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Prescription and Adherence to Lymphedema Self-Care Modalities among Women with Breast Cancer-Related Lymphedema

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Abstract

Purpose—To profile the prescription for and adherence to breast cancer related lymphedema (BCRL) self-care modalities among breast cancer (BrCa) survivors with BCRL in a 12-month randomized weightlifting trial.

Methods—We developed a questionnaire that assessed prescription for and adherence to 10 BCRL self-care modalities that included physical therapy exercise, pneumatic compression pump, medication, lymphedema bandaging, arm elevation, self-administered lymphatic drainage, therapist-administered lymphatic drainage, compression garments, skin care, and taping. We measured prescription for and adherence to BCRL self-care modalities at baseline, 3-, 6-, and 12-months. Longitudinal logistic regression was used to estimate the odds ratio (OR) and 95% confidence interval (95% CI) associated with prescription for and adherence to BCRL modalities over time.

Results—This study included 141 BrCa survivors with BCRL. Women were prescribed an average of 3.6±2.1 BCRL self-care modalities during the study. The prescription of therapist-administered lymphatic drainage (OR=0.92, 95% CI: 0.88–0.96), pneumatic compression pump use (OR=0.94, 95% CI: 0.89–0.98), and bandaging (OR=0.96, 95% CI: 0.93–0.99) decreased over 12-months of follow-up. No other prescribed BCRL self-care modalities changed during the study. Over 12-months, the average adherence to all BCRL self-care modalities varied with 13%, 24%, 32%, and 31% of women reporting <25%, 25–49%, 50–74%, and 75% adherence, respectively. Over 12-months, there was a noticeable change from high to low adherence in self-administered lymphatic drainage, such that there was a 15% increased likelihood

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Disclaimers: BSN Medical provided custom-fitted compression garments to all study participants.

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Conflicts of Interest

All authors declare no conflicts of interest exist. We (the authors) have had full control of all the primary data and agree to allow the editors of this journal access if requested.

of adherence <25% compared to 75% (OR=1.15 (95% CI: 1.05–1.26); p=0.002). The adherence patterns of all other modalities did not change over follow-up.

Conclusions—Our findings suggest the prescription of BCRL self-care modalities is variable. The average adherence to BCRL self-care was non-optimal. Future research is necessary to prepare BrCa survivors with the knowledge, skills, abilities, and resources necessary to care for this lifelong condition.

Keywords

compression; self-care; compliance; management; quality-of-life

INTRODUCTION

There are three million breast cancer (BrCa) survivors in the United States [1, 2]. A major concern that affects 6–70% of BrCa survivors is breast cancer-related lymphedema (BCRL) [3–8]. BCRL is a progressive chronic condition characterized by accumulation of protein-rich fluid in the upper limbs resulting in swelling, discomfort, altered physical function, impaired quality of life, and economic burden [9–15]. BCRL occurs from damage to the lymphatic system, such as that with sentinel node biopsy, axillary dissection, and fibrosis from radiation therapy [16–19].

There are no curative treatments for BCRL. Therefore clinical guidelines for BCRL management focus on lifelong practices to maintain arm health and minimize the risk of BCRL-related complication, such as cellulitic infection [20–22]. BCRL guidelines are multifactorial, encompassing a variety of modalities to maintain and promote arm health. Such modalities include self-administered lymphatic drainage, compression garments, therapeutic exercise, and meticulous skin care, among others. Each of these BCRL self-care modalities varies with the frequency they should be performed. For example, meticulous skin care is a daily activity, compression garments have been recommended for use during all waking hours, self-administered lymphatic massage has been recommended four times per week, and pneumatic compression pump therapy has been recommended for 30 minutes daily [23]. The complex lifelong requirements of BCRL self-care are associated with patient burden, reduced quality of life, and poor compliance [24–27]. Poor compliance to BCRL self-care modalities is associated with increased arm volume and progression of BCRL to more advanced stages [28].

The purpose of our study was to profile the prescription to and adherence of BCRL self-care modalities among BrCa survivors with BCRL who participated in a randomized weightlifting trial. Prescription is defined as a lymphedema clinician advising their patient to engage in a specific BCRL self-care activity. Adherence is defined as the percentage of the time the patient completed the BCRL self-care activity at the frequency recommended by the lymphedema clinician. The identification of adherence to BCRL self-care modalities is important because specific BCRL self-care modalities associated with low adherence can be the focus of additional efforts to provide patients with the knowledge, skills, abilities, and resources necessary to maintain satisfactory compliance to maximize health-related quality of life and BCRL outcomes.

METHODS

Study Design & Participants

This study is a secondary analysis of the physical activity and lymphedema (PAL) trial, a randomized controlled trial that included BrCa survivors with stable BCRL [29]. Participants in the PAL trial were randomized to a progressive weightlifting intervention versus no exercise. The primary aim of the PAL trial was to assess change in BCRL outcomes resulting from twice-weekly weightlifting among BrCa survivors. The primary outcomes and detailed methods of the PAL trial [29] have been reported previously [30, 31]. Participation criteria included the following: 1) female BrCa survivor 1–15 years post-diagnosis; 2) free from cancer at study entry; 3) 1 lymph node removed; 4) no medical conditions or contraindicated medications that would prohibit participation in an exercise program. Additional criteria included: 5) body mass index ≤ 30 kg/m²; 6) no plans for surgery during the intervention period; 7) no history of bilateral lymph node dissection; 8) no weightlifting in the previous one year; 9) weight stable and not attempting to lose weight [29].

For the purpose of the PAL study eligibility, BCRL was defined as $\geq 10\%$ interlimb difference, or meeting any of the Common Toxicity Criteria Adverse Event version 3.0 for BCRL (swelling, obscuration, pitting), or a prior clinical diagnosis of BCRL [29]. In addition, participants were ineligible if they had any of the following within the past three months: 1) intensive BCRL therapy (i.e., complete decongestive therapy); 2) a recorded $\geq 10\%$ change in volume or circumference of the arm that lasted for ≥ 7 days; 3) more than one BCRL related infection that required antibiotics; 4) a BCRL exacerbation that resulted in a change in activities of daily living. All participants were required to attend a one-hour educational lecture entitled the ‘Lymphedema Education Session (LES)’ that was based on material from the National Lymphedema Network (NLN) [32]. After completing baseline measures, all participants were provided with a compression sleeve to wear throughout the study, and with a second sleeve at 6-months. The patient cohort was recruited between October 2005 and February 2007. The University of Pennsylvania Institutional Review Board approved the study protocol, and informed consent was obtained from all participants.

BCRL Self-Care Prescription & Adherence

Participants completed a questionnaire that assessed prescription of and adherence to 10 BCRL self-care modalities, as outlined in the clinical practice guidelines for the treatment and care of BCRL [20]. These modalities included physical therapy exercises, pneumatic compression pump, medications, lymphedema bandaging, arm elevation, self-administered lymphatic drainage, therapist-administered lymphatic drainage, compression garments, skin care, taping, or any other modality prescribed, but not listed above. Participants were asked to report whether each modality had been prescribed as part of their lymphedema treatment care plan by the person who they identified as their primary lymphedema clinician. For each modality prescribed, women were asked to report how often they completed the BCRL self-care modality at the frequency recommended by the lymphedema clinician. Four adherence intervals were provided: less than 25% of the time (<25%), 25–49% of the time (25–49%), 50–74% of the time (50–74%), and more than or equal to 75% of the time ($\geq 75\%$). Study

participants completed this questionnaire at baseline, 3-, 6-, and 12-month time points. At baseline, the questionnaire asked about modalities prescribed in the prior 12-months, and all subsequent questionnaires asked since the last time this questionnaire was completed (i.e., in the past 3- or 6-months).

Demographic and Clinical Variables

Demographic characteristics, cancer treatment and medication history were obtained by self-report. Cancer staging was taken from state cancer registries, surgical pathology reports, or self-report. The number of lymph nodes removed was obtained from surgical pathology reports. These variables were collected at baseline.

Statistical Analysis

Descriptive statistics reported for variables include counts for categorical variables and means and standard deviations for continuous variables. To examine the association of changes in BCRL self-care prescription we conducted a longitudinal multivariable logistic regression to account for within subject clustering over time, adjusting for demographic and clinical variables, as well as randomized study group. To examine the association of changes in BCRL self-care adherence we conducted a longitudinal multivariable multinomial logistic regression to account for within subject clustering, adjusting for demographic and clinical variables, as well as randomized study group. In the multinomial regression, the adherence level 75% was designated as the reference group. The measure of association for the prescription and adherence analyses used an odds ratio (OR) and 95% confidence interval (95% CI) from the logistic regression models. We used the Holm-Bonferroni adjustment to maintain overall type I error at 0.05 for each set of analyses (prescription and adherence) [33]. All statistical analyses were performed with Stata SE 12.0 software (College Station, TX).

RESULTS

Participant Demographic Characteristics

The PAL trial randomized 141 women with BCRL to assess the primary outcome of changes in lymphedema. Two women were excluded from this analysis because of second primary or recurrent cancer. Participants were aged 37–80 at baseline (Table 1). The racial composition of the PAL study included 58% and 39% of women self-reporting white or black race, respectively. The occupational distribution of the PAL study included a variety of occupational backgrounds including 37% in professional occupations, and 31% who were retired.

Participant Clinical Characteristics

Time since BrCa diagnosis ranged from 1–15 years, and the number of lymph nodes removed ranged from 1–38. Participants in the PAL study were diagnosed most commonly with stage I (40%) or stage III (31%) BrCa. There was a wide distribution BCRL severity, grade, and frequency of symptoms using arm volume differences, Common Toxicity Criteria, and Norman Lymphedema Questionnaire, respectfully.

BCRL Self-Care Prescription

The most common BCRL self-care modality prescribed in the PAL study was the compression garment with an average prescription rate of 84% throughout the study (Table 2). The least common BCRL self-care modality prescribed in the PAL study was the use of medications with an average prescription rate of 4% throughout the study. One participant was prescribed water aerobics (the 'anything else' category). Therapist-administered lymphatic drainage prescription decreased over time with participants on average 8% less likely to be prescribed this modality (OR=0.92 (95% CI: 0.88–0.96); $p<0.001$). Pneumatic compression pump prescription decreased over time with participants on average 6% less likely to be prescribed this modality (OR=0.94 (95% CI: 0.89–0.98); $p=0.005$). BCRL bandaging prescription decreased over time with participants on average 4% less likely to be prescribed this modality (OR=0.96 (95% CI: 0.93–0.99); $p=0.011$). The prescription patterns of all other modalities did not change significantly during the study. Collectively, women were prescribed 3.6 ± 2.1 BCRL self-care modalities while in the study; this average did not change over time ($\beta=-0.02$; $p=0.115$). We did not identify any statistically significant group by time or race by time interactions in these analyses (results not shown).

BCRL Self-Care Adherence

Over 12-months, the majority of PAL participants (69%) reported BCRL adherence $<75\%$ adherence to all prescribed BCRL self-care activities (Table 3). Over 12-months, the most highly adhered to BCRL self-care modality in the PAL study was 9 skin care, as 72.5% of women had an adherence rate $\geq 75\%$ during the study. The most poorly adhered to BCRL self-care modalities over 12-months were similar among pneumatic compression pump use, self-administered lymphatic drainage, and therapist-administered lymphatic drainage, with approximately 42% of women with an adherence rate of $<25\%$ during the study. Over 12-months of follow-up, there was a noticeable change from high to low adherence in self-administered lymphatic drainage, such that there was a 15% increased likelihood of adherence $<25\%$ compared to $\geq 75\%$ (OR=1.15 (95% CI: 1.05–1.26); $p=0.002$). The adherence patterns of all other modalities did not change over 12-months. Collectively, 13%, 24%, 32%, and 31% of women reported an average adherence rate of $<25\%$, 25–49%, 50–74%, and $\geq 75\%$ during the study, respectively. These averages were consistent throughout the study. We did not identify any statistically significant group by time or race by time interactions in these analyses (results not shown).

DISCUSSION

Prescription of therapist-administered lymphatic drainage, pneumatic compression pump, and BCRL bandaging were prescribed less frequently as the study progressed from baseline to 12-months, with all other BCRL self-care modalities prescribed consistently over follow-up. In addition, self-administered lymphatic drainage adherence decreased from baseline to 12-months, with adherence to all other BCRL self-care modalities consistent throughout the study. Finally, overall adherence to all BCRL self-care modalities was non-optimal; 69% of participants reported an average adherence $<75\%$ of the self-care regimen recommended by their lymphedema clinician.

The 2001 clinical practice guidelines for the care of BCRL served as the foundation of this secondary analysis of the PAL trial data [20]. In 2009 a revised edition of clinical practice guidelines for the care of BCRL were published given evidence supporting the association of zenzopyrones with liver toxicity [21]. Both of these guidelines emphasized women with BCRL wear a well-fitting compression garment and use appropriate bandaging, perform physical therapy exercises, perform self-administered lymphatic drainage, be mindful of skin care, and for a subgroup of patients, use a pneumatic compression pump. Consistent with the clinical guidelines, the majority of participants were prescribed compression garments (84%), bandages (60%), and physical therapy exercises (55%). Inconsistent with the clinical guidelines, a minority of participants were prescribed self-administered lymphatic drainage (39%), skin care (36%), and a pneumatic compression pump (9.5%). Despite BCRL self-care prescriptions that were partially consistent with the clinical guidelines, participant adherence to the BCRL self-care program was regularly less than that recommended by the lymphedema clinician. Over the 12- months of the PAL trial, 60% of participants for whom compression garments were prescribed as part of self-care wore their compression garment <75% of the frequency prescribed by their lymphedema clinician. These patterns were consistent for bandaging (65.5%), exercise (77.5%), self-administered lymphatic drainage (81%), and use of pneumatic compression pump (70%), respectively. Skin care was the modality most adhered to as prescribed, 72.5% reported adherence 75%.

BCRL clinical guidelines have noted the main impediment to treatment success is patient compliance, which has historically been poor [20, 21]. The PAL trial was an exercise study to examine the safety of upper and lower extremity weightlifting among BrCa survivors with BCRL. We hypothesized the women who participated in the PAL trial were motivated to identify ways to manage their BCRL and were adherent to their current BCRL self-care program as prescribed by their lymphedema clinician. Furthermore, the PAL trial also provided the BCRL educational LES lecture. The LES lecture was a one-hour, pre-randomization, in person interactive class delivered by the principal investigator to provide all study participants with an equivalent level of BCRL knowledge. The LES provided participants with the current guidelines pertaining to exercise, BCRL risk reduction practices, BCRL treatment, and selection of a qualified BCRL clinician, as recommended by the NLN. Given the hypothesized enthusiasm about participating in a BCRL trial, and provision of the evidence-based LES, it is surprising that the majority of PAL participants (69%) reported BCRL adherence <75% adherence to prescribed BCRL self-care activities, and that adherence to BCRL modalities did not increase from baseline (i.e., after the LES lecture). Perhaps one reason for the lack of improvement in BCRL self-care adherence was that the mean time since BCRL diagnosis was approximately 5 years, and 81% of participants had BCRL diagnosed 1 year prior to enrolling in the study. It is plausible that since the time of BCRL diagnosis women had already established a self-care routine that was feasible for them and they believed to be efficacious. The PAL trial had a variety of inclusion criteria relating to BCRL stability and overall arm health. Women may have perceived their BCRL to be well-managed with their current adherence to BCRL self-care activities, thereby precluding any impetus to improve adherence beyond current levels.

Our findings support numerous prior reports that performing multiple BCRL self-care modalities is burdensome to BrCa survivors, and this burden manifests in poor adherence

[26]. Many BrCa survivors report that the BCRL management plan prescribed by their lymphedema clinician impairs quality of life [34]. For example, among 51 BrCa survivors, the main issues that influence BCRL self-care practices are: the garments are uncomfortable to wear [the compression sleeve is hot/itchy] (34%), the need to alter clothing options [because of compression sleeves] (30%), difficulty completing self-care modalities [such as wrapping with bandages] (30%), not having enough time to do everything (24%), and lifelong consciousness of arm monitoring [for insect bites or cuts] deterred quality of life (24%). These practical barriers to BCRL self-care adherence are troubling as it is known that poor adherence to bandaging and compression garment use is associated with 55%, and 61% increased risks of having an increase in arm volume over one year, respectively [35]. Our data demonstrated the likelihood of a prescription of bandaging decreased over 12-month follow-up ($p=0.011$). The reason for this is unclear.

Given the poor adherence to BCRL self-care, methods to improve adherence are needed. It has been noted that nurses who provide information regarding BCRL self-care increase patient awareness and knowledge to promote adherence to risk-minimization practices for BCRL [36]. Additional evidence supports increasing knowledge about BCRL and the care required to achieve optimal health outcomes [37]. Among women diagnosed with BrCa at risk for developing BCRL, levels of knowledge, self-efficacy, and belief in the controllability of BCRL were related to increased risk-reduction practices [36, 37]. We conducted multivariable analyses on variables listed in Table 1 and did not find any significant predictors of BCRL self-care adherence (results not shown). It is plausible that psychosocial and behavioral characteristics, such as knowledge, intention, and self-efficacy, are more important predictors of BCRL self-care than demographic or clinical characteristics [36, 37].

A recent systematic review of BCRL self-care modalities concluded the evidence for BCRL self-care modalities is scant, and no BCRL self-care modalities had sufficient data to recommend for practice based on the Oncology Nursing Society Implementation of Practice Guidelines [25]. Despite this limitation, the only BCRL self-care modality supported with randomized clinical trial data was full body exercise, such as that prescribed in the PAL trial [30, 38, 39]. Phase II complete decongestive therapy, consisting of therapeutic exercise, skin care, taping, and self-administered lymphatic drainage was also considered effective, despite relying solely on expert opinion [40–42]. Even with the widespread use of compression garment and pneumatic compression pumps, the depth and breadth of evidence to support the use of these modalities remains scant. All other self-care modalities lacked sufficient data to support the individual use of any one (or combination) of BCRL self-care modalities [25].

There are multiple other examples of chronic conditions for which self-care activities predict disease progression. As one example, patients diagnosed with Type 1 Diabetes need to check their blood glucose levels daily and coordinate caloric intake and physical activity according to results. There is a well-developed infrastructure to educate those with diabetes about their self-care: a team of dedicated staff and resources to guide patients with diabetes towards optimal diabetes self-care practices [43]. To date, no such infrastructure exists for BCRL [44]. A multidisciplinary approach to improve BCRL self-care practices that includes

physicians, nurses, therapists, and social workers has been proposed [34]. Empirically testing these services against the current standards of care would provide evidence causally linking lymphedema knowledge, skills, abilities, and resources with BCRL-related outcomes such as arm volume and symptom burden.

There exist limitations to our study that warrant discussion. The major limitation of our study is the fact that this is a secondary analysis of the PAL trial. Women who were too busy to participate in a yearlong, twice-weekly weightlifting exercise trial for BCRL were excluded from our sample. The PAL participants may represent a more motivated subset of BrCa survivors with BCRL, therefore it is plausible that our study overestimates the adherence to BCRL self-care modalities relative to BrCa survivors in the community. The small sample size for adherence outcomes for some modalities precluded a multivariable analysis to be conducted. This small sample size may have also precluded us from detecting significant group by time and race by time statistical interactions. The BCRL self-care questionnaire used in this study is based on self-report, and is not validated in the published literature. It is plausible a social desirability bias exists, such that women reported higher BCRL adherence on the questionnaire in attempt to satisfy the study staff who administered the questionnaire.

In conclusion, this study demonstrates that BCRL self-care prescription varies from the current clinical recommendations, as well as within woman over time. Further, adherence to 14 BCRL self-care modalities is consistently low on average over 12-month follow-up. Future research should seek to identify the most efficacious modalities to manage BCRL, and encourage the adherence to those specific modalities. The development of an infrastructure to provide the knowledge, skills, abilities, and resources necessary for BrCa survivors to care for this lifelong condition is warranted, similar to diabetes management [43]. A study design which examines efficacy outcomes and dissemination simultaneously is one approach to facilitate the early adoption and implementation of efficacious practices into clinical care for BCRL [45].

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Table 1Characteristics of study participants (n=139)^a

Characteristic	Value
Age – yr	57.0±9.7
Education	
High school or less	28 (20%)
Some college	50 (36%)
College degree or more	61 (44%)
Self-reported race – no. (%)	
White	80 (58%)
Black	54 (39%)
Other	5 (4%)
Occupation	
Professional	52 (37%)
Clerical or service	20 (14%)
Homemaker, student, or unemployed	11 (8%)
Other or unknown	13 (9%)
Retired	43 (31%)
Years since cancer diagnosis	6.9±3.8
Cancer stage	
I	56 (40%)
II	1 (1%)
III	43 (31%)
Data not available	39 (28%)
No. of nodes removed	15.2±8.2
Chemotherapy	113 (81%)
Radiation	110 (79%)
Cancer medications taken at study entry	
Tamoxifen	17 (12%)
Aromatase inhibitor	1 (1%)
Years since Lymphedema diagnosis	5.0±3.7
Arm Volume Percent Difference	16.0±15.1
Arm Volume Percent Difference	
Stage 0 (<5%)	30 (22%)
Stage I (5 – <10%)	21 (15%)
Stage II (10 – <30%)	63 (45%)
Stage III (30%)	25 (18%)
Common Toxicity Criteria Lymphedema grade	
0	12 (9%)
1	29 (21%)
2	58 (42%)
3	40 (29%)

Characteristic	Value
Norman Lymphedema Survey ^b	
No lymphedema (No symptoms)	11 (8%)
Mild lymphedema (1–3 symptoms)	62 (45%)
Moderate+ lymphedema (4 symptoms)	66 (48%)
Number of symptoms	5.5±2.8
Severity of symptoms	2.0±0.7

^aContinuous variables are mean ± standard deviation. Categorical variables are n (%) and may exceed 100% due to rounding error.

^bData were reported by patients regarding 14 symptoms: rings too tight, watch too tight, bracelets too tight, clothing too tight, puffiness, knuckles not visible, veins not visible, skin feels leathery, arm feels tired, pain, pitting, swelling after exercise, difficulty writing, or other. Severity of symptoms is the mean for all 14 symptoms, with the possible severity score for each ranging from 0 (no symptom) to 4 (very severe).

Table 2

Utilization of lymphedema management modalities^a

Modality Prescribed	Baseline (n=139)	3-months (n=131)	6-months (n=130)	12-months (n=125)	Odds Ratio (95% CI) ^b	P-Value
Exercise						
Yes	81 (58%)	72 (55%)	70 (54%)	68 (54%)	0.99 (0.96–1.02)	0.540
No	58 (42%)	59 (45%)	60 (46%)	57 (46%)		
Pneumatic Compression Pump						
Yes	16 (12%)	12 (9%)	14 (11%)	7 (6%)	0.94 (0.89–0.98)	0.005
No	123 (88%)	119 (91%)	116 (89%)	118 (94%)		
Medications						
Yes	7 (5%)	7 (5%)	3 (2%)	2 (2%)	0.89 (0.78–1.01)	0.075
No	132 (95%)	124 (95%)	127 (98%)	123 (98%)		
Bandaging						
Yes	94 (68%)	74 (57%)	78 (60%)	69 (55%)	0.96 (0.93–0.99)	0.011
No	45 (32%)	57 (43%)	52 (40%)	56 (45%)		
Elevation						
Yes	59 (42%)	38 (29%)	49 (38%)	49 (39%)	1.00 (0.97–1.04)	0.666
No	80 (58%)	93 (71%)	81 (62%)	76 (61%)		
Self-Administered Lymphatic Drainage						
Yes	54 (39%)	53 (40%)	49 (38%)	50 (40%)	1.01 (0.98–1.05)	0.402
No	85 (61%)	78 (60%)	81 (62%)	75 (60%)		
Therapist-Administered Lymphatic Drainage						
Yes	64 (46%)	40 (31%)	35 (27%)	33 (26%)	0.92 (0.88–0.96)	<0.001
No	75 (54%)	91 (69%)	95 (73%)	92 (74%)		
Compression Garment						
Yes	110 (79%)	116 (89%)	110 (85%)	105 (84%)	1.01 (0.96–1.06)	0.711
No	29 (21%)	15 (11%)	20 (15%)	20 (16%)		
Skin Care						
Yes	46 (33%)	49 (37%)	47 (36%)	47 (38%)	1.02 (0.99–1.05)	0.236
No	93 (67%)	82 (63%)	83 (64%)	78 (62%)		
Taping						

Modality Prescribed	Baseline (n=139)	3-months (n=131)	6-months (n=130)	12-months (n=125)	Odds Ratio (95% CI) ^b	P-Value
Yes	11 (8%)	4 (3%)	12 (9%)	11 (9%)		
No	128 (92%)	127 (97%)	118 (91%)	114 (91%)	1.05 (0.97-1.13)	0.260
Anything Else						
Yes	1 (1%)	1 (1%)	1 (1%)	0 (0%)		
No	138 (99%)	130 (99%)	129 (99%)	125 (100%)	Insufficient Observations ^c	—
Total No. of Lymphedema Management Modalities						
Mean±SD	3.9±2.2	3.6±2.0	3.6±2.1	3.5±2.1	-0.02 (-0.05-0.01)	0.115

^aVariables are n (%).

^bMultivariable adjusted longitudinal clustered (to account for repeated observations within subject) logistic regression, adjusting for age, education, race, occupation, time since diagnosis, cancer stage, radiation, chemotherapy, baseline arm volume difference, randomized group assignment, and diagnosis of lymphedema flare in the study. Other variables listed in Table 1 were omitted on the basis of multicollinearity.

^cDue to small cell sizes of these modalities, a statistical model could not be calculated.

^dMultivariable longitudinal regression, adjusting for factors listed above.

Table 3

Adherence to lymphedema management modalities^a

Modality Adherence	Baseline	3-months	6-months	12-months	Odds Ratio (95% CI) ^b	P-Value
Exercise						
<25%	42 (52%)	22 (31%)	20 (29%)	29 (43%)	0.97 (0.90–1.05)	0.447
25–49%	20 (25%)	14 (19%)	21 (30%)	15 (22%)	0.99 (0.90–1.08)	0.765
50–74%	8 (10%)	16 (22%)	10 (14%)	10 (15%)	1.00 (0.89–1.12)	0.988
75%	11 (14%)	20 (28%)	19 (27%)	14 (21%)	1 – Referent	
Pneumatic Compression Pump						
<25%	5 (31%)	6 (50%)	6 (43%)	3 (43%)		
25–49%	2 (13%)	2 (17%)	2 (14%)	1 (14%)		
50–74%	2 (13%)	1 (8%)	3 (21%)	1 (14%)	Insufficient Observations ^c	—
75%	7 (44%)	3 (25%)	3 (21%)	2 (30%)		
Medications						
<25%	3 (43%)	3 (43%)	1 (33%)	0 (0%)		
25–49%	2 (29%)	0 (0%)	1 (33%)	0 (0%)		
50–74%	0 (0%)	1 (14%)	0 (0%)	0 (0%)	Insufficient Observations ^c	—
75%	2 (29%)	3 (43%)	1 (33%)	2 (100%)		
Bandaging						
<25%	31 (33%)	31 (42%)	29 (37%)	27 (39%)	1.04 (0.94–1.15)	0.444
25–49%	13 (14%)	7 (9%)	10 (13%)	13 (19%)	1.10 (0.94–1.28)	0.233
50–74%	13 (14%)	8 (11%)	15 (19%)	8 (12%)	0.96 (0.85–1.10)	0.587
75%	37 (39%)	28 (38%)	24 (31%)	21 (30%)	1 – Referent	
Elevation						
<25%	16 (27%)	16 (42%)	14 (29%)	15 (31%)	1.08 (0.97–1.20)	0.146
25–49%	9 (15%)	5 (13%)	12 (24%)	11 (24%)	0.99 (0.90–1.11)	0.948
50–74%	16 (27%)	8 (21%)	15 (31%)	7 (14%)	0.92 (0.79–1.07)	0.292
75%	18 (31%)	9 (24%)	8 (16%)	15 (31%)	1 – Referent	
Self-Administered Lymphatic Drainage						
<25%	20 (37%)	22 (42%)	18 (37%)	27 (54%)	1.15 (1.05–1.26)	0.002
25–49%	13 (24%)	14 (26%)	12 (24%)	10 (20%)	0.91 (0.75–1.10)	0.310

Modality Adherence	Baseline	3-months	6-months	12-months	Odds Ratio (95% CI) ^b	P-Value
50–74%	9 (17%)	10 (19%)	7 (14%)	5 (10%)	1.02 (0.89–1.16)	0.790
75%	12 (22%)	7 (13%)	12 (24%)	8 (16%)	1 – Referent	
Therapist-Administered Lymphatic Drainage						
<25%	11 (17%)	16 (40%)	17 (49%)	15 (45%)	0.99 (0.94–1.05)	0.874
25–49%	14 (22%)	4 (10%)	2 (6%)	3 (9%)	0.98 (0.93–1.04)	0.605
50–74%	12 (19%)	3 (8%)	3 (9%)	5 (15%)	1.04 (0.98–1.10)	0.231
75%	27 (42%)	17 (42%)	13 (37%)	10 (30%)	1 – Referent	
Compression Garment						
<25%	27 (25%)	26 (22%)	19 (17%)	25 (24%)	0.99 (0.94–1.05)	0.874
25–49%	21 (19%)	20 (17%)	20 (18%)	15 (14%)	0.98 (0.93–1.04)	0.605
50–74%	17 (15%)	22 (19%)	28 (25%)	24 (23%)	1.03 (0.98–1.10)	0.231
75%	45 (41%)	48 (41%)	43 (39%)	41 (39%)	1 – Referent	
Skin Care						
<25%	1 (2%)	1 (2%)	1 (2%)	1 (2%)	1.02 (0.77–1.33)	0.932
25–49%	6 (13%)	2 (4%)	2 (4%)	5 (11%)	1.01 (0.88–1.16)	0.892
50–74%	7 (15%)	9 (18%)	10 (21%)	7 (15%)	1.00 (0.92–1.09)	0.939
75%	32 (70%)	37 (76%)	34 (72%)	34 (72%)	1 – Referent	
Taping						
<25%	3 (27%)	1 (25%)	4 (33%)	4 (36%)	Insufficient Observations ^c	—
25–49%	2 (18%)	0 (0%)	2 (17%)	2 (18%)	Insufficient Observations ^c	—
50–74%	1 (9%)	1 (25%)	6 (50%)	1 (9%)	Insufficient Observations ^c	—
75%	5 (45%)	2 (50%)	0 (0%)	4 (36%)	Insufficient Observations ^c	—
Anything Else						
<25%	0 (0%)	1 (100%)	1 (100%)	0 (0%)	Insufficient Observations ^c	—
25–49%	0 (0%)	0 (0%)	0 (0%)	0 (0%)	Insufficient Observations ^c	—
50–74%	0 (0%)	0 (0%)	0 (0%)	0 (0%)	Insufficient Observations ^c	—
75%	1 (100%)	0 (0%)	0 (0%)	0 (0%)	Insufficient Observations ^c	—
All Lymphedema Management Modalities (Overall Average)^d						
<25%	16 (13%)	19 (15%)	13 (11%)	15 (14%)	0.99 (0.92–1.07)	0.886
25–49%	26 (28%)	26 (21%)	28 (23%)	28 (26%)	1.00 (0.95–1.06)	0.812

Modality Adherence	Baseline	3-months	6-months	12-months	Odds Ratio (95% CI) ^b	P-Value
50–74%	39 (31%)	37 (30%)	43 (36%)	33 (31%)	1.01 (0.95–1.06)	0.799
75%	37 (29%)	41 (33%)	37 (31%)	32 (30%)	1 – Referent	

^aVariables are n (%).

^bMultinomial logistic regression, adjusting for age, race, occupation, education, time since diagnosis, cancer stage, no. of nodes removed, radiation, chemotherapy, baseline arm volume difference, randomized group assignment, and diagnosis of lymphedema flare-up while in the study, and accounting for within subject clustering. Other variables listed in Table 1 were omitted on the basis of multicollinearity.

^cDue to small cell sizes of these modalities, a statistical model could not be calculated.

^dExcluding the women who reported being prescribed no self-care activities in this time interval.