RESEARCH ARTICLE

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Using the Glasgow Benefit Inventory questionnaire to quantify the health benefits of lymphoedema treatment in patients with head and neck cancer



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Abstract

Background: Lymphoedema is a common side effect after treatment for head and neck cancer. Our treatment protocol involves staging the degree of lymphoedema and then offering treatment comprising skin care, manual lymphatic drainage, simple lymphatic drainage, compression and elastic therapeutic tape. The Glasgow Benefit Inventory is a validated post-interventional questionnaire applicable to otorhinolaryngology interventions which measures changes in health status. The aim of this study was to quantify the health benefits of lymphoedema treatment using the Glasgow Inventory Benefit questionnaire, in patients with a history of treated head and neck cancer.

Methods: Any patient who had undergone treatment with curative intent of a primary head and neck malignancy who had been referred for lymphoedema treatment within a 6 month period was eligible for inclusion. Patients completed a questionnaire after finishing the course of lymphoedema treatment.

Results: A total of 15 patients completed the questionnaire. Ten patients (67%) demonstrated some level of improvement in quality of life, while two (13%) reported no benefit and three (20%) reported negative improvements. The average score for the total Glasgow Benefit Inventory scale was + 7.2. The greatest benefit was demonstrated with the physical benefit subscale (+ 13.1). The average general benefit score was + 9.0.

Conclusions: Lymphoedema treatment involves techniques which can fairly easily be taught to patients to complete at home. In this study, there were mild improvements in patient reported quality of life using the Glasgow Benefit Inventory in the majority of patients. Clinical interest has increased in lymphoedema recently, but there is still limited information about the effectiveness of treatments and future research should look to address these issues

Keywords: Glasgow Benefit Inventory, Head and neck neoplasms, Lymphedema, Quality of life

Background

The morbidity associated with the treatment of head and neck cancer can be significant and most patients will have some side effects during treatment and for several weeks afterwards. Some side effects may become long-term and indeed others may develop months or even years after treatment. Lymphoedema is one of the side effects after treatment and can present with swelling to the neck, particularly in the submental area. It has been estimated that lymphoedema may affect up to 50% of patients treated for head and neck cancer [1, 2]. Risk factors for lymphoedema include the location of the tumour, time since the end of treatment, total dosage

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and days of radiation therapy, radiation status of surgical bed and number of treatment modalities [3].

Lymphoedema results when the lymphatic load exceeds the transport capacity of the lymphatic system and may be primary or secondary [4]. In secondary lymphoedema, there is inadequate drainage of the high protein lymphatic fluid caused by radiotherapy or surgery which may remove lymph nodes entirely or disrupt lymphatic flow. This results in overload of lymphatic fluid within the interstitial tissues which often produces internal and external oedema [5, 6]. This can have both cosmetic and functional consequences, including impairment in communication, swallowing and breathing [7]. It is important also to acknowledge that psychosocial distress is often a major symptom accompanying treatment for head and neck cancers, particularly if lymphoedema develops [6, 8].

Management of head and neck lymphoedema is often based on reasonable clinical judgement as there are a lack of randomised controlled trials producing evidence-based treatments [6]. Therefore, subjective assessment by a lymphoedema practitioner is used to ascertain the degree of oedema, any skin changes, tissue quality and range of movement of the cervical spine [9]. The subjective staging of the oedema can be based on staging systems such as those devised by Foldi [10] and the International Society of Lymphology [11], although it is acknowledged that these all have limitations when used to categorise lymphoedema. In recent years, the aim is to encourage self-care of lymphoedema which is key to successful maintenance and management of this chronic condition [9, 12].

In our department, as part of the routine care following head and neck cancer treatment, patients who have developed lymphoedema and who would like to consider treatment are offered referral to a lymphoedema team based at the local hospice. The hospice lymphoedema service protocol for treatment of patients with head and neck cancer related lymphoedema advises that on initial assessment the treatment and management plan is differentiated into two pathways depending on the severity of the oedema [Additional file 1]. For patients with mild/moderate oedema a programme which encourages self-management at home is taught at the initial appointment; this involves skin care, exercise, compression/taping and simple lymphatic drainage (SLD). For more severe oedema, manual lymphatic drainage (MLD) is offered as a course over several appointments.

 MLD – The roots of MLD may be credited partly to Danish massage therapist Emil Vodder who developed the techniques for chronic sinusitis in the 1930s [13, 14]. It was first used for the treatment of lymphoedema by Vodder in 1965 [15]. There are now several schools of MLD based on the principles of the Vodder techniques with recent knowledge of the mechanism of the lymphatic system producing an alternative form of MLD known as fluoroscopy guided MLD (FG-MLD or 'fill and flush' technique). The hand movements of FG-MLD on the skin assist in the movement of interstitial fluid through the tissue and the filling of the superficial lymphatics [16]. A deep oscillating machine can also be used to enhance the effect of the massage. Deep oscillating therapy works by using low frequency, electrostatic impulses which produces a tissue-relaxing and moderate vasoconstriction effect, which favours reabsorption of localised oedema and reduced fibrosis [17, 18]. This is particularly useful in areas harder to massage such as the head and neck.

Although the hospice protocol for mild/moderate oedema does not indicate that MLD is an element necessary for successful treatment, it is often used when the patient experiences substantial symptoms of psychological distress resulting in poor quality of life [5]. Nixon et al. found that having time with a health care professional during treatment for head and neck lymphoedema was reassuring and aided adjustment to a new normal following treatment [8].

- SLD This is a simplified version of MLD which patients can be taught for self-management at home. Traditionally, it is recommended that the swollen area itself is not massaged during SLD, as only a trained lymphoedema practitioner may be able to exert the correct pressure to encourage movement of the lymph fluid [19]. However, SLD is now rarely used in the traditional manner [20], and head and neck cancer patients can be taught to massage the oedematous area often with good effect.
- Compression This is traditionally one of the corner stones of treatment for lymphoedema [20]. Although compression garments are often thought not to be as useful in head and neck oedema as they are for oedema of a limb [6] the hospice clinic has found that wearing adapted compression is tolerated well and many patients find it a useful addition in the management of the condition.
- Elastic therapeutic tape (kinesiology tape) This
 may be used in areas of the body where it is difficult
 to apply compression hosiery or bandages. Care
 needs to be taken as the skin is vulnerable to tissue
 damage. Cancer patients using elastic therapeutic
 tape may have less pronounced symptoms of
 lymphoedema, although it must be used with
 caution [21].
- **Skin care** It is important that the healthcare professional encourages the patient to examine and care for their skin daily [22]. Skin care maintains

skin integrity and helps prevent infection; it is extremely important as part of a treatment plan for all patients with lymphoedema [23, 24].

The Glasgow Benefit Inventory is a validated post-interventional questionnaire applicable to otorhinolaryngology procedures which measures changes in health status. It was first described by Robinson et al. in 1996 and consists of a questionnaire of 18 questions each based on a five-point Likert scale (scored one to five) [25]. The 18 questions address health related aspects of general, social and physical health. The Glasgow Benefit Inventory scores range from – 100 to + 100, with a score of zero indicating no benefit and a score of + 100 indicating maximum benefit.

The aim of this study was to quantify the health benefits of lymphoedema treatment using the Glasgow Inventory Benefit questionnaire, in patients with a history of treated head and neck cancer.

Methods

This was a prospective study where patients were recruited from the head and neck oncology follow-up clinic. Any patient who had undergone treatment with curative intent of a primary head and neck malignancy who had been referred for lymphoedema treatment was eligible for inclusion. Patients were referred for lymphoedema treatment at one of their routine follow-up appointments if it was felt by the clinician and patient together during the consultation that the intervention may be helpful.

The lymphoedema treatment plan for each patient was devised as per our hospice lymphoedema service protocol [Additional file 1] depending on the severity of the oedema [9-11]. For mild/moderate oedema, the first appointment typically involved information provision, skin care advice, exercises, compression and SLD. A second visit at 4 weeks was offered to revisit skin care and SLD. A compression garment or tape was provided if necessary. A third visit after a further 3 months was offered if the patient was not self-managing their oedema, with further appointments every 6 months with the aim to discharge after 2 years. For patients with more severe oedema, or those with mild/moderate oedema but substantial symptoms of psychological distress resulting in poor quality of life, the treatment plan was altered to include a course of MLD over four to six visits.

All patients who returned for a subsequent follow-up appointment in the head & neck clinic after receiving the course of lymphoedema treatment were invited to take part in the study and provided with a questionnaire to complete at the end of the clinic consultation. Patients were recruited between September 2018 and February 2019 (inclusive). Completion of the questionnaire

was optional and did not change any subsequent clinical care that they received. Furthermore, referral for lymphoedema treatment was not made on the basis that the patient would subsequently take part in a questionnaire after the intervention.

The total score from all 18 questions on the Glasgow Benefit Inventory questionnaire was calculated and then averaged to give equal weight to each question. Three (i.e. the score associated with no change) was subtracted from the total and the result multiplied by 50 to produce a benefit score for the patient ranging from – 100 to + 100. Scores for three subscales were also calculated as follows: 12 questions relating to general factors, three questions relating to social support issues, and three questions concerning physical health.

Results

A total of 15 patients, aged between 51 to 78 years, with a mean age of 64 years, completed the post intervention questionnaire. The patient demographics are displayed in Table 1. One patient did not complete the questionnaire completely and did not provide answers to calculate the physical benefit and social benefits subscales.

Thirteen (87%) of patients were assessed as having mild submental oedema while the remaining two (13%) had moderate oedema.

All 15 (100%) patients were given skin care advice as part of the self-management plan and all were offered compression. Half of the patients (50%) wore the compression garment regularly, particularly during the evening when at home. All patients were taught how to carry out daily SLD. Two (13%) patients were aided by a partner to perform this. Five (33%) patients received FGMLD and four (27%) were taught how to apply elastic therapeutic tape to the submental region.

Ten patients (67%) demonstrated some level of improvement in quality of life with the total score for the Glasgow Benefit Inventory (Table 2, Fig. 1), while two (13%) patients reported no benefit and three (20%) reported negative improvements. The average score for the total Glasgow Benefit Inventory scale was +7.2. The greatest benefit was demonstrated with the physical benefit subscale, where the average score was +13.1. The average general benefit score was +9.0.

Discussion

Lymphoedema is a potentially common effect after treatment for head and neck cancer, where surgery and/or radiotherapy can disrupt the normal lymphatic flow. The incidence can vary between 12 and 54% yet the condition remains under-recognised and under-treated [26]. It can be associated with functional deterioration and poor quality of life [5, 27]. Clinical interest in lymphoedema in head and neck cancer has increased in the last decade

Table 1 Patient demographics and lymphoedema treatment provided

Characteristic	Patients (n (%))	
Sex		
Male	12 (80)	
Female	3 (20)	
Site of pathology		
Oropharynx	10 (67)	
Unknown primary	2 (13)	
Hypopharynx	1 (7)	
Larynx	1 (7)	
Submandibular gland	1 (7)	
Cancer treatment		
Chemoradiotherapy	5 (33)	
Chemoradiotherapy & surgery	4 (27)	
Radiotherapy	3 (20)	
Radiotherapy & surgery	3 (20)	
Disease status during lymphoedema treatment		
Disease free	14 (93)	
Active disease	1 (7)	
Site of oedema		
Submental	14 (93)	
Submental & cheek	1 (7)	
Severity of oedema		
Mild	13 (87)	
Moderate	2 (13)	
Treatment provided		
Skin care	15 (100)	
Exercise	15 (100)	
Compression	15 (100)	
Simple lymphatic drainage	13 (87)	
Simple lymphatic drainage by carer	2 (13)	
Manual lymphatic drainage with oscillator	5 (33)	
Elastic therapeutic tape	4 (27)	
Literature	15 (100)	

and recent reviews have attempted to examine the evidence and management of the condition, but there is still limited information about the evaluation and effectiveness of treatments [26, 28].

Lymphoedema associated with head and neck cancer appears to be a distinct entity from lymphoedema in other sites and therefore requires a specific regimen of therapy particularly targeted towards head and neck patients [29]. Possible treatments may include physiotherapy, or a form of MLD. This can be combined with other modalities including tissue compression, remedial exercises and skin

care [29]. MLD is relatively straightforward to teach and is not associated with any significant side effects. Other treatments may involve selenium, liposuction and lymphaticovenular anastomosis and while there are some studies suggesting these treatments are effective in a small number of patients, there are limited large randomised controlled trials [28].

A recent systematic review evaluated all established treatment modalities for lymphoedema associated with head and neck cancer [28]. Twenty-six articles were included in the review, totalling 1018 study subjects. The review concluded that there was limited evidence for the efficacy for all types of lymphoedema therapy. MLD was the most studied therapy, although liposuction and surgical treatments may also be effective in some patients.

There is no standardised way to grade the severity of lymphoedema or to quantify improvement after treatment. One group in the USA describe a number of different measurements to create a neck and facial composite score and lymphoedema rating scale which can be used to measure the degree of lymphoedema [29]. In this study, we describe using the Glasgow Benefit Inventory, a validated post-interventional questionnaire, to measure patient reported outcomes in relation to health status after treatment for lymphoedema. The Glasgow Benefit Inventory has become popular to use as a generic patient-recorded outcome measure in outcomes after intervention in otorhinolaryngology conditions.

In this current study, the average total Glasgow Benefit Inventory was positive (+7.2) suggesting an improvement in quality of life following lymphoedema treatment as reported by the patients. The general benefit (+9.0) and physical benefit (+13.1) subscales also demonstrated positive average scores. A recent review examined the reporting of Glasgow Benefit Inventory outcomes for different interventions and objectives [30]. The average levels of improvement reported in other studies is higher than in the current study, but this may reflect a discrete one-off intervention (for example cochlear implant) rather than a longer treatment regimen which requires ongoing compliance from the patient.

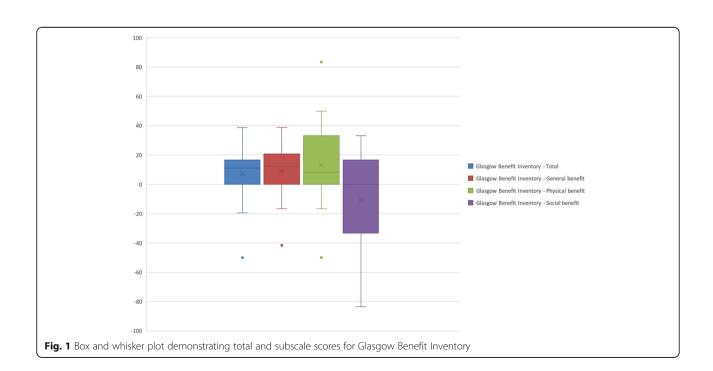
Unfortunately, not every patient reported improvement in their symptoms and indeed the social benefit subscale was negative. However, this does parallel other studies. In one large study of 1202 patients, 733 were evaluated for response to lymphoedema therapy and while 60% did show improvement in their symptoms after treatment, 40% did not [29].

The intervention described in this study involved patient education to teach self-care activities to help improve lymphoedema. Patients have previously expressed positive comments about lymphoedema self-care yet this requires patients to be motivated and compliant [31]. Those who are compliant with recommended treatment

Table 2 Outcomes from lymphoedema treatment using the Glasgow Benefit Inventory scores

Patient	Glasgow Benefit Inventory total score	Glasgow Benefit Inventory general benefit score	Glasgow Benefit Inventory physical benefit score	Glasgow Benefit Inventory social benefit score
Patient 1	-50.0	-41.7	-50.0	-83.3
Patient 2	-19.4	-16.7	-16.7	-33.3
Patient 3	0.0	0.0	0.0	0.0
Patient 4	+ 5.6	+ 4.2	0.0	+ 16.7
Patient 5	0.0	0.0	0.0	0.0
Patient 6	+ 16.7	+ 12.5	+ 33.3	+ 16.7
Patient 7	+ 13.9	+ 12.5	+ 50.0	-16.7
Patient 8	-2.8	0.0	+ 16.7	-33.3
Patient 9	+ 11.1	+ 20.8	+ 16.7	-33.3
Patient 10	+8.3	+ 12.5	0.0	0.0
Patient 11	+ 16.7	+ 20.8	+83.3	- 66.7
Patient 12	+ 25.0	+ 25.0	+ 16.7	+ 33.3
Patient 13	+ 13.9	+ 16.7	0.0	+ 16.7
Patient 14	+ 30.6	+ 29.2	+ 33.3	+ 33.3
Patient 15 ^a	+ 38.9	+ 38.9	=	=
Average	+ 7.2	+ 9.0	+ 13.1	-10.7

a This patient did not complete the questionnaire completely and has been excluded from calculation of the physical benefit and social benefit subscale scores



regimens have significantly better rates of improvement than those who are non-compliant [4]. However, even in those patients who are only partially compliant with treatment there may still be a demonstrable improvement in their symptoms [29]. Since the technique can fairly easily be taught to patients and most can complete the exercises at home without side effects or complications, it is something which should be offered to patients as they may derive some benefit from the treatment if they are motivated.

Conclusions

Lymphoedema is a common side effect after treatment for head and neck cancer. Treatment may involve various forms of compression, exercise, skin care and lymphatic massage which can be coordinated by a qualified lymphoedema practitioner. In this study, there were mild improvements in patient reported quality of life using the Glasgow Benefit Inventory in the majority of patients. Patient self-care is an important aspect of lymphoedema treatment but requires patient motivation. Lymphoedema associated with head and neck cancer is likely a distinct entity from lymphoedema in other sites and while clinical interest in the condition has increased recently, there is still limited information about the effectiveness of treatments and future research should look to address these issues.

Supplementary information

Supplementary information accompanies this paper at https://doi.org/10. 1186/s41241-020-00093-y.

Additional file 1.

Abbreviations

FG-MLD: Fluoroscopy guided manual lymphatic drainage; MLD: Manual lymphatic drainage; SLD: Simple lymphatic drainage

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Authors' contributions

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by EH and SFA. The first draft of the manuscript was written by EH with significant contributions from JG. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

The data used as part of this current study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

Ethical approval was not required for this questionnaire as it was completed after treatment and did not affect the care received by any of the patients.

Nevertheless, the questionnaire was provided to participants in accordance with the ethical standards of our institution and with the 1964 Helsinki declaration and its later amendments.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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