

LIMPRINT: Elucidating the Global Problem of Lymphedema

Stanley G. Rockson, MD, Editor-in-Chief

FOR THOSE WHO study the lymphatic system, and for those who administer medical care to lymphatic patients, it is an inescapable conclusion that lymphedema is a disorder that is a commonly encountered, difficult, universal medical problem. Nevertheless, paradoxically, medical practitioners and the lay public alike persistently and erroneously believe lymphedema to be a rare disorder, or one of only historical interest.¹ Accordingly, reliable incidence and prevalence data for lymphedema have been elusive or nonexistent. Published prevalence estimates for the population generally derive from extrapolations related to the soft data surrounding the relevant cancers and infections that predispose to acquired lymphedema.²⁻⁴ Data derived from health care databases, although helpful, likely underestimate the magnitude of disease burden through under-reporting of relevant diagnostic codes by the responsible health care professionals.⁵ Without data to support the extensive impact of this disease, supportive responses from government, industry, and third-party payers are not forthcoming,¹ all of which serves to perpetuate this individual and public health problem.

Thanks to groundbreaking efforts undertaken by the International Lymphoedema Framework (ILF), this paradoxical and problematic information gap has been addressed. The ILF, an international organization dedicated to the problems of the lymphedema community, has coordinated and completed the Lymphedema Impact and Prevalence—International Lymphedema Framework (LIMPRINT) project, an international study designed to define the scope and impact of chronic edema across the international landscape, with the intent of creating an evidence base to support the development of, and reimbursement for, lymphedema services. Coordinated by ILF through its participating national frameworks, the study was conducted in 40 sites distributed through 9 countries. The international data set of >13,000 patients was supported by an electronic data capture system and validated data collection tools.

The preliminary analysis of this extensive data set was presented at the Seventh International Conference of the ILF in Siracusa, Italy in 2017.

It is a great privilege for *Lymphatic Research and Biology* to communicate here the results of this monumental undertaking that illuminates, in very objective terms, the disease burden and population risk of chronic edema throughout the world. Through the 17 articles published in this issue of the journal, the entire scope of the project can be appreciated. In this issue, the authors have documented the concept of the study and development and validation of the methodology, which has permitted estimation of the prevalence of chronic edema and lymphedema in the acute hospital setting, in specialist lymphedema services, and in community nursing services. The clinical and ethical challenges of vulnerable populations are addressed, as are the health-related quality-of-life and sociological concerns.

The global reach of this project is represented through analysis of the data derived from Australia, Canada, Denmark, Japan, Turkey, and the United Kingdom, respectively. Finally, in a very unique and instrumental analysis, three final articles address

the unique challenges related to the problem of lymphedema management in children and adolescents.

The work of ILF is laudable and invaluable. With the availability of this incisive data set, one can envision a paradigm shift in which the international health care approach to chronic edema and lymphedema will arrive at more equitable solutions for this large segment of the nonhealthy population. It is a distinct honor for this journal to convey the results of LIMPRINT to the scientific medical literature.

Author Disclosure Statement

No competing financial interests exist.

References

1. Rockson SG. Lymphatic medicine: Paradoxically and unnecessarily ignored. *Lymphat Res Biol* 2017; 15:315–316.
2. Rockson SG. A population-based assessment of the problem of lymphatic disease. *Lymphat Res Biol* 2008; 6:1–2.
3. Rockson SG, Rivera KK. Estimating the population burden of lymphedema. *Ann N Y Acad Sci* 2008; 1131:147–154.
4. Rockson SG, *et al.* Cancer associated lymphedema. *Nat Rev Dis Primers* 2019; 5:22.
5. Brayton KM, *et al.* Lymphedema prevalence and treatment benefits in cancer: Impact of a therapeutic intervention on health outcomes and costs. *PLoS One* 2014; 9: e114597.