

1. Fundación Atrofia Muscular Espinal, FundAME, Madrid, Spain. email: cattinari@fundame.net . 2. Department of Applied Statistics and Operations Research and Quality, Universitat Politècnica de València, Spain. 3. Neuropediatric Department, Hospital Universitario y Politécnico la Fe, Valencia, Spain. 4. Rehabilitation Department, Hospital Universitario y Politécnico la Fe, Valencia, Spain. 5. Neuropediatric Department, Hospital Universitario Virgen del Rocío, Sevilla, Spain. 6. Neuromuscular Diseases Unit, Hospital Universitario y Politécnico la Fe, Institute for Health Research La Fe, Valencia, Spain. 7. Rehabilitation Department, Hospital Universitario Virgen del Rocío, Sevilla, Spain. 8. Neuromuscular Diseases Unit, Institut de Recerca Sant Joan de Déu. Esplugues de Llobregat, Spain. 9. Paediatric Neurology Section, Hospital Universitario Virgen del Rocío. Sevilla, Spain.

## Introduction

Despite pain being a frequently reported concern among patients with Spinal Muscular Atrophy (SMA), its significance has been underestimated in the clinical literature.

The description of chronic musculoskeletal pain, its association with different variables, and its impact on daily life were assessed in subjects under 18 years of age in the Spanish Clinical Registry of two Spanish hospitals.

This was a three-year prospective observational follow-up study.

## Facts



Forty-three percent of the 51 individuals reported musculoskeletal pain with a mean Visual Analog Scale (VAS) score of 5 (range: 2–10) and a median duration of 5.2 years (ranging from 0 to 10 years).

## Influences pain

Highly likely (>90%) to influence pain

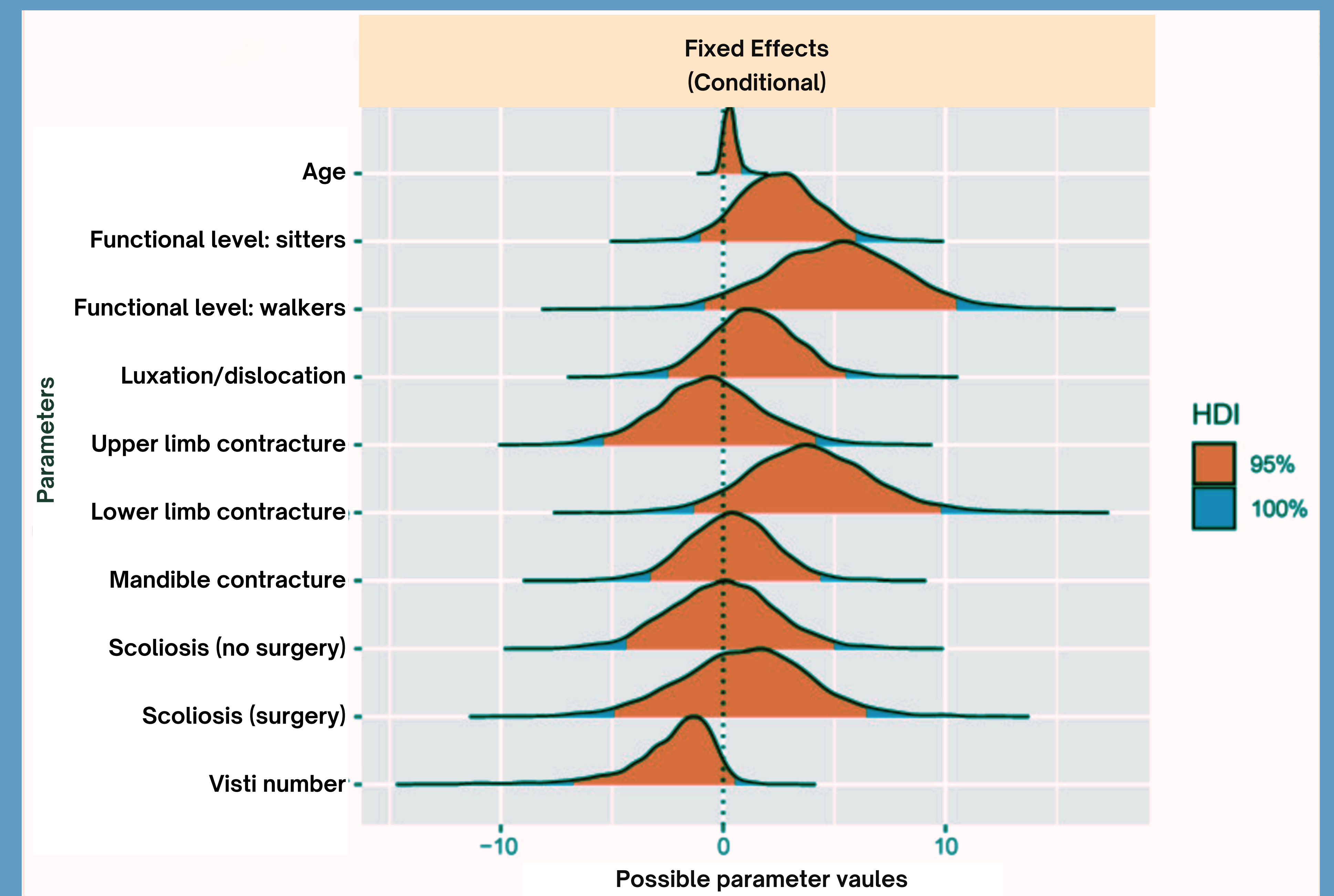
- Functional status
- Lower limb contractures
- Walkers
- Better RULM scale
- Hip dislocation

The Bayesian model indicated that functional status, lower limb contractures, and the number of visits are highly likely (>90%) to influence pain.

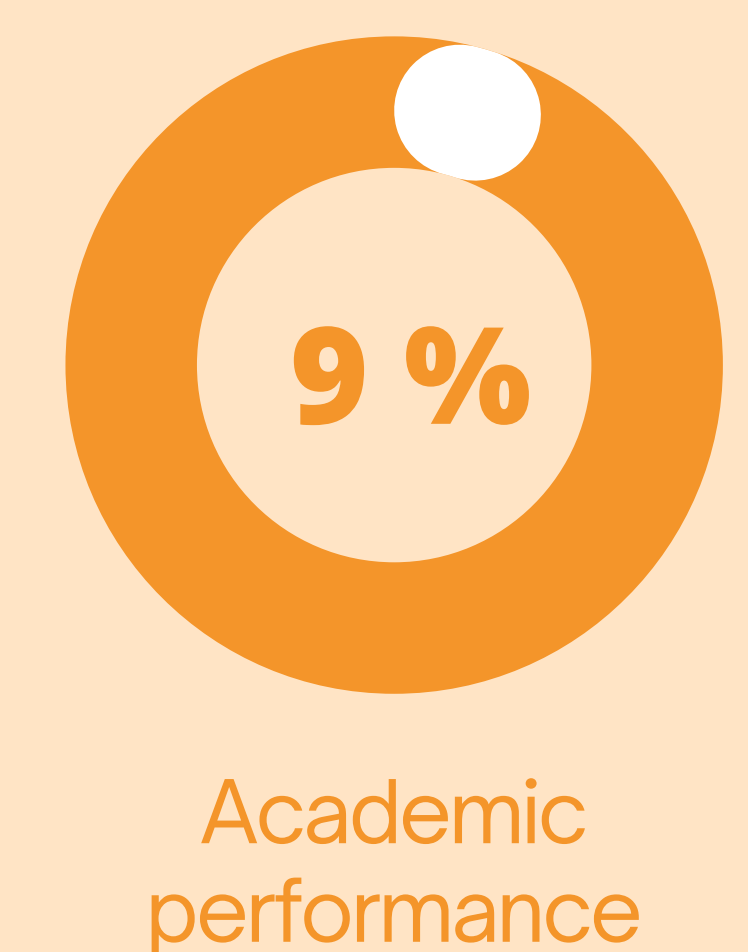
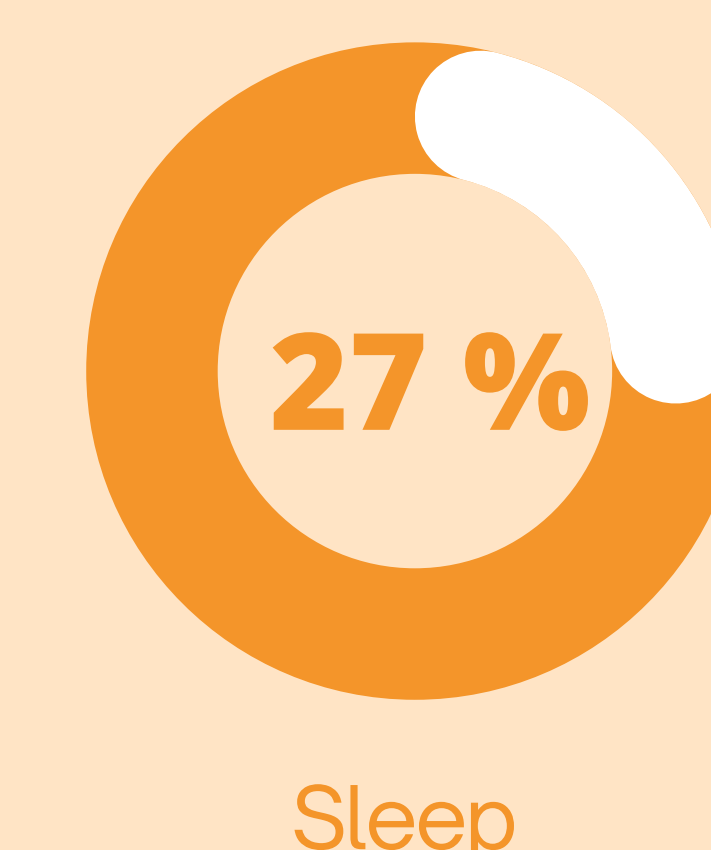
People who are walkers, with better results on the RULM scale, and those with lower limb contractures are more likely to experience increased pain.

Hip dislocations have a 75% probability of increasing the pain VAS score.

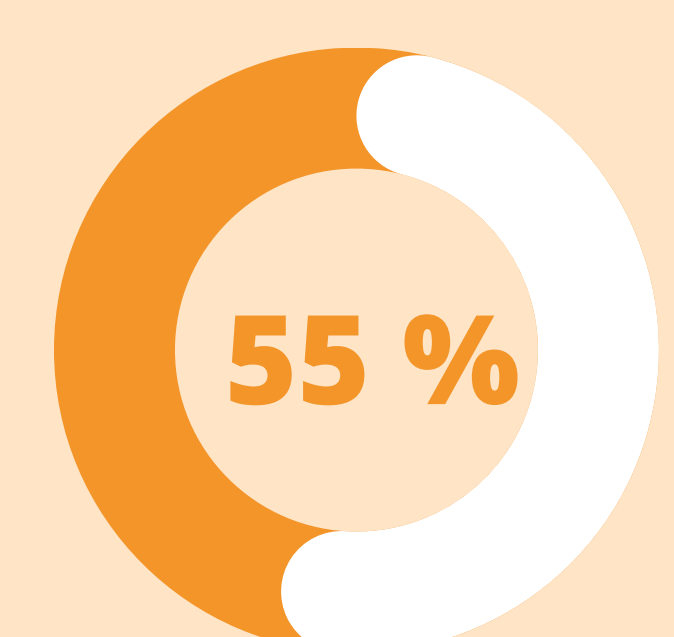
## Highest Density Interval (HDI)



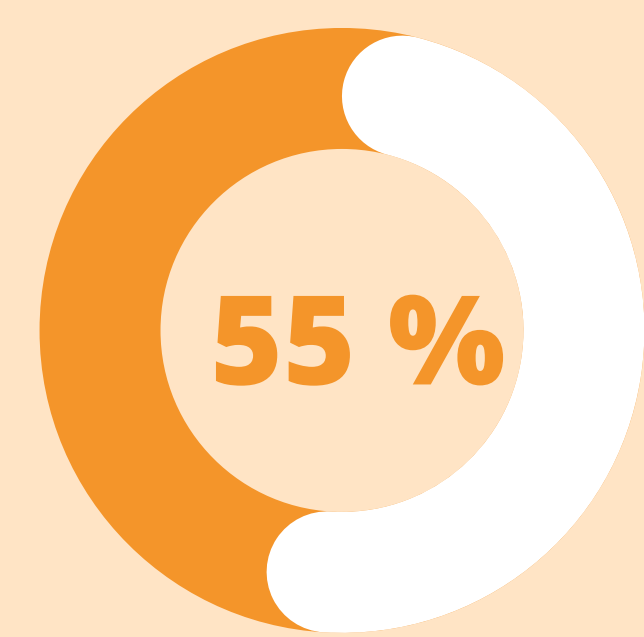
## Pain influences the Quality of life



## Contractures and pain



Experience pain during manipulation

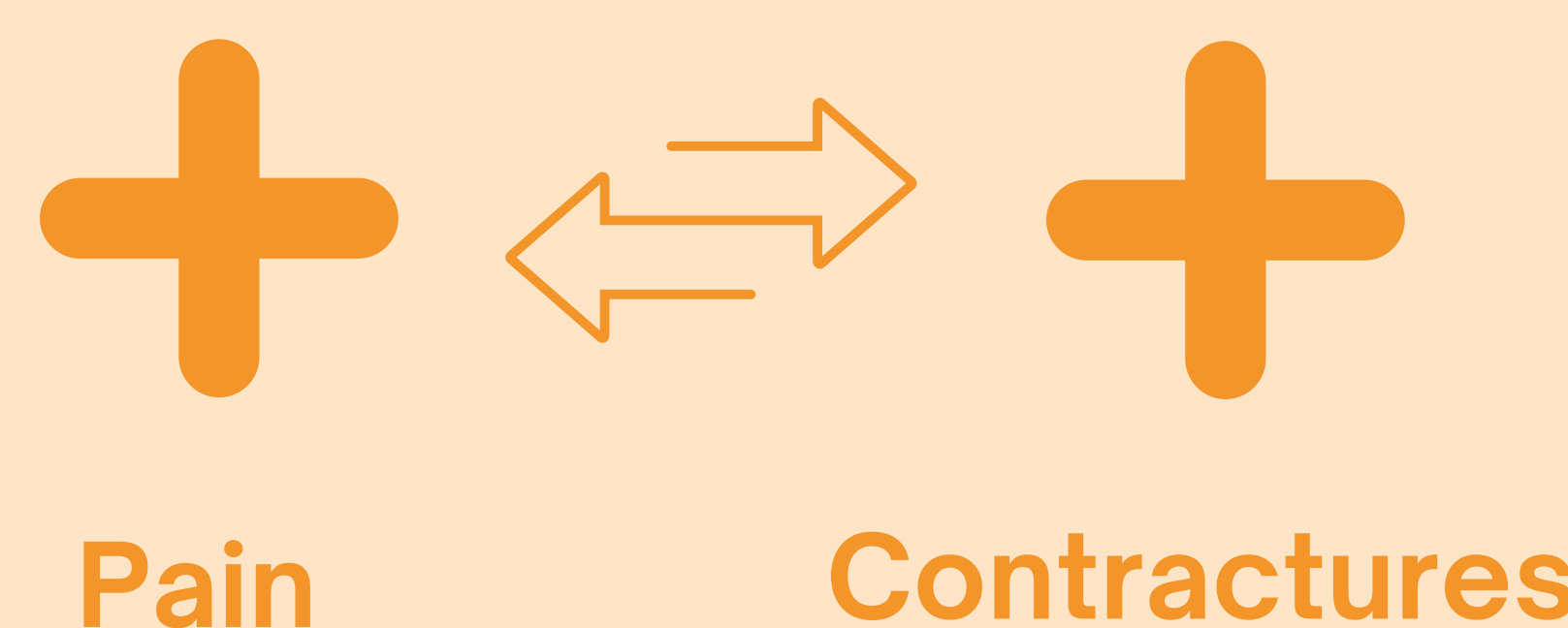


Reported pain during weight-bearing

The presence of contractures significantly correlates with higher pain levels.

Concurrently, pain commonly occurring during manipulations and weight-bearing complicates contracture treatment. This suggests a bidirectional relationship: contractures may cause pain, and pain during activities hampers contracture management.

Conversely, pain might contribute to contracture development. These findings stress the need for therapeutic approaches addressing both muscle contractures—possibly necessitating diverse management strategies—and accompanying pain to improve patient quality of life.



## Conclusions

Some children have lived more than half of their lives experiencing pain.

Preliminary findings suggest that including pain in the Standards of Care and adopting alternative strategies for managing contractures may be pivotal in addressing the comprehensive needs of individuals with SMA and improving clinical outcomes.

The findings underscore the importance of raising awareness and considering pain as a fundamental aspect of SMA management. This emphasizes the enhancement of patients' quality of life through a more comprehensive, patient-centred approach to care. Tailoring treatments to individual conditions is highlighted as pivotal for enhancing patient well-being.

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