Modelling of intended & ideal medication management processes for palliative care symptom control: an international scoping review

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Aim: To model existing evidence for intended/ideal medication management processes in symptom control practices for adults at home, in hospital and hospice settings.

Background:

UK health policy documents commit to improving equitable access to personalised well-coordinated palliative care.

The UK Health and Care Act 2022 places a statutory requirement for Integrated Care Boards to commission palliative and end of life care services.

Palliative care focuses on quality of life of patients and families who are facing life-limiting illness. This often involves using medications for symptom control.

Medication-related events are reported in 19% of NHS serious incident reports involving palliative patients, mostly in patient homes, with half when specialists were not involved.[1]

Methods: Scoping review using JBI methodology.[2]

- Population (P): (i) adults in the last phase of life, (ii) informal carers supporting those adults, (iii) healthcare professionals providing symptom control.
- Concept (C): multistep processes for medication use for symptom control in palliative care.
- Context (C): all care settings where palliative care may be anticipated, planned or happen.

Systematic searches in Medline, CINAHL, Embase, Google scholar and Google images. No date limits; English language only.

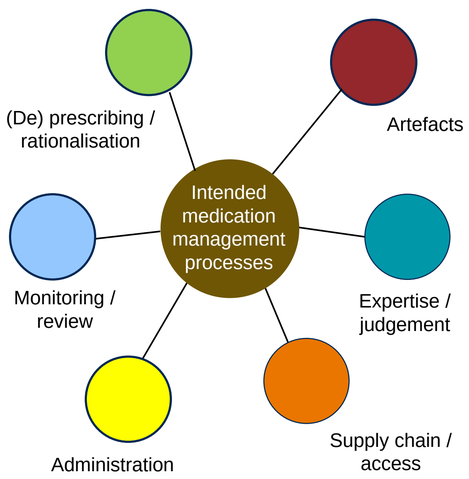
Published and unpublished literature meeting the PCC criteria included. Data screening and extraction performed by two independent reviewers. Studies categorised inductively and results collated descriptively.

Results

19,753 titles/abstracts screened; 929 underwent full text review; 308 peer-reviewed and grey literature documents retained to build the model. Most of these (212; 69%) named process steps (without practical detail) involving expertise/judgement, supply chain/access, administration, (de)prescribing/ rationalisation, monitoring/review. The remaining 96 papers warranted richer thematic analysis. Most studies were set in the UK, Australia or USA in home/community settings.

Analysis identified much ‘hidden work’ (participants’ actions in medication management), ‘hot spots’ (problematic areas such as out-of-hours care and the reliance on carers) and ‘cold spots’ (areas with less attention such as whose responsibility for keeping carers informed of changes and what is adequate support for safe medicines use at home).

Figure 1: Intended processes when palliative medications are prescribed and used for symptom control – what happens on paper



Regulatory frameworks clinical guidelines, education and guidance documents, patient/carer self-management documentation (e.g. symptom scales), medication administration charts, prescriptions (FP10s and electronic), medications (including pre-filled syringes, crisis packs, anticipatory medication), labelling, administration equipment (e.g. CSCIs), storage including controlled drug cabinet and locked boxes,

Multidisciplinary team, patient choice, involving families/carers, who does what? Contextual factors, work culture, attention to detail (knowing what has been tried before, reasons for stopping), discussion of risks/benefits, negotiations, safety netting opiates (dose adjustments, switching medications, rules), language/terminology, out-of-hours practice. Socio cultural beliefs about medication. Self-medication.

Pharmacist oversight to medication management processes, core palliative medication stock lists in local pharmacies, routine availability of symptom control and anticipatory medication, and administration equipment where and when needed, efficient supplies with prescription changes, managing security and diversion risks, affordability of medication (free at point of access/insurance coverage/affordability).

Complex medication regimens: dosage forms, routes, use of CSCI. Who is administering: professional/family carer – international variation in practice/perceived acceptability. Access to community-based staff for administration of injectables. Managing risks – interruptions. Carer anxieties about assessing need, appropriateness of medication, risk of overdosing. Co-ordination between different caregivers.

Medication regimen complexity. Positive culture of opioid safety. Feedback loop, evaluation, individualised care. Organisation, teamwork, advocacy. Roles, responsibilities, dynamics and documentation. Explanations to patients/carers/colleagues. Role of attitudes, beliefs and expectations. Understanding legal/ethical issues. Carer burden associated with managing medication and responding to symptoms.

Specialist knowledge: optimising medication regimens, conversions/off-label use/drug compatibilities. Prescribing opiates: managing stigma/myths. Decision-making in context of concurrent disease / reversible acute causes of deterioration. Non-medical prescribing. Anticipatory prescribing. Interdisciplinary discussion and involvement of patients to reach deprescribing decisions. Effective disposal/returns.

Figure 2: Additional features identified to support an *ideal* model of prescribing and medication use in symptom control in palliative care

Access to 24h drug information service with palliative expertise: medication choice, administration techniques, off-label use, information gaps. Guidance to support patients/carers with medication use, administration and individual advice.

Pharmacists with palliative expertise as a resource for patients/carers/other care providers. Roles & relationships between prescribers/non-prescribers and generalists/specialists. Support for carers with micro decisions in medication management.

Shared information with community pharmacies to proactively plan for palliative patient and carer needs. Addressing inequities: neighbourhood variation in availability of palliative medication and controlled drug delivery services.

Acknowledge symbolic significance of decisions about medication. Support carers re: concerns about potential medication errors. Expand options for carer involvement e.g. whole system approaches to carer-led subcutaneous administration of medication.

All pharmacies to have a stock supply of basic palliative medications to understand/support urgent need/ practical challenges/pre-emptive prescribing. Routine access to specific palliative medication management support for carers.

Routine availability of shared records across patients/carers, professionals and care settings. Delegation of care while retaining responsibility for medication. Pharmacists’ availability to contribute to medication decision-making. Transition management.

Discussion

There is growing interest in how people can best to work together across boundaries to enable getting the right medication to the right person at the right time and place. This scoping review documents the existing evidence of intended processes and a model of ideal prescribing and medication use in symptom control in palliative care. Using ethnographic methods and the conceptual tools of Activity Theory[3], we are currently deepening and refining understanding of hidden work, hot and cold spots with a study of what happens in practice[4] to build a theoretically-informed, empirically-evidenced model of medication management across palliative care contexts. This will facilitate the development of meaningful solutions to current challenges that are situated in the problems of practice i.e., based in work-as-done rather than work-as-imagined[5].

References

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