

## **Abstract**

Locked-in syndrome (LiS) is a neurological disorder caused by lesions affecting the ventral pons and midbrain and is characterized by loss of physical function, but with perceived consciousness intact. Despite severe limited function, previous studies have shown the quality of life (QoL) of patients to be more positive than naturally assumed by caregivers and relatives. The present review aims to synthesize the broad scientific literature focused on the psychological well-being of LiS patients.

A scoping review was performed to synthesize the available evidence on the psychological well-being of LiS patients. Eligible studies included those that targeted individuals with LiS as the study population, evaluated psychological well-being and explored the factors related to it. We extracted study population details, type of QoL methods, method of communication, and primary findings from the studies. We summarized the findings categorized into health-related QoL (HRQoL), global QoL, and other tools for assessing psychological status.

Across the 13 eligible studies, we generally observed that patients with LiS had reasonable or similar psychological well-being as the standard based on HRQoL and global QoL assessment. Caregivers and healthcare professionals seem to rate the psychological QoL of LiS patients lower than patients themselves. Studies showed evidence that longer duration of LiS to be factor that positively affects QoL, and augmentative and alternative communication tools and recovery of speech production showed positive effects as well. Studies reported a range of 27% to 68% of patients experiencing thoughts of suicide and euthanasia.

The evidence generally shows that LiS patients had reasonable psychological well-being. There appears to be differences between patients' assessed well-being and the negative perceptions by caregivers. Response shift and adaptation to disease by patients are considered potential reasons. A sufficient moratorium period and provision of information to support patients' QoL and appropriate decision-making seems necessary.