Knowledge base of wound, ostomy and incontinence nurses regarding lymphoedema: management and treatment in Brazil — results of a survey

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Key words

Lymphoedema, education, survey, wound, ostomy and incontinence nurses.

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Abstract

Background: Lymphoedema is a result of lymphatic drainage deficit and lymphatic system overload, which affects over 200 million people throughout the world. This condition can interfere with the individual's life, with stigma and disability associated with economic, physical and psychosocial consequences. Despite its incidence and prevalence in our populations, healthcare providers still have limited knowledge of lymphoedema. **Aim:** To assess Brazilian wound, ostomy and incontinence (WOC) nurses' knowledge of lymphoedema. **Methods:** A questionnaire was submitted to 250 WOC nurses in Brazil via an online survey application. The questionnaire consisted of quantitative and qualitative questions based on Wilson's (2012) questionnaire. **Results:** The questionnaire was sent to 250 WOC nurses and 97 completed the survey. Results showed that 25% of the WOC nurses routinely treat lymphoedema patients. Among the WOC nurses who completed the survey, 86% would like to learn more about how to approach lymphoedema treatment, and 60% face difficulties engaging patients during treatment. **Conclusion:** Lymphoedema is a recurrent disease for the WOC nurses in Brazil who manage wound care; however, most of them are not familiar with the diagnosis and treatment of lymphoedema. This study identified the main doubts and challenges for WOC nurses during care for patients with lymphoedema, which instigates further studies and developments around education.

Lymphoedema can be inherited or acquired due to the lack or failure of the lymphatic system, classified as either primary or secondary lymphoedema. Primary lymphoedema is characterised by a congenital malformation or a health condition in lymphatic circulation. It is divided into three sub-classifications, according to the age it first occurs: congenital lymphoedema occurs at birth, early-onset lymphoedema occurs in puberty, and late-onset lymphoedema occurs after the age of 35 years. Secondary lymphoedema occurs following any trauma in the lymphatic system caused by surgery, radiation therapy, burn, infection, cellulitis, neoplasm, sting, or hitting (Leduc and Leduc, 2007; Mortimer and Rockson, 2014).

The most common lymphoedema worldwide is filarial lymphoedema (Sleigh and Manna, 2019). In developed countries, the highest incidence is associated with neoplasms.

Globally, 140 to 200 million people have lymphoedema, and its prevalence depends on sex, age and aetiology. Lymphoedema is more prevalent in women and people over 65 years old; 83% of patients are women and it occurs in approximately 1 in every 200 people over the age of 65 (Moffatt et al, 2003; Foldi and Foldi, 2006; Brayton et al, 2014; Ramaiah and Ottesen, 2014).

Lymphoedema progression may affect the individual's life due to stigma and disability, which are associated with economic, physical and psychosocial consequences (Ko et al, 1998; FU et al, 2013; Ramaiah and Ottesen, 2014).

If diagnosed at an early stage, lymphoedema is more likely to have a positive outcome, since it is a progressive disease. Although lymphoedema is complex, it should not be overlooked, as proper diagnosis and treatment already exist (International Society of Lymphology, 2013).

In an Italian study, 69% of the interviewed nurses working in the community affirmed that most patients have chronic oedema, and this reflects the reality for many other healthcare providers, who often see patients with chronic oedema (Thomas et al, 2017; Moffatt et al, 2019).

The lack of lymphoedema education in undergraduate programmes and the lack of standardisation surrounding diagnosis and lymphoedema treatment results in a lack of proper care (Hodgson et al, 2011).

Research on oncology nurses that have frequent contact with patients who had

breast cancer-related lymphoedema showed overall that they could not diagnose or treat lymphoedema properly, which reinforces the need for lymphoedema education for those healthcare providers (Davies, 2012; Fu et al, 2012; Sharour, 2019).

Aim

This study aimed to identify Brazilian WOC nurses' knowledge and educational needs related to lympheodema. The identification of those needs will contribute to the development of tools and programmes in the future.

Methods

This was a prospective study developed in the Professional Master's Program in Science, Technology and Management Applied to Tissue Regeneration at Universidade Federal de São Paulo (UNIFESP). It was approved by the Research Ethics Committee via Plataforma Brasil and assigned as CAAE-78418517.1.0000.5505.

A literature review was conducted and the content selection of the following descriptors (DeCS) was used: lymphoedema, lymphatic oedema, healthcare providers, information dissemination, education, knowledge, and professional education. The search was conducted at the Latin American and Caribbean Literature in Health Sciences (LILACS), US National Library of Medicine National Institutes of Health (PubMed), Scientific Electronic Library Online (SciELO), Cochrane, Google® and Google Academic search sites.

The inclusion criteria were national and international publication studies addressing aetiology, epidemiology, pathophysiology, evaluation, diagnosis, treatment and prevention of lymphoedema, written in English, Portuguese and Spanish, for the past 10 years — from August 2009 to August 2019. The exclusion criteria were the articles that did not address lymphoedema education of healthcare providers.

Brazilian WOC nurses were invited to this research to check for their knowledge and main difficulties in assessing and treating patients with lymphoedema. The survey was conducted through an online questionnaire. The questionnaire survey was based on Wilson's questionnaire (2012).

The inclusion criteria for selected providers were nurses with more than five years of nursing experience, specialisation in WOC and care providers for patients with wounds.

The exclusion criteria were professionals with no specialisation in WOC, healthcare providers who do not treat patients with wounds and/or have less than five years of practice. From that group, 250 nurses were identified according to the inclusion criteria. The information letter and the informed consent form were sent to all the participants, explained and signed.

The online survey was divided into three parts: the first part consisted of the information letter and the informed consent form; the second part of the questionnaire consisted of 11 multiple-choice questions evaluating the respondent's knowledge of lymphoedema; finally, the third part of the questionnaire included three multiple-choice questions to find out the topics of interest for further learning and development.

The lymphoedema concepts discussed in the *6º Consenso Latinoamericano para el Tratamiento del Linfedema Ciucci* (2017) were used to check if the respondents' answers were correct. If correct, it was determined that the respondent "knows" the right answer. If incorrect, it was determined that the respondent "doesn't know" the correct answer. The questions were:

1. What is lymphoedema?
2. Who is at risk of developing lymphoedema?
3. Which moment is most likely for a patient to develop lymphoedema?
4. Which of the following symptoms may present in lymphoedema
5. Can you diagnose lymphoedema?
6. What is the best way of treating and reducing lymphoedema?
7. When should a patient seek the help of a healthcare provider?
8. What is the best wrapping material type to treat lymphoedema?
9. Does lymphoedema have a cure?
10. What can we do to prevent lymphoedema?
11. What action can help to prevent lymphoedema in post-mastectomy upper limbs?

The third part of the questionnaire included the following three multiple-choice questions to investigate the area/themes of interest to the respondents:

1. What would you like to know about lymphoedema?
2. What lymphoedema-related aspects do you believe that knowing it better would have helped you with your patients?
3. When treating a patient with wounds and/or acute or chronic oedema in the lower limbs, what are your main difficulties?

All questionnaire responses were entered into a Microsoft Excel file. All the answers to the survey were used to evaluate the questions and difficulties encountered by the respondents.

Results

A total of 536 articles written within the past 10 years were found in databases on lymphoedema education for healthcare professionals. After reading the abstracts, 32 articles were separated for full reading, and 17 of them were selected for concerning lymphoedema, lymphoedema education/knowledge, and the need for lymphoedema education for healthcare professionals working with patients who had or might have lymphoedema.

The online questionnaire was developed, and 250 nurses working with tissue regeneration were selected to receive the survey, of which 38% (97/250) answered the survey and met the inclusion criteria.

Of 97 participants completing the questionnaire, 91% (88/97) were female; 52% (51/97) had more than 15 years' experience in nursing and 25% (24/97) had 11 to 15 years of experience.

At the time, 24% (23/97) were working with wounds and lymphoedema, and 76% (74/97) were working only with wounds.

When asked if they could diagnose lymphoedema, 49% (46/97) said they could diagnose lymphoedema, and 51% (51/97) said they could not.

Regarding the questions evidencing the respondents' knowledge, from 1 to 11, the answers were checked based on "knows/doesn't know" and percentages are shown in *Figure 1*.

Questions 12–14 covered lymphoedema themes on which respondents would like to have more information.

When asked about what they would like to know about lymphoedema, 86% (83/97) of the participants said they would like to have some information on the WOC approach while treating lymphoedema patients. In addition, 57% (55/97) of the WOC nurses also would like to know more about lymphoedema and wounds.

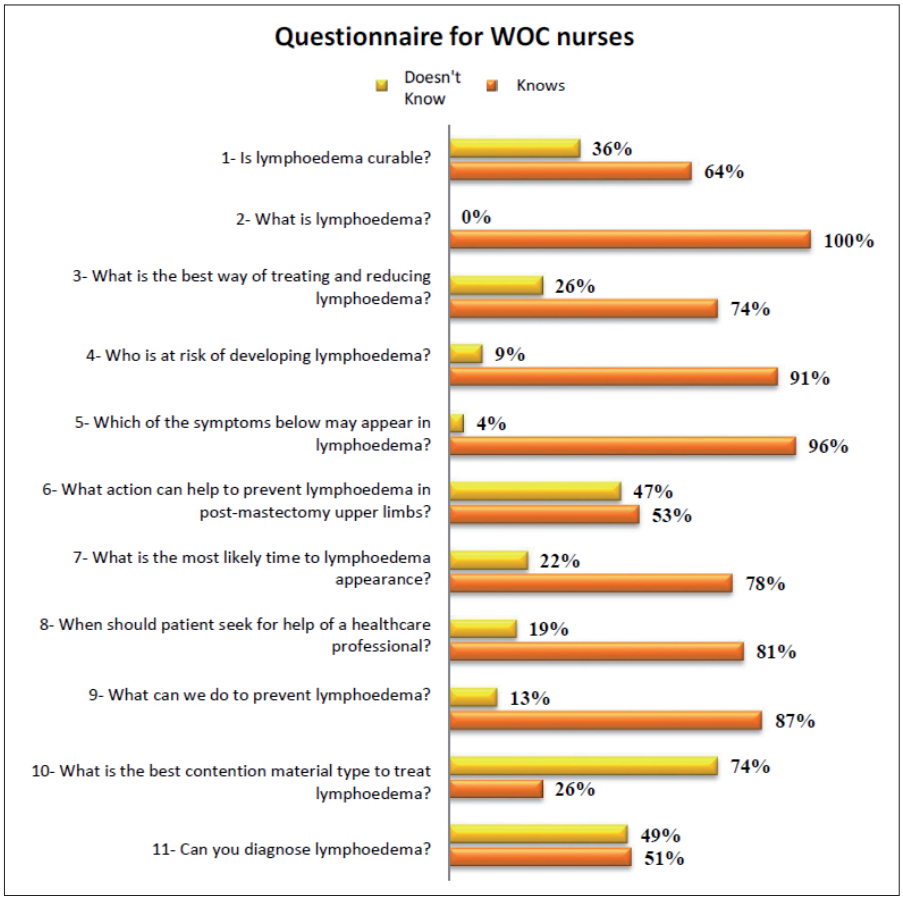

Figure 1. Answers to questions on lymphoedema.

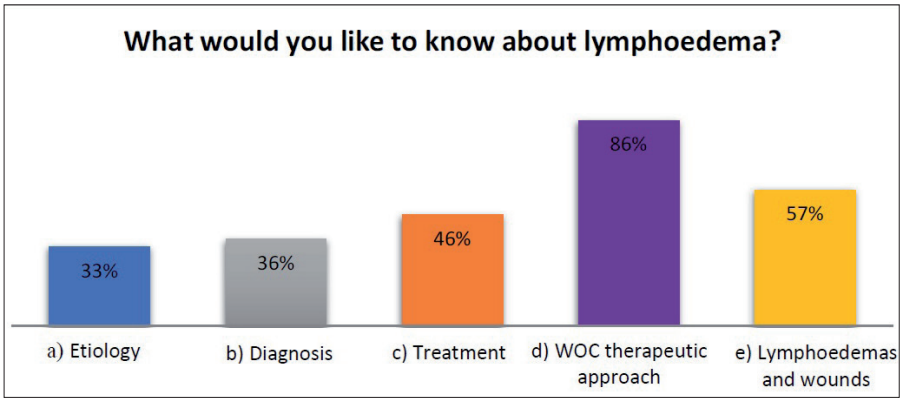

Figure 2. Lymphoedema themes WOC nurses would like to know more, in relative value.

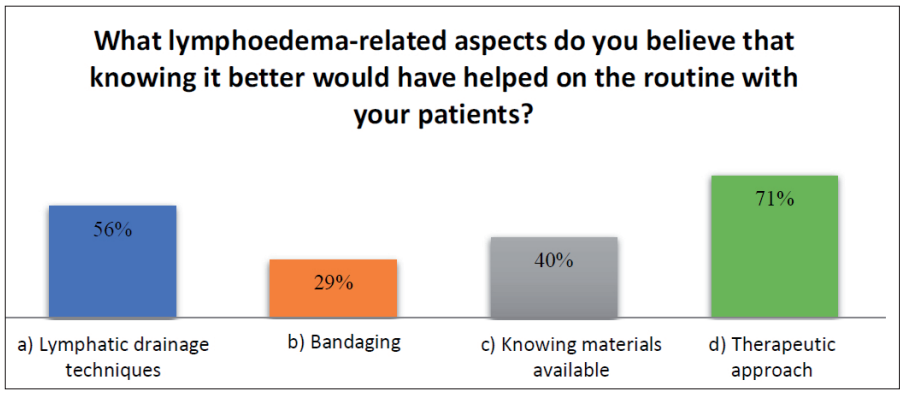

Figure 3. Relative frequency response about aspects from the interviewed providers assumed that, if they knew, would help in the routine work with patients.

The plot concerning question 12 is shown in *Figure 2*. In total, 71% (69/97) recognise the need for learning about the therapeutic approach in lymphoedema patients, and 56% (54/97) believed that knowing lymphatic drainage techniques would help their daily work.

The graphic concerning question 13 is shown in *Figure 3*. Of the WOC nurses, 64% (62/97) mentioned "engaging patients" as the main difficulty when treating patients with wounds and/or acute or chronic oedema in lower limbs.

Figure 4 shows the plot concerning question 14.

Discussion

Oedema is a known result of an imbalance between filtration and reabsorption, but signs and symptoms are not always clear. Some oedemas appear at night; others appear in the morning. Lymphoedema is a chronic oedema resulting from an overload in lymphatic circulation (Leduc and Leduc, 2007). The education of healthcare providers and patients is critical for the success of early diagnosis, intervention, and treatment of lymphoedema (Rourke et al, 2010). When healthcare providers are not trained sufficiently enough to recognise and provide the initial treatment for lymphoedema, the referral of lymphoedema patients is delayed, increasing more demanding symptoms and resources for treatment (Morgan et al, 2012; Todd, 2013).

This study identified the need for more lymphoedema education since basic concepts for the diagnosis and treatment of lymphoedema were not clear to all participants.

In the question about the best wrapping material type to treat lymphoedema, 40% of participants answered elastic bandage wraps, when the most appropriate material is the short-stretch bandage or the non-elastic bandage.

In the Latin-American consensus on lymphoedema, both large-stretch and short-stretch bandages are mentioned, with the latter recommended. During the application of high-working pressure (while the patient walks) and low-resting pressure (while the patient sleeps), the elastic wrapping is still used; short-stretch bandages are recommended (Ciucci, 2017).

In 2018, Tsuchiya et al reported that of 641 nurses completing a questionnaire

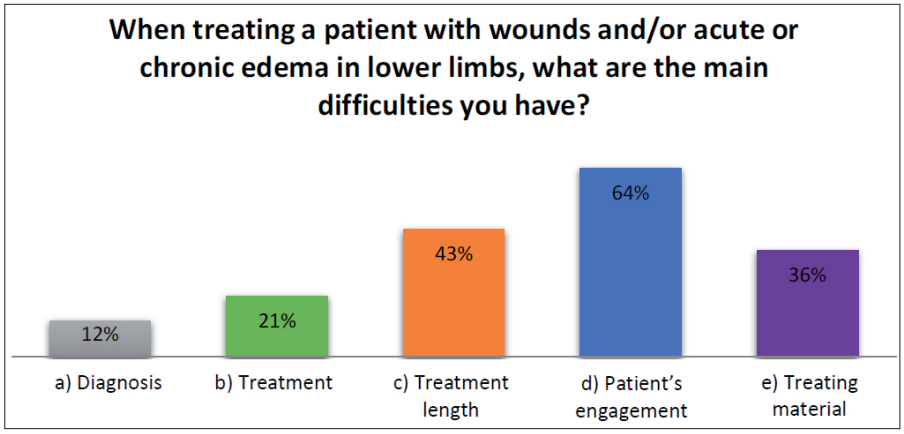

Figure 4. Relative frequency response on the providers' difficulties while treating patients with wounds and/or acute or chronic oedema in lower limbs.

on the risk of a patient developing lymphoedema, 70% were interested in providing patients with information on the risk of lymphoedema. Nursing providers should be properly trained on the aetiology, physiology and psychosocial impact in lymphoedema patients. A tool capable of following-up the lymphoedema progression and teaching a holistic self-care approach is essential (Emery and Johnson, 2014).

In Copenhagen, Denmark, nurses can only work in a multidisciplinary lymphoedema centre if they take a 2-year course covering skin management, bandages and wound healing; nurses also need a good working knowledge of compressive therapy. Those nurses are focused on the initial identification, diagnostic investigation, and treatment plan (Birkballe et al, 2012).

In Brazil, nurses are not supposed to treat lymphoedema patients, but this subject is covered in the specialisation in the WOC program.

This study pointed out that 25% of the WOC nurses already came across lymphoedema in their daily work. A similar study result was found in Japan with primary care nurses, in which 30% of them had previous experience with lymphoedema patients (Tsuchiya et al, 2018).

Other providers besides the vascular surgeon and the physical therapist treat patients with lymphoedema, without getting proper training. A multidisciplinary approach for these patients is very important since the knowledge and the exchange around the healthcare areas increases the chances of better outcomes (Godoy et al, 2008).

For the primary care NHS nurses, the focus is on the early diagnosis and treatment of chronic oedema by using the multilayer bandage technique, as these actions decrease the cost and improve patients' quality of life. For this, it is essential to have a team capable of treating lymphoedema (Thomas and Morgan, 2018).

In this study, 49% of the interviewed WOC nurses claimed they could not diagnose lymphoedema. The study aimed to shine a light on the need for improved lymphoedema education of healthcare providers.

Conclusion

Lymphoedema is a recurrent disease seen by WOC nurses in Brazil who manage wound care; however, most of them are not familiar with the diagnosis and treatment of lymphoedema.

This study identified the main doubts and challenges for WOC nurses during the care of patients with lymphoedema, which instigates further studies and developments around education.

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