DELAWARE
BREAST CANCER
COALITION

September
2020

About the Quality of Life Study

The Quality of Life Study collected feedback from respondents who entered DBCC programs between March 2016 and February 2017.

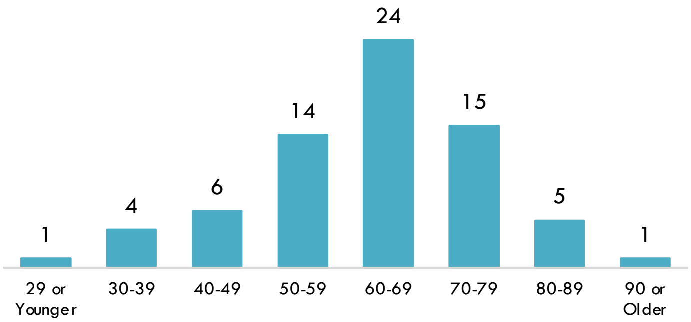
DBCC participants were offered the opportunity to participate in the Quality of Life Study if they met the following criteria:

- Participants were mentored by the DBCC and had had more than one conversation with a program manager;
- Participants were either newly diagnosed with breast cancer or newly diagnosed with a reoccurrence; and
- Participants had their first contact with DBCC as a mentee three months prior to completing their first survey.

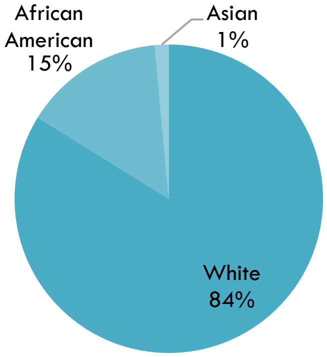
Respondents were asked to complete surveys about their sense of physical, social/family, emotional, and functional well-being at four points in time: three months after entry to DBCC services, six months after entry, one year post entry and two years post entry.

Who Participated in the Quality of Life Survey?

Respondents ranged in age from 26 to 97; the average age was 62. (N=70)



84% of respondents who reported their race were White. (N=68)



Most Respondents Reside in Delaware

- Most Delaware respondents (94%) resided in Kent County (n=30, 43%) or Sussex County (n=26, 37%), with 10 residents from New Castle County (14%).
- Three study participants resided in Maryland (n=3, 4%)
- One Participant resided in New Jersey (n=1, 1%).

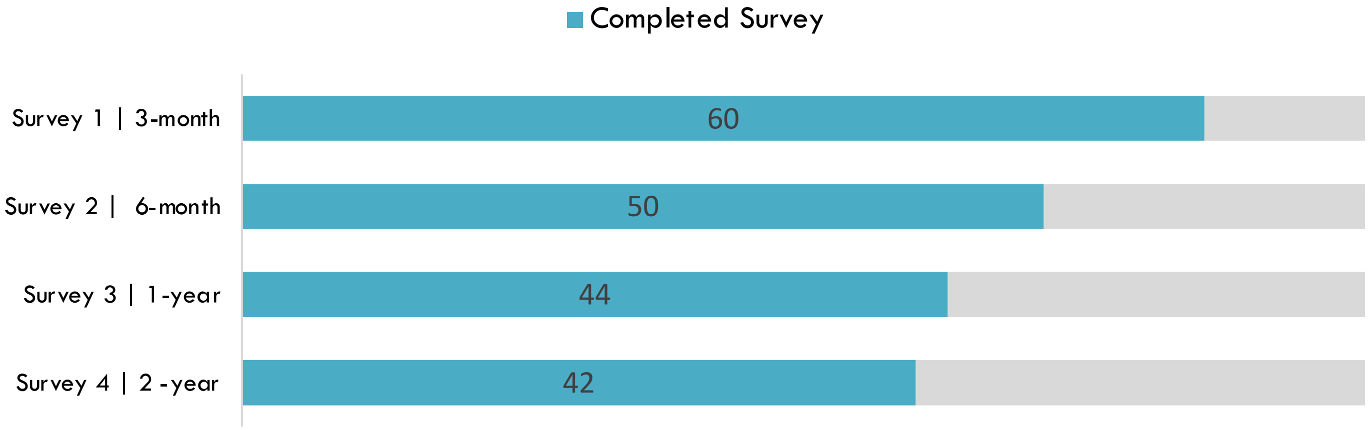
Note: The total does not sum to 100%; rounding error.

THE DBCC QUALITY OF LIFE STUDY

Participation was high, a testament to the investment of staff and the strong relationship between staff and DBCC participants.

- 70 (69%) of 102 eligible DBCC participants chose to join the Quality of Life Study by signing a consent form.
- 60 (86%) of those consented participants completed the 3-month survey.
- 50 of 70 (71%) consented participants completed the 6-month survey.
- 44 of 70 (63%) consented participants completed the 1-year survey.
- Of the 70 study participants who received the 2-year survey, 42 (60%) completed it.

RESPONDENTS REMAINED ENGAGED WITH THE QUALITY OF LIFE SURVEYS OVER THE TWO-YEAR PERIOD. (N=70)



ANALYSIS OF THE QUALITY OF LIFE STUDY

Respondents reacted to a series of statements touching on their well-being in four categories: physical, social/family, emotional, and functional. Individual participants' responses were matched and followed over a two=year period in order to understand if there were changes in respondents' sense of well-being and to determine if any changes were statistically significant. Matched responses were available for 36 respondents who completed *both* the first and fourth surveys.

Physical Well-Being

- At the two-year mark (survey four), the changes in all statements indicated that respondents improved physically. Significantly more participants **disagreed** in the fourth survey than they did during the first survey with the statement, **"I feel ill."**

Social Family Well-Being

- Statements about respondents' social/family well-being were stable over the two-year period; some statements indicated respondents were less reliant on family and friends at the two-year mark. No changes in responses to these statements were statistically significant.

Emotional Well-Being

- Responses to statements are largely stable over the two-year period. While respondents indicated lessened nervousness, some additional feelings of sadness and worry were also present. No statements yielded statistically significant findings.

Functional Well-Being

- All but one of the statements indicated that functional well-being improved over the two-year period and one statement yielded statistically significant findings from the time of the first survey to the last: **"I am able to work (including work at home)."**

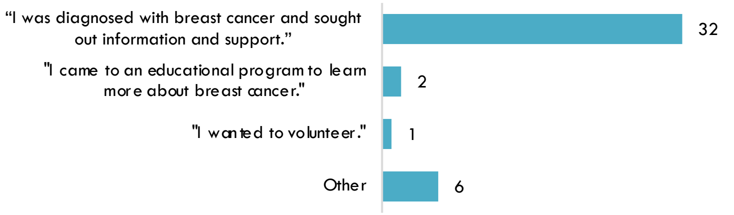
Additional Questions

- Most statements showed increased sense of improvement among the 36 matched sets of responses. One statement yielded statistically significant results: **"I worry about the effect of stress on my illness."**

RESPONDENT EXPERIENCES WITH DBCC

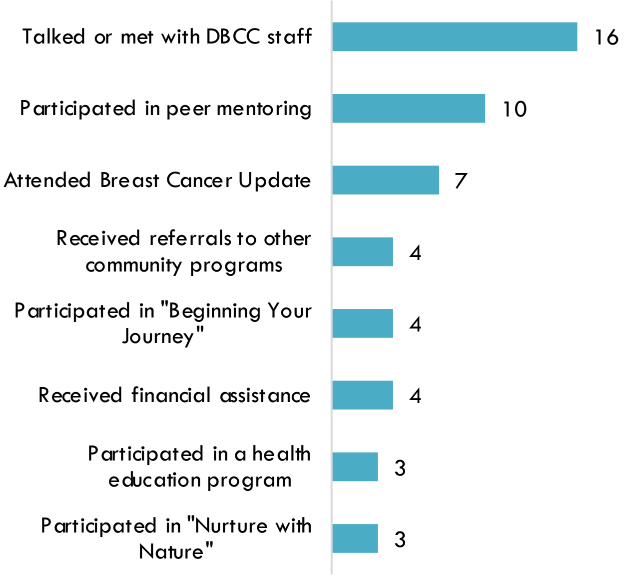
In the final survey, two years after their first experience with the DBCC, respondents were asked about their experiences with DBCC.

78% OF RESPONDENTS REPORTED THEY FIRST CAME TO DBCC FOR SERVICES OR PROGRAMS WHEN DIAGNOSED WITH BREAST CANCER.



Six respondents stated other reasons for attending DBCC programs including participation with a support group, a connection to a specific program manager, and one who said she came, "… to support a friend and ended up with cancer myself."

AFTER ENTERING DBCC PROGRAMMING, RESPONDENTS OFTEN USE ONE-ON-ONE INTERACTIONS BY TALKING WITH STAFF (39%) OR CONNECTING WITH A PEER MENTOR (25%).

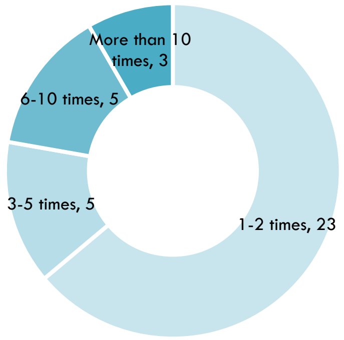


Individual respondents (2% each) also noted they used the screening mammogram with the mobile unit, participated in "Breast Cancer Conversations," participated in "Great Escape," or served as a peer mentor.

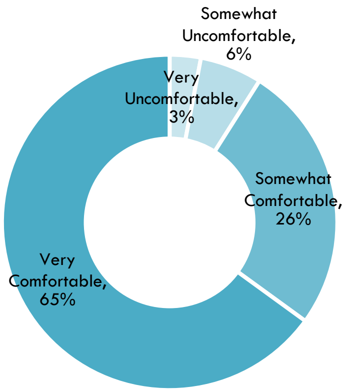
Three respondents (7%) noted they did not remember or "were too tired to remember" what had occurred the prior year.

Note: The total does not sum to 100%; respondents could check more than one response.

NEARLY TWO-THIRDS (64%) PARTICIPATE IN ACTIVITIES ONCE OR TWICE A YEAR.



MORE THAN NINE IN 10 (91%) STATED THEY FELT "VERY COMFORTABLE" (65%) OR "SOMEWHAT COMFORTABLE" (26%) ATTENDING EVENTS.



More than a quarter of 41 respondents (27%) stated they maintained contact with others — beyond DBCC staff members or a peer mentor — that they met through a DBCC program activity.

Nine (9) in 10 of 38 respondents reported that DBCC programs exceeded (37%) or met (53%) their expectations. The remaining respondents (10%) stated the experience had "fallen short of my expectations."