

include care of pwMND and their families during the COVID-19 pandemic. Keywords Amyotrophic Lateral Sclerosis, ALS, Motor Neurone Disease, MND, Perceptions, COVID-19, Integrated Approach, Multi-Disciplinary Team/MDT, Health Care Collaboration, Health and Social Care Professionals, terminally ill, Palliative Care, Hospice and Palliative Care Nursing, Home Care.

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# **EXPERIENCES OF PEOPLE LIVING WITH MOTOR NEURONE DISEASE AND THEIR FAMILIES DURING THE COVID-19 PANDEMIC IN THE UK: INFORMING CARE BY A RAPID DISSEMINATION OF EARLY FINDINGS**

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**Background** Motor Neurone Disease (MND) is a progressive, fatal neurological condition that leads to complex and variable difficulties for people living with MND (plwMND) and their families. Health and Social Care providers in the UK had to rapidly change the way they work and deliver care during the COVID-19 pandemic, but the experience and impact on plwMND and their families during this time is currently unknown. This study aims to explore the experiences for plwMND and their families and disseminate early findings to inform care delivery.

**Method** A simple mixed method design using an online data collection tool, Joint Information Systems Committee (JISC) and purposive snowball sampling were employed following ethical approval in August 2021 (SHFEC2021-086) to allow plwMND and their families to express their experiences during the COVID-19 pandemic. Descriptive statistical analysis of quantitative data and reflexive thematic analysis of narratives using NVIVO illustrates key early themes.

**Results** Twenty plwMND and 14 family carers have participated so far, giving rich accounts of their experiences during the pandemic. The challenges encountered by plwMND and families during the COVID-19 pandemic in the UK are explored. The main problems described occurred in the first and/or second wave, but some issues are described as ongoing. Communication needs assessment and virtual appointments are key themes. Family members also mentioned respiratory care, comfort care and financial issues. Family members who experienced bereavement during the pandemic described the support received as 'poor' or 'very poor' and only one family member so far was positive about the end-of-life care. Both groups mentioned lack of in-person care and isolation. Views on virtual appointments with clinicians are mixed.

**Conclusion** MND care in the UK has been impacted negatively by the COVID-19 pandemic. Dissemination of these early findings aims to inform future care delivery during ongoing and subsequent waves.

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# **IMPACT OF COVID19 ON PATIENT OUTCOMES WITHIN AN ACUTE PALLIATIVE CARE SERVICE**

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**Background** The COVID19 pandemic had wide ranging effects on healthcare services and systems within the NHS. There was a particular impact on the Specialist Palliative Care Hospital Liaison Service (SPCHLS) caseload in Northumbria Healthcare NHS Foundation Trust. Our objective was to determine the impact of the COVID19 pandemic on patient outcomes, time from admission to death and place of death.

**Methods** A retrospective analysis of patients admitted in January 2020 and 2021, with a palliative code on discharge or death.

**Results** More patients were referred to and seen by SPCHLS in January 2021 compared to January 2020 (n=70 vs 54) and of those patients, more died as an inpatient in January 2021 compared to 2020 (57% vs 37% respectively). 40% of patients died within 10 days of admission in January 2021 compared to 30% in 2020. Of those patients who died within 100 days of admission, less patients died at home in 2021 13% vs 38%. However, more died on a specialist palliative care unit 36% vs 23%.

**Conclusions** During the COVID19 pandemic more patients were referred to and seen by the specialist palliative care hospital liaison service. There were significantly more deaths and time to death from admission was significantly shorter. More patients died in an acute hospital setting and on specialist palliative care units, with a reduction in transfers to independent hospices. There is a need for continued investment and development of acute palliative care to reflect a potentially sustained change in services, and the requirement to increase the provision of high quality end-of-life-care in hospitals.

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# **A SERVICE EVALUATION: PATIENT, RELATIVE AND STAFF EXPERIENCES OF VIRTUAL VISITING DURING THE COVID-19 PANDEMIC AT CARDIFF AND THE VALE'S MARIE CURIE HOSPICE**

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**Background** The Covid-19 pandemic has had a profound impact on health services, including the implementation of measures to maintain safe social-distancing to reduce viral spread. This has included the visiting restrictions in hospitals and hospices and a subsequent increase in demand for virtual consultations and visiting.<sup>1 2</sup> This has impacted how in-patients, relatives and staff communicate daily.

**Aims** To investigate staff, patient and relative experiences of virtual visiting during Covid-19 in a hospice and to provide recommendations to improve current virtual visiting practices.

**Methods** A service evaluation was conducted in March 2021 using mixed methods. Interviews were held with current in-patients and two surveys were created with the aims of collecting patient, relative and staff experiences of virtual visiting. Participants were recruited in person and via emails and social media posts. Data collection was anonymous, containing no participant identifiable information.

**Results** All patients, relatives and staff who took part either in the interviews or surveys had partaken in virtual visiting using a range of personal and hospice devices. Analysis of qualitative data uncovered four key themes: the importance of keeping connected, technological literacy and usability, methods of