Breast Cancer Research and Treatment (2019) 175:721–731
https://doi.org/10.1007/s10549-019-05196-x

EPIDEMIOLOGY

Patient-reported symptoms following mastectomy alone or lumpectomy plus radiation for early stage breast cancer: a cohort study

Laura E. Davis[1] · Courtney Fulton[2] · Lev D. Bubis[2] · Jonathan Sussman[3,4] · Lesley Moody[3] · Lisa Barbera[5] · Qing Li[6] · Alyson L. Mahar[7] · Natalie G. Coburn[2,3,6,8,9,10] · Claire M. B. Holloway[3,9]

Received: 11 February 2019 / Accepted: 5 March 2019 / Published online: 16 March 2019

Abstract

Purpose Studies examining symptom differences between surgeries for breast cancer patients rarely incorporate the effects of adjuvant treatment choice. We sought to understand differences in patient-reported symptoms between lumpectomy plus radiation and mastectomy in the year following surgery.

Methods This cohort study used linked administrative datasets. The exposure was defined as lumpectomy plus radiation or mastectomy. The outcomes of moderate-to-severe (score ≥ 4) patient-reported symptoms were obtained using the Edmonton symptom assessment system (ESAS). Line plots were created to determine symptom trajectories in the 12 months following surgery, and the relationships between surgery and each of the nine symptoms were assessed using multivariable analyses. Clinical significance was determined as a difference of 10%.

Results Of 13,865 Stage I–II breast cancer patients diagnosed 2007–2015, 11,497 underwent lumpectomy plus radiation and 2368 underwent mastectomy. Symptom trajectories were similar for all nine symptoms until approximately 5 months postoperatively when they diverged and mastectomy symptoms started becoming more severe. On multivariable analyses, patients undergoing mastectomy were at an increased risk of reporting moderate-to-severe depression (RR 1.19, 95% CI 1.09–1.30), lack of appetite (RR 1.11, 95% CI 1.03–1.20), and shortness of breath (RR 1.16, 95% CI 1.04–1.15) compared to those undergoing lumpectomy plus radiation.

Conclusions Even with the addition of adjuvant radiation, patients who are treated with lumpectomy fare better in three of nine patient-reported symptoms. Further examination of these differences will assist in better shared decision-making regarding surgical treatments.

Keywords Lumpectomy · Mastectomy · Patient-reported symptoms · Edmonton symptom assessment system (ESAS) · Early stage breast cancer

Introduction

Breast cancer patients diagnosed at an early stage are often able to choose between lumpectomy plus radiation or mastectomy alone. Although both procedures have similar survival outcomes, patient-reported symptoms and quality of life may differ [1]. Understanding patient-reported symptoms and quality of life following surgery can help to facilitate shared decision-making regarding surgical management.

Conflicting evidence exists regarding the symptom burden among breast cancer patients following surgery [2–4]. Some studies demonstrate that those receiving lumpectomy have better quality of life when compared to mastectomy patients, while others show no difference [2–4]. Limitations

Natalie G. Coburn and Claire M. B. Holloway share senior authorship of this work.

Electronic supplementary material The online version of this article (https://doi.org/10.1007/s10549-019-05196-x) contains supplementary material, which is available to authorized users.

✉ Natalie G. Coburn
natalie.coburn@sunnybrook.ca

Extended author information available on the last page of the article

of the available studies are examination of few centers and small sample size, ranging from a few hundred to a few thousand patients [2, 5–7]. This may limit generalizability and may not take into account variation between patients. Another weakness of these studies is their cross-sectional nature, evaluating symptom burden at only one or a few points in time. Furthermore, studies often do not measure or adjust for adjuvant radiation which is standard of care following lumpectomy and may be associated with significant symptom burden [2, 6, 8].

In the province of Ontario, Canada, patient-reported symptom scores are collected on an opportunistic basis at all outpatient clinic visits using the Edmonton symptom assessment system (ESAS). These symptom scores are used in real time by the treating physician and are meant to improve patient satisfaction and communication between patients and clinicians by highlighting areas in which symptoms are poorly controlled. These point-of-care patient-reported outcomes are then collected centrally by Cancer Care Ontario, creating a unique opportunity to harness these data in order to describe symptom burden patterns in breast cancer patients.

The purpose of this study was to understand differences in patient-reported symptoms between women electing for lumpectomy plus radiation or mastectomy in the postoperative period. By exploring patient symptoms after different surgical procedures, inclusive of the necessary adjuvant treatment trajectories, we may be able to help patients and clinicians make more informed decisions regarding their treatment.

Methods

Study design and population

This was a cohort study examining routinely collected patient-reported symptom scores for early stage breast cancer patients receiving lumpectomy plus radiation or mastectomy diagnosed between 2007 and 2015. We used linked administrative datasets housed at ICES. The study was approved by Sunnybrook Health Sciences Centre ethics committee and meets the data confidentiality and privacy guidelines of ICES.

We included all patients ≥ 18 years of age with stage I–II breast cancer who accessed a Regional Cancer Centre or affiliate. Patients were included if they had received lumpectomy and radiation or mastectomy-alone and reported at least one symptom assessment within the year following surgery. Patients were excluded if they received mastectomy with radiation, or lumpectomy without radiation as well as any patients who received chemotherapy in the 12 months following surgery as we wanted to assess the effect of surgical treatment choice in early stage breast cancers, without confounding from non-standard or more advanced treatment pathways. In addition, we excluded patients who were male, received chemotherapy or radiotherapy in the year before surgery, or had another primary cancer diagnosis in the 2 years prior to or following breast cancer diagnosis.

Data sources

Provincial, administrative healthcare databases were linked to the symptom management database (SMRD) through a unique encoded patient identifier. The SMRD contains the date, location, and scores of all symptom assessments completed at outpatient cancer clinic visits in the province [9] Other administrative databases used in this study include the Ontario Cancer Registry (OCR), which captures diagnostic and staging details of incident cancer cases; the registered persons database (RPDB) which includes demographic data, such as age, sex, and rural living; the Ontario Health Insurance Plan (OHIP) database which contains physician claims for insured services, used to identify chemotherapy; the cancer activity level reporting database (ALR) which includes information on patient activity within regional cancer centers, specifically radiotherapy; the Canadian Institute of Health Information (CIHI) Discharge abstract database (DAD) which contains intervention data for hospital admissions; the CIHI same day surgery (SDS) database which contains information on outpatient surgeries; and the National ambulatory care reporting system (NACRS) which captures administrative and clinical information for emergency department visits and was used to calculate comorbidity.

Outcome: symptom scores

The province of Ontario implemented routine collection of symptom scores across all Regional Cancer Centers and affiliate institutions within the province using ESAS starting in 2007. This initiative has been described elsewhere [10, 11]. The validity and reliability of ESAS are well described, and it is commonly used as a screening tool to measure the prevalence and severity of nine common cancer-associated symptoms: pain, tiredness, drowsiness, nausea, lack of appetite, shortness-of-breath, depression, anxiety, and impaired well-being [9, 12–16]. Symptoms are scored on a scale of 0 to 10, 0 indicating the absence of symptoms and 10 indicating worst possible symptom severity. Previous research has categorized the severity of ESAS scores as mild (1–3), moderate (4–6), and severe (7–10) [10, 12, 13]. One dichotomous outcome was created for this study: score ≥ 4 (moderate-to-severe) measured at each month in the first year following surgery. If a patient reported ≥ 1 score in 1 month, the highest score was used.

Exposure: breast cancer surgery

The primary exposure was defined as lumpectomy plus radiation or mastectomy alone. Detailed information on surgery type was obtained from hospitalization (CIHI-DAD) and same day surgery (CIHI-SDS) records occurring in the year following cancer diagnosis. Canadian Classification of Health Interventions (CCI) codes were used to identify lumpectomy and mastectomy and were categorized based on previous studies [17, 18] (Appendix 1). If a patient received more than one surgical procedure on the same date, the most extensive surgical procedure was used (i.e., mastectomy). If patients had multiple procedures on different dates, the earliest date of the most extensive procedure was used. If a patient received lumpectomy, we looked forward 12 months from that date to determine whether they also had codes for radiation in the ALR (Appendix 2). In order to emphasize the differences between standard treatment options for breast cancer patients (i.e., lumpectomy plus radiation or mastectomy), we limited analysis to these two base case treatment scenarios.

Covariates

Age at surgery (18–50, 51–60, 61–70, 71–80, and ≥ 81), neighborhood income quintile, and rurality were obtained from the RPDB. Neighborhood income was defined by linking median community-level income from census data to patients' postal codes (quintile 5 highest). Rural residence was defined using the postal code of the patients' primary residence, with rural residence defined as those within a community size < 10,000 [19]. Cancer stage was defined through the OCR best stage and categorized as stage I or II [20]. Comorbidity was calculated using the Johns Hopkins ACG system and defined by the sum of aggregated diagnosis groups (ADG); ADGs ≥ 10 indicate elevated comorbidity burden [21]. Hospital volume was defined by number of breast cancer surgeries performed in each institution per year of study period; the median for all years was used for each hospital. Hospital volume was categorized as < 75th percentile (< 78 surgeries/year), 75 to > 90th percentile (78 to > 132 surgeries/year) and ≥ 90th percentile (≥ 132 surgeries/year), due to the large number of institutions performing a high number of surgeries. Time from surgery was defined as an ESAS assessment occurring in each of the 30-day intervals from the date of surgery up to 12 months. For example, if a patient reported an ESAS assessment on day 61, this would be defined as month 2. We were unable to measure provision of hormone therapy as it is administered orally and only captured in the administrative data for patients ≥ 65 years of age or qualifying for government assistance.

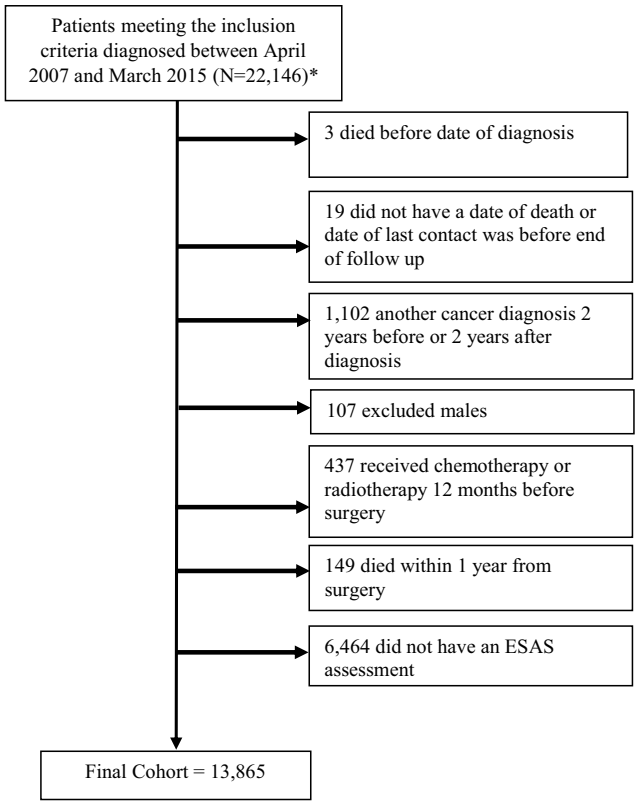
Statistical analysis

Baseline demographics were presented with numbers and frequencies. We used standardized differences to determine significant differences in ESAS scores between groups. Previous studies have indicated that a standardized difference of ≥ 0.1 is considered significant [22]. Patients completing the ESAS assessment were compared to patients who did not complete the ESAS assessment to determine generalizability of the study cohort. Symptom trajectories describing patients with at least one score ≥ 4 in each of the 12 months following surgery were presented graphically, using the number of ESAS assessments reported in each month as the denominator. Multivariable modified Poisson regression models with robust variance were used to investigate the association between surgery type and moderate-to-severe ESAS scores for all 9 symptoms separately. Generalized estimating equations with exchangeable correlation structures were used to account for clustering of repeated measurements at the patient level [23]. Confounders were identified a priori as age, comorbidity, income quintile, rural residence, stage, time from surgery, hospital volume. All variables were included in the model; relative risks (RR) and 95% confidence intervals (95% CI) were presented. Statistical significance was defined as a p value ≤ 0.05. Due to the large sample size and robust ability to detect small differences in relative risks between groups, we defined clinical significance a priori as a difference in symptoms of 10%. This number was chosen to parallel the previously identified clinically important difference of one point in the ESAS scale [24].

Results

A total of 22,146 patients were diagnosed with stage I or II breast cancer between 2007 and 2015 and received mastectomy-alone or lumpectomy plus radiation, with no neoadjuvant or adjuvant chemotherapy. After exclusions, the final cohort consisted of 13,865 patients (Fig. 1). 11,497 patients underwent lumpectomy plus radiation and 2368 patients underwent mastectomy-alone. Length of stay (median 1 day for both groups) and time between surgery and first ESAS median 49 days (IQR 31–79 days) for lumpectomy plus radiation and 42 days (IQR 29–78) for mastectomy were similar between the two groups. The median number of ESAS reports was 4 (IQR 2–6) and 76% of patients reported ≥ 2 ESAS assessments in the year following surgery; patients receiving lumpectomy plus radiation reported a slightly higher number of ESAS assessments (median 3 (IQR 2–4)) compared to mastectomy patients (median 2 (IQR 1–3)). Few differences were observed between patients who reported an ESAS score and patients who did not (Supplemental Table 1). Patients diagnosed in later years and patients receiving lumpectomy plus radiation were more likely to have an ESAS assessment.

Fig. 1 Cohort exclusions



*Inclusion criteria: Stage 1 or 2, at least 18 years of age, underwent mastectomy or lumpectomy + radiation in the year following diagnosis, did not receive chemotherapy and seen at a regional cancer center

Demographics and disease characteristics

Demographics and disease characteristics for patients receiving lumpectomy plus radiation or mastectomy are presented in Table 1. A greater proportion of patients receiving lumpectomy plus radiation had stage 1 disease (76.7%), compared to mastectomy patients (58.5%). Patients aged > 70, living in rural areas and those receiving surgery at hospitals with low volume (78 breast surgeries per year or less) were more likely to receive mastectomy.

Symptom trajectories

We examined symptom trajectories in the year following surgery, stratified by surgery regimen. Symptoms after lumpectomy plus radiation and mastectomy-alone followed a similar trajectory for all symptoms from months one to three. In months four and five, mastectomy patients diverged, reporting an increase in of all symptoms with the exception of nausea and pain. Nausea remained similar between groups and pain increased slightly for lumpectomy plus radiation around months three and four (Fig. 2 and Supplemental Fig. 1). In general, anxiety was highest immediately following surgery and decreased thereafter. A slight peak around months 3–6 was observed for drowsiness, lack of appetite and tiredness for both surgery types. All other symptoms remained steady or declined slightly over the study period.

Surgery

We investigated the association between treatment choice and the risk of reporting a symptom score ≥ 4 for each symptom (Table 2). Patients undergoing mastectomy were at a slightly higher risk of reporting severe symptoms, after controlling for confounders, for all symptoms except drowsiness, nausea, and pain compared to patients receiving lumpectomy plus radiation. However, differences were small and clinical significance of ≥ 10% was only achieved for depression (RR 1.19, 95% CI 1.09–1.30), lack of appetite (RR 1.11, 95% CI 1.03–1.20), and shortness of breath (RR 1.16, 95% CI 1.04–1.28).

Discussion

This study used patient-reported outcomes collected at a population level to determine differences in symptoms of patients receiving lumpectomy plus radiation compared to mastectomy. This is one of the few studies to incorporate adjuvant radiation in such a large cohort of patients examining symptoms over 1 year from surgery. We found that

Table 1 Patient and disease characteristics of stage I and II breast cancer patients receiving lumpectomy and radiation or mastectomy, *n* (%), (column %)

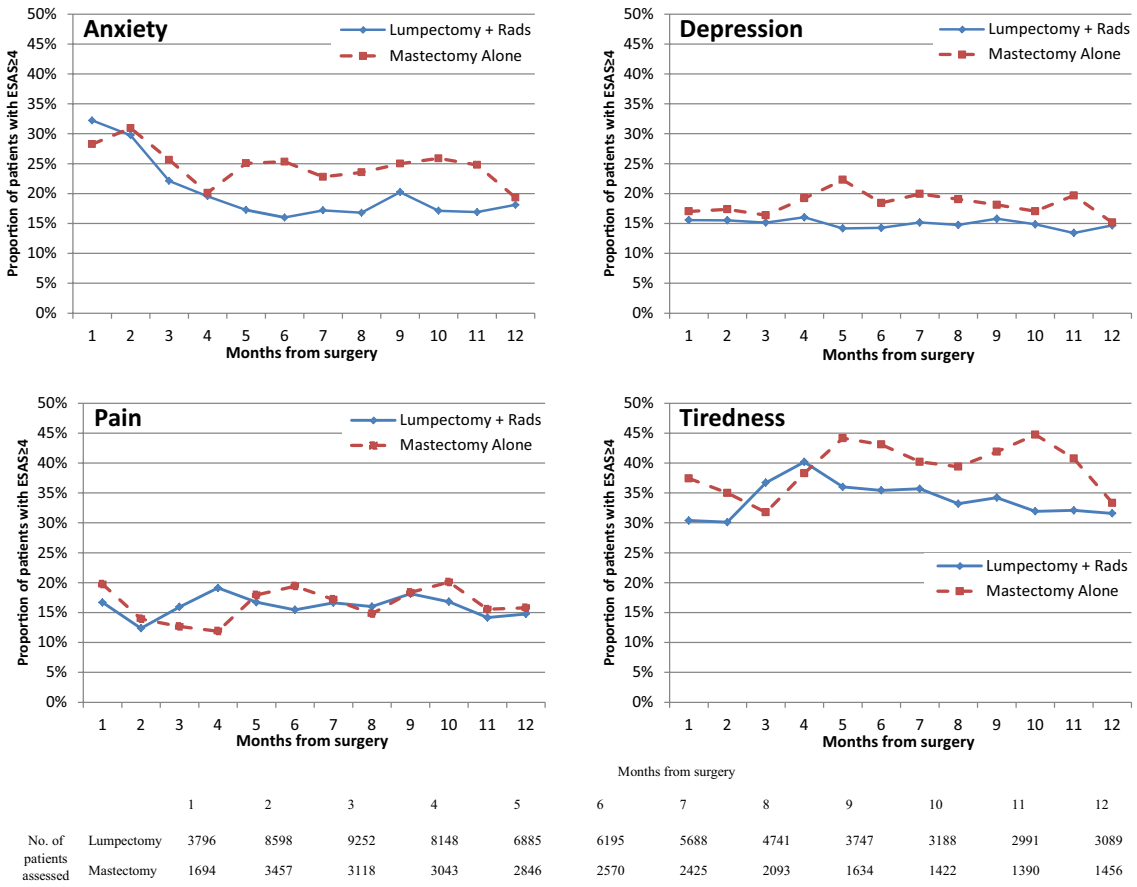
Variable	Value	Lumpectomy with radiation (*N* = 11,497) (%)	Mastectomy alone (*N* = 2368) (%)	Standardized difference[a]
Age	18–50	1430 (12.4)	247 (10.4)	0.37
	51–60	2833 (24.6)	366 (15.5)	
	61–70	3965 (34.5)	688 (29.1)	
	71+	3269 (28.4)	1067 (45.1)	
Stage	1	8815 (76.7)	1386 (58.5)	0.40
	2	2682 (23.3)	982 (41.5)	
Diagnosis year	2007	127 (1.1)	41 (1.7)	0.11
	2008	621 (5.4)	163 (6.9)	
	2009	1131 (9.8)	271 (11.4)	
	2010	1635 (14.2)	309 (13.0)	
	2011	1866 (16.2)	377 (15.9)	
	2012	2014 (17.5)	394 (16.6)	
	2013	1981 (17.2)	409 (17.3)	
	2014	1747 (15.2)	322 (13.6)	
	2015	375 (3.3)	82 (3.5)	
Comorbidities (ADG)	0–9	8972 (78.0)	1717 (72.5)	0.13
	10–32	2525 (22.0)	651 (27.5)	
Rural residence	Urban	9965 (86.7)	1950 (82.4)	0.12
	Rural	1525 (13.3)	417 (17.6)	
Income quintile	Q1	1689 (14.7)	431 (18.2)	0.13
	Q2	2169 (18.9)	473 (20.0)	
	Q3	2296 (20.0)	454 (19.2)	
	Q4	2513 (21.8)	528 (22.3)	
	Q5	2787 (24.2)	475 (20.0)	
	Missing	43 (0.4)	7 (0.3)	
Hospital volume	≤ 75th	3411 (29.7)	950 (40.1)	0.21
	75-90th	3555 (30.9)	636 (26.9)	
	≥ 90th	4107 (35.7)	751 (31.7)	
	Missing	424 (3.7)	31 (1.3)	

ADG aggregate diagnostic groups

[a]Standardized difference of ≥ 0.1 represents statistical significance. Tests for standardized differences do not include missing categories

breast cancer patients receiving mastectomy alone were at a slightly increased risk of reporting moderate-to-severe symptoms for depression, appetite, and shortness of breath following surgery compared to patients receiving lumpectomy plus radiation; however, differences were minimal.

Receipt of mastectomy-alone was associated with a 19% increased risk of reporting symptoms of depression compared with patients who received lumpectomy plus radiation. Rates of clinically significant depression follow surgery are common among breast cancer patients, ranging from 10 to 25% [25]. Although not all patients who report a high ESAS score for depression will fulfill clinical criteria for depression, the high scores noted within this study are concerning. Higher self-reported scores for depression among patients receiving mastectomy compared to lumpectomy may be associated with the loss of the breast and reflect differences in body image or sexual functioning, as other studies have found [6, 7, 26]. Since this study used a population-level symptom tool meant for all cancer patients, we were unable to capture important symptoms specific to breast cancer patients, such as body image, which may be captured by a more specific symptom tool such as the functional assessment of cancer therapy for patients with breast cancer (FACT-B) [27]. Alternatively, the higher risk of depression among patients who received mastectomy may reflect that patients who choose mastectomy have different baseline personality traits, such as anxiety, depression or simply a strong fear of recurrence, compared to patients who choose lumpectomy [28]. Other studies have demonstrated that a strong fear of recurrence and perceived survival benefits were strong predictors for patients choosing mastectomy over lumpectomy, even despite fully understanding



Months from surgery

		1	2	3	4	5	6	7	8	9	10	11	12
No. of patients assessed	Lumpectomy	3796	8598	9252	8148	6885	6195	5688	4741	3747	3188	2991	3089
	Mastectomy	1694	3457	3118	3043	2846	2570	2425	2093	1634	1422	1390	1456

Fig. 2 Symptom trajectories of lumpectomy + radiation compared to mastectomy alone in each of the 12 months following diagnosis. Trendlines facilitate visualization of trends over time and do not represent continuous data. Numbers below the horizontal axis indicate the denominator at each month. *ESAS* Edmonton symptom assessment system

that survival and recurrence are similar for both surgeries [29, 30]. Regardless, these results reflect that many patients might benefit from additional psychosocial support during the treatment phase and for many months following surgery.

Although statistically significant, only small differences in symptoms were observed between patients undergoing lumpectomy plus radiation and mastectomy after controlling for appropriate confounders, with the exception of depression. This finding should be reassuring to patients and providers concerned about symptoms associated with adjuvant radiation following lumpectomy, and those patients considering mastectomy alone to avoid these symptoms [31–33]. Nonetheless, many women still choose mastectomy with the aim of preventing recurrence and improving survival, regardless of the information provided to them [28, 34]. The information from this study can be used in conjunction with programs to further educate women on their choices and the benefits of lumpectomy plus radiation over mastectomy-alone.

Implications

Combined evidence indicates that while survival is similar between surgery regimens for early stage breast cancer patients, symptoms may be similar or slightly better among patients receiving lumpectomy plus radiation. The use of patient-reported outcomes data collected at a population level can be utilized to demonstrate symptom trajectories for the average patient, informing patient and physician decision making. Furthermore, in the clinic setting, patient-reported outcomes can be used to facilitate communication between physicians and patients, which in turn could increase patient involvement and informed decision making [35]. Evidence indicates that patients want to be more involved in decision making and furthermore that those patients who are more involved in their cancer care decision making have better overall quality of life, better physical and social functioning, and less tiredness compared to women who are not involved in their cancer care decisions [36, 37]. Collecting and analyzing patient-reported symptoms at all phases of breast cancer treatment will not only provide real-time evidence

Table 2 Multivariable Poisson regression analyses for association between lumpectomy + radiation or mastectomy and moderate-to-severe (≥ 4) ESAS score for each symptom. RR (95% CI)

Exposure	Anxiety	Depression	Drowsiness	Appetite	Nausea	Pain	Shortness of breath	Tiredness	Well-being
Surgery									
Mastectomy alone	**1.09 (1.02, 1.16)**	**1.19 (1.09, 1.30)**	1.04 (0.96, 1.12)	**1.11 (1.03, 1.20)**	1.04 (0.88, 1.23)	0.99 (0.91, 1.07)	**1.16 (1.04, 1.28)**	**1.09 (1.04, 1.15)**	**1.08 (1.02, 1.15)**
Lumpectomy + radiation	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref

Models control for age, stage, rural residence, comorbidities, hospital volume, and month of ESAS assessment

Bold font indicates p value < 0.05

of patient symptoms, but can also be used as a tool to inform patients of expected quality of life following surgery.

Limitations

There are several limitations to this study. First, in order to capture a cohort of patients who were exposed to the symptom screening program, we restricted the population to those seen at regional cancer centers, limiting our ability to generalize to patients treated outside of regional cancer centers. While all lumpectomy patients attended a regional cancer center as they all received radiation (which is only administered at regional cancer centers in Ontario), not all mastectomy patients are required to attend a regional cancer center. This might select mastectomy patients who are part of specific groups and may have better or worse symptoms compared to the general population of women undergoing mastectomy. Second, billing and administrative data regarding receipt of formal axillary lymph node dissection and sentinel lymph node biopsy data were inconsistent and therefore not included in the analysis; however, since the selection of appropriate axillary surgery is generally independent of the choice of surgical procedure for the breast, it may be assumed that these procedures were similarly apportioned between the lumpectomy and mastectomy groups. Furthermore, we were unable to measure nodal status or tumor size, which may impact symptoms, particularly for mastectomy patients. We attempted to mitigate this bias by excluding patients who received chemotherapy and limiting the cohort to stage 1 and 2, although we recognize patients with stage 2 disease may still have relatively large tumors. Third, we were unable to measure endocrine therapy, which may be associated with symptoms, as this is only captured for patients aged 65 or older or those receiving government assistance. However, the likelihood of being on endocrine therapy should be similar in women with low risk disease who attend a regional cancer center. Fourth, some important demographic variables were unavailable in the administrative databases, such as family history and genetic mutations, and may have resulted in uncontrolled confounding. Finally, we lacked baseline symptoms prior to surgery or diagnosis for most patients, limiting our ability to determine actual change in scores for individual patients. Due to the nature of the symptom management program, most patients complete their first symptom assessment after their cancer diagnosis when they attend a regional cancer center.

Conclusion

Receipt of mastectomy is associated with an increased risk of reporting depression, lack of appetite and shortness of breath compared to receipt of lumpectomy plus radiation;

however, effect sizes are small. Clinicians can use the symptom assessments as a tool to engage patients and commence discussion regarding their symptoms and how treatment options may impact symptoms over the course of their cancer journey.

Disclaimers Part of this work will be presented at the American Society of Breast Surgeons conference in May 2019. This study was supported by the Institute for Clinical Evaluative Sciences (ICES), which is funded by an annual grant from the Ontario Ministry of Health and Long-Term Care (MOHLTC). The opinions, results, and conclusions reported in this paper are those of the authors and are independent from the funding sources. No endorsement by ICES or the Ontario MOHLTC is intended or should be inferred. Parts of this material are based on data and/or information compiled and provided by CIHI. However, the analyses, conclusions, opinions, and statements expressed in the material are those of the author(s), and not necessarily those of CIHI. Parts of this material are based on data and information provided by Cancer Care Ontario (CCO). The opinions, results, view, and conclusions reported in this paper are those of the authors and do not necessarily reflect those of CCO. No endorsement by CCO is intended or should be inferred.

Funding This work was supported by a Cancer Care Ontario Clinical Programs and Quality Initiatives grant and the Sherif and MaryLou Hanna Chair in Surgical Oncology Research.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethics approval This article does not contain any studies with human participants or animals performed by any of the authors.

Informed consent Informed consent was not required for this study.

Appendix

Appendix 1 Canadian Classification of Health Interventions (CCI) codes for mastectomy and lumpectomy

Code	Description
Procedure codes for lumpectomy ($n=37$)	
1YK87LA	Excision partial, nipple using open excisional approach
1YK87LAXXA	Excision partial, nipple using open excisional approach and full thickness autograft
1YK87LAXXB	Excision partial, nipple using open excisional approach and split thickness autograft
1YK87LAXXE	Excision partial, nipple using open excisional approach and local flap (e.g., rotation, advancement, transposition, Z-plasty) for closure
1YK89LA	Excision total, nipple using open approach
1YK89LAXXA	Excision total, nipple using open approach and full thickness autograft
1YK89LAXXE	Excision total, nipple using open approach and local flap (e.g., rotation, advancement, transposition, Z-plasty)
1YK90LAXXA	Excision total with reconstruction, nipple using open approach and full thickness autograft (e.g., contralateral nipple, labia, thigh, retroauricular tissue]
1YK90LAXXE	Excision total with reconstruction, nipple using open approach and local skin flap (e.g., propeller, star, quadripod skate)
1YK90LAXXQ	Excision total with reconstruction, nipple using open approach and combined local flap (e.g., nipple) and autograft (e.g., areola)
1YL87LA	Excision partial, lactiferous duct using open approach
1YL89LA	Excision total, lactiferous duct using open approach
1YM87DA	Excision partial, breast using endoscopic approach with simple apposition
1YM87GB	Excision partial, breast using endoscopic guide wire (or needle hook) excision technique with simple apposition of tissue
1YM87LA	Excision partial, breast using open approach with simple apposition of tissue (e.g., suturing)
1YM87LAXXA	Excision partial, breast using open approach and autograft (to close defect)
1YM87LAXXE	Excision partial, breast using open approach and local flap (to close defect)
1YM87UT	Excision partial, breast using open guide wire (or needle hook) excision technique and simple apposition of tissue
1YM87UTXXA	Excision partial, breast using open guide wire (or needle hook) excision technique with autograft (to close defect)
1YM87UTXXE	Excision partial, breast using open guide wire (or needle hook) excision technique with local flap (to close defect)
1YM88LAPM	Excision partial with reconstruction, breast without tissue with implantation of prosthesis
1YM88LAPME	Excision partial with reconstruction, breast with local flap with implantation of prosthesis

Appendix 1 (continued)

Code	Description
1YM88LAPMF	Excision partial with reconstruction, breast using free flap with implantation of prosthesis
1YM88LAPMG	Excision partial with reconstruction, breast using distant pedicled flap with implantation of prosthesis
1YM88LAPMK	Excision partial with reconstruction, breast using homograft with implantation of prosthesis
1YM88LAQF	Excision partial with reconstruction, breast without tissue with implantation of prosthesis and expander
1YM88LAQFE	Excision partial with reconstruction, breast with local flap with implantation of prosthesis and expander
1YM88LAQFF	Excision partial with reconstruction, breast using free flap with implantation of prosthesis and expander
1YM88LAQFG	Excision partial with reconstruction, breast using distant pedicled flap with implantation of prosthesis and expander
1YM88LATP	Excision partial with reconstruction, breast without tissue with implantation of tissue expander
1YM88LATPE	Excision partial with reconstruction, breast with local flap with tissue expander
1YM88LATPF	Excision partial with reconstruction, breast using free flap with implantation of tissue expander
1YM88LATPG	Excision partial with reconstruction, breast using distant pedicled flap with implantation of tissue expander
1YM88LATPK	Excision partial with reconstruction, breast using homograft with implantation of tissue expander
1YM88LAXXE	Excision partial with reconstruction, breast using local flap with no implanted device
1YM88LAXXF	Excision partial with reconstruction, breast using free flap with no implanted device
1YM88LAXXG	Excision partial with reconstruction, breast using distant pedicled flap with no implanted device
Procedures codes for mastectomy ($n=14$)	
1YM89LA	Excision total, breast using open approach
1YM89LAXXA	Excision total, breast using open approach and autograft
1YM89LAXXE	Excision total, breast using open approach and local flap
1YM90LAXXE	Excision total with reconstruction, breast simple mastectomy with no node dissection using local flap with no implanted device
1YM91LA	Excision (modified) radical, breast without tissue
1YM91LAXXA	Excision radical (modified), breast using autograft
1YM91LAXXE	Excision (modified) radical, breast using local flap
1YM91TR	Excision extended radical, breast without tissue
1YM91TRXXA	Excision extended radical, breast using autograft
1YM91TRXXE	Excision extended radical, breast using local flap
1YM91WP	Excision super radical, breast without tissue
1YM91WPXXA	Excision super radical, breast using autograft
1YM91WPXXE	Excision super radical, breast using local flap
1YM92LAXXE	Excision radical with reconstruction, breast modified or NOS using local flap with no implanted device

Appendix 2 Codes for adjuvant treatment

Modality	Data source	Codes
Radiotherapy	ALR Database (NHPIP Codes)	500, 501, 510, 511, 519, 521, 530–541, 548, 549, 561, 563, 565, 566, 570–573, 575, 581, 592, 594, 566, 597

ALR activity level reporting, *NHPIP* national hospital productivity improvement project

References

1. Fisher B, Anderson S, Bryant J et al (2002) Twenty-year follow-up of a randomized trial comparing total mastectomy, lumpectomy, and lumpectomy plus irradiation for the treatment of invasive breast cancer. N Engl J Med 347:1233–1241. https://doi.org/10.1056/NEJMoa022152
2. Chow R, Pulenzas N, Zhang L et al (2016) Quality of life and symptom burden in patients with breast cancer treated with mastectomy and lumpectomy. Support Care Cancer 24:2191–2199. https://doi.org/10.1007/s00520-015-3027-8
3. Kim MK, Kim T, Moon HG et al (2015) Effect of cosmetic outcome on quality of life after breast cancer surgery. Eur J Surg Oncol 41:426–432. https://doi.org/10.1016/j.ejso.2014.12.002
4. Irwig L, Bennetts A (1997) Quality of life after breast conservation or mastectomy: a systematic review. Aust N Z J Surg 67:750–754. https://doi.org/10.1111/j.1445-2197.1997.tb04573.x
5. Janz NK, Mujahid M, Chung LK et al (2007) Symptom experience and quality of life of women following breast cancer treatment. J Womens Health 16:1348–1361. https://doi.org/10.1089/jwh.2006.0255
6. Arndt V, Stegmaier C, Ziegler H, Brenner H (2008) Quality of life over 5 years in women with breast cancer after breast-conserving therapy versus mastectomy: a population-based study. J Cancer Res Clin Oncol 134:1311. https://doi.org/10.1007/s00432-008-0418-y
7. Parker PA, Youssef A, Walker S et al (2007) Short-Term and long-term psychosocial adjustment and quality of life in women undergoing different surgical procedures for breast cancer. Ann Surg Oncol 14:3078–3089. https://doi.org/10.1245/s10434-007-9413-9
8. Arora NK, Gustafson DH, Hawkins RP, et al (2001) Impact of surgery and chemotherapy on the quality of life of younger women with breast carcinoma. Cancer 92:1288–1298. https://doi.org/10.1002/1097-0142(20010901)92:5%3C1288::AID-CNCR1450%3E3.0.CO;2-E
9. Seow H, Barbera L, Sutradhar R et al (2011) Trajectory of performance status and symptom scores for patients with cancer during the last six months of life. J Clin Oncol 29:1151–1158. https://doi.org/10.1200/JCO.2010.30.7173
10. Bubis LD, Davis L, Mahar A et al (2018) Symptom burden in the first year after cancer diagnosis: an analysis of patient-reported outcomes. J Clin Oncol 36:1103–1111. https://doi.org/10.1200/JCO.2017.76.0876
11. Tran K, Zomer S, Chadder J et al (2018) Measuring patient-reported outcomes to improve cancer care in Canada: an analysis of provincial survey data. Curr Oncol 25:176–179. https://doi.org/10.3747/co.25.3995
12. Oldenmenger WH, de Raaf PJ, de Klerk C, van der Rijt CCD (2013) Cut points on 0–10 numeric rating scales for symptoms included in the edmonton symptom assessment scale in cancer patients: a systematic review. J Pain Symptom Manage 45:1083–1093. https://doi.org/10.1016/j.jpainsymman.2012.06.007
13. Selby D, Cascella A, Gardiner K et al (2010) A single set of numerical cutpoints to define moderate and severe symptoms for the edmonton symptom assessment system. J Pain Symptom Manage 39:241–249. https://doi.org/10.1016/j.jpainsymman.2009.06.010
14. Barbera L, Sutradhar R, Howell D et al (2015) Does routine symptom screening with ESAS decrease ED visits in breast cancer patients undergoing adjuvant chemotherapy? Support Care Cancer 23:3025–3032. https://doi.org/10.1007/s00520-015-2671-3
15. Barbera L, Atzema C, Sutradhar R et al (2013) Do patient-reported symptoms predict emergency department visits in cancer patients? A population-based analysis. Ann Emerg Med 61:427–437.e5. https://doi.org/10.1016/j.annemergmed.2012.10.010
16. Watanabe SM, Nekolaichuk CL, Beaumont C (2012) The Edmonton symptom assessment system, a proposed tool for distress screening in cancer patients: development and refinement. Psycho-Oncology 21:977–985. https://doi.org/10.1002/pon.1996
17. Platt J, Zhong T, Moineddin R et al (2015) Geographic variation immediate and delayed breast reconstruction utilization in Ontario, Canada and plastic surgeon availability: a population-based observational study. World J Surg 39:1909–1921. https://doi.org/10.1007/s00268-015-3060-2
18. Zhong T, Fernandes KA, Saskin R et al (2014) Barriers to immediate breast reconstruction in the Canadian universal health care system. J Clin Oncol 32:2133–2141. https://doi.org/10.1200/JCO.2013.53.0774
19. CMA and CA: Detailed definition. https://www.statcan.gc.ca/pub/92-195-x/2011001/geo/cma-rmr/def-eng.htm. Accessed 19 Oct 2017
20. Clarke E, Marrett L, Kreiger N (1991) Cancer registration in Ontario: a computer approach. In: Cancer registration principles and methods. IARC Publication, Lyon, pp 246–257
21. Reid RJ, Roos NP, MacWilliam L et al (2002) Assessing population health care need using a claims-based ACG morbidity measure: a validation analysis in the province of Manitoba. Health Serv Res 37:1345–1364. https://doi.org/10.1111/1475-6773.01029
22. Austin PC (2009) Using the standardized difference to compare the prevalence of a binary variable between two groups in observational research. Commun Stat Simul Comput 38:1228–1234. https://doi.org/10.1080/03610910902859574
23. Lipsitz SR, Kim K, Zhao L (1994) Analysis of repeated categorical data using generalized estimating equations. Stat Med 13:1149–1163. https://doi.org/10.1002/sim.4780131106
24. Hui D, Shamieh O, Paiva CE et al (2015) Minimal clinically important differences in the Edmonton symptom assessment scale in cancer patients: a prospective multicenter study. Cancer 121:3027–3035. https://doi.org/10.1002/cncr.29437
25. Fann JR, Thomas-Rich AM, Katon WJ et al (2008) Major depression after breast cancer: a review of epidemiology and treatment. Gen Hosp Psychiatry 30:112–126. https://doi.org/10.1016/j.genhosppsych.2007.10.008
26. Han J, Grothuesmann D, Neises M et al (2010) Quality of life and satisfaction after breast cancer operation. Arch Gynecol Obstet 282:75–82. https://doi.org/10.1007/s00404-009-1302-y
27. Brady MJ, Cella DF, Mo F et al (1997) Reliability and validity of the functional assessment of cancer therapy-breast quality-of-life instrument. J Clin Oncol Off J Am Soc Clin Oncol 15:974–986. https://doi.org/10.1200/JCO.1997.15.3.974
28. Covelli AM, Baxter NN, Fitch MI et al (2015) 'Taking control of cancer': understanding women's choice for mastectomy. Ann Surg Oncol 22:383–391. https://doi.org/10.1245/s10434-014-4033-7
29. Nold RJ, Beamer RL, Helmer SD, McBoyle MF (2000) Factors influencing a woman's choice to undergo breast-conserving surgery versus modified radical mastectomy. Am J Surg 180:413–418. https://doi.org/10.1016/S0002-9610(00)00501-8
30. Fisher CS, Martin-Dunlap T, Ruppel MB et al (2012) Fear of recurrence and perceived survival benefit are primary motivators for choosing mastectomy over breast-conservation therapy regardless of age. Ann Surg Oncol 19:3246–3250. https://doi.org/10.1245/s10434-012-2525-x
31. Halkett GKB, Kristjanson LJ, Lobb EA (2008) 'If we get too close to your bones they'll go brittle': women's initial fears about radiotherapy for early breast cancer. Psychooncology 17:877–884. https://doi.org/10.1002/pon.1298
32. Halkett GK, Arbon P, Scutter SD, Borg M (2005) The breast cancer patient's experience of making radiation therapy treatment decisions. Radiographer 52:17–21. https://doi.org/10.1002/j.2051-3909.2005.tb00025.x

33. Hammick M, Tutt A, Tait DM (1998) Knowledge and perception regarding radiotherapy and radiation in patients receiving radiotherapy: a qualitative study. Eur J Cancer Care (Engl) 7:103–112. https://doi.org/10.1046/j.1365-2354.1998.00072.x
34. Rosenberg SM, Tracy MS, Meyer ME et al (2013) Perceptions, knowledge, and satisfaction with contralateral prophylactic mastectomy among young women with breast cancer: a cross-sectional survey. Ann Intern Med 159:373. https://doi.org/10.7326/0003-4819-159-6-201309170-00003
35. Perry S, Kowalski TL, Chang C-H (2007) Quality of life assessment in women with breast cancer: benefits, acceptability and utilization. Health Qual Life Outcomes 5:24. https://doi.org/10.1186/1477-7525-5-24
36. Tariman JD, Berry DL, Cochrane B et al (2010) Preferred and actual participation roles during health care decision making in persons with cancer: a systematic review. Ann Oncol 21:1145–1151. https://doi.org/10.1093/annonc/mdp534
37. Hack TF, Degner LF, Watson P, Sinha L (2006) Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer. Psychooncology 15:9–19. https://doi.org/10.1002/pon.907

Affiliations

Laura E. Davis[1] · Courtney Fulton[2] · Lev D. Bubis[2] · Jonathan Sussman[3,4] · Lesley Moody[3] · Lisa Barbera[5] · Qing Li[6] · Alyson L. Mahar[7] · Natalie G. Coburn[2,3,6,8,9,10] · Claire M. B. Holloway[3,9]

1 Evaluative Clinical Sciences, Sunnybrook Research Institute, Toronto, Canada
2 Division of General Surgery, Department of Surgery, University of Toronto, Toronto, Canada
3 Cancer Care Ontario, Toronto, Canada
4 Department of Oncology, McMaster University, Hamilton, Canada
5 Division of Radiation Oncology, University of Calgary, Calgary, Canada
6 ICES, Toronto, Canada
7 Department of Community Health Sciences, University of Manitoba, Winnipeg, Canada
8 Institute for Health Policy, Management, and Evaluation, University of Toronto, Toronto, Canada
9 Division of General Surgery, Sunnybrook Health Sciences Centre, Toronto, Canada
10 Sunnybrook Health Sciences Centre, 2075 Bayview Ave., Room T2 011, Toronto, ON M4N 3M5, Canada