

What are the perceived barriers that prevent patients with lymphoedema from continuing optimal skin care?

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Abstract

This project concentrated on the barriers patients with lymphoedema perceive which prevent them from continuing optimal skin care. Despite receiving education on the importance of skin care in the management of lymphoedema, many patients do not appear to maintain appropriate skin care continually. The project also investigated whether the expectation of skin care as provided in an education programme is acceptable and achievable for these patients. Eight clients diagnosed with lymphoedema attending a clinic were interviewed using semi-structured questions. The transcripts were then analysed to find common themes. The results found patients reported a need to be vigilant and make a psychological and physical commitment to achieving their lymphoedema care. Similarly the factors affecting a person's ability to maintain skin care, such as physical limitations, costs and motivational issues were identified in this study. Generally participants found the expectation of skin care was achievable for them but this was likely to be influenced by fear of the consequences of not achieving it. It became clear, during analysis of the responses, that participants were mostly achieving appropriate skin care but were unable to link its relevance in preventing secondary complications or worsening symptoms of lymphoedema. Educators may need to re-evaluate their programmes based on individual skills and need. Despite this, participants rated the education process highly.

Introduction

Background to the study

Lymphoedema is a progressive chronic condition resulting from an abnormality of, or damage to, the fluid transport mechanisms of the lymphatic system resulting in the accumulation of lymphatic fluid and constituents, in the skin and subcutaneous tissue. Swelling can occur in the limbs and corresponding quadrant of the trunk¹.

Regional immunodeficiency occurs as the ability of the lymphatic system to transport antigens, lymphocytes and macrophages is impaired. This increases the risk of developing acute inflammatory episodes (AIE) which, in turn, may exacerbate the lymphoedema^{2,3}. Skin problems and AIE are frequent in patients with lymphoedema⁴. The term AIE, in this discussion, incorporates the collective skin infections of cellulitis and erysipelas.

Maintaining skin integrity aims to preserve the skin's barrier function by actions which promote the protective lipid layer and reduce water loss. Subsequently this optimises the ability of intact skin to resist infection⁴.

Attaining this optimal condition in the barrier function of the skin suggests people suffering from lymphoedema would gain benefit from incorporating skin care into their health activities. If the likelihood of reducing AIE and secondary skin changes associated with the condition can be supported through persuading favourable skin care choices, then clinicians should aim to provide an education programme to patients capturing the benefits of skin care and encouraging positive choices.

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Other institution acknowledged: Research was attended at Mercy Health Lymphoedema Clinic.

Author statement: This edited original research was submitted as partial fulfilment of the requirements for the degree of Master of Wound Care, Monash University, June 2010.

The clinic setting

The setting of this study was the Mercy Lymphoedema Clinic, a multidisciplinary outpatient clinic operating from a large metropolitan hospital, where the author, a registered nurse, has worked as a lymphoedema practitioner for more than six years. People with all types of lymphoedema or those who are 'at risk' of developing the condition are able to attend the clinic.

Skin care education at the clinic

After a lymphoedema diagnosis is established, patients attending the clinic usually attend two education sessions regarding best practice management of the condition. Part of this focuses on the importance of skin care and a regime supporting optimal skin care for lymphoedema is reinforced to patients (Table 1).

Skin care is considered one of the four cornerstones in the management of this chronic condition. Compression therapy, manual lymphatic drainage (MLD) and decongestive exercise comprise the remaining components of complex decongestive therapy (CDT)¹.

Skin care is also an essential component in the prevention and care of advanced lymphoedema where secondary skin changes further compromise lymphatic function adding to the physiological and psychological burden⁵.

Table 1. Skin care prescribed at the lymphoedema clinic.

Daily skin hygiene using unperfumed, pH neutral soap substitutes

Application of at least daily emollient moisturiser

Specific skin softening foot care and treatment of tinea

Minimise trauma to the skin by

- Ensuring sunscreen, insect repellent and long sleeves are worn during exposure to the sun
- Using electric razor for hair removal
- Wearing gloves while washing dishes, gardening and in the laundry
- Using oven mitts
- Wearing boots
- Avoiding punctures to the skin from injections and blood samples

When injuries do occur

- Cleanse with water, dry thoroughly and cover with an adhesive dressing.
- Watch the skin's progress to healing.
- Responding to the signs and symptoms of cellulitis by seeking medical attention.

Investigating the dilemma

Despite receiving education on the importance of skin care, lymphoedema practitioners at the clinic observed that many patients attending the clinic do not maintain appropriate skin care continually.

This study aims to investigate the barriers that patients perceived, prevent them from achieving optimal skin care. This project utilised the qualitative rich detail of patients' own experiences and issues with skin care to explore if the skin care expectation described above was acceptable and achievable for them. This may assist health care practitioners providing skin care education in tailoring programmes appropriately.

Objectives

The objectives underlining the research question were:

- To determine what information the person with lymphoedema has been given regarding optimal skin care.
- To identify any physical, psychosocial and/or financial factors which affect the person with lymphoedema being able to maintain an optimal skin care regime as directed by the clinic.
- To explore if other factors influence an individual's decision making about skin care, such as contradictory advice from other sources.
- To investigate if patients feel the expectation of skin care as provided in the education programme is achievable for them.

Significance of the study approach

Interviews with open-ended questions were selected to explore these objectives for several reasons. To explore in detail the participants' attitude towards skin care, it was felt an interview would best give participants the opportunity to use their own words and tell their story of living with a chronic health condition needing daily input. This style of interviewing has been characterised as a means to uncover knowledge related to the respondents' lived experience through rich detail and the context which shaped the experience. It suggests the shared intimacy between interviewer and respondent reveals information not discussed in a questionnaire by illustrating an experience rather than deciphering it⁶.

The advantages of a semi-structured interview included personalising the study to allow for flexible probing of information, allowing spontaneity to the interviewee yet

controlling the topic by the interviewer⁷. It was hoped in this study that interviewing would allow the opportunity for the person involved to talk freely, providing for a full range of responses. The interviewer aimed at setting aside ideas, thoughts and preconceptions about the topic and letting the participant guide the researcher.

Methodology

Participant selection

Participants were randomly identified from their normal booked review appointment.

Inclusion criteria

Participants were eligible to participate if they had an established diagnosis of lymphoedema and attended the clinic for care. Participants were over the age of 18 years and able to understand and provide informed consent. They were English-speaking only.

Exclusion criteria

Participants were ineligible to participate if they did not meet the above criteria or if they attended the clinic campus the researcher works at. The aim here was to minimise a conflict of interest or coercion by the researcher as participants at the alternative campus were unknown to the researcher.

Results

Eight volunteers participated in the research, comprising three men and five women. Both primary and secondary lymphoedema patients were represented. Secondary causes included cancer, venous insufficiency and obesity. Themes arising from the interviews were sorted according to the aims and objectives of the study and are presented in Table 2.

Table 2. Nominated themes.

- | |
|-----------------------------------------------------------------|
| 1. Response to information given about skin care |
| · Anxiety |
| · Obligation |
| · Poor understanding |
| 2. Factors affecting the person's ability to maintain skin care |
| · Physical limitations |
| · Expense |
| · Motivation issues and social isolation |
| 3. Other factors influencing decision making about skin care |
| · Nowhere else to gain support |
| 4. Investigating expectation as achievable for participants. |

1. Determining information the participant with lymphoedema has been given regarding skin care and their response to the information.

In response to the questions about what participants learnt about skin care at the clinic the most frequent response participants emphasised, when asked what skin care they achieve was the need to moisturise daily and minimise trauma. Only one of the four participants with leg lymphoedema was able to achieve all of the skin care principles (skin hygiene, moisturising, minimising trauma and specific foot care) on a daily basis. In this study, those with arm lymphoedema (three) appear to indicate both better understanding of the principles and application of these on a daily basis. This data suggests those with upper limb lymphoedema are more successful at applying skin care to their daily regimes. Responses are collated under the following themes

Being constantly anxious and aware of risks

A frequent response from participants was a persistent feeling that they had to be aware of the potential risks of injuring the area of their body with lymphoedema and the subsequent opportunity for this to develop into an AIE. Phrases often repeated included:

"I've learnt to be very careful about insect bites, scratches ..."

"You've just got to be aware ..." (Participant 2)

"I'm wary ..." "... if you're going flat chat and you get a scratch or cut and you think that could lead to cellulitis." (Participant 4)

"I'm paranoid about injuring my skin." (Participant 8)

Anxiety and fear about the potential for injury seemed to be a strong motivator for achieving skin care, with each participant describing a sense of caution in their daily actions.

Incorporating skin care into a routine

A number of participants suggested they had learnt from the clinic that their skin care should become part of a routine to become successful. Consequently they had adopted changes as a duty.

"I considered what I heard was important and necessary if I was going to live, I hoped without chronic lymphoedema. I guess it's just like putting on makeup and I do it every morning ... I've just adopted it as part of my routine. I want to give myself the best chance, I guess." (Participant 3)

"... it is most necessary. It is very important. You sought of get into a regime. It's just memorising and obligation ... it's just

a sense of duty and responsibility that you have to instil into yourself.” (Participant 4)

Poor understanding

Several participants, when discussing the skin care principles taught at the clinic, appeared to lack the ability to link the symptoms of lymphoedema with their cause. Statements supporting this included,

“I assume it is this pressure (from the hosiery) which creates the rough skin.” (Participant 1)

“My skin has become so dry, and I don’t know if it has anything to do with lymphoedema.” (Participant 4)

“Feeling the scaly crap on the inside of my left leg is not very pleasant. It has to be from wearing these stockings ...” (Participant 8)

Participants' interpretation of the information might support the notion they often learnt the act of prescribed skin care but not necessarily were aware of the reasons for its value.

2. Identifying the physical, psychosocial and/or financial factors which affect the person with lymphoedema being able to maintain an optimal skin care regime as directed by the clinic.

Six participants identified the guidelines for the skin care as being easy or easy most of the time while two, both with leg oedema, found it difficult most of the time to complete. Interestingly though, the physical, psychosocial and financial issues identified here were not limited to those two individuals.

Physical constraints

For some participants, physical limitations prevented their ability to meet skin care. In particular, those with leg lymphoedema and comorbidities, including hand and back injuries, found their ability to achieve skin care was hampered. No participant with upper limb lymphoedema identified a problem with achieving skin care due to physical limitations.

“I have bung hands and there are just some days you just can’t get your hands around your own legs. Yes, it’s difficult to get down to the feet. Especially ... where there are a lot of bubbles from the cellulitis. I find it very hard, so I do what I can.” (Participant 5)

“I have trouble reaching down to my toes. If I’m trying to do it sitting down it’s awkward.” (Participant 6)

“As I said, I have a back injury, and with this it is hard to get down. Very difficult with my crook back and knee. Doing the skin care involves pain to other areas, my knee and back.” (Participant 8)

Two participants noted that while they could currently achieve their skin care, they were aware physical limitations might be an issue for themselves in the future.

Financial burden

The cost of purchasing specialised products to achieve skin care as prescribed during education was a common theme noted by some participants which might impact on their ability to maintain optimal skin care.

“I will tell you upfront, I can’t afford it. It will get prioritised with whatever else I need to get. So I might go a few months without it before I can afford it again. The cost is a problem if you’re a pensioner.” (Participant 5)

The inability to meet the cost of skin care products can also have a negative impact on actual usage. One participant reported she used the more expensive, richer product on her torso where she suffered dermatitis but confined a lesser quality moisturiser to the regions with lymphoedema on her legs. She felt she had to prioritise her choices based on the price.

Motivation and isolation

Most participants expressed high levels of motivation about achieving skin care. Although not commonly reported by participants, socially isolated participants identified a lack of motivation to continue daily care.

“... even though I’m aware that I have to look after the skin, a lot of mine is depending on how I’m feeling on the day. At the moment that’s not good but it’s what I have to go with. On bad days you think about it and then think I can’t be stuffed. If you’re on your own you don’t have anyone to help.” (Participant 5)

3. Exploring if other factors influence an individual’s decision making about skin care, such as contradictory advice from other sources.

All participants reported the lymphoedema clinic was their main source of information about skin care. Two stated the information was reinforced by a dermatologist and general practitioner. None mentioned they received contradictory advice. While exploring this category, a common theme recurred in some responses. Some participants expressed a general lack of understanding or discussion about lymphoedema in both their exposure to health care providers

and general community discussion. This may help to explain why participants identified the lymphoedema clinic as the sole provider of education and support. For example, one participant lamented she had many established sources for support whilst undergoing her cancer treatment but felt isolated when it came to lymphoedema support:

"Education here was good, really good. I think they do a great job. I don't know where else you would go. We are let down on the lymphoedema side of things. They could recognise there is such a complaint (lymphoedema) and people need help ... You get sick of seeing all this information about breast cancer, this and that, but nothing about what else we get because of it. Where is that blown up?" (Participant 4)

She felt angered at the disproportionate public and media attention given to breast cancer, while ignoring the consequences of lymphoedema.

4. Investigating if patients feel the expectation of skin care as provided in the education programme is achievable for them.

Each participant reported receiving education at the clinic and correctly identified the method of information dissemination. They reported the information was given over two weeks by a lymphoedema practitioner and social worker by means of verbal discussion, visual presentation with PowerPoint, video, written handouts and skin care samples. Each identified skin care as part of this programme. All answered they found it easy to understand. Only one participant stated they would attend an update if offered.

Understanding and feeling one can achieve guidelines is not the same thing. As discussed earlier, most participants found it easy to follow the guidelines and, therefore, one could interpret this as finding the programme achievable. As already emphasised, this particular group of participants indicated a strong sense of duty and commitment to achieve their skin care. The responses given by some do represent difficulty with financial burden, physical disability to achieve skin care and motivation to meet the skin care requirements. This raises doubt in the ability of some to meet the expectation even if they report it as easy to achieve. Further exploration of this theme with a larger group of lymphoedema patients may help to underline this concept.

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WC 126-02-11

Limitations

This study reported weaknesses. The small participant group suggested that the results will not be generalisable to a wider population. Selection bias is possible. Participant responses may have been influenced by face-to-face interviewing and answers reflecting what the participants believed the researcher wanted to hear.

Economic and educational backgrounds were not explored and may have been influencing factors. Despite these limitations, a varied demographic regarding age, gender, classification and cause of lymphoedema were represented in this study.

Future directions

The data generated from the interviews highlighted a number of themes, some of which deserve further investigation. In particular, the impact of client experiences incorporating each individual component of complex decongestive therapy into their daily lives as part of self-caring with a chronic health condition supports individual attention to these facets. Skin care, compression garments, exercise and manual lymphatic drainage need to be studied independently of the effect of their impact as a whole. Clients may be able to incorporate some aspects easier than others. Past experience, skill and ability no doubt influence one's response to each component of care, but little is known about wider societal and cultural impacts. The literature review is not included in this article, but it was noted from appraising the literature that research with this focus has not occurred in the past. The literature review also found gender differences, in response to self-management of lymphoedema, have had little research attention. One male participant in this study stated why he doesn't regularly achieve skin care. He remarked:

"Now that works for women because they are more conscious about that kind of thing. As far as I'm concerned my skin is for keeping my insides in." (Participant 8)

It could well be that the gender differences between achieving skin care impact significantly for the sexes. Indeed the remaining three components of CDT: hosiery, exercise and MLD are highly likely to have compelling influences based on gender differences. Men may consider wearing stockings and doing massage as 'women's domain'. This area of lymphoedema research warrants further exploration.

Conclusion

This study proposed to investigate the patient-perceived barriers that appear to prevent them from continuing optimal

skin care in the management of the condition lymphoedema. It used the methodological approach of face-to-face interviews with eight participants attending a lymphoedema clinic in an attempt to best give participants the opportunity to use their own words and tell their story of living with a chronic health condition needing daily input. Exploring transcribed interviews found several factors impacting on client choice and motivation to achieve daily skin care, as prescribed. These included fear of the consequences of not doing skin care and sometimes a poor understanding of the full role of skin care in lymphoedema management. Physical disability, financial burden and motivation to meet daily commitments also impacted on their success. In determining whether patients felt the skin care as prescribed during patient education was achievable for them it was noted that clients found the lymphoedema clinic to be their only source of information and support about lymphoedema. Some felt the medical community and other supports considered lymphoedema education of minor significance. Perhaps an element of dependency on the clinic has occurred if clients feel they have nowhere else to gain information. The ability to self-manage a chronic health condition such as lymphoedema involves individual physical, financial, psychosocial and emotional components. This study has revealed some of these dimensions in relation to skin care. The results of this study suggest that participants were very willing to share their story. Their personal experiences, as interpreted from their responses, have helped to add to the existing body of knowledge regarding the personal experience of living with the daily skin care management for the condition lymphoedema.

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