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The problems of patients with lymphoedema. Pilot study of breast cancer survivors

Abstract

Background and aims: Lymphoedema is a serious problem for many breast cancer survivors. It is a chronic condition, which can often limit patients' activities and result in dramatic life changes. The aim of the study was to define problems the patients contended with.

Material and methods: The clinical study involved 22 patients suffering from post-mastectomy lymphoedema. They were asked to fill in a special lymphoedema physiotherapy assessment form.

Results: All the patients included in the study underwent physiotherapy within lymphoedema treatment. Only three patients (14%) used complex decongestive therapy and most of the patients (82%) had therapy only once a year for twenty days. The results of the study confirm the fact, that lymphoedema is a chronic condition. Fourteen patients (63%) described their lymphoedema as permanent and increasing in time and only three patients (14%) as periodically retreating. The post-mastectomy pain syndrome is another serious problem of patients after surgery. Four of the patients (18%) suffered from pain with the average intensity of 9 on NRS scale (0–10). None of the patients received any special analgetic treatment, which proves that the post-mastectomy pain syndrome is rarely diagnosed and treated.

Conclusion: The study presents the outline of problems and needs of patients after breast cancer surgery. It also emphasizes the importance of physiotherapy in post-mastectomy patients. However, it ought to be continued in a bigger group of patients as to authenticate the observations.

Key words: post-mastectomy lymphoedema, breast cancer, physiotherapy

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Introduction

Lymphoedema is a very serious condition diminishing patients' quality of life [1]. It occurs when the transport capacity of the lymphatic system has fallen below the normal amount of lymph load, resulting in the abnormal accumulation of water and proteins principally in the subcutaneous tissue. The highest incidents of lymphoedema is observed following breast cancer surgery, particularly among those who undergo radiotherapy [2].

The aim of this pilot study was to define problems of the patients suffering from lymphoedema. In order to do that, physiotherapy assessment of patients and the evaluation of their daily living activity was performed.

Material and methods

The study protocol was accepted by the Ethics Committee of the Nicolaus Copernicus University, Collegium Medicum Bydgoszcz in Poland. Before

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the trial each patient signed an informed consent. The study involved 22 patients with post-mastectomy lymphoedema from rehabilitation clinic (PulsMed) and Breast Cancer Society in Koszalin. Their functional status was measured using Karnofsky Performance Scale (0–100). Each patient was asked to complete a survey consisting of four parts:

1. General information about patients.
2. Interview, observation and palpation.
3. Karnofsky Performance Scale and daily living activity measurement.
4. Limb volume measurement and shoulder joint functional assessment (Appendix).

   The surveys were carried out by the authors of the study while patients' staying in the rehabilitation clinic.

Results

The first part of the survey contained the general information to define the patients medical characteristics. The study involved 22 patients. Their demographic and clinical data are presented in the Table 1.

The second part of the survey included short interview, observation and palpation of lymphoedema. Eight patients (36%) claimed that lymphoedema appeared 5 years after the surgery, seven patients (32%) 2 years, five patients (23%) 10 years and two patients (9%) right after the surgery and was still present (Figure 1). None of the patients suffered from lymphoedema due to recurrence.

In the patients' opinion the most important trigger factor of lymphoedema was physical overwork (63%). Other factors included radiotherapy (23%) and operated side limb injury (14%)

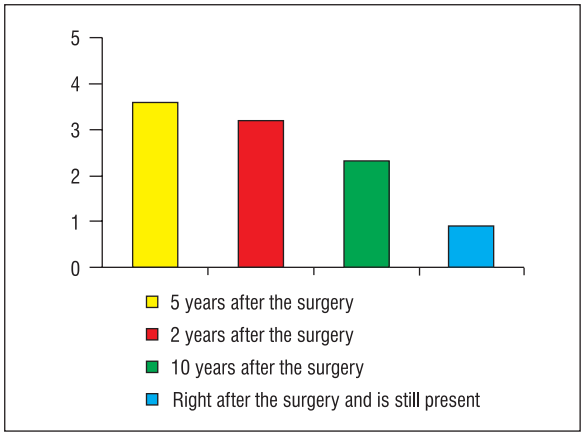

Figure 1. Time of lymphoedema appearance

The answers to the second question showed that fourteen patients (63%) described their lymphoedema as permanent and increasing in time, five patients (23%) as periodically retreating and three patients (14%) as permanent (Figure 2).

Over half of the surveyed patients (63%) described their lymphoedema as a feeling of heaviness, numbness and weakness of the limb. Other descriptions included stabbing and pain in the limb (37%).

Sixteen patients (73%) did not report any lymphoedema complications, 6 patients (27%) reported skin infection.

All the patients included in the study underwent physiotherapy treatment, but only 3 of them (14%) used complex decongestive therapy, which is a combination of MLD (manual lymphatic drainage), bandaging and exercises. The rest of them used exercises, MLD (manual lymphatic drainage) and pneu-

Table 1. Patients characteristics

Total number of patients	**22**
Gender	
Male	0
Female	22
Age (mean ± SD)	61.0 ± 8.9
Oncological treatment	
Surgery:	
Patey's operation (conservative radical mastectomy)	18
Bilateral Patey's operation	1
Sparing mastectomy	3
Complementary treatment:	
Radiotherapy	12
Chemotherapy	13
Hormonotherapy	14

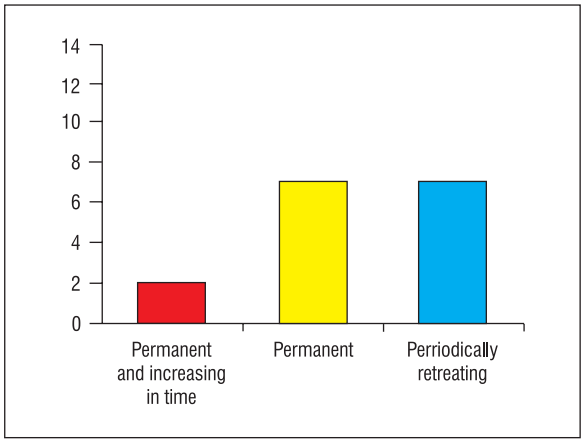

Figure 2. Description of lymphoedema

matic compression, however used separately, not at the same time as a complex form. Most of the patients (82%) had therapy only once a year for twenty days. None of the patients underwent physiotherapy treatment before surgery.

Over half of the surveyed patients (59%) suffered from pain associated with lymphoedema. Nine of them (40%) had skin and subcutaneous tissue pressure pain with the average intensity of 4.7 on NRS scale (0–10). Four of the patients (18%) suffered from pain characterized as burning and tearing, randomly occurring and causing problems with sleeping with the average intensity of 9 on NRS scale (0–10). None of the patients received any special analgetic treatment.

Detailed lymphoedema characteristics are presented in the Table 2.

The third part of the survey consisted in Karnofsky Performance Scale and daily living activity measurment. The values of Karnofsky Performance Scale Index were: 80 (n = 16) and 90 (n = 6). To estimate the changes in the daily living activity the patients were asked to compare the amount of time they spent on housework professional activity and leisure before and after the surgery.

The housework time decreased by 30% (± 26) on average, professional activity by 47% (± 51) and leisure time by 2% (± 16).

Table 2. Observation and palpation

Trigger Points (TrPs) examination
n = 13 (59%)
(m. pectoralis major — sternum attachments)
n = 9 (41%) — no TrPs
Location of lymphoedema
n = 7 (32%) — upper arm + elbow
n = 6 (27%) — upper arm + forearm + elbow
n = 5 (23%) — forearm + elbow
n = 2 (9%) — upper arm
n = 2 (9%) — forearm + hand
Consistency of lymphoedema
n = 15 (68%) + 2 pitting oedema
n = 5 (23%) + 1 pitting oedema
n = 2 (9%) non pitting oedema
Skin changes
n = 19 (87%) — no skin changes
n = 2 (9%) — skin reddening
n = 1 (4%) — higher skin temperature
Postoperative scar assessment
n = 17 (67%) — normal mobility
n = 5 (23%) — scar adhesion

The last part of the survey consisted in measuring the volume of lymphoedema and shoulder joint mobility. The average volume of the affected limb was 11% (± 6.59) bigger than the healthy one.

Thirteen patients (60%) were diagnosed with the restriction of shoulder joint mobility (medial rotation, abduction and flexion). In the muscle strength Lovett's tests the weakness of the medial rotatores, abductores and flexores was observed in the whole studied group (Figure 3).

Discussion

The patients included in the study were in relatively good physical condition (as Karnofsky Performance Scale shows).

The results of the study confirm the fact, that post-mastectomy lymphoedema is a chronic condition. Fourteen patients (63%) described their lymphoedema as permanent and increasing in time and only three patients (14%) as periodically retreating. Therefore it is very important to make patients aware of the fact that lymphoedema therapy should be continuous not occasional. Patients must know that once lymphoedema has started, it cannot be cured. However, they should be informed that an early and careful management can reduce symptoms and prevent it from getting worse.

Lymphoedema can develop even years after the oncology treatment. Over half of the surveyed patients (59%) claimed that lymphoedema appeared 5 years or more after the surgery. In the patients' opinion the most important trigger factor of lymphoedema was physical overwork (63%) and radiotherapy (23%) what is confirmed by other studies.

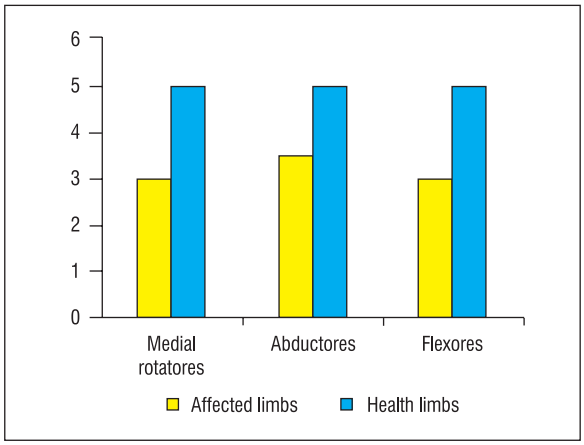

Figure 3. Comparison of shoulder joint muscles strength (Lovett's test)

Dziura et al. emphasize that, according to patients, physical overexertion was the most common factor causing lymphoedema [4]. Mortimer et al. stress that the frequency of lymphoedema increases twice in patients after Patey's operation who underwent radiotherapy [5].

Physiotherapy is a very important element of post-mastectomy patients' treatment who suffer from lymphoedema. All the patients included in the study underwent physiotherapy within lymphoedema treatment. Unfortunately, only few patients used complex decongestive therapy and most of them had therapy only once a year for twenty days, which shows a great disproportion between needs and possibilities. The study proves that it is necessary to increase CDT availability. Unfortunately, none of the patients underwent pre-operation physiotherapy treatment, which includes: chest-physiotherapy(CPT) and education. Education is an essential component of lymphoedema prevention and treatment. In their research Dziura et al. showed that patients with risk of lymphoedema present a low level of education in the matter and that they indicate problems with access to professional information on the topic of lymphoedema prevention. They claimed that properly trained medical staff rarely proved to be a source of information on the topic. Therefore it may be challenging for doctors, physiotherapists and nurses to create a good way of communicating with patients. Prevention of lymphoedema can help to avoid serious complications, such as infections (recurrent cellulitis or lymphangitis). Every third patient of the surveyed group reported skin complications. Hence it is crucial to inform patients about needs for special skin care. Skin complications are almost certainly due to reduced immune surveillance secondary to lymphatic dysfunction. Repeated episodes of cellulitis may impact upon patients' quality of life and affect their ability to work. Up to 10% of patients may be forced to change or lose employment as a result of their chronic edema [6, 7]. Professional activity of the surveyed patients decreased by 50% on average comparing with the pre-disease period.

As the results of the study show, the post-mastectomy pain syndrome is another serious problem of patients after surgery. Four of the patients suffered from post-mastectomy pain syndrome. Unfortunately none of the patients received any special analgetic treatment. It proves that the syndrome is rarely diagnosed and treated [8].

Conclusion

The study showed the variety problems affecting post-mastectomy patients suffering from lymphoedema. In spite of the fact that the study included only 22 patients it draws attention to great needs of patients with oedema both in the treatment and education fields. Similar problems afflict patients who did not have mastectomy. Therefore the study should be continued in a bigger and more diverse group.

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Appendix. The assessment form used in the study

I PART

Including general information about a patient (name, date of birth, sex, address, telephone number) and medical characteristics (diagnosis, oncology treatment).

II PART

II.A. Interview

The patients were asked questions:

1. When did lymphoedema appear? (Do you think its appearance was related to anything particular?)
2. Description of lymphoedema
   Periodically retreating ☐ Increasing in time ☐ Permanent ☐
3. How would you describe the feeling of having lymphoedema?
4. Did any complications occur?
5. Did you undergo any physiotherapy treatment? If yes, what kind of treatment was that?
6. Do you suffer from pain connected with lymphoedema? If yes, describe it (location, type, intensity).

II.B. Observation and palpation

1. Trigger Points examination.
2. Location of lymphoedema.
3. Consistency of lymphoedema.
4. Skin changes.
5. Postoperative scar assessment.

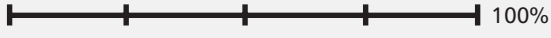
III PART

Including Karnofsky Performance Scale and daily living activity measurment.

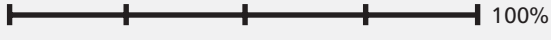
1. Karnofsky Performance Scale (0–100) ☐
2. How did the cancer and its consequences influence your activity?
   (100% — reference point, your activity before disease).

Housework

Professional activity



Leisure time (hobby, self-realization, body care and hygiene)



IV PART

IV.A. Lymphoedema measurement

Including circumferencial measurement of a patient's arm at several points from hand to axilla [3].

IV.B. Shoulder joint functional assessment

Including muscle strength assessment (Lovett test) and measurement of the shoulder joint mobility.

Załącznik. Wzór formularza wykorzystanego w badaniu

CZĘŚĆ I.

Zawiera ogólne informacje na temat pacjenta (imię i nazwisko, data urodzenia, płeć, dane kontaktowe) oraz informacje na temat dotychczasowego leczenia (rozpoznanie, leczenie onkologiczne).

CZĘŚĆ II.

II.A. Ankieta

1. Kiedy po raz pierwszy pojawił się obrzęk limfatyczny?
   (Czy kojarzy Pan/Pani pojawienie się obrzęku z jakimiś konkretnymi czynnikami?)
2. Obecność obrzęku:
   Okresowo ustępujący ☐ Narastający w czasie ☐ Utrwalony ☐
3. Subiektywnie: Jak odczuwa Pan/Pani obrzęk?
4. Czy występowały jakieś powikłania?
5. Czy dotychczas prowadzone było leczenie fizjoterapeutyczne obrzęku?
6. Czy odczuwa Pan/Pani ból związany z obrzękiem?

II.B. Obserwacja i palpacja

1. Ocena punktów spustowych.
2. Lokalizacja obrzęku.
3. Konsystencja obrzęku
4. Obecność zmian skórnych.
5. Ocena przesuwalności blizny pooperacyjnej.

CZĘŚĆ III.

Zawiera ocenę sprawności (*Karnofsky Performance Scale*) i aktywności życiowej pacjentów.

1. *Karnofsky Performance Scale* (0–100) ☐
2. Ocena aktywności życiowej

(za pkt. wyjścia obieramy 100% jako aktywność życiową z okresu przed chorobą)

Zajęcia domowe

0% ⊢——⊣——⊣——⊣——⊣ 100%

Aktywność zawodowa

0% ⊢——⊣——⊣——⊣——⊣ 100%

„Czas dla siebie" (hobby, samorealizacja, pielęgnacja i higiena)

0% ⊢——⊣——⊣——⊣——⊣ 100%

CZĘŚĆ IV.

IV.A. Pomiary wielkości obrzęku

Obejmowały pomiary obwodów na poszczególnych wysokościach kończyny [3].

IV.B. Ocena stawu barkowego

Obejmowała ocenę siły mięśniowej i zakresu ruchomości kończyny.