LIMPRINT Study: 
The Turkish Experience

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Abstract

Background: Lymphedema and chronic edema is a major health care problem in both developed and non-developed countries. The Lymphoedema Impact and Prevalence - International (LIMPRINT) study is an international health service-based study to determine the prevalence and functional impact in adult populations of member countries of the International Lymphoedema Framework (ILF).

Methods and Results: A total of 1051 patients from eight centers in Turkey were recruited using the LIMPRINT study protocol. Data were collected using the core and module tools that assess the demographic and clinical properties as well as disability and quality of life (QoL). Most of the Turkish patients were recruited from specialist lymphedema services and were found to be women, housewives, and having secondary lymphedema because of cancer treatment. The duration of lymphedema was commonly <5 years and most of them had International Society of Lymphology (ISL) grade 2 lymphedema. Cellulitis, infection, and wounds were uncommon. The majority of patients did not get any treatment or advice before. Most of the patients had impaired QoL and decreased functionality, but psychological support was neglected. Although most had social health security access to lymphedema centers, nevertheless access seemed difficult because of distance and cost.

Conclusion: The study has shown the current status and characteristics of lymphedema patients, treatment conditions, the unmet need for the diagnosis and treatment, as well as burden of the disease in both patients and families in Turkey. National health policies are needed for the prevention, diagnosis, and treatment in Turkey that utilize this informative data.

Keywords: lymphedema, lymphoedema, chronic edema, LIMPRINT, quality of life, impact
Introduction

Lymphedema is an incurable, debilitating, and progressive condition, characterized by persistent swelling of one or more parts of the body, because of the impairments in lymph transport. This chronic and progressive disease can occur at any time after cancer surgeries, can arise from congenital malformation of the lymphatic system, or because by damage to lymphatic vessels.1,2 It is a major health care problem in both developed and nondeveloped countries. It is serious because of its long-term physical and psychosocial consequences for the patients, if left untreated. When lymphedema is not diagnosed and treated in the earlier stages, the prognosis for these patients is worse and treatments are more costly. Lymphedema frequently leads to physical, emotional, and psychological challenges and impairs the quality of life (QoL) if it is underrecognized and undertreated.3,4 Treatment cost of lymphedema has also been identified as a barrier. The support and funding of medical conditions and complex care needs will ease the stress and treatment burden associated with lymphedema.5 There are also challenges of managing complex lymphedema patients with obesity, and those associated with chronic medical conditions and wounds.6 Therefore the awareness of this chronic condition by both health professionals and patients—knowledge comprising the characteristics of lymphedema patients, difficulties finding appropriate treatments or funding for care, and the impact of disease on functional, psychosocial status, and QoL are of great importance, especially in developing countries.

Lymphedema has been a rising condition in Turkey over the past 10–12 years. Awareness about lymphedema was low and the treatment methods were unknown and certified lymphedema specialists were lacking until recent years.7 There are no data about the incidence of lymphedema in Turkey. Patient characteristics or experiences of some patients are reported in some small studies.7–9 Considering all these points, an interest in being part of a study of Turkish lymphedema patients could be made and compare it with different countries. The participation in LIMPRINT study would be valuable and provide important information about the demographic, social, and QoL characteristics of Turkish patients. The study results would show the current status and characteristics of lymphedema patients, treatment conditions, the unmet need for diagnosis and treatment of those suffering with the condition, and burden of the disease in both patients and families in Turkey. The LIMPRINT study would also allow the comparison with different populations from different countries. In addition the data would be informative for developing national health polices and reimbursement procedures in diagnosis and treatment of lymphedema in Turkey.

Materials and Methods

Considering all these points, an interest in being part of LIMPRINT was shared with the executive members of ALA, and after unanimous approval, a request for Turkey to be involved was officially made in 2014 and accepted by the ILF. Two main institutions are related to lymphedema in Turkey: Anatolian Lymphedema Association and Hacettepe University Lymphedema Practice and Research Center. Therefore the participation in this international multicenter study proposal was sent to the health professional delegates of the ALA from different parts of Turkey working in centers who are managing patients with lymphedema. In addition, Hacettepe University Lymphedema Practice and Research Center were involved in the LIMPRINT study.
Center actively engaged and recruited a great number of patients in collaboration with the Department of Physical Medicine and Rehabilitation. Vascular surgeons and nurses were also informed. Most of the surgeons were not interested in joining the study. After this initial information the proposal was sent to 10 centers with 8 accepting to part of the study.

The local steering groups were Anatolian (Turkish) Lymphedema Association and Hacettepe University Lymphedema Practice and Research Center. The stakeholders were as follows, from five different areas of the country:

1. University of Hacettepe Faculty of Medicine Department of Physical Medicine and Rehabilitation (PMR) and Hacettepe University Lymphedema Research and Practice Center (Dr. Pınar Borman, Dr. Merve Denizli, Dr. Ayşeğül Yaman, Dr. Oya Özdemir, Dr. Füsun Terzioğlu, and Aysel Arikan Doğan). (4) Kirşehir Ahi Evran University Department of PMR (Dr. Eda Kurt).
2. Ankara Rehabilitation Training and Research Hospital (Dr. Meltem Vural, Dr. Sibel Ünsal Delialioglu). (5) Ege University Medical Faculty Department of PMR, Izmir (Dr. Sibel Eyigör).
3. Ankara Training and Research Hospital Clinic of PMR (Dr. Figen Ayhan, Dr. Burcu Duyur Çakıt, Dr. Seçil Vural). (6) Istanbul Rehabilitation Training and Research Hospital Clinic of PMR (Dr. Evrim Coşkun Çalış). (7) Istanbul Kanuni Sultan Süleyman Education and Research Hospital (Dr. Muge Kepeç). (8) Manisa Celal Bayar University Medical Faculty Department of PMR (Lale Cerrahoğlu).

All centers gained approval from their local ethical committees. The coordinator of the Turkish study was the chair of ALA and director of the HU Lymphedema Practice and Research Center—P.B. All the LIMPRINT questionnaires were translated to Turkish and back translated to ensure accuracy of language. The QoL questionnaires lymphedema quality of life (LYMQOL)-arm and LYMQOL-leg10 did not have Turkish validation. The cross-cultural Turkish validation studies of the LYMQOL-arm and LYMQOL-leg questionnaires were performed before this study began adding further validity to the methods.11,12 Then the Turkish data collection forms were sent.
to the included centers. All the centers filled the questionnaires and sent them by ordinary mail to the coordinator and they were then returned when completed in batches of 30. Data entry was undertaken from one center (Hacettepe University) with each center given an individual code.

The patients were recruited to the study according to the inclusion and exclusion criteria of the LIMPRINT study protocol. Data were collected using a Core Tool to determine the prevalence of chronic edema and a set of five Module Tools to assess the impact of chronic edema on the lives of sufferers. Data were entered into a secure central on-line database. The core tools included questions about type of facility in which data are collected, demographics, level of obesity, mobility, relevant comorbidities, classification and history of lymphedema, cellulitis history, categories of treatment, site of swelling, wound area, access to treatment, and subjective control of swelling. The module tools comprised demographics and disability, QoL, details of swelling, wounds, and cancer. The Turkish version of World Health Organization Disability Assessment Schedule 2.0 (WHODAS

Table 3. The Treatment Categories (N=051)

| Treatment Category                                  | All Patient (N=1051), n (%) | Female (n=980), n (%) | Male (n=71), n (%) | \( \chi^2 \) (df) or p-value |
|-----------------------------------------------------|-----------------------------|-----------------------|-------------------|-------------------------------|
| No treatment offered                                |                             |                       |                   |                               |
| No                                                  | 698 (66.41)                 | 652 (66.53)           | 46 (64.79)        | 0.09 (1)                      |
| Yes                                                 | 353 (33.59)                 | 328 (33.47)           | 12 (35.21)        | 0.76                          |
| Skin care advice                                    |                             |                       |                   |                               |
| No                                                  | 552 (52.52)                 | 516 (52.65)           | 36 (50.70)        | 0.10 (1)                      |
| Yes                                                 | 499 (47.48)                 | 464 (47.35)           | 35 (49.30)        | 0.75                          |
| Wound dressing                                      |                             |                       |                   |                               |
| No                                                  | 1020 (97.05)                | 957 (97.65)           | 63 (88.73)        | 18.40 (1)                     |
| Yes                                                 | 31 (2.95)                   | 23 (2.35)             | 8 (11.27)         | <0.001                        |
| Antibiotic                                          |                             |                       |                   |                               |
| No                                                  | 934 (88.87)                 | 880 (89.80)           | 54 (76.06)        | 12.63 (1)                     |
| Yes                                                 | 117 (11.13)                 | 100 (10.20)           | 17 (23.94)        | <0.001                        |
| Massage                                             |                             |                       |                   |                               |
| No                                                  | 594 (56.52)                 | 553 (56.43)           | 41 (57.57)        | 0.04 (1)                      |
| Yes                                                 | 457 (43.48)                 | 427 (43.57)           | 30 (42.25)        | 0.83                          |
| Physiotherapy                                       |                             |                       |                   |                               |
| No                                                  | 963 (91.63)                 | 902 (92.04)           | 61 (85.92)        | 3.24 (1)                      |
| Yes                                                 | 88 (8.37)                   | 78 (7.96)             | 10 (14.08)        | 0.07                          |
| Compression garment                                  |                             |                       |                   |                               |
| No                                                  | 638 (60.70)                 | 599 (61.12)           | 39 (54.93)        | 1.06 (1)                      |
| Yes                                                 | 413 (39.30)                 | 381 (38.88)           | 32 (45.07)        | 0.30                          |
| Multilayer bandage                                   |                             |                       |                   |                               |
| No                                                  | 716 (68.13)                 | 669 (68.27)           | 47 (66.20)        | 0.13 (1)                      |
| Yes                                                 | 335 (31.87)                 | 311 (31.73)           | 24 (33.80)        | 0.72                          |
| Pneumatic compression pumps                          |                             |                       |                   |                               |
| No                                                  | 903 (85.92)                 | 846 (86.33)           | 57 (80.28)        | 2.00 (1)                      |
| Yes                                                 | 148 (14.08)                 | 134 (13.67)           | 14 (19.72)        | 0.16                          |
| Debunking—lipedema—lymphatic surgery                |                             |                       |                   |                               |
| No                                                  | 1042 (99.14)                | 971 (99.08)           | 71 (100.00)       |                               |
| Yes                                                 | 9 (0.86)                    | 9 (0.92)              | 0 (0)             | 0.99<sup>a</sup>              |
| Exercise advice                                      |                             |                       |                   |                               |
| No                                                  | 517 (49.19)                 | 479 (48.88)           | 38 (53.52)        | 0.57 (1)                      |
| Yes                                                 | 534 (50.81)                 | 501 (51.12)           | 33 (46.48)        | 0.45                          |
| Cellulitis advice                                    |                             |                       |                   |                               |
| No                                                  | 811 (77.16)                 | 761 (77.65)           | 50 (70.42)        | 1.96 (1)                      |
| Yes                                                 | 240 (22.84)                 | 219 (22.35)           | 21 (29.58)        | 0.16                          |
| Psychological support                                |                             |                       |                   |                               |
| No                                                  | 963 (91.63)                 | 900 (91.84)           | 63 (88.73)        | 0.83 (1)                      |
| Yes                                                 | 88 (8.37)                   | 80 (8.16)             | 8 (11.27)         | 0.36                          |
| Complex decongestive therapy                        |                             |                       |                   |                               |
| No                                                  | 1035 (98.48)                | 965 (98.47)           | 70 (98.59)        | 0.99<sup>a</sup>              |
| Yes                                                 | 16 (1.52)                   | 15 (1.53)             | 1 (1.41)          |                               |
| Control of swelling                                 |                             |                       |                   |                               |
| No                                                  | 414 (51.30)                 | 372 (49.80)           | 42 (70.00)        | 9.07 (1)                      |
| Yes                                                 | 393 (48.70)                 | 375 (50.20)           | 18 (30.00)        | 0.003                         |

<sup>a</sup>Fisher’s exact test.
Results

A total of 1051 patients from eight centers of five different geographical areas took part in the study. Most of the patients were recruited from specialist lymphedema services. The majority of patients were women, housewives, nonobese, had full range of movement, and walked independently. The most common comorbidity was diabetes followed by hypertension. Half the patients stated that their edema was not under control. In Turkey the complex decongestive therapy is free in government hospitals for patients with obligative health insurance. Therefore the majority of the attendants replied to this question that treatment was free. But the cost of bandages for multilayer short stretch bandaging are not reimbursed and the amount of compression garments are only partially reimbursed in Turkey. Nearly 40% of the patients stated that if the treatment was not free, they could not cover the expenses for the treatment. Most of the patients suggested that lymphedema treatment was available for free within a reasonable travelling distance, as they are living in big cities or metropoles, but more than one third of them declared that the distance would prevent patients from accessing specialized centers. As the majority of patients did not have wounds or complicated lymphedema, they were not related to discharge from hospital or long stays in care centers (Table 4).

According to the demographics in the module data, most patients were in the age range of 45–64 years and were living with their partners or relatives. Eighty percent of the patients were owner occupiers and 55% had their own vehicle. As most of the patients were housewives, they were not the main provider for their family. Fifty-two percent of the patients stated that their swelling was not under control. In 91% of patients a great number of patients neglected in 91% of patients. A great number of patients expressed that their swelling was not under control. In 91% of patients. A great number of patients neglected in 91% of patients. A great number of patients expressed that their swelling was not under control. In 91% of patients. A great number of patients expressed that their swelling was not under control. In 91% of patients. A great number of patients expressed that their swelling was not under control. In 91% of patients. A great number of patients expressed that their swelling was not under control. In 91% of patients. A great number of patients expressed that their swelling was not under control. In 91% of patients. A great number of patients expressed that their swelling was not under control. In 91% of patients. A great number of patients expressed that their swelling was not under control. In 91% of patients. A great number of patients expressed that their swelling was not under control. In 91% of patients. A great number of patients expressed that their swelling was not under control. In 91% of patients. A great number of patients expressed that their swelling was not under control. In 91% of patients. A great number of patients expressed that their swelling was not under control.
stop their job/work that would affect their family income (Table 5).

The details of swelling in the module data are given in Table 6. The site of swelling was the upper extremity (arms) in 59% followed by legs (39.8%), Overall 55% did not have pitting edema. Tissues in the swollen area were mostly soft with 41% having a significant shape distortion. Thirty-six percent of the patients had not been told the reason for the swelling. Stemmer sign was positive in 75% of patients with lower extremity and 49% of patients in upper extremity.

### Table 5. Demographic Characteristics (n=048)

| Category                                      | n (%)     |
|-----------------------------------------------|-----------|
| Living with                                   |           |
| No one/live alone                            | 109 (10.4)|
| Partner/spouse                               | 724 (69.1)|
| Other relative                               | 212 (20.2)|
| Friend                                       | 2 (0.2)   |
| Other                                         | 1 (0.1)   |
| Living accommodation                         |           |
| Owner occupier                               | 838 (80)  |
| Public rented                                 | 11 (1.1)  |
| Privately rented                              | 189 (18)  |
| Nursing home                                  | 5 (0.5)   |
| Hospital                                      | 1 (0.1)   |
| Supported living accommodation                | 4 (0.4)   |
| Patients who had a car or other vehicle       |           |
| Yes                                           | 582 (55.5)|
| No                                            | 466 (44.5)|
| Working/job                                   |           |
| Employed full time                            | 148 (14.1)|
| Employed part time                            | 25 (2.4)  |
| Retired                                       | 208 (19.8)|
| Unemployed looking for work                   | 20 (1.9)  |
| Not working because of illness                | 68 (6.5)  |
| Looking after the house                       | 581 (55.4)|
| (housewives)                                  |           |
| Full or part-time education or training        | 15 (1.4)  |
| Other                                         | 3 (0.3)   |
| Patients were the main provider               |           |
| Yes                                           | 202 (19.3)|
| No                                            | 846 (80.7)|
| Age of graduation, mean±SD, median (minimum to maximum) | 16.3±4.9, 17 (8–45) |
| Degree of graduation                          |           |
| None (elementary school)                      | 549 (52.4)|
| School certificate/diploma                    | 265 (25.3)|
| University diploma/degree                     | 215 (20.5)|
| Master’s degree                               | 9 (0.9)   |
| Doctorate                                     | 10 (1)    |
| Patients who had to change their job or education/training |           |
| Yes                                           | 52 (5)    |
| No                                            | 996 (95)  |
| Patients who had to stop work or education/training |           |
| Yes                                           | 82 (7.8)  |
| No                                            | 966 (92.2)|
| Patients who had been affected/reduced their family income because of the swelling |           |
| Yes                                           | 99 (9.5)  |
| No                                            | 949 (90.6)|

### Table 6. Details of Swelling (n=050)

| Category                                      | n (%)     |
|-----------------------------------------------|-----------|
| Pitting                                       |           |
| Yes                                           | 475 (45.2)|
| No                                            | 575 (54.8)|
| Tissue in swollen area                        |           |
| Soft                                          | 715 (68.1)|
| Hard                                          | 335 (31.9)|
| Shape distortion in the affected limb         |           |
| Yes                                           | 436 (41.5)|
| No                                            | 614 (58.5)|
| Patients who had been told the reason for the swelling |           |
| Yes                                           | 671 (63.9)|
| No                                            | 379 (36.1)|
| The site of swelling                          |           |
| Arm                                           | 617 (59.0)|
| Leg                                           | 416 (39.8)|
| Both                                          | 12 (1.2)  |
| Stemmers sign                                 |           |
| Hand—positive                                 | 313 (49.3)|
| Foot—positive                                 | 329 (75.8)|
| Severity of the swelling                     |           |
| ISL stage I                                   | 289 (27.5)|
| ISL stage II                                  | 648 (61.7)|
| ISL stage III                                 | 113 (10.8)|

ISL, International Society of Lymphology.

### Table 7. The Disability and Quality-of-Life Scores (n=050)

| Category                          | Mean ± SD | Median | Minimum to maximum |
|-----------------------------------|-----------|--------|-------------------|
| WHODAS overall scores (n=1050)    | 31.7±21.8 | 27.1   | 0–100             |
| EQ-5D scores (n=1050)             | 0.56±0.32 | 0.62   | 0.59–1            |
| Overall health scores (n=1050)    | 61.2±20.5 | 60     | 0–100             |
| LYMQOL—upper extremity (n=630)    |           |        |                   |
| Function                          | 17.5±6.1  | 16     | 10–40             |
| Appearance                        | 9.4±3.6   | 9      | 5–20              |
| Symptoms                          | 12.3±4    | 12     | 6–24              |
| Emotion                           | 11.3±4.2  | 11     | 6–24              |
| Overall                           | 6.6±1.8   | 7      | 0–10              |
| LYMQOL—lower extremity (n=429)    |           |        |                   |
| Function                          | 19.1±6.4  | 19     | 8–32              |
| Appearance                        | 17.5±5.9  | 17     | 7–28              |
| Symptoms                          | 11.8±3.9  | 11     | 5–20              |
| Emotion                           | 12.9±4.5  | 12     | 6–24              |
| Overall                           | 5.1±2.1   | 5      | 0–10              |

EQ-5D, European Quality of Life Five Dimensional Questionnaire; LYMQOL, lymphedema quality of life; WHODAS, World Health Organization Disability Assessment Schedule.
swelling. The majority had ISL grade 2 swelling (61.7%) and 27.5% had ISL grade 1 lymphedema. The disability and QoL scores are given in Table 7. Most of the patients had impaired QoL and decreased functionality. These were prominent especially in lower limb chronic edema patients.

The cancer data showed the majority (84%) had breast cancer followed by endometrium (8%), cervix (2.8%), and ovarian (2.4%) cancers. All but five of them had received treatment for cancer, with 53% having local cancer and 32% being in remission. The most common type of cancer treatment was surgery followed by chemotherapy and radiation therapy. The duration of lymphedema was <5 years in the majority of the patients (88.8%). Twenty-one percent of patients developed swelling within 3 months, 32% in 3–11 months, and 34% developed in 1–5 years after cancer treatment. The summary of cancer data is given in Table 8.

The majority of patients (98%) did not have a wound. Of the patients with wounds, 55% had one to two wounds mostly grade 2 small venous ulcers with low exudate located in the legs. Most patients looked after their own wounds followed by physicians and hospital nurses. Nearly half of the wounds

| Table 8. Details of Cancer (n = 15) |  |
|-----------------------------------|---|
| Patients who had treatment for cancer | N (%) |
| Yes | 710 |
| No | 5 |
| Duration between swelling and cancer treatment (How long after the cancer treatment did you develop swelling in the affected area?) |  |
| <3 Months | 152 (21.3) |
| 3–11 Months | 253 (32.7) |
| 1–5 Years | 249 (34.8) |
| 6–9 Years | 40 (5.6) |
| 10+ Years | 32 (4.5) |
| Unknown | 5 (0.7) |
| Not applicable | 3 (0.4) |
| Current cancer status |  |
| Cured/remission | 229 (32.0) |
| Local cancer | 383 (53.6) |
| Distant metastases | 56 (7.8) |
| Do not know | 47 (6.6) |
| Type of cancer |  |
| Bladder cancer | 2 (0.3) |
| Breast cancer | 603 (84.3) |
| Cervical cancer | 20 (2.8) |
| Colorectal cancer | 2 (0.3) |
| Endometrial cancer | 57 (8.0) |
| Head and neck cancer | 1 (0.1) |
| Melanoma cancer | 6 (0.8) |
| Ovarian cancer | 17 (2.4) |
| Vulval cancer | 2 (0.3) |
| Other cancers | 16 (2.2) |
| Type of cancer treatments |  |
| Surgery | 703 (98.3) |
| Radiation therapy | 569 (79.6) |
| Chemotherapy | 595 (83.2) |
| Hormone therapy | 306 (42.8) |
| Molecular target therapy | 16 (2.2) |
| Other | 1 (0.1) |

| Table 9. Details of Wounds (n = 1) |  |
|-----------------------------------|---|
| Provider wound care |  |
| Physician | 13 (61.9) |
| Podiatrist | 0 |
| Self-care | 14 (66.7) |
| Family/friend | 6 (28.6) |
| Hospital nurse | 11 (52.4) |
| Practice nurse | 0 |
| Care home nurse | 2 (9.5) |
| Wound care specialist nurse | 0 |
| Home care/community nurse | 1 (4.8) |
| Lymphedema specialist nurse/therapist | 1 (4.8) |
| Other | 0 |
| No. of wounds |  |
| One | 7 (33.3) |
| Two | 9 (42.9) |
| Three | 2 (9.5) |
| Four | 1 (4.8) |
| Five | 1 (4.8) |
| Six | 1 (4.8) |
| Missing | 1 (4.8) |
| Pressure ulcer |  |
| None | 13 |
| Grade 1 | 0 |
| Grade 2 | 5 (62.5) |
| Grade 3 | 2 (23.0) |
| Grade 4 | 1 (12.5) |
| Leg/foot ulcer cause |  |
| No leg/foot ulcer | 6 |
| Venous ulcer | 6 (40.0) |
| Arterial ulcer | 1 (6.7) |
| Mixed (venous/arterial) | 1 (6.7) |
| Neuropathic | 1 (6.7) |
| Neuroischemic | 0 |
| Other foot ulcer | 2 (13.3) |
| Do not know ulcer type | 7 (46.7) |
| Acute/surgical wound |  |
| No acute/surgical wound | 10 |
| Primary closure | 0 |
| Open surgical wound | 0 |
| Postsurgical breakdown | 2 (18.2) |
| Dehisced wound | 5 (45.5) |
| Traumatic wound | 2 (18.2) |
| Do not know wound type | 2 (18.2) |
| Exudate level |  |
| None | 9 (42.9) |
| Low | 7 (33.3) |
| Medium | 4 (19.1) |
| High | 1 (4.8) |
| Location of the wounds |  |
| Head or neck | 21 (100) |
| Arms | 21 (100) |
| Chest | 19 (90.5) |
| Abdomen | 21 (100) |
| Back | 20 (95.2) |
| Sacrum | 21 (100) |
| Hips | 21 (100) |
| Upper leg | 20 (95.2) |
| Groin | 21 (100) |
| Lower leg/ankle | 9 (42.9) |
| Foot | 14 (66.7) |
| Other | 20 (95.2) |

(continued)
did not have signs of infection (47%) and had been present <6 months in the majority of the patients (70%). The wound details are given in Table 9.

One of the fundamental aims of the ILF is to support countries in the development of data to establish the size of the problem of chronic edema. Such data are essential in supporting the introduction of evidence-based practice and enabling each national framework to argue for appropriate financing and reimbursement. According to the aims of LIMPRINT as an international epidemiological research study; the preliminary demographic results of this study provided evidence-based data for the demographic and clinical properties of Turkish lymphedema patients. The LIMPRINT study brought a great opportunity and vision to our community. The reimbursement of pressure garments was very low in grades 2 and 3 lymphedema patients in Turkey. The ALA have prepared a file for reimbursement of pressure garments for lymphedema patients with grades 2 and 3 lymphedema. We believe that the final data indicate not only the size of the problem but also the impact of chronic edema on patient lives in terms of functionality and QoL. This will assist lymphedema services to provide evidence-based care. The Turkish LIMPRINT study results demonstrate that many patients cannot access treatment services because of the distance and cannot afford to pay for costly treatments as these are not completely reimbursed. We hope this evidence-based data will change the national policies for the care of Turkish patients with lymphedema or chronic edema.

**Conclusion**

This final LIMPRINT data reflect that upper extremity lymphedema is more common than lower extremity and the major cause is cancer treatment, predominantly breast cancer in the Turkish LIMPRINT. The most striking results are that the patients suffer for a long time, most of the patients have uncontrolled lymphedema mostly grade 2 and have not received any previous treatment before the study. Turkish patients had less wounds compared with other studies undertaken in the LIMPRINT study. This is most certainly because of the center characteristics that were rehabilitation services treating a high proportion of cancer patients, particularly breast cancer, rather than dermatology or vascular surgery services. The majority of patients had reduced functional status and decreased QoL. Although most of the patients had social health security for free complex decongestive therapy treatment, their ability to access these centers was more difficult than previously estimated. National health policies and planning are needed for the prevention, diagnosis, and treatment of those suffering this neglected condition in Turkish patients.

**Author Disclosure Statement**

No competing financial interests exist.

**References**

1. International Society of Lymphology. The diagnosis and treatment of peripheral lymphedema. 2013 Consensus Document of the International Society of Lymphology. Lymphology 2013; 46:1–11.
2. Borman P. Lymphedema diagnosis, treatment, and follow-up from the view point of physical medicine and rehabilitation specialists. Turk J Phys Med Rehab 2018; 64:179–197.
3. Keast DH, Despatis M, Allen JO, Brassard A. Chronic oedema/lymphedema: Under-recognized and under-treated. Int Wound J 2015; 12:328–333.
4. Tzani I, Tsichlaki M, Zerva E, Papathanasiou G, Dimakakos E. Physiotherapeutic rehabilitation of lymphedema: State-of-the-art. Lymphology 2018; 51:1–12.
5. Sierla R, Black D, Mun LEE TS, Killbreath S. Access to treatment for breast cancer-related lymphoedema in Australia. Aust Fam Physician 2013; 42:892–895.
6. Morgan PA, Murray S, Moffatt CJ, Honnor A. The challenges of managing complex lymphoedema/chronic oedema in the UK and Canada. Int Wound J 2012; 9: 54–69.
7. Borman P, Yaman A, Yasrebi S, Ozdemir O. The importance of awareness and education in patients with breast cancer-related lymphedema. J Cancer Educ 2017; 32:629–633.
8. Ozaslan C, Kuru B. Lymphedema after treatment of breast cancer. Am J Surg 2004; 187:69–72.
9. Müezzinler NE, Karayurt O. Investigation of experiences of women who developed lymphedema related to breast cancer treatment. J Breast Health 2014; 10:23–29.
10. Keeley V, Crooks S, Locke J, Veigas D, Riches K, et al. A quality of life measure for limb lymphedema (LYM-QOL). J Lymphoedema 2012; 5:26–37.
11. Borman P, Yaman A, Denizli M, Karahan S, Özdemir O. The reliability and validity of Lymphedema Quality of Life Questionnaire-Arm in Turkish patients with upper limb lymphedema related with breast cancer. Turk J Phys Med Rehab 2018; 64:205–212.
12. Borman P, Denizli M, Yaman A, Karahan S. The reliability and validity of lymphedema quality of life questionnaire-Leg (LYMQOL-Leg) in Turkish Patients with lower limb lymphedema. In 8th International Lymphedema Framework Conference, Rotterdam, Netherlands, June 6–9, 2018, Programme and Abstract Book, p:43. 2018ilconference.org Accessed April 2, 2019.
13. World Health Organization Disability Assessment Schedule II (2001). Available at www.who.int/icidh/whodas Accessed April 2, 2019.
14. Kutlay S, Küçükdeveci AA, Elhan AH, Oztuna D, Koç N, Tennant A. Validation of the World Health Organization disability assessment schedule II (WHODAS-II) in patients with osteoarthritis. Rheumatol Int 2011; 31:339–346.
15. Devlin NJ, Brooks R. EQ-5D and the EuroQoL group: Past, present and future. Appl Health Econ Health Policy 2017; 15:127–137.
16. Oksuz E. Prevalence, risk factors, and preference-based health states of low back pain in a Turkish population. Spine (Phila Pa 1976) 2006; 31:E968–E972.
17. Moffatt CJ, Pinnington LL. Facilitating the development of community based lymphoedema services through clinical education. A report prepared for the East Midlands Health, Innovation and Education Cluster. 2012. Available at http://emhiec.co.uk/projects/em13-derby-hospital-lymphoedema (accessed December 15, 2013).

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