

# Electronic supplementary material

**Article title:** Experiences and perspectives of patients with non-HIV associated lipodystrophies and their caregivers: A qualitative study

**Journal name:** The Patient

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**Supplementary material caption:** Coding tree

**Concepts**

**Categories**

**Codes**

Diagnostic Journey and Symptom Management

Diagnostic Journey

Symptom Recognition

Symptom Management

Understanding of Disease

Coping Strategies

Experience with Treatment

Diagnostic journey

Self-advocate (Patient)

Patient advocate (Caregiver)

Failure to recognize symptoms (Patient)

Clinical failure to recognize symptoms

Exasperation due to failure to diagnose

Clinical diagnosis – Appreciation towards clinicians

Clinical diagnosis – Validation

Retrospective understanding (Patient)

Retrospective understanding (Caregiver)

Retrospective understanding of family members (Patient)

Awareness of symptoms prior to diagnosis (Patient)

Ambiguous symptoms (Patient)

Difficulty managing symptoms (Patient)

Difficulty managing symptoms (Caregiver)

Symptom compartmentalization (Patient)

“Once we knew to look” (Patient)

Sense of accomplishment

Sense of defeat

Increased understanding of disease

Increased understanding of disease (Providers)

Increased understanding of disease (Family members)

Coping strategies related to hyperphagia (Patient)

Coping strategies related to hyperphagia (Caregiver)

Coping strategies related to fatigue (Patient)

Coping strategies related to fatigue (Caregiver)

Compartmentalization of burden

Hyperphagia as addiction

Allocation of energy

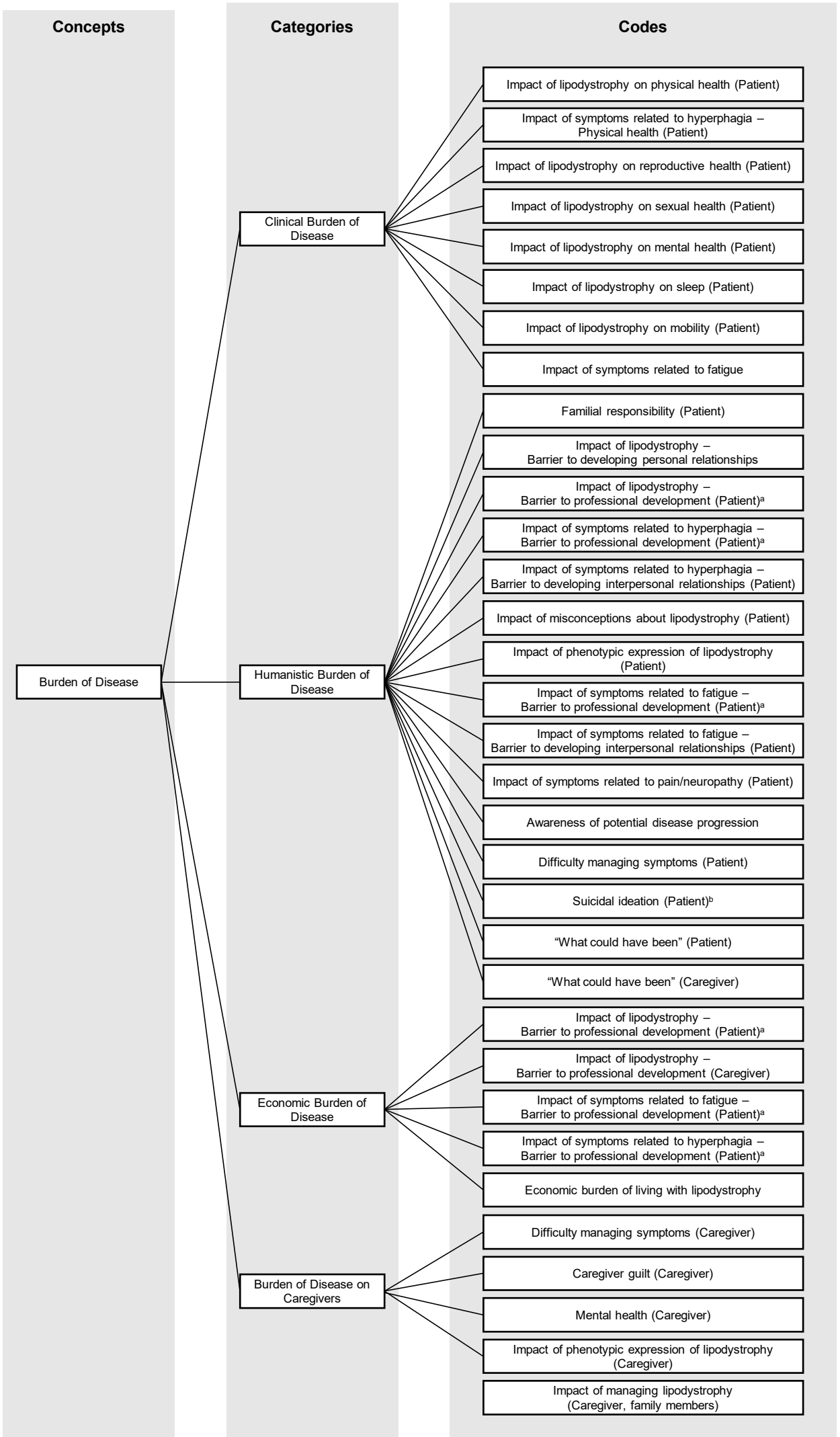
Impact of leptin treatment

Impact of symptom-specific treatment

Seeking treatment

Barriers to seeking treatment

Alternative treatments



**Footnotes:**

<sup>a</sup> This code was double-coded under Humanistic Burden of Disease and Economic Burden of Disease.

<sup>b</sup> When applying this code, Clinical Burden – Impact of lipodystrophy on mental health (Patient) was also coded.

