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# Development and Validation of a Telephone Questionnaire to Characterize Lymphedema in Women Treated for Breast Cancer

**Background and Purpose.** Accurate and economical characterization of lymphedema is needed for population-based studies of incidence and risk. The purpose of this study was to develop and validate a telephone questionnaire for characterizing lymphedema. **Subjects.** Forty-three women who were treated previously for breast cancer and who were recruited from physical therapy practices and a cancer support organization were studied. **Methods.** Questionnaire assessment of the presence and degree of lymphedema was compared with physical therapists' diagnoses, based primarily on circumferential measurements. Twenty-five of the 43 subjects were measured independently by 2 physical therapists to assess interobserver agreement. **Results.** Interobserver agreement on clinical assessments of the presence and degree of lymphedema was high (20/25, weighted kappa=.80); all of the disagreements were between judgments of whether there was no lymphedema or mild lymphedema. For the diagnosis of at least moderate lymphedema (differential in the circumferences of the upper extremities greater than 2 cm), sensitivity of the questionnaire varied from 0.86 to 0.92 and specificity was 0.90. However, sensitivity (varying from 0.93 to 0.96) was higher than specificity (varying from 0.69 to 0.75) for the diagnosis of any lymphedema. **Discussion and Conclusion.** A few straightforward questions exhibited excellent agreement with physical therapists' assessments for identifying at least moderate lymphedema. [Norman SA, Miller LT, Erikson HB, et al. Development and validation of a telephone questionnaire to characterize lymphedema in women treated for breast cancer. *Phys Ther.* 2001;81:1192-1205.]

**Key Words:** *Breast neoplasms, Health status, Lymphedema, Questionnaires.*

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**A**lthough lymphedema of the upper extremity has been identified by women experiencing it as one of the most distressing long-term consequences of breast cancer treatment,<sup>1-4</sup> there are inadequate data about the incidence of lymphedema or about the likelihood of mild, moderate, or severe lymphedema. Incidence rates of 60% or higher associated with the use of the Halsted radical mastectomy in conjunction with radiation no longer occur, but studies published since 1980 generally describe rates of lymphedema varying from 5% to 9%<sup>5-14</sup> at the low end to around 25% or greater.<sup>4,15-24</sup> Some of the variation may stem from the lack of consistent definitions and methods used to measure incidence.

*Incidence* is defined as "the number of new cases of a disease occurring in the population during a specified

period of time divided by the number of persons at risk of developing the disease during the period of time."<sup>25(p31)</sup> There are few published studies that are truly incidence studies. Most are retrospective studies of a series of patients at a single institution, often from single departments. The ability to estimate incidence rates is also limited because of incomplete information about the total number of patients at risk for developing lymphedema and incomplete information on the occurrence of lymphedema among those included in the analysis. There are also insufficient data on the time frame over which the lymphedema was measured and the time course during which lymphedema developed. Information about patient- and treatment-related risk factors for the occurrence of lymphedema is equally sparse, particularly regarding the interaction among these factors and the magnitudes of the relative risks

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associated with them. These factors also affect estimates of incidence.<sup>7,8,10-12,16,18-21,26-32</sup> Thus, there is a need for large, prospective, population-based studies to assess the incidence and degree of lymphedema among women who have been treated for breast cancer, as well as risk factors for its development and effect on quality of life.

Among the difficulties in conducting prospective studies of incidence is the expense of measuring the limbs of a large number of women to characterize lymphedema at multiple time points with methods currently practiced. Circumferential methods<sup>7,9,13,15,16,18,19,28-34</sup> and volumetric methods<sup>2,12,13,17,20,29,30,35</sup> generally compare the treated and untreated sides, with differences between the 2 sides exceeding specified criteria indicating the presence and degree of lymphedema. Assessments by clinicians or by patients also have been used to diagnose lymphedema,<sup>5,8,10,11,13,16,18,23,24,30</sup> and, although observation of swelling is generally a component of the diagnosis, the criteria used are not always clearly specified.

The primary objective of our study was to develop and validate a telephone questionnaire for studying the incidence and degree of lymphedema in women who have been treated for breast cancer. We believe that what is needed is a method for obtaining self-reports of upper-extremity swelling that would have excellent agreement with measurements commonly obtained by health care professionals. The method would be easily described and implemented, brief, relatively inexpensive to administer, and suitable for a large, prospective, population-based study. Contributing to our decision to try to characterize lymphedema by self-report was the fact that there is little agreement on other measures of lymphedema in the literature. Interestingly, in one study in which there were systematic comparisons of 3 methods of assessing lymphedema—volumetric, circumferential, and patient's and observer's assessment of lymphedema (described as subjective assessment)—the authors<sup>30</sup> considered the latter method to be the "more important" method, although the rationale for this decision was not stated. We will describe the developmental phases of the questionnaire and the first validation study.

## Methods

### *Questionnaire Development and Content*

We identified what we consider to be relevant aspects of lymphedema through a literature review and consultation with experts and by conducting 2 focus groups, one with 7 women and the other with 8 women who were diagnosed with breast cancer and who were being treated for lymphedema. Participants in the focus groups were asked, "How did you come to know that you had lymphedema?" and "What did you notice?" The

narratives indicated to us that it was possible for substantial time to elapse between a woman's first noticing a swelling in her upper extremity and the diagnosis of lymphedema. In some cases, the woman had approached a clinician with a concern about her upper extremity but had been told not to worry about it or that there was nothing that could be done, and diagnosis and treatment were delayed. Other women did not seek help, even though they may have noticed swelling, until someone else noticed the swelling and encouraged them to seek help. Thus, we concluded that a questionnaire that simply asked women whether they had lymphedema or whether they had ever been diagnosed with lymphedema by a health care professional would potentially miss a considerable number of people with the condition. The most consistently described ways in which people noticed a problem related to size were: (1) swelling, sometimes involving the whole upper extremity and sometimes limited to the hand or fingers, (2) watches, rings, bracelets, or clothing becoming too tight on one side, (3) puffiness, (4) difficulty in seeing knuckles or veins on one side, and (5) noticing that one upper extremity was larger than the other upper extremity after losing weight. Pain and changes in tissue texture were also noted, but not consistently, by the respondents. Some participants reported that the size of the affected body part changed gradually, and other participants said that the onset was sudden and striking.

Based on these responses during the focus groups, we developed a set of questions that asked, first, whether the respondent noticed that there was a difference in the size of her hands or arms, and, second, if a difference was noted, for an assessment of the degree of difference. In our questionnaire (available on request from the authors), we used the terms "lower arm" for forearm, "upper arm" for arm, and "arm" for upper extremity, because we believed that these less technical terms were best understood by the respondents. Throughout the remainder of this report, we will use the terms that were used in the questionnaire rather than the classic anatomical names. The following sequence of questions, repeated for the hands, lower arms, and upper arms, formed the basis for the diagnosis of lymphedema and assessment of its severity.

The women were first asked: "During the past 3 months, did your right and left [hands/lower arms/upper arms] seem to you to be different sizes from each other?" To assess the size of the difference, women who noticed any difference in size between the 2 limbs were asked: "During the past 3 months, would you say that, on average, the difference in the size of your [hands/lower arms/upper arms] was (1) very slight, you are the only person who would notice this, (2) noticeable to people who know you well but not to strangers, or (3) very

noticeable?" Our rationale for choosing these descriptions to categorize the amount of difference between the limbs was to be able to distinguish between women who noticed a very slight difference (ie, women who might be described as having mild edema but whose lymphedema might not be consistently diagnosed by health care professionals) and women with a degree of swelling that would indicate at least moderate lymphedema and that would also be more consistently diagnosed by a clinician. The method for scoring the answers to these questions in order to diagnose the presence and degree of lymphedema is described in the "Data Analysis" section.

More detailed information about potential symptoms of lymphedema was obtained using the format of the Memorial Symptom Assessment Scale (MSAS).<sup>36</sup> Symptoms included tightness of rings, watches, bracelets, and clothing on one side of the body and other differences between the 2 limbs such as puffiness; firm or leathery skin; tired, thick, or heavy hand or arm; pain; indentations in skin after leaning against something; inability to see the knuckles or veins on one hand; swelling after exercise; and difficulty writing. All women were asked about symptoms, even if they had not noticed any differences in the size of their hands or arms. The women were asked whether they had experienced each symptom in the past 3 months. Those answering "yes" for any symptom were asked: (1) "How often did this occur in the past 3 months—rarely, occasionally, frequently, or almost constantly?" (2) "How severe was it in the past 3 months—slight, moderate, severe, or very severe?" and (3) "How much did it distress or bother you in the past 3 months—not at all, a little bit, somewhat, quite a bit, or very much?" The presence of these symptoms was not used to diagnose lymphedema. Rather, this information was used to assess the agreement of perceived differences in size with the presence and severity of other relevant characteristics of lymphedema.

#### Questionnaire Validation

Before any data were collected, the questionnaire was reviewed by women with lymphedema and a panel of 12 experts to assess the face and content validity of future data to be collected with the questionnaire. The panel of experts included those in the fields of epidemiology; psychometrics; nursing; radiation oncology; surgery; oncology; physical therapy, with experience in the diagnosis and treatment of lymphedema; neurology, with expertise in use of the MSAS<sup>36</sup> for patients with cancer; and dermatology, with expertise in edema. Changes to the questionnaire were made as recommended. To assess concurrent validity, the questionnaire results were compared with physical therapists' diagnoses, which were based primarily on the measurement of lymphedema using circumferential measures of both arms.

#### Data Collection

**Subjects.** The study group consisted of 43 women who had been treated for breast cancer (41 with unilateral breast cancer and 2 with bilateral breast cancer). Sixteen of the subjects were volunteers recruited from the practices of 2 physical therapists (LTM and HBE), a private physical therapy center and a physical therapy practice at a large university hospital, respectively. All of these women had lymphedema according to their therapists' diagnoses. All patients with lymphedema who were seen by the 2 physical therapists during the recruitment period were offered the opportunity to participate; each patient was given a letter describing the study and inviting her participation. Twenty-seven participants were recruited through a mailing from the Wellness Community, a cancer support organization. The mailing encouraged women without lymphedema, as well as those with lymphedema, to participate.

The mean age of the respondents was 54.1 years (SD=11.4, range=33–78). Eighty-four percent of the participants were white, and 16% were black. Of the 43 respondents, 65.1% had 4 or more years of college, 16.3% had some college or some post-high school technical or vocational training, 14.0% had graduated from high school, and 4.7% had not completed high school. The mean time from first diagnosis of breast cancer to the start of the study was 3.0 years (SD=2.9, range=0–12). No woman noticed any difference in the size of her arms before her breast cancer surgery.

We formed the study group in an effort to provide a sufficient number of participants to estimate both the sensitivity and specificity of the questionnaire. *Sensitivity* indicates how often a test detects a condition when it is present.<sup>37</sup> Thus, we defined sensitivity as the proportion of women with clinically diagnosed lymphedema whose questionnaire results indicated the presence of lymphedema. *Specificity* indicates how often a test is negative in the absence of a condition.<sup>37</sup> Thus, we defined specificity as the proportion of women without lymphedema whose questionnaire results indicated that they did not have lymphedema. Because we were conducting an initial study to develop a questionnaire to assess lymphedema through self-report, it was necessary to begin with people who were previously diagnosed with varying degrees of lymphedema to determine whether the questionnaire could be used not only to identify the lymphedema but also to assess the severity of the lymphedema. A potential concern for us in using self-reports was whether the women would exaggerate the severity of their condition. However, if self-reported severity of lymphedema agreed with the physical therapists' diagnosis and assessment of severity, the credibility of the questionnaire results in a population-based study would be strengthened. All par-

ticipants signed a consent form approved by the Institutional Review Board at the University of Pennsylvania before participating in the study.

**Telephone interview.** The questionnaire was administered by telephone by a lay interviewer who did not know the lymphedema status of the participants prior to the interview. All interviews of the Wellness Community members were completed within a month prior to the physical measurements.

**Physical therapists' diagnoses of lymphedema.** A standardized form developed for the study was used to record circumferences of right and left arms at 6 points: palmar crease, wrist, forearm 4 and 6 in (10.2 and 15.2 cm) above the capitate bone, and upper arm 4 and 6 in above the midpoint of the olecranon. The 2 physical therapists (LTM and HBE) who did the measurements agreed in advance on differences between circumferences of the 2 limbs that would correspond to mild, moderate, and severe lymphedema. These differences were less than or equal to 2 cm (mild lymphedema), greater than 2 cm and less than 5 cm (moderate lymphedema), and 5 cm or more (severe lymphedema). Diagnosis of mild, moderate, or severe lymphedema was to be determined primarily by applying this rule to the maximum of the 6 circumference differences. The lower boundary for the diagnosis of lymphedema was not specified. The physical therapists were to use their expert judgment, as they would in their practices. Similarly, the therapists agreed that clinical judgment would also include considerations of tissue texture, handedness, and side of the breast cancer; these judgments would enter mostly into borderline decisions.

The measurements of the Wellness Community participants were done by both physical therapists, independently, on the same day to assess interobserver variation. For the 16 private patients of the physical therapists not seen at the Wellness Community, the physical therapist recorded her most recent measurements of the patients onto our form. The physical therapists were masked to the responses on the questionnaire.

### *Data Analysis*

**Assessing agreement.** Two approaches to measuring agreement between the questionnaire results and the therapists' assessments were used. Both approaches were based on assigning the characteristics of lymphedema to categories of "no lymphedema," "mild lymphedema," and "moderate/severe lymphedema." There were only 2 women in the study whom the physical therapists classified as having severe lymphedema; thus, the categories of "moderate lymphedema" and "severe lymphedema" were combined. Our first approach used the weighted

kappa ( $\kappa_w$ ) statistic,<sup>38</sup> which is used to measure the level of agreement and severity of disagreement corrected for the amount of agreement expected by chance. This approach does not assume that either the therapist's assessment or the questionnaire measurement is more accurate than the other. The weighted kappa is particularly useful when there are multiple categories and disagreement between adjacent categories is less serious than disagreement between categories that are further apart.<sup>39</sup> Large weighted kappa values indicate small disagreement, in comparison with chance levels. The maximum is value 1, corresponding to perfect agreement, and values greater than or equal to .75 are considered indicative of excellent agreement.<sup>39</sup>

The second measure of agreement we used was based on the assumption that the diagnoses based on the physical therapists' measurements were the criterion. Sensitivity and specificity of questionnaire diagnoses of lymphedema were assessed in comparison with the physical therapists' diagnoses, categorizing respondents as having any degree of lymphedema versus no lymphedema, and moderate/severe lymphedema versus mild or no lymphedema. We categorized the data in these 2 ways to provide information on the performance of the questionnaire when any degree of lymphedema (mild, moderate, or severe) was of interest and when at least moderate lymphedema was the criterion for lymphedema, because there is not consensus in the literature about the diagnosis or clinical importance of mild lymphedema. The weighted kappa statistic was also used to measure interobserver agreement between the 2 physical therapists.

**Classifying questionnaire-based measurements of lymphedema.** Based on the questionnaire results, women were classified as having or not having lymphedema depending on whether or not they noticed any difference in size between their 2 hands, lower arms, or upper arms. If a woman did not notice a difference at any location, she was considered as not having lymphedema. If a woman noticed a difference at one or more locations, she was classified as having lymphedema. For each location at which a difference was noted, the following scores were assigned, depending on how the differences were rated: 1 (very slight; you are the only person who would notice this), 2 (noticeable to people who know you well but not to strangers), or 3 (very noticeable).

Two different methods for using these scores to distinguish between women with mild lymphedema versus moderate/severe lymphedema were examined. According to the first method (questionnaire method 1), if the maximum of these scores was at least 2, the woman was considered, on the basis of the questionnaire results, as

**Table 1.**Agreement Between Physical Therapists' Assessments and Rule-Based Assessments<sup>a</sup>

Physical Therapist 1's Assessment	Rule-Based Assessment		
	No Lymphedema	Mild Lymphedema	Moderate/Severe Lymphedema
No lymphedema	15	2	0
Mild lymphedema	2	11	0
Moderate/severe lymphedema	0	0	13

  

Physical Therapist 2's Assessment	Rule-Based Assessment		
	No Lymphedema	Mild Lymphedema	Moderate/Severe Lymphedema
No lymphedema	14	2	0
Mild lymphedema	2	11	1
Moderate/severe lymphedema	0	0	13

<sup>a</sup> Assessment was done by the physical therapist indicated, except for women seen only by the other physical therapist.

having at least moderate lymphedema; otherwise, it was considered mild lymphedema. According to the second method (questionnaire method 2), if the sum of these scores was at least 4, the woman was considered, based on the questionnaire results, as having at least moderate lymphedema. If the sum was less than 4 but greater than 0, mild lymphedema was thought to be present. A sum of 4 could be obtained in a variety of ways, but it required that a difference be noticed at more than one arm location, and the difference at some location had to be at least "noticeable to people who know me well but not to strangers." Thus, questionnaire method 2 provided a more strict criterion for determining moderate/severe lymphedema.

#### *Classifying physical therapists' diagnoses of lymphedema.*

Because the objective of our study was to compare the questionnaire results with measurements normally obtained by health care workers, as would occur in practice, the primary comparison of the questionnaire results was with the physical therapists' diagnoses and classifications. However, because the criteria used by the therapists did not specify a lower boundary for any lymphedema and because clinical judgment is a factor in any diagnosis, we also examined a rule-based diagnosis and classification for each subject based on the measurements alone. We used the difference between the side with breast cancer and the side without breast cancer. (For the 2 women with bilateral breast cancer, the absolute difference between the sides was used.) For the rule-based assessment, categories of lymphedema were assigned based on the maximum of the differences at the 6 measurement locations (no lymphedema: less than or equal to 1 cm; mild lymphedema: greater than 1 cm and less than or equal to 2 cm; moderate lymphedema: greater than 2 cm and less than 5 cm; severe lymphedema: greater than or equal to 5 cm). With the exception of the boundary between no lymphedema and mild lymphedema, these were the cutoff points that the 2 therapists had specified in advance for their diagnoses. Our rule-based assessment was compared with the ther-

apist and questionnaire assessments of lymphedema to examine (1) how the therapists' decisions, which included measurement and clinical judgment, differed from decisions based on measurement alone, where a lower boundary was specified, and (2) how the questionnaire assessments compared with strict measurement criteria.

*Comparing diagnoses based on questionnaire results with frequency of other symptoms.* A one-way analysis of variance was used to compare the average number of symptoms in patients with diagnoses of no lymphedema, mild lymphedema, or moderate/severe lymphedema obtained with the questionnaire.

#### **Results**

Of the total group of 43 participants, 9 were patients of physical therapist 1 (LTM), and 7 were patients of physical therapist 2 (HBE). All of these women had lymphedema, according to their respective clinician's assessment. Of the remaining 27 women recruited from the Wellness Community, 25 were observed by both physical therapists, and 2 participants were measured by 1 of the 2 physical therapists. Interobserver agreement on clinical assessments was high (20/25), and the weighted kappa value was .80 (95% confidence interval [CI]=.59-1.00). The 20 agreements were 13 women with no lymphedema, 4 women with mild lymphedema, and 3 women with moderate/severe lymphedema. The 5 disagreements were all between judgments of whether there was no lymphedema or mild lymphedema, and neither observer was more likely than the other to classify the woman as having lymphedema. In each instance in which the physical therapists disagreed about whether the diagnosis was no lymphedema or mild lymphedema, the woman noticed a difference in the size of her arms.

Because interobserver agreement was not perfect and because only 25 of the 43 subjects were seen by both physical therapists, we have presented the results in 2

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**Table 2.**

Physical Therapists' Assessments: Agreement Between Questionnaire Results and Physical Therapists' Assessments<sup>a</sup>

	Physical Therapist 1			Weighted Kappa (95% CI)
	No Lymphedema	Mild Lymphedema	Moderate/Severe Lymphedema	
Questionnaire method 1				
No lymphedema	12	1	0	.74 (.56, .91)
Mild lymphedema	3	7	0	
Moderate/severe lymphedema	2	5	13	
Questionnaire method 2				
No lymphedema	12	1	0	.83 (.73, .93)
Mild lymphedema	5	9	1	
Moderate/severe lymphedema	0	3	12	
	Physical Therapist 2			Weighted Kappa (95% CI)
	No Lymphedema	Mild Lymphedema	Moderate/Severe Lymphedema	
Questionnaire method 1				
No lymphedema	12	1	0	.78 (.63, .92)
Mild lymphedema	3	7	0	
Moderate/severe lymphedema	1	6	13	
Questionnaire method 2				
No lymphedema	12	1	0	.84 (.74, .94)
Mild lymphedema	4	10	1	
Moderate/severe lymphedema	0	3	12	

<sup>a</sup> Assessment was done by the physical therapist indicated, except for women seen only by the other therapist. CI=confidence interval.

ways, first using physical therapist 1's results except for patients seen only by physical therapist 2 and then using physical therapist 2's results except for patients seen only by physical therapist 1. According to physical therapist 1's assessments, 26 women had lymphedema (13 with mild lymphedema and 13 with moderate/severe lymphedema), and 17 women did not have lymphedema. According to physical therapist 2's assessments, 27 women had lymphedema (14 with mild lymphedema and 13 with moderate/severe lymphedema), and 16 women did not have lymphedema.

Table 1 compares the physical therapists' assessments with rule-based assessments. Weighted kappa values were very high (physical therapist 1:  $\kappa_w=.93$ , 95% CI=.87-1.00; physical therapist 2:  $\kappa_w=.91$ , 95% CI=.84-.99). Virtually all of the disagreements were between judgments of whether there was no lymphedema or mild lymphedema. All but one disagreement involved the Wellness Community participants, and there was no overlap between physical therapists in which patients were classified differently based on the therapists' assessments and the rule-based assessments. All but one of these participants noticed a difference in the size of her arms.

As shown in Tables 2 and 3, both the therapists' and rule-based assessments showed excellent agreement with the questionnaire results. Table 2 shows the agreement between the physical therapists' determinations of no,

mild, and moderate/severe lymphedema and the questionnaire-based characterizations. Questionnaire method 2 showed better agreement with the therapists' assessments than questionnaire method 1. The weighted kappa values for questionnaire method 1 varied from .74 to .78, depending on the physical therapist. For questionnaire method 2, the weighted kappa values varied from .83 to .84. Table 3, comparing the rule-based assessments with the questionnaire results, also shows the superiority of questionnaire method 2. The weighted kappa value for questionnaire method 1 compared with the rule-based assessment was .70 for both physical therapists. For questionnaire method 2, the weighted kappa value was .76 for both physical therapists.

Tables 2 and 3 indicate that in most of the disagreements between the questionnaire results and the physical therapists' assessments, the patient's condition was judged to be more serious when based on the questionnaire results than when based on the therapists' assessments. The disagreements were on the off-diagonals, and there were more such observations below and to the left of the diagonal than above and to the right of the diagonal. This observation is expanded in Table 4, which shows the sensitivity, specificity, and overall proportion of women correctly classified when participants were categorized as (1) having any lymphedema versus no lymphedema and (2) having moderate/severe lymphedema versus mild lymphedema or no lymphedema. The physical therapists' assessments and the rule-based

**Table 3.**Rule-Based Assessment: Agreement Between Questionnaire Results and Physical Therapists' Assessments<sup>a</sup>

	Physical Therapist 1			Weighted Kappa (95% CI)
	No Lymphedema	Mild Lymphedema	Moderate/Severe Lymphedema	
Questionnaire method 1				
No lymphedema	12	1	0	.70 (.50, .91)
Mild lymphedema	2	8	0	
Moderate/severe lymphedema	3	4	13	
Questionnaire method 2				
No lymphedema	12	1	0	.76 (.57, .95)
Mild lymphedema	3	11	1	
Moderate/severe lymphedema	2	1	12	
	Physical Therapist 2			
	No Lymphedema	Mild Lymphedema	Moderate/Severe Lymphedema	Weighted Kappa (95% CI)
Questionnaire method 1				
No lymphedema	11	2	0	.70 (.52, .88)
Mild lymphedema	3	6	1	
Moderate/severe lymphedema	2	5	13	
Questionnaire method 2				
No lymphedema	11	2	0	.76 (.60, .92)
Mild lymphedema	4	9	2	
Moderate/severe lymphedema	1	2	12	

<sup>a</sup>Assessment was done by the physical therapist indicated, except for women seen only by the other therapist. CI=confidence interval.

assessments, respectively, were considered the "gold standard" in these analyses, which were done separately for each physical therapist. Results were similar when either the therapists' or rule-based assessments were the criterion. Sensitivity was higher than specificity when women were categorized as having any lymphedema versus none, indicating that although the questionnaire performed very well in identifying those women whom the physical therapists characterized as having lymphedema, the questionnaire tended to produce "false positives." However, there were only 2 instances in which both physical therapists agreed on the diagnosis of no lymphedema, and the women were diagnosed by use of the questionnaire (questionnaire method 2) as having mild lymphedema. All of the other instances of "false positives" were situations in which one but not the other physical therapist diagnosed lymphedema.

Questionnaire method 1 had higher sensitivity and a higher false positive rate (lower specificity) for moderate/severe lymphedema than questionnaire method 2 because it represented a more lenient criterion. Sensitivity (varying from 0.86 to 0.92) and specificity (0.90) were similar and high when questionnaire method 2 was used to categorize women as having moderate/severe lymphedema versus mild lymphedema or no lymphedema.

The overall proportion of women correctly classified as having or not having any lymphedema varied from 0.84

to 0.88, and the proportion correctly classified as having or not having moderate/severe lymphedema varied from 0.81 to 0.91, with the best performance for questionnaire method 2.

Substantiating the questionnaire assessments of the presence and degree of lymphedema, the mean number of symptoms experienced differed among women classified as having no lymphedema, mild lymphedema, or moderate/severe lymphedema (questionnaire method 2:  $F=20.6$ ;  $df=2,40$ ;  $P<.0001$ ). The 3 groups experienced, on average, 1.7, 3.7, and 7.2 symptoms, respectively, out of a possible total of 14 symptoms. Table 5 shows the most frequently reported symptoms on the affected side and the percentage of women in each group noticing each symptom. Unlike symptoms such as puffiness; tired, thick, or heavy arm; and indentations, pain was reported about as frequently in women without lymphedema as in those with mild lymphedema or moderate/severe lymphedema.

## Discussion

In this report we describe the developmental phases and first validation study of a telephone questionnaire designed for use in large, population-based studies to assess the incidence and degree of lymphedema in women who have been treated for breast cancer. To our knowledge, there have not been other such efforts.<sup>40</sup>



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**Table 4.**

Sensitivity, Specificity, and Overall Proportion Classified Correctly of the Total of 43 Participants<sup>a</sup>

	<b>Physical Therapist 1</b>					
	<b>Physical Therapists' Assessments</b>			<b>Rule-Based Assessments</b>		
	<b>Sensitivity (95% CI)<sup>b</sup></b>	<b>Specificity (95% CI)</b>	<b>Overall Proportion Correct (95% CI)</b>	<b>Sensitivity (95% CI)</b>	<b>Specificity (95% CI)</b>	<b>Overall Proportion Correct (95% CI)</b>
<b>Physical Therapist 1</b>						
<b>Physical Therapists' Assessments</b>						
<b>Rule-Based Assessments</b>						
Any lymphedema vs no lymphedema						
Questionnaire method 1	0.96 (0.80, 1.00)	0.71 (0.44, 0.90)	0.86 (0.72, 0.95)	0.96 (0.80, 1.00)	0.71 (0.44, 0.90)	0.86 (0.72, 0.95)
Questionnaire method 2	0.96 (0.80, 1.00)	0.71 (0.44, 0.90)	0.86 (0.72, 0.95)	0.96 (0.80, 1.00)	0.71 (0.44, 0.90)	0.86 (0.72, 0.95)
Moderate/severe lymphedema vs mild or no lymphedema						
Questionnaire method 1	1.00 (0.75, 1.00)	0.77 (0.58, 0.90)	0.84 (0.69, 0.93)	1.00 (0.75, 1.00)	0.77 (0.58, 0.90)	0.84 (0.69, 0.93)
Questionnaire method 2	0.92 (0.64, 1.00)	0.90 (0.73, 0.98)	0.91 (0.78, 0.97)	0.92 (0.64, 1.00)	0.90 (0.73, 0.98)	0.91 (0.78, 0.97)
<b>Physical Therapist 2</b>						
<b>Physical Therapists' Assessments</b>						
<b>Rule-Based Assessments</b>						
	<b>Sensitivity (95% CI)</b>	<b>Specificity (95% CI)</b>	<b>Overall Proportion Correct (95% CI)</b>	<b>Sensitivity (95% CI)</b>	<b>Specificity (95% CI)</b>	<b>Overall Proportion Correct (95% CI)</b>
Any lymphedema vs no lymphedema						
Questionnaire method 1	0.96 (0.81, 1.00)	0.75 (0.48, 0.93)	0.88 (0.75, 0.96)	0.93 (0.76, 0.99)	0.69 (0.41, 0.89)	0.84 (0.69, 0.93)
Questionnaire method 2	0.96 (0.81, 1.00)	0.75 (0.48, 0.93)	0.88 (0.75, 0.96)	0.93 (0.76, 0.99)	0.69 (0.41, 0.89)	0.84 (0.69, 0.93)
Moderate/severe lymphedema vs mild or no lymphedema						
Questionnaire method 1	1.00 (0.75, 1.00)	0.77 (0.58, 0.90)	0.84 (0.69, 0.93)	0.93 (0.66, 1.00)	0.76 (0.56, 0.90)	0.81 (0.67, 0.92)
Questionnaire method 2	0.92 (0.64, 1.00)	0.90 (0.73, 0.98)	0.91 (0.78, 0.97)	0.86 (0.57, 0.98)	0.90 (0.73, 0.98)	0.88 (0.75, 0.96)

<sup>a</sup> Assessment was done by the physical therapist indicated, except for women seen only by the other physical therapist.

<sup>b</sup> Exact binomial 95% confidence intervals.<sup>37</sup>

**Table 5.**

Percentage of Women in Each Group<sup>a</sup> Having Frequently Reported Symptoms on Breast Cancer Side

	<b>No Lymphedema (n=13)</b>	<b>Mild Lymphedema (n=15)</b>	<b>Moderate/Severe Lymphedema (n=15)</b>
Puffiness	8	67	93
Tired, thick, or heavy	23	47	80
Pain	46	53	53
Indentations	8	40	80
Clothes too tight	8	20	60
Skin felt different	15	27	80
Difficult to see veins	8	7	67

<sup>a</sup> Groups defined by questionnaire method 2.

We believe that several points should be considered in evaluating the utility of the questionnaire<sup>41</sup>: (1) Was the population used to test the questionnaire similar to the population in which the questionnaire will be used? (2) Was there a "blind" comparison with "gold standard"

clinical criteria? (3) Were the criteria used by the therapists well defined and acceptable to practitioners? (4) Did the results obtained with the questionnaire agree with the therapists' assessments? and (5) Was the questionnaire easy to administer and score?

Was the population used to test the questionnaire similar to the population in which the questionnaire will be used? By definition, population-based studies of the incidence of lymphedema require follow-up of random samples of women who have been treated for breast cancer who live in a defined population. The mix of women who would be administered the questionnaire would encompass those with and without lymphedema and could include those already diagnosed with lymphedema and perhaps treated for their condition; those who had noticed differences in the size of their arms but had not yet sought care or had been told by a clinician that they did not have lymphedema; those who may not have noticed any swelling until the survey was administered; and those not noticing any swelling, even when prompted to look for differences in the size of their arms, either because no swelling was present or because it was not detectable by the woman. Ideally, we believe, a newly developed instrument should be validated using a sample that includes all of these possibilities, covering an appropriate spectrum of severity of lymphedema, including no lymphedema, and situations in which the diagnosis would be equivocal.<sup>41</sup> With estimates of the occurrence of lymphedema among women who have been treated for breast cancer starting at a low of 5% to 9%, using a random sample for this validation study would have been very time-consuming and expensive for estimating sensitivity with any degree of precision because a population sample would have included mostly women without lymphedema.

As a first step in the development of an instrument, it is common practice to evaluate the sensitivity and specificity of data obtained with a new instrument in groups of people who are already known to have or not have the condition that the instrument is designed to detect.<sup>42</sup> Because sensitivity and specificity measure the proportion of people with and without the condition, respectively, whom the new instrument classifies appropriately, the calculation of sensitivity and specificity is not affected by the prevalence of the condition in the study population.<sup>37</sup> In our study, we used one group of women who were already diagnosed with lymphedema (the patients of the physical therapists) and another group of women who had been treated for breast cancer and who may or may not have had lymphedema. This latter group of volunteers from the Wellness Community was even more informative than a group of patients with breast cancer who did not have lymphedema, because some of these volunteers may have had concerns about lymphedema and wanted to have an expert clinical opinion. We believed that it was particularly important to know how the questionnaire would fare in such equivocal but commonly encountered situations.

Another commonly used test characteristic, in addition to sensitivity and specificity, is the predictive value.<sup>37</sup> As an example, in our study, the positive predictive value of a diagnosis based on the questionnaire of at least moderate lymphedema would be defined as the proportion of people with a questionnaire diagnosis of moderate/severe lymphedema who do have moderate/severe lymphedema as measured by the clinical criteria. Similarly, the negative predictive value would be the proportion of people whose questionnaire results do not indicate moderate/severe lymphedema who also do not have moderate/severe lymphedema according to the clinicians.

Predictive values are useful in estimating the probability of a condition being present or absent. Predictive values depend on sensitivity, specificity, and the prevalence of the condition in the population under study. The positive predictive value will be lower in a population with low prevalence than in a population with high prevalence. Because the primary objective of our study was to describe the sensitivity and specificity of the questionnaire, our study group, by design, had a higher prevalence of people with lymphedema than the general population of patients with breast cancer, thus exaggerating the positive predictive value. However, based on the estimates of sensitivity and specificity from our study, we believe that we can provide estimates of predictive value assuming different, more likely, population prevalences of lymphedema in women treated for breast cancer. For example, if the prevalence of moderate/severe lymphedema was 0.25 in the sample and the sensitivity and specificity of the questionnaire for detecting at least moderate lymphedema were 0.90, as our study suggests, the positive predictive value would be 0.75, meaning that 75% of the women whose questionnaire results indicated that they had moderate/severe lymphedema would be clinically diagnosed with at least moderate lymphedema. For a prevalence of 0.25, the negative predictive value would be 0.96; that is, when the questionnaire indicated that a person did not have moderate/severe lymphedema, 96% of the time the clinician would agree. If the prevalence were 0.10, the positive predictive value would decrease to 0.50, and the negative predictive value would be 0.99.

We believe that an important next step in the development of the questionnaire is to study validity in a broader base of women who have been treated for breast cancer. Our study group was more aware of lymphedema than the general population. All participants except one had heard of lymphedema. Most of the women with lymphedema were already being treated for this condition.

Was there a "blind" comparison with "gold standard" clinical criteria? Under ideal circumstances, all of the participants in the study would be assessed by clinicians who are unfamiliar with their history and treatment. This is a limitation of our study. We believe, however, that several factors minimize the effect of bias. First, the 2 physical therapists in our study were unaware of the results of the questionnaire and of the method by which the questionnaire would be scored to characterize lymphedema as absent, mild, or moderate/severe. Their diagnoses were based primarily on measurements, as evidenced by the high degree of correspondence between the therapists' assessments and the rule-based assessments. Second, the physical therapists' assessments were not confined to people with known diagnoses. They did not know in advance of meeting the volunteers from the Wellness Community whether they did or did not have lymphedema. Third, the high level of interobserver agreement between the 2 physical therapists on women measured independently by both therapists suggests that they would have agreed on their assessments for almost all of each other's patients. In addition, each of the physical therapists has had extensive experience in the diagnosis and treatment of lymphedema. Therapist 1 is Clinical Director of the Breast Cancer Physical Therapy Center in Philadelphia, a private practice that specializes in postoperative complications of breast cancer treatment, including lymphedema. She has been treating patients with lymphedema for 13 years. A nationally and internationally recognized expert in the treatment of lymphedema, she was one of the key participants in an American Cancer Society-sponsored workshop on breast cancer treatment-related lymphedema in February 1998.<sup>43</sup> Therapist 2, a physical therapist at the Hospital of the University of Pennsylvania and a specialist in orthopedic and oncologic physical therapy, has worked with patients with breast cancer for more than 17 years to restore shoulder and arm function and to prevent and treat lymphedema.

The telephone interviewer who administered the questionnaire was not aware of the status of the lymphedema in the participants. The questions on lymphedema in the questionnaire asked about the condition in what we believe are novel ways that, in our opinion, should not have revealed to the participants how the questionnaire would be scored. Thus, the women who previously had been diagnosed with lymphedema would not have had any clues about how the questions would translate into categories of degree of lymphedema.

Were the clinical criteria well defined and acceptable to practitioners in the field? In our study, the physical therapists took account of both swelling and tissue texture. These criteria are cited in the American Cancer Society report from the work group session on the

diagnosis and management of lymphedema.<sup>44</sup> Therapist 1 was co-chair of that work group. The participants in the American Cancer Society work group listed physical findings of post-breast cancer lymphedema that included, in addition to "any detectable swelling or enlargement," other indexes of changes in skin texture such as "pitting," "increase in thickness of skinfolds," "change in the texture or consistency of the skin," or "an asymmetric increase in the adiposity of the subcutaneous tissues."

Our criteria for detecting and classifying swelling or enlargement, based on the maximum of 6 circumferential differences, were less than or equal to 2 cm (mild lymphedema), greater than 2 cm and less than 5 cm (moderate lymphedema), and 5 cm or more (severe lymphedema). A lower boundary for the diagnosis of mild lymphedema was not specified. Our approach is within the range of criteria of other studies and official recommendations, which vary widely. For example, in studies in which circumferential measurements of the 2 arms were compared, the minimum defined difference for any lymphedema has varied from unspecified,<sup>28,29</sup> to 1 or 1.5 cm,<sup>9,15,33</sup> to 2 cm,<sup>14,19,31</sup> to greater than 2 cm.<sup>32,34</sup> Many authors<sup>31-34</sup> did not provide definitions for gradations of lymphedema. Among those authors who provided such definitions, the boundary between mild and moderate lymphedema generally varied from a 2- to 3-cm differential between the limbs.<sup>7,9,15,29</sup> Our definition of greater than 2 cm as the lower boundary for moderate lymphedema falls within that range. The American Physical Therapy Association's *Guide to Physical Therapist Practice*<sup>45</sup> defined mild lymphedema as less than a 3-cm differential between the affected limb and the unaffected limb; it did not specify a lower boundary for mild lymphedema.

To address potential concerns about a therapist's diagnosis that did not specify a lower boundary for lymphedema, we also constructed a rule-based assessment, requiring that there be more than a 1-cm difference at some location to diagnose mild lymphedema. This criterion is consistent with that of other researchers who have specified a lower boundary for mild lymphedema.<sup>9,15,27,33</sup> The decisions about mild lymphedema using the therapist and rule-based assessments, although not in perfect agreement, were very similar (Tab. 1). We believe it is interesting that the 2 physical therapists agreed so closely with each other, both in their diagnoses and in the rule-based assessments. Although we decided in advance on the measurement criteria for mild, moderate, and severe lymphedema, and on the 6 locations for the circumferential measurements on each upper extremity, there was no further attempt to standardize the 2 physical therapists' measurement techniques, such as the position of the limbs while they were

being measured or the type of tape measure used. Our objective was to assess the congruence of the questionnaire to clinical assessment as it is carried out in usual practice.

Did the questionnaire results agree well with the criteria for lymphedema? To be useful, the questionnaire should have excellent agreement with accepted criteria for lymphedema. At a minimum, the questionnaire should be useful in correctly classifying women for whom the diagnosis of lymphedema would be generally agreed upon. As shown in Table 4, when the physical therapists' assessments were considered the "gold standard," the questionnaire did not perform as well in assessing the presence of any lymphedema as it did in classifying women as having at least moderate lymphedema compared with mild or no lymphedema. Our results, as well as the general disagreement in the literature about the lower bound for lymphedema, suggest that population-based studies using this questionnaire may be more credible if the criterion for lymphedema is more strict, corresponding to differences between the arms of greater than 2 cm.

Even though the definition and clinical importance of mild lymphedema are less well accepted, it is possible that women can be the best judges of the earliest stages of lymphedema. This point was emphasized by the summary report of the international panel of lymphedema experts attending the American Cancer Society workshop in 1998: "In most cases, the diagnosis of lymphedema following breast carcinoma therapy will be established on the basis of clinical criteria. In this regard, it is important to underscore the value of the patient's subjective awareness of the symptoms or physical changes that accompany the appearance of lymphedema. These subjective complaints may herald the presence of pathology and may, at times, precede the ability of the clinician to detect objective changes of lymphedema on the physical examination. Early detection of pathology can promote the prompt institution of educational and other interventions."<sup>44</sup>(p2882)

Among the women measured by both physical therapists in our study, there were only 2 women whose questionnaire results indicating mild lymphedema were not corroborated by at least one physical therapist. Had we redefined the criteria used by the therapists to allow for the diagnosis of mild lymphedema if at least one physical therapist diagnosed mild lymphedema, the sensitivity and specificity of data obtained with questionnaire method 2 for diagnosing any lymphedema would have been 97% and 86%, respectively, diminishing the false positive rate considerably.

Was the questionnaire easy to administer and score? The questionnaire was designed to be very simple to administer and score. Because virtually all studies of the incidence of lymphedema have relied on some assessment of the difference in size of the 2 arms, our definition of lymphedema from the self-report retained a quantitative aspect, based on perceived differences in size between the 2 arms. If a woman noticed a difference between her hands, lower arms, or upper arms, regardless of how noticeable she felt the difference was, she was diagnosed as having at least mild lymphedema. If she did not notice any difference between any of these upper-extremity locations, she was classified as having no lymphedema. The 2 methods of scoring at least moderate lymphedema from the questionnaire were different from each other, but still simple to score. Both methods satisfy the criterion that moderate/severe lymphedema could not be diagnosed unless a score of 2 or greater ("noticeable to people who know me well but not to others") was observed at some location, but the criterion for at least moderate lymphedema based on questionnaire method 2 was more strict.

Questionnaire method 1 required that the difference between the 2 limbs at some location had to be at least "noticeable to people who know me well but not to strangers" for moderate lymphedema to be considered present. However, questionnaire method 1, although sensitive, proved to be not very specific. Questionnaire method 2 required that the sum of the scores on the questionnaire be at least 4, which could be achieved in a variety of ways. This method also required that a difference be noticed at more than one arm location and that the difference at some location had to be at least "noticeable to people who know me well but not to strangers." Because there were only a few questions used to define the presence and extent of lymphedema, the number of alternatives for determining the presence of at least moderate lymphedema was limited.

## Conclusion

In our study of 43 women who had been treated for breast cancer, use of a few questions led to agreement with therapists' judgments about lymphedema and a rule-based method of identifying at least moderate lymphedema. The choice of wording for the questionnaire was based on discussions of focus groups. The interviewer believed that the questions were easily understood and generally could be answered without difficulty. The methods for scoring the questionnaire were easily applied. We found that no woman recalled noticing any difference in the size of her arms before her breast cancer was diagnosed. In addition, corroborating the results of the questionnaire-based assessment of lymphedema, women with mild or moderate/severe lymphedema were more likely than those with no

lymphedema to also report other symptoms that have been related to lymphedema in the past, such as puffiness, indentations, and tired, thick, or heavy arm, with a predicted gradient across these groups. As advances continue in the treatment of breast cancer, accurate and economical measurements of potential morbidity associated with breast cancer and its treatment are needed. This questionnaire, which deals with the presence and severity of lymphedema, is one step in that direction.

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