Teaching Massage to Caregivers: the “Touch, Caring, and Cancer” Home Instruction Program

A Webinar with Tracy Walton, MS, LMT
and guest
William Collinge, PhD

Part 6 of the More about Cancer Care and Massage Webinar Series

Background

• Author
• Educator
• Researcher
• Massage Therapist
• Specialist in massage therapy and cancer care
Background

- Several NIH research grants in complementary therapies and caregiving
- Psychotherapist for people with cancer & other illnesses
- Caregiver training workshops

William Collinge, PhD

Looking back at the series...
More about Cancer Care and Massage

1. Foundations of Massage Therapy for Breast and Prostate Cancer
2. Hidden Contraindications: Lymphedema and Lymphedema Risk
3. Breast Cancer and Massage Therapy
4. How Breast Cancer Treatment Affects Massage Therapy
5. Prostate Cancer, Treatment, and Massage Therapy
6. Teaching Massage to Caregivers: the “Touch, Caring, and Cancer” Home Instruction Program
Things to think about

• How does caregiver massage instruction differ from professional oncology massage practice?
• How can we make massage provided by caregivers safe and effective?
• How can we embrace our role as touch educators as well as touch providers?
• What are the effects of caregiver-provided massage on symptoms and side effects of cancer treatment?
Background

- Prevalence of family and friend caregiving
- Potential benefits of touch as support
- During cancer treatment, patients experience
  - Unpleasant/painful touch
  - Isolation, stigma

Background

- Care partners wanting to touch
- Fearful about touching
- Not knowing how
- Feelings of helplessness
Background

- Access to professional massage limited/unequal
  - Language barriers
  - Financial barriers
  - Geographical barriers
  - Difficulty with traveling/going out
Background

• Project inspired by research at Memorial Sloan-Kettering suggesting that 1 session of professional massage could help cancer symptoms
• Could there be benefit by making touch available at home? Several times/week?

Project Goal and Support

• Develop multimedia instructional program
  – DVD and manual
  – Home instruction
• NIH/National Cancer Institute grant to Collinge & Associates
**Guiding Principles**

- Massage techniques for **comfort** and **relaxation**
- Touch as support, not “massage therapy”
- Minimal, uncomplicated technique
- Multicultural
- All types of relationships
  - Spouse/life partner
  - Parent/child
  - Other family relationships
  - Friend/close friend

**Steps of Project**

- Developed massage curriculum for lay audience
- Filmed 11 patient/care partner dyads learning it
- Showed how to adapt to home environment
Steps of Project

• Create video home instruction program
• Develop accompanying manual
  – Precautions checklist for patient and doctor
  – Reinforcement of concepts from film: centering, positioning, massage/touch techniques

DVD Contributors

• William Collinge, PhD, MPH
  – Collinge & Associates
• Janet Kahn, PhD, NCTMB
  – University of Vermont College of Medicine
• Tracy Walton, MS, NCTMB
  – Oncology Massage Educator
• David Rosenthal, MD
  – Dana Farber Cancer Institute/Harvard University
• Susan Bauer-Wu, PhD, RN
  – Emory University School of Nursing
DVD Contributors

22 wonderful people!
(11 care partner/patient dyads)

We Ended up with...

• Menu-driven DVD
  14 chapters, 78 min.
• Illustrated manual (66 pp.)
• Multilingual
  – English
  – Spanish
  – Cantonese
  – Mandarin
Techniques Taught for...

• Hands
• Feet
• Head, Face

Techniques Taught for...

• Neck
• Shoulders
• Back
• Acupressure pts.
A Few Techniques for Each Body Area

Simple, Memorable Names

- Head hold
- Ear circles/pulls
- A few techniques for each body area

- “Cats paws”
- “Hand sandwich”
- Finger trace
- Brow sweep
Emphasis on Holding

Emphasis on Holding
Emphasis on Comfortable Positioning

Emphasis on Centering
Emphasis on Safety

- Challenges designing program for a lay audience
  - Oncology massage still new
  - Myths about massage & cancer
  - Many contraindications in oncology massage
  - Contraindications complex, some lifelong
    Examples:
    - Bone involvement, bone strength
    - Lifelong risk of lymphedema
    - Elevated DVT risk

How to Explain Safety Concerns to Lay Audience?

1. Limit areas of body included
2. Precautions checklist to go over with doctor
3. Educate physician
PRECAUTIONS CHECKLIST (part 1)

CONDITION: Are you at risk for lymphedema?

☐ Yes
☐ No

If you answer yes to any of the following questions, you may be at risk for lymphedema.

☐ Is there lymphedema on your body, such as in the arms or legs?
☐ Have you had breast cancer or undergone radiation therapy for breast cancer?
☐ Have you had surgery or chemotherapy for breast cancer?
☐ Have you had a mastectomy?
☐ Have you had an injury or infection that caused swelling in your arm or leg?

IF YOU ANSWER YES TO ANY OF THE ABOVE QUESTIONS, YOU MAY BE AT RISK FOR LYMPHEDEMA.

PRECAUTIONS CHECKLIST (part 2)

CONDITION: ARE YOU AT RISK FOR LYMPHEDEMA?

☐ Yes
☐ No

If you answer yes to any of the following questions, you may be at risk for lymphedema.

☐ Have you had breast cancer or undergone radiation therapy for breast cancer?
☐ Have you had surgery or chemotherapy for breast cancer?
☐ Have you had a mastectomy?
☐ Have you had an injury or infection that caused swelling in your arm or leg?

IF YOU ANSWER YES TO ANY OF THE ABOVE QUESTIONS, YOU MAY BE AT RISK FOR LYMPHEDEMA.

PRECAUTIONS CHECKLIST (part 3)

CONDITION: ARE YOU AT RISK FOR LYMPHEDEMA?

☐ Yes
☐ No

If you answer yes to any of the following questions, you may be at risk for lymphedema.

☐ Have you had breast cancer or undergone radiation therapy for breast cancer?
☐ Have you had surgery or chemotherapy for breast cancer?
☐ Have you had a mastectomy?
☐ Have you had an injury or infection that caused swelling in your arm or leg?

IF YOU ANSWER YES TO ANY OF THE ABOVE QUESTIONS, YOU MAY BE AT RISK FOR LYMPHEDEMA.

SAFETY PRECAUTIONS

About Lymphedema

People at risk of lymphedema are sometimes advised to avoid putting pressure on an area with swelling, including pressure on the affected area.

FIGURE 1: LYMPH NODES AND Lymphedema Risk

- Light areas - areas of massage caution
  - Cervical nodes (in the neck)
  - Axilla (under the arm)
  - Inguinal nodes (in the groin)

- Areas of caution on the affected side:
  - The arm/leg from the elbow or knee down to the ankle or foot
  - The hand/foot from the wrist or ankle to the fingertips or toes

- Areas of caution on the unaffected side:
  - The opposite arm/leg from the elbow or knee down to the ankle or foot
  - The opposite hand/foot from the wrist or ankle to the fingertips or toes

Contact your doctor if you notice any changes in your lymph nodes or if you have any concerns about lymphedema.
Test the Program!

Tested in a controlled clinical trial:
- Will people use it?
- Will they benefit from it?
- Is it safe?

The Clinical Trial

- 97 dyads, 3 cities
- Randomized to 1 of 2 groups

20 min., 3-4X/wk touch/massage, using DVD (MASSAGE group)

20 min., 3-4X/wk Care partner reading to patient (CONTROL group)
Measuring “Session Effects”

• 5 X 8 session “report cards”

Psychosocial Measurements

• Caregiver attitudes and concerns
• Caregiver esteem scale
• Patient quality of life
• Perceived stress
Safety Monitoring

• Home visit by an Oncology Massage Therapist (OMT)
• Direct observation of dyad’s practice
• Home Visit Notes (standardized form)

Results: Session Effects

• Significant reductions in symptoms for both groups
  – Reading: ranged from 12—28% drops in symptoms
  – Massage: ranged from 29-44% drops in symptoms
• Symptom reduction in massage group was superior to reduction in reading group
Compared Caregiver Massage to Research on Professional Massage


1290 patients at Memorial Sloan-Kettering Cancer Center

Studied effects of 1 session pre-post session
Swedish, foot massage, light touch, combinations
20-60 min. massage (inpatients vs. outpatients)
21-52% reductions in pain, fatigue, anxiety, depression, fatigue
Caregiver Attitudes

- Both groups increased caregiver satisfaction
- Massage caregivers improved more in:
  - Comfort using touch/massage to support
  - Perceived self-efficacy in massage
Comments from Partners

• “My partner really enjoyed the massage provided by me so that really reflects on me and makes me feel very good about myself…”
• “She said the massage helped and I felt great being able to help.”
• “I look forward to the next session. It brings us closer together.”

What Did We Learn?

• Would people use the DVD? Yes.
• Can it be used safely? Yes. No “adverse events”
• Does it help?
  – Seems to help patient symptoms
  – Seems to help caregiver self-efficacy
• Is touch important?
  Seems to be, whether it’s personal or professional!
Integrating Partners into Patient Care

Opportunities...

- Caregiver support programs
- Family education events
- Patient/family hand-out materials
- Further research on caregiver massage
Where Do We Fit in?

- Learn some safety principles from DVD
- Making program available to clients
- Referring patients and families to program for supportive touch
- Teaching workshops in caregiver massage

What Does it Take to Teach Caregivers to Massage?

- In-depth knowledge of the special population
- Mastery of the massage contraindications, modifications for that population
  - During diagnosis
  - During treatment
  - End of life
  - Post-treatment, including “late effects”
- Dispel myths, do research, reassure, communicate
- Take leadership on contraindications/modifications
The Society for Oncology Massage

www.s4om.org

THE PLACE TO GO WITH YOUR MASSAGE AND CANCER QUESTIONS

Advocacy & Education
Standards of practice
Oncology massage therapist locator service
Recognized trainings

What is Our Role?

- Providers of touch
- Models of skilled touch
- Healing touch advocates
- Teachers of touch
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Where to Learn More

• 16 minute preview of DVD available at www.partnersinhealing.net
• 6 minute trailer and purchase single copies through www.partnersinhealing.net or www.tracywalton.com
• Purchase in volume for resale by writing william@collinge.org
• “Guide for Professionals” (getting local grants, leading workshops, talking to hospitals, etc.) is at www.partnersinhealing.net (free download)
Resources in Cancer and Massage

Books

Articles in massage publications

Society for Oncology Massage
www.s4om.org

Resources in Cancer and Massage

Thank you!
Questions?

Listen to music samples at www.partnersinhealing.net.

“Touch, Caring & Cancer: Simple Instruction for Family and Friends.”
CONTEST

How to enter:

• Write a review of a “More About Cancer Care and Massage” webinar on Facebook (www.facebook.com/BenjaminInstitute)
• You’re eligible for one entry per webinar

What you can win:

• Autographed copy of “Medical Conditions and Massage Therapy”
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