DEVELOPMENT OF A RESOURCE FOR FAMILY CARERS OF PEOPLE LIVING WITH DEMENTIA WITH NUTRITION AND HYDRATION DIFFICULTIES TOWARDS THE END-OF-LIFE

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Methods This study consisted of four phases: 1) qualitative systematic review; 2) a scoping review of existing resources; 3) 61 qualitative interviews with people with dementia, professionals, and family carers; 4) data synthesis and co-design development of an information resource.

We constructed a matrix synthesising the key findings from phases 1–3, devising themes of the key content across the evidence and providing summaries from each source of evidence. The matrix provided a transparent pathway of the evidence and content for the design process.

Results The main areas covered within the resource include: eating and drinking difficulties in dementia; end of life; managing swallowing difficulties; points to discuss with professionals in future appointments; support for family carers and; further resources. Information is presented in a booklet with a mix of formats including: diagrams; quotes; top tips; flow charts; and visual images.

Conclusions This practical resource is the first to focus on nutrition and hydration towards the end-of-life in dementia care. This study provides a transparent stepwise approach to developing interventions, key for future similar studies.
Introduction The Coronavirus pandemic (COVID19) brought unprecedented challenges to healthcare, and changed how we interact with patients. Recognising the dying patient is essential to deliver compassionate End of Life Care; allowing patients and loved ones to prepare for death, and facilitates opportunities for comfort and dignity. We have reviewed how COVID19 has influenced our approach to the dying patient.

Method We reviewed the electronic notes of all hospital inpatients who died at Milton Keynes University Hospital between 30/03/2020–31/05/2020 and compared key areas to the same period in 2019.

Results In 2020 there were more deaths (207 vs 143) and more occurred within 48 hours of admission (24% vs 18%). In 2020 more treatment escalation plans were completed (98% vs 85%), there were fewer deaths at ‘arrest calls’ (2 vs 7) and more deaths were anticipated (87% vs 83%). Further analysis of expected deaths occurring >48 hours of admission have shown that in 2020 (vs 2019) dying patients were more often:

- recognised as dying (84% vs 70%)
- reviewed by the Palliative Care team (74% vs 66%)
- on a personalised care plan for the dying patient (89% vs 82%)
- prescribed a syringe driver (50% vs 31%)/anticipatory medications (84–91% vs 79–85%)

However, patients:

- less frequently had visitors (44% vs 93%)
- less often discussed their preferred place of death (27% vs 43%).

Discussion We have reviewed how the pandemic changed our management of dying inpatients. Despite the increased number of deaths there were positive changes in our approach. Possible influencing factors are the perceived increased burden on ITU and encouragement of early discussion about escalation. Challenges like facilitating visitor’s have also been identified. It is vital that we learn from this experience to ensure our dying patients are managed compassionately, irrespective of the ongoing global crisis.