

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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Scientific summary

Medicines management in at-home care

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Scientific summary

Background

The Managing Medicines study investigated how seriously ill patients, their family caregivers and the health-care professionals who support them work together to manage medicines prescribed for the relief of symptoms, including those experienced at the end of life. More effective treatments enable patients to be cared for, and to die, at home, even when they suffer from serious illness that previously would have required care in hospital. Patients may be prescribed many medicines, including powerful painkillers, which can have serious side effects. The everyday work of medicines management includes ordering and collecting prescriptions, and storing, organising and administering medicines in different ways and at different times of day. These tasks must be organised around other commitments and daily routines. Little is known about how patients and family caregivers undertake the physical and emotional work of managing medicines or the support that they receive from health-care professionals and services. The experience of patients affected by conditions other than cancer or who come from minority, diverse or disadvantaged groups of the population have been under-researched.

Aim

To explore how patients, their family caregivers and the health-care professionals who support them engage in the tasks of managing complex medication regimens and routines of care in the domestic setting for patients with severe and terminal illness who are approaching the end of life.

Objectives

- To understand the experience of medicines management in end-of-life care for patients and family caregivers, especially from minority, under-researched and hard-to-reach groups. These include patients affected by illness other than cancer, living alone, affected by sensory or physical impairment, from ethnic minority communities, who are homeless or who are affected by serious mental illness.
- To compare and contrast the experience of symptom control and family caregiver involvement in medicines management for patients who have been referred to specialist palliative care services with those who have not.
- To establish what further support, information and training family caregivers and health-care professionals need to feel confident in managing medicines for seriously ill patients being cared for and dying at home.
- To explore lay and professional stakeholder perspectives about how community pharmacists could be better integrated into the network of care and support for families and health-care professionals in medicines management and end-of-life care.

Design and methods

A qualitative study of 30 months' duration based on three workstreams:

1. single semistructured qualitative interviews with bereaved family caregivers, and interviews and focus group discussions with health-care professionals

2. longitudinal patient case studies, including patients, family caregivers and health-care professionals with approximately 3 months' follow-up, including one to three interviews for each participant
3. end-of-project stakeholder workshops to disseminate and discuss study findings, implications for practice and priorities for future research.

Setting and recruitment

Participants who took part in workstreams 1 and 2 were recruited purposively through general practices, hospices, community nursing services and specialist palliative care services throughout Nottinghamshire and Leicestershire, UK. The recruitment of bereaved family caregivers and friends was also promoted through local community organisations. Stakeholder workshop participants included national and regional representation from education, practice and public and third-sector organisations.

Inclusion criteria

Workstream 1: interviews with bereaved family caregivers and friends and health-care professionals

- Bereaved family caregivers and friends of patients who were cared for at home during a substantial part of the last 6 months of life and who died at least 8 weeks prior to the invitation to take part in the study.
- Health-care professionals from specialist and community health-care services with relevant experience of supporting medicines management with seriously ill patients being cared for at home.

Workstream 2: patient case studies

- Patients identified as likely to be within the last 6 months of life by a health-care professional who is providing care.
- Family caregivers of eligible patients who are significantly involved in providing patient care at home.
- Health-care professionals directly involved in care and medicines management.

Workstream 3: stakeholder workshops

- Health-care professionals (including study participants).
- Representatives from national, regional and local voluntary groups, third-sector groups and patient and public involvement groups.
- Academics and educators.

All participants had relevant direct, personal, professional and/or research experience of medicines management. They were aged ≥ 18 years and able to give informed consent with the exception that patients lacking such capacity could be included subject to consultee agreement.

Analysis

Interviews and discussion groups were recorded with permission. The software package NVivo 12 (QSR International, Warrington, UK) was used to facilitate a thematic analysis of anonymised transcribed interview and focus group data based on the principle of constant comparison. The case study analysis triangulated different data sources, including baseline and follow-up interviews with patients, family caregivers and health-care professionals; observation of consultations between patients/family caregivers and health-care professionals; field notes; photographs of medicines in the home; and review of case notes;

and patient-centred ecograms depicting individual networks of care and informal support. A detailed narrative summary and composite ecogram was undertaken of each case using a structured template to facilitate cross-case analysis. Each data set was subjected to both separate and integrated analysis to enable identification and comparison of themes occurring within and between professional interviews and patient cases. Coding and analysis were ongoing throughout the study.

Ethics approval

NHS Research Ethics Committee approval was obtained in March 2017 (reference 17/EM/0091) and for two subsequent amendments to allow an increase in the sample size for workstreams 1 and 2 and to include the option to seek consultee advice in relation to research involvement of patients lacking capacity.

Patient and public involvement

The study has been supported by the University of Nottingham Dementia, Frail Older and Palliative Care Patient and Public Involvement Advisory Group. Members have discussed and commented on the study design, ethics issues and findings and have submitted written reviews of the final report.

Results

Participants

Twenty-one interviews were completed with bereaved family caregivers (15 women and six men). Thirteen of the patients described in the bereaved family caregiver interviews had a primary diagnosis of cancer, although multimorbidities were common and a wide range of conditions were represented. Reflecting on the high incidence of cancer in this group, the majority ($n = 16$) of patients in the bereaved family caregiver accounts had been in receipt of specialist palliative care. Forty health-care professionals, who came from a variety of professional roles from community and specialist palliative care services, took part in individual or group interviews. Twenty patient case studies were completed, each of which included between one and five participants (total $n = 48$). Fifty-four interviews were completed with patients, family caregivers and health-care professionals. Eleven observations were carried out and ecograms were completed for each case. Photographs were taken in 13 cases and a medical records review was completed in eight cases. Patients had a wide range of conditions and comorbidities, including heart failure, chronic obstructive pulmonary disorder, diabetes, motor neuron disease, renal failure and Parkinson's disease. Five patients had a primary diagnosis of cancer. Two end-of-project stakeholder workshops took place in Leicester and Nottingham in June 2019.

The work of managing medicines

The study findings have documented the considerable effort required by patients and family caregivers in carrying out the complex work of medicines management for serious illness. This tended to intensify as the patient's illness progressed, especially in the last months and weeks of life. Families varied in terms of their circumstances and composition, and in relation to the resources that they could mobilise through their informal and professional networks. Patients gradually relinquished responsibility for managing medicines to family caregivers, usually to one key individual, with some tasks delegated to others (e.g. collecting prescriptions from the pharmacy). The key family caregiver was usually a spouse, in the case of couples, or an adult son or daughter, in the case of patients who lived alone. Primary family caregivers who were spouses tended to be old and affected by frailty and poor health themselves. Problems with prescribing and accessing medicines were frequently reported by lay and professional participants, especially in critical situations and those arising out of hours.

Patients and family caregivers described the effort and anxiety involved in taking on the responsibility for managing complex medication regimens, and making judgements about administration dosage when the limits to their coping strategies had been reached, and when they needed to call for additional help and support. Control of pain was a frequent concern and not always achieved. Families commented that, although there were lots of resources and information available, they were not often pointed at these resources and often had to find information themselves. The family caregivers often found themselves in an ambiguous position. On the one hand, they desperately sought clarity and confidence in managing medicines, and ready access to help when critical situations arose. On the other hand, they felt frustrated when professionals failed to acknowledge their expertise, particularly their knowledge of the patient, the nature and severity of their symptoms, and how they responded to specific drugs.

The professional interviews revealed the considerable efforts and resourcefulness that health-care professionals could bring to bear in addressing issues of medicines management for terminally ill patients, especially those affected by disadvantage. They also reveal the extent to which professionals often had a limited awareness of the burden of treatment confronting families and the difficulties that they encountered, particularly in accessing help during a crisis.

System and complexity

Families developed more or less elaborate and personally effective systems for managing medicines and recording use. Patients and family caregivers varied in the extent to which they felt supported by professionals and services with which they interacted. The development of a strong relationship with a key professional was an important (but not sufficient) determinant of a positive experience of care. Although broadly appreciative of the care that they received from an NHS that they perceived to be under-resourced and under strain, lay participants described an experience of services that was often bureaucratic, task focused and poorly co-ordinated. Patients and family caregivers described taking on the role of a care co-ordinator, maintaining vigilance in their dealings with professional services and the medicines that could be prescribed, and changed, by different health-care professionals. They maintained and communicated up-to-date information about the patient's medicines and tried to fill in the gaps in interprofessional co-ordination and communication.

The quality of relations and communication between professionals could have a critical impact on families' experience. It was important to feel known within the system, but this was not achievable when patients saw a range of different professionals without continuity. This increased the difficulties of communication with and between health-care professionals. Problems and delays in accessing services, and problems of communication between and with professionals and services, were frequently encountered and criticised. Families who had worked out stable systems of medicines management were vulnerable to changes in prescribing or service provision, over which they had no control. Particular points of hazard were transitions to and from hospital and during the cascade of care, which often occurred during the last weeks or days of life when families' coping mechanisms were stretched beyond their capacity. Variations in family resources and responses to extending responsibility for administration of medicines in the home raise questions about the limits of what family caregivers could and should be asked to do, and how professional support can be tailored to individual preferences and circumstances. In this context, the largely unacknowledged role of home health-care workers in supporting medicines management at home, especially for patients living alone, will become increasingly critical in future.

The nature and function of small-world networks seemed to be a key determinant of the quality of experience of communication and care by patients and their families, rather than organisational properties of the system. The efficiency of transfer of information between staff and services was also crucial. Several bottlenecks were described, including delays in specialist clinicians communicating with general practitioners, lack of integration between systems of electronic records used by different parts of the system, and lack of information available to out-of-hours clinicians and community pharmacists. Hospices sometimes provided a nexus of care in which patients might attend outpatient consultations,

day care services and receive home visits from specialist nursing staff. The availability of a 24-hour hospice-based advice line was also highly valued by the few participants who knew about or had access to it. The existence of an efficient relationship between the general practitioner and the pharmacist was an important determinant of family experience of accessing medicines. The pharmacist's role was usually confined to supplying prescribed medicines and participants found their home delivery service valuable. However, both professional and lay participants identified problems of supply and access to medicines, especially controlled drugs and when out of hours.

Conclusion

The Managing Medicines study has documented the work involved in managing medicines at home for patients approaching the end of life as a core part of a considerable burden of care. In this respect, it adds considerably to the available literature on this topic, particularly through the case study triangulation of professional, patient and family caregivers' perspectives, and the narratives of bereaved family caregiver's experiences of the period leading up to the patient's death. The findings reveal the resourcefulness of many participants in developing routines and schedules of medicines management and the process of gradually working things out as they grappled with the confusion and impenetrability of a complex, fragmented and bureaucratic system of care. They also highlight the extent to which families struggled with different tasks and stages of illness, particularly in the weeks and days prior to the patient's death. The difficulties caused by complexity, the need for specialist palliative care for dying patients and their families 24 hours per day, 7 days per week, and the value of a key professional to help families navigate the system have been widely reported over a considerable time. NHS policy has been directed towards developing effective solutions and a clear vision of streamlined, supportive and co-ordinated care. Integrated care remains a long-term goal, and the commitment to providing access to support for terminally ill patients 24 hours per day, 7 days per week, is well established. Translating this vision into reality remains elusive, but must surely be based on an understanding of patient and family caregivers' experiences and perspectives of illness, and what is most valued in the provision of excellent health care.

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