Administration of end-of-life drugs by family caregivers during covid-19 pandemic

Doing this safely needs training, support, and careful prescribing

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Doctors, nurses, and family caregivers worldwide are facing tough decisions concerning the supply and administration of medications to manage symptoms when patients are dying from covid-19 or other conditions in the community or care homes. Proposed changes in practice aimed at ensuring adequate end-of-life symptom control need careful consideration alongside appropriate training and support.

Updated UK advice, including NICE rapid guidance on managing covid-19 symptoms in the community, reiterates the importance of prescribing medications in advance of need for pain, nausea and vomiting, agitation, and respiratory secretions. ¹ ² These drugs may be administered if needed by visiting doctors or nurses, as is already well established in some countries. ³ ⁴ However, this practice is being overhauled radically in response to the pandemic. ¹³

Prescribers are now being asked to consider drug administration by family caregivers when community nurses and doctors are not available to administer end-of-life drugs in a timely way. ¹ ³ Family caregivers willing to take on this role should be adequately trained and responsively supported with access to 24 hour phone advice. ¹³⁵

Risks for family caregivers

Prescriptions may need to include drug formulations that family caregivers administer buccally, sublingually, or rectally, in addition to the subcutaneous injection route, as these are easier for non-professionals. ¹ ² There is good evidence for the effectiveness of subcutaneous injections of drugs such as opioids and midazolam at the end of life. ⁴ ¹⁰ ¹¹ The buccal and sublingual routes are much less commonly used, however, and their limited evidence base comes primarily from professional experience and paediatric palliative care. ¹¹ ¹² Both rectal and buccal routes in covid-19 carry the risk of transmitting infection. ¹³

Although family caregivers commonly administer anticipatory medications in rural Australia, it is rare in the UK and many other countries. ¹³ ¹⁵ This is a big ask. Family caregivers may feel under pressure to undertake tasks for which they do not feel prepared or confident. ¹⁴ They may feel a tension between their emotional involvement and this clinical task. Clinicians often worry that they may have hastened death if a patient dies shortly after drug administration. ⁵ ¹⁰ This anxiety may be even greater for family caregivers, with some worrying that it amounts to euthanasia. These tensions require sensitive explanation from the outset ¹⁴ ¹⁰ since if the relative dies during the pandemic families will be confronting these concerns while grieving in isolation.

Timely supply

Increasing demand for drugs to control symptoms is also affecting prescribing decisions. ¹ The dilemma is whether to continue to prescribe anticipatory medications ahead of expected death, risking exhausting pharmacy supplies, or to delay until a patient is clearly dying. Acting to protect limited drug stocks for those who need them most risks delays in care and gives little time to prepare family caregivers to administer drugs. NICE guidance recommends that drugs continue to be prescribed ahead of need but in small quantities and cautions that patients with covid-19 can deteriorate rapidly so it is better to be prepared. ¹ This advice to continue judicious prescribing of anticipatory medications seems wise, provided that drug stocks remain adequate.

It would be helpful if community healthcare services could hold central stocks of the common end-of-life drugs, enabling rapid prescribing and dispensing. In care homes, allowing drugs prescribed for one resident to be used for another resident would ensure efficient use of limited supplies but would need legislative changes in many countries.

The pandemic is creating considerable challenges for end-of-life care across the world. It is vital to plan and provide suitable support now if changes in practice in the community are going to be safe and appropriate for patients and their family caregivers.

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