

# SELF-REPORTED SLEEP QUALITY AND DAYTIME SLEEPINESS IN PATIENTS WITH FSHD

## AUTHORS

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## INTRODUCTION

Facioscapulohumeral muscular dystrophy (FSHD) is a progressive disorder causing muscle loss, especially in the upper body. Sleep could be clinically impaired in patients due to sleep-disordered breathing, anxiety, obesity, or pain. However, no research to date has used a large, generalizable sample of patients to determine self-reported sleep characteristics. The objective of this study was to determine whether self-reported reduced sleep quality (SQ) and excessive daytime sleepiness (DS) are prevalent in FSHD patients.

## METHODOLOGY

A survey approach was used in this study. A survey consisting of four sections was designed and distributed to the patient database of the FSHD Society and completed by patients or their caretakers, regardless of perceived sleep quality. The demographic and clinical sections collected background information on patients such as age, gender, assistive equipment, and bedtime habits so that connections could be drawn to the sleep evaluations. The Pittsburgh Sleep Quality Index (PSQI) measured SQ, and the Epworth Sleepiness Scale (ESS) measured DS. Descriptive statistics, one-way ANOVAs, regression analysis, and posthoc tests were used to analyze data.

## REPRESENTATIVE SAMPLE

690 responses were collected. Selected background data is given.

Gender:

- 50% female; 50% male; <1% non-binary

Age:

- 24% 25-44 years old
- 44% 45-64 years old

Age of Diagnosis:

- 36% 20-39 years old

Wheelchair Usage:

- 25% using a wheelchair

Results indicated a representative sample.

## SUBJECTIVE SLEEP EVALUATION

**Self-Reported Sleep Quality:**

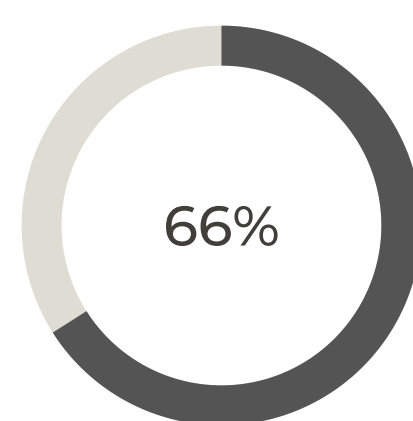
66% of respondents showed reduced sleep quality (PSQI>5).

**Self-Reported Daytime Sleepiness:**

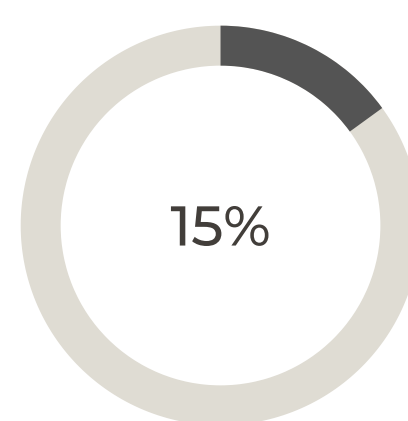
15% of respondents showed excessive daytime sleepiness (ESS>10).

**Correlation between SQ & DS:**

Regression analysis was used to discover a significant relationship between PSQI and ESS scores ( $p<.001$ ,  $R^2=.068$ ). Therefore, as SQ decreased, DS generally increased.



PSQI>5  
(reduced SQ)



ESS>10  
(excessive DS)

## PAIN VS SQ & OTHER CORRELATIONS

**Pain & PSQI (one-way ANOVA):**

There was a significant difference in SQ evaluation between those with and without nocturnal pain, indicating a large effect size ( $p<.001$ ,  $\eta^2=.192$ ). This finding suggests that pain management may be effective in improving sleep quality.

**Other Key Correlations (one-way ANOVAs):**

- **Age & PSQI:** Significant difference, small effect ( $p<.05$ ,  $\eta^2=.022$ )
- **Gender & PSQI:** Significant difference, small effect ( $p<.05$ ,  $\eta^2=.021$ )
- **Wheelchair & PSQI/ESS:** No significant difference

## CONCLUSION & NEXT STEPS

Patients with FSHD experience significantly reduced sleep quality but typical daytime sleepiness. Therefore, sleep quality should be monitored even if patients do not feel drowsy during the day. Physicians should place greater emphasis on sleep in care. Pain significantly impacts sleep quality, so effective pain treatment should be implemented to improve sleep quality. The physiological effects of pain during sleep should also be further investigated.

## ACKNOWLEDGEMENTS

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Statistical Analysis Reference:  
Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Erlbaum.