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EPIDEMIOLOGY

Employment trends in young women following a breast cancer diagnosis

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Abstract

Purpose Little is known about how a breast cancer diagnosis and treatment affects job-related outcomes in young women with breast cancer, who are an integral part of the workforce. We sought to describe employment trends among young breast cancer survivors.

Methods 911 women with non-metastatic breast cancer were surveyed about employment-related outcomes 1 year post-diagnosis. Participants were enrolled in the Young Women's Breast Cancer Study an ongoing, multi-center cohort of women diagnosed with breast cancer at age ≤ 40.

Results Among 911 women, median age at diagnosis was 36 years (range 17–40). Most women (80%, $n = 729$) were employed 1 year post-diagnosis. Among the 7% ($n = 62$) employed before diagnosis but who reported unemployment at 1 year, approximately half reported they were unemployed for health reasons. Among employed women, 7% said treatment affected their ability to perform their job. Women with stage-three disease (vs. stage 1 disease, odds ratio (OR): 3.73, 95% CI 1.39–9.97) and those who reported having money to pay bills after cutting back or difficulty paying bills at baseline (vs. having enough money for special things, OR 2.70, 95% CI 1.32–5.52) at baseline were more likely to have transitioned out of the workforce.

Conclusions Our results suggest an impact of disease burden and socioeconomic status on employment in young breast cancer survivors. There is a need to ensure young survivors who leave the workforce following diagnosis are sufficiently supported given the potential adverse psychosocial and financial impacts of unemployment on survivors, their families, communities, and society.

Keywords Employment · Breast cancer · Survivorship · Outcomes

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Introduction

The number of people surviving cancer is expected to rise to approximately 18 million by 2022 [1]. Female breast cancer represents approximately 15% of all new cancer cases in the United States (US), with an estimated 90% of breast cancer patients alive at 5 years after diagnosis [2]. Therefore, there is a need to focus on breast cancer survivorship issues to gain a better understanding of how a breast cancer diagnosis can impact long-term medical, emotional, and social outcomes [3].

Recent data suggest a substantial proportion (40–76%) of working-age females are employed when diagnosed with breast cancer, making it relevant and important to understand employment trends in breast cancer survivors [3–7]. Some prior studies suggested that most breast cancer

survivors are able to maintain employment (although some may take time off during treatment), while others indicate that a substantial proportion of patients do not return to work after cancer [5, 7, 8]. The prevalence of unemployment following breast cancer surgery ranged from 5.6 to 56.3% in a recently published systematic review and meta-analysis [9]. In one study, women who underwent surgery for breast cancer were three times more likely than healthy women to leave work within the first year of treatment [10] supporting other studies that have also found the risk of unemployment to be higher among survivors when compared to individuals without cancer [11]. In addition, breast cancer can impact survivors' ability to work and job performance (e.g., cancer-changed physical and cognitive functional ability can negatively impact work productivity) and lead to them experiencing higher work-related distress [4, 12–15].

Almost 10% of new breast cancer cases each year in the US occur in women younger than 40 [16, 17]. Breast cancer among younger patients usually requires more aggressive treatment that can lead to more physical and psychosocial suffering [16, 18]. Further, financial sequelae may be even more pronounced for young adults with cancer given their life stage, potentially increasing the burden for this vulnerable group [19]. Given that young women are an integral part of the workforce, a breast cancer diagnosis can have a profound impact on career and employment opportunities that may result in long-term social and economic consequences [12].

Young adult cancer survivors are poorly represented in most of the existent series addressing the socioeconomic burden of cancer with little known about the impact of a breast cancer diagnosis and treatment on a young woman's desire and ability to work. Using a contemporary cohort of young breast cancer patients, we sought to characterize employment patterns in the year following diagnosis, as well as to describe the work experience among those who remained employed and potential barriers to rejoining the workplace.

Methods

Participants

Helping Ourselves, Helping Others: The Young Women's Breast Cancer Study (YWS) is a multi-institutional prospective cohort study that enrolled women diagnosed with breast cancer at age 40 and younger between 2006 and 2016. Academic and community hospitals in Massachusetts and academic sites in Denver, Colorado and Rochester, Minnesota contributed data to this analysis. Women enrolled at a participating site in Canada were excluded because their baseline and follow-up surveys were modified and did not include employment items. Informed consent was obtained from all individual participants included in the study. After informed consent, women complete a baseline survey (median: 5 months after diagnosis) and then are surveyed twice a year for the first 3 years following diagnosis and annually thereafter. Women who responded to both the baseline and one year following diagnosis surveys were eligible for inclusion in the current analysis. The YWS is approved by the Institutional Review Board at the Dana-Farber/Harvard Cancer Center as well as at other study sites.

Measures

Employment trajectory

At baseline, a question adapted from the National Statistics Classification—Standard Occupational Classification asked participants to best describe their work life in the 3 months before they were diagnosed [20]. Options included employed full time, employed part time, self-employed, unemployed for health reasons, unemployed for other reasons, and full-time homemaker. At 1 year, participants were asked about their work life "right now," with the same response options. Women who reported any type of employment (full time, part time, or self-employed) were categorized as "employed," while those who reported unemployment or being a homemaker were categorized as "unemployed." Employment trajectory was categorized as follows: (1) women who reported employment both pre-diagnosis and at 1 year after; (2) women not in the workforce at both time points; (3) women unemployed pre-diagnosis but employed at 1 year; (4) women who reported pre-diagnosis employment but were no longer in the workforce when surveyed 1 year after diagnosis.

Employment after cancer

Job satisfaction was assessed with a single question on the 1-year survey with four response options including completely dissatisfied, somewhat dissatisfied, somewhat satisfied, completely satisfied. Additional items that assessed job outcomes at 1 year included the degree to which cancer or cancer treatment limited one's ability to perform job responsibilities (not at all, a little bit, quite a bit, very much), whether an employer made accommodations so it was easier to do one's job (yes; no, but accommodations were needed; no, I did not need any special accommodations), and how likely it was that the respondent would be working at all in 1 year (very unlikely, somewhat unlikely, somewhat likely, very likely) [21]. Transition out of the workforce was defined as women who reported pre-diagnosis employment but were no longer in the workforce when surveyed 1 year after diagnosis.

Study population characteristics

Socio-demographic characteristics, including education, marital status, and parity, as well as insurance status, were assessed on the baseline and/or one-year survey. Race and ethnicity were also self-reported at baseline. If missing or unknown, we obtained this information from the medical record. Perceived financial comfort at baseline was measured with a single question asking participants to describe their current financial situation, with the following response options: after paying the bills, still have enough money for the special things that you want; you have enough money to pay the bills, but little spare money to buy extra or special things; you have enough money to pay the bills, but only because you have cut back on things; you are having difficulty paying the bills no matter what you do [22].

Medical records were reviewed to ascertain disease stage and receptor status. Treatment information, including chemotherapy, radiation, and surgery, were evaluated using patient self-report on study surveys in combination with medical record review.

Statistical analysis

We described the overall cohort and employment trajectories with frequencies and means calculated for categorical and continuous covariates, respectively. We used *t* tests and calculated Chi-square statistics to examine socio-demographic differences in employed and unemployed women prior to diagnosis, and differences in job-related outcomes by baseline perceived financial comfort among women employed at one year after diagnosis. Finally, we used univariable and multivariable logistic regression (excluding women who reported being out of the workforce at both timepoints) to identify factors associated with transitioning out of the workforce at one year following diagnosis; p values ≤ 0.05 were considered statistically significant. Analyses were conducted using SAS v9.4 (Cary, N.C.).

Results

Cohort characteristics

Among 2162 women deemed eligible following pathologic record review, 1302 provided written informed consent and were enrolled in the YWS (response rate: 60%). The analytic cohort included 911 women with Stage 0–3 breast cancer who had reported their employment status data on both the baseline and 1-year survey (Fig. 1). Patient, disease, and treatment characteristics are detailed in Table 1. Median age at diagnosis was 36 years (range 17–40), 78% of women were married or living as married, almost two-thirds had

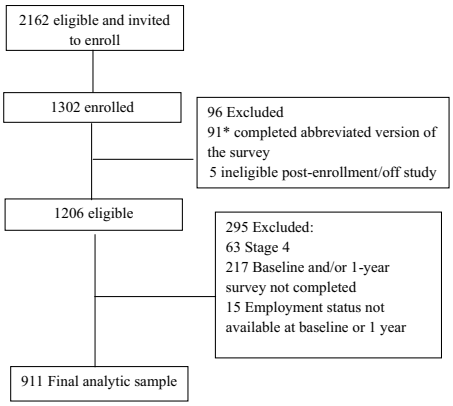

Fig. 1 Study flow chart of participants included in the analytic sample

a child prior to diagnosis, and 85% had at least a college degree. Most (86%) identified as white and non-Hispanic. Regarding perceived financial comfort, 53% reported that after paying the bills, they still had enough money for special things; 29% said they had enough money to pay the bills, but little spare money to buy extra or special things; and 19% said they had enough money to pay the bills, but only because they cut back on things or they had difficulty paying the bills. Most women presented with either stage 1 or stage 2 (77%) disease; the vast majority received chemotherapy (75%) and had a mastectomy (70%).

Employment prior to diagnosis

Most women were employed either full time ($n=578$, 63%), part time ($n=148$, 16%), or identified as self-employed ($n=36$, 4%) in the three months prior to their breast cancer diagnosis, while 3% ($n=30$) were unemployed for health or for other reasons and 13% ($n=119$) were full-time homemakers. Among those not in the workforce, 90% had at least one child (vs. 60% of employed women, $p<0.0001$) and 91% were married/living as married (vs. 76% of employed women, $p<0.0001$). Those employed prior to their diagnosis were also younger at diagnosis (mean age: 35.9 years vs. 37.0 years, $p<0.0004$).

Employment outcomes at one year post-diagnosis

Most women ($n=700$, 77%) were employed both before diagnosis and at 1 year after diagnosis. Three percent ($n=29$) of women were unemployed prior to diagnosis but reported employment at 1 year. Thirteen percent ($n=120$) were unemployed both before diagnosis and at 1 year, while 7% ($n=62$) were employed prior to diagnosis but reported unemployment at 1 year. Among those who transitioned out

Table 1 Study population characteristics

	$n=911$
Median age at diagnosis (range)	36 (17–40)
	No. (%)
Race/ethnicity	
White non-Hispanic	787 (86)
Other race/ethnicity	124 (14)
Insured	
Yes	903 (99.9)
No	1 (0.01)
Missing/unknown	7
Education	
College degree or greater	771 (85)
No college degree	137 (15)
Missing/unknown	3
Financial comfort	
Enough money for special things	474 (53)
Enough money to pay bills but little spare money for extras	258 (29)
Money to pay bills but only after cutting back/difficulty paying bills	167 (19)
Missing/unknown	12
Marital status	
Married/living as married	709 (78)
Unmarried	200 (22)
Missing/unknown	2
Parity	
At least one child before diagnosis	588 (65)
No children	315 (35)
Missing/unknown	8
Stage	
0	78 (9)
1	322 (35)
2	384 (42)
3	127 (14)
Chemotherapy	
Yes	685 (75)
No	226 (25)
Radiation	
Yes	570 (63)
No	341 (37)
Surgery	
Mastectomy	639 (70)
Lumpectomy	272 (30)

Table 2 Univariable and multivariable analysis of factors associated with transition out of the workforce 1 year post-diagnosis ($n=772$)

	Univariable OR (95% CI)	Multivariable OR (95% CI)
Age at diagnosis (years)	0.99 (0.92–1.05)	0.99 (0.91–1.06)
Race/ethnicity		
White non-Hispanic	1.24 (0.55–2.80)	1.41 (0.59–3.38)
Other race/ethnicity	Reference	Reference
Education		
No college degree	**2.39 (1.30–4.41)**	1.77 (0.90–3.46)
College degree or greater	Reference	Reference
Financial comfort		
Enough money for special things	Reference	Reference
Enough money to pay bills but little spare money for extras	1.72 (0.90–3.30)	1.49 (0.75–2.94)
Money to pay bills but only after cutting back/difficulty paying bills	**3.41 (1.79–6.51)**	**2.70 (1.32–5.52)**
Marital status		
Married/living as married	1.06 (0.57–1.97)	0.99 (0.48–2.05)
Unmarried	Reference	Reference
Parity		
At least one child before diagnosis	1.70 (0.95–3.04)	1.56 (0.78–3.12)
No children	Reference	Reference
Stage		
0	1.11 (0.30–4.04)	2.69 (0.45–16.10)
1	Reference	Reference
2	1.68 (0.83–3.43)	1.26 (0.56–2.83)
3	**5.57 (2.63–11.81)**	**3.73 (1.39–9.97)**
Chemotherapy		
Yes	**3.81 (1.50–9.65)**	3.34 (0.79–14.23)
No	Reference	Reference
Radiation		
Yes	1.55 (0.86–2.76)	1.09 (0.50–2.38)
No	Reference	Reference
Surgery		
Mastectomy	**2.13 (1.09–4.16)**	1.42 (0.63–3.22)
Lumpectomy	Reference	Reference

Bold values (OR/CI) indicate statistically significant results

Excludes women ($n=120$) who reported being out of the workforce both before diagnosis and 1 year after diagnosis and women who were missing data for variables included in the univariable and multivariable models ($n=19$)

OR odds ratio, *CI* confidence interval

of the workforce ($n=62$), approximately half (52%, $n=32$) reported they were unemployed for health reasons.

Factors associated with transition out of the workforce are included in Table 2. In univariable analyses, women with stage 3 disease (vs. stage 1, odds ratio [OR] 5.57, 95% confidence interval [CI] 2.63–11.81), those who reported having money to pay bills after cutting back or difficulty paying bills at baseline (vs. having enough money for special things, OR 3.41, 95% CI 1.79–6.51), those treated with chemotherapy (vs. no chemotherapy, OR 3.81, 95% CI 1.50–9.65), those who had a mastectomy (vs. lumpectomy, OR 2.13, 95% CI

1.09–4.16), and those without a college degree (vs. college educated, OR 2.39, 95% CI 1.30–4.41) were more likely to have transitioned out of the workforce. In multivariable analyses, having stage 3 (vs. stage 1 disease, OR 3.73, 95% CI 1.39–9.97) and those who reported having money to pay bills after cutting back or difficulty paying bills at baseline (vs. having enough money for special things, OR 2.70, 95% CI 1.32–5.52) remained significantly associated with transitioning out of the workforce. Marital status, parity, race/ethnicity, receipt of radiation, and age at diagnosis were not significantly associated with workforce transition in either univariable or multivariable analyses.

Among women employed 1 year after diagnosis (Table 3), 73% ($n = 529$) were somewhat or completely satisfied with their job, while 27% ($n = 192$) were dissatisfied. Only 7% ($n = 51$) said cancer or treatment limited their ability to perform their job quite a bit or very much. Ninety-six percent ($n = 688$) said they were somewhat or very likely to be working 1 year from now. Two-thirds ($n = 464$) of women reported a willingness by their employer to make accommodations following a breast cancer diagnosis. While 34% ($n = 240$) of patients said that their employer did not make any accommodations to make their jobs easier, for the majority ($n = 211$, 88%) special accommodations were not reported as necessary. Women who reported financial stress at baseline were more likely to report dissatisfaction with their job ($p = 0.008$) and less likely to report that their job was willing to make needed accommodations for them following their diagnosis ($p < 0.001$).

Table 3 Perceived financial comfort at baseline and employment outcome and perceptions among those employed at 1 year post-diagnosis

	Total, no. (%) ($n = 723$)[a]	After paying, still have enough money for special things, no (%) ($n = 387$)	Enough money to pay bills but little spare money for extras, no. (%) ($n = 213$)	Money to pay bills but only after cutting back/difficulty paying bills, no. (%) ($n = 123$)	*p* value
How satisfied are you with your job?					0.008
Somewhat/completely satisfied	529 (73)	299 (78)	151 (71)	79 (64)	
Somewhat/completely dissatisfied	192 (27)	86 (22)	62 (29)	44 (36)	
Missing (*n*)	2	2	–	–	
How much does your cancer or cancer treatment limit your ability to perform your job responsibilities?					0.62
Not at all/a little bit	669 (93)	357 (93)	200 (94)	112 (91)	
Quite a bit/very much	51 (7)	27 (7)	13 (6)	11 (9)	
Missing (*n*)	3	3	–	–	
After your cancer diagnosis, did your employer make any accommodations so it was easier for you to do your job?					< 0.001
Yes	464 (66)	256 (67)	142 (68)	66 (57)	
No, but accommodations were needed	29 (4)	8 (2)	8 (4)	13 (11)	
No, but I did not need any special accommodations	211 (30)	116 (31)	59 (28)	36 (31)	
Missing (*n*)	19	7	4	8	
How likely is it that you will be working at all 1 year from now?					0.34
Very/somewhat likely	688 (96)	368 (96)	205 (97)	115 (94)	
Very/somewhat unlikely	30 (4)	15 (4)	7 (3)	8 (7)	
Missing (*n*)	5	4	1	–	

[a]Of 729 employed at 1 year, $n = 6$ excluded due to missing perceived financial comfort information

Discussion

It is a societal responsibility to understand the effect of cancer on employment and return to work after diagnosis [4]. This study represents one of the first to examine the question of employment exclusively among women diagnosed with breast cancer at age 40 and younger in the United States. In this large cohort of young women with breast cancer, the vast majority of patients were working 1 year after diagnosis. Nevertheless, a substantial minority (20%, approximately one-third of whom were previously employed) was unemployed at that time point. Of those who were previously employed, over half cited their health as the reason for not being employed at 1 year. Although most patients employed after cancer did not report work difficulties, 27% were not satisfied with their work and this was associated with greater financial stress as reported at baseline. In addition to higher stage of disease, financial stress was also associated with transition out of the workforce.

Prior research has revealed that women who continue working through treatment and recovery, or who resume work after treatment demonstrate lower levels of psychosocial distress, higher levels of physical and mental functioning, improved quality of life as well as higher self-esteem and social functioning [3, 23]. Heterogeneous studies, focused on different populations, time frames, and employment outcomes, have demonstrated variable employment trends among breast cancer survivors [12–15]. Our study focused on a young population suggested that employment difficulties are not a major issue for a high proportion of patients who were employed at 1 year following their diagnosis; most were satisfied with their work.

However, employment after breast cancer still posed challenges for some women. Employment difficulties are likely complex and multifactorial, as supported by our data. Our study shows that financial stress can influence not only transition out of the workforce but also job satisfaction. This is consistent with data from prior studies suggesting that the most fragile patients are at higher risk of work difficulties after cancer, with financial factors having a profound influence on the employment status of breast cancer survivors: lower household income, part-time employment, and duration of unemployment before diagnosis have been associated with employment problems after diagnosis [8, 24, 25]. African American and Latina women additionally report greater job loss after cancer compared to white women at 18 months [26–28], though we did not find an association between race/ethnicity and employment in our population. Although we did not directly examine the effect of employer support on return to work, our findings indicate that those who experience more financial stress are less satisfied at work and have less support/accommodation from their employers. This is consistent with prior data among cancer survivors that have shown a relationship between a worse employment experience and perceived weak social support in the workplace as well as employer discrimination/inflexibility [24, 29, 30]. Our finding that those with at least a college degree were less likely to have transitioned out of the workforce was not maintained in the multivariable model. Prior research has revealed conflicting data regarding the impact of education on employment in breast cancer survivors: some find an association with lower levels of education and reduced likelihood of return to work and others do not [8, 10, 24, 30].

Also consistent with prior studies in which women with more aggressive tumors and those undergoing chemotherapy have lower employment rates after breast cancer diagnosis [7, 31, 32]. In our analysis, patients with higher stage tumors were more likely than others to transition out of the workforce, though receipt of chemotherapy was not associated with lower employment on multivariable analysis. Importantly, standard chemotherapy would generally have been completed prior to the 1-year follow-up survey, and while many women may have taken some time off during treatment, most would be back working as they were prior to diagnosis by 1 year.

It is possible that other factors that we did not investigate could negatively impact employment, such as having a comorbid condition. Further, employed breast cancer survivors may experience work-related difficulties that were not explored here, including work productivity, ability, stress, and longer-term sustainability issues [12]. While among those who were employed at 1 year job satisfaction was high and most indicated that diagnosis or treatment did not negatively affected job performance, we were unable to explore whether those who did leave the workforce did so due to low job satisfaction or to the lack of accommodations made by their employer.

Findings from our study should be considered in the context of its limitations. Our cohort population is predominantly white and non-Hispanic, insured, and well educated, and most young women do not report major financial difficulties. It is possible that the proportion of young survivors who would not rejoin the workforce or would be unsatisfied with work at 1 year would be larger in a more diverse population. In addition, findings from this analysis may not be generalizable to women in other countries, where work environments, expectations, and laws are different. Without a healthy control population, it is not possible to make comparisons with an age-matched non-cancer survivor cohort although all of these women were 40 and under at diagnosis. We also do not have sufficient information to assess to what degree return to work was financially or quality-of-life

driven, or to assess the perceived impact of cancer on ability to work or productivity.

Our results represent good news for the majority of young breast cancer survivors, but also reinforce that some of our patients experience work difficulties. Currently there have been few evidence-based interventions that have successfully targeted improved employment outcomes following cancer. Further research is warranted to better understand long-term work trajectories in more diverse populations of young patients as well as work ability, productivity, and stress among those who remain employed after cancer. Appropriate intervention focused on those struggling to participate in the labor force after cancer remains a significant, unmet need [33].

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Compliance with ethical standards

Conflict of interest Dr. Partridge: Royalties from UpToDate. Dr. Vaz-Luis: Novartis, Astra-Zeneca, Ipsen (paid speaker). No other authors report relevant disclosures.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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