

Palliation in a pandemic: the human cost of achieving the greater good

Hannah O'Brien¹ and Tony O'Brien

Palliative Care & Social Practice

2022, Vol. 16: 1–5

DOI: 10.1177/
26323524221141720

© The Author(s), 2022.
Article reuse guidelines:
sagepub.com/journals-
permissions

Abstract The onset of the COVID-19 pandemic in early 2020 created major challenges for specialist palliative care services. Significant ethical challenges have arisen in practising a holistic approach to patient and family care, while observing local and national health care policy in the face of a global pandemic. This report highlights the challenges that arose for a patient, family members and staff consequent on COVID-related visiting restrictions. An integrated specialist palliative care inpatient unit and elderly care facility in Ireland. A 50-year-old married mother of three teenagers and one 12-year-old child with advanced amyotrophic lateral sclerosis is described. The patient could not speak or move her limbs. She communicated using an eye gaze device. She had previously declined enteral feeding, and noninvasive ventilatory support was not tolerated. Her husband was particularly attentive and remarkably intuitive in identifying her unspoken needs. At the start of the pandemic, visiting was severely curtailed in line with national policies. The change in visiting policies caused enormous distress to the patient, her family and to the staff members. IT devices were of limited benefit. The current pandemic has had a significant impact on families and health care professionals in which balancing individual need and traditional freedoms against the wider societal need are necessary in limiting the spread of COVID-19.

Keywords: ALS, COVID-19, ethical challenges, holistic care, palliative care, pandemic

Received: 5 April 2022; revised manuscript accepted: 8 November 2022.

Introduction

Since the first case of COVID-19 or SARS-CoV-2 virus was confirmed in Wuhan in December 2020, the world has changed dramatically. All aspects of human activity have been affected, and the economic, societal and personal consequences are incalculable.¹ This virus does not respect age, sex, ethnicity or borders and its devastating pattern of spread prompted the World Health Organization to declare a global pandemic on 11 March 2020.² Health care services worldwide struggle to respond to the scale of the catastrophe while simultaneously trying to maintain essential time-critical non-COVID-related activity.³ Individual health care professionals carry a particularly onerous responsibility and face challenging ethical dilemmas as they try to balance the needs of infected patients without jeopardising their own health and perhaps endangering family members and loved ones.^{4,5}

Profound ethical concerns came into sharp focus like never before, and the core ethical principles that underpin our practice came under greater scrutiny.^{5,6} Palliative care services supporting both hospital and community-based teams continued to practice and promote a holistic approach to patient and family care to the greatest extent possible.^{7,8} Each new spike in infection rates or 'waves' and consequent lockdown of normal social, educational and commercial activity brought additional burdens and stresses to already over-stretched health care teams and to wider society.

In palliative medicine, the family is the unit of care.^{7,8} Family does not only refer to people related by blood or marriage, but it also includes close friends, partners, companions and others who a patient may wish to play a role in their care or 'all those for whom it matters'.⁹ Family

Correspondence to:
Hannah O'Brien
Marymount University
Hospital & Hospice, Cork,
T12 A710, Ireland.
hannahobrien201@gmail.
com

Tony O'Brien
Marymount University
Hospital & Hospice, Cork,
Ireland.



members are an essential and integral element of the caring team – they know their loved one's likes, preferences and values better than we can ever hope to do.⁸ Over the course of a typical admission episode, family members become well known to staff members and strong professional relationships are established. The close interface between family members and staff serves a dual function. Staff offer family members emotional and practical support, and in turn, family members provide us with an insight into their loved one's wishes, preferences, values and expectations, particularly in circumstances in which the patient is unable to do so.⁸

Typically, specialist palliative care facilities operate very relaxed visiting policies and family members are actively encouraged to spend as much time as they wish with their loved one, including overnight stays. Our 44-bed inpatient unit in Ireland is no exception. We ordinarily operate a policy of open visiting and provide facilities for close family member(s) to stay in a patient's room overnight or immediately adjacent in hotel-room style accommodation if preferred.

With the outbreak of the COVID-19 pandemic, these policies changed rapidly over time reflecting and being revised in accordance with the national policy and guidance. Our country was in an effective state of lockdown with only essential workers allowed to travel to their place of work. There were limitations in the availability of personal protective equipment (PPE) and no available vaccines. Family members were now viewed as potential vectors of a deadly virus, and hence, their access to the inpatient unit was restricted in line with local and national health care policy.

Hence, visiting policies shifted from facilitating the individual need to protecting the greater good. But this comes at an enormous personal cost. Time and opportunities were lost that could never again be recovered. Patients and families were enormously distressed by this change in policy and frequently make a compelling case that their situation is unique – as indeed it is unique – and they understandably promote the view that their circumstance is the exception to the rule. In discussion, patients and families could quite readily accept the need for the restrictions for other patients, but not for their loved one. Every effort was made to facilitate face-to-face visiting, albeit with the use of PPE as indicated, and additional resources were made

available to facilitate video connection between patients and family members.

Nevertheless, we observed a radically different dynamic evolve whereby very ill patients started to request immediate discharge because they could not handle the pain of separation from close family. A significant number of very ill people went home in circumstances that were less than ideal. This was a worry not least because of the existing pressures on an already over-stretched community team. In parallel, a high proportion of very ill patients in community settings who needed specialist inpatient palliative care refused admission for the same reason. For some of these, by the time they finally consented to admission, they were profoundly unwell and rapidly approaching end of life. In the conflicting dilemma between place of care and quality of care, the former frequently reigns supreme.

Case description

Jennifer is a 50-year-old married woman who has advanced amyotrophic lateral sclerosis (ALS) who was admitted from home to the specialist palliative care inpatient hospice unit prior to the onset of the COVID-19 pandemic. She cannot speak or move her limbs, and she is totally dependent on nursing care. Jennifer communicates with the outside world by means of eye gaze technology. Because of her poor head control, this apparatus must be positioned in precisely the right place and tilted at exactly the right angle to work effectively. Jennifer had previously declined percutaneous endoscopic gastrostomy (PEG) feeding and did not tolerate a trial of assisted ventilatory support at home. Jennifer's respiratory function is severely compromised, and she is at ongoing risk of acute-on-chronic ventilatory failure. Hence, like many similar patients, death could occur quite 'suddenly'.

Throughout her course, Jennifer is tremendously well supported by her husband Rob and their three teenage children and 12-year-old child. Rob is extraordinarily attentive and previously sat with his wife for many hours each day. He seemed to know intuitively what she needed at any time, which might be a small change in her degree of arm flexion or a very modest adjustment in her head position. Equally, Jennifer was greatly reassured by his presence and was much more relaxed and calm when he was there. Jennifer took great delight in

the regular visits of her children and became visibly more animated and engaged when hearing their accounts of school and sport activities.

When the COVID-19 visiting restrictions were introduced, all visiting was curtailed. The only limited exception was applied in of respect individual close relatives visiting imminently dying patients. This, of course, presupposes that we can always predict the timing of death with some degree of accuracy, which is not necessarily true and particularly so in the case of ALS.

The palliative care team members – including doctors, nurses and medical social worker – met with Jennifer and Rob both together and individually on numerous occasions and explained the new visitor policy and the rationale informing its introduction. Jennifer became inconsolably distressed and persistently so. Rob could understand the purpose of the restrictions at a rational level, but emotionally he was devastated. We spoke about keeping in touch using the various technologies that are freely available, but this offered little reassurance or comfort. In discussion, it was subsequently agreed to make some concessions in this instance, and Rob was allowed a 30-min visit twice a day.

Some few days later, Rob sent an email outlining his distress. With his permission, I share the following excerpts:

Last night with Jennifer was tough. As I was leaving her, she started to get upset. My 30 minutes were up so I couldn't stay to console her. This is wrong on so many levels. I have been everything to Jennifer and she is everything to me. What has happened to Jennifer is like taking a guide dog from a blind person. Jennifer depends on me for everything. What is going on in the world is madness but in the midst of this madness we have a duty to keep Jennifer's spirits (and mine and the kids) up. Jennifer is an exceptional case and she never asked for this illness. We need to do better. We need to do the right thing. I'm afraid I will crack under these conditions. Leaving her upset because my time is up horrendous.

The palpable distress so powerfully conveyed in the email correspondence was not limited to Jennifer and her family. Members of the multidisciplinary palliative care team shared the sentiments expressed and repeatedly explored the available options with a view to finding some mechanism that would allow Rob and the

children greater access. As in many other similar cases, this included an exploration of the feasibility of supporting Jennifer's discharge home. Sadly, her care needs were far in excess of what could reasonably or safely be supported in a domestic environment.

Discussion and implications for care

Jennifer's case illustrates the tension that arises when balancing the individual patient/family need against the wider societal good. By way of context, it is noted that Jennifer was an inpatient in the early phase of the pandemic and at a time when PPE was severely limited, and vaccine was a distant dream. When viewed from the perspective of the patient and her husband, it is indeed wrong to seek to limit the time they may spend together. Equally, we were aware that we had a very vulnerable cohort of palliative care patients in a facility that we shared with a large number of equally vulnerable elderly care residents. Social distancing is not an option when providing complex personal and intimate care to highly dependent patients.¹

A collaborative approach including patients and their families, continuity of care and excellent communication was never more important. Our palliative care team supported the family in the use of video and audio calls in line with good practice guidelines.¹⁰ In this instance, Jennifer's husband set up a Skype video call so that their family could share time together during his visits. Health care professionals have an important role in facilitating video and audio calls for patient and their families.^{8,10} While we accept the limitations of technology, particularly for patients whose communication is as compromised as Jennifer's was, it does nevertheless provide a supplementary communication tool.^{10,11}

In palliative care, bereavement support begins when we first meet with a patient and family and continues throughout the care episode and extends beyond the death as appropriate.^{7,12} Family members and caregivers of patients with ALS may experience adverse effects on their own physical, psychological and social wellbeing associated with the unrelenting nature of the disease.¹³ Recent studies suggest that caregivers of patients with a diagnosis of ALS may be at greater risk of complicated grief than other bereaved populations; however, they may not receive an offer of bereavement support, instead being informally

supported in the community by family and friends already involved in their lives in addition to Motor Neuron Disease Associations, general practitioners (GPs) and funeral providers.^{13–15} A national Australian study of bereaved caregivers found that 63% of those surveyed required bereavement support beyond family and social support, however.¹⁶ The potential impact of COVID-19-related visiting restrictions on the grieving process is yet to be fully characterised. Social distancing, isolation, PPE, uncertainty relating to infection risk and status and inability to perform and attend normal rituals both before and after the death may prove significant.¹⁷

The impact of the visiting restrictions is not limited to patients and families. Staff members often feel conflicted in this regard, particularly when their role changes from patient advocate to regulation enforcer.¹⁸ Moral distress (not being able or being constrained from doing what you think is right) is a concern for staff and family members alike.^{18,19} The impact of the COVID-19 pandemic on the psychological wellbeing of health care workers, family and patients with pre-existing conditions or COVID-19 themselves has been well documented.²⁰ Visiting restrictions, particularly as a patient approaches end of life, may have far reaching effects for all concerned.¹⁹

Conclusion

This report brings into sharp focus the conflict that arises for families and health care professionals in the current pandemic crisis between balancing individual need and traditional freedoms against the wider societal need in respect of limiting the spread of COVID-19. In normal circumstances, the individual freedoms enjoyed by family members of palliative care inpatients do not conflict with the wider societal good. In these unprecedented times, however, we need to strive for compromise such that each individual situation is reviewed and assessed on a regular and ongoing basis. The longer-term consequences for families in terms of bereavement risk and complications will become evident in due course.

Declarations

Ethics approval and consent to participate

Informed consent was obtained from the patients spouse and personal details have been changed to

preserve anonymity. Ethical approval was not required.

Consent for publication

All authors participated in the writing and revision of the manuscript. Informed consent was obtained from the patient's spouse, and personal details have been changed to preserve anonymity.

Author contributions

Hannah O'Brien: Conceptualisation; Writing – original draft; Writing – review & editing.

Tony O'Brien: Conceptualisation; Supervision; Writing – original draft; Writing – review & editing.

Acknowledgements

None.

Funding

The authors received no financial support for the research, authorship and/or publication of this article.

Competing interests

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Availability of data and materials

Not applicable.

ORCID iD

Hannah O'Brien  <https://orcid.org/0000-0002-9401-4205>

References

1. Chu DK, Akl EA, Duda S, *et al.* Physical distancing, face masks, and eye protection to prevent person-to-person transmission of SARS-CoV-2 and COVID-19: a systematic review and meta-analysis. *Lancet* 2020; 395: 1973–1987.
2. Perumal V, Curran T and Hunter M. First case of covid-19 in Ireland. *Ulster Med J* 2020; 89: 128.
3. Al-Tawfiq JA, Al-Yami SS and Rigamonti D. Changes in healthcare managing COVID and non-COVID-19 patients during the pandemic: striking the balance. *Diagn Microbiol Infect Dis* 2020; 98: 115147.

4. Sperling D. Ethical dilemmas, perceived risk, and motivation among nurses during the COVID-19 pandemic. *Nurs Ethics* 2021; 28: 9–22.
5. Robert R, Kentish-Barnes N, Boyer A, *et al.* Ethical dilemmas due to the Covid-19 pandemic. *Ann Intensive Care* 2020; 10: 84.
6. Department of Health. Procedural values for decision-making in a pandemic, <https://www.gov.ie/en/publication/0ac07-procedural-values-for-decision-making-in-a-pandemic/> (2020, accessed 16 August 2020).
7. White Paper on standards and norms for hospice and palliative care in Europe: part 1 – recommendations from the European Association for Palliative Care. *Eur J Palliat Care* 2010; 17: 22–33.
8. Steinhauser KE, Voils CI, Bosworth H, *et al.* What constitutes quality of family experience at the end of life? Perspectives from family members of patients who died in the hospital. *Palliat Support Care* 2015; 13: 945–952.
9. Committee on Approaching Death: Addressing Key End of Life Issues and Institute of Medicine. *Dying in America: improving quality and honoring individual preferences near the end of life*. Washington, DC: National Academies Press, 2015.
10. Etkind SN, Bone AE, Lovell N, *et al.* The role and response of palliative care and hospice services in epidemics and pandemics: a rapid review to inform practice during the COVID-19 pandemic. *J Pain Symptom Manage* 2020; 60: e31–e40.
11. Collier A, Morgan DD, Swetenham K, *et al.* Implementation of a pilot telehealth programme in community palliative care: a qualitative study of clinicians' perspectives. *Palliat Med* 2016; 30: 409–417.
12. Hudson P, Remedios C, Zordan R, *et al.* Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. *J Palliat Med* 2012; 15: 696–702.
13. Aoun SM. The palliative approach to caring for motor neurone disease: from diagnosis to bereavement. *Eur J Pers Cent Healthc* 2018; 6: 675–684.
14. Aoun SM, Noonan K, Thomas G, *et al.* Traumatized, angry, abandoned but some empowered: a national survey of experiences of family caregivers bereaved by motor neurone disease. *Palliat Care Soc Pract* 2021; 15: 26323524211038584.
15. Aoun SM, Cafarella PA, Rumbold B, *et al.* Who cares for the bereaved? A national survey of family caregivers of people with motor neurone disease. *Amyotroph Lateral Scler Frontotemporal Degener* 2021; 22: 12–22.
16. Aoun SM, Kissane DW, Cafarella PA, *et al.* Grief, depression, and anxiety in bereaved caregivers of people with motor neurone disease: a population-based national study. *Amyotroph Lateral Scler Frontotemporal Degener* 2020; 21: 593–605.
17. Wallace CL, Wladkowski SP, Gibson A, *et al.* Grief during the COVID-19 pandemic: considerations for palliative care providers. *J Pain Symptom Manage* 2020; 60: e70–e76.
18. Andrist E, Clarke RG and Harding M. Paved with good intentions: hospital visitation restrictions in the age of coronavirus disease 2019. *Pediatr Crit Care Med* 2020; 21: e924–e926.
19. Anderson-Shaw LK and Zar FA. COVID-19, moral conflict, distress, and dying alone. *J Bioeth Inq* 2020; 17: 777–782.
20. Luo M, Guo L, Yu M, *et al.* The psychological and mental impact of coronavirus disease 2019 (COVID-19) on medical staff and general public – a systematic review and meta-analysis. *Psychiatry Res* 2020; 291: 113190.

Visit SAGE journals online
[journals.sagepub.com/
 home/pcr](https://journals.sagepub.com/home/pcr)

 SAGE journals