

# Loneliness and quality of life in adult SMA patients: the experience of the Parma centre

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Patients with Spinal Muscular Atrophy (SMA) have historically reached adulthood following the natural history of the disease. However, with the advent of neonatal screening and novel therapeutic approaches, the phenotypic spectrum of SMA is expected to change, highlighting the need to characterize the current condition of adult SMA patients for future comparison. While quality of life (QoL) in SMA is often associated with motor function, aspects such as social participation, independent living, and loneliness, which can significantly impact well-being, are rarely assessed in clinical practice. This study aims to fill this gap by evaluating quality of life, social integration, autonomy, and loneliness in adult SMA patients, providing a comprehensive overview that extends beyond motor abilities.

At the University Hospital of Parma, 13 adult patients with SMA are currently under follow-up. A survey was conducted among 9 adult SMA patients (3 males, 6 females; mean age 44.5 years; 2 with SMA type II, 7 with SMA type III). The assessment included the UCLA Loneliness Scale, the WHO Quality of Life Scale (WHOQOL), and the Activities of Daily Living/Instrumental Activities of Daily Living (ADL/IADL) scales to measure autonomy.

Additional data were collected on living arrangements, educational attainment, and employment status.

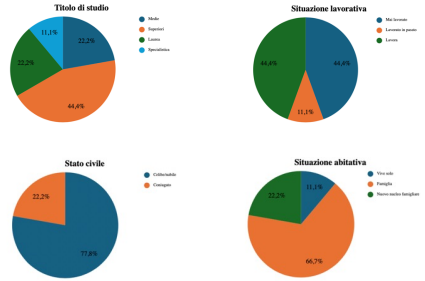


Fig. 2 Demographic data of the patients from the Parma centre.

Patients reported, on average, a moderate level of loneliness (mean UCLA score  $36 \pm 10.9/80$ ), even though over 50% of them had scores within the low-loneliness range (fig. 1), suggesting that social and psychological factors may compensate for physical limitations. Quality of life, as measured by the WHOQOL, was comparable to that of healthy adults (mean score  $93.67 \pm 11.4/105$ ), despite reduced autonomy (mean ADL 2.78/6; mean IADL 4/8). Regarding employment, 44% were employed, another 44% had never worked. In terms of living arrangements, 67% lived with their parents, 22% with their own family, and 11% alone (fig. 2).

## UCLA Loneliness Scale (UCLA-LS)

- How often do you feel that you are "in tune" with the people around you?
- How often do you feel that you lack companionship?
- How often do you feel that there is no one you can turn to?
- How often do you feel alone?
- How often do you feel part of a group of friends?
- How often do you feel that you have a lot in common with the people around you?
- How often do you feel that you are no longer close to anyone?
- How often do you feel that your interests and ideas are not shared by those around you?
- How often do you feel outgoing and friendly?
- How often do you feel close to people?

- How often do you feel left out?
- How often do you feel that your relationships with others are not meaningful?
- How often do you feel that no one really knows you well?
- How often do you feel isolated from others?
- How often do you feel that you can find companionship when you want it?
- How often do you feel that there are people who really understand you?
- How often do you feel shy?
- How often do you feel that people are around you but not with you?
- How often do you feel that there are people you can talk to?
- How often do you feel that there are people you can turn to?

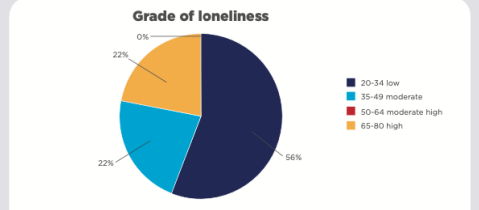
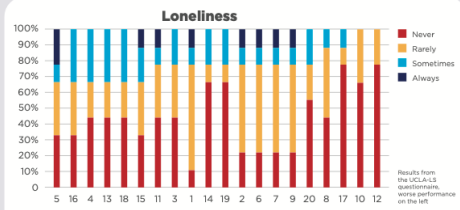


Fig. 1 UCLA Loneliness Scale and results: columns are ordered starting from the questions associated with the highest reported levels of loneliness. Grade of loneliness in our patients.

These findings indicate good social integration among adult SMA patients, regardless of their degree of autonomy. There is a growing need for SMA-specific patient-reported outcome measures, particularly those addressing subjective domains such as loneliness, to better capture the real-life impact of interventions beyond motor milestones. As the phenotype of adult SMA patients evolves, further improvements in quality of life and reductions in loneliness are anticipated, but new social and psychological needs are also likely to emerge, including integration into education, employment, and community life. Longitudinal studies with larger cohorts will be essential to monitor these changes and ensure that therapeutic advances translate into meaningful improvements across all aspects of life.

Senese, V. P., Nasti, C., Morosio, F., Sergi, L., Masarini, R., & Grillo, A. (2023). The Relationship Between Loneliness and Psychological Adjustment: Validation of the Italian Version of the Interpersonal Acceptance-Rejection Loneliness Scale. *Frontiers in Psychology*, 12, 655440. Bottaro, R., Valenti, G. D., & Falaci, P. (2023). Assessment of an Epidemic Urgency: Psychometric Evidence for the UCLA Loneliness Scale. *Psychology Research and Behavior Management*, 16, 2843-2855. Messina S, Frongia AL, Antonaci I, Pera MC, Coratti G, Pane M, Pastemak A, Civiello M, Montes I, Mayhew A, Finkel R, Murttoni F, Marcuri E. ISMAc group. A critical review of patient and parent caregiver oriented tools to assess health-related quality of life, activity of daily living and caregiver burden in spinal muscular atrophy. *Neuromuscular Disease*. 2019 Oct;29(12):940-950. doi: 10.1016/j.nmd.2019.10.001. Epub 2019 Oct 22. PMID: 31793871.