My Personal Opinion - Acupuncture and Lymphedema

It is rare that in this website I offer my own personal opinion on a treatment option...However, there is one treatment that is beginning to be used for lymphedema that I feel so strongly about, I must comment.

Dangers with Acupuncture and Lymphedema...

- Four years after this page first came out, I stand firm in my opinion the acupuncture has no place in the treatment of lymphedema.
- Please before you even begin to try this treatment, consider well the consequences.

Moxibustion:

- Uses heat generated by burning a herb (Artemisia vulgaris or mugwort) to stimulate the acupuncture points, as well as, or instead of, needles

Using acupuncture and moxibustion to promote wellbeing and improve quality of life in cancer survivors with secondary lymphoedema

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www.lymphedemapeople.com
Lymphoedema (LE) – What is it?
- Characterised by swelling of limbs and sometimes the corresponding trunk quadrant. It can also affect the head, neck, breast, or genitalia
- It is:
  - Chronic
  - Progressive
  - Not curable
  - Poorly understood
  - Undiagnosed, mistreated or untreated until advanced

Classification
- **Primary:** Congenital, caused by abnormalities or disease originating in the lymphatics
- **Secondary:** Due to surgery, trauma or disease not originating in the lymphatics
  - All lymphoedema may be primary

Secondary LE
- Developing world: filariasis
- Developed world:
  - Most often the result of cancer and its treatments
  - Associated with surgery (lymph node excision) and radiotherapy
  - May occur immediately after or many years after cancer treatment

Incidence & prevalence
- Estimated 200,000 cases of chronic LE in UK
- 1 in 6000 develop primary LE at birth (Moffat et al 2003)
- Secondary LE associated with cancer:
  - 3-89% in breast cancer (Williams et al 2005)
  - 30% breast cancer patients (Hayes et al 2008)
  - 45,000 breast cancer diagnoses annually in UK
  - Potential 15,000 new cases per year
  - 28-47% in gynaecological cancer
  - Prostate, head neck throat, skin cancers

Associated symptoms & problems
- Lymphoedema itself
  - Swelling
  - Acute infection (cellulitis)
  - Lymphorrhoea
  - Deep vein thrombosis
- Physical & psychosocial health:
  - Pain, discomfort
  - Depression, anxiety
  - Sleep problems
  - Physical disability
  - Obesity
  - Body image problems
  - Sexual function
  - Adjustment to cancer diagnosis
  - Loss of employment
  - Relationship problems

Best practice guidelines
- Available at [http://www.woundsinternational.com/pdf/content_175.pdf](http://www.woundsinternational.com/pdf/content_175.pdf)
**Maintenance therapy**

1. Skin care
   - Maintain good tissue condition
   - Reduce risk of infection (cellulitis)
2. External support/compression
   - Compression garments
3. Exercise & movement
4. Simple lymphatic drainage (SLD)
   - “4 cornerstones of maintenance therapy” carried out
   - Every day
   - For life

**Moderate to severe LE**

Decongestive lymphatic therapy:
- Intensive, 2-4 weeks
- Multi-layer LE bandaging (MLLB)
- Manual lymphatic drainage (MLD)
- Skin care & exercise
- Followed by maintenance

Other possible options:
- Sequential pneumatic compression
- Surgery
- Drug regimes

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**Skin care (excerpt)**

- Avoid any interventions that break the skin, including:
  - Taking blood, injections, or taking blood pressure
  - Insect bites
  - Injuries when gardening, doing housework, etc
  - Injuries from pets
  - Shaving with a razor blade
  - Cutting nails with scissors
  - Needle injuries when sewing
- To be observed by people with or at risk of lymphoedema

**Acute inflammatory episode**

- **Cellulitis**
  - Rapid onset
  - Flu like symptoms, rash, pain, increased swelling
  - Potentially life-threatening
  - Prompt administration of antibiotics
  - Can require hospitalisation
  - Prophylactic antibiotics for recurrent attacks
  - Leads to deterioration of overall health

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**Exacerbating lymphoedema**

“If a foreign object, e.g. a needle, is placed in the arm, an immune response occurs which involves an inflammatory response, and this puts the lymphatic system under more stress. This added burden on an already compromised lymphatic system can be enough to instigate swelling within the limb.”


**Acupuncture and lymphoedema**

- Avoid any interventions that risk
  - Introducing infection
  - Exacerbating lymphoedema
  - Acupuncture used with caution or avoided
  - Needling affected area is contraindicated
  - Safety is an issue
- Scant literature:

“It is worth investigating some alternative therapies for Lymphoedema such as Bowen Technique, Kinesiology, Reflexology, etc ... However, therapies such as Acupuncture or Aromatherapy, especially on the affected limb, are not recommended”

www.UKLymph.com
Controversy: positions taken

- All acupuncture should be avoided by people with lymphoedema (lymphedemapeople.com)
- Acupuncture okay, if needling avoided in:
  - The affected area eg, arm (Filshie 2001)
  - The affected quadrant eg, arm and torso on affected side (de valois et al 2011)
- Needling the affected area using clean technique is safe
- Needling the affected area is safe and effective for treating lymphoedema (Cassileth et al 2010, Matecki 2009)

There is little, if any, evidence to support any of these positions.

Research: why acupuncture?

- Previous research showed improvements in quality of life
- Used in chronic disease for symptom improvement and improved physiological and psychological coping
- Cancer patients are users of acupuncture

Study Questions

1. Can acu/moxa improve wellbeing in cancer survivors with lymphoedema?
2. What symptoms are most troublesome for these individuals?
3. Is acupuncture a safe intervention for people with lymphoedema?
4. Are acupuncture and moxibustion acceptable to patients and their clinicians?
5. What happens if you avoid needling in large areas of the body?

Study Design

- Patient-centred, mixed methods, comprising 3 steps:
  1. Focus groups (qualitative) to:
     - Identify difficult symptoms
     - Assess acceptability of acu/moxa as an adjunctive treatment
  2. Clinical treatment phase (quantitative & qualitative) to:
     - Obtain first measure of the effects of acu/moxa on wellbeing
     - Test acceptability of acu/moxa
  3. Focus groups (qualitative) to:
     - Gather data on participants’ experiences and perceptions of treatment.
     - Upper body lymphoedema in breast and head & neck cancers
     - Bilateral breast cancer excluded

Step 1: Focus Groups

- 8 focus groups (n=39):
  - 4 with breast cancer participants (n = 7, 4, 6, 6)
  - 2 with head & neck cancer participants (n = 4, 4)
  - 2 with healthcare professionals (n = 5, 3)
- Key messages:
  - Yes, we want this acu/moxa treatment!
  - But, avoid needling in the affected area:
    - Arm and entire torso quadrant on affected side (breast cancer)
  - Participants reported a wide range of symptoms, with diverse and individual symptom patterns
  - Data used to design Step 2: Clinical Treatment.
Step 2: Clinical Treatment

- Single arm observational study
- Participants undergoing maintenance care for LE at Mount Vernon Cancer Centre
- 13 treatments offered, comprising:
  - 7 treatments = “Series 1”
  - 6 treatments = “Series 2” (optional, decided by participant)
- Treatments:
  - Administered once a week (with some flexibility)
  - Given by 2 British Acupuncture Council members
  - “Real-world” acupuncture, high external validity

Notes on acu/moxa

- Drew on 5 Elements and 8 Principles frameworks
- No set protocol
- Emulate, as far as possible, usual clinical practice
- Individualised treatment, changing as patient changed
- Sole restriction was avoiding needling the affected area:
  - Arm and torso on affected side for breast cancer patients
  - Points on the midline (Ren and Du channels) were needled
  - Moxa administered as appropriate to individual
  - Indirect moxa used on the affected side in some patients

Outcome measures

- Measure Yourself Medical Outcome Profile (MYMOP)
  - Main outcome: changes in MYMOP scores at end of Series 1 and 2
  - Participants specify the symptoms they want treated
- SF-36 and Positive and Negative Affect Scale (PANAS)
  - Secondary measures
  - Administered at baseline, end of each Series, and 4 and 12 weeks after last treatment
- Change in volume (swelling) was not an outcome
  - But was measured in breast cancer participants, primarily as a safety measure.

Step 2: Results

- 35 participants recruited
  - 27 BC, 8 HNC
- 30 completed Series 1 and 2
  - 24 BC, 6 HNC
- 3 completed Series 1 only:
  - 1 HNC relocated
  - 1 BC found travelling onerous
  - 1 BC found treatment not beneficial
- 2 lost to study
  - 1 HNC cancer recurrence
  - 1 BC carer, found attendance too difficult

MYMOP

- For MYMOP, participants specify and/or rate:
  - Symptom 1 and Wellbeing (mandatory)
  - Symptom 2 and an Activity (optional)
- Use a 7 point scale:
  - 0 is “as good as it could be”
  - 6 is “as bad as it could be”
- MYMOP Profile = the mean of the sum of specified items
- A change of over 0.5 – 1.0 point on the MYMOP scores is clinically significant, and meaningful to the participant.

MYMOP Results: Series 1
MYMOP Results: Series 2

<table>
<thead>
<tr>
<th>MYMOP Items</th>
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<th>MYMOP Items</th>
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<tr>
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<td>MYMOP Profiles</td>
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SF-36: Mean Change from Baseline (Breast Cancer)

<table>
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<tr>
<th>Scale</th>
<th>Series 1</th>
<th>Series 2</th>
<th>4 Week Followup</th>
<th>12 Week Followup</th>
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<tr>
<td></td>
<td>P</td>
<td>P</td>
<td>P</td>
<td>P</td>
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<tr>
<td>Physical Function</td>
<td>2.6</td>
<td>0.179</td>
<td>2.9</td>
<td>0.034</td>
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<tr>
<td>Role</td>
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<td>0.104</td>
<td>5.2</td>
<td>0.101</td>
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<td>Bodily Pain</td>
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<td>12.0</td>
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<td>0.008</td>
<td>27.0</td>
<td>0.006</td>
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<td>General Health</td>
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<td>0.308</td>
<td>1.5</td>
<td>0.302</td>
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<tr>
<td>Vitality</td>
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<td>0.002</td>
<td>10.5</td>
<td>0.001</td>
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<tr>
<td>Social Health</td>
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<td>0.004</td>
<td>2.6</td>
<td>0.003</td>
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<td>0.271</td>
<td>4.2</td>
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<tr>
<td>Health</td>
<td>14.3</td>
<td>0.195</td>
<td>4.2</td>
<td>0.371</td>
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</tbody>
</table>

Adverse events

- No serious adverse effects were reported or observed
- Minor adverse effects included incidents of:
  - Bruising or bleeding at the needle site
  - Tiredness after treatment
  - Pain on needling
  - One participant reported feeling lightheaded after treatment
  - One experienced headaches after treatment
- Two incidents of cellulitis were reported during the study: neither were related to acu/moxa treatment
- No changes in volume outside of the normal range

Step 3: Focus groups

- 32 study participants invited, 23 participated
- 17 breast cancer, 6 head and neck cancer
- 6 focus groups facilitated by external qualitative researcher
- Qualitative data:
  - Confirmed quantitative data collected in Step 2
  - Provided rich insights into participants’ experiences
- See handout of poster for details

BC Participant Quotations

- "...I had dreadful pain in my elbow and in my wrist, and each treatment seemed to improve it. And by Christmas the pain had gone, and that felt wonderful, because I think without the pain I felt more positive...I haven’t taken any painkillers since Christmas."
- "...I’ve joined Weight Watchers, I’m being really positive about this and I’m working on my exercises for the lymphoedema, I’m really working hard...and I honestly say this is the acupuncture and moxibustion...it changed the way I thought about myself."
HNC Participant Quotations

“…when I was having acupuncture, I could move my arm and my shoulders, and then when it seized up I had to go back to the tablets to be able to do it…it gradually wore away.”

“I’d never had it before, so I was apprehensive but I thought I’d give it a try…I didn’t feel it was going to work, to be honest.” (009 HNC)

“…it helps you get on with life really, accepting it as what you’ve got”

Limitations

- Uncontrolled design
- Single centre
- Small numbers of participants
- Research acupuncturist also principal investigator

Research conclusions

Acu/moxa has the potential to:
- Improve wellbeing
- Address a range of symptoms experienced, including:
  - Lymphoedema-associated problems
  - Non-lymphoedema related symptoms
- Be effective even when large areas of the body cannot be needled
- Be a safe intervention for people with lymphoedema

More research conclusions

- Acu/moxa is acceptable to cancer survivors and clinicians
- It can lead to improved self-management
- There is potential for acupuncturists and lymphoedema specialists to work in partnership
- Further research is warranted

Next Steps

- Disseminate results, to change perceptions among:
  - Lymphoedema healthcare specialists
  - People with lymphoedema
  - Acupuncture practitioners
- Further research
  - RCT for breast cancer related lymphoedema
  - Exploratory study into lower body lymphoedema
  - Systematic review

Role for acupuncturists

- Know who is at risk
- Early identification of lymphoedema
  - Clothing or jewellery becoming tighter
  - Feeling of heaviness, tightness, fullness, stiffness
  - Aching
  - Observable swelling
- Referral to specialist services
- Encourage patients to adhere to self-management
- Reduce the symptom burden
- Reduce the lymphoedema?
Case study – “Ann”

- Name and details changed
- “Ann” has consented to her case being used
- Heaviness, pain, grip
- Embarrassment, body image
- Frustration, “out of control”
- Poor sleep, nightmares
- Poor diet, overweight
- Exhaustion, headaches, bowels
- "Emotionally off balance"
- Guilt about surviving cancer
- Anxiety, lack of confidence

Priorities and progress

**MYMOP treatment priorities**

**Progress**

**Series 1 (Treatments 1–7)**
- Relieve pain in arm and shoulder
- “Get back into balance”
- Activity: sewing

**Series 2 (Treatments 8 – 13)**
- Relieve pain in arm
- Improve confidence
- Activity: sewing

- Reduced heaviness, pain
- Feeling calmer
- Improved sleep
- Improved grip
- Improved diet, lost 10 pounds
- Improved bowels
- Looked after self
- Less anxiety, less guilt
- Able to cope with bereavement
- Improved confidence

"Ann’s” feedback

- "Normally I put off going to the doctor until things are really bad; this time I had the confidence to request an urgent appointment and get prompt treatment. I feel this is due to the acupuncture/moxibustion treatment I received.

I feel like the person I was “before cancer” and friends and family have commented on the change in me”

Main publications


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