Chapter 67
Lymphedema Management by the Therapists

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This chapter is aimed at introducing the crucial contribution of nurses and hands-on therapists in recognition of the need, development, standardization, provision of care, and patient advocacy for chronic lymphedema.

Recognition of Lymphedema as a Nursing Problem

In the mid 1980s, nurses were increasingly seeing patients with lymphedema, particularly in the emerging cancer centers. As they searched for more information and education, it was recognized that the lymphedema often had been neglected by the medical field because of a lack of sufficient knowledge. This void left nurses without options with regard to quality care for their patients, which was often carried out independently with no proper support by the medical community.

As a consequence, patients with lymphedema were often misdiagnosed, underdiagnosed, or simply neglected. They often became frightened, with many experiencing serious complications and at times devastating lifestyle and psychological changes, all of which could have been mitigated.

It was this need presented by patients that led to the lymphedema clinic in the United States and such a clinic was often organized by nurses for the care of patients all by themselves.

It became apparent that there was a great need for more clinics along with education, awareness, and most importantly, effective multimodal treatments for patients with lymphedema.

Such a movement was started by a dedicated nursing group led by Saskia Thiadens et al. in early 1988: the National Lymphedema Network (NLN®)[1] soon became a leading non-profit providing much needed information on lymphedema to medical professionals, lymphedema patients, and the general public throughout the country.

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As a patient advocate group, it also offered a training program for patients who want to become advocates for clinical and basic research and a parents' network for families that have children with lymphedema, focusing on treatment options as well as diagnostic approaches and basic and clinical research focused on patients with lymphedema.

In the early 1990s, when complex decongestive therapy (CDT) was introduced to the USA, hundreds of dedicated physical therapists and nurses took on a crucial role in accepting it as standard of care on a day-to-day basis.

Indeed, such extraordinary efforts and devotion by the specialized nurse group gave a new opportunity for the right care for the first time to the patients, who either received no care, had inappropriate treatment, or both, which often made their condition worse.

Later, in 1998, the newly organized Lymphology Association of North America (LANA)[2] started to provide new sets of the standards/guidelines for appropriate treatment and training of professionals to become lymphedema therapists to maintain appropriate knowledge fundamental to the treatment of lymphedema.

The Specialized Role of Nurses in Lymphedema Care

Over the last two decades, nurses (especially those who work in the oncology field) have expressed interest in the swollen limb and are often frustrated not knowing how to educate and treat patients after lymph node removal and radiation. Some nurses have become certified lymphedema therapists and are hoping to bring more nurses to the forefront to be involved with patients who are at risk of developing or who already have lymphedema.

However, sometimes nurses have to resist the notion that only physical and occupational therapists should be treating patients with lymphedema, and that nurses should only educate patients.

Another dilemma for nurses is that at the moment there is no reimbursement for nurses treating patients with lymphedema.

Many nurses are working in breast centers or other cancer-related areas, and meet with patients pre- and postoperatively and are in an excellent position to educate patients in risk reduction practices[1] and provide behavioral training, resources, and obtain baseline measurements of both arms.

Educated nurses are capable of assessing lymphedema-related symptoms, such as heaviness, tightness, firmness, pain, and numbness or decreased mobility, and diagnose latent stage lymphedema.[3] In practice, many women treated for breast cancer do not receive appropriate information about lymphedema and risk reduction,[4] and the educated oncology nurse is in a prime position to provide these guidelines.

Nurses are also frequently in the best position to identify patients' needs and provide emotional support and effective counseling.[5] We are fortunate to also have a growing group of nurse researchers in this country who are greatly contributing to multiple areas of clinical and basic research in the treatment of patients with lymphedema and receiving peer-reviewed funding for their work.[3-10]

Legislation, Reimbursement, and Patient Advocacy by Therapists

Although the reimbursement issue is set aside as a separate chapter in this book, its importance cannot be overemphasized. Hence, we will reiterate its basic issues here in this chapter as a mission for the nurse dedicated to lymphedema management.

Despite the increased awareness and education among patients and professionals, access to care and reimbursement continues to be problematic. Patients often cannot receive treatment and have to fight for reimbursement. Many therapists and organizations led by therapists are at the forefront of introducing and promoting new legislation, such as the Women's Health and Cancer Rights Act of 1998.[11]

There have been successes in securing a lymphedema treatment mandate in the Commonwealth of Virginia in 2003 and in the state of North Carolina in 2009 and Congressman Larry Kissel has sponsored HR 4662, the Lymphedema Diagnosis and Treatment Cost Saving Act of 2010, which was officially introduced in the House on 23 February 2010. One of the significant provisions of HR 4662 is to allow Medicare to reimburse lymphedema-trained registered nurses for lymphedema services, which is not currently provided

Now, lymphedema is identified as a legitimate condition in the United States, and CDT-based treatment is fully recognized as the most current standard treatment by most of the university-based clinics, hospitals, rehabilitation centers, and free-standing facilities.

It also has been recognized as an effective treatment protocol by the Medicare Evidence Development Coverage Advisory Committee (MEDCAC).[12]

Nurses and therapists have encouraged more patient advocates to step up and work for patient rights. Currently, awareness and education among the multidisciplinary teams in these breast centers is expanding throughout the United States and has facilitated the gathering of much needed data on lymphedema in general, outcomes of early diagnosis and breast cancer treatment, and follow-up measurements of affected limbs.

Summary

Today, skilled nursing is invaluable in the care of patients with lymphedema. The largest and oldest patient-centered organization for patients with lymphedema (NLN) was founded by and is still run by a nurse. Most quality of life research in the United States is led by nurses.

Multiple National Institutes of Health (NIH; and other) funded research programs are led by nurses, including genomic and microarray studies, as well as studies exploring the latest assessment and treatment technologies.

In many cancer centers and clinics across the nation, a nurse is frequently the point person to inform, assess, and even treat patients with lymphedema. Although nursing care for lymphedema may have had its origins with a single nurse impelled by patient advocacy, today, nurses are a critical part of all aspects of care for patients with lymphedema.

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