Evidence and tradition in conflict: The Swedish experience of lymphedema treatment and care

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The basis of lymphedema treatment programs were first developed in Germany early last century. The treatment principles developed during later years and until recently been similar based around manual lymph drainage (MLD), compression, skin care and exercise. The cancer related lymphedemas are often recognized at an early stage and the lymphedema treatment is an integrated part of rehabilitation. The goal of lymphedema treatment is not only to reduce and/or improve function, but also to improve patients quality of life and for those at risk of developing lymphedema deliver education on prevention. In terms of rehabilitation, at Karolinska University Hospital in Stockholm, patients are educated to recognize the early signs of lymphedema and usually present early with minimal edema (1,2). This is possible since in Sweden a referral from the doctor is not required and patients often contact lymphedema therapists in primary care directly. Lymphedema therapists are generally fully responsible for initiating and evaluating the lymphedema treatment plan. This includes the ordering and fitting of compression garments and also to guide, motivate and empower patients, helping them take an active role in treating their edema (3). Traditionally, the main outcome measure of successful lymphedema treatment has been reduced edema volume. Treatment has been focused on MLD. However based on more recent research, a paradigm shift in therapy is underway (4,5). Manual lymph drainage (MLD) performed by the lymphedema therapist in Stockholm is never the first choice of treatment. Instead patients are informed about the lack of evidence for MLD, but are encouraged to undertake self massage for a short period to evaluate its effects. Where self massage is ineffectual, the patient can discontinue and focus on wearing compression garments and being physically active for improving lymphatic- and blood circulation. We suggest less emphasis on manual lymph drainage and more on compression, exercise and weight reduction (6,7,8).

Some patients are sometimes disappointed that the health care system is too evidence-based and does not use complementary methods to the extent they would like. This leaves a number of important questions unanswered. Is it outcomes other than reduced edema volume that some patients expect from treatment? How well can therapists meet these patients needs? Is the patient asking for MLD for reasons other than edema volume reduction? Is it perhaps the touch/tactile stimulation or the soothing effect of MLD? Should this additional demand be met by
Lymphedema therapists or should these patients seek a private massage therapists? A paradigm shift in treatment can more easily be implemented by greater holistic thinking. Though, support from the patients organisations is essential for best outcomes: communication and interaction between the lymphedema therapists and patient organisation is a critical part of this process. Lymphedema therapists need to examine how we can accelerate change in our approach to edema management and how this should be integrated into health care systems.

References

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