

completed on 8 forms, however, only 3 records referred to children.

Documented relationships with children included parent, grandparent and great-grandparent.

Two families raised concerns about talking to children with staff. In one case there was no evidence that concerns were addressed, in the second the issues were managed by a consultant in palliative medicine and followed up during the hospice admission.

There was no documented evidence that members of staff offered to speak with children. A children's bereavement charity was reported as supporting one family, whilst another family's children received support at school and from a counselling service.

Conclusion Important conversations with children are not being included as part of routine clinical care. The results of this survey and the literature about the impact of timely information for children when an important adult is receiving palliative care, will be shared across our service. These discussions will inform an action plan to facilitate family-focused conversations.

P-9 UNDERSTANDING THE EXPERIENCE OF CHILDREN WHO HAVE A PARENT WITH MOTOR NEURON DISEASE: A THEMATIC ANALYSIS

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Background/Aims Children who have a parent with Motor Neuron Disease (MND) often have carer responsibilities and require extra support from others. MND is also a life-limiting disease and the children require support. Asking the children about their experiences will help healthcare professionals better understand their unique needs and may help facilitate better pre-bereavement support.

Methods Semi-structured interviews were conducted with three children aged 6 to 12 who have a parent with MND. The children were asked about their understanding of MND, what support they receive or would like, and their interactions with peers and healthcare professionals. A thematic analysis of the interviews was performed.

Results Four themes were identified: (1) perception of MND, (2) learning about MND, (3) emotional wellbeing and support, and (4) the role of a carer. The children had a limited understanding of MND, and the children felt excluded from discussions with healthcare professionals around their parent's illness and treatment. Despite its negative aspects, the children acknowledged that MND allowed the family to spend more time together. Even though the children did not self-identify as carers, they had significant carer responsibilities. They found that this negatively affected their schooling, such as completing homework. Although they felt that MND was poorly understood by their classmates, the children found young carer groups beneficial and were able to meet other young carers and relax.

Conclusion Thematic analysis of interviews with MND patients' children provided invaluable insight into the children's experiences and what support would be beneficial. Guidelines should be established around communication between healthcare professionals and children, and actively involving children in the care of their parent would facilitate

the family dynamic. Greater advertising of resources for young carers would allow more children to meet other young carers. Children must have an active voice in discussions around their support.

P-10 HOW DO THE PROGNOSTIC PERCEPTIONS OF PARENTS, AND ITS CONCORDANCE WITH THOSE OF HCPS, INFLUENCE DECISIONS ABOUT GOALS OF CARE IN CHILDREN WITH LIFE-LIMITING ILLNESSES?

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Background The prevalence of children with life-limiting conditions is set to increase, resulting in an increased number of parents being involved in their child's treatment decisions. These decisions are influenced by the medical information conveyed and their own evaluations of this knowledge. The aim of this review was to explore the alignment between parental and Healthcare professional (HCP) prognostic perceptions and treatment preferences, whilst presenting possible explanations for any differing opinions.

Methods A literature search, using the databases: Medline, Trip, PubMed, PsychINFO and EMBASE was conducted. The inclusion criterion applied was – published since 2000, written in English, focused on children of 0–18 years. Peer reviewed data on the prognostic perceptions of parents and HCPs, and their goals of treatment for children with life limiting condition were selected.

Results Overall, in the eleven papers included there was a lack of parental prognostic understanding with a poor alignment to the prognostic views of HCPs. Parents promoted more aggressive treatment options relative to HCPs more palliative approach. This is hypothesised to result from particularly fathers remaining hopeful for a cure. Studies showed discrepancies remained after prognostic conversations were held between parent's and HCPs, with others indicating parents' insight of there being no cure resulted before being openly disclosed by a HCP.

Conclusions This study postulates poor prognostic insight may arise from a lack of open communication, resulting in parents advocating for more aggressive treatment with hope of finding a cure. However, given the cross-sectional nature of the studies, this review is only able to suggest these correlations. Future studies are recommended to explore the trajectory of parental prognostic understanding and how it is influenced by communication with HCPs.

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P-11 HAVING VISION: THE ROLE OF QUALITY IMPROVEMENT IN SUSTAINING RATES OF CORNEAL DONATION THROUGH THE COVID PANDEMIC

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Introduction Normalising the discussion and practice of Corneal Donation amongst hospice inpatients has been the focus

of quality improvement (QI) work at the hospice for several years. Previous successful interventions include multi-professional education, developing a referral flow chart, alerts on the electronic patient record to flag potential donors and encouraging staff to observe the retrieval process. Prior to 2018, corneal donation was not routinely discussed and there was only one donation over 3 years compared to 211 referrals and 140 donors over the last 3 years. The COVID pandemic introduced unique challenges for corneal donation in the hospice, including reduced bed capacity, redeployed staff and tissue donation contraindicated in patients with recent COVID infection.

Method(s) Routinely collected data of hospice deaths, including eligibility to be donors, evidence of discussions with patients and families and referral numbers were analysed comparing data during 2019–2020 with 2020–2021.

Results In April 2020–March 2021, 157 patients died at the hospice, which was just under half the number of deaths during April 2019–March 2020 (322), in keeping with the number of beds halved from 28 to 14. In 2020–2021 62% of patients were deemed eligible to donate, compared with 64% eligible during the preceding year. 82% of eligible patients were offered the opportunity to discuss tissue donation in 2020–2021, compared with 80% the previous year. There were 51 corneal donors at the hospice in 2019–2020 (24.6% of all considered eligible) compared to 25 donors in 2020–2021 (24.5% of those considered eligible).

Conclusion(s) These results demonstrate that despite the numerous challenges of the pandemic, previously undertaken QI work has enabled sustained change, with the relative rate of tissue donation, frequency of discussions and subsequent referrals preserved during the pandemic period. QI is a fundamental tool for recovery from the pandemic and visualising future positive and sustained change.

P-12 ON THE FRONTLINE: THE EXPERIENCES OF ONE SUPPORTIVE AND PALLIATIVE CARE TEAM (SPCT) DURING THE FIRST 12 MONTHS OF THE COVID-19 PANDEMIC AND WHAT WE LEARNT FOR THE FUTURE

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Introduction Early in the pandemic, 26% of UK COVID-19 hospitalised patients died, often with high symptom burden. However the needs of non-COVID patients also had to be met. We describe the experiences of one hospital SPCT and lessons learnt.

Methods

1. Retrospective case series review of all patients referred to SPCT (COVID (C) 2nd pandemic phases. Variables collected: demographic/clinical data, AKPS/POI, outcomes.
2. Semi-structured anonymised online survey of SPCT regarding working experiences/needs during both phases.

Summary statistics describe 1st and 2nd phases and compare data between phases (and with same time period year before COVID).

Results Total of 1159 (863NC/296C) patients in 2nd phase (Sep 20–Feb 21); this compares with total 956 same time year before and an increase from 904 (856NC/48C) in 1st phase (Mar–Aug 20). SPCT were involved in six times the number

of patient episodes in second phase compared with first phase (296 vs. 48) and in 46% of all acute hospital COVID deaths (increase from 30% involvement in first phase). Mean AKPS was 26% in 1st phase, with 80% dying compared with AKPS 18% and 82% dying in 2nd phase. Mean caseload duration 4.1 vs. 2.3 days (1st/2nd phases). Nearly half (5/11, 46%) of team self-isolated during second phase compared with 1/3rd in first phase. Second phase team experience changed with more referrals and more symptomatic dying patients who were rapidly deteriorating. First phase helped second phase with team confidence in managing patients and preparation, but the team highlighted high caseload/symptom burden and personal impact. Improvements instituted include daily cross-site SPCT morning meetings, 7-day CNS service, flexibility using virtual meetings and measures sustaining team wellbeing.

Conclusions SPCT were busy with COVID patients whilst still supporting numbers of Non-COVID patients. Future focus centered on sustaining work flexibility and team wellbeing.

P-13 PERCEPTIONS OF PEOPLE WITH MOTOR NEURONE DISEASE, FAMILIES AND HEALTH AND SOCIAL CARE PROVIDERS PRE AND DURING THE COVID-19 PANDEMIC – A RAPID REVIEW OF THE INTERNATIONAL AND UK LITERATURE

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Background Motor Neurone Disease (MND) or Amyotrophic Lateral Sclerosis (ALS) is a rapidly progressive terminal neurodegenerative disease caused by degeneration of the upper and lower motor neurones in the central nervous system of the brain. The effects of MND are multifaceted, leading to many adjustments in everyday life. COVID-19 has changed how care is delivered to people with MND and this literature review aims to explore and compare experiences prior and during the pandemic.

Method A comprehensive search of the literature between 2010–2021 in all major health care databases and websites resulted in 61 papers selected for review, with 4 of these relating to COVID-19. Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines were followed. Studies were quality assessed and data extraction techniques were informed by Hawker et al's (2002) three stages of assessment of relevance for review questions based on inclusion criteria; data extraction and scoring for methodological rigor. Themes were developed using Thematic Analysis.

Findings Key themes in the pre-COVID-19 literature were perceptions of a lack of knowledge and educational needs for staff; delayed diagnosis; communication problems, high levels of burden for people with MND and family carers, and perceptions of poor standards of care. The literature on MND experiences during the COVID-19 pandemic is limited but indicates that professionals found the delivery of high-quality care challenging. Restrictions to face-to-face services and virtual care was disruptive to usual treatment and supportive care especially during the early waves of the COVID-19 pandemic.

Conclusion COVID-19 has impacted on MND care and service delivery, but there is currently a lack of research exploring the impact of this from the perspective of people with MND and their families. Further research is required to explore