

COMMENTARY**PSYCHOLYMPHOLOGY: WHY NOT ALL PATIENTS WITH
CHRONIC LYMPHEDEMA WANT THERAPY****L. Clodius**

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There is no ideal, simple clinical answer or
cure for most patients with lymphedema.

- Thrust of discussions on the ISL
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ABSTRACT

*This Commentary provides the reader
with various motivations and psychologic
factors patients have for refusing as well as
for accepting long-term therapy of
lymphedema.*

Keywords: quality of life, lymphedema,
therapeutic choice, psycholymphology

Why this peculiar title? Since the
Pharaonic times until today, we are
constantly striving for rational scientific
progress. In ancient Egypt the question was:
Will I dare to treat this patient? Today it is
the era of the decoding of the human genome,
of organ transplantation,
of techniques for cloning. For several
thousand years, mankind has been building

the magnificent cathedral of science (1). But
our human cognition recognizes progress not
only as composed of abstract findings and
rational deliberations, but also consisting of
our patients' personal feelings and emotions
(2).

Medicine and feelings: Are feelings not
rather irrational, irritating, unobjective,
changing? As physicians, we are used to
facts. What would our malpractice insurance
do without them? We follow reason. But
reason is complex (3). It enables us to track
down the essence of facts as well as the
complexity of the arguments of our patient
with chronic arm lymphedema, here
described.

This Commentary provides the reader
with the patient's various motivations for no
therapy of her secondary arm Lymphedema.

EVIDENCE BASED?

In general, textbooks, specialized
journals, symposia, national and international
meetings provide for scientific progress, e.g.,
in *Lymphology*, in particular the management

of chronic lymphedemas. On a long-term basis, most lymphedemas cannot be cured by surgery (4,5). Therefore, conservative therapy is indicated and requires a lymph therapist and the art of self-treatment. The patient should learn to train the mind for wishing a stable, good clinical result: an emotional as a scientific success.

Each patient is a world of his or her own, and more than rational reason. The more the actual health problem is no immediate threat to life, the less the urge is felt to be treated.

INDIVIDUAL PROBLEMS

Recently, on the street of my hometown, I met my former, now retired, head nurse. In the past, therapy of her breast cancer had included axillary dissection. For her secondary arm lymphedema, she had optimal treatment and practiced the art of self-therapy. She fully realized its importance, also the threat of a Stewart-Treves angiosarcoma (6). As long as she took care of the patients at the hospital, she had an almost normal-looking arm. She abhorred the possibility that a patient, noticing the swollen dorsum of her hand, might ask her about her breast cancer. Now — she told me — "I have retired." Looking now at her swollen arm and hand she said, "Look doc: Yes, my arm is again thick. Medically [she meant intellectually or scientifically], you are right. It's the problem of the reduced lymphatic transport capacity at my armpit, ever since it was done. But now, this is no longer my problem. My problems now are my clothes, these looks of others, probably making them think, 'Ah — she had breast cancer.' About every ten weeks my arm gets red, the infection makes me sick, but I get over it with an antibiotic. Look — I want to be independent." This is what this and other patients have been telling

me. Scientifically speaking, they don't care about their reduced lymphatic transport capacity, but they do care about their own problems or emotions. The reader will agree: This patient needs an overall thoughtful approach : Optimal therapy for her reduced lymphatic transport capacity as well as for her individual and subjective ideas, due to her personal experiences with her swollen arm. Caring for the individual patient is more than trying to balance the lymphatic load versus the lymphatic transport capacity. In the realm of diseases, the patient (with emotions) is king (7). Statistically, half of the patients with secondary arm lymphedema find themselves to be less attractive and unsatisfied with their quality of life. 76% wear adjusted clothing, and almost 70% have problems with their work situation (8).

Our patient, the nurse, understanding well the cause and therapy for her swollen arm, sensed the changes in her life, and thus abandoned her previous successful "complete decongestive therapy" (6).

EMOTIONS

In general: What are the motives for not having or refusing therapy, when affected by extremity lymphedema, a non-immediate life-threatening problem? Reasoning, all of us included, has two basic functions: cognition (in this patient the fact of her reduced lymphatic transport capacity) and her personal, individual evaluation (9). Since the final decision is the patient's, we enter the difficult world of the individuality — of each patient, of her subjective views and priorities in her daily life with her lymphedema:

LYMPHOPSYCHOLOGY

Some general, interlocking points are:

1. The patient is not motivated.

2. The patient misjudges the importance of her problem.
3. She is used to her swollen arm.
4. She expects too much, a "pat" situation.
5. Time and money are a consideration, i.e., too great an expenditure.

Personal Negative Reasons

1. The patient dislikes her therapist.
2. The patient considers her disease (breast cancer) more important than other "non-related" therapy.
3. The patient dislikes her treatment. CDT is not only mechanics, it is a framework of anatomical and functional facts, to be understood and also applied by an engaged patient (art of self-treatment).

The difficult patient, as seen by the therapist:

1. Differences in language, in understanding, in background.
2. The magnification syndrome (10): Personal problems are dramatized, their own capacity or performance underestimated. By demonstrating her complaints (diffuse, uncharacteristic pains, inability to care for her arm unless success is guaranteed), the patient tries to satisfy her emotions. Rational arguments are of no help. The conversation may be best started by: "How can I help you?" or: "What is most important for you?".

The demanding patient

She feels (emotions!) she has a right to a fast and a definitive cure.

The pessimistic patient

Previously the patient has often seen other therapists. There is no help, she

believes. Again she may display her swollen extremity and is often depressed. From visit to visit the therapist may demonstrate the successes of CDT, including the satisfaction resulting from the art of self-treatment.

The "sticky" dependent patient

"My therapist must always be available, whenever I need him." This confidence is graciously acknowledged, but the patient must understand that time and knowledge are limited.

This incomplete list reveals that the identity of patients may not be divided into two unrelated parts: The patient with her "big arm" — symptom of disparity of lymphatic load/lymphatic transport capacity — and her emotions.

Integrated Therapy

Trying our best for the patient, what should we know about psycholymphology, what about emotions? Our retired nurse reveals her individual code of values, her affective response to what she considers as beneficial or harmful to herself. Still working at the hospital, she was coping with her problems on a rational basis, we believe. Emotions are judgments of values as products of thinking or as failure to think (11). Emotions are affective responses to a subconscious evaluation of a perceived or considered object or action, believed to be beneficial or harmful to oneself (12) (e.g., Joy: I achieve my value. Desire: I want to get my value. Emotions are subjective value judgments, they may change according to the premises of the individual. Value judgment: Our patient is convinced that her conclusions are correctly based on her personal values. This may well lead to a clash with our professional convictions.) To practically

solve the problem, we may try to understand the patient's code of values since emotions — significant for our patient — are not necessarily based on the perception of an objective reality.

How can the therapist do the best for a patient with chronic lymphedema? He or she should try to clearly differentiate between the patient's rational thoughts and her emotions. Every rational judgment is accompanied by emotions, unconsidered judgments (13). Rational judgment and subjective emotion should not compete; the skilled therapist should harmonize them.

A rational process may be emotional — and an emotional process may also be rational. Lymphedema is a chronic disease. Its conservative therapy makes time available to check on the patient's premises, on possible areas of ignorance and to discuss not only the textbook's but also the individual values of our patient.

REFERENCES

1. Clodius, L: The ISL meets in Florence. *Progress in Lymphology*. Avicenum, Prague, 1981.
2. Goleman, D: *Emotional Intelligence*. Bantam, New York, 1995.
3. Peikoff, L: *Objectivism*. Meridien, New York, London, Toronto, 1993.

4. Földi, E, M Földi, L. Clodius: The lymphedema chaos: A lancet. *Ann. Plast. Surg.* 22 (1989), 505.
5. Clodius, L: Lymphedema common sense. *Europ. J. Plast. Surg.* 25 (2002), 66.
6. Földi, M, M Földi, S Kubik: *Textbook of Lymphology*. Urban & Fischer, Munich, Jena, 2003.
7. Clodius, L: Paracelsus and plastic surgery today. *Europ. J. Plast. Surg.* 17 (1994), 57.
8. Tassenoy, A, Ph van der Veen, P Lievens: Study on the quality of life of woman with secondary arm lymphedema after breast surgery with axillary XIX International Congress of Lymphology, 9/1-6/03, Freiburg, Germany, Abstract Booklet, p.175.
9. Branden, N: Emotions and Values. *The Objectivist* 5 (1966), 65.
10. Matheson, LN: Symptom magnification syndrome. In: *Work Injury*. Aspen Publ., Gaithersburg, 1988.
11. Binswanger, H: *Emotions*. Second Renaissance Books. Irvine, 2002.
12. Rand, A: *For the New Intellectual*. Penguin Books. New York, London, Toronto, 1961.
13. Locke, E: *Reason and Emotion*. Second Renaissance Books. Irvine, 1997.

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