



DOI: 10.32768/abc.20229140-49



## Quality of Life Concerns of Young Breast Cancer Survivors in the U.S. Gulf States by Race at Treatment and One-year Post-treatment

 Donna Williams\*<sup>a</sup>, Yu-Wen Chiu<sup>a</sup>, Nikka Khorsandi<sup>a,b</sup>, Lisa Moses<sup>a</sup>, Barbara Craft<sup>c</sup>
<sup>a</sup>School of Public Health, Louisiana State University Health Sciences Center, New Orleans, Louisiana, USA

<sup>b</sup>School of Medicine, Louisiana State University Health Sciences Center, New Orleans, Louisiana, USA

<sup>c</sup>University Hospital, University of Mississippi Medical Center, Jackson, Mississippi, USA

## ARTICLE INFO

**Received:**  
24 July 2021  
**Revised:**  
24 August 2021  
**Accepted:**  
06 October 2021

**Keywords:**  
Breast neoplasms,  
survivorship,  
quality of life, cancer  
survivors,  
health status disparities

## ABSTRACT

**Background:** Young breast cancer survivors (YBCS) face greater needs than their older counterparts. These needs require characterization for success of breast cancer assistance programs because needs vary by survivor race and where they are in their survivorship journey. This study evaluated quality of life (QOL) for YBCS in three states with poorer survivorship outcomes and identified differences in QOL for white and African American (AA) YBCS.

**Methods:** A survey identifying QOL needs was sent to YBCS in Louisiana, Mississippi, and Alabama. It assessed domains including relationships, women's health, employment, fertility, and menopause. The survey was resent to participants after one-year completion of the first survey to identify QOL changes.

**Results:** Overall, 371 baseline surveys and 127 follow-up surveys were collected. At baseline, AA YBCS faced more problems in five QOL domains and were less likely to have spoken with healthcare providers about genetic testing for breast cancer than white YBCS. After one year, all YBCS showed improvement in five different QOL domains, but indicated an increase in memory problems.

**Conclusion:** Survey results reflect existing literature that AA YBCS face greater QOL issues as well as disparities in the provision of genetic counseling. Additionally, all YBCS require more counseling from providers related to various physical and psychological symptoms. This survey identified QOL deficiencies faced by YBCS and differences based on survivor race. Defining and understanding these features allows for the development of culturally appropriate programming for survivors, while adapting to YBCS' QOL changes as they move further from treatment.

Copyright © 2022. This is an open-access article distributed under the terms of the [Creative Commons Attribution-Non-Commercial 4.0 International License](https://creativecommons.org/licenses/by-nc/4.0/), which permits copy and redistribution of the material in any medium or format or adapt, remix, transform, and build upon the material for any purpose, except for commercial purposes.

## INTRODUCTION

U.S. mortality rates of breast cancer have been decreasing and have therefore galvanized investigation into breast cancer survivor quality of life (QOL).<sup>1, 2</sup> With lower incidence rates of breast cancer in women younger than 45 years old, much less is understood

regarding their QOL—even though young breast cancer survivors (YBCSs) tend to have more aggressive disease as compared to older breast cancer survivors, and face greater concerns about fertility, body image, sexuality, genetic testing, and psychosocial support.<sup>3-5</sup>

As QOL grows as a primary outcome, understanding its dynamic changes in the years after diagnosis is crucial to the creation of supportive interventions for YBCS.<sup>1</sup> QOL can be defined through a number of domains, including physical symptoms, psychological health, and social support. Breast cancer survivors face

## \*Address for correspondence:

Dr. Donna Williams  
School of Public Health, 2020 Gravier St., 3<sup>rd</sup> Floor, New Orleans, Louisiana 70112 USA  
Tel: +1-504-568-5680  
Email: [dwilli3@lsuhsc.edu](mailto:dwilli3@lsuhsc.edu)



a range of physical side effects including hot flashes, premature menopause, infertility, fatigue, weight gain, and sleep disturbances.<sup>6</sup> Psychological and social stressors of breast cancer survivors include concern for disease recurrence, a changing body image, a decrease in social support network size, and sexual difficulties in relationships.<sup>7-10</sup> While QOL is lower in YBCS compared to older breast cancer survivors, the differing needs requirements for the younger cohort include greater concerns about self-esteem, future work opportunities, financial difficulties, concern for cancer recurrence, depressive symptoms, and fertility issues.<sup>11,12</sup>

Differences in QOL are not only found in various age cohorts of breast cancer survivorship, but also in different races. African American (AA) breast cancer survivors have a higher level of emotional adaptation to their cancer diagnosis and fewer symptoms of sexual dysfunction, but more concerns with a changing body image and lower emotional well-being when compared to white breast cancer survivors.<sup>13,14</sup> Unfortunately, AA YBCSs continue to be overlooked for the development of resources and social support and require further understanding of QOL needs to provide appropriate assistance.<sup>15</sup>

QOL has also been shown to improve as the time from diagnosis increases for the breast cancer survivor, especially in physical function, pain, and body image.<sup>7,16</sup> However, follow-up with breast cancer survivors at three- and five-years cancer-free has identified decreases in survivors' social support and interpersonal relationships.<sup>7,17</sup> While YBCS face a poorer QOL as compared to older breast cancer survivors when they first complete treatment, they recover the deficit in overall QOL as the length of their survivorship increases.<sup>7,18</sup>

Alabama, Louisiana, and Mississippi, hereafter known as the U.S. Gulf States, represent an area of the country in dire need of cancer services, particularly for women under 45 and AA women. While all the three states were below the national average for incidence of breast cancer in the period 2012-2016, Louisiana and Mississippi ranked among the top 3 states in the U.S. for deaths from breast cancer. The U.S. Gulf States also ranked among the top ten states for deaths from breast cancer for women under 50 and deaths from breast cancer in AA women.<sup>19</sup> These poor outcomes depict the dire need for culturally tailored survivorship support in these states.

To better inform current and future programming geared towards the U.S. Gulf States YBCS, a survey was designed for women diagnosed with breast cancer less than 46 years old in Louisiana, Mississippi, and Alabama. The survey was sent to YBCS once after their diagnosis and again one calendar year later. It evaluated measures of QOL domains including relationships, women's health, employment, fertility,

menopause, and other concerns. The goal of this investigation was to better understand the unique needs of white and AA YBCSs in the U.S. Gulf States and how they varied at one-year post-diagnosis.

## METHODS

This study surveyed young breast cancer survivors in Louisiana, Mississippi, and Alabama with a paper and online survey both at cancer diagnosis and one year after completion of the first survey. The survey assessed multiple components of QOL and was used to quantify differences between racial groups and cancer survivors at diagnosis and one year later.

### *Inclusion and exclusion criteria:*

Eligible participants were women diagnosed in one of the U.S. Gulf States with breast cancer between the ages of 18 and 45, spoke English, and were able to complete the survey. The Surveillance Epidemiology and End Results Program Database Management System was queried monthly for newly diagnosed, eligible women at the time of breast cancer diagnosis by browsing data from the previous 6 months.

All eligible women with contact information and their managing physician's contact information proceeded to the next enrollment step; the physician was contacted to request consent to contact their patient(s). A letter describing the study was sent to the physician asking for medical reasons explaining why the patient should not be contacted. Patient contact was permitted if the physician did not indicate that the patient should not be contacted, no response was garnered from the physician within two weeks, or if physicians also provided consent by returning a completed form. Physicians denying consent submitted the completed form, providing their reason, within two weeks.

### *Ethical consideration*

The survey and methodology for this study were approved by the Louisiana State University Health Sciences Center-New Orleans Institutional Review Board. This study complies with the Declaration of Helsinki. Informed consent for participation and publication was obtained from all the participants included in the study.

### *Measures and survey development*

Permission was attained to use and modify the Cancer Rehabilitation Evaluation System (CARES), a comprehensive assessment tool evaluating cancer patients' QOL and rehabilitation needs.<sup>20</sup> The CARES consists of 31 validated subscales. Due to the length of the CARES, only the physical, marital, psychosocial, sexual, and miscellaneous domains were used for this survey. The subscales were selected based upon formative work including review of the literature and discussions with the project's community advisory board, including YBCS, caregivers, and service prov-



iders. The instructions were modified to ask how much each issue applied to participants at any time since cancer diagnosis, rather than just within the past month. As rapid case ascertainment was used, potential participants were identified shortly after their diagnosis, but could have completed the survey more than one month after diagnosis. The CARES five-point Likert scale asks how much an issue applies (0- not at all; 1- a little; 2- a fair amount; 3- much; 4- very much). The CARES does not address premature menopause, pregnancy, lymphedema, or genetic testing, which are all issues of importance to YBCS. As a result, 12 statements based on these YBCS-relevant topics were added. An open-ended question asking survey participants for additional concerns or comments was added.

#### *Instrument used*

The revised instrument was initially trialed with key informant groups: YBCS (N=35); community-based health and service providers (N=15); family members of YBCS (N=9). Survivors were identified through local breast healthcare and service providers. Special emphasis was placed on recruiting minority survivors. Participants received \$20 for completing the draft survey.

#### *Data Collection*

Data was mainly collected on paper surveys. However, to increase participation rates, an online option was provided via an online link. Study subjects could also complete the survey by telephone by contacting the study coordinator or by selecting this option when contacted by phone for follow-up if they had not returned a completed survey.

Once physician consent requirement was met, the potential participant was mailed a survey packet, which included:

- An invitation letter;
- Survey questionnaire (IRB-approved);
- Informed consent form (The patient was not required to sign unless she chose to as a waiver of informed consent and HIPAA was obtained);
- A postage paid, self-addressed, business reply envelope.

The online survey differed only by prompting the participant to enter her ID number listed on the invitation letter. The mailed paper survey in the invitation packet contained an ID number, a brief description of the program, and the program's website.

If there was no response to the survey packet after two weeks, the potential participant was contacted by phone to assess whether she received the packet and answer any questions she may have. The YBCS was then encouraged to complete the baseline survey either over the phone or online by visiting the study's website. If the YBCS did not answer, she was contacted again by phone two weeks later (maximum

of two recruitment phone calls). The initial survey packet was re-mailed (maximum of two packets) to the YBCS two weeks after the second recruitment phone call if still not completed. Any refusals to participate by potential participants prevented further attempts to contact them.

The survey methodology in Mississippi followed the one used in Louisiana with a few exceptions. Consent from physicians was not required, so consent packets were mailed directly to identified YBCS. Passive consent was not allowed, and participants were required to return a signed consent before receiving the survey. The follow-up survey implemented the same procedures as the baseline survey, starting from the step of mailing out the survey packet through follow-up calls starting one year after completion of the original survey to better understand how these needs have changed. The follow-up survey is referred to as the "post-survey" in the remainder of this paper. In Alabama, the survey was only available online through the U.S. Gulf States Young Breast Cancer Network (GSYBCSN) website.

#### *Data analysis*

Since the surveys were sent to the respondents at both a baseline and one-year interval, the sample size calculation was conducted by assuming a statistical significance level of 0.05, a paired t-test with 90% power to detect statistically significance difference on the variables of interest: "working" and "ability". According to our estimates, we needed a sample size of 89 to detect a difference of 0.532 between pre- and post-survey for "working" and a sample size of 131 to detect a difference of 0.416 between pre- and post-survey for "ability". If we adopt power of 80%, the minimum sample size requirements drop to 67 and 98, respectively. Therefore, we concluded that with a sample size of 127, we have enough power to detect statistically significance differences in the variables of interest between pre-and post-surveys.

Descriptive statistics were used to characterize the distribution of demographic characteristics, relationships, women's health, employment, fertility, menopause, and other concerns for the YBCS. The number of YBCS that chose to omit responding to questions is listed in the data tables as "missing". Problems faced by YBCS were assessed using the Student's t-test or the Chi-square test, as appropriate. To compare the follow-up survey with the baseline survey, a paired t-test was used to compare scaled variables while McNemar's test was used for categorical variables. All *P* values were two-sided and analyses were conducted using IBM SPSS Statistics 25. Significant differences were identified at  $P \leq 0.05$ .



## RESULTS

The surveys were conducted between January 2016 and July 2018. In Louisiana, the initial search for eligible women resulted in 671 patients. Of those, 30 were deemed ineligible because they were from out of the state, deceased, or requested not to be contacted. One physician asked that one patient not be contacted. A resulting 640 women received the survey materials for participation. Of those, 286 (45%) completed the paper or online survey. In addition, four paper surveys were collected during a local support group meeting for a total of 290 survey participants from Louisiana, 78.2% of all survey participants. In Mississippi, consent materials were

sent to 547 women. Of those, 91 (16.6%) returned a signed consent form, and 73 completed the survey (19.7% of all survey participants). Alabama YBCS only had access to the survey via the GSYBCSN website and eight women completed the survey (2.2% of all participants).

At baseline, a total of 371 women completed the survey with the average age being 39.6 years (SD=4.544). The majority of participants were white (69.50%), followed by AA (25.6%), and other races (4.9%). At the time of the survey, 11.6% had attended a support group since diagnosis and only 8.4% had visited the GSYBCSN website (Table 1).

**Table 1.** Selected characteristics of baseline survey participants.

Variables	Number	%
Race		
African American	95	25.60%
White	258	69.50%
Other	18	4.90%
Survey Type		
Mailed Survey	297	80.10%
Online Survey	70	18.90%
From Supporting Group	4	1.10%
Had attended a support group since diagnosis <sup>a</sup>		
Yes	43	11.60%
No	325	88.30%
Had visited the GSYBCSN* website before receiving the survey <sup>b</sup>		
Yes	31	8.40%
No	338	91.60%
Total	371	100%

a: missing =3; b: missing =2; \*: Gulf States Young Breast Cancer Survivor Network

Table 2 shows that AA YBCS were more likely than white YBCS to report problems in the following areas: cancer or cancer treatments causing difficulty finding work (2.08 versus 1.70,  $P=0.06$ ), interfering with ability to work (2.18 versus 1.72,  $P=0.02$ ), difficulty sleeping (2.44 versus 2.11,  $P=0.06$ ), worry about inability to self-care (1.74 versus 1.42,  $P=0.08$ ), and having financial problems (2.69 versus 1.88,  $P<0.001$ ). We observed that white YBCS were more interested in genetic testing than AA YBCS (2.68 versus 2.05,  $P<0.01$ ). In addition, white YBCS were more likely to report that they had discussed genetic testing for breast cancer (94.55% versus 82.22%,  $P<0.01$ ) and more likely to discuss the relationship between breast cancer and menopause (65.37%

versus 54.74%,  $P=0.07$ ) with a healthcare provider than AA YBCS.

Among the survey participants, 127 participants completed the post-survey at one-year follow up (34%) with 113 being from Louisiana and 14 from Mississippi. About 80% were white, 17% were AA, and less than 4% were other races (data not shown). Table 3 shows that YBCS reported significant improvements in difficulties with planning ( $P<0.01$ ), difficulty finding work ( $P<0.01$ ), inability to do work ( $P<0.01$ ), worry regarding inability to self-care ( $P=0.04$ ), and stress score ( $P=0.05$ ) when comparing responses between baseline and post-surveys. However, they also experienced increased difficulty with remembering in the post-survey ( $P=0.04$ ). A race specific analysis was not conducted on follow-up



surveys because the sample size was too small to yield any significant values.

**Table 2.** Comparison for individual measures of QOL and significant factors in AA and white participants at baseline.

	AA (n=95) Mean (SD)	White (n=258) Mean (SD)	P
Cancer or cancer treatments has led to:			
Decrease in energy level <sup>a</sup>	2.53 (1.265)	2.39 (1.379)	0.37
Difficulty with planning <sup>b</sup>	1.82 (1.516)	1.68 (1.289)	0.43
Difficulty finding work	2.08 (1.773)	1.70 (1.485)	0.06
Inability to work <sup>c</sup>	2.18 (1.691)	1.72 (1.463)	0.02
Difficulty with clothes fitting <sup>c</sup>	1.85 (1.502)	1.59 (1.437)	0.15
Embarrassed by my body	1.41 (1.608)	1.50 (1.439)	0.63
Uncomfortable changes in my body <sup>c</sup>	1.97 (1.576)	1.91 (1.369)	0.74
Anxiety level	1.94 (1.515)	2.05 (1.373)	0.54
Feeling overwhelmed	2.27 (1.455)	2.1 (1.379)	0.33
Difficulty sleeping	2.44 (1.514)	2.11 (1.379)	0.06
Difficulty concentrating <sup>c</sup>	2.05 (1.454)	1.89 (1.293)	0.35
Difficulty remembering	2.11 (1.440)	2.06 (1.282)	0.77
Difficulty asking others for help	1.97 (1.567)	1.95 (1.457)	0.91
Worry about cancer progression	2.06 (1.597)	2.22 (1.369)	0.39
Worry about inability to self-care <sup>b</sup>	1.74 (1.586)	1.42 (1.306)	0.08
Poor sexual attractiveness	2.24 (1.507)	2.31 (1.418)	0.69
Financial problems	2.69 (1.598)	1.66 (1.397)	<0.0 1
Interest in genetic testing	2.05 (1.765)	2.68 (1.716)	<0.0 1
Worry that other family members have a higher cancer risk <sup>d</sup>	2.40 (1.633)	2.56 (1.525)	0.41
Difficulty with sexual intimacy <sup>d</sup>	1.99 (1.662)	2.11 (1.495)	0.54
	<b>N (%)</b>	<b>N (%)</b>	
I have discussed the relationship between breast cancer and menopause with a healthcare provider.	52 (54.74%)	168 (65.37%)	0.07
I have discussed genetic testing for breast cancer with a healthcare provider.	74 (82.22%)	243 (94.55%)	<0.0 1

a: missing = 4; b: missing = 2; c: missing = 1; d: missing value = 3

## DISCUSSION

Healthy People 2030 contains a high-priority objective to increase the mental and physical health-related QOL of cancer survivors, but it recognizes

these objective lacks evidence-based interventions.<sup>21</sup> The National Action Plan for Cancer Survivorship, therefore, recommends YBCS should receive care and



support through all three phases of survivorship—living “with,” “through,” and “beyond” their cancer. The action plan suggests developing and disseminating culturally tailored public education programs that

develop new materials where information is lacking and identify existing resources for cancer survivors to make informed decisions.<sup>22</sup>

**Table 3.** Comparison of individual measures of QOL at baseline and post-surveys (N =127).

Cancer or cancer treatment has led to:	Baseline survey	Post-survey	P
	Mean (SD)	Mean (SD)	
Decrease in energy level <sup>a</sup>	2.18 (1.374)	2.11 (1.404)	0.66
Difficulty with planning <sup>a</sup>	1.79 (1.346)	1.12 (1.311)	<0.01
Difficulty finding work <sup>b</sup>	1.75 (1.527)	1.22 (1.447)	<0.01
Inability to work <sup>a</sup>	1.78 (1.486)	1.36 (1.405)	<0.01
Difficulty with clothes fitting <sup>b</sup>	1.44 (1.395)	1.67 (1.491)	0.12
Embarrassed by my body <sup>c</sup>	1.47 (1.473)	1.58 (1.415)	0.41
Uncomfortable changes in my body <sup>b</sup>	1.93 (1.340)	1.84 (1.445)	0.45
Anxiety level	1.95 (1.485)	1.91 (1.428)	0.66
Feeling overwhelmed	2.08 (1.473)	1.89 (1.503)	0.08
Difficulty sleeping	1.96 (1.422)	1.94 (1.539)	0.90
Difficulty concentrating	1.76 (1.342)	1.65 (1.399)	0.28
Difficulty remembering	1.83 (1.285)	2.06 (1.359)	0.04
Difficulty asking others for help	1.91 (1.509)	1.73 (1.561)	0.22
Worry about cancer progression	2.20 (1.420)	2.10 (1.452)	0.44
Worry about inability to self-care <sup>b</sup>	1.59 (1.416)	1.34 (1.381)	0.04
Poor sexual attractiveness	2.15 (1.502)	2.17 (1.495)	0.89
Financial insecurity <sup>b</sup>	1.74 (1.514)	1.63 (1.552)	0.37
Interest in genetic testing	3.31 (2.415)	3.55 (3.319)	0.53
Worry that other family members have a higher cancer risk <sup>b</sup>	2.52 (1.527)	2.49 (1.542)	0.79
Difficulty with sexual intimacy <sup>a</sup>	2.24 (1.504)	2.19 (1.558)	0.73
Fears about the cancer spreading <sup>e</sup>	2.65 (1.367)	2.43 (1.529)	0.10
Fears about the cancer returning <sup>f</sup>	2.87 (1.336)	2.63 (1.464)	0.05
Stress score	36.37 (18.620)	33.95 (18.616)	0.05

a: missing = 2; b: missing =1; c: missing = 3; d: missing =3; e: missing=15; f: missing=16

This unique study offers an expanded understanding of the needs of young breast cancer survivors in the Gulf States, a region of the United States with not only a great need for YBCS resources, but also with a diverse survivorship population that require culturally tailored programs for effective support. To provide this programming, further understanding of the unique needs of AA YBCS is vital.

AA YBCS survey respondents reported significantly more concerns including three measures of financial/work difficulties as well as difficulty sleeping and worry about self-care. This is consistent with another study that found young AA women with

breast cancer have more QOL concerns than older AA women or white women with breast cancer.<sup>15</sup> Another study looking at financial toxicity in women diagnosed with breast cancer indicated that 54.7% of AA women reported their financial status was worse off at least partly because of their cancer compared to 37.3% of white women.<sup>23</sup> While financial toxicity related to cancer treatment is an increasingly recognized concern, it is important to note that the impacts may be greater in young AA women with breast cancer than in their white counterparts.

A statistically significantly lower percentage of AA women reported discussing genetic testing with their healthcare providers at baseline. This is concerning in



light of studies that have shown a greater prevalence of mutations that increase the risk of breast cancer in AA women and more specifically in young AA women.<sup>24,25</sup> At baseline, AA women rated their interest in genetic testing significantly lower than white women, possibly indicating a need for attention to education regarding genetic testing and its implications in AA women. As further support, one recent study indicated physicians are less likely to refer AA women for genetic evaluation as compared to white women.<sup>26</sup> Another study found that AA women were less likely to undergo genetic testing, but that surgeon attitudes toward genetic testing and volumes of breast cancer greatly influenced whether they were referred for genetic testing.<sup>27</sup> These results highlight the need for regional YBCS support programs to ensure that AA survivors are being offered the appropriate counseling from their healthcare providers and to spend greater time advocating for expanded financial resources for cancer survivors.

The majority of the QOL measures remained statistically unchanged from baseline to year one for all respondents. However, the mean scores for inability to work and worry about self-care were lower at year one. As the surveys were conducted within six months of diagnosis, it is not surprising that women would be having difficulty working. Going through surgery, chemotherapy, and other treatment can pose barriers to working. One study found barriers to working while in treatment for breast cancer included symptoms, emotional distress, changes in appearance such as loss of hair, unsupportive supervisors, juggling work and treatment schedules, among other things.<sup>28</sup> At the time of the follow-up survey, many women would have completed treatment, and would likely be having far fewer of these issues.

Mean scores for difficulty remembering increased from the initial survey to the follow-up surgery. At least one study has found that breast cancer patients were more likely to report significant cognitive declines at least six months post chemotherapy.<sup>29</sup> Chemo brain, an increasingly recognized change in cognitive function after chemotherapy, is described as having difficulties remembering, concentrating, or learning new skills.<sup>30</sup> As YBCS get further from their treatment date, survivorship organizations should consider offering treatment solutions such as cognitive rehabilitation, exercise, or meditation.<sup>30</sup>

Participant responses indicated that there were significant increases in the proportion of YBCS that had looked for a job, discussed premature menopause with a healthcare provider, and visited the GSYBCSN website between the baseline and post-surveys. While eleven (8.9%) participants indicated they had looked for a job after their diagnosis at baseline,<sup>35</sup> (28.2%) indicated they had in the post-survey ( $P<0.01$ ). For

discussing premature menopause, the figure was 76 at baseline (60.3%) and 92 (73.0%) in the post-survey ( $P<0.01$ ). While it is unclear if the women looking for jobs were doing so because their health had improved or because they had lost their jobs possibly because of issues related to treatment, it is encouraging that the majority of respondents reported discussing the issues of premature menopause with their healthcare provider. Of note, a statistically significantly lower percentage of AA women reported discussing premature menopause with their healthcare provider at baseline (55% of AA respondents as compared to 65% of white respondents). While the sample is small, AA women had caught up to white women at year one for discussing premature menopause (72.7% versus 73.5%). It is encouraging that these discussions are being had, although this could be the case because of complaints of symptoms of premature menopause that occurred during the treatment process. Ideally, the probability of these symptoms would be discussed when treatment decisions are being made. However, it is not known if some cursory discussions were had early in the treatment process and simply not recalled by respondents as respondents may be more focused on issues related to life or death.

In this study, virtually all eligible women in Louisiana and Mississippi had the opportunity to participate. This gave us an overall response rate of 30% of eligible population, which is well within a 5% margin of error.

Consent methods differed between Louisiana and Mississippi. In Louisiana, women received the survey along with a consent letter that explained the survey. A signed consent form was not required, and women were informed that completing and signing the survey constituted their consent. In Mississippi, a signed consent form was required before receiving the survey. Response rates differed considerably between the two states, likely because of these differences (45% versus 17%). The higher response rates in Louisiana may make these results more generalizable to this state.

There may be demographic differences in the women who responded versus those who did not. While we do not have any information on non-responders to make this assessment, we do have information on YBCS as a group, particularly in Louisiana. We do know that, while 25% of the respondents were AA, this is lower than the percentages of the populations in Louisiana and Mississippi identified as AA (33% and 38% respectively).<sup>31</sup> Also, in the period from 2011 through 2015, 39.7% of the YBCS survivors in all three states were AA.<sup>32</sup> This is similarly reflected in the 39.0% percent of AA YBCS in Louisiana between 2016 and 2018.<sup>33</sup> The drop off in responses from AA women from the initial survey to the survey one year later is



particularly noted. In addition, general demographic information such as education and income was not collected, so we are unable to compare responders to non-responders on these variables. This may limit the generalizability of these results. However, clearly a significant percentage of YBCS are experiencing the concerns indicated by these survey results.

When addressing QOL issues in cancer survivorship, it is important to note that young women with breast cancer face challenges that differ from their older counterparts and that these needs may differ by race. This necessitates programs that are geared to the specific needs and challenges. Due to breast cancer's lower incidence in younger women, survivorship research rarely focuses on this cohort and even more rarely evaluates the unique needs of AA YBCS, as evidenced in a recent publication.<sup>34</sup> Some of these issues, such as genetic testing, symptoms of premature menopause, and chemo brain call for discussions with the healthcare provider early in the treatment process. Others, such as potential financial toxicity, suggest the need for partnerships with service organizations.

## CONCLUSION

This study illustrates the multiple issues related to a breast cancer diagnosis and how these issues can vary by race and from baseline to year-one post diagnosis. Additional research may be needed to determine what interventions could be effective in alleviating these issues, which may be different at

baseline than at year-one post diagnosis. What is clear is that given how far treatment of breast cancer has come and the fact that many young women with breast cancer could go on to lead long, productive lives, it compels us to continue to explore ways to address issues that lead to reduced QOL for these women.

## ACKNOWLEDGEMENTS

The authors wish to acknowledge each young woman with breast cancer who took the time to complete the survey, thereby making this work possible. This article is dedicated to the memory of Dr. Karen Meneses of the University of Alabama at Birmingham School of Nursing who worked closely with us until her untimely death in 2018.

## FUNDING

This project was supported by a grant from the Centers for Disease Control and Prevention (1U58-DP005412-01), Multiple Approaches to Increase Awareness and Support among Young Women Diagnosed with Breast Cancer.

## CONFLICT OF INTEREST

The authors do not have affiliations, financial agreements, or conflicts of interest to disclose as reported in the manuscript.

## REFERENCES

- Hsu T, Ennis M, Hood N, Graham M, Goodwin PJ. Quality of life in long-term breast cancer survivors. *J Clin Oncol*. 2013;31(28):3540-8. doi: 10.1200/JCO.2012.48.1903.
- National Cancer Institute. Cancer Stat Facts: Female Breast Cancer 2021 [Access date: 15 April 2021]. Available from: <https://seer.cancer.gov/statfacts/html/breast.html>.
- Partridge AH. Cancer survivorship and the young breast cancer patient: addressing the important issues. *Oncologist*. 2013;18(8):e19-20. doi: 10.1634/theoncologist.2013-0300.
- Buchanan N, Roland KB, Rodriguez JL, Miller JW, Fairley T. Opportunities for public health communication, intervention, and future research on breast cancer in younger women. *J Womens Health (Larchmt)*. 2013;22(4):293-8. doi: 10.1089/jwh.2012.4239.
- Cathcart-Rake EJ, Ruddy KJ, Bleyer A, Johnson RH. Breast Cancer in Adolescent and Young Adult Women Under the Age of 40 Years. *JCO Oncol Pract*. 2021;17(6):305-13. doi: 10.1200/OP.20.00793.
- Mols F, Vingerhoets AJ, Coebergh JW, van de Poll-Franse LV. Quality of life among long-term breast cancer survivors: a systematic review. *European journal of cancer*. 2005;41(17):2613-9. doi: 10.1016/j.ejca.2005.05.017.
- Bloom JR SS, Chang S, Banks PJ. Then and now: quality of life of young breast cancer survivors. *Psychooncology*. 2004;13(3):147-60. doi: 10.1002/pon.794.
- Dow KH. A review of late effects of cancer in women. *Semin Oncol Nurs*. 1995;11(2):128-36. doi: 10.1016/s0749-2081(05)80020-8.
- Marsh S, Borges VF, Coons HL, Afghahi A. Sexual health after a breast cancer diagnosis in young women: clinical implications for patients and providers. *Breast Cancer Res Treat*. 2020;184(3):655-63. doi: 10.1007/s10549-020-05880-3.
- Gorman JR, Drizin JH, Smith E, Flores-Sanchez Y, Harvey SM. Patient-Centered Communication to Address Young Adult Breast Cancer Survivors' Reproductive and Sexual Health Concerns. *Health Commun*. 2021;36(13):1743-58. doi: 10.1080/10410236.2020.1794550.





11. Avis NE CS, Manuel J. Quality of life among younger women with breast cancer. *Clinical Oncology*. 2005;23(15):3322-30. doi: 10.1200/JCO.2005.05.130.
12. Howard-Anderson J, Ganz PA, Bower JE, Stanton AL. Quality of life, fertility concerns, and behavioral health outcomes in younger breast cancer survivors: a systematic review. *J Natl Cancer Inst*. 2012;104(5):386-405. doi: 10.1093/jnci/djr541.
13. Powe BD, Hamilton J, Hancock N, Johnson N, Finnie R, Ko J, et al. Quality of life of African American cancer survivors. A review of the literature. *Cancer*. 2007;109(2 Suppl):435-45. doi: 10.1002/cncr.22358.
14. Northouse LL, Caffey M, Deichelbohrer L, Schmidt L, Guziatek-Trojniak L, West S, et al. The quality of life of African American women with breast cancer. *Res Nurs Health*. 1999;22(6):449-60. doi: 10.1002/1098-240x(199912)22:6<449::aid-nur3>3.0.co;2-a.
15. Samuel CA, Pinheiro LC, Reeder-Hayes KE, Walker JS, Corbie-Smith G, Fashaw SA, et al. To be young, Black, and living with breast cancer: a systematic review of health-related quality of life in young Black breast cancer survivors. *Breast Cancer Research and Treatment*. 2016;160(1):1-15. doi: 10.1007/s10549-016-3963-0.
16. Ganz PA. Quality of Life in Long-Term, Disease-Free Survivors of Breast Cancer: a Follow-up Study. *CancerSpectrum Knowledge Environment*. 2002;94(1):39-49. doi: 10.1093/jnci/94.1.39.
17. Lu W, Cui Y, Chen X, Zheng Y, Gu K, Cai H, et al. Changes in quality of life among breast cancer patients three years post-diagnosis. *Breast Cancer Research and Treatment*. 2008;114(2):357-69. doi: 10.1007/s10549-008-0008-3.
18. Bantema-Joppe EJ, de Bock GH, Woltman-van Iersel M, Busz DM, Ranchor AV, Langendijk JA, et al. The impact of age on changes in quality of life among breast cancer survivors treated with breast-conserving surgery and radiotherapy. *British Journal of Cancer*. 2015;112(4):636-43. doi: 10.1038/bjc.2014.632.
19. Centers for Disease Control and Prevention IN. State Cancer Profiles 2020 [Access date: Apr 15 2020. Available from: <https://statecancerprofiles.cancer.gov/>].
20. Schag CA, Heinrich RL. Development of a comprehensive quality of life measurement tool: CARES. *Oncology (Williston Park)*. 1990;4(5):135-8;discussion 47. doi: 10.1136/bmjspcare-2014-000725.
21. US Department of Health and Human Services Center for Disease Control and Prevention. Cancer - Healthy People 2030 2020 [Access date: August 20 2020. Available from: <https://health.gov/healthypeople/objectives-and-data/browse-objectives/cancer>].
22. National Center for Chronic Disease Prevention and Health Promotion (U.S.); Centers for Disease Control and Prevention (U.S.); Armstrong Foundation. A National action plan for cancer survivorship; advancing public health strategies. 2004. doi: Not Applicable.
23. Jagsi R, Ward KC, Abrahamse PH, Wallner LP, Kurian AW, Hamilton AS, et al. Unmet need for clinician engagement regarding financial toxicity after diagnosis of breast cancer. *Cancer*. 2018;124(18):3668-76. doi: 10.1002/cncr.31532.
24. Pal T, Bonner D, Cragun D, Monteiro AN, Phelan C, Servais L, et al. A high frequency of BRCA mutations in young black women with breast cancer residing in Florida. *Cancer*. 2015;121(23):4173-80. doi: 10.1002/cncr.29645.
25. Churpek JE, Walsh T, Zheng Y, Moton Z, Thornton AM, Lee MK, et al. Inherited predisposition to breast cancer among African American women. *Breast Cancer Research and Treatment*. 2014;149(1):31-9. doi: 10.1007/s10549-014-3195-0.
26. Pepin A PJ, Thomas R, Johnson K, Stark E, Biagi T, et al. Evaluating racial disparities in breast cancer referrals for hereditary risk assessment. *BASIC SCIENCE*. 2009;115(10):29. doi: 10.1002/jgc4.1250.
27. Katz SJ, Bondarenko I, Ward KC, Hamilton AS, Morrow M, Kurian AW, et al. Association of Attending Surgeon With Variation in the Receipt of Genetic Testing After Diagnosis of Breast Cancer. *JAMA Surgery*. 2018;153(10). doi: 10.1001/jamasurg.2018.2001.
28. Sun W, Chen K, Terhaar A, Wiegmann DA, Heidrich SM, Tevaarwerk AJ, et al. Work-related barriers, facilitators, and strategies of breast cancer survivors working during curative treatment. *Work*. 2016;55(4):783-95. doi: 10.3233/WOR-162449.
29. Janelins MC, Heckler CE, Peppone LJ, Kamen C, Mustian KM, Mohile SG, et al. Cognitive Complaints in Survivors of Breast Cancer After Chemotherapy Compared With Age-Matched Controls: An Analysis From a Nationwide, Multicenter, Prospective Longitudinal Study. *J Clin Oncol*. 2017;35(5):506-14. doi: 10.1200/JCO.2016.68.5826.
30. The American Cancer Society. Chemo Brain 2020 [Access date: April 15 2020. Available from: <https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/changes-in-mood-or-thinking/chemo-brain.html>].
31. U.S. CENSUS BUREAU. QuickFacts: Mississippi; Louisiana; United States; New Jersey 2020 [Access date: April 15 2020. Available from: <https://www.census.gov/quickfacts/fact/table/MS,LA,US,NJ/SBO030212>].
32. US Department of Health and Human Services Center for Disease Control and Prevention. National Program of Cancer Registries and Surveillance,



- Epidemiology, and End Results [Access date: April 15 2020. Available from: [www.cdc.gov/cancer/uscs/public-use/](http://www.cdc.gov/cancer/uscs/public-use/)].
33. Louisiana Tumor Registry. Characteristics of Race and Age for the Population Diagnosed with Breast Cancer in Louisiana, Diagnosis 2016-2018 [Available from: <https://sph.lsuhs.edu/louisiana-tumor-registry/data-usestatistics/>].
34. Rosenberg SM, Dominici LS, Gelber S, Poorvu PD, Ruddy KJ, Wong JS, et al. Association of Breast Cancer Surgery With Quality of Life and Psychosocial Well-being in Young Breast Cancer Survivors. *JAMA Surg.* 2020;155(11):1035-42. doi: 10.1001/jamasurg.2020.3325.

### How to Cite This Article

**Williams D, Yu-Wen CH, Khorsandi N, Moses L, Craft BL. Quality of Life Concerns of Young Breast Cancer Survivors in the U.S. Gulf States by Race at Treatment and One-year Post-treatment. *Arch Breast Cancer.* 2022; 9(1):40-49.**

Available from: <https://www.archbreastcancer.com/index.php/abc/article/view/444>