

Home-monitoring in ALS/MND care: patients' and professionals' experiences with personalized ALS/MND care through eHealth

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Background: eHealth can stimulate personalized care by optimizing the timing of care, patient participation and continuous exchange of information between patient and healthcare professionals. For this reason a tailored eHealth care process was developed for ALS care which consists of an interactive eHealth application for self-monitoring, automated alerts, personalized feedback, and tailored ALS-care.

Objectives: To evaluate patients' and professionals' experiences with the eHealth care process.

Methods: Patients diagnosed with ALS, and referred to the multidisciplinary ALS care team of the academic hospital in Utrecht, were invited to use the tailored eHealth care process. Key features include (1) self-monitoring of well-being (single question "How are you today?"), body weight and functional impairment (ALSFERS-R), (2) alerting, and (3) nurse practitioner follow-up. Patients' experiences and satisfaction with the eHealth care process were further explored through semi-structured interviews. Descriptive statistics were used for questionnaire data and content analysis was conducted on the transcribed interviews.

Results: Of 29 newly diagnosed patients with ALS, 24 patients (82%) have adopted the eHealth care process as part of their usual care, three have not been approached (nursing home residency, life expectancy < 6 months, comorbid psychiatric disorder), and one declined participation. Results from 22 users on satisfaction showed that 19 patients (86%) reported increased control over their care, 16 considered the eHealth of added value, 21 would recommend it to other patients and none consider the monitoring a burden. Themes that emerged from the interviews with patients (n=20) were: easy to use application; insight in and reflection on health and wellbeing; sense of reassurance resulting from continuous monitoring by the care team; flexible consultations based on needs and symptoms. Professionals reported increased efficiency of consultations; improved system of control, due to alerts; improved timing of education of patients; acceptable extra workload (5 minutes/ patient per week).

Discussion and conclusions: This innovative eHealth care process is appreciated by patients as well as professionals and provides patients increased control over their care and professionals efficient consultations. It allows for a more personalized care. Therefore, eHealth should be considered a useful addition to the usual care for patients with ALS.