

Preliminary development of a leg lymphoedema self-care adherence questionnaire

JL Martin, NW Doyle and ML McCarroll

Key words

Information-Motivation-Behavioral Skills model, self-care adherence,

Martin JL is Assistant Clinical Professor, School of Occupational Therapy, Texas Woman's University Dallas, TX, USA; Doyle NW is Lecturer, College of Health and Rehabilitation Sciences: Sargent College, Department of Occupational Therapy, Boston University Boston, MA, USA; McCarroll ML is President and CEO, Strength-Based Solutions, LLC Dallas, TX

Declaration of interest: None.

Abstract

Lymphoedema is a chronic, incurable condition that requires lifelong self-care management. Chronic disease self-care management is a complicated process that varies between clients at both the group and individual levels. The Information-Motivation-Behavioral Skills model is a social psychological conceptualisation designed to understand and promote health-related behaviour. The LifeWindows Information-Motivation-Behavioral Skills Adherence Questionnaire was adapted to create the Information-Motivation-Behavioral Skills Leg Lymphoedema Self-Care Adherence Questionnaire (IMB-LL-SCAQ). The IMB-LL-SCAQ is a client self-reported questionnaire with 18 statements or questions and a numeric rating scale designed to help lymphoedema practitioners objectively assess client factors related to self-care adherence. This project examined preliminary face validity and clinical utility of the IMB-LL-SCAQ. Two out of four lymphoedema therapists completed the questionnaire review and a survey. Based on the responses, self-care adherence is relevant to their practice. In terms of clinical utility, the therapists reported the IMB-LL-SCAQ was easy to follow and understand, and they felt their clients would be able to complete it in a timely fashion. The IMB-LL-SCAQ is a step towards understanding our clients' self-care adherence strengths and weaknesses.

Chronic oedema is defined as swelling that lasts for more than 3 months, while lymphoedema is a type of chronic oedema of a limb or the trunk due to the accumulation of protein-rich interstitial fluid (Keeley, 2018). Lymphoedema is classified as primary or secondary (Grada and Phillips, 2017).

Lymphoedema is a chronic, incurable condition that requires lifelong management (Keast et al, 2019). It is generally treated using a chronic disease model that focuses on self-care management combined with professional support for assessment, treatment and monitoring (Keast et al, 2019). The gold standard treatment for leg lymphoedema is complete decongestive therapy (CDT; National Lymphoedema Network [NLN], 2011).

CDT combines manual lymphatic drainage, skin care, decongestive exercises, compression garments, and a self-care programme to reduce a swollen limb (NLN, 2011). Leg lymphoedema clients who participate in CDT are discharged from therapy with a self-care programme

made up of the same components used in therapy (NLN, 2011). These specific self-care behaviours are designed to maintain the progress gained in therapy and clients who adhere to their self-care programme can reduce the need for recurrent courses of CDT throughout the year. Clients who do not adhere often have a return of swelling which, if left untreated, can lead to wounds, infection, hospitalisation and the need for another course of treatment (International Lymphoedema Framework [ILF], 2006). The impact of uncontrolled leg lymphoedema can affect a client's physical, emotional and social wellbeing (ILF, 2006).

The Information-Motivation-Behavioral Skills (IMB) model is a social psychological conceptualisation designed to understand and promote health-related behaviour (Fisher et al, 2003). Fisher et al (2003) support the use of the IMB approach in a variety of health domains. The IMB model asserts that a client who is well informed, motivated to act and possesses the requisite behavioural skills for effective

action will likely initiate and maintain health-promoting behaviours. Conversely, if a client is not well informed, motivated to act, or does not possess the requisite skills to perform self-care, nonadherence with self-care programmes is likely (Fisher et al, 2003).

Using the IMB model as a framework in the context of leg lymphoedema self-care, relevant client information might include:

1. What is lymphoedema?
2. How does lymphoedema develop?
3. How is it treated?
4. What strategies should be used to manage symptoms?
5. What happens when lymphoedema goes untreated?

The motivation component of the IMB model includes one's personal attitude towards performing requisite self-care behaviours (personal motivation) and clients' perception of whether they have social support to help them adhere to their self-care programmes (social motivation). The behavioural skills components of the IMB model include the skills and strategies

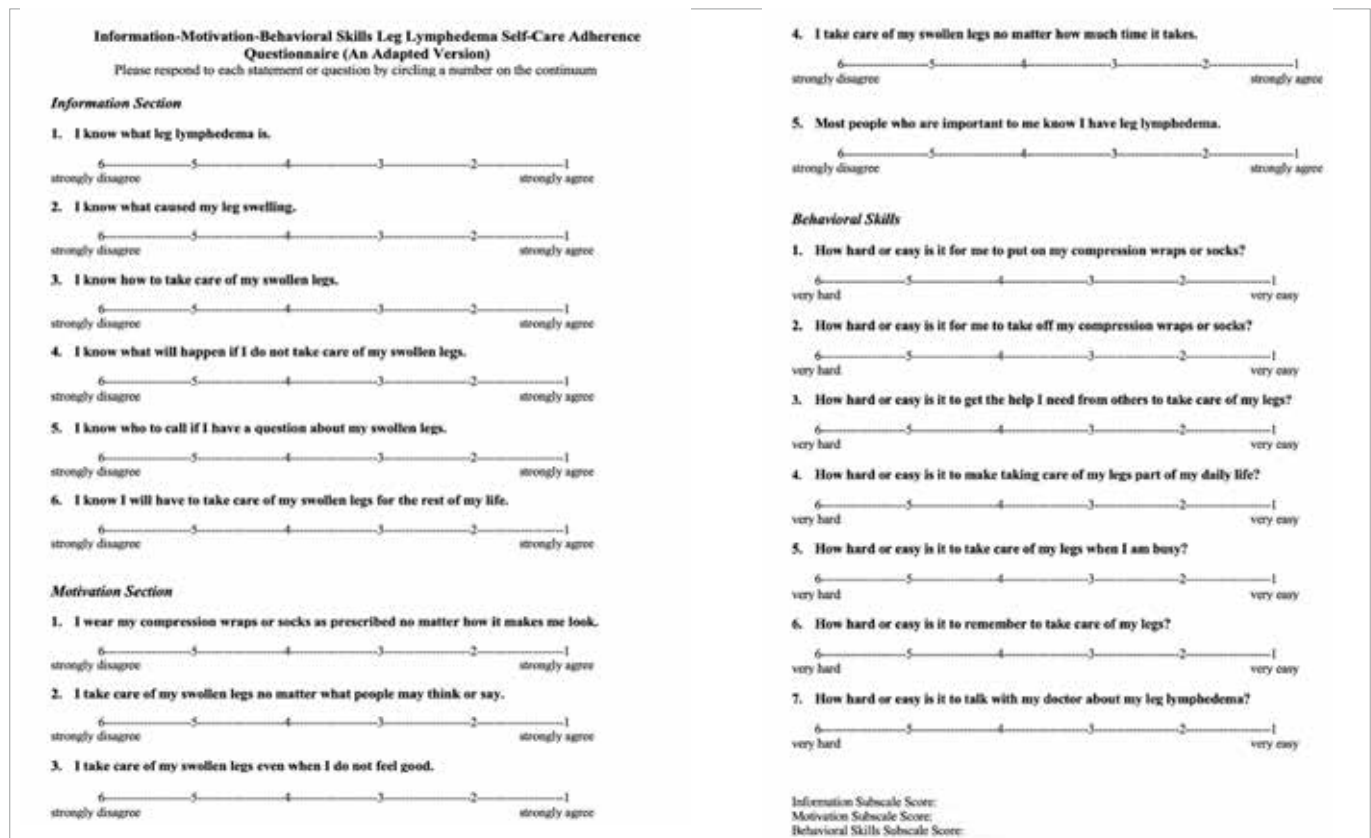


Figure 1. Information-Motivation-Behavioral Skills Leg Lymphedema Self-Care Adherence Questionnaire (IMB-LL-SCAQ).

used by clients to adhere to their self-care programmes (Fisher et al, 2003). This includes self-care self-efficacy, habits and routines, functional and cognitive abilities, asking for support, and access to supplies (Fisher et al, 2003).

The LifeWindows Information-Motivation-Behavioral Skills Adherence Questionnaire (LW-IMB-AAQ) was designed to measure barriers to antiretroviral therapy adherence among HIV positive patients in a clinical care programme (LifeWindows Project Team, 2006). The LW-IMB-AAQ is based on the IMB Skills model and was designed to be used with the LifeWindows adherence intervention software program. Each item is designed to quantify one's information, motivation, and behavioural skills, strengths and weaknesses, and signal which IMB adherence-related deficits should be addressed in order for adherence to improve.

The purpose of this project was to create an adaptation of the LW-IMB-AAQ to apply directly to the precepts involved in lymphoedema self-care adherence.

Methods

The authors adapted the LW-IMB-

AAQ with permission from the study's principal investigator (J Fisher, personal communication, March 4, 2019) to form the Information-Motivation-Behavioral Skills Leg Lymphedema Self-Care Adherence Questionnaire (IMB-LL-SCAQ; Figure 1). This was designed to help lymphoedema practitioners objectively assess client factors related to lymphoedema self-care adherence. The IMB-LL-SCAQ is a client self-report questionnaire with 18 statements or questions and a numeric rating scale. Clients can complete the questionnaire at evaluation, re-evaluation, and discharge to establish a baseline and measure change over time. The questionnaire has three subscale areas-information, motivation and behavioural skills, which are designed to measure a client's information, motivation and behavioural skills related to their lymphoedema self-care. Practitioners can add up the subscale scores and the higher the subscale score, the higher the deficit. Subscale scores may assist practitioners choose targeted adherence promoting interventions based on identified information, motivation, and behavioural skill deficit areas.

The development of the IMB-LL-SCAQ is part of a larger project aimed at

improving self-care adherence with leg lymphoedema clients. This early phase preliminary face validity and clinical utility exploration surveyed expert practitioners. Face validity supports content validity and does not consider what is measured but focuses on appearance (Zamanazdeh et al, 2014). To initiate this phase, the authors created a survey to ascertain professional perspective on using the IMB-LL-SCAQ in their practice. Colleagues recommended area certified lymphoedema therapists to be invited to complete the survey. According to 45 CFR Part 46, this preliminary study survey was not considered Human Subjects Research.

Four credentialed practitioners were identified from local clinics and emailed a link to a Google Form survey and a copy of the IMB-LL-SCAQ for expert review regarding clinical application.

The authors chose a small group of local contacts to frame the beginning of a larger study, as access to a larger expert pool has been limited due to the COVID-19 pandemic.

The expert participants reviewed the IMB-LL-SCAQ and indicated their dichotomous (yes or no) survey responses

to the following questions:

1. Is self-care adherence relevant to your practice?
2. Is the IMB-LL-SCAQ format easy to follow?
3. Are the IMB-LL-SCAQ questions and responses easy to understand?
4. Is the IMB-LL-SCAQ content relevant and appropriate for the lymphoedema population based on their experience?
5. Would their clients be able to complete the IMB-LL-SCAQ questionnaire in a timely fashion?

The next section of the survey focused on the certified lymphoedema therapist's current evaluation processes. Each participant was asked:

1. How do you currently measure self-care knowledge, motivation, and skill level with your lymphoedema clients?
2. What did you like and dislike about the IMB-LL-SCAQ questionnaire?

Results

Two out of four lymphoedema therapists completed the IMB-LL-SCAQ review and Google Form survey. Due to COVID-19, the associated lack of clinician availability, as well as practicing therapists, the sample was small. Also, this represents a 50% reply rate, which may on the face of it appear low but is above the 30% average for survey rates.

Based on the therapist's responses, self-care adherence is relevant to their practice. In terms of clinical utility, the therapists reported the IMB-LL-SCAQ was easy to follow and understand and they felt their clients would be able to complete it in a timely fashion. The responding therapists reported that they currently obtained information about their client's self-care barriers and strengths from the baseline evaluation interview and during treatment visits. One therapist reported that they utilised the Lymphedema Life Impact Scale to gather additional information about the client's quality of life (Table 1).

The therapists stated that they liked that the questionnaire assesses current knowledge regarding lymphoedema, because it indicates where more education is needed, and that it assesses how difficult lymphoedema self-care can be. Another therapist mentioned that the questionnaire assesses life tasks that a client may not mention in conversation. One therapist felt that clients may be more honest in

Table 1. Survey of expert therapists.	
Questions	Answer format
1. The Information-Motivation-Behavioral Skills (IMB) Model asserts that a client who is well informed, motivated to act, and demonstrates requisite behavioural skills will be adherent with their self-care programs. This IMB-based questionnaire is designed to assess a client's lymphoedema related self-care knowledge, motivation, and behavioural skills. Theoretically the information you gain from the questionnaire will help you to design a self-care program for your clients that promotes adherence by targeting potential problem areas. Do you think this information is relevant for your practice?	Yes: 2 No: 0 Maybe: 0
2. Is the format of the questionnaire easy to follow?	Yes: 2 No: 0 Maybe: 0
3. Are the questions and the responses easy to understand?	Yes: 2 No: 0 Maybe: 0
4. Is the wording technically correct and appropriate?	Yes: 2 No: 0 Maybe: 0
5. Will your clients be able to complete the questionnaire in a timely fashion?	Yes: 2 No: 0 Maybe: 0
6. How do you currently measure your client's lymphoedema related knowledge and their self-care related motivation and behavioural skills? (Behavioural skills includes self-efficacy, accessing outside support, and one's physical ability to perform the components of a self-care programme.) Please check all that apply.	During interview: 2 During course of treatment: 2 Lymphedema Life Impact Scale: 1 Leg Lymphedema Complexity Score: 0 Another functional outcome study: 0 Other: 0
7. What do you like about the questionnaire?	I like that it assesses current knowledge and indicates areas where more education is needed. I also like that it assesses how difficult self-care of lymphoedema is. It's specific to personal life tasks that the patient may not mention in conversation.
8. What do you not like about the questionnaire?	I like the questions. However, I'm not sure that patients will be more honest on the questionnaire than in person/interview with their expected compliance to the treatment plan.

conversation than on a questionnaire in regards to adherence to a treatment plan.

Discussion

Leg lymphoedema, while a common occurrence, is generally poorly recognised and clients are often not referred for early treatment (Moffatt et al, 2019).

The Lymphedema Impact and Prevalence International Study was developed by the ILF to estimate the prevalence and impact of chronic oedema (Keast et al, 2019). Sixty-eight clients at an outpatient wound clinic were enrolled in the Canadian study and the majority of clients had leg lymphoedema (65 out of 68). The most

common underlying condition was venous disease (72%) and only eight clients had a history of cancer. More than half of the participants (54%) were morbidly obese (BMI over 40), 72% of participants reported at least one episode of cellulitis in the past, 10% had been hospitalised in the past year, and 39% had an open wound (Keast et al, 2019).

Leg lymphoedema self-care adherence is important for clients to maintain skin integrity and reduce the development of infections and wounds. While there are numerous factors and situations in which lymphoedema clients do not adhere with their self-care programmes, there are few resources lymphoedema practitioners can use to objectively identify self-care barriers and strengths that will help them design personalised self-care programmes to promote adherence. Addressing these factors by using the IMB-LL-SCAQ through the framework of the IMB model may make it easier for practitioners to choose targeted self-care adherence promoting interventions.

After receiving feedback from the expert therapists to determine preliminary face validity and clinical utility, the IMB-LL-SCAQ is ready for full content validity evaluation and statistical analysis in a larger future study. After content validity is established a pilot test will be performed to assess the feasibility and test-retest reliability of the questionnaire (Rattray and Jones, 2007). These preliminary results are encouraging and support the ILF's mission to improve care for people with lymphoedema and global awareness of the incidence and impact of lymphoedema (Moffatt et al, 2019).

While the number of therapists surveyed was limited, this preliminary study did achieve a 50% return rate during the COVID-19 pandemic. The authors chose four local therapists to ascertain interest in the subject matter and to determine whether a future, larger study on questionnaire content validity and statistical analysis was feasible. One strength of this small study is that the therapists demonstrated interest in leg lymphoedema self-care adherence, as there is currently no theory-based instrument to measure this important area in this specific population.

Chronic disease self-care management is a complicated process that varies between clients at both the group and individual levels (van Dulmen et al, 2008). Clients gain more knowledge, skill, motivation, and confidence if practitioners take the time to find out their knowledge baseline, direct clients to appropriate learning experiences to fill their knowledge gaps, and provide clients with experiential and skill building opportunities (Wigg, 2017). The IMB-LL-SCAQ is a step towards understanding our clients' self-care adherence strengths and weaknesses.

Conclusion

Chronic disease self-care management is a complicated process that varies between clients at both the group and individual levels (van Dulmen et al, 2008). Clients gain more knowledge, skill, motivation and confidence if practitioners take the time to find out their knowledge baseline, direct clients to appropriate learning experiences to fill their knowledge gaps and provide clients with experiential and skill building

opportunities (Wigg, 2017). The IMB-LL-SCAQ is a step towards understanding our clients' self-care adherence strengths and weaknesses.

References

- Fisher WA, Fisher JD, Harman J (2003) The Information-Motivation-Behavioral Skills Model: a general social psychological approach to understanding and promoting health behavior. In: Suls J, Wallston KA, eds. *Social Psychological Foundations of Health and Illness*. Blackwell Publishing, Oxford: 82–106
- Grada AA, Phillips TJ (2017) Lymphedema: pathophysiology and clinical manifestations. *J Am Acad Dermatol* 77(6): 1009–20
- International Lymphoedema Framework (2006) *Best Practice for the Management of Lymphoedema. International consensus*. London: MEP. Available from: <https://www.lympho.org/portfolio/best-practice-for-the-management-of-lymphoedema> (accessed 04.06.2021)
- Keast DH, Moffatt C, Janmohammad A (2019) Lymphedema impact and prevalence international study: the Canadian data. *Lympha Res Biol* 17(2): 178–86
- Keeley V (2018) Every kind of edema is lymphedema. *Veins and Lymphatics* 7(3): 142–3
- LifeWindows Project Team (2006) The LifeWindows Information-Motivation-Behavioral Skills ART Adherence Questionnaire (LW-IMB-AAQ). Available from: <https://chip.uconn.edu/research/intervention-resources/lifewindows> (accessed 20.08.2021)
- Moffatt C, Keeley V, Quere I (2019) The concept of chronic edema – a neglected public health issue and an international response: the LIMPRINT study. *Lymphatic Res Biol* 17(2): 121–6
- National Lymphedema Network (2011) Position statement of National Lymphedema Network: The diagnosis and treatment of lymphedema <https://lymphnet.org/position-papers> (accessed 20.08.2021)
- Rattray J, Jones MC (2007) Essential elements of questionnaire design and development. *J Clin Nurs* 16(2): 234–43
- van Dulmen S, Sluijs E, van Dijk L et al (2008) Furthering patient adherence: a position paper of the international expert forum on patient adherence based on an internet forum discussion. *BMC Health Serv Res* 8: 47
- Wigg J (2017) Enhancing lymphoedema patients' learning through education. *Br J Nurs* 26(4): 204–6
- Zamanazdeh V, Rassouli M, Abbaszadeh A et al (2014) Details of content validity and objectifying it in instrument development. *Nursing Practice Today* 1(3): 163–71