

*INVITED COMMENT***WHEN ABSENCE OF CONTROLS CAN HELP IN THE GAINING OF CONTROL – SITUATIONS WHERE FINDINGS ARE LIKELY TO BE VALUABLE FOR PRACTITIONERS AND PATIENTS**

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In many countries there are increasing numbers of patients seeking to manage their medical conditions at home, in particular those which are not life-threatening but progressive such as lymphedema. One of the factors encouraging home management is the explosion of information, debate, and views available on the internet that were previously inaccessible. Further encouraging home management are the issues of increasing costs/declining insurance reimbursement for healthcare, difficulties with accessing the appropriate practitioners (e.g., scheduling and transportation), medical uncertainty of what is the best treatment option for each particular patient, and the affordability of the selected treatment. Additionally, most home based modalities can be linked to the area loosely called alternate or complementary treatments, which in itself generates tension when interacting with the mainstream medical or scientific fraternity.

This tension arises from the contrary views and opinions among various health professionals about which treatment/management regimens are best and most appropriate for the individual. Individuals are just that—a unique person with a specific set of problems—and often not at all like the homogenous member of a large clinical trial group- and they know that! On top of this,

often the evidence for the practitioner-controlled treatment is not as strong as it could be in terms of the underlying science (i.e., methodology, sampling and sample size, and evidence), but it is perceived as being a bit more “mainstreamed” (and therefore more accepted even with its lack of rigor).

This leaves patients left with some rather difficult options and a range of confusing information and recommendations. In order for patients to optimally manage their condition and to be given some sense of empowerment in this process, they need to be provided with information that is rigorous in its collection, reflective of their individual situation, and informative about likely outcomes. It is clear that in many of these patient-based studies blinding is not always possible, and there are many potentially confounding variables as well as some opportunities for bias. However, such studies are better than anecdotal reports in the “grey” literature and in health/lifestyle magazines, which are often the only other source of materials for information-hungry patients as well as some practitioners.

Studies such as the three included in this issue are stimulated by patient demands for knowledge and are aimed at providing a breadth of information about what can be expected (often both objectively and

subjectively) if a particular treatment regimen is followed. They are often out of necessity (and of reality—for that is what patient groups are like in our communities) heterogeneous rather than homogenous, there are confounders and often sub-optimal analyses, and grey areas of interpretation. But life is like that—it's a potpourri. "Elite" science denies it and demands the opposite—control, homogeneity, blinding, randomization, and large scale studies in multiple centers.

There is no claim that the vast majority of alternative/complementary studies represent the highest possible level of evidence acquisition. What they do is to inform, direct, and hopefully lead to larger and more controlled studies which will then begin to satisfy the ideals of the medical and scientific worlds. But how real are these findings then to the individual who is trying to manage his or her lymphedema at home? Will we always be searching for the Holy Grail in terms of solutions for our patients? Do we know what it is and when and if it's found will we even be happy with it then? Possibly no! There is nothing that we have

ever seen in terms of even the highest level studies where the results, methods, or some other aspect are ever taken as the ultimate truth and final answer to questions or solutions for all of our patient's woes. There will always be doubts, no matter the perceived level of our science or the level of rigor we impose on our trials and that is how we must advance. We must take the first steps, and we must never be afraid of doing this. To start and to invite critique is better than to never start at all and thus to deprive practitioners and patients of some small but important addition to our knowledge.

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