



Lipoedema – Diagnosis, treatment, and experiences

A systematic review and assessment of the medical, economic, social and ethical aspects

Executive summary

Background

SBU has assessed the scientific base with respect to the diagnosis and treatment of lipoedema at the behest of the Swedish Government (S2019/05315/RS).

There are no known tests or internationally accepted diagnostic criteria for lipoedema. The Swedish diagnostic code for lipoedema is R60.OB. A diagnosis of lipoedema is made based on a combination of the person's medical history, their symptoms and a clinical examination, as well as by ruling out other conditions with similar symptoms such as lymphoedema, Dercum's disease, and obesity (BMI>30). Lipoedema is distinguished by the symmetrical accumulation of fat on the hips, thighs, lower legs and or arms that does not involve the hands or the feet. The condition is characterized by pain and sensitivity to pressure in the affected tissues.

There is currently no known cure for lipoedema. Interventions are therefore primarily aimed at relieving symptoms or at reducing functional limitations. Available treatments include diet and exercise advice, compression treatments, and liposuction.

Aim

The aim of this report is to assess the scientific evidence with respect to the diagnosis and treatment of lipoedema, experiences and perceptions of those who have lipoedema regarding their care and support when interacting with healthcare, health economics, and ethical aspects.

Method

A systematic review was conducted in accordance with the PRISMA statement (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) and SBU's handbook. The certainty of evidence was assessed with GRADE (<http://www.gradeworkinggroup.org>).

Conclusions

- ▶ No scientific studies assessing tests to diagnose lipoedema, or methods to distinguish between lipoedema and other conditions were identified.
- ▶ There is a lack of scientific studies, with an acceptable risk of bias, assessing methods to treat or cure lipoedema.
- ▶ No scientific studies exploring the perceptions or experiences of people living with lipoedema, nor of healthcare professionals who care for people with lipoedema were identified.
- ▶ There is insufficient scientific evidence to support a full health economic evaluation.

Internationally accepted diagnostic criteria should be considered as a reference standard in future studies

investigating methods to diagnose lipoedema. Such studies are needed to assess the diagnostic accuracy of such methods.

Controlled clinical trials are needed to assess the effects of methods for the treatment of lipoedema. These future studies should, for example, clearly describe the study participants, report why participants are lost to follow-up and use standardized outcome measures. Studies into the perceptions and experiences of those living with lipoedema and the healthcare personnel who care for them are also required.

From an ethical perspective, there is a risk for healthcare inequity and infringements on autonomy. The lack of scientific evidence can lead to a situation where people with lipoedema are not recognized by the healthcare system and do not receive adequate healthcare.

Inclusion criteria

Diagnosis

Population: Persons with suspected lipoedema

Index test: Method to diagnose or detect lipoedema

Reference test: Internationally accepted diagnostic criteria used to detect lipoedema

Outcome: Diagnostic accuracy

Study design: Randomized controlled trials (RCT) and cross-sectional studies

Study size: At least 10 persons

Language: Swedish, English, Danish and Norwegian

Treatment

Population: Persons with lipoedema. No limitations regarding age or comorbidities

Interventions:

- Change in lifestyle including exercise, change in diet and weight loss
- Intermittent pneumatic compression (IPC), low-frequency vibrotherapy
- Manuel lymph drainage
- Self-care including moisturizing cream or the above mentioned intervention performed by the patient itself
- Liposuction
- Bariatric surgery
- Other interventions aiming to treat lipoedema or alleviate symptoms

Control:

- Placebo
- No treatment
- Waiting list
- Other treatment than the intervention

Outcome:

Primary:

- Pain
- Sensitivity to pressure
- Function including self-assessed capability
- Quality of life
- Bruising
- Side effects of an intervention or control treatment

Secondary:

- Volume
- Swelling
- Motivation

Study design: RCT and controlled clinical trials (CCT). If no other study design is identified, case studies measuring an outcome before or after treatment are included.

Follow-up time: No limitation

Study size: At least 10 persons

Language: Swedish, English, Danish and Norwegian

Experiences

Setting: No limitation

Perspective: A person with lipoedema or a health professional treating a person with lipoedema. No limitations regarding age or comorbidities

Evaluate:

Experience regarding:

- living with lipoedema
- receiving a treatment
- caring for someone with lipoedema

Study design: Qualitative studies or mixed-method studies

Follow-up time: No limitation

Study size: At least 10 persons

Language: Swedish, English, Danish and Norwegian

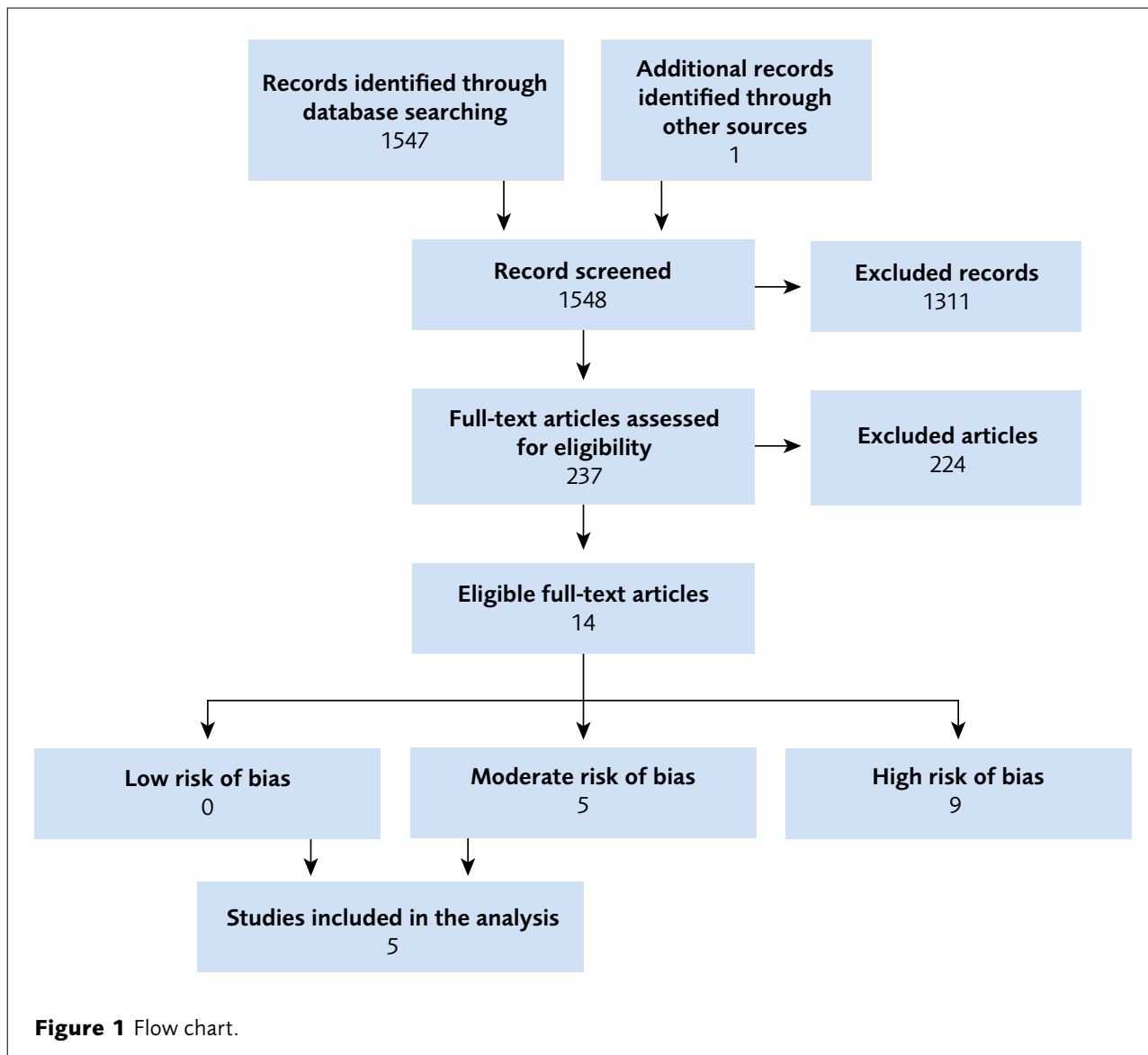
Search period: Final search March 2021. No limitation regarding year of publication

Databases searched: CINAHL (EBSCO), Cochrane Library (Wiley), EMBASE (Embase.com), Medline (Ovid) and Scopus (Elsevier)

Client/patient involvement: No

Results

After a systematic literature search and assessment of the retrieved studies, no scientific study assessing a method to diagnose lipoedema was found. Fourteen studies assessing treatments for lipoedema were



identified, but none of the studies were judged to be sufficient to inform practice. Five studies with few participants and a moderate risk of bias studied the effects of non-surgical treatments such as manual lymph drainage, physical activity, and diet.

Eight studies with high risk of bias studied the effect of liposuction of affected tissues and one study with high risk of bias studied the effect of bariatric surgery. None of the studies had included a control group. Instead, they had studied or interviewed patients before and after liposuction or bariatric surgery. These studies were evaluated to have a high risk of bias because of risks in participant selection, because participants were not well enough described, because it is difficult to blind studies of liposuction, as well as insufficient reporting of why some people were lost to follow-up. In addition, the results, that are based on patients' symptoms before and after, are presented at the group level rather than individually. Adverse events were

reported in seven of the studies. The most common reported adverse event was post-operative bruising.

There are no qualitative studies that explore experiences and perceptions of living with lipoedema. Neither are there any studies that explore how healthcare providers experience or perceive caring for people with lipoedema.

Cost-effectiveness was not assessed due to lack of scientific evidence from studies with sufficiently low risk of bias for any outcome or method.

The ethical discussion focused on the lack of evidence for the diagnosis and treatment of lipoedema. The situation may lead to both underdiagnosis and misdiagnosis, and that the time between when a person's first initiates contact with healthcare and when a correct diagnosis is established may take an unreasonably long time. This delay increases the risk that

lipoedema may negatively affect the persons quality of life and may allow time for the condition deteriorate, so that they experience more pain and more physical limitations. Which in turn may increase the negative impact lipoedema can have on the person's ability to have an adequate work- or private life (e. g. parenthood).

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