CLINICAL TRIAL



Medical care disruptions during the first six months of the COVID-19 pandemic: the experience of older breast cancer survivors

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Abstract

Purpose Older cancer survivors required medical care during the COVID-19 pandemic, but there are limited data on medical care in this age group.

Methods We evaluated care disruptions in a longitudinal cohort of non-metastatic breast cancer survivors aged 60–98 from five US regions (n=321). Survivors completed a web-based or telephone survey from May 27, 2020 to September 11, 2020. Care disruptions included interruptions in seeing or speaking to doctors, receiving medical treatment or supportive therapies, or filling prescriptions since the pandemic began. Logistic regression models evaluated associations between care disruptions and education, medical, psychosocial, and COVID-19-related factors. Multivariate models included age, county COVID-19 death rates, comorbidity, and post-diagnosis time.

Results There was a high response rate (n = 262, 81.6%). Survivors were 32.2 months post-diagnosis (SD 17.5, range 4–73). Nearly half (48%) reported a medical disruption. The unadjusted odds of care disruptions were higher with each year of education (OR 1.22, 95% CI 1.08–1.37, p = <0.001) and increased depression by CES-D score (OR 1.04, CI 1.003–1.08, p = 0.033) while increased tangible support decreased the odds of disruptions (OR 0.99, 95% CI 0.97–0.99, p = 0.012). There was a trend between disruptions and comorbidities (unadjusted OR 1.13 per comorbidity, 95% CI 0.99–1.29, p = 0.07). Adjusting for covariates, higher education years (OR1.23, 95% CI 1.09–1.39, p = 0.001) and tangible social support (OR 0.98 95% CI 0.97–1.00, p = 0.006) remained significantly associated with having care disruptions.

Conclusion Older breast cancer survivors reported high rates of medical care disruptions during the COVID-19 pandemic and psychosocial factors were associated with care disruptions.

Clinicaltrials.gov Identifier NCT03451383

Keywords Medical care disruptions · COVID · Cancer survivors · Breast cancer · Older adults

Introduction

The COVID-19 pandemic has had broad effects on medical care delivery, with delays in routine care and postponement of non-COVID-19-related services [1, 2]. The risks of delaying care during the COVID-19 pandemic have been high among those with chronic illnesses, including cancer [3]. These same groups also have the highest risk of severe complications and mortality from COVID-19 infection. Guidelines during the pandemic have focused on treatment

J. S. Mandelblatt mandelbj@georgetown.edu for new cancer patients [4, 5]. There has been less attention to the impact of the pandemic on existing cancer survivors or associated disruptions in care. Additionally, pandemicrelated social isolation could exacerbate depression, anxiety, and sleep disturbances after cancer, increasing the need for medical care [6, 7].

In this study, we describe the impact of the COVID-19 pandemic on the medical care of older breast cancer survivors enrolled in the Thinking and Living with Cancer (TLC) longitudinal cohort study. We describe the prevalence of care disruptions and explore factors that might be associated with disruptions that occurred during the first 6 months of the pandemic. The results are intended to inform survivorship care during and beyond the pandemic.

Extended author information available on the last page of the article

TLC is an Institutional Review Board approved study that has been reported previously [8] and was conducted across sites in five regions. The COVID survey used in this study was IRB approved at all sites.

Population

The target population included 705 participants recruited between August 1, 2010 and March 1, 2020 who were 60 years or older and newly diagnosed with AJCC stage 0–III breast cancer at study entry. Those with neurological disorders, hearing, or vision impairments that precluded assessment, a history of other cancers or any prior chemotherapy, or were non-English-speaking were excluded.

For the current study, we excluded participants who were no longer active in TLC, including those who had a recurrence, completed study follow-up, dropped out, or died (n=367). We also excluded participants with missing treatment data (regarding hormone or chemotherapies) and/or a COVID-19 diagnosis (n = 17). Among the 321 eligible for this study, 81.6% (n = 262) completed the COVID-19 survey and constitute the analytic sample (Fig. 1). There was no significant difference in the characteristics of the 59 cases that refused or did not answer vs. the 262 that responded, except the responders were more likely to be White (84.7% vs. 72.9%, respectively, p = 0.03). The analytic sample was also similar to the overall target population, except for having slightly more comorbidities [3.0 (SD 2.1) vs. 2.5 (SD 1.9), p < 0.01 and a lower rate of chemotherapy receipt (20.6% vs. 29.7%, *p* < 0.01).

Data collection

As a part of TLC assessment participants (cases) completed a baseline, pre-systemic therapy survey at enrollment with annual follow-up. The COVID survey was developed and reviewed by a committee of TLC investigators and included standard study assessments, items from the National Institute of Mental Health (NIMH) Psychosocial Impact of COVID-19 survey [9], and additional COVID-related measures. The survey was conducted online between May 27, 2020 and September 11, 2020. Participants who did not have an email address on file were called to provide one. If participants did not respond to the initial emailed invitation, the link was automatically re-sent every week for 3 weeks up to three times; if no response, study staff called the participant to complete the survey by phone. Most completed the survey online (87.2%).

Measures

The outcome measure was having any medical care disruption "since the pandemic began" (yes/no) based on response to items adapted from the NIMH-NIH survey [10]: disruptions in seeing or speaking to doctors, receiving medical treatment, filling prescriptions, or receiving supportive therapies (e.g., physical therapy, massage, acupuncture).

We examined potential factors hypothesized to be associated with care disruptions. Pandemic-specific factors included cumulative per capita rates of COVID-19 deaths in the county of the participants' residence through the week of survey completion [10, 11]. Pandemic-related concerns were based on items from the NIMH-NIH survey [9]: job loss

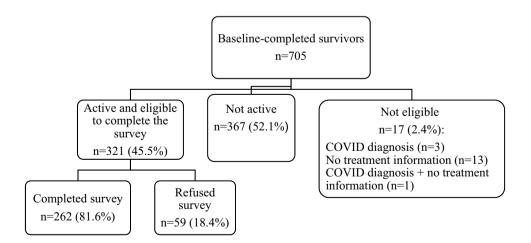


Fig. 1 A sample for evaluation of medical disruptions in older breast cancer survivors. Participants were excluded if they were not active (i.e., had completed the study, dropped out, or deceased) since the start of survey data collection. The percentage who completed and

refused was calculated among those active and eligible to complete the survey. ¹Participants were ineligible if they had a COVID-19 diagnosis or were missing information about chemotherapy or hormonal treatment for breast cancer

(self or family), loss of insurance was graded with yes/no response options; worries about being infected with COVID-19, food access, finances, housing, and transportation during the pandemic were rated on a 1–10 scale from not worried to very worried.

Socio-demographic factors include age, race (White vs non-White), and total number of years of education. Clinical factors included AJCC cancer stage, time from diagnosis, and type of systemic therapy at enrollment and number of comorbidities on the last pre-COVID assessment. Psychosocial variables from the last pre-COVID assessment included: anxiety (20-item State-Trait Anxiety Inventory) [12], depression (20-item Center for Epidemiologic Studies Depression [CES-D] Scale) [13], two questions from the CES-D about sleep disturbance, emotional, and tangible support subscales of the MOS [14], and quality of life (Functional Assessment of Cancer Therapy—General [FACT-G]) [15].

Statistical analysis

Univariate logistic regression methods were used as a first step to describe the association between having medical care disruption vs. not and covariates. Variables with p < 0.1association in the univariate logistic regression were then considered in a multivariable logistic regression model. Age, education, time from diagnosis, cumulative per capita rate of deaths, and comorbidities were also retained in the final model for face validity. We determined the final multivariable model using backward selection with a threshold of p < 0.1. Goodness-of-fit was reported based on Akaike Information criterion (AIC), Bayesian Information Criterion (BIC), and the concordance statistics (C-statistics). Odds ratios and corresponding 95% confidence intervals were provided for all analyses. Statistical significance was determined with a two-sided p value < 0.05. All analyses were conducted in SAS Version 9.4.b (SAS Institute Inc., Cary, NC, USA).

Results

The survivors' average age was 68 years (range 60–82) and 97.7% had internet access. The majority (66.4%) were ≥ 2 years from breast cancer diagnosis with 22.8% diagnosed within the preceding year (Table 1). Nearly one half (48%) of survivors reported having had any medical disruption during the first 6 months of the pandemic. Disruptions included interruptions in seeing or speaking to their doctor (reported by 48.4%), disruptions in medical treatments (51.2%), and difficulty in obtaining supportive care therapies (40.2%). While the mean number of medications was 3.8 (SD 2.2), only 4.7% of survivors reported difficulty filling prescriptions.

Several factors were associated with having medical care disruptions in analyses (Table 1). For each additional comorbidity, there was an increase in reporting medical disruptions (OR 1.13, 95% CI 0.99–1.29, p = 0.071). More years of education was significantly associated with the odds of reporting medical care disruptions (OR 1.22 per 1-year increase, 95% CI 1.08–1.37, p < 0.001). More tangible support pre-COVID was associated with not having medical disruptions during the pandemic (OR 0.98, 95% CI 0.97–1.00, p = 0.012). Survivors with higher CES-D scores (more depressive symptoms) at their last pre-COVID assessment were also more likely to report medical disruptions (OR 1.04 per one-point increase in depressive symptoms, 95% CI 1.003-1.080, p = 0.033). Participants with better quality of life pre-COVID were less likely to experience medical disruptions (OR 0.95 per one-point increase in FACT-G score, 95% CI 0.932-0.980, p < 0.001). There were no significant associations of care disruptions with cancer-specific factors such as time since diagnosis, stage, or initial therapy.

In multivariable-adjusted analyses, only tangible social support and education remained significantly associated with medical disruptions: the odds of reporting disruptions were lower for those with more tangible social support pre-COVID (OR 0.98 per 1-point per increase, 95% CI 0.97–0.995, p = 0.006) and 23% higher for each increase in years of education (OR 1.23, 95% CI 1.09–1.39, p = 0.001) (Table 1).

Discussion

This study examined medical care among older US breast cancer survivors in the first 6 months of the COVID-19 pandemic. Nearly one half of these older survivors reported experiencing medical care disruptions. Having more tangible social support reduced the odds of having medical care disruptions during the pandemic. Survivors with more education reported more disruptions than those with less education although the mean number of years of education for the participants was > 12 years or beyond high school level.

About half the survivors reported difficulties seeing or speaking with their doctors or receiving supportive therapies (including integrative treatments and physical therapy). The latter finding may reflect some institutions' protocols prioritizing medical therapies rather than supportive care during the pandemic [1, 3, 16]. Since these older cancer survivors are part of a longitudinal cohort study, we may be able to assess the impact of care disruptions on subsequent quality of life in the future.

The rate of medical care disruptions among older breast cancer survivors was consistent with rates reported from general populations. The Centers for Disease Control reported that approximately 41% of US adults delayed or

Table 1 Odds of having medical care disruptions during the COVID-19 pandemic among older breast cancer survivors

	No disruptions $N = 135$ Disruptions $N = 127$ Percent (<i>n</i>) or mean (SD)		Factors associated with having medical care disruptions			
			Unadjusted OR (95% CI)	p value	Adjusted OR (95% CI) ^a	p value
Demographic factors						
Age, years	68.0 (5.2)	67.8 (5.5)	0.993 (0.95,1.04)	0.753	0.99 (0.95, 1.04)	0.548
Race					-	
Non-White	47.5 (19)	52.5 (21)	1.21 (0.62, 2.37)	0.580)	
White	52.3 (116)	47.7 (106)	Reference			
Education, years, per 1-year increase in education	15.1 (2.3)	16.0 (2.0)	1.22 (1.08, 1.37)	< 0.001	1.23 (1.09, 1.39)	0.001
Clinical factors						
Months from diagnosis	33.5 (18.0)	30.6 (16.7)	0.99 (0.98, 1.01)	0.191	0.99 (0.97, 1.01)	0.168
Stage (AJCC v.6)						
0–I	52.2 (108)	47.8 (99)	Referent		-	
II or III	48.9 (22)	51.1 (23)	1.14 (0.60, 2.17)	0.689)	
Systemic treatment					-	
Chemotherapy \pm hormonal	45.1 (23)	54.9 (28)	1.38 (0.75, 2.55)	0.307		
Hormonal only	53.1 (112)	46.9 (99)	Referent			
Comorbidities (prior to COVID), number	2.7 (1.8)	3.1 (2.0)	1.13 (0.99, 1.29)	0.071	1.09 (0.94,1.26)	0.238
Prescription drugs (prior to COVID), number	3.6 (2.2)	4.0 (2.6)	1.08 (0.97, 1.19)	0.170) <u> </u>	
COVID-related factors						
Family/household member lost their job (yes/no)	34.5 (10)	65.5 (19)	2.20 (0.98, 4.93)	0.056	i –	
COVID-related worries ^b	16.8 (6.5)	18.5 (9.2)	1.03 (1.00, 1.06)	0.085	i _	
Per capita COVID deaths in county per 1000°	0.9 (0.9)	0.8 (0.8)	0.86 (0.65, 1.15)	0.319	0.80 (0.58, 1.11)	0.179
Psychosocial factors prior to COVID (fr	om most recent study asso	essment prior to COV	ID)			
Depressive symptoms ^d	5.5 (5.4)	7.5 (8.6)	1.04 (1.00, 1.08)	0.033	i —	
Anxiety ^e	27.5 (5.5)	28.8 (7.5)	1.03 (0.99, 1.07)	0.120) _	
Tangible social support ^f	83.8 (19.3)	76.9 (23.8)	0.99 (0.97, 1.00)	0.012	0.98 (0.97, 1.00)	0.006
Emotional support ^f	82.7 (17.9)	78.1 (20.4)	0.987 (0.98, 1.00)	0.053	i —	
Sleep disturbance ^g	52.4% (44)	47.6 (40)	0.95 (0.57, 1.60)	0.849) _	
FACT-G Total ^h	71.0 (9.1)	66.2 (11.8)	0.96 (0.93, 0.98)	< 0.001	-	
Model fit statistics BIC = 365.11; AIC =	340.37; <i>C</i> =0.673					

^aLogistic regression including all variables on the table

^bCOVID-related worries based on 7 items from COVID survey. Scores range from 7 to70, with higher scores reflecting more COVID worries

^cBased on cumulative death rates per capita in county of residence from pandemic to date of interview per 1000 based on data reported to the NY Times [11] and the US Census [12]

^dBased on the CES-D, Center for Epidemiologic Studies Depression Scale [16]. Scores range from 0 to 60, with higher scores reflecting more psychological distress

^eBased on the State-Trait Anxiety Inventory [15]. Scores range from 20 to 80, with higher scores reflecting more anxiety

^fBased on the normalized MOS-Tangible social support [18]. Scores range from 0 to 100, with higher scores reflecting more tangible social support

^gThe presence of a sleep disturbance (yes/no) was determined from the endorsement of one or both of 2 questions [24] from CES-D: "During the last 7 days, I have been sleeping well" (with subjects who reported "not at all" or "a little bit" coded as having a sleep disturbance) and "During the past week, my sleep was restless" (with subjects who reported "occasionally or moderate amount of time" or "most or all the time" coded as having a sleep disturbance

^hBased on the FACT-G [19]. Scores range from 0 to 84, with higher scores reflecting better functioning

avoided routine and urgent medical care due to the COVID-19 pandemic [17], and studies worldwide similarly indicated a rise in missed medical appointments during the pandemic [18, 19]. Most studies that included cancer patients or survivors have focused on newly diagnosed patients [6], with limited information on disruptions experienced by long term or older cancer survivors [1, 2, 20]. Our cohort was on average, two to 3 years from diagnosis and might be less vulnerable to care disruptions as women newly diagnosed with breast cancer. Although our study focused on cancer survivors, specific questions about cancer care were not included which limit our assessment of the impact of these disruptions on breast cancer follow-up and treatment. In addition, our survey asked about disruptions "since the pandemic began" and this time frame could vary by region and COVID-infection rates at the time of survey delivery.

The results of this study also highlight how common issues affecting cancer survivors such as social support can buffer disruptions in medical care during a pandemic. This observation may reflect the direct impact of social support on transportation to medical care or arranging appointments. Alternatively, social support may reflect other aspects of cancer survivors' lives not captured by our measures, including having more social connections. The positive effects of social support in cancer survivorship have been reported in other studies. The Nurses' Health Study demonstrated that the degree of social support in breast cancer survivors affected physical function and adverse cancer-related symptoms [21], and other studies have shown associations between social isolation and increased mortality for cancer survivors [22]. However, there is less literature on the impact of social support specifically on obtaining medical care.

Contrary to expectation we found that as years of education increased the odds of reporting medical care disruptions increased. This may be related to higher education's association with more general awareness of the need for health maintenance, as lower education and health literacy have been linked to less use of screening and routine preventive care appointments [23]. A limitation is that information about the highest degree attained was not included. Alternatively, higher education may be a proxy for a greater desire for medical care or increased caution about COVID risk.

It will be important to compare our findings to newer reports on health care disruptions.

The study has many strengths including the ability to consider COVID-related medical care disruptions in the context of an ongoing longitudinal cohort of older cancer survivors and having data on pre-existing factors that could affect survivors' ability to respond to unexpected events. However, there are limitations that should be considered in evaluating our results. Fewer non-White participants in the cohort responded to the survey than White participants. Non-White adults have had higher infection rates and greater economic losses than White adults during the pandemic [24]. To the extent that older non-White participants were under-represented, we could have under-estimated the overall rate of medical care disruptions among breast cancer survivors. The majority of our cohort had greater than a high school level of education (mean 15-16 years) and their experiences may not reflect access to health care among other survivor groups. The questions regarding medical care disruptions were limited in scope and did not include information about the degree of disruption (weeks vs. months), impact on cancer care, or the use of telehealth appointments, and we did not specifically address medical care needs although there was a trend toward association of disruptions with number of comorbidities. While we considered the per capita regional rate of COVID-19 deaths, there are variations in effects of state or local lockdown orders, social distancing, and media messages that we did not capture in our measures.

Overall, this study shows that during the first 6 months of the COVID-19 pandemic nearly 50% of older breast cancer survivors experienced some type of disruption in medical care. It will be important to determine if these disruptions persist or resolve as a larger proportion of the population become vaccinated or whether the initial disruptions in care will have long-lasting effects on health and function. Until then, older breast cancer survivors appear vulnerable to losses in medical care and should be considered in future studies of the growing impact of the COVID-19 pandemic on health care.

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Author contributions AD was responsible for conceptualization, writing—original draft, and writing—review/editing; WZ was responsible for formal analysis, data curation, and writing; KR was responsible for conceptualization, writing—review/editing, and data curation; XZ was responsible for formal analysis, data curation, and writing, TA was responsible for conceptualization, investigation, resources, writing, project administration, and funding acquisition; JA was responsible for supervision, methodology, formal analysis, data curation, and writing; TB was responsible for conceptualization and writing—review/editing; JEC was responsible for funding acquisition, conceptualization, and writing and editing; HJC was responsible for conceptualization and writing and editing; DG was responsible for investigation, resources, and writing; HJ was responsible for investigation, resources, writing, project administration, and funding acquisition; BCM was responsible for investigation, resources, writing, project administration, and funding acquisition; ZN was responsible for conceptualization, writing—review/editing; JA was responsible for conceptualization, data curation, formal analysis, and writing—review/editing; SP was responsible for investigation, resources, writing, and project administration; JCR was responsible for investigation, supervision, and writing; BJS was responsible for supervision, data curation, formal analysis, and writing; AJS was responsible for investigation, resources, writing, project administration, and funding acquisition; DT was responsible for investigation, nesources, writing; JSM was responsible for conceptualization and writing—review/editing; JSM was responsible for conceptualization, investigation, resources, writing and editing, supervision, project administration, and funding acquisition.

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Data availability Not applicable.

Declarations

Conflict of interest AAD attended the Cardinal Health 2020 Advisor Board Oncology Committee. HSJ: Consulting or Advisory Role: Janssen Pharmaceuticals and RedHill Biopharma. DG: Stock and Other Ownership Interests: Cota. AJS: Consulting or Advisory Role: Bayer AG Research Funding: Eli Lilly (Inst).

Ethical approval The study protocol was approved by the Institutional Review Boards at all sites (ClinicalTrials.gov Identifier: NCT03451383).

Consent to participate All participants provided informed consent.

Consent for publication All authors have approved the final manuscript and provided consent for publication. The results have not been published or presented elsewhere.

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