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Impact of a Breast Cancer Diagnosis on Finances and Marital Status in Young Women

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Abstract

Purpose A breast cancer diagnosis can impact every aspect of a woman's life, particularly for women diagnosed before age 45 when they are in the process of establishing stability in their personal and professional lives. This study investigated the impact of a breast cancer diagnosis on employment, finances, and personal relationships among young breast cancer survivors.

Methods We conducted descriptive statistical analysis of survey data from 315 women diagnosed with breast cancer before age 45. Surveys were administered electronically and included 40 questions on demographics asking about employment, insurance, income, and marital status at two time points: at diagnosis and at the time the survey was completed. Descriptive and regression analyses were conducted. The McNemar-Bowker Test of Symmetry was used to calculate the significance of changes in employment, insurance, income, and marital status at the two time points.

Results We found significant changes following diagnosis in employment and insurance. Prior to diagnosis, 68.6% of respondents were employed full time, compared to 52.4% following diagnosis – falling from 212 to 162 respondents. Individuals who were unable to work increased by 14.6% after diagnosis, rising from 4 to 49 respondents. The decline in full-time employment was highest among those with a diagnosis of Stage IV cancer (33.9%), with the number of full-time worker respondents falling from 79 to 41. We found a significant change in insurance ($p < .001$) with a decline in individuals with private or no insurance of 4.7% and 3.4%, respectively, while those with public insurance increased by 8.1%.

Conclusion Our findings suggest that young breast cancer survivors are particularly vulnerable to changes in employment, with more than a tenfold increase in the number of young women who reported being unable to work following diagnosis. Our findings also indicate a significant shift from private to public insurance, particularly for individuals living with Stage IV cancer. These results point to opportunities to address the specific needs of young women diagnosed with breast cancer and improve their overall quality of life.

Keywords Breast cancer, Survivorship, Young women, Employment, Insurance

Background

A breast cancer diagnosis often has a far-reaching impact, affecting nearly every aspect of life. Treatment-related toxicities can affect physical health, resulting in both long-term and short-term impairments, such as chronic fatigue, cardiotoxicity, sexual dysfunction, or neuropathy [1]. Cancer survivors are also at higher risk for poor mental health compared to individuals who have no cancer history [2, 3]. A diagnosis can have a considerable impact

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on overall quality of life, with changes in family relationships, spirituality, and future life plans [4].

Studies of the financial impact of a cancer diagnosis have often focused on the cost of care, with an emerging awareness of the broader impact of cancer and cancer treatment on employment, income, and household stability. Recent research points to multiple factors that can impact employment after a cancer diagnosis. Employment can provide a sense of purpose, and working after a cancer diagnosis offers some cancer survivors a feeling of control and a sense of normalcy or distraction, which can be beneficial, particularly when the work environment supports their needs [5]. However, employment decisions may also be driven by other factors, including financial concerns as well as physical and mental health issues [6, 7]. One study showed that more than 50% of young breast cancer survivors had a disruption to employment, such as quitting a job or reducing hours due to cancer or treatment-related toxicities [6]. Breast cancer survivors who continue to work may struggle with long-term disabilities such as fatigue, neuropathy, or cognitive impairment that affect their job performance and job satisfaction [8–10].

Women with breast cancer may hesitate to change jobs or stop working for fear of losing income or employer-sponsored health insurance. This is particularly important for survivors in the U.S., where there is no universal health coverage. Individuals may purchase insurance, commonly referred to as “private insurance” or may be covered under a government-sponsored plan, commonly referred to as “public insurance.” Most individuals in the U.S. (53%) purchase insurance for themselves and their family through an employer, called “employer-sponsored insurance.” [11] Private insurance may also be purchased directly from an insurance company. Public insurance includes programs for individuals who are over age 65 (Medicare), low income or have a disability (Medicaid), Veterans (Veterans Administration) or actively serving in the military (TRICARE). There is considerable variability in the cost of insurance and the services covered, which can have a significant impact on cancer outcomes [12–14]. Cancer survivors across all cancer types showed a decline in personal and family income in the years immediately following diagnosis [15–17]. While some evidence indicates that the impact lessens over time [16], there is insufficient evidence on long-term disruptions in earnings and productivity [17].

A cancer diagnosis can also have an impact on intimate relationships. Research on the general population of cancer survivors suggests that cancer is associated with a slightly decreased divorce rate [18]. Glantz and colleagues identified gender as a significant factor in rates of divorce or separation among heterosexual couples after a cancer diagnosis, with significantly higher rates

of divorce among women diagnosed with cancer compared to men diagnosed with cancer [19], however there have been few follow-up studies that have explored this topic. Similarly, older studies point to the impact of the financial stressors of a cancer diagnosis on intimate relationships [20–22], however there has been limited more recent research in this area.

Many of these challenges are intensified in individuals diagnosed with breast cancer before age 45, exacerbated by issues unique to their age and life stage, including interruptions to career and family life when young people may be in the early stages of establishing stable employment, finances, and personal relationships [23, 24]. Research on health state utility (HSU)—a parameter for calculating quality-adjusted life-years or life-expectancy – among women with breast cancer found a significantly greater impact among those aged 18–44 years when compared with those aged 45 and over [25]. Young women diagnosed with breast cancer experience significantly greater per-capita economic losses from both missed work and home productivity among breast cancer survivors aged 18–44 compared with survivors aged 45 and over and their peers with no history of cancer [26]. One study found that 40% of young women diagnosed with breast cancer experienced employment issues [27]. Several factors put young women at greater risk for disruption of partner relationships, including higher rates of emotional distress, issues with personal and household finances and employment, and changes in physical health and sexual function [27–30].

As cancer incidence among young adults rises and the number of cancer survivors grows, there is an urgent need to better understand the underlying mechanisms that disrupt their lives. This is particularly significant for young survivors who may live for decades beyond the initial diagnosis and often struggle with cancer-related challenges in their employment, finances, and personal lives. There is limited research that investigates how gender and young age at diagnosis impact the challenges facing young women diagnosed with breast cancer.

The Young and A Survivor Network for Health Equity Among Young Breast Cancer Survivors (YAAS!) at the University of Illinois at Chicago is a multi-sectoral collaboration to enhance support for women diagnosed with breast cancer before the age of 45. In 2021, YAAS! launched a survey to document the experiences of young women during the diagnosis process. The goal of the study was to gain a systematic understanding of the diagnostic pathway of young women with breast cancer, identify gaps in care, and develop resources and interventions to address these gaps [31, 32]. In the demographic section of the survey, we asked respondents to report changes in employment, insurance, income, and marital

status following their diagnosis. In this secondary analysis of these survey data, we examine these self-reported demographic data to investigate the question of what the impact of a breast cancer diagnosis before age 45 is on employment, insurance, income, and marital status. The results of this study will contribute to a better understanding of disruptions in the lives of young women diagnosed with breast cancer and inform the design of interventions to support this vulnerable population.

Methods

We analyzed data from a survey-based study exploring the pathways to breast cancer diagnosis in women 18–44 years old. Invitations to participate in the survey were distributed via social media and through online breast cancer advocacy and support organizations. Inclusion criteria were adult females diagnosed with breast cancer before age 45 living in the U.S. and able to complete the survey in English. Data were collected using a 52-item online survey that included 12 open-ended questions about diagnosis experience and 40 multiple-choice and short-answer questions on demographics and disease status. This analysis focuses on the responses to the 40 questions on demographics. Before full deployment of the survey, it was administered to a small, representative group of women diagnosed with breast cancer before age 45 to identify inconsistencies or ambiguities. All survey items were discussed by the group to ensure questions were interpreted as intended. This study was performed in line with the principles of the Declaration of Helsinki. The Institutional Review Board at the University of Illinois at Chicago (Protocol # 2019–1331) determined this study to be exempt. Data were collected from January 2021 to May 2021 and August 2021 to December 2022. (Data were not collected in June and July of 2021 due to pausing to find advocacy groups from underrepresented populations through which to recruit.)

Measures

The survey included questions about respondents' race, age at diagnosis, and year of diagnosis. The study also asked questions about changes in employment, insurance, income, and marital status at two time points: at diagnosis and at the time the survey was completed. We used categorical variables for analysis of age (18–29, 30–39, and 40–44), years since diagnosis (<5 years, 5–9 years, 10–19, and >19 years), and income (less than \$60,000; \$60,000 to \$85,000; and greater than \$85,000). We used two categories for cancer stage – early (Stage I–III) and advanced (Stage IV) to distinguish between those who have completed or expect to complete treatment (early stage) and those who expect to remain in active treatment for the rest of their lives (metastatic).

Statistical analysis

We conducted descriptive and regression analyses using SPSS. Statistical significance was defined as $p < 0.05$. We used the McNemar-Bowker Test of Symmetry to calculate the significance of changes in four areas (employment, insurance, income, and marital status) at the two time points. We also calculated the significance of changes in these areas across the two time points among groups that often experience greater challenges due to sociodemographic or disease factors, including respondents diagnosed with Stage IV disease, without a four-year college degree, and within five years of initial diagnosis. We excluded survey responses with missing data at either time point so that the analysis does not rely on incomplete information. The target population of young women with breast cancer is specialized, and we aimed for a margin of error between 5–10%. Our total of 315 respondents should have a margin of error between 5–7.5% [33].

Results

A total of 315 individuals completed the 40-item demographic section of the survey. Our cohort was majority white race (85.4%). At the time of the survey, most participants were married (75.6%), had a household income greater than \$85,000 (52.4%), were employed full-time (52.4%), had private insurance (79.6%), and had been diagnosed with breast cancer within five years (73.9%). Participants ranged in age from 23 to 44 at the time of diagnosis, with a mean age of 35.5. Among the respondents who reported their cancer stage at the time of the survey (85.3%), almost half (42.8%) were living with metastatic breast cancer. Table 1 presents the characteristics of the respondents.

We found significant changes following diagnosis in both employment status and insurance, which we detail in Table 2. Since diagnosis, individuals working full-time declined overall by 16.2%, and those unable to work increased by 14.6%. Individuals with private insurance and no insurance declined by 4.7% and 3.4%, respectively, while those insured through public insurance increased by 8.1%. We found no significant changes in marital status ($p = 1.00$), with less than 1% difference in the number of people married or living with a partner before and after diagnosis. Similarly, we found no significant change in household income ($p = 0.892$) after diagnosis, with less than 1% difference in the number of respondents with a household income higher than \$85,000 before and after diagnosis. We found no significant differences in any of the four areas by race, ethnicity, or age at diagnosis.

Table 1 Sociodemographic and cancer-related characteristics of respondents at time of study (N = 315)

	N (%)
Race	315
White	269 (85.4%)
Non-white	46 (14.6%)
Relationship status	311
Married/Living with partner	235 (75.6%)
Unmarried	76 (24.4%)
Household income	302
< \$60,000	74 (23.5%)
\$60,000–\$85,000	63 (20.0%)
> \$85,000	165 (52.4%)
Employment status	309
Full-time	162 (52.4%)
Self-employed	17 (5.5%)
Part-time	28 (9.1%)
Underemployed	3 (1.0%)
Unemployed (looking for work)	9 (2.9%)
Unemployed (not looking for work)	41 (13.3%)
Inability to work	49 (15.9%)
Insurance status	299
Private Insurance	238 (79.6%)
Public Insurance	60 (20.1%)
Uninsured	1 (0.3%)
Cancer stage	269
Stage I, II, & III	154 (57.2%)
Stage IV	115 (42.8%)
Age at Diagnosis	
Mean (SD)	35.51
Total	315
Years since diagnosis	307
20+ years	4 (1.3%)
10–20 years	25 (8.1%)
5–10 years	51 (16.6%)
5 years or less	227 (73.9%)

*some percents may not sum to 100 due to rounding

Employment

There were significant changes in employment across the cohort. Prior to diagnosis, 68.6% of all respondents were employed full-time, compared to 52.4% following diagnosis. The rate of those unable to work grew from 1.4% prior to diagnosis to 15.9% following diagnosis. The impact on other types of employment was much lower, with no change in self-employment, less than a 1% decline in part-time employment and those who were unemployed/looking for work, and a 3.7% increase in those who were unemployed/not looking for work.

The decline in full-time employment was highest among those with a diagnosis of Stage IV cancer

(33.9%), followed by those without a 4-year college degree (16.8%), and those within five years of diagnosis (15.2%). Similarly, the increase in being unable to work was highest among those with a diagnosis of Stage IV cancer (31.2%), followed by those without a college degree (23.7%), and those within five years of diagnosis (15.2%).

Insurance

We found a significant change in insurance status ($p < 0.001$) across all respondents and among those diagnosed with Stage IV disease. Among all respondents, we found the largest decline among those who were uninsured, which fell from 3.7% to 0.3%. Those with public insurance increased from 11.7% prior to diagnosis to 19.8% after diagnosis. For women living with Stage IV cancer, the number of respondents with no insurance dropped from 5.7% to less than 1%. Those with private insurance declined 14.4%, from 84% to 69.8% and those with public insurance grew nearly three-fold, from 10.4% to 29.2%.

Discussion

Our analysis explored the impact of a breast cancer diagnosis on employment, insurance, income, and marital status among a cohort of young breast cancer survivors. Our findings suggest that young survivors are particularly vulnerable to changes in employment, with more than a tenfold increase in the number of young women who reported being unable to work following diagnosis. Our findings also indicate that a breast cancer diagnosis may result in changes in insurance status, with a significant shift from private to public insurance, particularly for individuals living with metastatic breast cancer.

Disruptions in employment after a cancer diagnosis have been attributed to a range of factors. Changes in physical capacity [34–36], mental health [37], and personal values and priorities can affect job performance and job satisfaction [5, 38–40]. The constraints and uncertainties of daily life during treatment can also impact employment. A demanding treatment schedule, frequent clinic visits, and treatment toxicities, from nausea and fatigue to neutropenia, diarrhea, and constipation, can result in missed work and lower job performance. The workplace environment also plays a key role in the level of overall support and access to accommodations, paid leave, and protection from discrimination [5, 41]. Changes in insurance following the enactment of the Affordable Care Act (ACA) have increased protections and expanded options for insurance coverage for young women, particularly with respect to the need to continue working so as not to lose access to health insurance [27].

Table 2 Change in demographic characteristics since breast cancer diagnosis among respondents

Sociodemographic characteristics	Entire population (N = 315)			Stage IV at time of study (N = 115)			Did not complete Bachelor's degree (N = 102)			Less than 5 years from diagnosis (N = 227)		
	T1 n (%)	T2 n (%)	Change n (%)	T1 n (%)	T2 n (%)	Change n (%)	T1 n (%)	T2 n (%)	Change n (%)	T1 n (%)	T2 n (%)	Change n (%)
Employment status	(n = 309)	p-value^a < 0.001		(n = 112)	p-value^a < 0.001		(n = 95)	p-value^a < 0.001		(n = 223)	p-value^a < 0.001	
Full-time employment	212 (68.6%)	162 (52.4%)	-16.2	79 (70.5%)	41 (36.6%)	-33.9	57 (59.4%)	40 (41.7%)	-17.7	156 (70.0%)	122 (54.7%)	-15.3
Self-Employment	17 (5.5%)	17 (5.5%)	-	6 (5.4%)	4 (3.6%)	-1.8	7 (7.3%)	4 (4.2%)	-3.1	11 (4.9%)	11 (4.9%)	-
Part-time employment	30 (9.7%)	28 (9.1%)	-0.6	8 (7.1%)	11 (9.8%)	+2.7	13 (13.5%)	4 (4.2%)	-9.3	22 (9.9%)	19 (8.5%)	-1.4
Unemployed	2 (0.6%)	3 (1.0%)	+0.4	*	*	*	-	-	-	2 (0.9%)	2 (0.9%)	-
Unemployed (looking for work)	10 (3.2%)	9 (2.9%)	-0.3	4 (3.6%)	3 (2.7%)	-0.9	2 (2.1%)	2 (2.1%)	-	8 (3.6%)	9 (4.0%)	+0.4
Unemployed (not looking for work)	34 (11.0%)	41 (13.3%)	+2.3	13 (11.6%)	16 (14.3%)	+3.7	14 (14.6%)	20 (20.8%)	+6.2	22 (9.9%)	32 (14.3%)	+4.4
Inability to work	4 (1.3%)	49 (15.9%)	+14.6	2 (1.8%)	37 (33.0%)	+31.2	3 (3.1%)	26 (27.1%)	+24.0	2 (0.9%)	28 (12.6%)	+11.7
Health insurance status	(n = 299)	p-value^a < 0.001		(n = 106)	p-value^a < 0.001		(n = 93)	p-value^a 0.140		(n = 215)	p-value^a**	
Private Insurers	252 (84.6%)	238 (79.9%)	-4.7	89 (84.0%)	74 (69.8%)	-14.2	67 (72.0%)	62 (66.7%)	-5.3	182 (84.7%)	176 (81.9%)	-2.8
Public Insurer	35 (11.7%)	59 (19.8%)	+8.1	11 (10.4%)	31 (29.2%)	18.8	21 (22.6%)	30 (32.3%)	+9.7	26 (12.1%)	39 (18.1%)	+6.0
Uninsured	11 (3.7%)	1 (0.3%)	-3.4	6 (5.7%)	1 (0.9%)	-4.6	5 (5.4%)	1 (1.1%)	-4.3	7 (3.3%)	-	-3.3

Note: Bold values indicate two-sided significance at $p < 0.05$.

T1 – At diagnosis || T2 – At the time of the study || Change – Change between T1 and T2.

^a McNemar-Bowker Test of symmetry; p -values are based on comparisons between respondents' status at the time of diagnosis and at the time of the study.

*Excluded 1 "underemployed" at dx to get McNemar result || **Significance not calculated due to lack of symmetry.

Our findings suggest that cancer or treatment-related disability was the primary reason that young survivors were not working following their diagnosis, with only a small percentage of survivors reporting that they were unemployed, whether looking for work or not. The impact of a cancer diagnosis on employment was even greater for young women living with metastatic breast cancer and those with less than a 4-year college degree. This is consistent with other studies that point to the physical, practical, and psychological demands of active cancer treatment, which can make it especially challenging for young women living with metastatic disease to continue to work [41]. Survivors without a 4-year college degree may be more vulnerable because they are more likely to be in hourly rather than salaried jobs with limited access to work accommodations or paid leave [42].

The results from this study are consistent with other studies that suggest that young breast cancer survivors do not receive adequate support related to employment after a diagnosis [7, 27, 38, 41–43]. Our analysis builds on prior studies focused on individuals diagnosed with Stages I–III, to include the impact on individuals living with Stage IV breast cancer, documenting the disproportionate impact of a Stage IV diagnosis on both employment and insurance [27]. These issues are often exacerbated by cancer-related stigma, what Melhem and colleagues describe as the “hidden burden of breast cancer as a chronic illness” [44]. Stigma is disproportionately higher among breast cancer survivors compared to survivors of other cancers [45]. Several studies report that cancer survivors who experience stigma are more likely to lose their jobs compared with survivors who do not experience stigma [33, 37]. Stigma can impact employment by delaying access to healthcare and supportive services to address issues affecting job performance or workplace accommodations to mitigate the impact of cancer-related symptoms on work [44, 45]. Stigma can also manifest in the form of discrimination by employers or coworkers who make negative judgments about cancer survivorship, for example, fear of working with someone with cancer or an assumption that a survivor’s work capacity is diminished, and others will have to compensate for them. This is not only linked to job loss, but also to being demoted, denied promotion, or denied wage increases [27].

Our findings show significant changes in insurance, most notably a 70% increase in the number covered by public insurance. All but one of the respondents were insured following diagnosis. These results point to the availability of public insurance following a cancer diagnosis for those who cannot maintain private insurance; however, it also suggests that many respondents maintained private insurance despite being unable to work,

either through a spouse/partner or the marketplace. This raises several questions, including the financial burden of maintaining private health insurance, the disruptions of changing insurance, and the impact of that change at the time of diagnosis. Numerous recent studies have explored the association between health insurance status and cancer outcomes such as stage at diagnosis, access to quality care, and survival [12–14, 42]; however, there is limited research that examines shifts in insurance following a cancer diagnosis, from private to public insurance or employer-sponsored to marketplace insurance. Changes in insurance coverage can be disruptive and challenging for cancer survivors, with potential changes in the provider network, out-of-pocket costs, and coverage of procedures or prescriptions. Our results point to the significance of these changes for young survivors and suggest a number of avenues for future research.

Our study found no significant changes in household income despite significant changes in employment following diagnosis. We also found no significant changes in marital status following diagnosis. This may be related to the fact that at the time of the study, 76% of respondents were married, over half of the participants had a household income exceeding \$85,000, and less than one-fourth had a household income of less than \$60,000. Research shows that marital stability is higher among higher-income people than lower-income people [24, 27], which may help explain the marital status findings.

Limitations

There were some limitations in our study. The study relied on self-reported data, so there may have been recall bias when the respondents did not accurately remember their experiences, and social desirability bias and stigma associated with a breast cancer diagnosis may have influenced where respondents provided answers they believed were more socially acceptable. Excluding missing data could have impacted the ability to identify significant effects in the analysis. Data were collected during the COVID-19 pandemic, which caused significant disruptions in the lives of the general population, and the changes we observed may reflect the impact of a global pandemic. The sample is not representative of the diversity of the population of the U.S. or young breast cancer survivors. Despite efforts to recruit participants from under-represented races, sexual orientations, and income groups, the sample is over-representative of individuals who are white, high income, high education levels, and married. Furthermore, there is limited data on rates of disease progression so there is uncertainty if the sample accurately represents the distribution of individuals with Stage IV disease in the general young breast cancer population. The distribution of survey invitations via social media

and breast cancer advocacy and support organizations, may have introduced selection bias, potentially limiting the generalizability of the findings to broader populations. Categorizing cancer stages into "early" (Stages I – III) and "advanced" (Stage IV) may oversimplify the complexity of disease progression, which could affect the differences captured in the analysis. Future analysis could help establish causal inference by incorporating more potential confounding factors such as time since diagnosis or treatment type and employing other types of study designs, such as a randomized controlled trial.

Conclusion

Our findings contribute to the growing evidence of the importance of providing services tailored to the needs of young women – in this case, to destigmatize breast cancer-related disabilities and provide support so that young women can continue to thrive at work after a breast cancer diagnosis. As the population of cancer survivors grows and cancer incidence among young adults rises, there is an urgent need to better understand the impact of a cancer diagnosis on the lives of young survivors, with greater attention to the mechanisms through which disruption occurs. Loss of employment after a breast cancer diagnosis can have far-reaching implications for physical and mental quality of life and financial stability. As previously noted, work can be critical to identity, provide meaning and purpose, expand social networks, and contribute to financial stability, particularly for young people. The cost of lost productivity impacts the survivor and her family, as well as the larger economy. Young breast cancer survivors potentially have decades of life years ahead, and a comprehensive support system that responds to their specific needs can mitigate some of the long-term effects and improve overall quality of life and well-being.

Authors' contributions

T.H. and S.S. contributed to the study conception, study design, and data collection. M.F. and R.J. conducted statistical analysis. T.H., M.F., and M.C.H. conducted data interpretation. M.F. prepared the tables. T.H., M.F. and M.C.H. prepared the first draft of the manuscript. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability

The data that support the findings of this study are available from the corresponding author (T. H.) upon reasonable request. The data are not publicly available due to their containing information that could compromise the privacy of research participants.

Declarations

Ethics approval consent to participate

This study was submitted to and reviewed by the Institutional Review Board at the University of Illinois at Chicago (Protocol # 2019–1331) and determined to meet the criteria for exemption as defined in the U.S. Department of Health and Human Services Regulations for the Protection of Human Subjects [45 CFR 46.104(d)]. Y.

Informed consent was obtained from all individual participants included in the study. Participants were informed of the nature and goals of the study. To protect confidentiality, no personal identifiers were collected. All participants were assigned a study number and confidentiality was strictly maintained. Participation was fully voluntary; all participants were informed of their right to skip questions they chose not to answer or withdraw from the study at any time if they wished to do so for any reason without affecting their relationship with healthcare providers or other services. Data were collected and stored on a secure University server.

Consent for publication

Not Applicable.

Competing interests

The authors declare no competing interests.

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