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Research Report

Stress, anxiety, and health-related quality of life in BRCA1/2-positive women with and without cancer: A comparison of four US female samples

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ABSTRACT

Introduction: Women with *BRCA1/2* mutations have a 11–72% increased risk of breast/ovarian cancers throughout their lifetime. The current study examines psychosocial differences between the current sample of *BRCA1/2*-positive women with and without cancer histories and three comparable United States (US) female samples without *BRCA1/2* mutations.

Methods: Sixty *BRCA1/2*-positive women (with and without cancer histories) were recruited through multiple private online support groups in the US. Participants completed an online survey outlining sociodemographic and genetic counseling information, and anxiety, stress, and health-related quality of life (HRQoL) outcomes. Outcomes were compared to three similar US female normative samples via independent samples *t*-test analyses.

Results: State and trait anxiety ($p = 0.00$) and stress ($p = 0.001$) were significantly worse in the current sample of *BRCA1/2*-positive women compared comparable US female samples. All HRQoL domains were significantly better in the current sample except energy/vitality, which was significantly lower ($p = 0.02$) in the current sample. Results were stratified by cancer and recurrence status.

Conclusions: This study provides insight into how a sample of *BRCA1/2*-positive women both with and without cancer fare post-genetic counseling as compared to three normative female populations. Results infer the need for additional education, patient-provider training, and mental health referrals to support this population in order to circumvent unintended consequences and to improve psychosocial health in those being tested for, and those who test positive for, *BRCA1/2* genetic mutations.

1. Introduction

One in 8 women will be diagnosed with breast cancer in their lifetime and only 5–10% of women diagnosed have a *BRCA1* and/or *BRCA2* (BReast CAncer) genetic mutation (American Cancer Society (ACS), 2019). These mutations naturally occur in biological family units, and women with these mutations are at an increased rate of breast and ovarian cancers (Suryavanshi et al., 2017). Women with *BRCA1/2* live with a 69–72% increased risk of breast cancer and 11–39% of ovarian cancer by the age of 70 (BeBRCAware.org, 2022). The rate of breast cancer recurrence, estimated to be between 25 and 30%, is also elevated among *BRCA1/2*-positive cancer survivors compared with cancer survivors without a *BRCA1/2* genetic mutation (Blanter et al., 2020). Depending on preventive treatment the risk for breast cancer recurrence varies, leading oncologists to recommend prophylactic mastectomy and salpingo-oophorectomy procedures once determined to be *BRCA1/2*-positive (Nilsson et al., 2014).

The risk of cancer and associate uncertainty for women living with these mutations may lead to adverse mental health effects and reduced health-related quality of life (HRQoL) (Graves et al., 2012). Stress and anxiety appear most often among those actively undergoing genetic testing or counseling (Moyer, 2014) and afterward due to prophylactic treatment since their stress has been found to be highest due to test results and surgeries for subsequent risk reduction (Wenzel et al., 2012). *BRCA1/2*-positive women who have received clear surveillance results (no abnormalities seen), for instance, concurrently have reported better HRQoL scores (Bradbury et al., 2007). As shown in previous literature by Metcalfe and colleagues (Metcalfe et al., 2015), HRQoL appears to be fluid over time, relative to when choices are made regarding these treatments and if any cancer diagnosis occur. Therefore, HRQoL may

Abbreviations: BRCA, BReast CAncer; NCI, National Cancer Institute; PCP, Primary care physician; US, United States.

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ebb and flow since the time of genetic testing/counseling and if preventive surgeries and surveillance are conducted (Harmsen et al., 2015).

Although genetic testing/counseling provides preventive opportunities for risk management, it has been shown to decrease HRQoL in response to increases in anxiety/stress as well as the life-changing nature of what a positive genetic test means for not only the individual but the family unit (Harmsen et al., 2015). Research has demonstrated the importance of understanding HRQoL among *BRCA1/2*-positive individuals regarding prophylactic (preventive) decision-making and ongoing surveillance despite increased in-person provider communication and knowledge (Connors et al., 2014; Dean, 2016) and adverse psychosocial reactions to these genetic testing/counseling and results, surgeries, and surveillance measures (Bradbury et al., 2007; Jones et al., 2020). Previous research, however, does not examine potential differences among subpopulations of *BRCA1/2*-positive samples, such as those with cancer recurrence(s) or those without cancer, due to relatively small sample sizes that have most notably qualitative decision-making and family interactions thus limiting implications assisting medical professionals working directly with these populations (Donnelly et al., 2013; Rowland et al., 2016).

The current study provides a unique comparison of potential psychosocial differences between the current sample of *BRCA1/2*-positive women with and without cancer histories and three comparable US female samples without *BRCA1/2* mutations. We hypothesized that *BRCA1/2*-positive women would report significantly higher stress and anxiety, and worse HRQoL than females in three similar samples. We also hypothesized that female cancer survivors in the current sample would report significantly higher stress and anxiety, but worse HRQoL, than females without a cancer history.

2. Materials & methods

2.1. Study design

The current study is part of a larger mixed-methods study completed in 2019 aimed at collecting preferential and patient reported outcomes of genetic testing/counseling among a sample of *BRCA1/2*-positive women in the United States (US). Data collection for the larger study was conducted in two steps: 1) participants completed a web-based survey, and 2) a subset of the overall sample were invited to complete a follow-up telephone or webcam interview, which has been published elsewhere (Dibble et al., 2022). This analysis focuses on the quantitative approach that analyzed how *BRCA1/2*-positive women's psychosocial outcomes may differ using two approaches: 1) subgroup analysis of *BRCA1/2*-positive women (those with cancer histories v. those without); and 2) comparison with three previously published standardized data sources from comparable female samples.

2.2. Study population

Participants were recruited through national, but private, online support groups: *BRCA1* or *BRCA2* Genetic Ovarian and Breast Cancer Gene group on Facebook, *BRCA* Genetic Sisters group on Facebook, and *BRCA* Strong group on Facebook in 2019. One study recruitment post was posted per week within each group with written permission obtained from the groups' moderators prior to posting an announcement introducing the study, eligibility criteria, and a link to an anonymous screener survey. Participants were eligible if they were 18 years or older, female, lived in the US, could read/speak in English, and had tested positive for either (or both) *BRCA1* and/or *BRCA2* pathogenic mutations within the past five years. All eligible participants were rerouted to the full online survey to complete via RedCAP (Harris et al., 2019). Participants who completed the online survey were compensated with a $20 Amazon e-gift card. The current study utilized an online convenience sampling method in which participants referred *BRCA1/2*-positive family members or social support group Facebook friends for study participation. Recruitment lasted two months before reaching saturation. This study was approved and conducted according to the ethical standards of the University of Connecticut Institutional Review Board (IRB# H18-173).

Data saturation. The primary aim of the original study was to capture the lived qualitative experiences of *BRCA1/2*-positive women who have undergone genetic testing or counseling (Dibble et al., 2022). Thus, adequate sample size was contingent on qualitative data saturation, previously suggested being between 20 and 40 participant interviews (Braun and Clarke, 2019; Braun and Clarke, 2006; Morgan and Nica, 2020; Vogel et al., 2018). Data saturation was reached at 28 interviews; however, all 34 participant interviews were included and analyzed (Dibble et al., 2022). At this point, the number who completed the quantitative survey portion was 60, so it was decided to stop recruitment at this point.

2.3. Online survey measures

The web-based survey collected data about participants sociodemographic, genetic testing/counseling, and clinical cancer information. Psychosocial variables were collected focusing on perceived stress, state and trait anxiety, health-related quality of life (HRQoL), and perceived overall health, which are outlined below.

Perceived stress. The Perceived Stress Scale-10 (PSS-10) (Cohen et al., 1983) was used to measure the current stress of participants at the time of survey completion. The PSS-10 was composed of 10 items on a 5-point Likert scale, ranging from 0 (never) to 4 (very often), with an example as follows: "In the last month, how often have you felt nervous and 'stressed'?". Scores for four items (4, 5, 7, and 8) were reversed, and all items added for a total score ranging from zero (lower stress) to 40 (higher stress) (Cohen et al., 1983). The PSS-10 has been previously used in breast cancer research and has an acceptable to good reliability (α = 0.78–0.91) (Cohen et al., 1983; Cohen and Janicki-Deverts, 2012). The internal consistency of the current sample was good ($\alpha = 0.89$).

State and trait anxiety. The State-Trait Anxiety Inventory (STAI) (Spielberger and Gorsuch, 1983) was used to measure the state and trait anxiety levels of participants at the time of survey completion. State anxiety can be defined as the current state of anxiety or how individuals feel "right now" versus trait anxiety, which can be described as stable aspects of calmness, confidence, and security, or "anxiety proneness" (Spielberger and Gorsuch, 1983). The STAI was comprised of 40 items on a 4-point Likert scale, ranging from 1 (almost never) to 4 (almost always) and from 1 (not at all) to 4 (very much), such as "I feel secure" or "I am presently worrying over possible misfortunes". State and trait subscales were each comprised of 20 items, from 1 to 4, with 4 indicating high levels of anxiety for the specific item (Spielberger and Gorsuch, 1983). Clinical cutoffs for state anxiety via the STAI have been included to reflect clinical significance (scores $\geq$ 39) (Knight et al., 1983). The STAI has previously been used widely in breast cancer patients and survivors (Maass et al., 2015), with good reliability (α = 0.90–0.94) within the general US population (Julian, 2011) and excellent in the current sample (state $\alpha = 0.95$, trait $\alpha = 0.91$).

Health-related quality of life (HRQoL). HRQoL was measured using the Medical Outcomes Scale Short Form-36 version 2 (SF-36). The SF-36 is a 36-item Likert scale used in both healthy groups and populations with chronic conditions, such as cancer or those with predispositions to cancer (Razdan et al., 2016). The SF-36 measures eight HRQoL domains, including physical functioning, bodily pain, role limitations due to physical health problems, role limitations due to personal/emotional problems, emotional wellbeing, social functioning, energy, and general health perception (Ware and Sherbourne, 1992). An example of an included item was, "During the past four weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? Cut down the amount of time you spent on work or other activities" (Ware and Sherbourne, 1992). Each domain ranged from zero to 100, with a higher domain

score indicating better functioning or HRQoL. Coding scheme varied per domain and used the coding and summation syntax for IBM Statistical Package for the Social Sciences (SPSS) Version 27 (IBM Corp, 2020). Two additional component domains (physical component score [PCS], mental component score [MCS]) were calculated by summing the following domain scores: PCS (bodily pain, physical functioning, role limitations due to physical health problems, energy) and MCS (emotional wellbeing, social functioning, role limitations due to personal/emotional problems) (Ware and Sherbourne, 1992). The SF-36 has good to excellent reliability among the general US population (α = 0.78–0.93), which was also the case within the current sample (α = 0.76–0.92).

2.4. Comparable female samples

Differences between psychosocial outcomes (i.e., perceived stress, state and trait anxiety, HRQoL) in the *BRCA1/2*-positive current sample and three comparable US female samples without *BRCA1/2* mutations were analyzed utilizing independent samples *t*-test and Pearson chi-square analyses. Perceived stress, calculated from the PSS-10, was compared using a subset sample of US females (N = 1,032), aged 18 years or older, collected in 2009 as a part of the eNation Survey recruited from the Synovate's Consumer Opinion Panel (SCOP)'s national panel of households. Each subsample was weighted to be representative of the general female US population based on region, sex, age, and household income data from the 2000 US Census (Cohen and Janicki-Deverts, 2012). The female demographic characteristics of the Cohen and Janicki-Deverts (Cohen and Janicki-Deverts, 2012) study was observed to be similar to those of the current study by age, race, ethnicity, education, and employment status.

Using the STAI, state and trait anxiety scores from the current sample were compared to that of standardized US female population scores from the original scale manual (Spielberger and Gorsuch, 1983). Although the STAI manual has different scores per population (military, psychiatric populations), the current study utilized the normative female population aged 19 to 70 years. The manual did not provide overall female state and trait anxiety scores, but scores were provided by age cohort. Therefore, the mean scores and standard deviations were averaged to create two cohesive female state and trait anxiety scores. Spielberger's (Spielberger and Gorsuch, 1983) norm female sample could not be compared to the current sample, as demographic characteristics from this manual were not published.

The current study makes comparisons to a study by Maglinte, Hays, and Kaplan (Maglinte et al., 2012), who administered the SF-36 to 3,844 adults in the 2005–2006 National Health Measurement Study (NHMS) telephone survey. Maglinte and colleagues (Maglinte et al., 2012) published data from a female subset sample (N = 2,203) from a larger sample of US normative men and women. Overall, female mean scores were not distinctly published but were stratified by 2000 US Census population on age (e.g., 18–34, 35–44, 45–64, 65–89). Therefore, to create an overall female mean score for each subscale, mean scores and associated standard deviations per subscale were averaged across age groups. Demographic characteristics were compared and were found to be similar to those of the current sample on race and ethnicity; their sample was slightly older in age and less educated. The Maglinte et al. sample (Maglinte et al., 2012) did not provide marital or employment status for comparison.

2.5. Data analysis

Sample means and corresponding standard deviations were calculated for continuous variables (i.e., participant age, years since genetic testing/counseling, outcome subscale scores), in addition to frequencies and percentages for categorical variables (i.e., age cohort, education, ethnicity, race, marital status, employment status, region, previous cancer diagnoses, recurrence, avenue for genetic testing/counseling, genetic testing/counseling result). Normality was assessed; if nonnormal variables were found, they were transformed to a normal distribution through standardization. Using basic frequency statistics, missing item-level outcomes were identified, ranging from 0.0% to 6.7%. Therefore, out of the 60 participants, none were missing over 20% of questions that made up a composite scale, so no cases were eliminated from analysis.

The comparison female samples' scale mean and standard deviation statistics from Cohen and Janicki-Deverts (Cohen and Janicki-Deverts, 2012), Spielberger (Spielberger and Gorsuch, 1983), and Maglinte, Hays, and Kaplan (Maglinte et al., 2012) were entered into IBM SPSS 27© (IBM Corp, 2020). The data were analyzed through group mean scores on the PSS, STAI subscales, and SF-36 subdomains, comparing current sample scores to the three previously published female sample scores using the same measures. Using independent sample *t*-test analyses and frequencies, group differences were identified on the PSS, STAI, and SF-36 domain scores. The current sample was then stratified by previous cancer diagnosis (i.e., no previous cancer diagnosis, previous cancer diagnosis) and by recurrence status (i.e., did not experience a recurrence, experienced a recurrence) to determine within group differences. Post hoc power analyses were also conducted to determine adequate statistical power and clinical meaningfulness of comparisons drawn between current study findings and those previously published (Cohen and Janicki-Deverts, 2012; Spielberger and Gorsuch, 1983; Maglinte et al., 2012) in addition to those with and without cancer histories within the current sample. Post hoc power was calculated using G*Power (Faul et al., 2007), with strong statistical power between the current and comparable female samples ranging from 0.96 to 0.97. Statistical power between participants with and without cancer histories was 0.41, indicating that these results should be interpreted with caution.

3. Results

3.1. Sample characteristics

Demographic characteristics for the current study sample and comparison samples (Cohen & Janicki-Deverts (Cohen and Janicki-Deverts, 2012), Spielberger (Spielberger and Gorsuch, 1983), and Maglinte et al. (Maglinte et al., 2012) can be found in Table 1. Among the 60 participants who completed the current study's online survey, the mean age was 43.3 years (*SD* = 10.9, range = 24–71 years), with the majority completing an undergraduate degree or above (*n* = 43, 71.1%). Most were married or living as married (*n* = 44, 73.3%), employed (*n* = 43, 71.1%), and primarily from the Northeast (*n* = 18, 30.0%) and Midwest (*n* = 18, 30.0%) regions of the US. The genetic mutation(s) for which participants tested positive were similar, as 48.3% (*n* = 29) had a *BRCA1* mutation, 50.0% (*n* = 30) had a *BRCA2* mutation, and one participant (1.7%) had both pathogenic variants. Only 18.3% (*n* = 11) of the current sample had experienced breast cancer, 6.7% (*n* = 4) had ovarian cancer, two reported another type of cancer (3.3%), and one had multiple cancers (1.7%), whereas 16 (26.7%) reported any type of cancer recurrence. In the current sample, there was limited variability in ethnicity, race, and genetic testing/counseling approach; therefore, these variables were not included in subsequent analyses. The majority of women in the current sample were considered by the STAI measure to have clinically significant anxiety (*n* = 43, 71.7%), whereas the minority (*n* = 16; 26.7%) did not. Demographic comparisons of the current sample to the three US female population samples are presented in Table 1.

3.2. Comparable US and current sample differences

The current study hypothesized that women who received a positive *BRCA1/2* genetic test result will report higher stress and anxiety and worse HRQoL than women in the comparable US female sample who have not tested positive for a *BRCA1/2* mutation. Overall, our first

Table 1
Demographic characteristics of the *BRCA1/2*-positive (N = 60), Cohen & Janicki-Deverts (N = 1,032 US females) and Maglinte, Hays, & Kaplan (N = 2,203 US females) samples.

	Current 2019 sample			Cohen & Janicki-Deverts sample		Maglinte, Hays, & Kaplan sample	
	M	***SD***	***t*-test**[a]	***M***	***SD***	***M***	***SD***
Age	43.3	10.9	0.027	44.6	15.5	54.3	13.5
Years since genetic counseling	1.83	2.15	0.095	–	–	–	–
	n	**%**	χ^2 [b]	***n***	**%**	***n***	**%**
Age							
<25	–	–	N/A	114	11.1	–	–
25–34	–	–		224	21.7	–	–
35–44	–	–		171	16.5	–	–
45–54	–	–		217	21.1	–	–
55–64	–	–		191	18.5	–	–
65 and older	–	–		115	11.1	–	–
Education							
Less than undergraduate	17	28.3	7.17**	647	62.7	1420	64.4
Undergraduate or above	43	71.1		385	37.3	769	34.9
Missing	0	0.0		0	0.0	14	0.7
Ethnicity							
Non-Hispanic	60	100.0	N/A	990	95.9	2123	96.3
Hispanic	0	0.0		42	4.0	67	3.0
Missing	0	0.0		0	0.0	13	0.7
Race							
White	57	95.0	0.129	880	85.3	1468	66.6
African American/ Black	3	5.0		51	5.1	622	28.2
Asian	0	0.0		0	0.0	19	0.8
Other	0	0.0		43	4.1	82	3.7
Missing				16	1.5	12	0.7
Marital status							
Not married	16	26.7	0.002	–	–	–	–
Married	44	73.3		–	–	–	–
Missing	0	0.0		–	–	–	–
Employment status							
Not working full-time	17	28.3	0.045	86	8.3	–	–
Working full-time	43	71.1		535	51.8	–	–
Other	–	–		404	39.1	–	–
Missing	–	–		7	0.8	–	–
Region							
Northeast	18	30.0	1.74	–	–	–	–
Southeast	9	15.0		–	–	–	–
Southwest	3	5.0		–	–	–	–
Midwest	18	30.0		–	–	–	–
West	12	20.0		–	–	–	–
Cancer history							
No cancer diagnoses	42	70.0	0.892	–	–	–	–
Breast cancer	11	18.3		–	–	–	–
Ovarian cancer	4	6.7		–	–	–	–
Another type of cancer	2	3.3		–	–	–	–
Multiple cancers	1	1.7		–	–	–	–
Recurrences							
No primary cancer diagnosis	42	70.0	0.326	–	–	–	–
None	2	3.3		–	–	–	–
1 or 2	16	26.7		–	–	–	–
State-Trait Anxiety Inventory (STAI) clinical significance							
Not clinically significant (≤38)	16	26.7	0.575	–	–	–	–
Clinically significant (≥39)	43	71.7		–	–	–	–
Missing	1	1.7		–	–	–	–
Avenue for genetic counseling							
Private genetic counseling office	19	31.7	0.430	–	–	–	–
Hospital	24	40.0		–	–	–	–
Primary care physician (PCP)	13	21.7		–	–	–	–
	2	3.3		–	–	–	–
Direct-to-consumer (DTC)							
Missing	2	3.3		–	–	–	–
Genetic counseling result							
BRCA1	29	48.3	0.89	–	–	–	–
BRCA2	30	50.0		–	–	–	–
Both BRCA1 & BRCA2	1	1.7		–	–	–	–

Note. $p < 0.05$*; $p < 0.01$**; The Spielberger (1983) article did not provide details on demographic information and therefore was not included in this table.
[a,b] indicates independent samples *t*-test or chi-square analysis among current sample only by cancer history (no, yes) – not enough information was provided in Cohen & Janicki-Deverts, Spielberger, and Maglinte, Hays, & Kaplan samples to calculate in comparable samples. Pearson chi-square analyses were unable to be conducted for the ethnicity and preferred approach of genetic counseling because they had no variability.

hypothesis was supported. Perceived stress was significantly higher in the current sample ($M = 18.9$, $SD = 6.77$, $p = 0.001$) compared with women in the comparison sample (Cohen and Janicki-Deverts, 2012) ($M = 16.1$, $SD = 7.56$). Women with *BRCA1/2* genetic mutations scored significantly worse on state ($M = 46.0$, $SD = 13.1$, $p = 0.00$) and trait anxiety ($M = 44.2$, $SD = 11.9$, $p = 0.00$) than women in the comparable US female sample (state: $M = 34.8$, $SD = 10.2$; trait: $M = 34.3$, $SD = 8.87$) (see Table 2).

The second hypothesis was not supported; rather, the findings were

Table 2
Comparison of current sample of *BRCA1/2*-positive women (N = 60) and comparable female sample mean scores on psychosocial and HRQoL outcomes.

	***BRCA1/2*-Positive Women**		**Comparable US Female Sample**		***t*-test**	***P***
	M	***SD***	***M***	***SD***		
Stress[a]	18.9	6.77	16.1	7.56	3.29	0.001**
State anxiety[b]	46.0	13.1	34.8	10.23	6.58	<0.00**
Trait anxiety[b]	44.2	11.9	34.3	8.87	6.41	<0.00**
Physical functioning (PF)[c]	82.9	21.7	48.3	15.7	12.3	<0.00**
Role limitations due to physical health problems (PRL)[c]	65.4	42.4	48.0	14.6	3.17	0.03*
Role limitations due to personal/emotional problems (ERL)[c]	67.2	40.4	50.8	12.3	3.14	0.03*
Energy/vitality (EN)[c]	45.6	22.3	52.5	15.0	2.36	0.02*
Emotional wellbeing (EW)[c]	62.6	18.3	53.6	13.4	3.83	<0.00**
Social functioning (SF)[c]	70.5	27.1	50.6	14.6	5.69	<0.00**
Bodily pain (BP)[c]	67.1	26.1	49.4	15.8	5.23	<0.00**
General health (GH)[c]	68.8	20.4	49.5	16.3	7.36	<0.00**
Physical component score (PCS)[c]	72.7	24.1	47.4	15.5	7.68	<0.00**
Mental component score (MCS)[c]	61.3	22.4	53.6	12.8	2.75	0.007**

Note. $p < 0.05$*, $p < 0.01$**;
[a] indicates independent samples *t*-test analysis between the current sample and Cohen & Janicki-Deverts' US female population sample;
[b] indicates independent samples *t*-test analyses between the current sample and Spielberger;
[c] indicates independent samples *t*-test analyses between the current sample and Maglinte, Hays, & Kaplan US female population sample. Physical component score (PCS) calculated adding PF, PRL, BP, & GH; Mental component score (MCS) calculated adding ERL, EN, EW, & SF.

the opposite of what was expected. The current sample reported significantly higher HRQoL scores in the majority of domains compared with women in the comparison sample (Maglinte et al., 2012). Specifically, women in the current sample scored significantly better than the comparable US female sample (Maglinte et al., 2012) on the following subscales: physical functioning, role limitations due to physical health, role limitations due to personal/emotional problems, emotional well-being, social functioning, bodily pain, general health perception, PCS, and MCS (all p-values < 0.05). The US general female population scored significantly better on the energy/vitality subscale ($M = 52.5$, $SD = 15.0$, $p = 0.02$) than the current sample ($M = 45.6$, $SD = 22.3$). Detailed information is presented in Table 2.

3.3. Exploratory differences by cancer diagnosis and/or recurrence

In the current sample, a total of 18 participants (30.0%) reported having been diagnosed previously with breast, ovarian, or another type of cancer. As hypothesized, those who had reported a cancer history scored significantly worse on physical functioning ($M = 72.9$, $SD = 22.0$, $p = 0.02$), bodily pain ($M = 56.3$, $SD = 23.9$, $p = 0.03$), and PCS scores ($M = 60.6$, $SD = 24.9$, $p = 0.02$) compared with women in the current study sample with no previous cancer history (physical functioning: $M = 87.3$, $SD = 20.4$; bodily pain: $M = 59.6$, $SD = 19.2$; PCS: $M = 75.8$, $SD = 22.5$). However, women with previous cancer diagnoses reported significantly better emotional wellbeing (or mental health) ($M = 69.7$, $SD = 14.0$, $p = 0.02$) than women with no cancer history ($M = 59.6$, $SD = 19.2$), which does not support what we hypothesized. More information is depicted in Table 3. Among those who had a previous cancer diagnosis, the majority ($n = 16$, 88.9%) had experienced a recurrence. Additionally, we found those women who experienced a cancer recurrence reported significantly better emotional wellbeing ($M = 71.0$, $SD = 13.2$, $p = 0.03$) compared with women who had not experienced a recurrence (n = 2; $M = 60.0$, $SD = 22.6$). There were no other differences among perceived stress, state/trait anxiety, or any other HRQoL domains between these groups. See Table 3 for more detailed information.

4. Discussion

The current study is one of the few (Ringwald et al., 2016) to examine psychosocial outcomes from three standardized US female population samples with women living with *BRCA1/2* mutations. It is evident that stress and anxiety may continue after receiving a positive *BRCA1/2* genetic test result, as these women have shown higher levels than comparable US female samples (Spielberger and Gorsuch, 1983; Maglinte et al., 2012). Past literature has found that anxiety and stress may peak immediately after genetic testing/counseling but decrease over time (Bosch et al., 2012). Specifically, these fears are cancer-related and are often mixed, resulting from uncertainty and inundation of information relating to what being *BRCA1/2*-positive means (Bramanti et al., 2021). Therefore, we cannot make comparisons of anxiety/stress rates because most literature has depicted these rates at *BRCA1/2* disclosure, which differs from the current study.

Our findings suggest that the stress and anxiety that may be heightened during the genetic testing/counseling processes (Ringwald et al., 2016) may be an ongoing experience but may be dependent on factors like family interaction and personal history of cancer (Wenzel et al., 2012). Previous literature has also found that women who are actively deciding on prophylactic surgeries and ongoing surveillance remain stressed (Ringwald et al., 2016), which may partially explain the results of the current study. Therefore, it would be increasingly important to prospectively follow women prior to genetic testing/counseling as they progress through these processes and prophylactic decision-making, identifying major points of stress and anxiety. This would allow researchers to map stress and anxiety trajectories to inform future provider care and interventions to assist in allocating resources (e.g., provider training, mental health counseling, employment leave, etc.) where it is most needed for all involved parties (e.g., providers, patients, families, etc.). Future research should focus on implementing larger, population-based studies focused on collecting information regarding prophylactic decision-making, *BRCA1/2*-related cancer diagnoses, and associated recurrence(s) to further understand how prevalent feelings of stress and anxiety are within this population. More specialized training for medical providers (e.g., nurses, physicians, mental health professionals) working with *BRCA1/2*-positive women should occur on a regular basis to further inform pre- and post-genetic testing/counseling care. To mitigate the impact of anxiety and stress related to associated *BRCA1/2*-oriented care, additional medical support and referrals to mental health services, such as utilizing online support groups (Facing Our Risk of Cancer Empowered (FORCE), 2022; Sharsheret.org, 2022) should be provided to women who need them, as similar literature has identified that the majority of women testing positive for these mutations are not referred by providers (Dibble et al., 2022), but rather, may

Table 3
Comparison of current sample mean scores, stratified by previous cancer diagnoses and recurrence, on psychosocial outcomes.

	Cancer History $n = 18$			**No Cancer History** $n = 42$	t (p)[b]	t (p)[c]
	Recurrence $n = 16$	**No Recurrence**[a] $n = 2$	**Total**	**Total**		
	M (*SD*)	*M* (*SD*)	*M* (*SD*)	*M* (*SD*)		
Perceived stress	17.7 (5.93)	23.0 (0.00)	18.3 (5.83)	19.2 (7.19)	**3.53 (0.00)**	0.48 (0.62)
State anxiety	43.5 (12.2)	44.0 (5.65)	43.5 (11.5)	47.1 (13.8)	0.09 (0.92)	1.01 (0.31)
Trait anxiety	40.9 (9.96)	40.5 (12.0)	40.8 (9.80)	45.6 (12.6)	0.49 (0.96)	1.56 (0.12)
Physical functioning	74.0 (23.0)	65.0 (14.1)	72.9 (22.0)	87.3 (20.4)	0.77 (0.52)	**2.29 (0.02)**
Role limitations due to physical health problems	57.8 (39.4)	–	51.3 (41.5)	71.4 (41.6)	2.01 (0.06)	1.70 (0.09)
Role limitations due to personal/emotional problems	70.8 (40.1)	16.6 (23.5)	64.8 (41.9)	68.2 (40.2)	2.78 (0.11)	0.29 (0.77)
Energy	53.4 (17.4)	25.0 (35.3)	50.2 (20.6)	43.6 (23.0)	1.12 (0.45)	1.09 (0.28)
Emotional wellbeing	71.0 (13.2)	60.0 (22.6)	69.7 (14.0)	59.6 (19.2)	0.67 (0.61)	**2.28 (0.02)**
Social functioning	69.1 (30.9)	62.5 (0.00)	68.3 (29.0)	71.4 (26.6)	0.29 (0.77)	0.37 (0.71)
Bodily pain	57.8 (24.6)	45.0 (17.6)	56.3 (23.9)	71.7 (25.9)	0.91 (0.47)	**2.21 (0.03)**
General health	59.1 (23.1)	40.0 (7.07)	56.6 (29.2)	70.4 (19.3)	0.57 (0.10)	0.79 (0.50)
Physical component score	63.5 (24.9)	37.5 (6.18)	60.6 (24.9)	75.8 (22.5)	**3.42 (0.01)**	**2.22 (0.02)**
Mental component score	66.1 (20.5)	41.0 (2.71)	63.3 (20.9)	60.7 (23.0)	**4.57 (0.00)**	0.42 (0.67)

Physical component score (PCS) calculated adding PF, PRL, BP, & GH; Mental component score (MCS) calculated adding ERL, EN, EW, & SF.
Bold font indicates $p < 0.05$.
[a] Results regarding "no recurrence" subgroup cannot be interpreted with confidence due to extremely small subsample size in HRQoL outcomes.
[b] Recurrence comparison within survivor status, p-values from independent samples t-tests (t).
[c] Survivor/no cancer comparison, regardless of recurrence status, p-values from independent samples t-tests (t).

have found them on their own.

Consequently, the current sample scored better on the majority of HRQoL domains except for energy/vitality. These results are inconsistent with past literature however several studies have noted that HRQoL may be variable depending on factors such as cancer history (Harmsen et al., 2015). This remains notable, as undergoing treatments for cancer risk reduction are considered major and are very time-, energy-, and cost-intensive, but within this population, may be considered necessary for survival. Concurrently, mental health referrals for women who are identified as struggling may also be imperative to maintain psychosocial health (Hoskins and Gotlieb, 2017). It is also possible that physical HRQoL domains are better among the current sample because the majority of women had already completed some form of prophylactic surgery and returned to an HRQoL equilibrium. Similarly, it is possible that this sample may be appreciative and/or grateful for knowing genetic testing/counseling information, as it gives them information to make informed decisions (Dibble et al., 2022) and where benefit finding in response to cancer risk or diagnosis has suggested (Mols et al., 2009). These results can further inform clinical practice and providers as to how HRQoL may impact (if at all and at what time) the genetic testing/counseling, ongoing surveillance, and prophylactic treatment experiences following a *BRCA1/2*-positive result.

As expected, women in the current study with cancer histories reported worse physical functioning, bodily pain, and overall physical HRQoL than women without a cancer history, mirroring past literature (Winters-Stone et al., 2019). These women also reported better emotional wellbeing, inconclusive of whether from the support of friends and family, medical professionals such as physicians and/or nurses, and mental health services. Related literature has suggested that resiliency and emotional control can actually attenuate adverse mental health outcomes in response to cancer risk and diagnoses (Macía et al., 2020.). Consequently, women in the current study who experienced a cancer recurrence scored better on emotional wellbeing than women who did not experience a recurrence. Therefore, building resiliency to respond to challenges remains important among this population, as previous literature has outined the promotion of optimism, gratitude, confidence, and hardiness are positively correlated with resilience (Zhang et al., 2018). Future research should focus on ways in which to promote and maintain resiliency throughout the cancer continuum (screening to survivorship), especially among those struggling, to understand the possible trajectories of HRQoL, stress, and anxiety from diagnosis (and recurrence) to survivorship.

4.1. Limitations

The current study has several limitations. It was cross-sectional which does not allow causal relationships to be determined. Recall bias also may have been an issue, as participants were asked to recall information up to five years prior regarding their genetic testing/counseling experience. Self-report survey information was analyzed as primary variables of interest which could introduce response bias in participants. It is not extremely common to be tested for *BRCA1/2* mutations, so a widened five-year limit was set to ensure that participant saturation was met. Future research should control for time since genetic test results statistically to account for how time may vary HRQoL due to differing cancer or cancer prevention events. Furthermore, the PSS-10 is not a clinical measure of symptoms relating to stress disorders and should not be interpreted as such. The current study did not collect information regarding time of cancer diagnosis or risk-reducing surgery/chemoprevention because the cancer experience was not the primary aim of the research. These results, especially those regarding HRQoL, should be interpreted considering this limitation. Generalization is limited to educated, mostly insured, non-Hispanic white women who had tested positive for *BRCA1/2* mutations within the US. Non-Hispanic white women from middle-to-high income with higher educational attainment are more likely to undergo testing/counseling for *BRCA1/2* because these groups have access to quality healthcare and cost-related resources that other groups do not have. These participants were recruited from online support groups, which may introduce bias by being more open and willing to share experiences than others not in support groups. Statistical power was lacking regarding comparisons between current study subgroups (i.e., those with v. without cancer histories) and should be interpreted with caution. Additionally, the three comparison samples utilizing the PSS, STAI, and SF-36 may not be entirely similar, as sample sizes differed and several demographic characteristics (e.g., categorical age, marital status, employment status, geolocation) (Cohen and Janicki-Deverts, 2012; Spielberger and Gorsuch, 1983) were not published for use. There existed large gaps in time between primary source (current study) and secondary source data (1983, 2005–2006, 2009), and it is possible that these data were affected by cultural shifts in understanding, awareness, and acceptance of mental health issues such as anxiety and the importance of HRQoL among cancer survivors.

4.2. Implications

Among a sample of *BRCA1/2*-positive US-based women, stress and anxiety were significantly worse, but HRQoL was significantly better, than comparable US female samples. Compared to past literature, our findings appear to be similar to the trends found of high anxiety/stress post-genetic testing/counseling (Bosch et al., 2012; Bramanti et al., 2021), but changes in these rates cannot be determined due to our study's cross-sectional nature. It is apparent that this population, dependent on where they are in their care (e.g., testing/counseling, surveillance, prophylactic surgery), requires informative and supportive resources to improve mental health and quality of life longitudinally. Nurses, therefore, remain on the forefront of *BRCA1/2*-oriented patient care, whether in genetic testing/counseling, ongoing surveillance for early detection, and/or risk-reducing prophylactic surgeries.

Findings from the current study have suggested that elevated stress and anxiety may first begin during the genetic testing/counseling process (Ringwald et al., 2016), but are an ongoing concern throughout follow-up care (Wenzel et al., 2012). A qualitative study conducted by Dibble and colleagues (Dibble et al., 2022) have collected recommendations for providers and nurses working with *BRCA1/2*-positive populations, noting the importance of sympathy, ongoing education, and mental health referrals to ease the burden of stress and anxiety among this population. There are online educational resources such as Bright Pink (Bright Pink.org, 2022), FORCE.org (Facing Our Risk of Cancer Empowered (FORCE), 2022), and Sharsheret (Sharsheret.org, 2022) to assist in spousal support, advocacy, phone/online support, recent peer-reviewed literature, and educational resources pertaining to genetic testing/counseling, ongoing surveillance, risk, prophylactic surgeries, and cancer. Nurses are the frontline resource for assisting *BRCA1/2*-positive populations navigate, both physically and emotionally, their predetermined risk for breast and ovarian cancers and can inform patients about these resources if needed. Nurses can also improve *BRCA1/2*-related knowledge and whether patients are at risk for such mutations by using a mobile health technology application, the Ontario Family History Assessment Tool, one of the tools recommended by the US Preventive Services Task Force (Moyer, 2014) in its *BRCA*-related cancer risk assessment. This tool and tools such as this are two-fold in benefit; they can be helpful for nurses in primary care settings when assessing women for *BRCA*-oriented genetic risk as well as provide education for nurses who are often patients' first contact, thereby improving quality patient care.

5. Conclusions

This study provides a fresh approach to understanding the impact of *BRCA1/2* mutations on women with and without cancer as compared to several US female populations without *BRCA1/2* mutations. Providing

this perspective allowed us to make statements relating to differences between the current sample and previous female samples for stress, anxiety, and HRQoL levels, even years after testing disclosure. Future research can target the development of anxiety and stress-related triggers during and after *BRCA1/2* testing using prospective longitudinal study designs, while interventions can focus on continual advanced training for medical professionals working with this population. Clinically, medical professionals such as physicians and nurses should offer referrals to mental health resources for all *BRCA1/2*-positive patients, not only those who are visibly struggling. With genetic testing/counseling becoming more available, it is possible that women may need immediate and ongoing post-genetic testing/counseling resources to reduce inequities among those testing positive for these mutations as well as subpopulations with breast or ovarian cancer histories.

CRediT authorship contribution statement

Kate E Dibble: Conceptualization, Methodology, Formal analysis, Investigation, Resources, Writing – original draft, Writing – review & editing, Visualization, Project administration, Funding acquisition. **Laura K.M. Donorfio:** Conceptualization, Writing – original draft, Writing – review & editing, Visualization. **Preston A Britner:** Methodology, Formal analysis, Resources, Writing – original draft. **Keith M Bellizzi:** Conceptualization, Methodology, Resources, Writing – original draft, Writing – review & editing, Formal analysis, Supervision, Funding acquisition.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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