Benefit Finding in Response to BRCA1/2 Testing

Carissa A. Low, M.A. · Julienne E. Bower, Ph.D. · Lorna Kwan, M.P.H. · Joyce Seldon, M.S.

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Abstract

Background Undergoing genetic testing for BRCA1/2 mutations may be accompanied by elevated worry and distress, but the potential for the experience to catalyze positive psychological and life changes has not been studied.

Purpose This study was designed to examine the relationship between mutation carrier status, personal cancer history, and the potential positive impact of genetic testing (i.e., benefit finding). We also tested two predictors of benefit finding (BF) derived from the theoretical and empirical literature on positive outcomes of stress: impact of the experience and approach-oriented coping.

Methods Women undergoing genetic testing for BRCA1/2 mutations (n=108) completed questionnaires assessing test-related distress, approach-oriented coping, and BF after receipt of test results. BRCA1/2 status was determined from genetic test results and personal cancer history from interviews conducted with study participants before testing.

Results Reports of BF in this sample were highly variable, as some women did not perceive the testing experience as having any noticeable effect on their lives, whereas others reported positive changes similar to those observed in cancer patients (e.g., significantly improved relationships, greater appreciation for life). Contrary to hypotheses, women who tested positive for BRCA1/2 did not report higher levels of BF in response to genetic testing than those who tested negative. However, BF scores were elevated among mutation carriers who had a previous cancer diagnosis. As predicted, test-related distress and approach-oriented coping were also positively associated with BF, and approach-oriented coping mediated the relationship between carrier status × cancer history and BF.

Conclusions Findings suggest that positive life changes can occur among women who test positive for BRCA1/2 mutations, particularly cancer survivors.

Keywords BRCA · Genetic testing · Cancer · Benefit finding

Introduction

Although psychologists have historically focused on the potential for adverse consequences and distress after stressful experiences, there is growing recognition that reports of personal growth and other benefits are also prevalent among stressed populations. According to theoretical models of “benefit finding” (BF; [1]), the mortality threat and life disruption that accompany major life stressors (e.g., life-threatening illnesses, physical assaults, bereavement) can catalyze profound positive life changes [2–6]. These disruptive events may shatter an individual’s
sense of meaning, mastery, and self-esteem, prompting a reconstruction of prior assumptions about life and a sense of greater personal strength and resources [7, 8].

Reports of BF have been particularly prevalent in the psycho-oncology literature, as cancer patients and survivors commonly report that the experience has changed them in positive ways [9–13]. Most of this research has been done in the context of breast cancer, and up to 83% of breast cancer patients report that they perceive at least one benefit that has resulted from their cancer diagnosis [12]. These positive changes include strengthened relationships with family and friends, enhanced spirituality, renewed appreciation for daily life, improvements in one’s psychological resources, skills, or personal attributes, valued change in priorities and goals, and a sense of new possibilities and pathways in life [11, 12]. As a testament to this burgeoning literature, a recent review identified 35 published studies documenting the phenomenon of BF after cancer, 22 from the past 5 years [14].

Thus, there is considerable evidence to suggest that receiving a diagnosis of cancer can catalyze positive life changes. What about receiving information that one is at increased risk for developing cancer in the future? Women who are identified as carriers of a BRCA1 or BRCA2 mutation have a 55–85% lifetime risk of developing breast cancer, 23–63% lifetime risk of developing ovarian cancer, and up to a 95% chance of developing either cancer before age 70 [15, 16]. Although some women report no adverse effects of genetic testing [17, 18] women’s psychological responses to testing are highly variable, and the genetic testing experience has the potential to generate distress and worry among some participants. For example, anticipating genetic test results led to increased anxiety among some women [19], and receiving a mutation-positive test result has been linked to a short-term increase in test-related distress [20] as well as elevated risk of posttraumatic stress disorder [17]. Receiving information that one carries a genetic predisposition to breast and ovarian cancer shares important features with receiving a cancer diagnosis, as it conveys the prospect of a future cancer diagnosis and the associated mortality threat, life disruption, and other negative psychological sequelae [21, 22]. In addition, being identified as a mutation carrier involves more proximal challenges unique to the genetic testing context, such as having to communicate risk information to family members and make prophylactic treatment decisions. However, this disruption may also produce positive changes, such as heightened support from family members, enhanced awareness of the preciousness of life, or an increased sense of control related to options for prophylactic surgery or chemoprevention. In one retrospective qualitative study, both mutation-positive and mutation-negative women reported that the genetic testing experience had led to “a reassessment of priorities and a renewed appreciation for life” (p. 127, [22]). No quantitative research to date has documented whether genetic testing can elicit positive life changes, although there is evidence that other populations report benefits in response to risk notification (e.g., individuals testing positive for HIV [5]). Unlike most other groups in which BF has been examined, women undergoing genetic testing face no immediate mortality threat and generally experience minimal disruption of daily life or physical health. Thus, one goal of the present study was to examine whether BRCA1/2 testing is sufficiently disruptive to produce BF. We hypothesized that women identified as carriers would be more likely to find benefit in the experience, as receiving a mutation-positive result is likely to be more threatening than receiving a negative result.

We were also interested in examining the relationship between previous cancer history and reports of BF in response to genetic testing. Women who decide to pursue genetic testing because they have already been diagnosed with and treated for breast or ovarian cancer (“affected” women) may differ in significant ways from women who seek testing because of a strong family history of cancer. For example, women who have been previously affected by cancer may be more prepared to be told that they are at high risk for developing another cancer [20]; thus, genetic testing may have less psychological impact on this group [23]. Undergoing genetic testing may also feel insignificant relative to the reality of cancer diagnosis and treatment. On the other hand, some affected women report heightened anxiety and sensitivity to genetic testing, as it may lead to increased fear of recurrence [24, 25]. Theoretically, little is known about the effect of previous stress exposure on reports of BF in response to subsequent stressors. Perhaps, adapting successfully to a cancer diagnosis involves the development of personal resources that are remobilized in response to the experience of genetic testing, leading to enhanced benefit finding. Receiving a positive test result may also help affected women to make sense of their previous diagnoses and may provide an opportunity to generate genetic information for family members [25]. A second goal of the study was to examine the relationship between personal cancer history and the potential positive impact of genetic testing.

Finally, we were interested in examining key psychological processes implicated in BF. Theoretical models of BF posit that meaningful positive life changes are facilitated by (1) the subjective impact of a stressor and (2) intentional cognitive and emotional engagement with the stressor [8, 26]. According to Janoff-Bulman [26], events that carry greater impact may be more likely to challenge fundamental assumptions about oneself and the world, creating the opportunity for positive shifts in priorities, goals, and perspectives. These shifts are facilitated by
active engagement with one’s thoughts and feelings about the event, which aid in the reconstruction of meaning and identification of benefits in the experience. To some degree, these predictions have been borne out in the cancer literature, as both subjective impact and approach-oriented coping strategies and personality attributes have been linked to reports of greater BF [27–33]. Approach-oriented coping strategies such as cognitive processing have also been linked to finding meaning in the context of other stressors [3, 34]. Thus, we hypothesized that greater subjective impact (indicated by test-related distress) and greater intentional engagement with the experience (indicated by approach-oriented coping) would be associated with greater BF in the genetic testing context. We also examined whether different levels of BF reported by carriers or affected women might be mediated by differences in subjective impact or approach-oriented coping.

Method

Participants

Participants in this study were women who sought testing for BRCA1/2 mutations through the UCLA Familial Cancer Registry and Genetic Evaluation Program. These patients were part of a larger registry composed of individuals at high risk for cancer. To be eligible for registry testing, participants were required to meet the following criteria: (1) age 18 or older and (2) personal or family history of breast, ovarian, or other cancer consistent with BRCA1/2 heredity and/or 10% prior probability of carrying a BRCA1/2 mutation based on published risk assessment data. Referrals to the registry came from a variety of sources including physicians, other registry participants, and other sources (e.g., Internet, media). The registry began accepting participants in September of 1998 and recruits new participants on an ongoing basis; women eligible for inclusion in the current sample were tested between April 1999 and July 2003. For the purposes of this study, only women who completed a follow-up questionnaire mailed to the 160 women who had undergone testing during this interval are included in the analyses \( (n=108 \text{ women; 68\% response rate}) \). There were no significant differences between respondents and non-respondents with regard to ethnicity, age, mutation carrier status, personal cancer history, or posttest distress \((p's>0.05)\). The age of participants at the time of enrollment ranged from 25 to 88 years (mean=47.1). Most (88%) participants were white and well-educated (53% college graduates). More than half (57%) of the sample reported a history of breast or ovarian cancer \((n=57 \text{ and } 6, \text{ respectively})\), with a mean post-diagnosis interval of 8.1 years (range=0–33 years).

Procedures

After women were determined to be eligible for the general registry, they were invited to a pretesting visit with a genetic counselor to learn about the testing process and provide informed consent to participate in genetic testing. Women returned to the clinic a second time to have blood drawn for the genetic testing and to complete a baseline questionnaire packet. Women received the result of the genetic test at a third meeting with a genetic counselor. Before test disclosure, women were given the opportunity to decline receiving their test results; however, none of the women in this study declined test result receipt. Women received one of three test results: BRCA1/2 mutation-negative, BRCA1/2 mutation-positive, or variant of uncertain significance. Discussion at the time of result receipt included test implications and recommendations for future surveillance and preventive options. Women were mailed psychosocial questionnaires 1 and 6 months after test result receipt.

To assess coping strategies and perceptions of BF as a result of the genetic testing experience, women were mailed a separate packet of questionnaires in the Fall of 2003. This questionnaire was administered an average of 20.9 months after genetic testing result receipt \((\text{range}=9 \text{ days}–54.0 \text{ months})\).

Measures

Demographic

At baseline, women provided demographic and medical information, including current age, education level, and race/ethnicity, as well as personal cancer history.

Mutation Carrier Status

Genetic test results (i.e., BRCA1/2 mutation carrier or non-carrier) were obtained from the registry database.

Test-Related Distress

To assess subjective impact of the genetic testing experience, we administered the revised Impact of Events Scale \((\text{IES-R}; [35, 36])\). This 22-item instrument asks participants to rate how distressing intrusive thoughts, avoidance, and hyperarousal “with respect to your genetic testing and counseling” had been for them over the past week on a five-point response scale (ranging from “not at all” to “extremely”). Because responses in this sample were skewed toward lower scores, analyses were conducted with \(\log(\text{IES-R}+1)\). Participants completed the scale before test result receipt as well as at 1 and 6 months posttest. We focus here on 1-month posttest distress, as this assessment best captures subjective distress in the immediate aftermath.
of test result disclosure. Analyses were also conducted on 6-month IES-R scores, and results were similar.

Coping

To assess approach-oriented coping, we administered fourteen items from the Brief COPE [37] and the Emotional Approach Coping Scale [38]. A composite measure of approach coping was constructed using two items from each of the following scales: active coping (I take action to try to make the situation better; I concentrate my efforts on doing something about the situation), planning (I try to come up with a strategy about what to do; I think hard about what steps to take), acceptance (I learn to live with it; I accept the reality of the fact that it happened), instrumental social support seeking (I get help and advice from other people; I try to get advice or help from other people about what to do), emotional social support seeking (I get comfort and understanding from someone; I get emotional support from others), emotional expression (I let my feelings come out freely; I allow myself to express my emotions), and emotional processing (I take time to figure out what I’m really feeling; I realize my feelings about the situation are valid and important) [38]. All subscales included in the approach-oriented coping score were positively and significantly correlated with each other ($r$=0.50 to 0.78, $p<0.05$). Participants completed all items in reference to “what you’ve been doing to cope with the genetic testing and your test results” and rated items on a response scale of 1 (I don’t do this at all) to 4 (I do this a lot). The composite scale score represents the mean of all fourteen items ($\alpha=0.95$).

Benefit Finding

BF was assessed using the Post-Traumatic Growth Inventory (PTGI), a scale which measures positive life changes often reported following stressful experiences (e.g., enhanced relationships, greater life appreciation) that has been used extensively with cancer populations. Developed by Tedeschi and Calhoun [1], the PTGI is a 21-item measure yielding five-factor analytically derived subscales (i.e., personal strength, appreciation of life, interpersonal relationships, new possibilities in life, and spiritual change) and a total score. In completing the items, women reported the extent of change experienced as a result of the genetic testing on a scale from 0 (I did NOT experience this change as a result of my genetic testing/test results) to 5 (I experienced this change to a VERY GREAT degree as a result of my genetic testing/test results).

Analytic Plan

First, descriptive statistics regarding sample characteristics and prevalence of positive life changes are reported. Multiple regression analyses were then conducted to assess group differences in BF between carriers and non-carriers, between affected and non-affected women, and the interaction of the two groups. Multiple regression analyses were also used to test the relationship between theoretically derived psychological predictors (subjective impact and approach coping scores) and BF. Finally, hierarchical regression analyses were conducted to evaluate the predictive utilities of carrier status, cancer history, subjective impact, and approach coping on BF. Of note, sample sizes were reduced for certain analyses, as four women did not complete the COPE, indicating that it was not applicable, and five women missed items on the COPE, the PTGI, or the IES-R.

To determine what demographic and medical control variables would be included as covariates, bivariate correlations between BF and potential confounds (i.e., age, education, time since genetic test result receipt, and time since cancer diagnosis) were examined. BF was not associated with age, with the amount of time elapsed between genetic test result receipt and PTGI completion, or with time since personal cancer diagnosis (all $p$’s $>0.44$). Consistent with previous research [39], education level was significantly and negatively correlated with BF ($r=-0.42$, $p<0.001$). Thus, education was entered as a control variable in all analyses.

Results

BRCA1/2 Mutation Test Results

Of the 108 women tested, 26 were determined to be mutation carriers, 75 were identified as non-carriers, and 7 received a result of variant of uncertain significance. Variants of uncertain significance were grouped together with negative results because follow-up and medical management guidelines are the generally the same for these subgroups; in addition, levels of test-related distress among women who received unclassified variant results did not differ from those who received a negative result. There were also no significant differences in test-related distress between women who received unclassified variant and positive results ($p>0.67$). Of note, the non-carrier group included both true and uninformative negatives [40].

Demographic characteristics and cancer history of the two groups are reported in Table 1. Women who were identified as mutation carriers were significantly more likely to have a personal history of breast or ovarian cancer ($\chi^2[1, n=108]=3.84$, $p<0.05$) and less likely to have graduated from college ($\chi^2[1, n=108]=4.53$, $p<0.05$). Mutation carriers with no personal cancer history reported greater posttest distress than the other three groups (see Table 2).
Prevalence of Benefit Finding

The mean PTGI score was 26.26 (SD=27.93), substantially lower than the mean PTGI scores observed in previous samples of breast cancer patients (mean=64.1, [11]; mean=58.4, [12]). However, the scores ranged across the entire scale of the instrument, from 0 to 105, demonstrating that reports of BF were highly variable in this sample. Overall, 83.3% of women undergoing genetic testing endorsed that they had experienced at least one positive life change to at least a very small degree.

Correlates of BF

Two of the primary goals of this study were (1) to examine whether women identified as mutation carriers would report more BF and (2) to determine the relationship between previous cancer history and reports of BF. To address these questions, we conducted a hierarchical multiple regression on PTGI scores, entering education on the first step, carrier status and cancer history on the second step, and the interaction between carrier status and cancer history on the third step. The final model was significantly predictive of PTGI scores ($R^2=0.29$, $F(4,101)=10.12$, $p<0.01$). Analyses revealed no main effect of carrier status on total PTGI scores ($\beta=0.11$, $p>0.05$) or on any subscale of the PTGI (data not shown). However, there was a significant effect of cancer history on total PTGI scores ($\beta=0.28$, $p<0.05$), which was moderated by carrier status ($\beta=0.29$, $p<0.01$).

Post hoc comparisons revealed that PTGI scores were significantly higher among BRCA1/2 carriers with a history of breast or ovarian cancer than carriers without a personal cancer history or non-carriers, who did not differ from each other. This was true for total PTGI scores (see Fig. 1) and all five PTGI subscales (data not shown).

The next goal of the study was to examine whether subjective impact and engagement were related to reports of BF. To test the hypothesis that subjective impact would be associated with greater BF, we conducted a hierarchical multiple regression with education on the first step and IES-R scores on the second step. As hypothesized, BF was significantly positively associated with test-related distress at 1 month ($\Delta R^2=0.05$, $F(1,101)=5.63$, $\beta=0.21$, $p<0.05$). To test the hypothesis that approach coping would be associated with greater BF, we conducted a hierarchical regression with education on the first step and approach coping on the second step. Results revealed that approach coping was significantly positively related to PTGI scores ($\Delta R^2=0.20$, $F(1,98)=30.62$, $\beta=0.45$, $p<0.001$), consistent with hypotheses. Test-related distress and approach coping were not significantly correlated ($r(97)=0.17$, $p>0.05$). When distress and approach coping were entered into a regression equation simultaneously, controlling for education, approach-oriented coping remained a significant predictor of PTGI scores ($\beta=0.42$, $p<0.001$), whereas posttest distress did not ($\beta=0.13$, $p>0.05$).

Mediation Analyses

Results indicated that BRCA1/2 mutation carriers with a history of cancer reported the highest levels of test-related BF; indeed, PTGI scores in this group approached levels seen in previous samples in response to a cancer diagnosis. We conducted mediation analyses [41] to determine

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**Table 1** Characteristics of BRCA1/2 mutation carriers and non-carriers

<table>
<thead>
<tr>
<th></th>
<th>Carrier (n=26)</th>
<th>Non-carrier (n=82)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years (mean±SD)</td>
<td>44.7±9.4</td>
<td>47.9±13.2</td>
</tr>
<tr>
<td>% White</td>
<td>81</td>
<td>90</td>
</tr>
<tr>
<td>% With college degree*</td>
<td>35</td>
<td>59</td>
</tr>
<tr>
<td>% With history of breast or ovarian cancer*</td>
<td>73</td>
<td>51</td>
</tr>
</tbody>
</table>

*p<0.05

**Table 2** Group means for test-related distress and approach coping

<table>
<thead>
<tr>
<th></th>
<th>1 month IES-R</th>
<th>Approach coping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affected carriers</td>
<td>2.04 (0.39)</td>
<td>3.13 (0.15)</td>
</tr>
<tr>
<td>Affected non-carriers</td>
<td>1.60 (0.18)</td>
<td>2.31 (0.13)</td>
</tr>
<tr>
<td>Non-affected carriers</td>
<td>5.83 (2.47)</td>
<td>2.32 (0.18)</td>
</tr>
<tr>
<td>Non-affected non-carriers</td>
<td>1.37 (1.10)</td>
<td>2.37 (0.14)</td>
</tr>
</tbody>
</table>

Standard errors are displayed in parentheses. Although analyses on IES-R scores used log-transformed values, raw group means are presented for illustrative purposes. Column means with different subscripts differ significantly at $p<0.05$.

**Fig. 1** PTGI total scores were significantly higher among women who tested positive for the BRCA1/2 genetic mutation and had a personal family history of breast cancer, or “affected carriers” ($F(3,101)=5.03$, $p<0.01$, $\eta=0.13$)
whether the observed group differences might be due to greater use of approach-oriented coping in affected carriers. For mediation analyses, the carrier status × cancer history interaction was coded to isolate our group of interest (i.e., affected carriers=1; all other groups=0), and the group difference in PTGI scores remained significant using this classification (for total PTGI, $\beta=0.43$, $p<0.01$). The significant association between approach coping and benefit finding was established in previous regression analyses. We next tested whether approach-oriented coping was significantly higher among affected carriers. The carrier status × cancer history interaction was significantly associated with approach-oriented coping ($\Delta R^2=0.04$, $F(1,98)=4.63$, $\beta=0.40$, $p<0.05$), with affected carriers reporting the highest levels of approach coping in post hoc analyses (see Table 2 for group means). On average, affected carriers reported that they used approach-oriented coping strategies “A medium amount” to “A lot”, whereas women in the other three groups used approach-oriented coping “A little bit” to “A medium amount.”

The final step in establishing that approach coping mediates the effect of affected carrier status on PTG was to test whether the effect of carrier status × cancer history was reduced when approach-oriented coping was statistically controlled. A hierarchical regression analysis was conducted, entering education at the first step as a demographic control, approach coping at the second step, and carrier status, cancer history, and carrier status × cancer history at the third step.

Consistent with mediation of a significant amount of variance in BF, the previously significant effect of carrier status × cancer history was reduced to statistical non-significance when the variance accounted for by approach-oriented coping was entered in an earlier step ($\Delta R^2=0.02$, $F(1,95)=2.67$, $\beta=0.26$, $p>0.05$). The Sobel test further indicated that the indirect effect was significant ($z=1.96$, $p<0.05$). These analyses suggest that affected carriers report higher levels of BF in response to genetic testing because they engage in higher levels of intentional approach-oriented coping. This relationship is depicted graphically in Fig. 2.

Discussion

The purpose of the present study was to examine benefit finding among women undergoing genetic testing for the BRCA1/2 mutation. We predicted that women identified as mutation carriers would report more positive life changes given the greater threat associated with a positive test result. However, contrary to hypotheses, mutation carriers did not report significantly greater BF in response to the testing process than did non-carriers. Rather, the effect was moderated by personal cancer history such that only carriers with a previous diagnosis of breast or ovarian cancer (i.e., affected carriers) reported elevated levels of BF. In response to the genetic testing experience, affected carriers reported positive life changes that were comparable in magnitude to the changes described by previous samples in response to a cancer diagnosis [11, 12], with mean PTGI scores that were significantly higher than those of the other women undergoing testing.

It is important to note that the overall level of BF reported by the current sample was low, indicating that positive life changes in response to genetic testing are not as prevalent or as extreme as those reported by cancer patients and other populations facing a more immediate (rather than future anticipated) stressor. Sample responses to an open-ended question about positive life change after genetic testing include “Genetic testing is a blip on the screen for me” and “This was a straightforward medical test for informational purposes, not a life-changing experience.” Thus, many women do not experience genetic testing as stressful or as having discernible impact on their lives and, thus, may be unlikely to experience positive changes as a result of the experience. To our knowledge, this is the first study to examine the prevalence of BF in response to an anticipated and uncertain mortality threat, and the low overall prevalence of both distress and positive life change in the context of this mildly threatening stressor may inform theories of BF.

Why might BRCA1/2 mutation carriers with a previous cancer diagnosis find benefits in the genetic testing experience whereas other groups do not? Our results suggest that the type of coping strategies used by these women may be an important determinant of their positive response. Affected carriers reported using more approach-
oriented coping strategies to manage the stress of the genetic testing process, such as problem-solving and emotional expression, and use of these strategies mediated the association between cancer history × carrier status and benefit finding. The significant positive relationship between approach-oriented coping and BF is consistent with the literature on BF after cancer [12, 14, 31] as well as theoretical models of BF [8, 26]. These findings suggest that adapting to cancer may involve the development of active coping resources which can then be mobilized in response to future stressors, facilitating the discovery of meaning or benefit from the experience. At a more general level, our results identify previous stress exposure as a potentially important determinant of benefit finding in response to subsequent stressors; although previous stress exposure has been the subject of research in the area of resilience [42], it has not been carefully examined in the literature on BF.

Theories of BF also require that the stressor be sufficiently disruptive to core beliefs and daily life to prompt a search for meaning [8, 26], and research with cancer samples has revealed that degree of perceived life threat and subsequent distress is positively associated with reports of BF [12, 39]. In the current sample, test-related distress 1 month after test result disclosure was significantly and positively correlated with PTGI scores, but the effect of test-related distress became non-significant when controlling for approach-oriented coping. Furthermore, although non-affected carriers reported the highest levels of posttest distress, they also reported the lowest levels of BF. Thus, coping processes, specifically active engagement with the stress of genetic testing, appear to be more strongly predictive of benefit finding in the context of genetic testing.

Although demographic correlates of BF were not the focus of this report, results indicated that women who were less educated reported higher levels of BF. This relationship has also been observed in previous research with cancer patients and survivors, although results have been inconsistent [13, 39]. Theoretically, lower levels of education may be related to lower levels of socioeconomic resources, making the experience of genetic testing more threatening, and thus, more likely to lead to BF. Consistent with this idea, women with lower education did report greater test-related distress ($r(101) = -0.24, p < 0.05$), but controlling for distress did not reduce the significant effect of education on BF. The role of education and other resource variables merits more focused attention in future research.

Several important methodological limitations of the current study should be noted. First, approach coping and BF were assessed concurrently and retrospectively, up to 4.4 years after genetic test result receipt. This limits our ability to draw conclusions about the predictive association between coping and BF and also increases the likelihood that these reports were affected by similar cognitive biases as well as intervening life experiences that may have occurred after test result receipt. Second, there was substantial variability in the timing of the BF assessment, although the lack of association between time since result receipt and reports of BF suggest that this variability was not a major confound. Third, this was a demographically homogenous and self-selected sample; in particular, because all women sought genetic testing, it is likely that the current sample is more knowledgeable and approach-oriented than women who would not agree to enroll in a genetic testing registry. Finally, because analyses comparing affected carriers with other groups were based on a relatively small sample, these findings should be considered preliminary and require replication in a larger cohort of women. Future research should examine BF and positive coping processes longitudinally in a larger sample of individuals undergoing genetic testing procedures. Additional research in this area might also examine whether similar results are observed in, for example, individuals being screened for the Huntington’s disease gene, a genetic testing context which differs significantly from BRCA1/2 testing with respect to risk conferred by the mutation, uncertainty reduction available with genetic testing, and preventive options available [43].

A more general criticism of the BF literature is that self-reported BF is not a valid measure of positive change or growth, but is instead motivated by illusory and biased cognitions, such as downward social comparison, cognitive dissonance reduction, and derogation of one’s past self [44]. In addition, the measure of BF used in this study (PTGI) requires retrospective judgments about how one has changed as a result of a specific stressor, an approach which is subject to reporting bias and social desirability effects. For women who have a personal or familial history of cancer, it may be particularly difficult to disentangle positive psychological changes resulting from genetic testing from benefits germane to the cancer experience. These limitations could be addressed in future research by including measures of BF that are less susceptible to bias, including reports of positive changes observed by significant others, and evaluating behavioral manifestations of BF. For example, in the context of BRCA 1/2 testing, it would be interesting to evaluate whether reports of BF are associated with prophylactic surgery and chemoprevention, screening, and other health behaviors related to cancer prevention. Indeed, comments about life changes experienced by participants included, “I am more conscientious about keeping on top of…my health and getting appropriate and timely testing.”

The present study suggests that genetic testing may lead to positive psychological and interpersonal changes for
women with previous cancer diagnoses who are notified that they carry the BRCA1 or BRCA2 mutation, although the majority of women undergoing testing do not report finding benefit from the experience. Further, benefit finding appears to be facilitated by use of approach-oriented coping strategies. These findings suggest that perceptions of positive life change can occur in response to events that are not particularly traumatic; this may be particularly true when these events evoke coping strategies and possibly other resources developed in response to previous stressors. Although it has been recommended that clinicians not prescribe or expect BF from all patients, genetic counselors could listen for and reinforce reports of positive changes in attitudes, relationships, or other life domains. In particular, for women who do report heightened test-related distress, interventions that encourage approach-oriented coping strategies might increase recognition of the positive as well as negative psychosocial sequelae of genetic testing.

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