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## Impact of COVID-19 social distancing on the quality of dying: A call for discretionary application of rules

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3 **REFLECTION**  
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6 **Impact of COVID-19 social distancing on the quality of dying: A call for**  
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8 **discretionary application of rules.**  
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### *The quality of living and dying*

During the COVID-19 pandemic the media and the regulators have given limited attention to the impact of social distancing rules on the quality of living and dying, not only for COVID-19 patients, but for anyone who has reached the end of life from natural causes in hospitals and residential aged care facilities (RACFs). Fear for the safety of other patients, visitors, and healthcare clinicians during the pandemic (Gordon AL et al. 2020), triggered unprecedented isolation practices including limiting staff numbers attending to patients, transitioning to virtual rounds (Arora VM 2020), restricting hours and duration of visiting, isolating patients in ICU at end of life, and enacting policies on numbers of bedside family/caregivers who can accompany terminal patients (Wakam GK et al. 2020). In some institutions, nursing staff, and social workers on shift are taking the place of families, providing a compassionate presence to dying patients: others are dying unaccompanied. Unfortunately, these extraordinary circumstances place an immediate and ongoing emotional burden on clinicians and families alike. While it is true that people will eventually adapt and that those of us who lived through the pandemic will recover from the shock and unexpected changes to our lifestyle and clinical practice, many who lost loved ones without a proper farewell due to draconian health service rules will experience prolonged, complicated grief responses, post-traumatic stress (Selman et al. 2020) and separation distress (Gesi C et al. 2020). Meanwhile the strict rules have caused clinicians job dissatisfaction, and moral distress (Canadian Medical Association 2020) . The quality of dying has been negatively impacted. The ethical dilemma for clinicians is reconciling the need for compliance with internal policies and the competing need for holistic management of the individual.

### *Typical scenarios with restrictions*

During the pandemic social workers continue to be involved in psychosocial support and advocacy activities on behalf of patients and families (Moon and McDermott 2020), their competence in organising family conferencing can greatly assist in ensuring clear two-way communication and support (Johns, Blackburn, and McAuliffe 2020), as well as leading advance care planning discussions (Raftery, Lewis, and Cardona 2020). While some have facilitated family visiting or final phone calls (Tenorio, Johnson, and Grudier 2020), the ability for social workers to systematically influence practice change under the restriction policies has been limited. There has been anger, anxiety and/or despondency regarding the enforced separations and appeals to health care clinicians that concessions on visitor restrictions only in the last days or hours of life have prevented important interpersonal exchanges and care opportunities. Restrictions often meant that the sole visitor present at a death was without the comfort of a companion. Clinicians have been distressed and divided about visitor concessions. Interstate and international border closures have also impacted individual family caregivers who were not local or had visited ‘hotspots’: thus restricting or precluding visiting.

Older persons such as spouses were also fearful of contracting COVID-19; which lead to dilemmas about visiting their dying loved one. Some hospitals and RACFs restricted families and informal caregivers to a single one hour visit during a particular, pre-scheduled, and inflexible, time period. This caused trauma, given the uncertainty about the patient’s prognosis, and risk of death. Some families set up complex plans and rotations that also allowed the legal guardian to have regular contact with doctors to be updated on tests, procedures, and patients’ health status. Miscommunication from all parties involved also heightened frustration and the stress of missing out on seeing a loved one. Timely

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3 communication about transfers between facilities both in the private and public system was  
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5 not always possible, especially when visiting hours for families were outside the clinical  
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7 teams' routine hours.  
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12 Some families and staff felt let down and perceived that there was a lack of compassion in  
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14 these pandemic responses to protect patients, visitors, and staff. Were the blanket measures  
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16 justifiable, or did they go too far and generate unintended and preventable harm: reducing  
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18 opportunities for goals of care and discussions about or honouring of advance care  
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20 preferences? Could the policies have been moderated to minimise further emotional pain?  
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26 As the pandemic continued and infection rates fluctuate, the perceived risk posed by COVID-  
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28 19 was reassessed, restrictions were eased and increased discretionary options for visiting in  
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30 end of life care scenarios were established: however, some new problems arose. When  
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32 determining risk and applying discretionary visiting rules clinicians are reliant on the honesty  
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34 of the answers of visitors to screening questions. There were instances where family/  
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36 caregivers retrospectively admitted to dishonesty about reporting dates they had visited  
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38 hotspots to circumvent restrictions. Clinicians were placed in the unenviable position of  
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40 managing breaches, which however motivated, could compromise infection control. Such  
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42 breaches resulted in further pressure on staff attempting to ensure duty of care to patients,  
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44 families, colleagues, and the broader community. There were emotional and physical  
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46 demands involved in drafting plans that may be needed if staff had to be isolated. As well,  
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48 there is still the problem of trying to avoid a reactive swing to a stricter application of the  
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50 rules to prevent any further perceived harm to the team or patients. Fortunately, such  
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52 incidents have been minimal.  
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### *Proposed solutions for recurring pandemic waves*

If there are options to minimise persistent complex bereavement, there is a duty to implement them. A degree of flexibility, understanding, and discretionary application of the institutional rules using individualised approaches in cases where there appears to be no potential harm to the people involved. This can enhance clinician-health consumer relationships and reduce the moral injury suffered by clinicians enforcing severe restrictions. We know that transmission potential is lower from asymptomatic individuals (Byambasuren O et al. 2020), and that contacts of less than 15 minutes also reduce chances of infection (Centres for Disease Control and Prevention 2020b). If such institutional distancing policies had been more flexible would those 15 minutes of grace [“prolonged exposure”] have made a difference to someone’s end of life experience?

Anecdotal evidence shows creative initiatives within hospitals such as; drive through fever pre-screening, rapid PCR testing, offer of protective equipment to visitors (Centres for Disease Control and Prevention 2020a); and when visitors are potentially a risk to staff or other non-terminal patients, widespread use of, and access to, virtual visits or all-hours telephone calls, and bereavement support could be provided (Gorodeski et al. 2020; Selman et al. 2020; Wakam GK et al. 2020). As the pandemic lingers, some of these technologies have become commonplace in some regions: but they should not be a substitute for personal interaction with families.

Lessons can be learned from New Zealand, an exemplar on pandemic control. Within RACF’s site managers and clinicians were allowed to make exemptions to visitor restriction recommendations for palliative care or end-of-life situations on a case-by-case basis (New Zealand Ministry of Health 2020) without detriment to patient safety. In parts of Australia,

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3 compassionate concessions for RACF visitors include use of protective equipment, escorts  
4 into the facility and avoidance of common areas: but the exemptions have to be authorised by  
5 the Chief Health Officer (Queensland Government 2021). This delays the discretionary  
6 application of rules at a time when every minute counts.  
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14 We should design policies that enable patients to die with at least one loved one by their side.  
15 For instance, by allowing one family member, if tested negative, to stay overnight could have  
16 settled a loved one who was anxious and alone in an unfamiliar environment. To reduce staff  
17 stress, it is crucial to ensure the clinical team members communicating the restrictions to the  
18 public possess advanced interpersonal skills and an understanding of the grief response.  
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## 28 **Conclusions**

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30 Unquestionably this pandemic is teaching health clinicians and the public in general, many  
31 lessons about protective behaviours, generosity, compassion and what is required to preserve  
32 public health. For people who, because of the pandemic, have lost their autonomy, their right  
33 to freely see family, and their choice for place of death, we would recommend consideration  
34 of institutional restrictions within context, remembering that one size does not fit all during a  
35 global crisis. Service managers and clinicians should be able to make informed and optional  
36 exemptions when implementing isolation rules and visiting protocols for people who may not  
37 require extreme versions of them. More than ever, during this unprecedented time, there is a  
38 need to incorporate psychosocial needs in a more humane, person-centered care equation.  
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40 Having rules that are discretionary and individualised can at least empower the clinical team  
41 to facilitate the 'best under the circumstances death' during this continuing pandemic.  
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