

Qualitative Assessment of the Experience of Telemonitoring in Ventilated Patients with Motor Neurone Disease

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Background: The National Institute for Health and care Excellence (NICE) has recently issued recommendations on the care of people with motor neurone disease (MND), promoting tailored care for each patient, Guideline 42, 2016. Previous studies suggest remote monitoring offers a facility to regularly monitor and interact with patients, providing timely interventions so it may facilitate delivery of the recommendations. The efficacy of this approach is dependent upon acceptability of telemonitoring to patients.

Aim: To understand the experiences of using telemonitoring in ventilated patients with MND.

Methods: Semi-structured interviews were conducted with seven patients (male=5; mean age=63yrs). The median illness duration was 14m (range=7m-13yrs 7m) and the median non-invasive ventilation (NIV) usage was 12m (range=0m-3yrs). Participants used a telemonitoring device (Docobo CAREPORTAL®) for six months, completed weekly nocturnal pulse oximetry and symptom-related questions. Five caregivers were present at the interviews and provided their feedback. Interviews were audio recorded and transcribed verbatim. Thematic analysis was conducted to find overarching themes. The interpretation was reviewed and supported by a multidisciplinary team examination.

Findings: Five themes were identified: Technical Challenges, Increased Self-Awareness, Taking Initiative, Benefits of Timely Intervention, and Reducing the Unnecessary. Whilst participants expressed general ease of Careportal® use, technical issues included; messaging system challenges, oximetry transmission, device fault, mobile signal loss. No other negative experience of using Careportal® was reported. Overall, participants expressed how telemonitoring enabled symptom awareness and interpretation. The device also enabled the participants to raise their concerns and/or requests to the healthcare professionals via the messaging system, and this was depicted as a sharp contrast to current communication with hospitals. Timely interventions were observed as a result of regular monitoring, contributing to both physical and psychological well-being of the participants. It was also suggested that using Careportal® could reduce unnecessary cost/time and hassles created by attending hospital appointments.

Conclusions: Telemonitoring enabled participants to be actively involved in their care and they felt that the interventions were timely delivered to meet their needs. The findings suggest potential benefits of utilising Careportal® in routine care as a contact point to accommodate different individual's needs.

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