

Palliative and end-of-life care in primary care during the COVID-19 pandemic and beyond

INTRODUCTION

The COVID-19 pandemic has been associated with the highest death rate in the UK for over 10 years.¹ There has been a marked shift of place of death into the community across the UK between March 2020 and 2021. Deaths at home increased by 67% during the first wave of the pandemic. There was a sustained increase of 33% above expected between the first two waves, and 43% above expected in the second wave.¹ Nationally reported data identifies large changes in where people are dying, but little is understood about the circumstances of these deaths, the quality of end-of-life care in the community during the pandemic, or the services received.²⁻³

Palliative care is holistic, person-centred care focused on quality of life for people with advanced disease and their family carers. It is an approach to care that extends well beyond specialist services and is recognised as core to the role of primary care by the World Health Organization.⁴ Primary and community care services deliver the majority of palliative and end-of-life care for people at home and in care homes. Throughout the COVID-19 pandemic, they adapted rapidly as the numbers of people dying in the community increased, providing care to people with highly complex needs at home and to large numbers of care home residents at the end-of-life. The work has been challenging and associated with emotional distress for clinicians.⁵

PALLIATIVE CARE IN THE COMMUNITY IS A GROWING BUT SHARED CONCERN

Prior to the pandemic, the delivery of high-quality palliative and end-of-life care in the community was already a pressing concern, with increasing numbers of patients living longer with frailty, complex multimorbidity, and associated palliative care needs worldwide.⁶ Early identification of palliative care needs has been described as a 'first-class ticket' to enhanced care in the community, but general practice

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end-of-life care registers are largely populated by people with cancer rather than non-malignant disease.⁷ Specialist palliative care services, including hospices, which in the UK rely largely on voluntary sector funding, have never had capacity to provide care to all dying people.⁸ The COVID-19 pandemic has compounded the need for community palliative care, with more patients affected by frailty⁹ and more patients presenting with advanced cancer, distressing symptoms, and nearness to the end-of-life.¹⁰ The impact of disruptions in chronic disease monitoring in general practice on multimorbidity, and delayed diagnosis of other conditions including dementia, is yet to be seen.

WORKING IN PARTNERSHIP TO MEET INCREASED NEED

As the NHS in England develops Integrated Care Systems, new primary care, community, and specialist palliative care partnerships are needed to deliver novel, integrated services that make optimal use of the limited workforce to provide patient care. There is an urgent need to improve healthcare system infrastructure to support these cross-boundary, multidisciplinary approaches.¹¹ This could include education, training, and career development models for primary care teams, including physician associates, therapists, community pharmacists, and social prescribers, as well as GPs and community nurses.

Any such developments require robust evaluation and research based in the community. Increased understanding of

the new ways of working adopted during the COVID-19 pandemic is vital to identify priorities for future service delivery, for example, the mechanisms and processes that enabled or hindered the integration of services. Technological solutions that were adopted rapidly during the pandemic, including virtual consultations and online team meetings, require evaluation to understand how to ensure that these new service developments are most effective into the future. This will require greater involvement of primary care clinicians to shape, participate in, and conduct palliative care research.

The relatively small proportion of research funding received by both palliative care and primary care presents a significant shared challenge. New research partnerships across specialist and primary palliative care could bring together cross-sector clinical and methodological expertise to deliver policy- and practice-relevant research proposals. Effective implementation into clinical practice must be considered at all stages. Working in partnership would enhance the translation of new knowledge into practice, with improved understanding of current pressures across services.

KEEPING PATIENTS AND FAMILIES AT THE CENTRE OF CARE AND RESEARCH

Increasing participation and involvement for people with palliative care needs and their families in palliative care research is a national priority and key to the delivery of high-quality services for all. Ethical issues relating to the vulnerability of patients towards the end-of-life and their capacity to provide informed consent, as well as gatekeeping by clinical staff, can hinder participation in research for this population.¹² Patient and public involvement (PPI) is essential to ask research questions important for patients and families, design studies that enable participation, and for the findings to impact care delivery. This requires investment in shared infrastructure

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ADDRESS FOR CORRESPONDENCE

Sarah Mitchell

University of Sheffield, Department of Oncology and Metabolism, Weston Park Hospital, Whitham Road, Sheffield S10 2SJ, UK

Email: S.J.Mitchell@sheffield.ac.uk
[@MacGPsSarah](https://orcid.org/0000-0001-9411-1111)

for PPI more widely across organisations to strengthen and sustain this vital aspect of research design, and increase the meaningful involvement of people from diverse areas. Recruitment via primary care presents an opportunity to reach people from a wide range of socioeconomic and cultural backgrounds.

CONCLUSION

Primary care clinicians frequently describe how much they value the palliative and end-of-life care aspects of their work. Healthcare systems must recognise, prioritise, and enable this core function of primary care. The COVID-19 pandemic presents an opportunity for all those who provide palliative care to consider how best to move beyond traditional service delivery models towards more integration with primary care teams and networks, and to engage in multidisciplinary research to evaluate and inform aspects of their work. Addressing longstanding inequalities in access to palliative care depends on shared vision and purpose among all professionals and teams delivering palliative care to effectively meet patient need.

Sarah Mitchell,

Clinical Research Fellow, Department of Oncology and Metabolism, University of Sheffield, Sheffield.

Stephen Barclay,

Associate Professor in General Practice and Palliative Care, Department of Public Health and Primary Care, University of Cambridge, Cambridge.

Catherine Evans,

Professor of Palliative Care and Ageing, Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London, London.

Katherine Sleeman,

Laing Galazka Chair in Palliative Care, Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London, London.

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