





WHAT ARE THE NEEDS AND PREFERENCES OF LIPOSARCOMA PATIENTS? A literature review and qualitative interviews

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BACKGROUND & OBJECTIVE



- Little is known about **perceptions**, **needs** and **preferences** concerning treatment and care in liposarcoma
- Lack of insights on the views of the patients and healthcare professionals (HCPs) involved





- What are the health-related needs and preferences of well-differentiated liposarcoma (WDLPS) and dedifferentiated liposarcoma (DDLPS) patients?
- ➤ Are WDLPS and DDLPS patients involved in treatment and care choices? And if so, how?
- ➤ What are the perceptions and insights of HCPs?

METHODS



Literature review

Scientific databases: PubMed & Embase

- Systematic search string: ("patient preferences"
 OR "unmet needs") AND ("liposarcoma")
- Extraction table based on the NEED framework
 from the Belgian Healthcare Knowledge Centre

Clinical trial databases

- Screening of phase 3 liposarcoma clinical trials with treatments
- Overview of commonly reported adverse events



Interviews with HCPs and WDLPS and DDLPS patients

Semi-structured interviews following a predefined topic guide based on the literature

Transcribed and analysed using thematic framework analysis

Interviews still ongoing: Interviews with HCPs started in April 2024; interviews with patients started in August 2024

RESULTS



Literature review

Scientific databases: PubMed & Embase

 90 articles eligible for data extraction: Mostly case reports (n=33); retrospective descriptive studies (n=30); case reports with literature review (n=12)

Themes most discussed

Life expectancy

Impact op LPS on life expectancy

Treatment efficacy

Burden of treatments

Side effects and complications; Hospital stay; Psychological burden

Quality of care

Research needs

Difficulties in diagnosis; Uncertainties regarding treatment; Lack of evidence

Clinical trial databases

• 9 clinical trials included (3 in phase 2+3; 6 in phase 3)

Adverse events commonly reported

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Anemia	Nausea
Fatigue	Alopecia
Febrile neutropenia	

Interviews with HCPs – preliminary findings

> 8 HCPs involved in the treatment of liposarcoma patients

> Preliminary findings

- Importance and difficulties related to an accurate diagnosis
- Multidisciplinary approaches in treatment and care decisions
- Importance of involving patients and patients' preferences in treatment and care choices



Interviews with WDLPS and DDLPS patients – preliminary findings

- > 15 liposarcoma patients
 - 7 female patients; 8 male patients
 - 10 DDLPS patients 5 WDLPS patients
 - Treatments: all patients underwent surgery (tumour resection), for some patients received additional radiotherapy

Preliminary findings

- Importance of clear and open communication and information
- Trust in the expertise of the HCPs and the multidisciplinary team
- Mental burden of the disease (anxiety, stress, fear of the unknown)
- Importance of follow up and after care

CONCLUSIONS



Important (unmet) needs and preferences in treatments and care in liposarcoma

- Diagnosis and research needs
- Information needs and communication
- Follow up and after-care
- Basis for the broader qualitative patient preference study and analysis, aiming to:
 - Refine what matters most to patients
 - Further investigate how and if patients and HCPs perceptions and perspectives align

LIST OF ABREVIATIONS

DDLPS: dedifferentiated liposarcoma; HCPs: Healthcare professionals; NEED: needs examination, evaluation and dissemination; LPS: liposarcoma; WDLPS: well-differentiated liposarcoma

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