

## ***Perspectives on COVID-19 and palliative care research***

Back in April I wrote an editorial where I set out some of my hopes for palliative care in the context of the COVID-19 pandemic<sup>1</sup>. I hoped that palliative care would be seen as an important component of care for those with COVID-19, that we would be brave and bold in adapting to new situations, that we reach out to support people dying in all settings, that we maintain our humanity and compassion in providing care, and that palliative care research would be fundamental to informing our approaches to care. I think many of those hopes have been realised – I have been humbled and inspired many times by the way that palliative care has responded innovatively to needs created by the pandemic<sup>2</sup>, although remain frustrated that this is not always reflected in policy or funding decisions. Here, however, I primarily reflect from a researcher and editor perspective about how research has been highlighted as of fundamental importance during this pandemic.

Certainly, in the UK, where I live, research – or certainly data – have been forefront in the public consciousness in a way that I do not remember seeing before. We are bombarded with information about vaccine trials, tests, positive cases, hospital usage statistics and deaths, including modelling, projections and their interpretation. We are told that policy is ‘following the science’. There has been an explosion of research – over 8000 preprints are available on COVID-19 SARS-CoV-2 from medRxiv, for example. As a new disease it is obvious that research is needed to guide practice. Here at *Palliative Medicine* you can see all our COVID-19 papers collated in one place on our website (<https://journals.sagepub.com/topic/collections-pmj/pmj-4-covid-19-articles/pmj>). Examples of important research shared include information on optimal symptom management<sup>3,4</sup>, on equity of access to care<sup>5</sup>, on possible palliative care need<sup>6</sup>, and on predicting mortality<sup>7</sup>. With great support from our reviewers we are fast-tracking COVID-19 papers through our systems, and making them freely available when published.

I argue that what is needed now is to briefly pause and take stock of where we are in terms of COVID-19 and palliative care research. The need for research in this area will not diminish, the virus is likely here to stay with us for quite some time. This is a moment for palliative care research to be visible and important, and we need to ensure that it remains relevant and robustly conducted. What are the key research questions that face us now and for the medium-term future? Questions that require attention are likely to include a consideration of when, to whom, and by which services palliative care should be offered. Effective approaches to symptom management and palliation, including palliative rehabilitation, for those with COVID-19 need to be further studied. We need a greater understanding of ‘Long COVID’ and how this might affect, if at all, the patients that we provide care for. We need to understand the longer-term impact of some of the service changes that we have had to adopt such as remote working, a shift to home care, and teleconsultation for all patients, whether with COVID-19 or not. What is impact of changes in provision on family carers both during care and in to bereavement. A focus on community and primary care settings may be particularly important given we know that there appear to be excess home deaths, and many patients may be reluctant to access in-patient care. In particular the experiences and voices of our patients have been challenging to understand in the short term, but need to be an integral part of research going forwards.

For all research areas I believe that we need to focus on coordinated, joined up efforts. Much COVID-19 palliative care research to date has been small and local in scale and scope. This is not to denigrate this important research, and how teams responded rapidly, but large team or multi-national research may reap greater benefits for the future in terms of transferrable knowledge that can influence practice. A health care example has been the RECOVERY trial here in the UK, focused on COVID treatments, that recruited 2,000 participants from 176 different hospitals within the first

three months. Whilst perhaps not possible at this scope and scale, I argue that we need to be bold in our vision for how palliative care research can be planned and executed if we are to see maximum benefit for our patients.

We also need to think about those conducting research, and how they are able to work effectively. We feared that the pandemic would have a negative impact on submissions to the journal, for example, due to the pressures of clinical care, the pausing of some research, and the general effect of restrictions such as home-based working or caring responsibilities. This hasn't happened thus far, with more papers being submitted to the journal than ever before. It may be, however, that these effects will not be felt yet as papers submitted now are likely to be related to projects where data collection had already completed. A particular concern across the science community is the potential for these effects on research and research careers to affect women disproportionately<sup>8</sup>, with evidence emerging that they are less likely to be first authors on COVID related papers<sup>9</sup>. In many countries palliative care/research is female dominated, and our specialty might be particularly adversely affected by these issues. Whilst perhaps not as scientifically robust as these cited papers, we have looked at the gender of submitting authors to the journal from Jan-Oct 2019 and for the same time period in 2020. In 2019 66% of submitting authors were female, in 2020 this dropped to 56%, with every month having a lower proportion of female submitting authors than in 2019. A particular low point was in April 2020 when only 48% of papers had a female submitting author. It does therefore appear to be the case that the pandemic has had some effect on research or its dissemination amongst female colleagues. It is important that we think creatively about how we can be part of a system that enables and facilitates all research contributions if palliative care research overall is not to be particularly adversely affected.

Here at *Palliative Medicine* we hope we can continue to play our part in effectively promoting and disseminating robust research. We have continued to grow and develop through the pandemic, albeit managing our own personal challenges of home-working, caring and clinical responsibilities that are affecting palliative care and research more generally. We welcome two new members to our Editorial Board, chosen through an open competitive process: Professor Lorna Fraser from York University in the UK who has a special interest in paediatric palliative care; and Dr Melissa Bloomer from Deakin University in Australia whose work focuses on palliative care in acute care settings. We have also welcomed new members of our Editorial Advisory Board from North America and Europe. As an international journal we are seeking further representation from a broader range of countries, and hope to continue to serve our international community of readers as well as possible in what will no doubt continue to be a challenging year ahead.

## References

1. Walshe C. COVID-19: A personal perspective. *Palliative Medicine* 2020; 34: 687-688. DOI: 10.1177/0269216320921639.
2. Dunleavy L, Preston N, Bajwah S, et al. 'Necessity is the mother of invention': Specialist palliative care service innovation and practice change in response to COVID-19. Results from a multi-national survey (CovPall). *medRxiv* 2020: 2020.2010.2029.20215996. DOI: 10.1101/2020.10.29.20215996.
3. Jackson T, Hobson K, Clare H, et al. End-of-life care in COVID-19: An audit of pharmacological management in hospital inpatients. *Palliative Medicine* 2020; 34: 1235-1240. DOI: 10.1177/0269216320935361.

4. Hetherington L, Johnston B, Kotronoulas G, et al. COVID-19 and Hospital Palliative Care – A service evaluation exploring the symptoms and outcomes of 186 patients and the impact of the pandemic on specialist Hospital Palliative Care. *Palliative Medicine* 2020; 34: 1256-1262. DOI: 10.1177/0269216320949786.
5. Chidiac C, Feuer D, Flatley M, et al. The need for early referral to palliative care especially for Black, Asian and minority ethnic groups in a COVID-19 pandemic: Findings from a service evaluation. *Palliative Medicine* 2020; 34: 1241-1248. DOI: 10.1177/0269216320946688.
6. Bone AE, Finucane AM, Leniz J, et al. Changing patterns of mortality during the COVID-19 pandemic: Population-based modelling to understand palliative care implications. *Palliative Medicine* 2020; 34: 1193-1201. DOI: 10.1177/0269216320944810.
7. Fiorentino M, Pentakota SR, Mosenthal AC, et al. The Palliative Performance Scale predicts mortality in hospitalized patients with COVID-19. *Palliative Medicine* 2020; 34: 1228-1234. DOI: 10.1177/0269216320940566.
8. Myers KR, Tham WY, Yin Y, et al. Unequal effects of the COVID-19 pandemic on scientists. *Nature Human Behaviour* 2020; 4: 880-883. DOI: 10.1038/s41562-020-0921-y.
9. Andersen JP, Nielsen MW, Simone NL, et al. COVID-19 medical papers have fewer women first authors than expected. *eLife* 2020; 9: e58807. DOI: 10.7554/eLife.58807.