## **BRIEF REPORT**

# Changing perceptions: using acupuncture in the management of lymphoedema

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## **Abstract**

Acupuncture in the management of lymphoedema is controversial because needling the affected area is assumed, and this procedure is perceived to carry the risk of exacerbating the condition or introducing infection. This innovative three-step, patient-centred, mixed-methods study explored the use of traditional acupuncture as an adjunct to usual care for lymphoedema by testing its acceptability, and measuring its impact on the well-being and quality of life of cancer survivors with breast cancer, and head and neck cancer (BC and HNC, respectively). In step 1, it was established that focus groups involving patients and clinicians found traditional acupuncture to be an acceptable intervention, providing that the affected area was not needled. Step 2 was a single-arm observational study that tested recruitment, acceptability and effects. Participants received seven traditional acupuncture treatments (S1) with six additional optional treatments (S2). The Measure Yourself Medical Outcome Profile (MYMOP) and the 36-Item Short Form Health Survey (SF-36) were administered at baseline, and at the end of S1 and/or S2, with SF-36 follow-up at 4 and 12 weeks post-treatment. The primary outcome was a change in MYMOP scores at the end of each series. In step 3, six focus groups explored the participants' experiences. Thirty-five participants were recruited for step 2 (BC=27; HNC=8): 30 completed S1 and S2; three completed only S1; and two were lost to the study. The mean changes in MYMOP scores were clinically and statistically significant at the end of each series; the SF-36 scores for Vitality and Bodily Pain were significant at 4 weeks post-treatment. No serious adverse affects were reported, and there were no changes in volume for subjects with BC outside of the normal range. Traditional acupuncture can be a safe and acceptable adjunct to usual care, and it has the potential to reduce the symptom burden in cancer survivors with upper-body lymphoedema. Improvements in well-being may lead to improved concordance with long-term management.

Keywords: cancer, chronic illness, lymphoedema, survivorship, well-being.

#### Introduction

Lymphoedema is a condition that is characterized by chronic swelling. It may affect one or

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Acupuncture is not usually considered a treatment option for people with lymphoedema. It is assumed to involve needling the affected area, which is perceived to carry the risk of introducing infection in the form of cellulitis. There are also fears that needling may cause an inflammatory response, potentially leading to an exacerbation of the swelling. Consequently, many specialists advise people with lymphoedema to avoid this form of complementary medicine.

Funding from the National Institute for Health Research (NIHR) programme Research for Innovation, Speculation and Creativity (RISC) facilitated exploratory research into using traditional acupuncture (including both needling and the use of moxibustion, referred to here as "acu/moxa") in the management of cancerrelated upper-body lymphoedema. This study, started in April 2008 and now in its final stages, was carried out at the Lynda Jackson Macmillan Centre, a cancer support and information centre associated with Mount Vernon Cancer Centre, Northwood, Middlesex, UK. It was approved by Hertfordshire Research Ethics Committee.

There is little in the literature about using acu/moxa to treat lymphoedema. Kanakura et al. (2002) reported a small Japanese study using acu/moxa to treat and prevent lymphoedema in gynaecological cancer patients. More recently, Brazilian researchers Alem & Gurgel (2008) reported a case series using acupuncture to increase mobility in breast cancer (BC) patients with arm oedema. In light of the paucity of data, the present authors chose to focus on using acu/moxa to promote well-being and improve quality of life (QoL) in cancer survivors with upper body lymphoedema; specifically, BC, and head and neck cancer (HNC). It was not an aim of the present study to treat the lymphoedema itself: the intention was to treat the patient, not the disease.

As early-stage exploratory research and following the Medical Research Council guidelines for developing research into complex interventions (Craig *et al.* 2008), the study investigated these key questions:

- Is acu/moxa acceptable to lymphoedema patients and their healthcare professionals?
- Can traditional acupuncture improve well-being in cancer survivors with lymphoedema?

• Is acupuncture a safe intervention for people with lymphoedema?

# Subjects and methods

To answer these questions, the present authors set up a three-step study design. In step 1, they conducted a series of focus groups (n=8) including cancer survivors with lymphoedema (n=31) and their healthcare professionals (n=8) to explore whether acu/moxa was an acceptable intervention if used as an adjunct to usual care. The participants were almost unanimous in agreeing that this could be a beneficial approach, providing that needling of the affected area was avoided. For BC patients, this meant avoiding needling in the torso quadrant on the affected side as well as the arm.

This agreement was the green light to continue to step 2, the clinical treatment phase, which was a single-arm observational study using beforeand-after measures. Breast cancer and HNC patients under the care of the Mount Vernon Lymphoedema Service, Mount Vernon Hospital, Northwood, Middlesex, UK, were referred by the Lymphoedema Nurse Specialist. The eligibility criteria included a diagnosis of mild-tomoderate uncomplicated lymphoedema, no active cancer disease, at least 3 months since finishing active cancer treatment and management by the lymphoedema service for a minimum of 2 months. Breast cancer patients who had undergone bilateral surgery were excluded. To test whether participants would prefer shortor long-term treatment, they were offered two series of acu/moxa treatments: (1) seven treatments delivered on a weekly basis; and (2) an optional additional six treatments. It was the participant's decision whether or not to continue to series 2.

The acu/moxa sessions was administered by two experienced members of the British Acupuncture Council. Treatments were individualized according to the needs of the participant, changed as he or she progressed through treatment, and sought to emulate usual clinical practice. As agreed in the step 1 focus groups, needling was avoided in the affected area, including the quadrant on the affected side of the BC participants. However, points were needled on the midline. Lifestyle advice was given, and could

include advice for healthy dietary habits, rest, exercise or other advice as appropriate for the individual participant. There were no restrictions on developing the therapeutic relationship. The acupuncturists also reinforced the messages about self-management, as prescribed by the Lymphoedema Nurse Specialist.

Participants set their treatment priorities using the Measure Yourself Medical Outcome Profile (MYMOP), a validated, patient-centred measure, and the mean change in MYMOP scores at the end of each series compared with baseline was the main outcome. The 36-Item Short Form Health Survey (SF-36), a widely used, validated health-related QoL questionnaire covering a number of relevant domains, was administered at baseline, at the end of each series, and at 4 and 12 weeks after the end of treatment. The participants also completed semi-structured questionnaires at end of treatment and at the two follow-up points. Reduced volume was not an outcome of the present study; however, BC patients were measured by the lymphoedema nurse specialist at intervals throughout the study to ensure that acu/moxa treatment was not exacerbating the swelling.

Thirty-five participants were recruited to the clinical phase and of these:

- 24 BC and six HNC participants completed series 1 and 2 (13 treatments);
- two BC and one HNC participant completed only series 1 (seven treatments); and
- one BC and one HNC participant were lost to the study.

## Results and discussion

The MYMOP scores for all participants showed statistical and clinical significance at the end of each series. The SF-36 scores for Bodily Pain and Vitality showed significant improvement at the end of each series and at 4-week follow-up. No serious adverse effects were observed or reported, and there were no increased or decreased volumes outside of the normal range for each participant.

In step 3, the present authors conducted a further series of focus groups with the participants who were involved in step 2 in order to gather data on their perceptions of acu/moxa treatment. Six focus groups (n=23) were con-

ducted by an independent qualitative researcher. The participants discussed a range of physical and emotional benefits, including reduced pain, improved sleep, increased energy levels, reduced stress levels and reduced medication. Although it was not the authors' aim to treat the lymphoedema itself, many participants reported changes in associated sensations and increased mobility. These could be either short-term or long-lasting effects. The majority of participants were enthusiastic about their experiences of acu/moxa, and several reported increased motivation to manage their long-term health issues.

A detailed analysis of the results of the present investigation are currently being written up for publication. This innovative early-stage exploratory study pioneers research into using acupuncture in the management of lymphoedema. It suggests that acupuncture can be a safe intervention for this patient group, and that it has a potential role to play in improving their well-being and QoL. This treatment is acceptable as an adjunct to usual care to both patients and their healthcare professionals. It also helped some participants to be able to accept and to cope better with their chronic condition. In the words of one BC participant:

"I think we were always made aware from the very beginning that it wasn't going to cure lymphoedema... And I think we've had such incredible results from it for other things that it almost overshadowed what was happening with the lymphoedema... It wasn't such a dominating factor in your life."

Further research is warranted. There is also considerable work to do to start to change firmly held perceptions about the use of acupuncture in the treatment of people with lymphoedema. Whilst making no claims about the ability of acupuncture to treat lymphoedema itself, this study opens the door to reassuring people with the condition that they can safely use acupuncture to manage a range of physical and emotional conditions, thereby increasing their options for managing their healthcare. For the acupuncture community, it provides evidence that acupuncture treatment can be effective, even if large areas of the body are inaccessible for needling. The present study also demonstrates that acupuncturists and lymphoedema specialists can work together to bring about improved healthcare for patients. Let us hope that this early exploratory work can help to bring about changes in perceptions, and begin to break down the taboos associated with acupuncture and lymphoedema.

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Beverley de Valois PhD LicAc MBAcC graduated from the College of Integrated Chinese Medicine, Reading, UK, in 1999. She has worked as a research acupuncturist in the NHS since 2000, focusing on using acupuncture to manage symptoms related to cancer treatment. Beverley was awarded a PhD in 2007 by the University of West London (formerly Thames Valley University), London, UK, for research into using acupuncture to manage hot flushes in BC survivors. In 2008, she was awarded a grant by the NIHR to conduct an exploratory study into using acupuncture to improve QoL for cancer survivors with lymphoedema.