

As described by the Lipoedema UK survey, patients' quality of life can be affected by more than the symptoms and physical issues associated with the disease.^{5,12,15,16} Patients must also contend with the mental health issues that often accompany the challenges of managing lipedema. It is currently unknown whether mental health issues precede or occur with onset of lipedema; however, such stressors affect patient quality of life in terms of:

- Psychological health (e.g., anxiety, depression)
- Level and quality of social relationships, including support and engagement of friends and other lipedema patients (see box)
- Perception of the environment (e.g., stigma)

To account for psychosocial stress, the Dutch Society of Dermatology and Venereology developed a guidelines document (Dutch Lipedema Guidelines) which included a holistic assessment and care model that assesses a patient's physical state and levels of psychosocial distress.^{7,17} This model was based on evidence- and expert-based recommendations to inform and define the criteria for a medical diagnosis of lipedema.

Importantly, the guidelines propose a minimum data set of repeated clinical measurements, or clinimetrics, to outline and assess a chronic care model for lipedema measuring the impact and success of conservative treatment programs for the disease (see Treatments section).¹⁷⁻¹⁹ The value of this clinimetrics-based care model is derived from its holistic approach to assessing a patient's physical state, daily and individual-driven treatment program, and levels of lipedema-associated psychosocial distress.

The application of clinimetrics to evaluate diagnosis and treatment is exemplified by the calculation of mean VAS values before and after liposuction surgery to assess changes in pain and psychosocial stress.¹⁴

Along with the active and connected lipedema patient community, these efforts set the stage for a holistic and quantitatively driven approach that will hopefully capture and understand the true health burden of lipedema.

Facebook Lipedema Patient Groups

High levels of social connectedness were found to correlate with high levels of quality of life and satisfaction of life. Listed below are online patient groups focused on lipedema:

- ❖ Friends of Lipedema Sisters USA (anyone can join)
- ❖ Fat Disorders Research Society (FDRS)
- ❖ Lipedema Sisters USA
- ❖ Lipedema Education
- ❖ Loving Life with Stage 1 and 2 Lipedema
- ❖ Lipedema Stage 3 and 4
- ❖ Lipedema Fitness
- ❖ Liposuction for Lipedema
- ❖ Lipedema USA Español
- ❖ Lipedema Canadian Support Group
- ❖ Lipoedema Australia Support Society
- ❖ Lipoedema UK
- ❖ Lipoedema Ladies UK
- ❖ Talk Lipoedema

Some groups are private and request that interested people agree to their rules before contacting or joining the group.
