

Cancer Survivors with Lymphoedema : Perceptions of Using Traditional Acupuncture as an Adjunct to Usual Care

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Introduction

Use of acupuncture by people with lymphoedema is controversial. It is assumed to involve needling the affected area, raising concerns about aggravating the condition or risking infection. Therefore people with lymphoedema are often advised to avoid having acupuncture.

We conducted a 3-step, patient-centred, mixed-methods study to investigate using acupuncture and moxibustion to promote wellbeing and improve quality of life in cancer survivors with upper-body lymphoedema. Step 3 of this study used qualitative methods to gather data about the perceptions and experiences of research participants who had undergone traditional acupuncture treatment.



Methods

We invited 32 breast cancer and head and neck cancer survivors with lymphoedema to take part in focus groups to discuss their experience of having traditional acupuncture. Invitees had previously participated in Step 2 of our study, during which they received up to 13 individualised traditional acupuncture treatments, which aimed to improve their overall wellbeing and quality of life.

An independent researcher facilitated the focus groups, and analysed the transcripts using a thematic framework approach. Coding was checked by a second researcher to ensure systematic analysis.

Needling was avoided in the affected area. The acupuncture treatment was an adjunct to usual care, and did not aim to treat the lymphoedema.

Results

Six head and neck and 17 breast cancer survivors (n=23: 20 female, 3 male) participated in 6 focus groups during the summer of 2009. Data from the key themes that emerged are summarised below.

Personal Context

Diagnosis of lymphoedema was seen as the “last straw” after cancer and its treatment. In addition to the shared experience of lymphoedema, there were other common physical and emotional symptoms, including:

- Fatigue
- Pain
- Sleep problems
- Anxieties about coping
- Low self-esteem
- Poor body image
- Social embarrassment
- Depression
- Stress
- Side effects of medication.

“When I was diagnosed with breast cancer, it was like the worst thing ever ... And then I developed lymphoedema, and it was as if I'd hit rock bottom. It was horrible.”

Perceived purpose of the research and expectations of treatment

Participants were clear that the acupuncture was intended to improve wellbeing, rather than treat lymphoedema. Most were positive about the idea, although some were sceptical about what it could do for them. Several had reached the point where they were “willing to try anything”, and felt that nothing could be worse than what they had already been through. For others, fear of needles presented a substantial barrier:

“My biggest fear, was the needles...[after] having chemotherapy...I thought ‘oh no, do I really want another round of having needles put in?’”



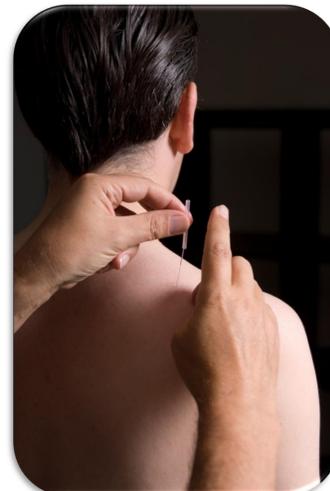
The experience of having traditional acupuncture

Participants appreciated the “whole person” approach taken by the acupuncturists, who paid attention to individual's needs, and adapted treatments accordingly. They contrasted this with the medical approach, which they felt was disease focussed:

“...[the acupuncturist] was listening to me. And she was ... looking at me as a whole, not just at the medical problems that I had.”

Acupuncture and wellbeing

Participants spoke of a range of beneficial effects, both physical and emotional. While some lasted only for the duration of treatment, others were long-lasting. Physical effects included increased energy, improved sleep, reduced pain and improvements in other symptoms. Many participants spoke in terms of personal empowerment, reporting increased self-confidence and more positive attitudes to life. Such changes often motivated participants to improve their self-care:



“...I've joined Weight Watchers, I'm really being positive about this and I'm really working on my exercises for lymphoedema, I'm really working hard.... And I honestly say this is the acupuncture and moxibustion... It changed the way I thought about myself.”

The acupuncture was not directly used to treat lymphoedema, but some participants felt it contributed to a reduction of swelling and discomfort, although sometimes this lasted only for the duration of the treatments. Others felt that the process of having acupuncture helped them to have a more positive attitude towards the lymphoedema:

“We were always made aware from the very beginning, that it wasn't going to cure the 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.”

Future aspirations

Participants were almost unanimous in saying they would like to have further acupuncture treatments. For most, however, the cost of private treatment was a barrier. Overall, they reported few unhelpful aspects and many benefits:

“What this does, it helps you to get on with life really, accepting it as what you've got.”

“So all in all, I've really got my life back”

Conclusion

Qualitative data from these focus groups substantiate the quantitative data collected in Step 2 of this study, and provide rich insights into the experiences of cancer survivors with lymphoedema. The findings contribute to a deeper understanding of the challenges of living with a chronic condition, and of how traditional acupuncture can help.

This study begins to challenge the perception that acupuncture is an unsafe treatment for lymphoedema patients. The participants found the treatment enjoyable and beneficial. While some reported minimal or short-term benefit, for others the process of having acupuncture facilitated major changes in wellbeing, self-care, and attitudes to having lymphoedema.

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