Research Passages in Cancer Symptom Management and Lymphedema

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Outline

• Early Journey-The Starting Point
• Career Passage
• Program of Research
  – Focus
  – Descriptive/Clinical Discovery
  – Measurement
  – Intervention
  – Impact
• Upcoming Passages
Early Journey

Railroad Depot Museum
Fordsville, KY USA
Early Journey-The Starting Point

- Began in rural Western Kentucky, USA
- Small family farm
- Few modern conveniences
- Primary farm laborer
- Learned to:
  - willingly accept responsibility
  - set mutually agreed upon goals
  - work as part of a team
  - problem solve and think ahead
  - think out of the box
  - have very strong work ethic

Farmhouse- Trisler, KY, USA
General Jackson Riverboat,
Nashville, TN, USA
Career Passage-Trajectory

- PhD – 2003
- Post Doc – 2004
- Assistant Professor – 2006
- Associate Professor – 2011
- Full Professor – 2012
- Endowed Chair – 2013

My Support Team
Career Passage- Factors for Success

- Understudied POI
- PhD Program first semester
  - Continuous funding
- Mentors
  - Scholarship
  - Research
  - Hard work
- Multiple funding sources
  - ACS
  - ONS
  - NIH
  - Industry
Godchaux Hall Vanderbilt School of Nursing, Nashville, TN, USA
Focus

Cancer Symptom Management

- Descriptive/clinical discovery
  - Symptom cluster
  - Influencing factors
    - Physical
    - Psychosocial
  - Economics
- Measurement
- Intervention
  - Self-care
  - Adherence
  - CAM

The Lymphatic System
Breast Cancer

- Lymphedema Symptom Cluster
  - alteration in limb sensation
  - loss of confidence in body
  - decreased physical activity
  - fatigue
  - psychological distress

- Comorbidities
  - body mass index
  - orthopedic issues
  - cardiac medications (cardiac, hormone blockers, osteoporosis)
  - co-occurrence of diabetes and carpal tunnel syndrome approached statistical significance
Breast Cancer Lymphedema

• Themes
  – marginalization and minimization
  – multiplying losses
  – yearning to return to normal
  – uplifting resources

• Daily Living with Lymphedema
  – Relationship issues, including a lack of empathy and sexual difficulties, are more intense and distressing than physical problems
  – Breast cancer survivors with lymphedema are not “disabled”, they are individuals coping with a chronic medical conditions.
Head and Neck Cancer-Lymphedema and Fibrosis

- **Pre-Treatment:**
  - Lymphedema external: 62.7%, internal: 41.7%, or combined: 29.2%, and fibrosis: 42.2%

- **Late-effect rates were even higher:**
  - Lymphedema external: 81.9%-90.1%, internal: 80.4%-89.4%, combined: 70.6%-80.9%, and fibrosis: 66.7%-77.4%

- **Approximately 75% have a late-effect trajectory characterized by moderate to severe external or internal lymphedema; ~47% had moderate to severe fibrosis**
• Head and Neck Internal and External Lymphedema and Swallowing
  – VHNSS swallow/nutrition items scores correlate with NOMS/DOSS ratings \( (p < 0.001) \)
  – VHNSS swallow/nutrition scores correlated with maximum grade of swelling for any single structure on Patterson scale: ss \( (0.43; p = 0.001) \); sl \( (0.38; p = 0.004) \); nt \( (0.41; p = 0.002) \)
  – Internal lymphedema of aryepiglottic/pharyngoepiglottic folds, epiglottis, and pyriform sinus were most strongly correlated with VHNSS and NOMS ratings
  – External lymphedema ratings correlated NOMS/DOSS ratings \( (> = -0.34; p < 0.01) \).
  – No meaningful correlations exist between VHNSS swallow/nutrition items and external lymphedema \( (< \pm 0.15, p > 0.20) \)
Head and Neck Internal and External Lymphedema and other symptoms

- Twenty-three pairs of patients were identified and matched on the age, primary tumor site, tumor stage, and time since end of cancer treatment.

- Relative to patients without lymphedema, matched patients with lymphedema reported either increased symptom prevalence or severity or distress level for the following symptoms (prevalence differences of at least 15% between the matched groups and p < 0.05):
  
  1. numbness; 
  2. tightness; 
  3. heaviness; 
  4. warmth; 
  5. pain without head/neck movement; 
  6. problems swallowing mashed or pureed foods; 
  7. trouble breathing; 
  8. blurred vision; 
  9. feel worse when flying in an airplane; and 
  10. swelling.
Cost of lymphedema immediately post breast cancer treatment

- Approximately 10% of 1,877 patients had claims indicating treatment of lymphedema
- Predictors included treatment with full axillary node dissection (odds ratio [OR] = 6.3, p < .001) and chemotherapy (OR = 1.6, p = .01). A geographic variation was observed; women who resided in the West were more likely to have lymphedema claims than those in the Northeast (OR = 2.05, p = .01)
- The matched cohort analysis demonstrated that the BCRL group had significantly higher medical costs ($14,877 to $23,167) and was twice as likely to have lymphangitis or cellulitis (OR = 2.02, p = .009)
- Outpatient care, especially mental health services, diagnostic imaging, and visits with moderate or high complexity, accounted for the majority of the difference
Descriptive/Clinical Discovery

- Impact of compression device use on health-care utilization/health outcomes
  - The sample included 718 patients (374 in the cancer cohort and 344 in the non-cancer cohort).
  - In both cohorts, use of an APCD was associated with similar reductions in adjusted rates of cellulitis episodes (from 21.1% to 4.5% in the cancer cohort and 28.8% to 7.3% in the non-cancer cohort), lymphedema-related manual therapy (from 35.6% to 24.9% in the cancer cohort and 32.3% to 21.2% in the non-cancer cohort), and outpatient visits (from 58.6% to 41.4% in the cancer cohort and 52.6% to 31.4% in the non-cancer cohort).
  - Among the cancer cohort, total lymphedema-related costs per patient, excluding medical equipment costs, were reduced by 37% (from $2597 to $1642, p = .002). The corresponding decline in costs for the non-cancer cohort was 36% (from $2937 to $1883, p = .007).
Measurement

• **Self-Report Tools**
  – VHNSS version 1 and 2
  – Lymphedema Symptom Intensity And Distress Scale (Battery of Tools near completion)
  – Health Related Family Quality of Life (in progress)
Measurement

- Bioelectrical Impedance Spectroscopy (BIS)
  - Established use outside of laboratory setting
  - Established feasibility and efficacy of use for self-monitoring
  - Human factors testing and first use of new home self-measurement device
Intervention

• Self-Monitoring
  – Eighty-six women with lymphedema were screened: 62 were eligible, 50 were enrolled, 10 withdrew, and 1 had incomplete data, thus N=39
  – No between group differences were noted in participant characteristics
  – The self-monitored group had higher days of garment use (p=0.005) that remained stable after self-monitoring stopped. The median number of days of simple manual lymphatic drainage increased in the intervention group (p=0.004) with a downward trend after self-monitoring ceased
Web-based Multimedia

- Reduction of mood symptoms for the group completing the Web intervention compared to completing the Booklet intervention both short-term (1-month) and long-term (12-months) (Cohen’s $d = -0.53$ and $-0.47$ respectively, $p < 0.05$)

- Statistically significant differences in different directions of the change in use of “Supportive Coping” and “Humor” were observed at 1-month post-completion of intervention ($p < 0.05$) but not at the 12-month assessment point. In the Booklet group, there was a decrease in self-reports of supportive coping relative to their baseline which was not apparent in the Web group (Cohen’s $d = 0.54$)
Intervention

- Expressive Writing
  - Hypothesized moderators of change in QoL were dispositional optimism, avoidant behaviors, and time since lymphedema diagnosis
  - There was no statistically significant intent-to-treat main effects of expressive writing on QoL
  - Statistically significant moderating effects on change in different indicators of QoL were observed for all three moderators.
  - Expressive writing was more effective for improving QoL in women who were higher on optimism, lower on avoidance and had less time since a lymphedema diagnosis
Intervention

• Yoga in Head and Neck Cancer
  – Seventy-three individuals were screened and 40 were eligible
  – Feasibility was affirmed as participants were recruited and retained in the study, there were no adverse events, fidelity to protocol was demonstrated, and satisfaction rates were high.
  – Efficacy measures indicated potential benefit for shoulder ROM ($d=0.57-0.86$, $p<0.05$), pain ($d=0.67-0.90$, $p<=0.005$), and anxiety ($d=0.59$, $p=0.015$)
Intervention

- Low Level Laser—3 Group Design
  - No statistically significant between-group differences were found in volume reduction; however, all groups had clinically and statistically significant reduction in volume. No group differences were noted in psychological and physical symptoms or QoL; however, treatment-related improvements were noted in symptom burden within all groups. Skin improvement was noted in each group that received LLLT.
  - LLLT with bandaging may offer a time-saving therapeutic option to conventional MLD. Alternatively, compression bandaging alone could account for the demonstrated volume reduction.
Intervention

• Compression Devices
  – ACPD quasi-experimental, pre-treatment, post-treatment design was used. Twelve participants received a total of ten self-administered, consecutive, one hour per day treatments
  – Statistically significant improvement in truncal symptoms and sleep were found. Changes in function and girth were not statistically significant in this initial study
Intervention

Breast Cancer Related Lymphedema Prevention

• **Primary Aim:**
  - To determine if subclinical detection of extracellular fluid accumulation via BIS spectroscopy and subsequent early intervention reduce the rate of progression to CDP relative to rates seen using standard tape measurements.

• **Secondary Aims:**
  - To evaluate factors associated with progression requiring CDP (e.g., Body Mass Index (BMI), Seroma, Smoking, Age, Air Travel).
  - To evaluate time to progression requiring CDP.
  - To determine if subclinical detection of extracellular fluid accumulation and subsequent early intervention improves skin condition, symptoms, and quality of life compared with standard tape measurements.
Lymphedema Re-conceptualized

From:
- “A condition in which fluid and protein accumulate in the extra vascular and interstitial spaces” (Ramos, O’Donnell & Knight, 1999, p. 313)

To:
- “Lymphedema is a pathophysiological condition in which fluid and protein accumulate in the interstitial space. This condition contributes to the development of associated physical (e.g., pain, altered sensations, reduced function) and psychosocial (e.g., psychological distress, body image disturbance, social isolation) symptoms that requires extensive self-management.” (Ridner, Fu, Wanchai, Stewart, Armer, & Cormier, 2012)
Translation to Bedside

- **VHNSS**
  - Most used symptom assessment tool for patients with head and neck cancer in the USA

- **LISDS-A**
  - Used internationally in English and non-English speaking countries
Translation to Bedside

• Bioelectrical impedance device – human factors testing
  – Upper and lower extremity lymphedema
  – Congestive heart failure
  – Body composition
  – Pregnancy

• Compression Device for Head and Neck Lymphedema
  – FDA approved
Policy and Accreditation Standards

- Medicare
  - MEDCAC Hearing
  - Outcomes beyond volume reduction must be documented for reimbursement

- National Lymphedema Network
  - International Position papers
  - National Accreditation Program for Breast Centers
    - Lymphedema education
    - On-going assessment for lymphedema
Upcoming Passages

- Continued development of assessment tools
- Completion of prevention study
- Additional intervention studies with multiple funding sources

VUSN Expansion-2018