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REVIEW

To be young, Black, and living with breast cancer: a systematic review of health-related quality of life in young Black breast cancer survivors

Cleo A. Samuel[1,2,3,4,5] · **Laura C. Pinheiro**[1] · **Katherine E. Reeder-Hayes**[2,6,7] · **Jennifer S. Walker**[8] · **Giselle Corbie-Smith**[3,4,5,9,10] · **Shekinah A. Fashaw**[1] · **Cheryl Woods-Giscombe**[11] · **Stephanie B. Wheeler**[1,2,4]

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Abstract

Purpose Compared with young White women, young Black women are more likely to present with aggressive breast cancer (BC) subtypes that are potentially linked to worse health-related quality of life (HRQOL); however, there is limited consensus regarding HRQOL needs among young Black BC survivors. Employing Ferrell's framework on QOL in BC (i.e., physical, psychological, social, and spiritual well-being), we conducted a systematic review on HRQOL among Black BC survivors aged <50 years and proposed recommendations for advancing HRQOL research and care for this population.

Methods Literature searches were conducted in MEDLINE/PubMed, EMBASE, CINAHL, and PsycINFO to identify relevant articles published from 1995 to 2015. Abstracts and full-text articles were screened using predetermined inclusion/exclusion criteria and evaluated for quality.

Results A total of 2533 articles were identified, but six met eligibility criteria. Most studies examined multiple HRQOL domains, with the psychological domain most represented. Compared with their older, White, and BC-free counterparts, young Black BC survivors reported greater fear of dying, unmet supportive care needs, financial distress, and lower physical/functional well-being. However, spiritual well-being appeared favorable for young Black survivors. Research gaps include the absence

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✉ Cleo A. Samuel
cleo_samuel@unc.edu

[1] Department of Health Policy and Management, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, 1105F McGavran-Greenberg Hall, Chapel Hill, NC CB#7411, USA

[2] Lineberger Comprehensive Cancer Center, University of North Carolina at Chapel Hill, 450 West Drive, Chapel Hill, NC CB#7295, USA

[3] Center for Health Equity Research, University of North Carolina at Chapel Hill, 323 MacNider Hall, Chapel Hill, NC CB#7240, USA

[4] Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, 725 Martin Luther King, Jr. Blvd, Chapel Hill, NC CB#7590, USA

[5] North Carolina Translational and Clinical Sciences (NC TraCS) Institute, University of North Carolina at Chapel Hill, Brinkhous-Bullitt Building, Second Floor, 160 N. Medical Drive, Chapel Hill, NC CB#7064, USA

[6] UNC Breast Center, NC Cancer Hospital, 101 Manning Drive, Chapel Hill, NC, USA

[7] UNC School of Medicine, Division of Hematology/Oncology, University of North Carolina at Chapel Hill, Physicians Office Building, Third Floor, 170 Manning Drive, Chapel Hill, NC CB#7305, USA

[8] University of North Carolina Health Sciences Library, 335 S. Columbia Street, Chapel Hill, NC CB#7585, USA

[9] Department of Social Medicine, UNC School of Medicine, University of North Carolina at Chapel Hill, 333 S. Columbia Street, MacNider Hall, Room #348, Chapel Hill, NC CB#7240, USA

[10] Robert Wood Johnson Foundation Clinical Scholars Program, University of North Carolina at Chapel Hill, 111 Mason Farm Road, Chapel Hill, NC CB#7105, USA

[11] School of Nursing, University of North Carolina at Chapel Hill, 4015 Carrington Hall, Chapel Hill, NC CB#7460, USA

of longitudinal studies and under-representation of studies examining physical, social, and particularly, spiritual HRQOL in young Black BC survivors.

Conclusions Young Black BC survivors generally experience suboptimal HRQOL after BC diagnosis. As few studies have reported on HRQOL among this group, future research and oncology care should prioritize young Black women in ways that recognize their unique concerns, in order to ensure better HRQOL outcomes both during and after treatment.

Keywords Breast cancer · Black African-American · Premenopausal · Quality of life

Introduction

Breast cancer (BC) is the most common cancer among women worldwide [1]. Yet, studies indicate that BC risk and burden are not evenly shared between White and Black women in the U.S. For example, although BC incidence rates are similar in White and Black women, mortality rates are higher in Blacks [2–8]. These findings may be partly explained by the fact that Black women tend to be diagnosed at younger ages (i.e., premenopausal) [9, 10] and with more aggressive BC subtypes (i.e., hormone receptor negative, lymph node positive) [11, 12] that require more aggressive treatments (e.g., chemotherapy and radiation) and are associated with worse prognosis [11, 12]. Aggressive treatments and greater risk of death negatively impact both physical and psychosocial health-related quality of life (HRQOL) [13–16]. Given that Black women with BC are at increased risk for aggressive, premenopausal BC [17], understanding HRQOL needs specific to this population is imperative.

Four distinct HRQOL domains have been identified in BC survivors and vary by race: physical (e.g., fatigue, nausea, lymphedema), social (e.g., distress, sexuality, personal relationships), psychological (e.g., fear of recurrence, anxiety, depression), and spiritual (e.g., hopefulness, uncertainty about the future, self-discovery) well-being (Fig. 1) [17–19]. Overall, BC survivors report deterioration in physical and mental health during diagnosis, treatment, and survivorship [20]; however, Black BC survivors report poorer HRQOL than Whites [21–24]. Specifically, Blacks report worse physical and functional well-being [24, 25]. Conversely, Black BC survivors also report positive emotional growth throughout the BC care continuum, which may explain reports of fewer psychological and spiritual well-being decrements compared with White BC survivors [26, 27].

Overall, after adjusting for demographic and clinical characteristics, BC survivors younger than 50 years report worse HRQOL compared to their 50 and older counterparts [28, 29]. A systematic review on HRQOL in young BC survivors documented psychosocial HRQOL decrements such as depression and anxiety, as well as menopausal symptoms including weight gain, hot flashes, and vaginal dryness in this survivor group [28]. One potential explanation for these differences is that younger women are more likely to be active in the workforce and have childcare responsibilities than older women [30, 31]. Issues surrounding fertility and treatment-induced menopause may also be more concerning for younger BC survivors [30, 32, 33], who are more likely to be premenopausal at diagnosis [17]. Thus, compared with older women, younger women may experience more difficulty adjusting to a BC diagnosis [17, 30].

Independent of their BC diagnosis, young Black women may experience high levels of stress due to cultural and contextual factors [34–36]. Research on the nuanced experiences of life stressors among Black women suggest that Superwoman Schema, or perceived obligations to present an image of strength, suppress emotions, resist support from others, achieve success with inadequate resources, and prioritize caregiving over self-care can adversely affect health-promoting behaviors and HRQOL [35, 37]. Moreover, Network Stress, or the stress experienced by Black women as a result of life challenges experienced by family members and friends [36], might magnify ways in which stress negatively influences aspects of HRQOL in this population. Such role perceptions and stress-related processes may be more pronounced among young Black BC survivors who are faced with the unique intersectional experience and challenges of being young, Black, and diagnosed with BC.

Although previous systematic reviews investigated HRQOL in Black women, these reviews failed to stratify outcomes by both race and age group, there by masking HRQOL needs specific to young Black BC survivors [21, 38–40]. Furthermore, previous studies limited definitions of "cancer survivor" to the period following active treatment or the 5-year survival landmark, overlooking HRQOL concerns immediately following diagnosis [21, 40]. As young Black BC survivors present with more aggressive disease, experience more burdensome treatments, and potentially worse HRQOL beginning from diagnosis, there is a need to better understand HRQOL concerns specific to this group. As such, we conducted a systematic review examining existing evidence on HRQOL patterns among young Black BC survivors.

Employing Ferrell's conceptual framework on *QOL in Breast Cancer* and a lifetime definition of BC survivor (diagnosis to death) [38, 41], we evaluated literature on HRQOL among Black BC survivors under age 50 [21, 39]. The objective of this study was to synthesize evidence on

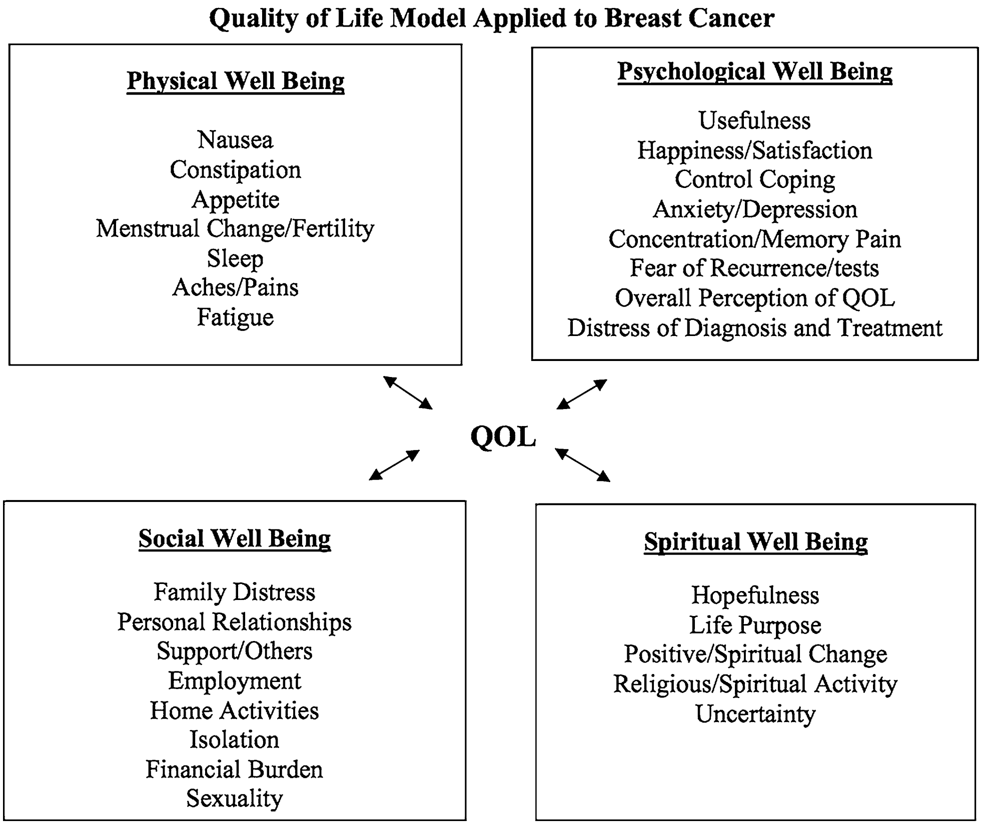

Fig. 1 Ferrell's Conceptual Framework on quality of life in Breast Cancer

contemporary HRQOL concerns and needs among young Black BC survivors in the U.S., identify gaps in research and clinical practice, and propose recommendations for advancing HRQOL research and improving support services for this patient population.

Methods

Literature search strategy

A comprehensive literature search was developed and conducted in MEDLINE/PubMed, EMBASE, CINAHL, and PsycINFO to identify relevant articles published from 1995 (publication year of Ferrell's original article on *Measurement of QOL in Cancer Survivors*, which informed Ferrell's 1996 conceptual framework on *QOL in Breast Cancer*) [18, 19] through July 24, 2015. The literature search included Medical Subject Headings and Emtree headings and related text and keyword searches when appropriate, focusing on terms used to describe HRQOL in young Black BC survivors. An experienced librarian conducted the searches, with input from clinician and non-clinician research team members (see Appendix 1 for search strategy).

Inclusion and exclusion criteria

Eligibility criteria were developed with respect to the population, outcomes of interest, study design, and publication type. Studies were eligible for inclusion if they presented stratified data on HRQOL [18, 19] among Black female BC survivors under age 50. Fifty years was selected as the young women age cutoff because this is the mean age of menopause in Black women [42] and a commonly used cutoff in other studies examining BC-related outcomes in young women [28, 43, 44]. Consistent with current definitions of a "cancer survivor," we employed a lifetime definition capturing time from diagnosis until death [41, 45]. Conference abstracts and non-peer-reviewed publications were excluded, as were non-empirical studies, non-English studies, non-U.S.-based studies, and studies not separately reporting HRQOL for our target population (i.e., Black BC survivors under age 50).

Study selection

Two trained research team members independently screened titles and abstracts for inclusion using the eligibility criteria. Studies with titles and abstracts that met the inclusion criteria or lacked adequate information to determine inclusion/exclusion underwent full-text review. A senior member of the review team resolved conflicts.

During the full-text review, two trained members of the team independently reviewed full-text articles for inclusion/exclusion. If both reviewers agreed that a study did not meet eligibility criteria, the study was excluded. If reviewers disagreed, conflicts were resolved by consulting a senior member of the team.

Literature search results

A total of 3759 articles were identified through database searching, of which 2533 were non-duplicates. A total of 2146 articles were excluded during the abstract screening phase, 381 articles were excluded during full-text review, and six articles met all eligibility criteria for inclusion (see Fig. 2 for article disposition).

Data extraction and quality appraisal

Four independent reviewers abstracted data from the six eligible articles. Abstracted data were organized into a standardized table that included study purpose, conceptual framework, setting and participant eligibility criteria, sample characteristics, study design, HRQOL measures and instruments, and key HRQOL domain findings (based on Ferrell et al. [18, 19]) specific to young Black BC survivors (Table 1).

Two independent reviewers assessed the quality of each article using the 22-item Strengthening the Reporting of Observational Studies (STROBE) tool [46]. One study, which employed qualitative and quantitative methods, was also assessed using the ten-item Critical Appraisal Skills Program (CASP) qualitative tool [47]. Table 1 includes an appraisal tool ratio, calculated as the number of STROBE/CASP criteria met by the study divided by the total number of tool criteria [21]. No studies were excluded based on quality appraisal outcomes.

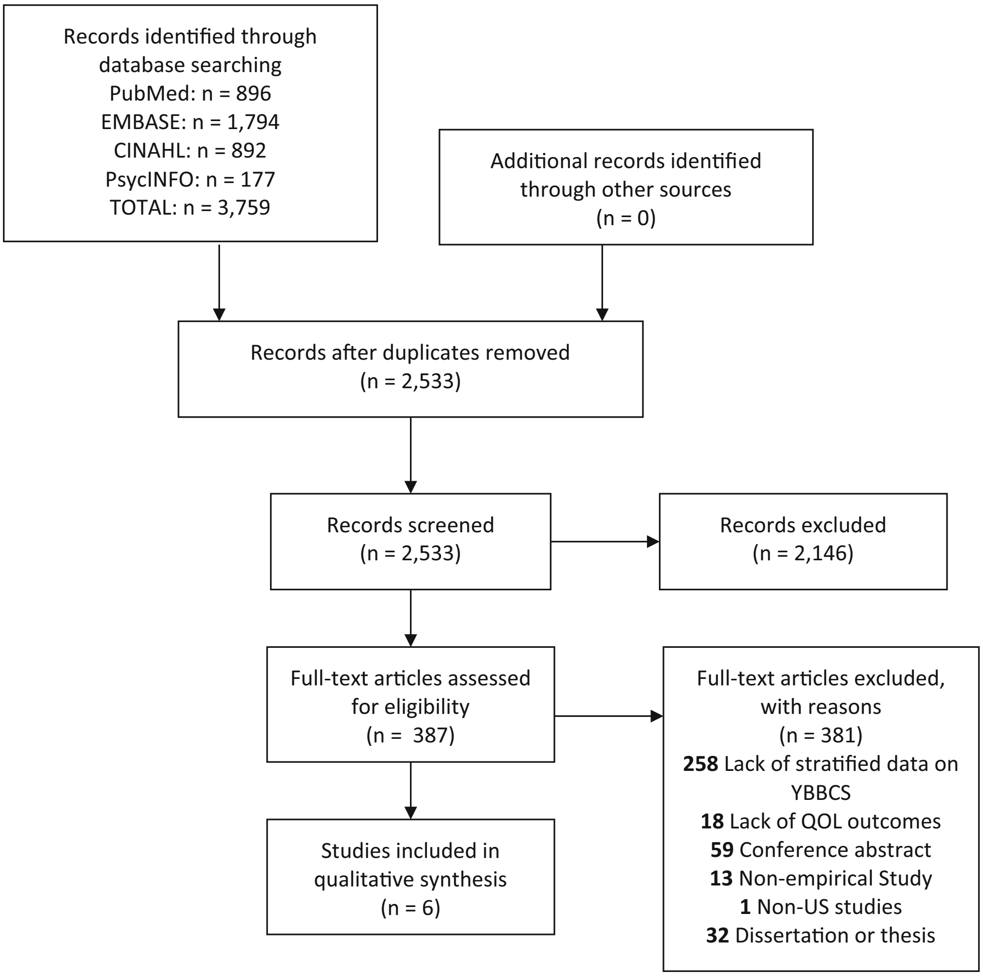

Fig. 2 Literature flow diagram

Table 1 Summary of included studies

First author (year)	Study objectives (pg no.)	Conceptual framework (pg no.)	Setting and eligibility criteria (pg no.)	Sample and key participant characteristics (pg no.)	Study design and data collection methods (pg no.)	HRQOL measures [and instrument, if applicable] (pg no.)	HRQOL dimension(s) [physical, psychological, social, spiritual] (pg no.)	Key findings for YBBCS (pg no.)	Appraisal tool and number of items met on checklist out of total (STROBE or CASP)
Beder (1995)	Identify the unique social support challenges faced by socioeconomically disadvantaged Black women who had mastectomies and use these findings to instruct social workers and service providers on how to better serve this patient population—pg 57	N/A	Setting: recruited from 6 New York City area hospitals Eligibility criteria: Black women, 65 years or younger with a first-time diagnosis of stage I, II, or III breast cancer, and who underwent a mastectomy—pg 58	Sample: 50 socioeconomically disadvantaged Black women who were 3 months post-mastectomy and 50 socioeconomically disadvantaged Black women who were 12 months post-mastectomy ($N = 100$)—pg 57 Participant characteristics: Age range: 25–65 85 % US-born 78 % not married 71 % had 12 years or less of education 97 % had children 69 % were working at the time of their surgery 33 % lived alone—pg 61	Study design: cross-sectional, quantitative—pg 57 Data collection Method: survey interview—pg 58	HRQOL measures included psychological adjustment (Psychological Adjustment to Illness Scale - PAIS, Derogatis and Derogatis, 1990) Social support (Interpersonal Support Evaluation List - ISEL, Cohen 1985)—pg 59	Social well-being—pg 55 psychological well-being—pg 57	Black breast cancer survivors aged 25–45 years reported significantly worse adjustment (i.e., psychological well-being) compared to Black breast cancer survivors aged 45–65 years—pg 66 Black breast cancer survivors aged 25–45 years reported greater levels of perceived social support (i.e., social well-being) compared with Black breast cancer survivors aged 45–65 years—pg 67	13/22 (STROBE)

Table 1 continued

First author (year)	Study objectives (pg no.)	Conceptual framework (pg no.)	Setting and eligibility criteria (pg no.)	Sample and key participant characteristics (pg no.)	Study design and data collection methods (pg no.)	HRQOL measures [and instrument, if applicable] (pg no.)	HRQOL dimension(s) [physical, psychological, social, spiritual] (pg no.)	Key findings for YBBCS (pg no.)	Appraisal tool and number of items met on checklist out of total (STROBE or CASP)
Gibson (2014)	Describe breast cancer fear according to phase of survivorship, determine whether breast cancer fear levels differed across survivorship phases, and determine the relationship between fear and age in Black breast cancer survivors—pg 135	Psychological well-being construct defined in the QOL Model by Ferrell & Grant (1996)—pg 137	Setting: recruited from outpatient oncology facilities in the southeastern US, and Black/African-American cancer organizations, church groups, sorority groups, and other organizations Eligibility criteria: Black breast cancer survivors—pg 137	Sample: 46 women from outpatient facilities and 116 women from Black women's cancer organizations (*N* = 162) Participant characteristics: Age range: 31–85 87 % were not receiving any active treatment Mean income range between $30,000 and 34,999, with 40 % making more than $40,000 66 % were college educated—pg 138	Study design: cross-sectional, quantitative Data collection Method: secondary data analysis of previously collected data—pg 137–138	HRQOL measures included (Quality of Life/Breast Cancer Psychological Well-Being (PWB) Subscale, Ferrell and Grant, 1996))—pg. 137–138 Breast cancer fear (Adapted from the Quality of Life/Breast Cancer Psychological Well-Being (PWB) Subscale, Ferrell and Grant, 1996)—pg. 137–138	Psychological well-being—pg 138	Black breast cancer survivors aged 31–49 years reported lower levels of fear (psychological well-being) compared with Black breast cancer survivors aged 50–64 and 64–85 years—pg 140	17/22 (STROBE)
Janz (2009)	Determine whether racial/ethnic differences in quality of life exist among White, Black, and Latina women in the early phase of breast cancer survivorship—pg 212	N/A	Setting: recruited from Los Angeles and Detroit Surveillance Epidemiology and End Results (SEER) program registries Eligibility criteria: women aged 20–79 years diagnosed with primary ductal carcinoma in situ (DCIS) or invasive stages I, II, or III breast cancer—pg 213	Sample: 2268 Black, White, and Latina women (mean time since diagnosis = 9 months)—pg 212 Participant characteristics: Age range: 20–79 Black and Latina women were more likely than White women to be under age 50 at time of diagnosis—pg 215	Study design: cross-sectional, quantitative Data collection Method: survey interview—pg 213	HRQOL measures included physical well-being; emotional well-being; functional well-being; and social/family well-being (The Functional Assessment of Cancer Therapy-Breast (FACT-B))—pg 214	Physical well-being and psychological well-being—pg 214	Black breast cancer survivors under age 50 reported lower levels of physical and psychological well-being compared with Black breast cancer survivors aged 50–70 and >70 years—pg 220	21/22 (STROBE)

Table 1 continued

First author (year)	Study objectives (pg no.)	Conceptual framework (pg no.)	Setting and eligibility criteria (pg no.)	Sample and key participant characteristics (pg no.)	Study design and data collection methods (pg no.)	HRQOL measures [and instrument, if applicable] (pg no.)	HRQOL dimension(s) [physical, psychological, social, spiritual] (pg no.)	Key findings for YBBCS (pg no.)	Appraisal tool and number of items met on checklist out of total (STROBE or CASP)
Lewis (2012)	Examine how Black women cope with breast cancer and whether societal pressures may add to coping difficulties—pg 2	N/A	Setting: recruited through a national survey Eligibility criteria: Black women younger than 45 years that were at least 1 year post-diagnosis of breast cancer, off active treatment other than hormonal therapy, and demonstrated adequate English skills—pg 2–3	Sample: 33 women Participant characteristics: Age range: 25–45—pg 1	Study design: cross-sectional, mixed methods Data collection method: survey interview—pg 3	HRQOL measures included the impact of cancer on women's living situations, employment, relationships, fertility, and sexuality (Instrument: N/A—internally developed by study research team)—pg 3	Psychological and social well-being—pg 1; physical well-being—pg 8); spiritual well-being—pg. 8	Black breast cancer survivors under age 50 (entire cohort) reported problems with relationships and isolation (social well-being), emotional and functional support (social well-being), and infertility and sexual dysfunction (physical well-being)—pg 6 61 % of Black breast cancer survivors reported increased anxiety (psychological well-being) related to fear of dying—pg 6 Black breast cancer survivors reported strong spiritual well-being—pg 8	7/10 (CASP) 20/22 (STROBE)

Table 1 continued

First author (year)	Study objectives (pg no.)	Conceptual framework (pg no.)	Setting and eligibility criteria (pg no.)	Sample and key participant characteristics (pg no.)	Study design and data collection methods (pg no.)	HRQOL measures [and instrument, if applicable] (pg no.)	HRQOL dimension(s) [physical, psychological, social, spiritual] (pg no.)	Key findings for YBBCS (pg no.)	Appraisal tool and number of items met on checklist out of total (STROBE or CASP)
Morrow (2014)	Demonstrate the differential effects of age, race, cancer diagnosis, and treatment on quality of life in young breast cancer survivors—pg 21	N/A	Setting: Recruited from University of Texas MD Anderson cancer center Eligibility criteria: Women aged 18 or older who were younger than 45 at the time of breast cancer diagnosis, were more than 12 months past their breast cancer diagnosis, and have received or were currently undergoing surgery, chemotherapy, radiation therapy, or adjuvant endocrine therapy for breast cancer—pg 21–22	Sample: 1090 Black, Asian, Hispanic, Native American, and White women Participant characteristics: Age range: 18–45 78 % married More than half underwent a mastectomy —pg 23	Study design: cross-sectional, quantitative Data collection method: self-administered survey—pg 22	HRQOL measures included the appearance concerns, financial problems, distress over recurrence, family-related distress, and benefits of cancer (Quality of Life in Adult Cancer Survivors (QLACS))—pg 21–22	Social well-being—pg 22	Black breast cancer survivors under age 45 reported greater levels of financial distress (social well-being) compared with White breast cancer survivors under age 45—pg 28	21/22 (STROBE)

Table 1 continued

First author (year)	Study objectives (pg no.)	Conceptual framework (pg no.)	Setting and eligibility criteria (pg no.)	Sample and key participant characteristics (pg no.)	Study design and data collection methods (pg no.)	HRQOL measures [and instrument, if applicable] (pg no.)	HRQOL dimension(s) [physical, psychological, social, spiritual] (pg no.)	Key findings for YBBCS (pg no.)	Appraisal tool and number of items met on checklist out of total (STROBE or CASP)
Sheppard (2013)	Assess levels of depressive symptomatology in Black women with breast cancer compared to women without breast cancer, and examine demographic, psychosocial, and clinical factors correlated with depression—pg 292	N/A	Setting: recruited from Washington, DC and surrounding suburbs Eligibility criteria: *Entire Cohort* - Black women between 40 and 50 years, not currently being treated for depression, and not currently engaged in abuse of illicit drugs. *Breast Cancer Cohort* -Women with breast cancer were eligible if diagnosed with breast cancer within 12 months of data collection—pg 292–293	Sample: 152 ($n = 76$ breast cancer cases; $n = 76$ non-breast cancer controls) women Participant characteristics: Age range: 40–50 Over 25 % with incomes over $40,000 Over 65 % were college educated—pg 294	Study design: cross-sectional, quantitative Data collection method: self-administered survey—pg 294	HRQOL measures included depressive symptomatology-(Beck Depression Inventory-Short Form) effective functioning, adaptability, and personal resourcefulness (Barron's Ego Strength Scale (MMPI-2))—pg 294	Psychological and physical well-being—pg 294	Black breast cancer survivors aged 40–50 reported higher levels of depression (psychological well-being) compared with Black women aged 40–50 without breast cancer—pg 294 Black breast cancer survivors aged 40–50 reported worse functioning (physical well-being) compared with Black women aged 40–50 without breast cancer—pg 294	20/22 (STROBE)

HRQOL Health-related quality of life, *CASP* Critical appraisal skills program, *STROBE* Strengthening the reporting of observational studies, *YBBCS* Young Black breast cancer survivors

Results

Summary of existing literature

Among the six articles included, five were cross-sectional quantitative studies and one was a cross-sectional mixed-methods study (Table 1). Eligibility criteria related to time since diagnosis varied, with one study sampling only BC survivors within 12 months of diagnosis, two studies sampling BC survivors at least 12 months post-diagnosis, and three studies sampling BC survivors regardless of time since diagnosis. Three studies were limited to Black BC survivors, two studies focused on young women, and one study recruited only young Black BC survivors. One study employed a conceptual framework, specifically Ferrell and Grant's Quality of Life Model [18, 19]. All studies employed a range of validated HRQOL measurement tools, including the Psychological Adjustment to Illness Scale [48], Interpersonal Support Evaluation List [49], Quality of Life/Breast Cancer Psychological Well-Being Subscale [18, 19], Functional Assessment of Cancer Therapy-Breast [50], Quality of Life in Adult Cancer Survivors [51], Beck Depression Inventory-Short Form [52], and Barron's Ego Strength Scale [53]. All studies met 50 % of the critical appraisal criteria, and five studies met over 70 % of appraisal criteria. A summary of key findings by HRQOL domain is described in the following sub-sections.

Psychological well-being

Five studies reported on at least one aspect of psychological well-being in young Black BC survivors. In one study, younger Black BC survivors reported significantly worse psychological adjustment post-surgery than older Black BC survivors [54]. Two studies examined fear in Black BC survivors. Findings from one study suggested that compared with older survivors, younger Black BC survivors were less likely to report high levels of fear of recurrence (67 vs. 37 %) [55]. However, another study indicated that 61 % of young Black BC survivors reported anxiety related to fear of dying [56]. Moreover, one study documented lower psychological well-being among younger Black BC survivors relative to older Black survivors [57]. Similarly, another study found that young Black BC survivors were more likely to report depressive symptoms than young Black women with no BC history [58].

Social well-being

Issues related to social support, relationship strain, and financial distress were described in three studies. One study reported greater levels of social support among younger Black BC survivors compared with older Black survivors [54]. Findings from another study revealed substantial emotional (70 %) and functional support (56 %) needs among young Black BC survivors [56]. Most young Black BC survivors in that study indicated that they received emotional (58 %) and functional support (67 %) from families and community; however, 30 % reported unmet emotional support needs around time of diagnosis. In the same study, romantic relationship strain and feeling isolated emerged as key concerns. Finally, a third study found that young Black BC survivors reported higher levels of financial distress than their White counterparts [59].

Physical well-being

Findings from the three studies reporting on physical functioning suggest that young Black BC survivors experience substantial decrements in physical well-being. Compared with older Black BC survivors and young Black women without BC, young Black BC survivors reported lower physical well-being and functioning [57, 58]. Issues related to infertility and sexual dysfunction (e.g., loss of sexual desire, vaginal dryness, pain during intercourse) were reported among young Black participants in one study [56]. Approximately half of young Black BC survivors in that study reported wanting to have a child near time of BC diagnosis; however, 48 % of women did not recall discussing infertility with providers and fewer than 15 % became pregnant since completing BC treatment. This study, however, did not report on pregnancy attempts or infertility.

Spiritual well-being

One study reported on spiritual well-being in young Black BC survivors. Fifty percent of women reported that their BC diagnosis positively changed their outlook for the future and helped them develop a new appreciation for life. Additionally, 18 % indicated that their illness strengthened their spirituality and religious faith [56].

Gaps in existing literature

Several gaps in the existing literature are worth noting. Overall, few studies were grounded in HRQOL theory and none were guided by theories that accounted for race- or age-related differences in HRQOL (e.g., Superwoman Schema, Network Stress, Weathering Effect [35, 36, 60–62]). Such theories can help inform our understanding of modifiable pathways leading to differential HRQOL outcomes in young Black BC survivors. Additionally, no study quantified potential mediating factors (i.e., targets for intervention, such as patient–provider communication, supportive care access) impacting HRQOL outcomes. Similarly, the absence of longitudinal studies examining HRQOL changes over time and intervention studies targeting HRQOL outcomes in young Black BC survivors represents a significant research gap that hinders progress in identifying critical time points for intervention and effective strategies for optimizing HRQOL in this survivor group.

Moreover, compared with the psychological domain, evidence on physical, social, and spiritual HRQOL in this patient population is scarce. Previous studies indicate that Black cancer survivors typically experience worse physical functioning and side effects relative to Whites [25, 26]. Therefore, exploring this aspect of HRQOL in young Black BC survivors is especially important, as their physical HRQOL needs may differ from their older counterparts. Furthermore, despite high levels of spirituality commonly reported among Black women [63–66], only one study examined spirituality in young Black BC survivors.

Discussion

This systematic review summarized and critiqued the limited available literature describing HRQOL among young Black BC survivors across the BC continuum, from diagnosis until death, and highlights the need for more research on HRQOL in this important patient population. The review revealed that young Black women generally experience worse overall HRQOL after BC diagnosis, compared with their older Black, younger White, and older White counterparts, as well as compared with young Black women without BC. Although comparison groups varied across studies, regardless of the comparison, young Black women with BC fared worse in most HRQOL domains, except in spiritual well-being (where there was no between group comparisons). With respect to psychological well-being, young Black women with BC reported greater fear of dying, but not fear of recurrence, compared with older Black women [55, 56]. They also reported greater depressive symptoms compared with young Black women without cancer [58]. Regarding social well-being, despite reporting greater social support than older Black women with BC, 30 % of young Black women expressed unmet social needs [58]. Compared with young White women with BC, young Black women experienced greater financial distress [59]. Moreover, relative to older Black women with BC and young Black women without BC, young Black BC survivors reported lower physical and functional HRQOL [57, 58].

These findings suggest a need for routine HRQOL assessments, especially distress screening, among young Black BC survivors. Distress screening identifies psychosocial (cognitive, behavioral, emotional), social, and spiritual signs that may indicate depression, anxiety, financial distress, social isolation and lack of social support, or other threats to individual well-being [67]. Ideally, screening for distress in oncology patients should occur during an initial medical visit, employ a standardized and validated instrument, and, when warranted, lead to timely referrals to psychosocial services, financial counseling, or other support services [68]. Given the 2012 American College of Surgeons Commission On Cancer (CoC) recommendation that providers should screen patients for psychosocial distress, findings from our review suggest that young, Black women, in particular, may benefit more from systematic distress screening than other subgroups since their burden of distress is greater across most HRQOL domains. However, as shown in this review, for young Black women, it is essential that distress-screening tools target areas such as depression and financial distress. The National Comprehensive Cancer Network Distress Thermometer and Problem List is one screening instrument that can be used quickly and efficiently to identify cancer patients in distress [69]. Using this tool, 30 % of BC patients have reported high levels of distress (scores >5 on a ten-point scale), but more research is needed in large, racially diverse populations to understand whether or not young Black women report greater distress using such instruments, and if so, whether referral and intervention mechanisms need to be tailored in ways to mitigate distress in this population [70].

Moreover, our findings have important implications for clinical practice and supportive care. First, because HRQOL varies by race and age, with young Black women more often experiencing worse HRQOL, routinized distress screening [67–70] can potentially help providers identify and address unique psychosocial issues that disproportionately affect this population. Specifically, routine screening can enhance providers' surveillance and follow-up on these issues (e.g., social isolation) and may lead to referral (e.g., social worker and mental health services) and care delivery that is more timely, appropriate, patient centered, and culturally sensitive than has historically been provided.

Second, patient and survivor resources must target specific needs of young Black women; for example, by offering culturally relevant interventions [71], including peer support counseling that emphasizes unique experiences and concerns of young Black women—many of whom are employed, with young children or fertility intentions that may be less relevant to older women. Moreover, because experiences of Superwoman Schema and Network Stress are well documented in Black women [35, 36], approaches that simultaneously promote stress management, effective coping with multiple demands, and the importance of self-compassion and self-care may be especially beneficial to improving HRQOL in young Black BC survivors [72].

Third, young Black women often present with advanced BC disease, resulting in aggressive treatments [11]. Providers and support staff should be transparent in informing young Black women regarding treatment expectations and outcomes and addressing specific treatment-related concerns unique to this group (e.g., treatment-induced infertility).

Finally, considering the greater financial vulnerability of young Black BC survivors, evidenced by higher financial distress reported in this review [59], and greater representation of young Black women among uninsured and Medicaid populations [73], systematic referrals to financial counselors, social workers, and other support services to address financial concerns may be particularly important to mitigating financial-related stress and anxiety that young Black women with cancer differentially experience.

These findings suggest a number of research implications. First, despite initially identifying 2533 potentially relevant articles, after applying eligibility criteria, only six articles were included in this review. Still, these articles met most STROBE/CASP quality appraisal criteria [46, 47]. The paucity of HRQOL data, however, points to a critical need for additional HRQOL studies and culturally tailored psychosocial interventions targeting young Black BC survivors and the providers serving them. Furthermore, given that all six studies were cross-sectional, future work should assess HRQOL changes over time across the BC continuum, as cross-sectional HRQOL assessments may limit our understanding of experiences and needs of this group. This review also highlights how studies providing only overall estimates of HRQOL (i.e., non-domain-specific) may fail to recognize spirituality as a protective coping mechanism among young Black women [56]. Therefore, exploring more fully (and designing interventions to enhance) spiritual well-being may be especially impactful in this group.

Several limitations warrant mention. In this review, studies which categorized “young” BC survivors as those less than 55 years of age were identified, but excluded studies based on the predetermined eligibility criteria. As described, 50 years is the age threshold commonly reported in the literature [28, 43, 44] to dichotomize young and old women and reflects the mean age at menopause in Black women. Therefore, studies using alternative definitions of “young” were excluded from this review. However, one would not expect findings among Black BC survivors ages 50–55 to vary substantially from results reported in this study. Finally, findings should be interpreted with a focus on understanding HRQOL experiences of Black women with BC who are less than 50 years of age, and not experiences of older Black women, young Black women without cancer, women with cancers other than BC, or other minority groups, all of which were outside the scope of this review.

Based on our findings, the following recommendations for advancing HRQOL research and improving supportive care services for this patient population are proposed: (1) Expanding HRQOL research among young Black BC survivors is critical. Moreover, because young Black women are not often the focus of targeted resources and social support and less often enrolled in clinical trials [74], clinicians and researchers should broaden the aperture to design and test interventions that encompass the needs of this group (e.g., whole-person, family, and culturally oriented care), with specific recruitment strategies to promote inclusion of young Black BC survivors. (2) HRQOL assessments (e.g., distress screening) should be routinized in patient and survivorship care, as recommended by current CoC guidelines [68], with attention to providing opportunities to elicit patient-reported outcomes, in non-academic and lower resourced oncology environments, where many Black women with BC are being treated [75]. (3) Providers should recognize that young Black women’s BC experiences may differ significantly from older White and older Black women’s experiences (e.g., young Black women may experience and witness more aggressive BC and BC-related deaths in their communities, which may influence risk perception and fatalistic attitudes). In light of these differences, providers and supportive care staff should be aware of this lived experience and seek opportunities to understand and address these perceptions, socially embedded norms/expectations, and behaviors. (4) Considering that young Black women are potentially facing competing demands within their family structures and stress within social and economic networks (e.g., juggling unpaid time off from work with the need to complete expensive BC treatments), providers should be cognizant of and responsive to the possible existence of unique social roles and compounded stressors among some Black women, as well as culturally nuanced strategies for stress-coping, managing daily obligations, and caring for others [34, 72]. As such, programs and services that focus on optimizing resilience (including self-care and stress management) and provide resources to help ease BC burden in the context of other competing demands may be most impactful in this population. In summary, young Black women must be prioritized in the oncology care environment in ways that recognize their unique concerns, competing demands, and HRQOL needs to ensure optimal HRQOL outcomes both during and after BC treatment.

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Black Woman with Breast Cancer inspired this contribution to research and clinical practice.

Compliance with ethical standards

Conflict of Interest All other authors have no conflicts of interest to disclose.

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