

## Health-related quality of life in children with Spinal Muscular Atrophy at Siriraj Hospital

Manassanan Aksaraliksunti<sup>1</sup>, Oranee Sanmaneechai<sup>1,2\*</sup>.

<sup>1</sup> Department of Pediatrics, Faculty of Medicine Siriraj Hospital, Mahidol University, Bangkok, Thailand

<sup>2</sup> Neuromuscular research network, Faculty of Medicine Siriraj Hospital, Mahidol University, Bangkok, Thailand

**Background:** Spinal muscular atrophy is a chronic disease with slow progression. Quality of life has been recognized as an indicator of health in patients with neuromuscular disorders. There is no cure for spinal muscular atrophy in Thailand, improvements in symptomatic therapy and preventing complications have increased quality of life.

**Objective:** To evaluate the health-related quality of life in children with SMA and study factors affecting their quality of life and provide basic information for further improvement of patients' healthcare.

**Methods:** A cross-sectional study was conducted at the neurological clinic of Siriraj Hospital in Thailand. HRQOL was measured using The PedsQL 4.0 Generic Core Scales. The PedsQL was administered to children and their parents aged 2-18 years. A sociodemographic data was completed as well.

**Results:** A total of 42 families participated. The mean $\pm$ SD total scores were 57.3 $\pm$ 13.6 for child self-report and 54.3 $\pm$ 14.8 for parent proxy-report. The parent reported scores are lower than those of the children in all domains. PedsQL scores of SMA patients was lower than healthy Thai children. Although, the psychosocial scores came close to healthy population.

The association between sociodemographic and HRQOL demonstrated that ambulatory and higher income had better physical health scores.

**Conclusions:** HRQOL in SMA patients were worse than healthy children in both child and parent perspectives, associated with disease progression. However, most patients have better psychosocial health than expected. Ambulation and higher income were associated with better physical health. Supporting economy, physical therapy, accessibility to medical services could lead to improve HRQOL.