cultural communication patterns (Peshkin et al., 2016). Education on culturally sensitive communication may help genetic clinicians recognize signs of distress and provide better support to all people.

Another discrepancy was that minority women were significantly less likely to proceed with genetic

KNOWLEDGE TRANSLATION

- Remotely delivered genetic counseling was noninferior to traditional, in-person genetic counseling for knowledge attainment and psychological outcomes.
 - Patients who received in-person genetic counseling had higher rates of genetic testing completion compared to patients who received remotely delivered genetic counseling.
 - Patient satisfaction with the modality of genetic counseling received was equivalent between methods, but remotely delivered counseling was more convenient.
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testing when receiving TGC (Butrick et al., 2015). This may have been because of competing time demands, emotional concerns, or fear of discrimination (Peshkin et al., 2016). Given that minority participants were vastly underrepresented in each of these studies, additional studies that reflect a more diverse population are needed and should explore potential reasons for the outcome disparities.

Limitations

One of the limitations of the studies was lack of inclusion of several important subgroups of high-risk patients, such as newly diagnosed patients with breast cancer, patients with metastatic ovarian cancer, and men (Peshkin et al., 2016; Schwartz et al., 2014). As noted, most of the study participants were non-Hispanic Whites. In addition, newly diagnosed patients often need prompt genetic testing because it may affect their surgical decision. TGC may not be a feasible option for this group of patients if there is a delay in specimen collection. Additional studies should compare the outcomes of TGC and IPGC in a more diverse patient population, which may help to increase generalizability of these results.

Another potential limitation of the generalizability of this review is the relatively small number of recent randomized studies comparing modalities of genetic counseling delivery for HBOC. Among the studies that were included in the review, Zilliacus et al. (2011) had a small sample size of 195 women, which may also limit the broader application of the findings. In addition, Schwartz et al. (2014) approached a significant number of women to participate in a study, but many declined because of a stated preference for IPGC (Schwartz et al., 2014). For those who have a strong preference for IPGC, TGC would likely be less effective; therefore, the results of the study may be skewed to positively favor outcomes of remotely delivered counseling modalities. At this time, no randomized

trials compare IPGC, TGC, and telegenetics, which would be beneficial to help distinguish if one modality is superior to the others when evaluating BRCA knowledge acquisition, psychosocial outcomes, testing uptake, patient–counselor communication, cost, and patient satisfaction.

Recent advances in cancer genomics have resulted in the identification of numerous genes beyond *BRCA1/2* that may contribute to HBOC risk. In many clinical settings, the use of multigene panels to assess hereditary cancer susceptibility has become commonplace. To date, a randomized, controlled trial comparing IPGC to TGC in the setting of multigene panel testing for HBOC has not been conducted. It is important to explore the use of various modalities of genetic counseling in those receiving multigene panel testing, particularly because this is becoming the standard of care.

Implications for Nursing

Oncology nurses and advanced practice nurses strive to improve understanding, decision making, and treatment outcomes for patients with cancer through the integration of genetic information into the care they provide (Hassen, Eggert, & Loud, 2016). As outlined in *Essential Genetics and Genomics Competencies for Nurses With Graduate Degrees*, advanced practice nurses can provide genetic education, counseling, and testing within their scope of practice and clinical setting (Greco, Tinley, & Siebert, 2012). City of Hope, Fox Chase Cancer Center, and Cincinnati Children's Hospital Medical Center offer intensive training programs in cancer genetics designed for nurses to broaden their professional practice (Hassen et al., 2016). Since 2014, advanced practice nurses have been able to receive certification in advanced genetics nursing from the American Nurses Credentialing Center through preparation of a professional portfolio (Senter & Hatfield, 2016). Nationwide, there are about 50 advanced practice nurses credentialed in genetics (Senter & Hatfield, 2016). As the need for genetics services grows, more nurses will pursue this credential and play a critical role in filling this healthcare void.

Increasing the number of advanced practice nurses working in genetics, coupled with embracing the role that telehealth has in expanding patient access to care, can reduce geographic barriers for rural women seeking genetic counseling services (Henderson, Davis, Smith, & King, 2014). Advanced practice nurses who are not specialized in genetics but who are caring for high-risk cancer populations should be informed about the scope of genetics services that are available. These patients will likely need referral to genetic testing to make informed decisions about their medical care. Ad-

vanced practice nurses should be aware that telegenetics and TGC exist as alternatives to traditional IPGC, information that may help providers connect their rural patients with resources that best suit their needs.

Conclusion

The demand for genetic counseling is expected to grow in the coming years as innovation in cancer genomics reveals genes that may contribute to cancer predisposition. Without increased access to genetic counseling services, people residing in nonmetropolitan areas may not be able to receive comprehensive counseling (Schwartz et al., 2014). Innovative delivery models to increase access to genetic counselors and clinicians are paramount moving forward. Insurance reimbursement continues to be a barrier to more widespread implementation of telegenetics and TGC. However, if TGC produces comparable outcomes to IPGC at a reduced cost, there is a strong case for insurance companies to provide reimbursement for these services.

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