

Patient-Reported Outcome Measures With Secondary Lower Limb Lymphedemas: A Systematic Review

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Abstract

Background: Patient-reported outcome measures are measures of patients' health-related quality of life. They should be added to other lymphedema measurements. With an improved disease-free survival of secondary lower limb lymphedema, attention must focus on such assessments. **Objective:** The objectives of this study were to locate and critically appraise suitable patient-reported outcomes measures for lower limb lymphedemas and search for existing valid translations for native German speakers. **Methods:** A systematic literature research was conducted. 20 semantical categories for qualitative analysis were evolved. Six questionnaires available in English and some in validated translations remained for analysis. **Results:** Lower limb lymphedema patients experience poor quality of life, and one of the most critical denominators is skin quality. To establish skin care and prevent cellulitis, patients must learn about skin problems. Only two tools asked for past infections. This is considered crucial because of knowledge building and prophylactic behavior. Questions on movement restrictions were available in one questionnaire. As these have a close connection to one's ability to perform activities of daily life, they can affect quality of life. Afflicted patients have problems with the choice and availability of clothing. Only three questionnaires asked questions about clothing or shoes. Lymphedema patients are exposed to more psychological stress than healthy subjects, but only three questionnaires covered questions about this burden. There was a lack of reporting on psychometric data (Cronbach's alpha, intraclass correlation), which hinders the external validity. Analyzed questionnaires were available in English but only one in German. **Conclusions:** The analyzed questionnaires were in English, and only one was adapted and tested for native German speakers. For clinical practice, Devoogdt's questionnaire is recommended despite some shortcomings. There is a need for validated lymphedema questionnaires in German.

Lymphedema is a chronic progressive disease characterized by an accumulation of lymphatic fluid leading to the swelling of various body parts. Lymphedema can lead to different negative consequences, such as skin changes, connective tissue fibrosis, loss of quality of life, or social retreat (Sleigh & Manna, 2020). The standard treatment for lymphedema is complex decongestive therapy, which includes manual lymphatic drainage, compression therapy, exercise, skin care, and diet. On the other hand, adiposity, skin puncture, and aggressive cancer treatment increase the risk of developing an edema (Ribeiro Pereira et al., 2017). People at risk of lymphedema should be monitored closely for early disease detection and, if necessary, adequate treatment referral (Cho et al., 2020). Medical personnel and patients must therefore be able to recognize symptoms properly and in a timely manner. Medical staff such as physiotherapists, nurses, occupational therapists, and others are in close contact with lymphedema patients in the course of their ongoing treatment and often serve as patients' confidants. Therefore, these individuals may be the first to suspect a lymphedema condition.

It is for this purpose that different assessments are currently used, such as circumference measurement, water displacement, bioimpedance spectroscopy, or VEGF-C or lymphedema predisposing genes (Hidding, et al., 2016; Preuß et al., 2018; Sun et al., 2016; Visser et al., 2019). Apart from these measurements, there is increasing awareness about the need for disease-related patient-reported outcome measures (PROMs). Various experts agree that health-care systems must focus more on the patient's perspective (Deshpande et al., 2011; Mejdahl et al., 2018).

Patient-reported outcomes measures are defined by the National Health Service Department of Health as measures of patients' health status or health-related quality of life (HRQoL). They are concise, self-completed questionnaires collected at the beginning and end of an intervention and provide insight into patients' quality of life (QoL; Ousey & Cook, 2011). PROMs guarantee patient-centered evaluation and serve as distinguishing tools for disease detection. Such questionnaires are particularly relevant to clinical practice, because they are easily and expeditiously applied. If

certain prerequisites have been fulfilled, such as a sensitivity and specificity analysis, they can also serve for research purposes.

A critical review of existing tools is needed. Lymphedema symptoms and complaints can vary considerably, and a sufficient tool should preferably incorporate all the conceivable items. A comprehensive tool could detect lymphedema earlier, thus preventing patient suffering and saving treatment costs. It could be used as a repetitive evaluation during lymphedema treatment to depict medical practitioners' efforts. With a valid tool for lymphedema detection available, patients could be spared invasive procedures.

Primary (congenital) and secondary (acquired) lymphedema, because of delayed diagnostics, progress, and comorbidities, often lead to pronounced restriction in QoL and associated parameters (Deng et al., 2013a; Taghian et al., 2014; Yost et al., 2013). Generic instruments, such as the Global Health Status EORTC QLQ-C30 or the Hospital Anxiety and Depression Scale (Ferrandina et al., 2014) can depict certain aspects of QoL but fail with typical disease-specific details. Others, like the Nottingham Health Profile, are not sensitive enough to capture the disease-specific symptoms, especially when it comes to emotional or psychologic properties (Sitzia & Sobrido, 1997). Patient-reported outcomes measures should be added to volume measurement, skin-fold measurement, and others in order to diagnose and observe lymphedemas of the limbs and other body parts.

In a systematic review, Cemal and colleagues (2013) criticized the paucity of PROM deployment and application. Previous studies focused on upper limb (UL) and breast cancer-related lymphedema (Noble-Jones et al., 2014a; Pusic et al., 2012), but with a disease-free 10-year survival of 79% (Hwang et al., 2001), attention must shift to lower limb lymphedema (LLL). The incidence of secondary leg lymphedema lies between 7.1% and 38% (Iyer et al., 2018; Lim et al., 2014; Mitra et al., 2016; Todo et al., 2010) due to the heterogenic diagnostics and type of cancer. These edemas can be followed by a considerable number of comorbidities. Cemal and colleagues (2013) even emphasize the notion that leg lymphedemas have more serious consequences than arm lymphedemas. For example, Forner-Cordero and colleagues (2016)

reported gait differences such as a shorter step, elongated stance phases, and ground force reaction differences in patients with LLL, depending on case severity. These facts support the demand for suitable tools for the assessment of LLL. Such tools can additionally be used by self-reliant and well-informed patients for the early and sufficient recognition of edema symptoms (Lim et al., 2014).

In 2015, 18,654 women in Austria were newly diagnosed with a malignancy, with 9% of these women with uterine or ovarian neoplasms. 23% of 21,252 men newly diagnosed with a malignancy were diagnosed with prostate cancer, the most common malignancy reported in the same period (Hackl & Ihle, 2018). According to these figures, with a mean incidence of 22.4%, about 376 Austrian women faced the onset of lower limb gynecologic cancer-related lymphedema. Patient-reported outcomes measures must be available in patients' native language for applicability. The objectives of this study were therefore to locate and critically appraise suitable PROMs for LLL and search for existing valid translations for native German speakers.

METHOD

A systematic literature research conducted from November 25 to 29 in 2018 in various medical and nonspecific databases (PubMed, PEDro, ResearchGate, Google) was conducted. The search was updated with the same keywords on November 19, 2019, to look for possible new studies in the field, which yielded one additional study. No limits, neither linguistic, methodic, nor time-framed, were activated to open the search to older tools and to diminish potential language or single-source bias (George & Panday, 2017). Studies were included in English, German, Spanish, French, and Italian. The following keywords were used: (lower limb edema OR lower limb oedema OR leg lymphedema OR leg lymphoedema) AND (patient reported outcomes OR patient reported outcome measures OR patient-centered outcomes OR questionnaire).

Semantical categories ($n = 20$) considered crucial for further qualitative analysis and comparison were elaborated inductively out of the text (Ruin, 2017). Qualitative categories are complex content-related predications at the center of an analysis (Larcher, 2010), and are shown in Table 1. The

questionnaires were scrutinized as to whether their questions covered the previously mentioned categories and how many questions were designed for this category. The data of questionnaire structure and answer formats were analyzed. Psychometric data about questionnaire validity were gathered and compared. The results are presented, followed by a discussion organized by topic categories.

RESULTS

The search strategy and flow of studies are shown in Figure 1. Ten questionnaires remained for full-text screening (nine from the original search, one from the update). Of these, another four had to be excluded (Lymphedema Life Impact Scale [LLIS], Lymphedema Quality of Life Inventory [LyQLI], Freiburg Life Quality Assessment for Lymphoedema [FLQA-LS], and Lymphedema Quality of Life Score [LeQOLiS]) because of incompatibility with the research question. This left six assessment tools for the qualitative synthesis. All the questionnaires were available in English, some of them in validated translations in other languages.

Gynecologic Cancer Lymphedema Questionnaire

The Gynecologic Cancer Lymphedema Questionnaire (GCLQ) was developed for women with genital malignomas and comprises 20 questions. It has been translated into several languages. The first six questions deal with joint mobility and the rest with the edema and linked physiological parameters. Answers are to be given dichotomously (yes/no). Four supplemental items ask about lymphedema awareness, history, and treatment methods (Carter et al., 2010). In 2017, Kim and colleagues developed a short version based on only seven items. In 2019, Carter and colleagues demonstrated that the GCLQ is able to detect lymphedema in patients with and without a lymphedema diagnosis.

Lymphoedema Functioning, Disability and Health Questionnaire for Lower Limb Lymphoedema

The Lymphoedema Functioning, Disability and Health Questionnaire for Lower Limb Lymphoedema (Lymph-ICF-LL) can be retrieved in English, Danish, Turkish, Chinese, and Portuguese. It consists of 28 questions with a numeric rating scale (NRS, 0–10). The domains covered are

physical function (pain, severity, infections, etc.; six questions), mental function (confidence loss, mourning, attractiveness, etc.; six questions), general activities (dependency, household activities; three questions), mobility (basic activities of daily living [ADL]; seven questions) and social life (job, sports, leisure time, etc.; six questions; Devoogdt et al., 2014). In 2019, Allofs and colleagues released a German translation of the Lymph-ICF-LL.

Lymphoedema Quality of Life Questionnaire

The Lymphoedema Quality of Life Questionnaire (LYMQOL Leg) contains four domains (symptoms, body image/appearance, function, and mood) with 28 questions. The revised version is shorter than the first, because statistical analysis revealed redundancy, suggesting the omission of questions. Answers are scaled with a 4-point Likert scale (not at all/a little/quite a bit/a lot). The first question is further subdivided into six questions about impact on ADLs. Question 2 is first Likert scaled and also an open question about leisure-time activities. For question 28, the patient should give a general evaluation about their QoL with an NRS ranging from poor = 0 to excellent = 10 (Keeley et al., 2010). Van de Pas and colleagues (2016) translated and validated the LYMQOL Leg into Dutch.

Lymphedema Genito-Urinary Cancer Questionnaire for Men

The Lymphedema Genito-Urinary Cancer Questionnaire for Men (LGUCQ) first locates the swelling (lower extremity, genitals). It then asks about deterioration in intraday volatility, edema susceptibility for certain ADLs (6 questions), skin condition (4 questions), type of discomfort, and demand for analgesics (3 questions). All these questions are to be answered with a 4-point Likert scale (not at all/a little bit/quite a bit/very much), so that the personal limitation is calculated as a percentage. The questionnaire proceeds with numerical episodes of erysipelas and demand for antibiotics (yes/no). It includes a picture of the lower body and the genitals for the delineation of the swelling and an open question about the physical and emotional effects (Noble-Jones et al., 2014a). The Lower Limb and Genital Lymphoedema Questionnaire (LLGLQ) is almost identical; it has one

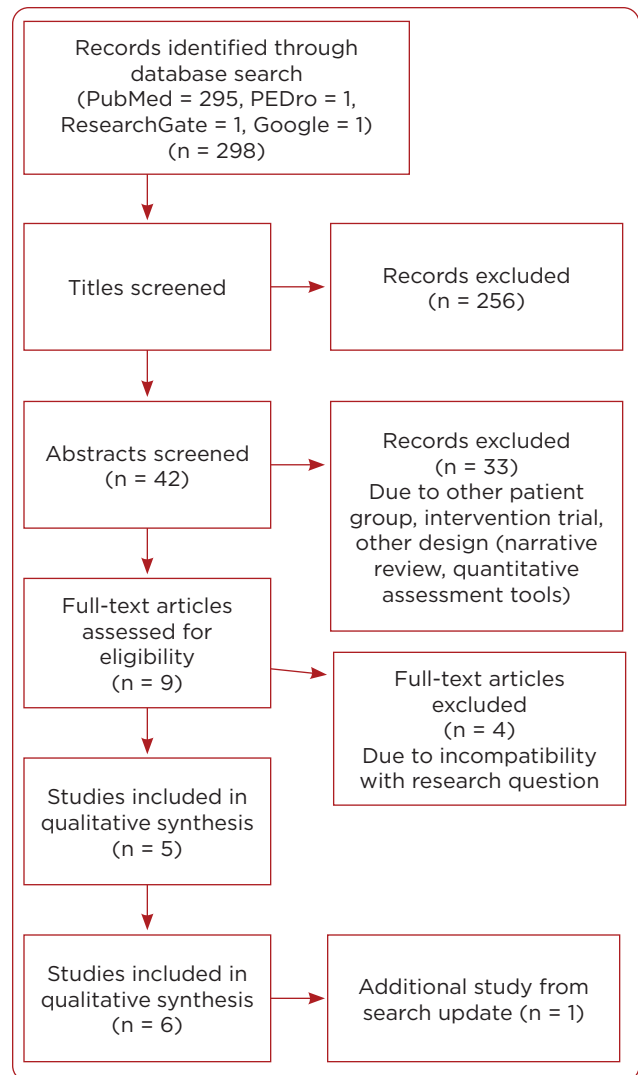


Figure 1. Flow diagram of studies.

additional question about the edema-causing onset (Noble-Jones et al., 2014b).

Lower-Extremity Lymphedema Screening Questionnaire

The Lower-Extremity Lymphedema Screening Questionnaire (LELSQ) has 13 questions (skin tension, feeling of heaviness, pain, daily course, and edema localization). Answers are scaled on a 5-point Likert scale (not at all/a little bit/some-what/quite a bit/very much; Yost et al., 2013). It was designed for and tested with women with confirmed LLL. During questionnaire development, the expert panel review recommended to add an image of the LL front view; however, the appendix offered no such image.

Lymphedema Symptom Intensity and Distress Survey–Lower Limb

The newly developed Lymphedema Symptom Intensity and Distress Survey–Lower Limb (LSIDS-L) consists of 31 questions. It was reduced from a first draft (36 questions). The questionnaire should be answered first dichotomously (yes/no) and second with a 5-point intensity and distress rating (1 = slight and 5 = severe) if the first answer was “yes.” The questions are summarized in eight clusters (overall activity, soft tissue sensation, pain, resources, biobehavioral, neurological sensation, function, sexuality). Individual scores are calculated by summing up the intensity and distress ratings for the “yes” responses; “no” responses were assigned a value of zero (Ridner et al., 2018).

The questionnaire lengths had a range of 13 to 31 questions (mean: 23.8; standard deviation: 6.03). For an assessment on the topics of questions, see Table 1. The psychometric data is presented in Table 2.

DISCUSSION

Need for Specific PROMs

In the past, generic instruments were used to assess the HRQoL in cancer patients with lymphedema and patients with other lymphedema origins with questionable outcomes because of reduced patient centering and sensitivity. Fayers and Machin (2002) report the necessity of assessments, which can evaluate more than a “simple” HRQoL. Health-related quality of life must be perceived as a valuable and crucial outcome parameter for lymphedema patients. But even questionnaires dedicated to lymphedema and QoL can easily reach their limitations if multiple edema localizations (arm, leg, head, trunk, genitals) are reconsidered. Therefore, Klernäs and colleagues (2015) promoted the use of specifically developed questionnaires to evaluate the specific symptoms and problems of this patient group. Kohlmann (2014) supports this notion and recommended the use of disease-specific questionnaires if health restrictions cannot be captured sufficiently by generic instruments. This allows a discriminated evaluation over a longer period. The rate of secondary LLL increased slightly by 2% in the 1.5 years following surgery (Watson et al., 2019), showing the need for a practical instrument. In everyday practice, practitioners from

different health professions need instruments that are (a) comprehensible (foremostly for patients), (b) easy to interpret, (c) time-saving to apply, and (d) reliable measurements of whether an existing lymphedema is worsening or improving, in order to reflect the disease-specific quality of life.

Lower Limb Specifics

Edema of the UL and the LL are comparable in various, but obviously not all, parameters. Questionnaires for LL and genital lymphedemas are indispensable, because patient-specific complaints differ distinctly from those of patients with arm lymphedemas. Ridner and colleagues (2012) showed in a sample of 1,837 patients that LLL patients have significantly worse symptoms, more infections, and hospital admissions. Therefore, early diagnosis and medical health-seeking behavior can lead to sufficient therapy and avoid unwarranted physiological and psychological consequences, such as edema deterioration or social retreat.

Patients with leg lymphedema show a worse QoL than patients with arm lymphedema (Noh, et al., 2015). For Morgan and colleagues (2005) and Beesley and colleagues (2007), the most critical denominators affecting QoL were numbers of experienced erysipelas, the presence of pain, skin quality, edema localization on the dominant hand, and a restricted limb range of motion, respectively. Upper limb dominance is certainly more important than lower limb dominance, but the other denominators should also be present in a LL tool. For example, questions about the skin were missing in two questionnaires (Keeley et al., 2010; Ridner et al., 2018; Table 1), even though skin problems are very common in lymphedema (MacLaren, 2001). To establish adequate skin care and prevent episodes of cellulitis (Rich, 2007), patients must be sensitized towards skin problems, which justifies questions such as those listed in the other tools (Table 1). Only two tools (Devoogdt et al., 2014; Noble-Jones et al., 2014b) asked about past infections. This is considered crucial because of knowledge building and subsequent adequate prophylactic behavior. Episodes of erysipelas/cellulitis worsen the lymphedema status (Oh, 2015) and lead to a further compromise in HRQoL.

Questions on pain and/or discomfort are crucial because of pain presence even in the primary

Table 1. Questionnaires by Semantical Category

	Yost	Keeley	Devoogdt	Carter	Noble-Jones	Ridner
Year of publication	2013	2010	2014	2010	2014	2018
Name of assessment	LELSQ	LYMQOL	Lymph-ICF-LL	GCLQ	LGUCQ	LSIDS-L
<i>Semantical category</i>	<i>Number of questions</i>					
1. Edema/edema localization/fistulas	8	0	0	5	4	1
2. Skin problems	2	0	1	3	4	0
3. Pain/pain localization	1	1	1	1	1	4
4. Complaints/discomfort (e.g., numbness, stiffness, tightness, tenderness because of compression, dysesthesia, tingling)	1 ^a	2	2	4	2	6
5. Heaviness	1	1	1	1	0	1
6. Activities of daily life (ADL function, job, household tasks, cognitive function)	0	7	8	0	3	4
7. Sleep	0	1	0	0	0	1
8. Movement restrictions (limbs, overall)	0	0	0	5	0	0
9. Strength	0	1	0	1	0	0
10. Infections	0	0	1	0	2	0
11. Psyche	0	5	5	0	0	5
12. Financial strain (therapy costs, compression costs)	0	0	0	0	0	2
13. Clothes/shoes	0	4	1	0	1	0
14. Information/advice on lymphedema	0	0	1	0	2	0
15. Overall QoL	0	1	0	0	1 ^b	0
16. Time periods	1	0	0	0	1	0
17. Sexual/urogenital function	0	0	0	0	2	4
18. Leisure/social activities	0	3 ^c	4	0	0	2
19. Dependency	0	1	3	0	0	0
20. Appearance	0	1	0	0	0	1
Sum of items	13	28	28	20	23	31

Note. ^aPain and complaints were combined in one question, so this is just one question.

^bOpen question.

^cQuestion was first closed then combined with an open question to specify certain leisure activities.

absence of swelling. Pain in lymphedemas is more prevalent than expected: In one study, 50% of patients experienced pain (Moffatt et al., 2003). In every questionnaire scrutinized, pain is considered an important matter.

A restriction in the range of motion is a potential complication of lymphedema (Grada & Phillips, 2017). Questions on movement restrictions were found in one of the questionnaires (Carter et al., 2010). As movement restrictions have a close connection to one's ability to perform normal

ADLs, they can affect QoL or lead to the need for help in certain situations (Kuvalekar et al., 2015).

Only two assessments (Devoogdt et al., 2014; Noble-Jones et al., 2014b) covered questions about patient-related lymphedema knowledge. Disease knowledge and the best management of this knowledge are paramount for patients. A lack of information or delayed information is a frequent complaint (Beesley et al., 2007; Biglia et al., 2017). The course of lymphedema and HRQoL could be improved by patient-centered knowledge building

Table 2. Psychometric Data

Author/Year	ICC/Test-Retest Reliability	Internal consistency/Cronbach's alpha	Sensitivity (%)	Specificity (%)	Construct validity/correlation	MCID
Yost, 2013	NR	NR	92.6	86.1	NR	NR
Keeley, 2010	0.542–0.909	0.874–0.945	NR	NR	EORTC QLQ-C30: 0.644–0.805	NR
Devoogdt, 2014	0.92	0.96	NR	NR	SF-36: -0.46 to -0.86 moderate to strong ^a ; 0.04–0.32 no to weak ^b	20
Carter, 2010	NR	0.95	64.29–96.43 ^c	63.33–100	NR	NR
Noble-Jones, 2014	NR	NR	NR	NR	NR	NR
Ridner, 2018	NR	0.940	NR	NR	MCSDS-SFC-0.05, FAS-Q: -0.65, POMS-SF: 0.67	NR

Note. NR = not reported; ICC = intraclass correlation coefficient; MCID = minimal clinically important difference; MCSDS-SFC = Marlowe–Crowne Social Desirability Scale Short Form C; EORTC-QLQ = European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; SF-36 = Short Form Health Survey.

^aConvergent validity.

^bDivergent validity

^cAt a potential clinical cutoff score ≥ 3 to ≥ 6 .

and proper patient education (Wittink & Oosterhaven, 2018).

Activities of daily living can be impaired because of heavily swollen limbs, leading to overexertion and pain (Elumelu-Kupoluyi et al., 2013). Activities of daily living vary distinctly in relation to the limb. A gripping function impairment cannot be compared with the decline of locomotion, as could be shown by Manns and Chad (2001), who examined subgroups among spinal cord injury patients. For this reason, lymphedema questionnaires should focus on just one limb. Two tools, those of Yost and colleagues (2013) and Carter and colleagues (2010), did not include questions about ADLs, although a correlation between QoL and ADL could be shown in different diseases (Allami et al., 2017; Chang et al., 2017).

Genital Edema and Sexual Function

Even a restriction to LLL can prove insufficient because of sex. Male genitalia may demand further differentiation when it comes to edema localization. Questionnaires for both sexes must consider the language of the target population; hence, the wording must be accurate and comprehensible (e.g., “penis” or “labia”); technical jargon should be avoided (Choi & Pak, 2005). A genital lymphedema represents first a taboo, secondly often a disfigurement, and thirdly affects sexual function

(Garaffa et al., 2008). This affects QoL gravely (Atta et al., 2018; Carter et al., 2013). Questions about genital edema and/or sexual or urogenital function are often missing in generic instruments. Four of the mentioned questionnaires (Carter et al., 2010; Noble-Jones et al., 2014b; Ridner et al., 2018; Yost et al., 2013) ask about edema or edema localization, respectively (Table 1). Noble-Jones and colleagues (2014b) added a drawing of the lower body and the male genitalia. Noble-Jones and colleagues (2014b) and Ridner and colleagues (2018) were the only ones to ask about sexual and/or urogenital function, as were Augustin and colleagues (2018) in their tool (FLQA-LS) for both extremities. Body charts can facilitate and complete the patients' answers and give a clearer picture about their awareness (Cheung et al., 2016); they can therefore be recommended. In 2016, Yamamoto and colleagues introduced the Genital Lymphedema Score (differently weighted questions, nine points in total), which asks about “urinary troubles” and “genital lymphedema” and found it well associated with the genital lymphedema severity staging system.

Clothing and Shoes

The edema localization makes a great difference for afflicted patients with respect to the choice

and availability of clothing (Ridner, 2009). Larger outer garments for the upper body are easier to come by than bigger shoes, which may only be necessary for one foot. Many patients are obese as well, so finding clothing is further compromised. The inability to find suitable clothes/shoes also affects patients' self-esteem (Grada & Phillips, 2017). Nonetheless, only three questionnaires (Devoogdt et al., 2014; Keeley et al., 2010; Noble-Jones et al., 2014b) offered questions about clothing and/or shoes. An example of addressing clothing options can be found in the Laval Questionnaire, which is designed to measure the QoL in heavily obese patients and contains a special domain for clothing (Therrien et al., 2011). As obesity has a positive correlation with lymphedema (McNeely et al., 2011), the weight of the patient should be assessed.

Psychological Stress

Lymphedema patients are exposed to more psychological stress than healthy subjects. Zaleska and Olszewski (2017) demonstrated an elevated cortisol level in a population sample. Stress and poor QoL are correlated in healthy populations (Opoku-Acheampong et al., 2017) and even more so in patients (Yagil et al., 2018). Depression or anxiety are therefore possible comorbidities in lymphedema patients (Grada & Phillips, 2017).

Three questionnaires (Devoogdt et al., 2014; Keeley et al., 2010; Ridner et al., 2018) covered questions in relation to the psychological burdens linked to lymphedema disease. Better informed patients bear their disease burden more easily. Disease-related knowledge, which was communicated with the patient in the course of their diagnosis and treatment, can influence stress and therefore affect outcomes (Ivarsson et al., 2017). Deng and colleagues (2013b) and Beesley and colleagues (2007) emphasized the poor level of information concerning causes, risk factors, and possible complications in patients with LLL. It is therefore legitimate, responsible, and helpful to ask about a patient's information level and their difficulties in coping.

Questionnaire Length and Style

It is a challenge to offer sufficient questions on extensive subthemes but also limit the questionnaire's length in order to enhance the response

rate (Choi & Pak, 2005; Sahlqvist et al., 2011). The range in this sample of questionnaires lay between 13 to 31 questions. A meta-analysis by Rolstadt and colleagues (2011) indicated that the selection of the appropriate tool should be based more on content than on the number of questions. Patients with LLL show a wider variety of symptoms than patients with ULL; therefore, more questions are justified. Kohlmann (2014) drew the same conclusion. According to the criteria of appropriateness, a qualified tool should reflect the expected HRQoL value range in a structured and systematic manner; otherwise, floor or ceiling effects can accumulate. This leads to negative consequences on the tool's responsiveness (Kohlmann, 2014). Considering the number of possible answers in a psychometric/Likert-based rating scale, Krosnick and Presser (2010) suggested that in terms of the reliability, validity, and differentiation, a number from five to seven answers suits the purpose best. The favorable number depends on the proband's cognitive skills. Verbal items should be favored as opposed to numerical items (Devoogdt et al., 2014). More answers enhance the precision of the variable in question, while fewer answers jeopardize the ordinally measured continuum. Dichotomous answers (Carter et al., 2010) offer a swift overview but lack differentiation.

Double-barreled questions (Choi & Pak, 2005), that is, two questions combined in one, carry the risk of ambiguity and attenuate the questionnaire's validity. "Pain" and "discomfort" were combined by Yost and colleagues (2013), which is an example of double barreling. This can lead to missing answers and should ideally be avoided (Kohlmann, 2014). Pain and discomfort may be seen as synonyms, but the connotations can be different. The task force on taxonomy of the International Association for the Study of Pain defines pain as "An unpleasant sensory or emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Kumar & Elavarasi, 2016). Discomfort may mean mild pain or can also comprise a broader spectrum of health-related symptoms, as Williams demonstrated (2003). Correspondingly, Klernäs and colleagues (2015) in their tool (LyQLI) differentiated pain and discomfort in two questions. A tool for efficient clinical practice contains all the imaginable disease-

specific categories needed to distinguish whether the condition is present or not, or whether it is stable or unstable, but it also needs to avoid redundancy.

Edema and Financial Strain

Specific questions about therapy and other expenses, such as compression garments, are missing in all of the analyzed tools except for that of Ridner and colleagues (2018), who asked about insurance issues. Financial strain can present a significant factor in HRQoL, because lack of money is one potential psychosocial factor for stress (Butcher et al., 2009). The average cost for the handling of ULL after breast cancer was A\$977 per year, with 40% of this sum dedicated to compression garments (Boyages et al., 2017). Financial expenses were mentioned by Klernäs and colleagues (2015) and Augustin and colleagues (Knöfel, 2014), two nonextremity-specific tools. Not only are the rehabilitation and treatment costs of relevance (Ridner, 2009), additional financial efforts in terms of more/other clothes, hot weather/sun protection, being prepared for emergencies (Klernäs et al., 2015), and inability to work and dependency on social benefits are to be considered (Biglia et al., 2017). Lymphedema is often a lifelong condition; therefore, the financial strains can be grave (Beesley et al., 2007; Ostby & Armer, 2015). This is aggravated when the costs are considered too high or problems with insurance reimbursement arise (Ridner, 2009).

Psychometric Data

Cronbach's alpha is an important measure in questionnaire reliability. It demands only a single test application. Cronbach's alpha should always be reported when Likert-type scales are used (Gliem & Gliem, 2003). A level of 0.80 to 0.89 is considered "good," and a level between 0.90 to 0.95 indicates excellent internal consistency. Levels above 0.95 indicate redundancy and therefore superfluous items. Cronbach's alpha is missing for two questionnaires (Noble-Jones et al., 2014a; Yost et al., 2013, Table 2). Devoogdt and colleagues (2014) exceeded the 0.95 threshold, indicating a slight redundancy (Gabel et al., 2013). The best results were achieved by Keely and colleagues (2010) and Ridner and colleagues (2018). The German version of Devoogdt's Lymph-ICF-LL by

Allofs and colleagues (2019) showed moderate to strong internal consistency (Cronbach's alpha of 0.69–0.88) and was classified as the first "reliable and valid ICF-based questionnaire for patients with lower limb lymphoedema in Germany." Van de Pas and colleagues (2016) reported good internal consistency (Cronbach's alpha of 0.89) in the Dutch version of Keeley's LYMQOL Leg (van de Pas et al., 2016). Finally, a recent study tested the LYMQOL Leg in a Turkish-speaking population and conceded good internal consistency and test-retest reliability (Cronbach's alpha of 0.85–0.90, test-retest intraclass correlation coefficient [ICC] of 0.68–0.85), respectively, as well as external construct validity (Borman et al., 2020).

The ICC is a widely used coefficient to evaluate the interrater, test-retest, or intrarater reliability, respectively. It is used to specify test reliability in continuous and categorical variables (Lee et al., 2012). The ICC estimates should include a 95% confidence interval (CI) for further narrowing, whether the value lies in the poor range (< 0.5), moderate range (0.5–0.75), good range (0.75–0.9), or excellent range (> 0.9; Koo & Li, 2016). Two questionnaires reported the ICC, and four did not (Table 2). Ridner and colleagues (2018) saw the need to assess test-retest reliability later on. For the rest, it was either excellent (for the whole tool) or between moderate and excellent (for the different subscales). Allofs and colleagues (2019) stated a "moderate to very strong ICC for different subscales (0.36–0.95)" test-retest reliability for the German version. According to statistical standards, a level of 0.36 is deviated from being moderate (Koo & Li, 2016; Perinetti, 2018). This could only be explained by the very low number of subjects ($n = 10$), where the moderate range shifts downwards to start from 0.30 (Bortz & Döring, 2006). The ICC for the total score was in fact moderate (0.67) but with a very broad CI (0.13–0.91; Allofs et al., 2019). One explanation could also be the low number of subjects or a low variability between these subjects, as shown by Bland and Altman (1990) and further explained by Lee and colleagues (2012). Van de Pas' test reliability in the Dutch version was between 0.73 (ICC overall QoL) and 0.91 (appearance/body image), with also a good construct validity compared with the physical components of the 36-Item Short Form Health Survey (SF-36; van de Pas et al., 2016).

The minimal clinically important difference (MCID) is defined as “the smallest difference in score in the domain of interest which patients perceive as beneficial and which would mandate...a change in the patient’s management” (Cook, 2008; Jaeschke et al., 1989). The MCID is important in distinguishing between statistically significant changes and clinically relevant changes, because even small differences could become significant without a perceivable change for the patient. For computing, a numerical recoding of Likert-scaled questionnaires is necessary. Only Devoogdt and colleagues (2014) calculated the MCID, which reached 20 points in their assessment tool (Table 2).

Two tests (Carter et al., 2010; Yost et al., 2013) offered a sensitivity and specificity analysis. Noble-Jones and colleagues (2014a) declared further research to establish sensitivity/specificity would be required. This analysis provides further value when tests should be used as a screening instrument. Especially high sensitivity numbers are crucial if screening is intended (Cleland & Koppenhaver, 2011). To determine this data, a definitive indicator, the so-called gold standard, displays the reference (Trevethan, 2017). Unfortunately, the gold standard for lymphedema diagnosis is still being debated (Hidding et al., 2016). There is agreement that in many cases, accurate anamnesis and clinical assessments should suffice (Greene & Goss, 2018; O’Donnell et al., 2017; Ure & Döller, 2011). Greene and Goss (2018) propose lymphoscintigraphy for definitive diagnoses with 96% sensitivity and 100% specificity. Ward (2009) strongly encourages the bioelectrical impedance spectroscopy (BIS), whereas circumference measurement is limited to 42% sensitivity and 88% specificity compared with BIS. There is agreement with Chromy and colleagues (2015) that most methods measure total limb volume, but a differentiation between edema, muscle mass, or fat is not possible. Therefore, CT and MRI, although expensive, should be offered as new appropriate measurements.

There are ongoing debates in scientific research on the demand of diagnostic clear and valid cut-off values for the diagnosis and monitoring of lymphedemas (Göker et al., 2013; Levenhagen et al., 2017; Ward et al., 2011). Valid and reliable questionnaires can function as sensitive cut-off values for the (self-)

discrimination of patients with or without lymphedemas. Carter and colleagues (2010) proposed using questionnaires as a time-efficient method to screen patients in a clinical setting. Beyond that, such tools should also be used in extramural medical care. With longer-stretched time sequences of postsurgery cancer care, patients are more likely to present themselves at private practices. Furthermore, such issues should be addressed not only once but more often before cancer patients are discharged after surgery and during their following therapies. When taking only PROMs into account to create a cut-off value for lymphedema, a sensitivity/specificity analysis is indispensable. Therefore, for research purposes, the tools by Yost and colleagues and Carter and colleagues would be recommended. If one is measuring treatment efficacy in patients’ terms and wants to ensure the change from the patients’ point of view, Devoogdt and colleagues’ tool should be used. For everyday clinical practice and because of its comparatively good comprehensiveness (missing questions on edema localization, sexual/urogenital function, financial strain, specific movement restrictions, and sleep), Devoogdt and colleagues’ questionnaire can also be recommended.

The only German translation by Allofs and colleagues (2019) was faced with a poor construct validity and could therefore accept only 5% percent of their hypotheses. It remains questionable that the test measures what it is supposed to measure given the concept of construct validity (Smith, 2005). This leaves room for further research on LLL assessments and translations into German. Ideally, assessments from specialized therapists and PROMs should amend each other and be consistent in their evaluation (Iyer et al., 2018).

CONCLUSION

The analyzed questionnaires were in English or translated into other languages, and only one was adapted and tested for native German speakers. The questionnaires differed in length, scope, style, focus, and answer schemes. There was a lack of psychometric reporting. The lack of clear cut-off values for lymphedema and the notable lack of diagnostic accuracy of lymphedema further complicated the analysis. Given the content, every questionnaire has its advantages and disadvan-

tages. Therefore, recommendations for a certain tool differ depending on the purpose. For clinical practice, Devoogdt and colleagues' questionnaire is recommended despite some shortcomings. Further studies should center on standardized, validated questionnaires with broad coverage of disease-specific topics. There is a need for validated lymphedema questionnaires in German. ●

Disclosure

The author has no conflicts of interest to disclose.

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