

A qualitative analysis of an evidence-based lymphoedema booklet for melanoma patients

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Aims: Develop and evaluate an evidence-based resource booklet for lymphedema in melanoma survivors. **Methods:** Melanoma patients and healthcare professionals were surveyed between January and April 2013. Booklet structure and content, and familiarity with lymphedema topics pre- and post-booklet reading were assessed. All questionnaires were evaluated using aggregate descriptive statistics for quantitative data and thematic data analysis for qualitative data. **Results:** Patient interviews revealed dissatisfaction with lymphedema management and a strong desire for informational resources. Knowledge of lymphedema improved modestly after booklet reading. Patients provided strong positive feedback on the content and structure of the booklet (9.4/10), with all categories scoring above 9. Surveyed professionals reported a high degree of familiarity with lymphedema topics (9.2/10), and a majority were likely to recommend the booklet to newly diagnosed melanoma patients. **Conclusions:** Preliminary evaluation of our evidence-based resource booklet generated positive feedback and suggests it has utility for improving patient education and management of lymphedema.

Melanoma is the seventh most commonly diagnosed cancer in Canada and its incidence rate is projected to increase over the next 15 years (Guy et al, 2015; Canadian Partnership Against Cancer, 2010). Sentinel lymph node biopsy (SLNB) is a minimally invasive procedure commonly used in identifying lymph node metastasis, staging and prognosticating melanoma (Tanis et al, 2001). Although a SLNB is associated with significantly less morbidity than a complete lymph node dissection, the procedure still presents with complications up to 4.6% of the time (Chao et al, 2003).

A notable complication is lymphoedema, a chronic and progressive condition where regional buildup of protein-rich lymph fluid can lead to severe swelling and subsequent increased risk for infections, disfigurement and pain in the affected area (Warren et al, 2007). In the case of an extensive lymph node dissection, the swelling may affect an entire limb (Rockson and Rivera, 2008).

Lymphoedema represents one of the most significant survivorship issues after surgery in

melanoma patients due to its palliative, rather than curative, management and its potential to significantly impair the activities of daily living (Towers et al, 2008; International Society of Lymphology, 2013). Melanoma patients experiencing lymphoedema are also more likely to suffer from depression, anxiety and poor psychological adjustment (Mcwayne and Heiney, 2005; Morgan et al, 2005). Moreover, they are at increased risk of acquiring infections requiring admission to hospitals for IV antibiotics (Moffatt et al, 2003).

There is currently a paucity of melanoma patient-directed information about lymphoedema. Surveys of survivors found that almost half would prefer more education about the long-term effects of melanoma, including lymphoedema (Palesh et al, 2014).

Among health professionals, the topic of lymphoedema can also be poorly understood, with experts acknowledging that many patients fail to receive timely diagnosis, adequate treatment, or risk reduction education (Hodgson et al, 2011). Lymphoedema patients who receive limited information about their condition often

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Table 1. Patient group baseline demographics and clinical characteristics

Variable	Value, n=5
Mean age, years	51.4 ± 15.8
Gender, no. (%)	
Male	1 (20%)
Female	4 (80%)
Ethnicity, no. (%)	
White	5 (100%)
Language, no. (%)	
English	5 (100%)
Mean annual income, \$CAD	50,400 ±
Mean time since melanoma diagnosis, years	21,200
Stage and grade of melanoma included	6.6 ± 3.5
Lymphoedema symptoms, no. (%)	2a, 3a, 3b, 5 (100%)

Mean ± standard deviation

experience significant psychological distress as a result (Towers et al, 2008). Early identification and treatment can play an essential role in limiting irreversible intradermal fibrosis and minimising the chronic complications of lymphoedema and should, therefore, be a focus of management (Shah et al, 2016).

It is well documented that print resources can help patients manage chronic diseases by strengthening key educational messages (Udermann et al, 2004; King et al, 2007; Farris, 2012). Empirically, we note that before this pilot study, there were no complete informational materials on lymphoedema for melanoma patients available in Canadian hospitals, clinics or charitable organisations. As such, the authors aimed to create and evaluate an evidence-based patient booklet that it was hoped would fulfill what they see as an unaddressed gap in melanoma patient education and management of lymphoedema.

Methods

Ethics approval was obtained from the University of Toronto Research Ethics Board on January 15, 2013. Data were collected between January 2013 and April 2013. Patients were informed that there were no direct risks or benefits of participating and that their choice would not affect their future care. Participants were deidentified and assigned a surrogate number for confidentiality purposes. The study population consisted of two groups: a patient group with five newly diagnosed melanoma patients with active lymphoedema referred by the Melanoma Network of Canada, and a professional group consisting of five

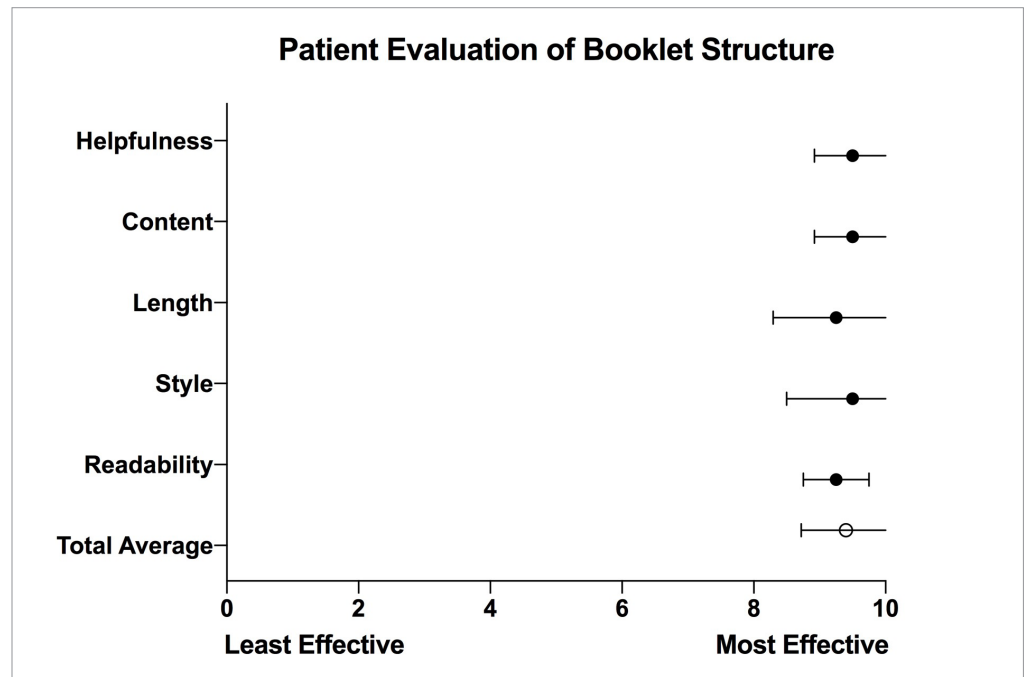
health professionals with melanoma-specific training (a registered nurse, physiotherapist, massage therapist, medical oncologist and a dermatologist).

All questionnaires were structured using a 10-point Likert scale. Those in the patient group were initially asked to complete a self-evaluation of their lymphoedema knowledge by ranking their comfort with major topics. Gaps in patient education and recommendations for healthcare resources were elicited through structured interviews of patients conducted by A.L. that were audiotaped and transcribed. Patient interviews were analysed using the grounded theory method, which is effective at extracting common themes from large pools of data and condensing data into categories (Starks et al, 2007).

A systematic search was then conducted for published evidence on lymphoedema management. Inclusion criteria included publications in English within the last 10 years and research done in humans. Medline was searched using the following keywords: lymphoedema, melanoma, treatment and self-care. Relevant articles were reviewed by A.L. for information pertinent to patient concerns under the general themes of lymphoedema causes, development, signs and symptoms, management, complications, emotional aspects, risk factors and prevention. Evidence statements from the review were assembled into a lymphoedema resource booklet and reiterative drafts refined its content and readability. A copy of the final resource booklet is available from the authors upon request.

A follow-up questionnaire was administered

Figure 1. Patient evaluation of booklet content and structure (n=4). Error bars represent \pm SD



to the patient group 4 weeks after their initial recruitment and immediately after having read the final version of our prepared booklet, asking them to rank their understanding of the same topics. Patients were also asked to rank the booklet on its perceived readability, style, length, content and helpfulness. Professionals were given a separate questionnaire asking them to rank their own knowledge of lymphoedema and the comprehensiveness of knowledge covered in the booklet. They were also asked how likely they are to recommend the booklet to a melanoma patient with lymphoedema. A copy of each questionnaire is available from the authors upon

request. Because this is a pilot study and these measurement tools are newly created, they contain preliminary content validity and have not yet been tested for reliability.

All quantitative data was analysed using Prism 8.1.0 (Graphpad Software, Inc., La Jolla, CA, US).

Results

Patient demographics

Demographics and clinical characteristics of the patient group are summarised in *Table 1*. Four patients were female, and one was male. All five patients were Caucasian and spoke English. The group had a mean annual income of CA\$50,400.

Table 2. Mean values (standard deviation) for patient knowledge of lymphoedema by topic before and after reading booklet

	Before (n=5)	After (n=4)
Causes	7.6 (2.3)	8.5 (1.0)
Development	7.4 (2.2)	9.0 (0.8)
Signs and symptoms	8.2 (1.1)	9.0 (0.8)
Management options	7.6 (1.5)	8.8 (1.5)
Self-care	8.0 (1.4)	8.8 (1.5)
Complications	6.2 (2.5)	8.8 (1.0)
Emotional aspects	7.2 (2.6)	8.0 (1.4)
Prevention	6.4 (3.0)	8.5 (1.0)
Risk factors	6.4 (2.4)	7.5 (2.5)
Management costs	6.6 (2.7)	8.2 (1.3)
Total average	7.2 (2.2)	8.5 (1.3)

Mean \pm standard deviation Differences between mean scores were tested by two-sided unpaired t-test but no statistical significance was found for any topic

Table 3. Mean values (SD) for professional knowledge of lymphoedema and booklet accuracy as evaluated by professionals

	Professionals (n=4)	Booklet (n=4)
Causes	9.3 (0.5)	7.3 (2.5)
Development	9.3 (0.5)	6.8 (2.0)
Signs and symptoms	9.3 (0.5)	6.0 (1.7)
Management options	9.3 (0.5)	5.8 (1.3)
Self-care	9.3 (0.5)	6.0 (1.7)
Complications	9.0 (0.8)	6.0 (1.3)
Emotional aspects	8.8 (0.5)	6.3 (3.7)
Prevention	9.3 (0.5)	6.5 (2.1)
Risk factors	9.5 (0.6)	8.5 (1.3)
Management costs	9.3 (0.5)	6.3 (3.8)
Total average	9.2 (0.5)	6.5 (2.1)

The mean time since melanoma diagnosis 6.6 years, and melanoma grades included stage 2a, 3a, and 3b. All patients reported experiencing lymphoedema symptoms.

Patient interviews

When interviewed, patients reported having a good general understanding of lymphoedema, but emphasised that most of what they had learned was through self-education. Patients uniformly expressed that their healthcare team did not handle their education appropriately, citing a lack of acknowledgement of their lymphoedema and misinformation about management as key concerns. A majority of patients also highlighted their frustration at a perceived lack of pertinent and regulated information and how the existing resources are often tailored specifically for breast cancer survivors and upper-limb lymphoedema that may not always translate well for melanoma survivors. When asked about the development of an evidence-based resource booklet about lymphoedema management from a melanoma patient perspective, patients unanimously approved of the idea and preferred a concise booklet composed of both illustrations and words in paragraph and bullet point form. Most of the patients recommended that the booklet be available electronically for convenience and in paper form to cater towards older people, who comprise most of the lymphoedema population.

Patient evaluation of booklet and lymphoedema knowledge

The results from the patient questionnaires are given as means and standard deviations (SD) summarised in *Table 2*. There was a strong preexisting knowledge of lymphoedema before

reading the resource booklet, with a total average knowledge score of 7.2 on a 10-point scale (10 indicating most comfortable with the content). The data revealed no statistically significant increase in knowledge scores but trended towards improvement after reading in all topics. Topics that patients were notably less comfortable with before reading the booklet include Complications, Prevention, Risk Factors, and Management Costs. The average patient rating of booklet content and structure was 9.4/10 (with 10 indicating the strongest approval), and all categories scored above 9 (*Figure 1*).

Professional evaluation of booklet and lymphoedema knowledge

The total average knowledge score reported by professionals was 9.2, with Emotional Aspects being the only topic that scored below a 9. Professional evaluation of booklet information showed a wide variance in scoring, with Risk Factors scoring the best (8.5), followed by Causes (7.3) and Development (6.8). The lowest scored items were Management Options (5.8), Signs and Symptoms (6.0), Self-Care (6.0), and Complications (6.0). The Booklet content was scored significantly lower compared to professional knowledge in Prevention, Complications, Self-Care, Management Options, and Signs and Symptoms. An overview of these statistics is provided in *Table 3*. A total average booklet score of 6.5 was given and a majority of professionals were likely to recommend the booklet to a melanoma patient with lymphoedema.

Discussion

Interviewing melanoma survivors with lymphoedema illustrated several notable

themes. First, we observed that the negative impact of lymphoedema on quality of life was made worse by the perception that health professionals did not fully acknowledge their lymphoedema concerns. The literature reports that a majority of primary care physicians are not comfortable monitoring lymphoedema independently and that many healthcare professionals feel they had not received adequate training about the condition (Van Londen et al, 2017). Part of the problem lies with the debate surrounding almost everything associated with lymphoedema, including its definition, measurement and treatment course. To present day, the medical community has yet to accept a standardised measurement technique for lymphoedema and the paradigm of best management practices are continuously shifting (McLaughlin, 2019). The recent emphasis on early detection over reactionary intervention and the rapidly evolving nature of lymphoedema care might account for any prior medical oversight presented in patient experiences.

Second, patient attempts to self-educate were frustrated by resources that lacked consistency and were targeted predominately for breast cancer patients. The incidence rates and distribution of secondary lymphoedema vary depending on the type of cancer (Voss et al, 2015). Lymphoedema resources for breast cancer survivors focus exclusively on upper limb lymphoedema and, consequently, fail to address the lower limb lymphoedema commonly seen with melanoma. Lower limb lymphoedema is more likely to present with swelling, heaviness, tightness, and skin concerns, which do not lend themselves well to strength training interventions commonly used for upper limb lymphoedema (Katz et al, 2010; Langebecker et al, 2008). Where the two share principles for management, lower limb lymphoedema patients may still have difficulty translating concepts into specific practice and might benefit from detailed instruction. Patients with lower limb lymphoedema are also more likely to have progressed to a chronic stage before consulting a health professional, perhaps because they have fewer resources designed with their illness in mind (Tran et al, 2017). Among the patients interviewed who were distressed by the limited availability of information, 80% were experiencing lower-limb lymphoedema.

The authors' evidence-based resource booklet appeared to modestly improve patient understanding of lymphoedema topics.

Although the differences in knowledge scores before and after reading the booklet never reached statistical significance, the lower than expected magnitude of the shift might be attributed to the relatively long mean time since diagnosis of our patient population (6.6 years). Patients who have already had several years to gather their own information about the disease might not learn as much from our booklet. When examined in a population of newly-diagnosed melanoma patients, the availability of this resource booklet would be expected to provide a greater benefit. Patients also rated the booklet very strongly on its readability and style. This deserves special consideration because most online lymphoedema resources have been shown to be above the recommended level of complexity for the average adult (Tran et al, 2017). Efforts made to ensure that materials are considerate of the patient's knowledge level will improve their effectiveness.

Professional feedback on the accuracy of information in the booklet was encouraging and a majority were likely to recommend the booklet as a resource to newly diagnosed melanoma patients. Although the scores for the booklet's accuracy were positive, they showed a wide range and were marked lower than professional knowledge without exception. This could be due to the fact that content was simplified for comprehension by the patient and might be missing details that are of consideration for professionals in their reading. Professionals uniformly reported strong familiarity with lymphoedema topics, in contrast to previous studies that demonstrated otherwise, a difference that could reflect the changes taking place in the narrative surrounding post-operative cancer care and its growing focus on lymphoedema (Palesh et al, 2014).

Limitations

Limitations of our study include the size and diversity of our sample. The predominately white and middle-aged status of our patients mirrors the typical patient population for melanoma, but one key distinction was that our patients were mostly female (80%), whereas melanomas can also occur in males (American Cancer Society, 2019). This may affect the type of patient concerns that receive attention in the booklet and future studies should seek to clarify whether these aims are truly representative. Additionally, qualitative feedback from professionals was not recorded and analysed, potentially causing outliers in the surveys that could not be explained.

Conclusions

In summary, while lymphoedema is becoming a more commonplace topic in healthcare communities, patients still feel that their condition is mismanaged. It is extremely important for lymphoedema education to be improved and accessible, not only for patients but also for health professionals challenged with the task of staying current with a quickly growing field. In order to ease patient anxiety and facilitate early detection and treatment of lymphoedema, informational materials must be designed with more than the breast cancer patient in mind and written at a level understood by the patient. The evidence-based resource booklet we have created here shows preliminary signs of success with melanoma survivors and it is our hope that this booklet can be distributed to all major cancer centres across Canada. WAS

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