

Family and health-care professionals managing medicines for patients with serious and terminal illness at home: a qualitative study

Kristian Pollock,^{1*} Eleanor Wilson,¹ Glenys Caswell,¹
Asam Latif,¹ Alan Caswell,² Anthony Avery,³
Claire Anderson,⁴ Vincent Crosby⁵ and Christina Faull⁶

¹School of Health Sciences, University of Nottingham, Nottingham, UK

²Patient and Public Involvement Representative, Dementia, Frail Older and Palliative Care Patient and Public Involvement Advisory Group, University of Nottingham, Nottingham, UK

³School of Medicine, Faculty of Medicine and Health Sciences, University of Nottingham, Nottingham, UK

⁴School of Pharmacy, University of Nottingham, Nottingham, UK

⁵Nottingham University Hospitals NHS Trust, Nottingham, UK

⁶LOROS Hospice, Leicester, UK

*Corresponding author Kristian.Pollock@nottingham.ac.uk

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Plain English summary

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Plain English summary

More effective treatments enable patients to be cared for, and to die, at home, even when they have a serious illness that previously would have required care in hospital. Managing a person's medicines at home in these circumstances is very difficult. Patients and family caregivers need to organise getting prescriptions; collect, store and administer medicines at different times of day; and fit these tasks into other care work and daily routines. Patients may be prescribed many medicines, including powerful painkillers that can have serious side effects. This study explored the experience of patients and family caregivers in managing medicines for symptoms resulting from life-limiting illness, what they felt about doing this and how they were supported by health-care professionals and services involved in providing care.

This qualitative study included:

- 21 interviews with bereaved family caregivers
- 40 interviews with health-care professionals
- 20 patient case studies with up to 4 months' follow-up
- two stakeholder workshops to discuss the study findings and suggest ways to improve support for patients and family caregivers.

Patients and family caregivers described the work of managing medicines to be very difficult, especially as the patient's condition worsened in the last weeks and days of life. Health-care professionals often did not really understand the practical and emotional difficulties involved. All participants experienced difficulties in communication and organisation within a health-care system that they felt was complicated and poorly co-ordinated. Having a key health professional to support and guide patients and family caregivers through the system was important to a good experience of care.

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