Assessing the Burden of Lipodystrophy: Insights from a Patient-Driven Survey

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Lipodystrophy United

Background: Lipodystrophy is a rare and complex condition characterized by abnormal fat distribution and severe metabolic complications, significantly impacting the quality of life of affected individuals. To better understand the experiences of patients, Lipodystrophy United, a patient advocacy group, conducted a survey assessing disease burden.

This survey aimed to capture the multifaceted challenges faced by individuals with lipodystrophy, including physical, mental, and social health concerns.

Aim: To capture the multifaceted challenges faced by individuals with lipodystrophy, including physical, mental, and social health concerns.

Methods: Data was collected via an online platform to ensure accessibility and confidentiality. The survey included both open-ended and targeted questions, designed to capture a broad spectrum of experiences and challenges.

Open-ended question:

Describe the symptoms, if any, that you face in daily life with lipodystrophy.

Symptom-specific questions:

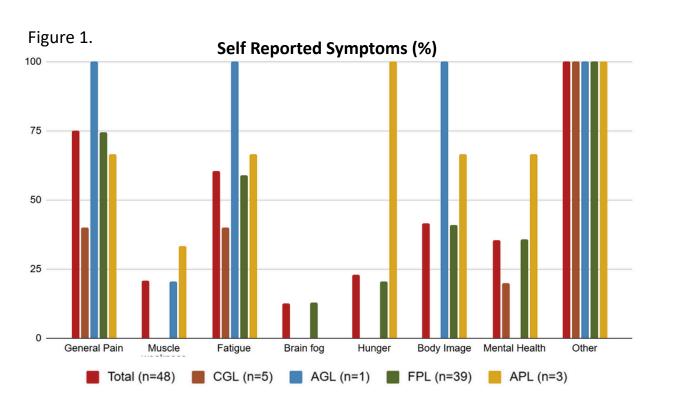
Rate the following statements (1 - not at all, 10 - all the time):

- I feel that my general life quality is poor (QoL).
- I suffer from emotional distress and anxiety (Emotional distress).
- I feel tired, which limits things that I can do (Fatigue).
- I suffer from pain in more than one area of my body (Pain).
- I cannot control the feeling of hunger (Hunger).
- I am not happy with my physical appearance (Appearance).

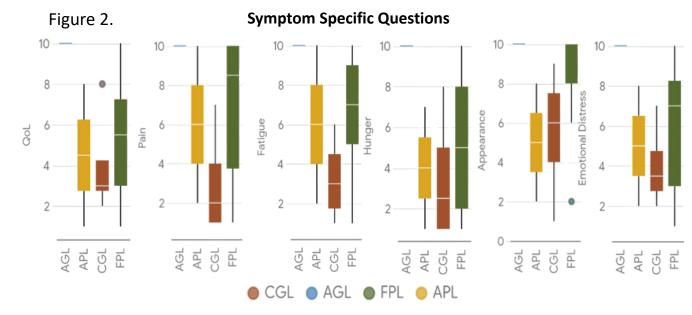
Results: 48 participants responded to the survey. Clinical characteristics are shown in Table 1.

Table 1.	Total,	Total, N=48		CGL, N=5		AGL, N=1		FPL, N=39		APL, N=3	
	n	%	n	%	n	%	n	%	n	%	
Gender	48		5		1		39		3		
Male	3	6	2	40	0	0	1	3	0	0	
Female	45	94	3	60	1	100	38	97	3	100	
Age											
Median Age (y)	43		27		62		36		46		
Median Age at Diagnosis (y)	37		23		59		44		45		
Treatment								0			
Any Prescribed Treatment	32	67	4	80	1	100	25	64	2	67	
Leptin Replacment Therapy	5	10	2	40	0	0	3	8	0	0	
GLP-1/GIP treatment	9	19	1	20	0	0	8	21	0	0	
Combination therapy	2	4	1	20	0	0	1	3	0	0	

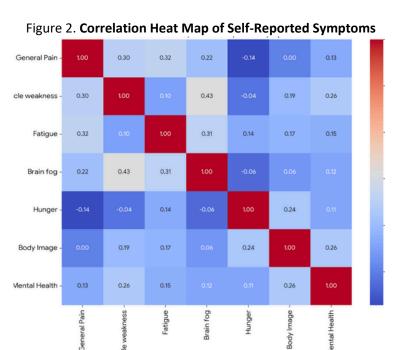
Self-reported symptoms: Participants were asked an open-ended question: "Describe the symptoms you experience in daily life with lipodystrophy." Responses were grouped into clinical categories. Figure 1 shows the number of individuals reporting each category, overall and stratified by diagnosis.



Symptom-Specific Questions: Participants rated six symptom-specific statements on a scale from 1 (not at all) to 10 (all the time), covering quality of life, emotional distress, fatigue, pain, hunger, and dissatisfaction with physical appearance. Figure 2 displays the distribution of responses within each diagnosis group.



The self-reported symptom correlation heat map shows minimal to no correlation between symptoms, suggesting that each symptom may represent a distinct aspect of the lipodystrophy experience rather than resulting from shared underlying causes or direct symptom-to-symptom relationships.



Conclusion: Our findings highlight the substantial physical and psychological burden of lipodystrophy. The prevalence of symptoms reported through open-ended questions was higher than previously documented in studies using validated symptom-specific measures. Additionally, our survey identified symptoms either not reported or rarely reported in prior research, such as body image concerns, muscle weakness, and brain fog.