

# 'It Becomes the New Everyday Life'

## Experiences of Chronic Pain in Everyday Life of People with Limb-Girdle Muscular Dystrophy

Louise Toft Holm Vrist<sup>1</sup>, Lone F. Knudsen<sup>2</sup>, Charlotte Handberg<sup>1,2</sup>



Lone Knudsen  
Clinical psychologist  
Researcher, PhD  
lokn@rcfm.dk



Charlotte Handberg  
Senior Researcher,  
Associate Professor, PhD  
chha@rcfm.dk

1. Department of Public Health, Faculty of Health, Aarhus University, Denmark  
2. National Rehabilitation Center for Neuromuscular Diseases, Aarhus, Denmark

### Aim

To investigate experiences and reflections on challenges in everyday life of people living with LGMD and chronic pain in order to improve rehabilitation.

### Method

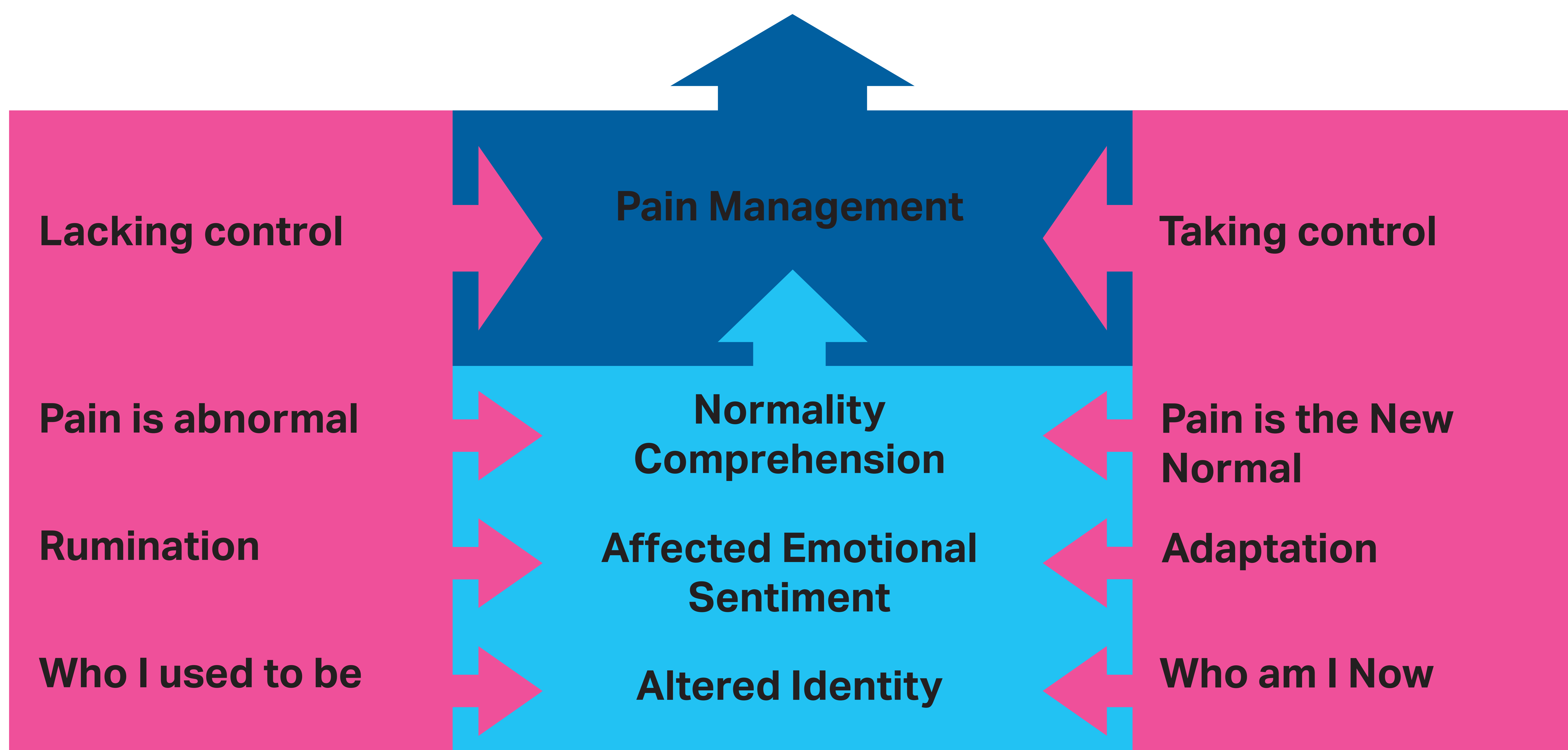
The design for this study was qualitative using the Interpretive Description methodology and the salutogenic theory of Sense of Coherence as the theoretical framework. Four semi-structured focus group interviews were conducted with 19 adults with LGMD and chronic pain from April to May 2021 (Table).

### Conclusion

Healthcare professionals should acknowledge possible chronic pain secondary to LGMD.

Chronic pain appeared to be a prevalent problem in people with LGMD with negative impact on everyday life, yet patients with LGMD do not receive sufficient information and necessary tools from health professionals to cope with chronic pain. Thus, adequate pain management appears to be a difficult and self-taught process. Educating health professionals on how to support patients with LGMD and chronic pain is needed.

Figure: Chronic Pain in Everyday Life of People with Limb-Girdle Muscular Dystrophy



### Background

- LGMD is the fourth most prevalent genetic neuromuscular disease and is characterized by weakness in the hip and shoulder girdles and the proximal muscles
- Chronic pain is a facet of living with LGMD that has been understudied despite a high prevalence of chronic pain (50-66%) (1, 2)
- In Denmark, people with LGMD are offered specialized rehabilitation in multi-professional teams at the National Rehabilitation Center for Neuromuscular Diseases.

### Results

Living with chronic pain and LGMD affected everyday life in terms of the participants' overall Sense of Coherence. Beneficial or unfavorable coping strategies were identified within four interrelated categorical themes (Figure). Pain management emerged as a sense of lacking or taking control of pain which guided the overall consequences of everyday life. The participants' capability to manage pain and cope with everyday life was guided by their comprehension of pain as either abnormal or the new normal, an affected emotional sentiment of rumination or adaption, and an altered identity.

Table: Characteristics of the participants

	Total participants (N=19)
Age, years, mean (range)	54.2 (27-83)
Sex, females, n (%)	8 (42.1)
Age at diagnosis, years, mean (range)	38.8 (9-69)
Duration of LGMD, years, median (range)	11.0 (2-56)
Pain duration, years, median (range)	13 (3-80)
Pain intensity (NRS 0-10), mean (range)	4.3 (0.75-8.5)
Pain intensity (NRS 0-10)	n (%)
Mild pain (≤4)	11 (57.9)
Moderate pain (>4-6)	4 (21.1)
Severe pain (>6)	4 (21.1)
Ambulant/non-ambulant, n (%)	12 (63.2)/7 (36.8)
Employed, yes/no, n (%)	7 (36.8)/12 (63.2)

### Implications for rehabilitation

- Health professionals should acknowledge and address the possibility of chronic pain secondary to LGMD and educate patients in pain management
- Physiotherapy, energy management and engagement in meaningful activities may help patients gain some control of pain and limit the consequences of pain on everyday life
- Supporting patients to accept pain and to shift focus towards their current capabilities may potentially improve pain management
- Educating health professionals on how to support patients with LGMD and chronic pain is needed.

### References

- (1) Tiffreau V, Viet G, and Thévenon A. Pain and neuromuscular disease: the results of a survey. Am J Phys Med Rehabil, 2006. 85(9): p. 756-66.  
(2) Stokholm, RN, Handberg C, and Knudsen LF. Prevalence of chronic pain in a national cohort of patients with limb-girdle muscular dystrophy: a cross-sectional study. Disabil Rehabil, 2021: p. 1-9.

COI: The authors declare no conflicts of interest