Is Surviving Enough? Coping and Impact on Activities of Daily Living Among Melanoma Patients with Lymphoedema

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Abstract

We assessed the impact of lymphoedema (defined as >10% limb volume change) on quality of life (QOL), ability to perform activities of daily living (ADLs), and coping in 277 melanoma patients. Limb volume was measured prospectively, preoperatively, and every 3–6 months for 18 months postoperatively using a perometer. Three questionnaires were administered to measure quality of life, coping and impact on activities of daily living. Statistical analyses were conducted using longitudinal logistic regression models. At 18 months, 31% of patients with upper-extremity nodal basin treatment and 40% of lower extremity nodal basin treatment patients had lymphoedema. Patients with lower-extremity lymphoedema reported lower QOL scores than those with upper-extremity lymphoedema. Over 18 months, both groups with mild and moderate lymphoedema showed improvement in coping (odds ratio [OR]: 7.2, 95% confidence interval [CI]: 3.5–14.5) and performance of ADLs (OR: 6.8, CI: 3.2–14.3). Over the course of 18 months, males were found to have poorer coping scores than females (OR: 2.4, CI: 1.2–5.1). Lymphoedema was associated with improvement in coping over time (p=0.08) and a higher reported interference with ADLs (OR: 2.5, CI: 1.3–5.0), primarily household tasks and sleep. Patient education about lymphoedema at the time of surgical consent may improve self-efficacy and coping ability. Effective management of lymphoedema may improve patient QOL and reduce interference with ADLs.

Keywords

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1. Introduction

The worldwide incidence of melanoma was estimated to be 232,130 in 2012 (GLOBOCAN, 2012). Fortunately, more than 90% of melanomas are diagnosed when they are surgically resectable (Burnet et al., 2005). Five-year overall survival for patients with surgically treatable melanoma are favourable at early stages, with significant variation based on stage at diagnosis: 97% with stage I, 53% with stage II, and 39% with stage III (Balch et al., 2009). Considering the large number of melanoma survivors, examining the long-term morbidity associated with melanoma treatment is important (DeSantis et al., 2014).

Lymphoedema continues to be one of the most common patient-reported physical issues in melanoma survivors (Beckjord et al., 2013). Surgical treatment of melanoma typically includes a wide local excision of the primary tumour and sentinel lymph node biopsy (SLNB) for the pathologic assessment of regional nodal basins,(NCCN, 2010) with or without subsequent therapeutic lymph node dissection (TLND). Both TLND and SLNB put patients at risk for lymphoedema (Hyngstrom et al., 2013). A systematic review of studies that reported the incidence of lymphoedema following lymph node surgery for melanoma found that this incidence ranged from 1% to 39% following axillary lymph node surgery and from 6% to 66% following pelvic and/or inguinal lymph node surgery; due to variability in the criterion for diagnosis of lymphoedema and lack of prospective data a specific prevalence estimate is unknown (Cormier et al., 2010).

A number of psychological outcomes are known to impact compliance with respect to self-care for lymphoedema prevention and/or management: coping style, perceived social support, and anxiety (Cohen et al., 2001). Among breast cancer survivors, self-efficacy—a construct of social cognitive theory that represents a person's belief in their ability to influence and change perceived situations (Bandura, 1997)—is linked to compliance with lymphoedema risk reduction strategies (Sherman and Koelmeyer, 2012). Similarly, in melanoma patients, increased self-efficacy has been directly tied to increased compliance with recommended sun-protection and skin self-examination behaviours (Manne et al., 2004, Mujumdar et al., 2009). Thus, teaching patients to perform lymphoedema self-care and self-maintenance through lymphoedema risk reduction strategies could be best accomplished by improving self-efficacy, despite the negative psychological effects of treatment.

To maximize self-efficacy, patients need to return to as normal a life as possible after definitive surgical treatment for melanoma. It has been found that the appearance of surgical scars is often bothersome to patients, and increased swelling of the treated limb may reduce confidence in one's appearance and comfort level in social settings (Cassileth et al., 1983, Fu et al., 2013). Furthermore, lymphoedema has been widely shown to negatively impact self-efficacy and coping abilities in cancer survivors (Tobin et al., 1993, Pyszel et al., 2006), in particular, the ability of breast cancer survivors to complete activities of daily living (ADLs) and self-care (Dunberger et al., 2013, Ridner et al., 2012). To date, the effects of lymphoedema on self-efficacy in patients who have been treated for melanoma has not been evaluated. Self-efficacy in the oncology setting is influenced by patient age, performance status, and sex; however, a gap in the knowledge related to self-efficacy and management of

lymphoedema among melanoma patients still exists (Mystakidou et al., 2010). The purpose of the current study was to evaluate lymphoedema coping efficacy, the ability to adapt and adjust to the diagnosis of lymphoedema, the impact of lymphoedema on daily activities, and the overall quality of life (QOL) of melanoma patients before and after lymph node surgery.

2. Methods

2.1. Patient cohort

Patients were approached for participation in this prospective, longitudinal study prior to definitive surgical intervention that included SLNB and/or TLND at the ilio-inguinal node basin or the axillary node basin for pathologically confirmed stage I to III cutaneous melanoma (Balch et al., 2009). We excluded patients who had distant metastases (stage IV), were younger than 18 years, had previously undergone lymph node surgery in the affected nodal basin, had previously been diagnosed with lymphoedema, had implanted medical devices (i.e., a replacement joint or pacemaker), were currently undergoing treatment for another malignancy, or did not speak English. All patients underwent surgical treatment for their melanoma at The University of Texas MD Anderson Cancer Center between 2006 and 2012 and agreed to return for regular follow-up visits after treatment at 3–6 month intervals for a total of 4 potential visits. Baseline demographic and clinical data were collected using patients' medical records and limb volume, coping efficacy, impact of lymphoedema on ADLs, and QOL were collected at the time of consent and at each follow-up appointment. All patients enrolled in the study underwent SLNB and/or TLND within 30 days of the baseline visit. All assessments were administered again at each follow-up visit. The study protocol was approved by the MD Anderson Cancer Center Institutional Review Board, and enrolled patients provided written informed consent to participate in the study.

2.2. Limb volume assessment

Limb volume was measured in the Melanoma and Skin Center at MD Anderson in a climate-controlled room with a standard air temperature of 22° Celsius using an upright perometer (Perometer Type 1000 M, Per-System, Wuppertal, Germany) which is an optoelectronic volumetry device that uses infrared light to calculate limb volume (Tierney et al., 1996). All patients underwent limb volume measurement at baseline and at least one of a total of four subsequent measurements at 3- to 6-month intervals for the first 18 months following surgery. The affected limb and the contralateral unaffected limb were measured at each time point to allow for comparisons accounting for changes in body weight over time. Patients were asked to refrain from excessive alcohol consumption or strenuous exercise within 24 hours prior to the measurement appointments. For upper-extremity measurements, patients were positioned with the arm to be measured at a 45° laterally from the long axis of the body while holding a fixed hand block; arm volume was measured from the styloid process of the ulna to the limiting point of the axilla. Lower-extremity measurements were taken with the leg placed on a fixed marker on the base of the perometer and the patient standing upright; the perometer frame was raised up the limb from the lateral malleolus to the highest point possible within the perineum. Patients who reported symptoms of lymphoedema and showed a limb volume change (LVC) of at least 10% were referred for evaluation by a lymphoedema therapist.

LVC was calculated as a percentage change from baseline, taking the affected and contralateral limbs into account, using the following formula (Ancukiewicz et al., 2011):

$$LVC = \frac{A_{follow-up}/C_{follow-up}}{A_{baseline}/C_{baseline}} - 1$$

A indicates the affected limb, and *C* indicates the contralateral unaffected limb. For the purposes of this analysis, patients who had lymph node surgery in bilateral nodal basins were excluded. Patients who missed more than 2 of the 4 measurement time periods were also excluded from this analysis. Patients were stratified into three groups with LVCs of 5% or less (no lymphoedema), 5% to less than 10% (at risk for lymphoedema), and 10% or more (lymphoedema) (Cormier et al., 2009, Hyngstrom et al., 2013).

2.3. Coping efficacy instrument

Coping Efficacy with Lymphoedema is a 13-item instrument that is scored on a Likert scale of 1 to 6, with 1 indicating "strongly agree" and 6 indicating "strongly disagree," and a maximum total score of 78 (Heppner et al., 2001). This instrument is designed to assess self-reported problem-solving strategies and problem-solving efficacy in patients with lymphoedema. The instrument has been validated in the breast cancer–related lymphoedema population.

For modelling purposes, coping was categorized as a dichotomous variable, with outcomes defined as either above or below the overall median for all patients in the cohort with measurements at that time point. These groups were classified as "coping well" or "coping poorly," respectively, with respect to lymphoedema for the purposes of this study.

2.4. Assessment of impact on ADLs

Effects of Lymphoedema on Activities of Daily Living is a 12-item tool with a maximum total score of 120 that captures the impact of lymphoedema on personal factors such as mood, body image, and relationships and on functional factors including ability to work, sleep, complete housework, drive, and perform self-care tasks. Each item is scored on a scale from 0 ("does not interfere") to 10 ("completely interferes"). This instrument was developed on the basis of qualitative assessments of patients with secondary lymphoedema due to breast cancer treatment (Armer et al., 2008). To our knowledge, this is the first time this tool has been used in a melanoma population.

2.5. QOL assessment

QOL was assessed using the Functional Assessment of Cancer Therapy–Melanoma (FACT-M).(FACIT, 2010) The FACT-M is a 50-item instrument with a maximum total score of 172 that was validated for use in patients with all stages of melanoma (Askew et al., 2011, Askew et al., 2009, Swartz et al., 2012). The FACT-M was found to have strong internal consistency (Cronbach α=0.85) and test-retest reliability (r=0.81). The melanoma subsection of the instrument includes surgery-specific questions and several items that address lymphoedema-related concerns, such as swelling and range of motion.

2.6. Statistical analysis

All statistical analyses were completed using longitudinal mixed model regression, controlling for body mass index (kg/m^2), age, sex, and treatment factors. Coping efficacy and ADL interference scores were converted to binary outcomes using the median score as the cut-off point. Bivariate general linear mixed models were created to examine the association of patient factors (including body mass index, age, and sex), treatment factors (extremity and surgery type), and LVC group. All outcomes were evaluated over time using longitudinal logistic regression models. Missing outcomes were assumed to be missing at random. Longitudinal mixed model evaluation takes these missing and unbalanced results into account when building models. Reported p-values are two-sided, and significance was defined by a p-value of 0.05. All analyses were conducted using SAS version 9.1.3 statistical software (SAS Institute, Cary, North Carolina).

3. Results

3.1. Patient cohort

A total of 277 patients were enrolled. A total of 142 (51.3%) of the participants were female, the majority were white (n=266, 96.0%), 168 (61.3%) were of normal weight (body mass index 30), and 171 (61.7%) were at least 50 years old (range, 19–85 years) (Table 1). One hundred twenty-five (45.1%) patients underwent an SLNB as their most invasive lymph node surgery, and the other 152 (54.9%) underwent a TLND either independently or following an SLNB that had revealed node-positive disease. Twenty-four patients were treated with adjuvant radiation to the nodal basin following TLND, and five patients were treated with radiation to the primary tumour bed (recurrence or satellite disease) following wide local excision. A total of 244 patients had follow up data at 3 to 6 months, 197 patients at 9 to 12 months, and 126 patients at 15 to 18 months.

3.2. Lymphoedema

Limb volume data were available for 245 patients at baseline, 197 patients at 3–6 months, and 126 patients at 15–18 months (Table 2). At 15–18 months, an LVC greater than 10% was observed in 36.8% of patients who had upper-extremity TLND, 38.7% of those who had lower-extremity TLND, 10% of those who had upper-extremity SLNB, and 25.0% of those who had lower-extremity SLNB. The cumulative incidences of lymphoedema, which is the incidence of all patients who had LVC over 10% at any single time point, at 15–18 months stratified by type of surgery and extremity were 44.7% for upper-extremity TLND, 51.6% for lower-extremity TLND, 15.2% for upper-extremity SLNB, and 25.0% for lower-extremity SLNB (Fig. 1). When stratified by body mass index, 35.4% of patients with a body mass index of at least 30 had lymphoedema whereas only 18.7% of patients with a BMI less than 30 had lymphoedema (Fig. 2). The mixed models showed that the factors most strongly associated with lymphoedema were a body mass index of 30 (odds ratio [OR]: 2.19, 95% confidence interval [CI]: 1.37–3.52) and TLND (OR: 1.65, 95% CI: 1.65–4.41). Sex, age, and extremity where node surgery was done (upper vs. lower) were not found to be associated with lymphoedema.

3.3. Coping efficacy

In general, scores for coping efficacy improved minimally over time. Patients who had lower-extremity surgery reported a greater improvement in coping scores from baseline to 15–18 months than patients who had upper-extremity surgery (Fig. 3). At 9–12 months, those at risk for developing lymphoedema (LVC of 5% to <10%) reported a higher median coping efficacy score than those with a LVC of <5% or those with lymphoedema; however, none of these differences were statistically significant at any time point. Female sex was associated with coping well (above the median score) (OR: 2.91, 95% CI: 1.35–6.27). Time since baseline was also associated with coping well (OR: 8.36, 95% CI: 4.01–17.42) and coping scores at 15–18 months were more likely to be above the median than scores at baseline (OR: 6.67, 95% CI: 3.3–3.47). Other covariates that were included, but not found to be significant in the model, included extremity, surgery type, and QOL scores.

3.4. Impact of lymphoedema on ADLs

After 9–12 months, those at risk for lymphoedema reported a higher median score for impact of lymphoedema on ADLs than those in other LVC groups, but all scores remained very low. Significant variability was noted for each of the 12 items of this instrument, with the range for each item encompassing the full scale, from 0 (no interference) to 10 (complete interference). An evaluation of means showed that those with lymphoedema reported limited but more interference compared to those at risk or without lymphoedema in most items, with the most variation in sleep and choice of clothing (Fig. 4).

Since these scores varied so widely, a model was structured to define the outcomes as either above or at 0 for any item. Interference with ADLs to any LE outcome was significantly associated with lower-extremity lymph node surgery (vs. upper–extremity surgery) (OR: 2.32, 95% CI: 1.23–4.38), TLND (vs. SLNB) (OR: 3.99, 95% CI: 1.23–4.38), and lymphoedema (vs. no lymphoedema) (OR: 2.53, 95% CI: 1.29–4.97). ADL scores using the binary model indicated an increase in interference over time using a longitudinal model compared with the baseline (OR: 9.28, 95% CI: 4.24–20.26). Sex was not associated with ADL interference and was controlled for in the model.

3.5 QOL

QOL (FACT-M) scores were fairly stable throughout the duration of the study, but baseline scores and later scores did differ significantly in some patient subsets stratified by extremity and LVC. Lower-extremity patients with LVC <10% showed improvements in median FACT-M scores over time, whereas the FACT-M scores of lower-extremity patients with lymphoedema (LVC >10%) declined from baseline (Fig. 5A). Interestingly, in upper-extremity patients, median FACT-M scores declined over time for those considered at risk for lymphoedema but increased slightly for those with an LVC   10% (Fig. 5B). In the mixed model, patients who had lower-extremity surgery (vs. upper-extremity) (OR: 2.43, 95% CI: 1.34–4.35, p<0.01) or TLND (vs. SLNB) (OR: 3.11, 95% CI: 1.63–5.93, p<0.01) had lower FACT-M scores. In general, FACT-M scores improved over time, but remained relatively stable (minimal changes over time) with patients reporting significantly higher scores than at baseline (OR: 6.75, 95% CI: 3.19–14.29, p<0.01). Sex and lymphoedema were controlled for, but not found to be a significant predictor of overall FACT-M scores.

4. Discussion

Lymphoedema developed in a substantial proportion of patients with melanoma who underwent definitive surgical treatment with lymph node surgery, including those who received SLNB alone. The incidences of lymphoedema (LVC 10%) following SLNB were 25% after lower-extremity surgery and 12% after upper-extremity surgery. These changes in limb volume were accompanied by negative effects on ADLs and coping efficacy. For instance, patients who developed minimal swelling (LVC of 5% to <10%) had increased interference with ADLs. This result confirms our previous report that a minimal LVC can have a profound and lasting impact on patients (Cormier et al., 2009). In addition, patients with lymphoedema experienced more interference with ADLs than those without lymphoedema (OR: 2.53, 95% CI: 1.29–4.97). Similarly, previous studies in gynaecologic cancer survivors have reported that patients with lower-limb lymphoedema are more likely to take extended sick leave or file for disability than patients who do not develop lymphoedema in the post-treatment period (Dunberger et al., 2013). This post-treatment morbidity can increase the burden of cancer and can decrease the social well-being, functional well-being, and financial security of a patient and his or her family (Mrazek and Chao, 2014).

Furthermore, coping efficacy improved slightly over time for all patients regardless of lymphoedema status. This is in contrast to a recent qualitative study of 19 Stage III melanoma survivors who were between 6 months and 3 years post-treatment and their caregivers which found patients and caregivers feel that they did not receive appropriate information related to the risk for lymphoedema following surgical treatment (Tan et al., 2014). In the study by Tan and colleagues, at least one patient specifically stated he had no understanding of lymphoedema or how to apply compression. The results of this study mirror our findings in that all patients over time reported that they were able to better cope with their melanoma and associated long-term side effects of treatment, including lymphoedema. Therefore, education about lymphoedema, the early identification of lymphoedema signs and symptoms, and lymphoedema risk reduction practices (National Lymphedema Network, 2014) should be a component of pre-operative education in patients undergoing lymph node surgery.

Despite its strengths, this study had a few limitations. The first is the limited number of patients within each group at later time points, which makes subgroup analysis difficult. Also, only a small number of patients in this cohort were treated with radiation therapy (24 had radiation to the nodal basin, and five had radiation to the primary tumour site), which limited any analysis of radiation therapy as a risk factor. Radiation therapy has been shown to predict lymphoedema in breast and cervical cancer patients (Kim et al., 2012, Shah et al., 2012). Finally, missing data due to failure to follow-up or obtain measurements is a limitation within this prospectively collected data.

Patient education about the risks of developing lymphoedema and the early signs and symptoms of lymphoedema is increasingly being recognized as a critical component of medical care for patients undergoing lymph node surgery and may help increase self-efficacy. It is important to ensure that the increasing number of melanoma survivors feel

capable of managing post-surgical morbidities such as lymphoedema. Self-efficacy has been shown to significantly predict compliance with management strategies for chronic illnesses, such as diabetes,(Basak Cinar and Schou, 2014) chronic obstructive pulmonary disease, (Jackson et al., 2014) and hepatitis C (Bonner et al., 2013). Similarly, in this study patients who develop lymphoedema report better coping over time which would indicate increased self-efficacy and ability to cope with any prescribed lymphoedema treatment. However, due to the large number of patients who travel for treatment at the institution, compliance was not studied in this cohort. In a study of people with filarial lymphoedema in India, an intervention was designed to improve self-efficacy through education about skin care and simple exercises that can be done to control the swelling; not only self-efficacy related to lymphoedema care, but also overall QOL, improved after the intervention was delivered (Narahari et al., 2013). Although the oncologic setting is very different from that of filarial lymphoedema, it is reasonable to believe that proper education may help improve QOL and self-efficacy, particularly when managing lymphoedema in the post-operative period.

Our results demonstrate that lymphoedema is a significant risk after either SLNB or TLND and confirm that lymphoedema can be accompanied by decreased self-efficacy and increased interference with ADLs. To our knowledge, this is the first study to prospectively measure lymphoedema after lymph node surgery and its impact on these psychological outcomes in patients with melanoma. Future research should be designed to improve education about lymphoedema and the identification and awareness of lymphoedema in high-risk groups.

Acknowledgments

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- Lymphoedema impacts quality of life

- Lower extremity lymphoedema patients cope less effectively with lymphoedema but improve over time

- Household chores and sleep are most impacted by lymphoedema
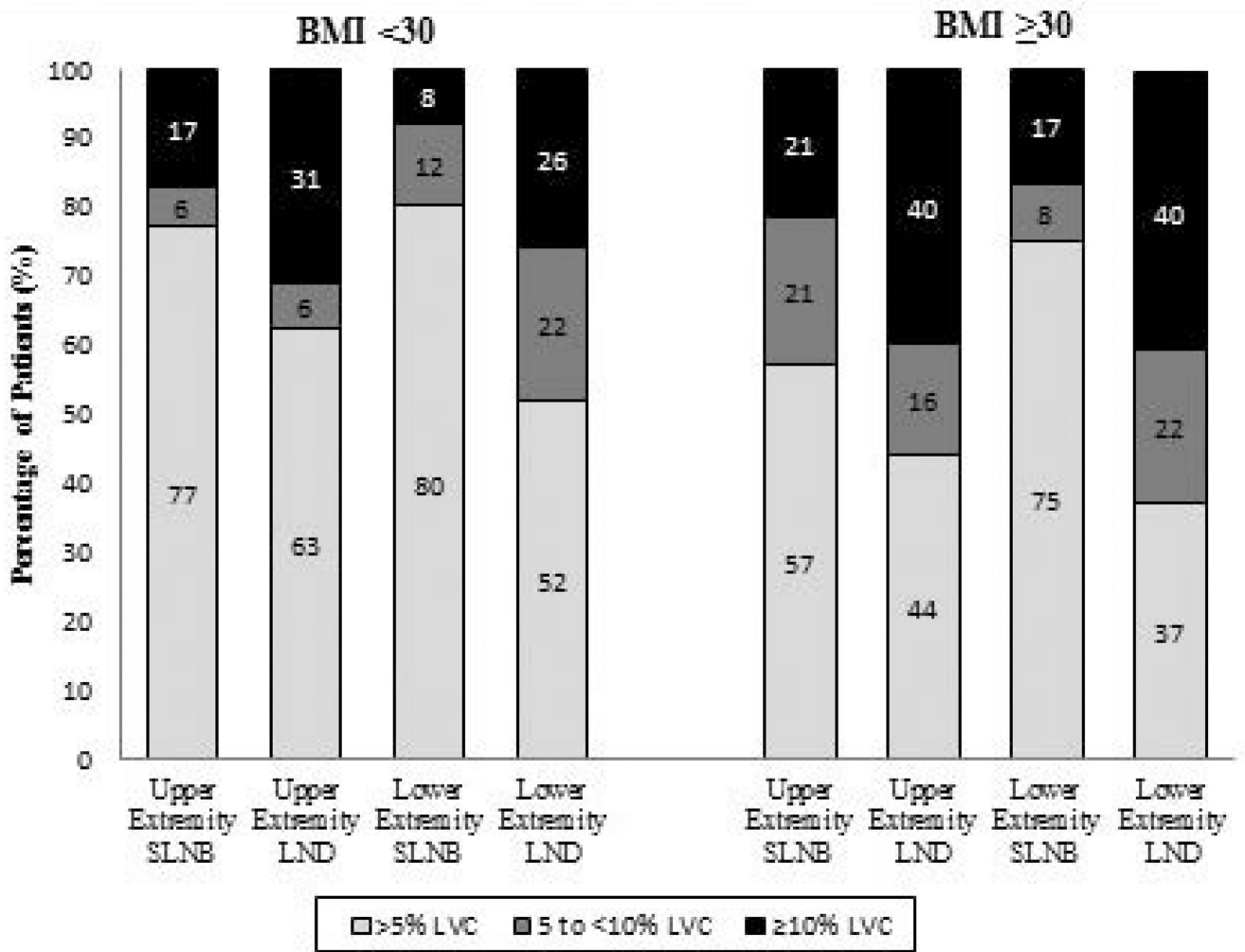
Figure 1.
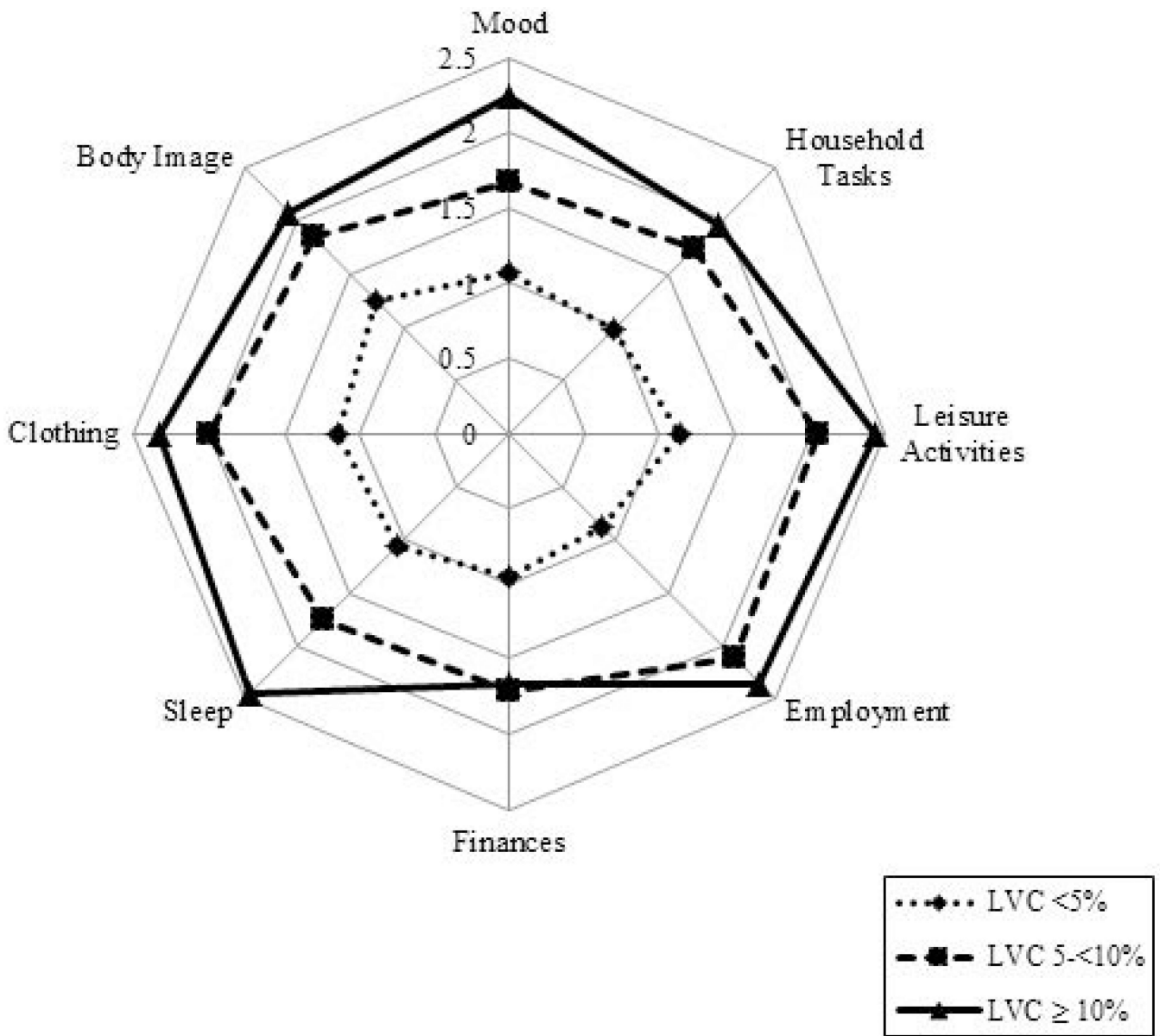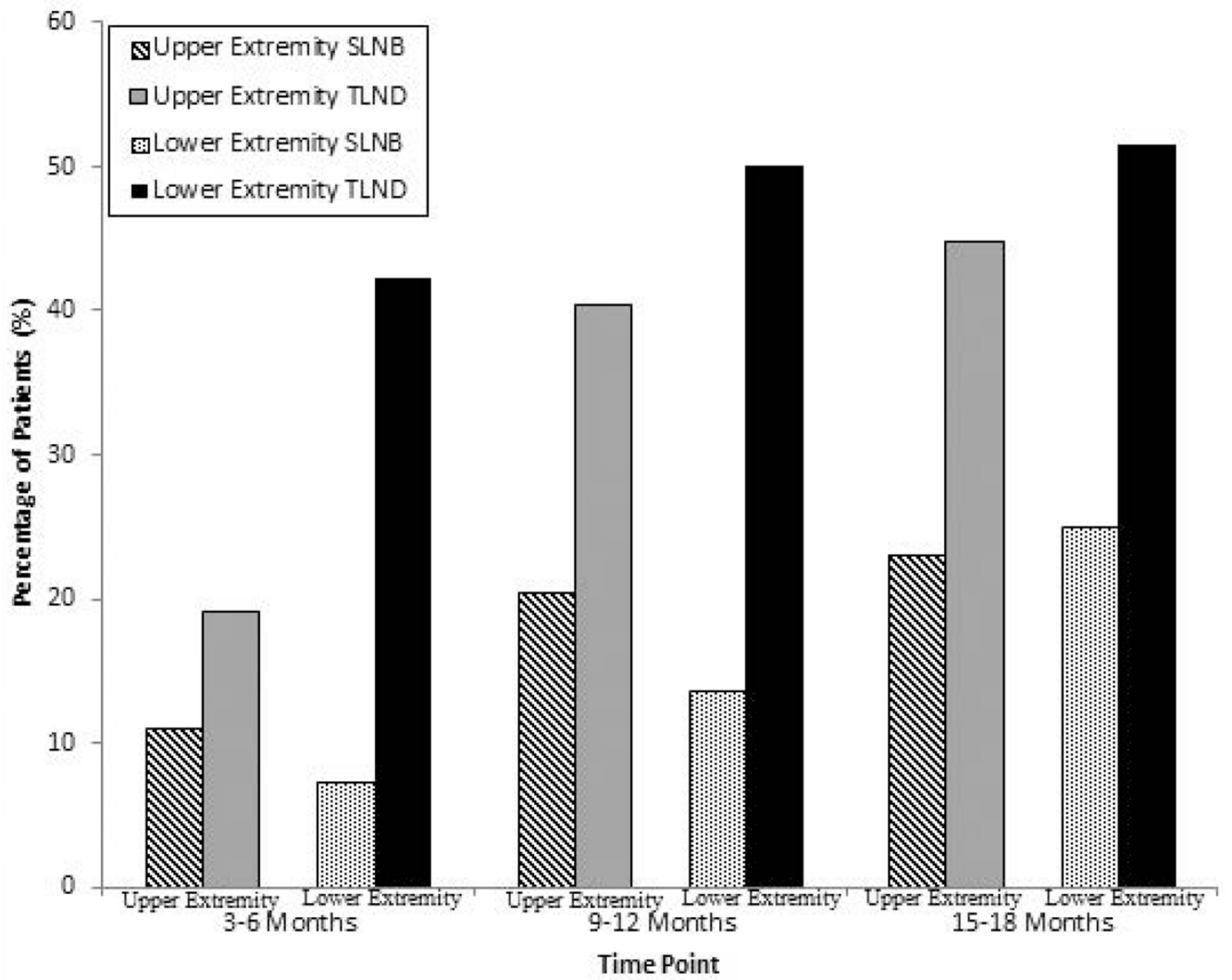
Figure 2.

Figure 3.

Median Coping Score

Figure 4.

Median FACT-M Score of Lower Extremity Patients

Median FACT-M Score of Upper Extremity Patients

Figure 5.

Table 1

Characteristics of patients in cohort (n=277).

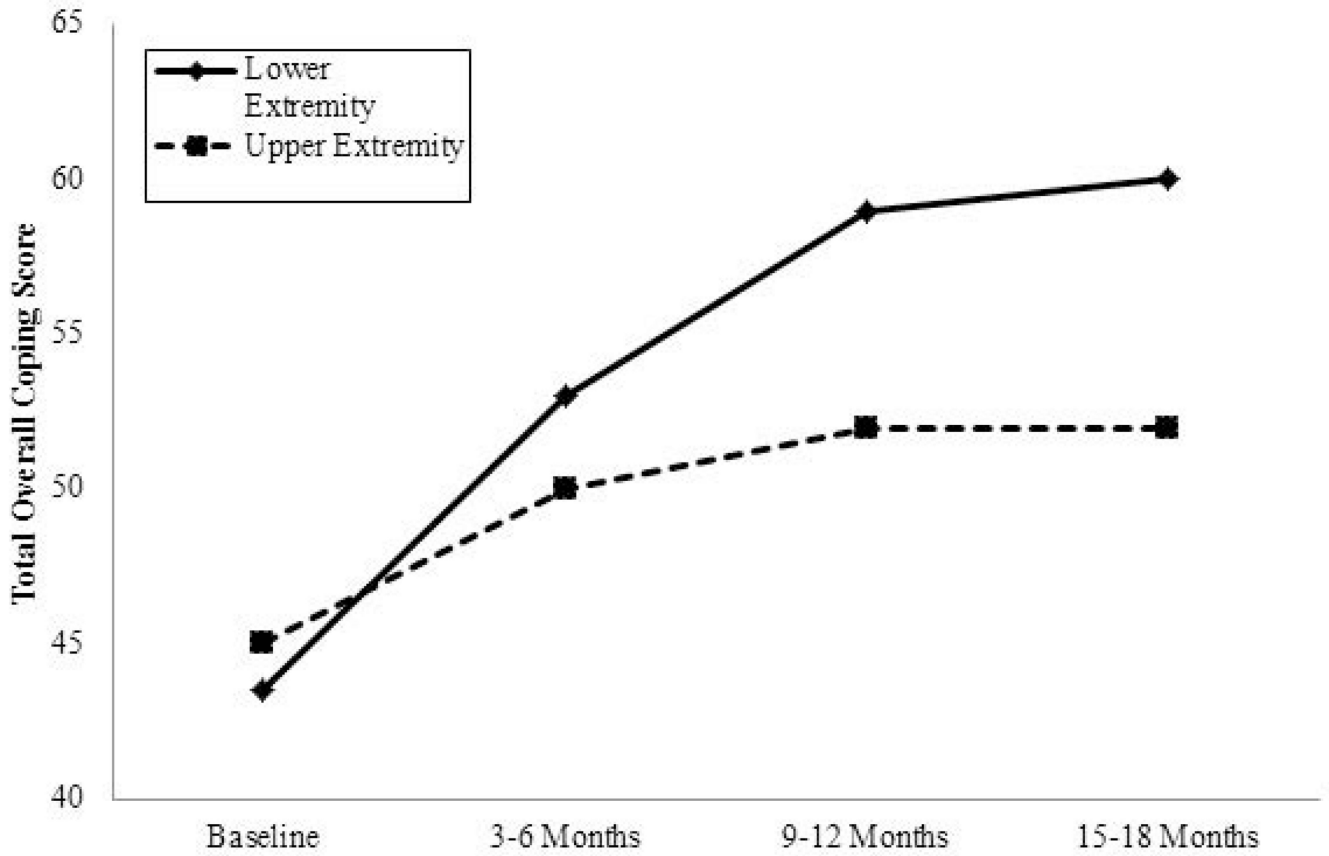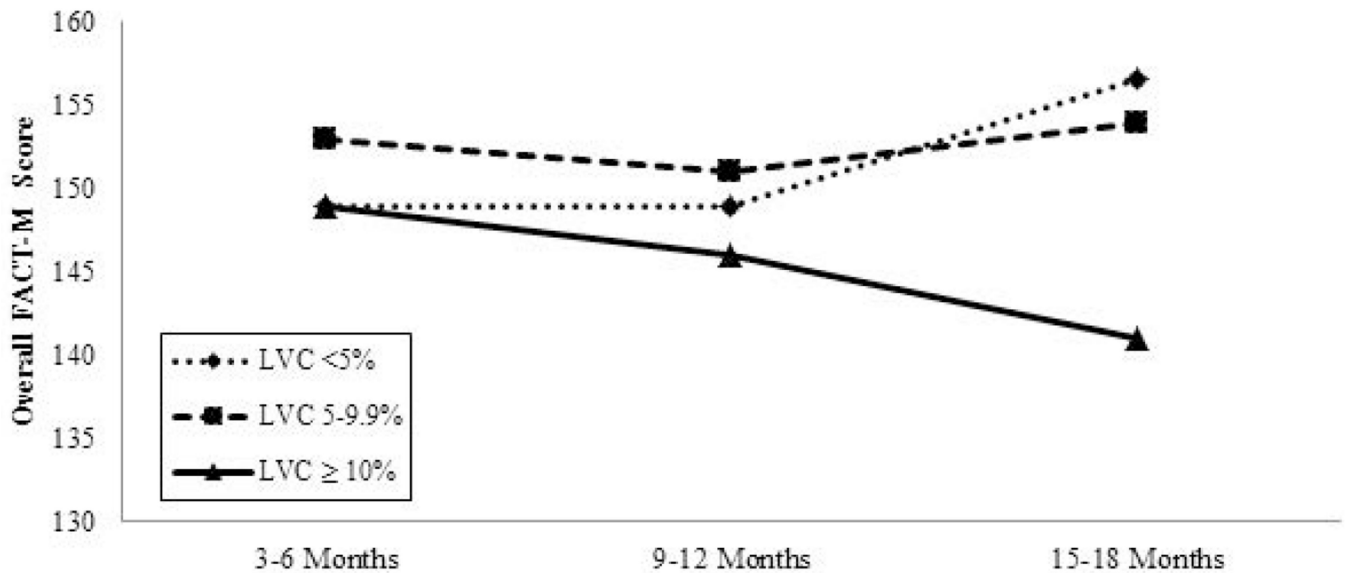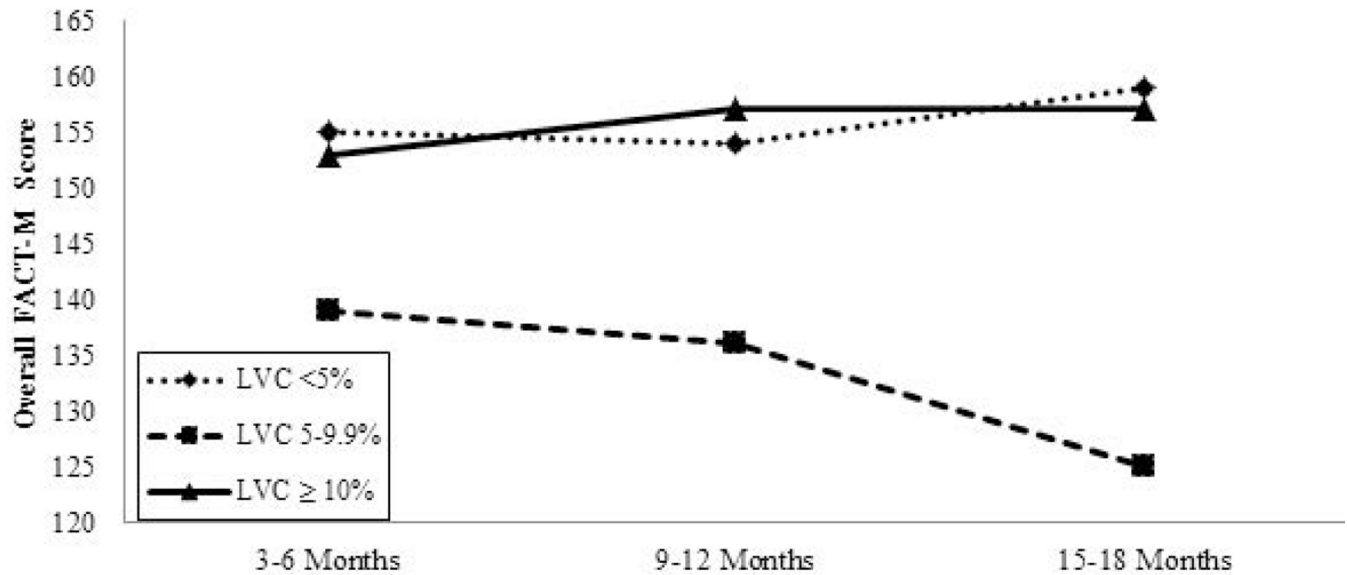| Characteristic	Lower extremity		Upper extremity		Total	
	No.	%	No.	%	No.	%
Sex						
Male	48	37.5	87	58.4	135	48.7
Female	80	62.5	62	41.6	142	51.3
Age						
Under 50 years	50	39.1	56	37.6	106	38.3
50 years or older	78	60.9	93	62.4	171	61.7
Race						
White	121	94.5	145	97.3	266	96.0
Hispanic	4	3.1	1	0.7	5	1.8
African American	3	2.3	2	1.3	5	1.8
Other	0	0.0	1	0.7	1	0.4
Education						
High school or less	40	31.3	28	18.8	68	24.6
Some college	35	27.3	41	27.5	76	27.4
College graduate	35	27.3	54	36.2	89	32.1
Graduate school or more	18	14.1	21	14.1	39	14.1
Unknown	0	0.0	5	3.4	5	1.8
Surgery type						
SLNB	52	40.6	73	49.0	125	45.1
TLND	76	59.4	76	51.0	152	54.9
Body mass index						
Under 30	75	58.6	93	63.7	168	61.3
30 or over	53	41.4	53	36.3	106	38.7
Surgery side						
Right	65	50.8	64	43.0	129	46.6
Left	61	47.7	75	50.3	136	49.1

SLNB: sentinel lymph node biopsy, TLND: therapeutic lymph node dissection

Table 2

Limb volume change over time stratified by extremity, surgery type, and body mass index

	LVC at 3–6 months (n=244)						LVC at 9–12 months (n=197)						LVC at 15–18 months (n=126)					
	<5% (n=153)		5–10% (n=38)		>10% (n=53)		<5% (n=119)		5–10% (n=27)		>10% (n=51)		<5% (n=73)		5–10% (n=17)		>10% (n=36)	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Upper Extremity	89	67.4	23	17.4	20	15.2	66	62.3	11	10.4	29	27.4	45	63.4	8	11.3	18	25.4
SLNB	45	70.3	12	18.8	7	10.9	35	71.4	5	10.2	9	18.4	26	78.8	3	9.1	4	12.1
TLND	44	64.7	11	16.2	13	19.1	31	54.4	6	10.5	20	35.1	19	50.0	5	13.2	14	36.8
Lower Extremity	64	57.1	15	13.4	33	29.5	53	58.2	16	17.6	22	24.2	28	50.9	9	16.4	18	32.7
SLNB	33	80.5	5	12.2	3	7.3	29	78.4	4	10.8	4	10.8	18	75.0	0	0.0	6	25.0
TLND	31	43.7	10	14.1	30	42.3	24	44.4	12	22.2	18	47.4	10	32.3	9	29.0	12	38.7
Body mass index																		
< 30	103	69.1	25	16.8	21	14.1	81	68.1	13	10.9	25	21.0	49	62.8	10	12.8	19	24.4
30	50	52.6	13	13.7	32	33.7	38	48.7	14	18.0	26	33.3	24	50.0	7	14.6	17	35.4
Total	153	62.7	38	15.6	53	21.7	119	60.4	27	13.7	51	25.9	73	57.9	17	13.5	36	28.6

LVC: limb volume change; SLNB: sentinel lymph node biopsy; TLND: therapeutic lymph node dissection