

Nationwide survey of 780 Japanese patients with amyotrophic lateral sclerosis: Their present status and expectations from brain–computer interfaces

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Introduction: Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease that causes eventual death through respiratory failure unless mechanical ventilation is provided. Brain–computer interfaces (BCIs) may provide brain control support for communication and motor function. Based on preliminary results of a small-scale questionnaire survey [1], we performed a large-scale questionnaire survey to investigate the interests and expectations of patients with ALS concerning BCIs supported by the Japan Amyotrophic Lateral Sclerosis Association.

Material, Methods and Results: We conducted an anonymous questionnaire survey of 1918 patients with ALS regarding their present status, tracheostomy use, interest in BCIs, and their level of expectation for communication (conversation, emergency alarm, Internet, and writing letters) and movement support (postural change, controlling the bed, controlling household appliances, robotic arms, and wheel chairs).

Seven hundred eighty participants responded. Fifty-eight percent of the participants underwent tracheostomy. Approximately 80% of the patients felt stress or having trouble during communication. For all nine supports, more than 60% participants expressed expectations regarding BCIs. More than 98% of participants who underwent tracheostomy expected support with conversation and emergency alarms. Participants who did not undergo tracheostomy exhibited significantly greater expectations than participants with tracheostomy did regarding all five movement supports. Seventy-seven percent of participants were interested in BCIs. Participants aged <60 years had greater interest in both BCIs.

Discussion: Communication and emergency alarms should be supported by BCIs initially. BCIs should provide wide-ranging and high-performance support that can easily be used by severely disabled elderly patients with ALS.

Significance: This is the first large-scale survey to reveal the present status of patients with ALS and probe their interests and expectations regarding BCIs.

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References

[1] Kageyama Y, Hirata M, et al. Severely affected ALS patients have broad and high expectations for brain-machine interfaces. *Amyotrophic lateral sclerosis & frontotemporal degeneration* 15(7-8):513-9, 2014.