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Concerning quality of life questionnaires in breast cancer-related lymphedema patients : review of the literature by Cornelissen et al.

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Letter to the Editor

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Quality of Life Questionnaires in Breast Cancer-Related Lymphedema Patients: Review of the Literature.

Cornelissen AJM¹, Kool M², Keuter XHA¹, Heuts EM², Piatkowski de Grzymala AA¹, van der Hulst RRWJ¹, Qiu SS¹.

With great interest we have read the recently published review ~~established~~ by Cornelissen et al^[1]. In this review, a systematic literature search was performed in order to provide a structured overview within the plethora of Quality of Life (QoL) questionnaires applied in patients with breast cancer-related lymphedema (BCRL). In view of this, the aim was to assess which questionnaire(s) is the most complete and accurate one for this population, not only based on its clinimetric properties validity, but also on the amount of different aspects of QoL that are being taking into account. In our opinion, this research is of tremendous value since the use of adequate patient reported outcome measures n(PROMS) provides a better understanding of a patient's condition in general. The solely use of objective measurements quantifying the amount of lymphedema, on the contrary, lacks the power to encounter the real burden of lymphedema.

The conclusion of this review showed that the Lymphedema Functioning, Disability and Health questionnaire for the upper limb (Lymph-ICF), together with the Lymphedema Quality of Life Inventory (LyQLI), seem to be the two most complete and accurate questionnaires for examining QoL in patients with BCRL. Hereby was mentioned that "the Lymph-ICF investigates all predefined QoL domains, except the sexual functioning domain. This aspect it is making no part of the questionnaire because, during the development phase of the Lymph-ICF questionnaire, none of the patients reported sexual dysfunction as a missing complaint. Nevertheless, we are absolutely conscious of the fact that, for many women, lymphedema can be an embarrassing morbidity after the treatment of breast cancer. It induces not only functional impairments, but it can also entail a negative impact on psychosocial well-being with occurrence of psychosocial problems such as depression, low self-esteem, social avoidance, a decrease in self-confidence and an altered body image^[2,3], which can be reflected in sexual concerns and issues^[4]. To admit the latter, a certain amount of self-confidence is needed."

Besides assessing various QoL domains, the Lymph-ICF was the only questionnaire examining all nine arm symptoms as defined in the review of Cornelissen et al. In addition, it is considered to be the only lymphedema-specific questionnaire that makes use of a VAS score, as opposed to categorical scoring methods. Hereby, the difference between both answering types is being

discoursed as well, as stated in the discussion section: “A VAS is a commonly used method to rate subjective experiences with the advantage of having a wide score range and high sensitivity, however, an important disadvantage is that they have a lower completion rate than other rating scales^[5]”.

Despite the abovementioned disadvantage of having a lower completion rate, the Lymph-ICF questionnaire has proven to be a valid and reliable Dutch questionnaire in patients with BCRL^[6]. However, patients mentioned that the use of a scoring system with gradation like a numeric rating scale (NRS), would be an easier scoring method instead of the current VAS scoring system. Therefore, in 2014 when the Lymph-ICF-LL questionnaire for lower limbs was developed, the scoring mechanism was revised by implementing a NRS instead of a VAS^[7] since research also concealed that a NRS is related to a higher compliance, better responsiveness with lower error rate, and better applicability compared to VAS^[8].

For that reason, and as a reply to the valid remark of Cornelissen et al regarding the answering type of the original Lymph-ICF, we would like to inform the authors that recently, revision of the scoring mechanism of the Lymph-ICF has been extended, resulting in the Lymph-ICF-UL questionnaire which contains a NRS instead of a VAS. This revised questionnaire is also found appropriate and useful in clinical practice by showing very good (reliability) to good (validity) clinimetric properties in patients with BCRL (article under review). We would like to thank the authors for their elucidating review as a contribution of great relevance to the literature of this important topic.

1. Cornelissen AJM, Kool M, Keuter XHA, et al. Quality of Life Questionnaires in Breast Cancer-Related Lymphedema Patients: Review of the Literature. *Lymphat Res Biol* 2018 doi: 10.1089/lrb.2017.0046[published Online First: Epub Date]].
2. Pusic AL, Cemal Y, Albornoz C, et al. Quality of life among breast cancer patients with lymphedema: a systematic review of patient-reported outcome instruments and outcomes. *Journal of cancer survivorship : research and practice* 2013;**7**(1):83-92 doi: 10.1007/s11764-012-0247-5[published Online First: Epub Date]].
3. Morgan PA, Franks PJ, Moffatt CJ. Health-related quality of life with lymphoedema: a review of the literature. *International wound journal* 2005;**2**(1):47-62 doi: 10.1111/j.1742-4801.2005.00066.x[published Online First: Epub Date]].
4. Winch CJ, Sherman KA, Koelmeyer LA, Smith KM, Mackie H, Boyages J. Sexual concerns of women diagnosed with breast cancer-related lymphedema. *Support Care Cancer* 2015;**23**(12):3481-91 doi: 10.1007/s00520-015-2709-6[published Online First: Epub Date]].
5. Hauser K, Walsh D. Visual analogue scales and assessment of quality of life in cancer. *The journal of supportive oncology* 2008;**6**(6):277-82
6. Devoogdt N, Van Kampen M, Geraerts I, Coremans T, Christiaens MR. Lymphoedema Functioning, Disability and Health questionnaire (Lymph-ICF): reliability and validity. *Phys Ther. United States*, 2011:944-57.
7. Devoogdt N, De Groef A, Hendrickx A, et al. Lymphoedema Functioning, Disability and Health Questionnaire for Lower Limb Lymphoedema (Lymph-ICF-LL): reliability and validity. *Phys Ther* 2014;**94**(5):705-21 doi: 10.2522/ptj.20130285[published Online First: Epub Date]].
8. Hjerstad MJ, Fayers PM, Haugen DF, et al. Studies comparing Numerical Rating Scales, Verbal Rating Scales, and Visual Analogue Scales for assessment of pain intensity in adults: a

Met opmerkingen [TDV1]: Of mag dit niet gezegd worden als dit momenteel bij een ander journal is en de resultaten dus eigenlijk nog niet gepubliceerd zijn? Moet dan eerder iets gezegd worden als: “Research into clinimetric properties is ongoing and we are looking forward to inform you about the results of our study”?

Ik zou idd niet zeggen dat dit onder review is. Eerder iets zeggen dat onderzoek heft aangetoond dat er een beter optie is om te scoren.

systematic literature review. *Journal of pain and symptom management* 2011;**41**(6):1073-93
doi: 10.1016/j.jpainsymman.2010.08.016[published Online First: Epub Date]].