University of Southampton

Improving access to medicines to support palliative care at home: challenges and opportunities

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CONTEXT

More than half a million people die each year, and many live with a life expectancy of less than a year at any one time. The number of people needing palliative care is set to rise by at least 25% in the next two decades. It is estimated that improved recognition of palliative care needs and services outside hospital could enhance care and reduce hospital costs by £180 million per year.

Medicines play a critical role in patients’ ability to manage symptoms, including pain, at home, with the help of informal carers and health professionals. Good symptom control prevents unnecessary patient and family suffering, and reduces burden on the health service through avoiding unplanned and emergency use of services, including A&E attendance and hospital admission. Currently, in the last year of life patients typically experience three emergency hospital admissions, equating to 1.6 million admissions, costing the NHS £2.5bn.

Palliative care symptoms can change rapidly and patients and carers are often emotionally and physically vulnerable. This creates an urgent need for rapid, efficient and effective access and supply of medicines into the home.

Yet evidence suggests prescription, dispensing, supply and information about medicines are experienced by patients as often difficult, complex, demanding, lacking co-ordination, and involving a multiplicity of health professionals.

Relevant UN Sustainable Development Goals

3 GOOD HEALTH AND WELL-BEING

FINDINGS AND IMPLICATIONS

1. Over-reliance on GP prescribing and under-development of nurse prescribing is inefficient and causing delays

For many patients, GP services remained the main route for access to new prescriptions, and yet - in the context of a declining GP workforce and rising patient demand - they were often associated with burdensome and delayed access. Most specialist nurse prescribers considered themselves very competent, and prescribed frequently for patients, who valued the information specialist nurse prescribers gave them. They also co-ordinated services for patients. We estimated that costs for GP prescribing services for end-of-life patients are approximately £30 million more expensive than a nurse specialist prescribing service over a 5 year period. Additionally, we found that GP services may be associated with higher costs in terms of patients’ planned and unplanned hospital admissions and visits than a nurse prescribing service. Yet less than a half (42%) of specialist nurses and only a quarter (27%) of generalist community nurses were trained to prescribe. **More nurse, and potentially pharmacist, prescribers delivering palliative care are needed to speed and simplify access to medicines for patients in the last year of life.**

> “The chemist said, ‘oh well we’ll have to get another prescription it could take four or five hours for a doctor to phone you’. We came back and phoned [Clinical Nurse Specialist] and within 20 minutes she had another prescription… and gave us a choice of places to go and collect it.”
>
> **Carer**

> “…Ringing up the surgery in order to speak to somebody about getting meds is an absolute nightmare…”
>
> **Patient**

2. Co-ordinating access is time-consuming and burdensome

Significant co-ordination was required to access medicines: communication with numerous health professionals, in different parts of the health care system, against a backdrop of urgent medicines need. Co-ordinating access was undertaken by health professionals and / or patients and carers, and was often overly lengthy and burdensome, and sometimes caused distress. Co-ordination was a response to deficiencies in the access chain: hard-to-reach GP prescribing services, and community pharmacies whose stock of medicines was unreliable. Effort and time spent in co-ordinating access would be reduced if more nurses were able to prescribe directly to patients, all health professionals were able to access shared electronic records, and community pharmacy stock was more reliable (see below). **A named responsible co-ordinating clinician or single point of access could reduce duplication of work across health professionals, and act as a single point of contact for both patients and health professionals.**

3. Relationships support good access to medicines

Underpinning the co-ordination required to access medicines were pre-existing relationships between health professionals, patients and carers, and between health professionals in a locality. Relationships exerted traction on the access process, generating commitment to action and speeding the processes involved. In contrast, where relationships were absent, this hindered elements of the access process. There was also potential for greater awareness by some health professionals of each other’s medicines access services. Lack of awareness means signposting patients to such services, as well as health professionals’ own use of them, may be less than optimal.

As pressures on the healthcare system increase, and in the face of staff turnover, there is great potential for discontinuity, lack of inter-professional awareness and further fragmentation of care, which will be likely to increase the effort and length of medicines access processes. **Service commissioners and providers should promote inter-professional communication and awareness, as well as continuity of care wherever possible.**

4. Shared access to records and electronic prescribing systems is inadequate

Access to shared patient records to underpin decisions about medicines was a key area of health professional dissatisfaction; specialist nurses in particular were dissatisfied with their current access. Findings suggested that professionals’ access to records was a significant determinant of pain levels of patients on their caseload. Health care staff also identified this as one of the top four solutions to problems with current service delivery. Access to records when faced with a patient needing a medicine is essential for safe and accurate prescribing, which needs to be based on full knowledge of clinical and medicines history. The study also highlighted current inequity in access to electronic prescribing systems, with a majority of current nurse and pharmacist prescribers only able to issue handwritten scripts. The impact of this was nurses often referring back to GPs to prescribe - to ensure electronic transfer of scripts to pharmacy - thus delaying patient access to medicines.**Given the multiple system components involved in the medicines access process, streamlined cross-system communication through both inter-professional access to electronic shared patient records and electronic prescribing available to all, is critical to support timely access to end-of-life medicines.**

5. Community pharmacy, team integration and medicines stock

Findings highlighted problems with community pharmacy services supporting access to end-of-life medicines. Pharmacists were not integrated within primary and community care teams – for example, many pharmacists reported lack of awareness of patients’ palliative care status, limiting their ability to advise patients about medicines, and prescriptions from GPs did not always match medicines in stock, creating delays. Lack of reliable stock of the right medicines in community pharmacies was also a key finding, even sometimes at pharmacies commissioned to provide stocks of palliative care medicines. This caused work for both patients and carers and health professionals trying to source stock from other pharmacies, and delayed access and increased potential for distress. In addition, the time and work required by pharmacists to secure medicines from fragmented, remote wholesaler and distributor supply chains, was often unnecessarily onerous.

Community pharmacies specially commissioned to provide access to end-of-life medicines were often viewed as effective; but there were an insufficient number and uneven geographical spread of pharmacies in some areas, low awareness of services, variable medicines’ lists between and within services, and not all offered out-of-hours access. **Greater integration of community pharmacists within healthcare teams and provision of more universal and reliable stock of end-of-life medicines in community pharmacies will support access more effectively and equitably.**

RECOMMENDATIONS

Implement named end-of-life care co-ordinators (Finding 2 and 3)
Implement named end-of-life care co-ordinators, in line with current end-of-life policy, who can act as single points of contact for patients and health professionals, including initiating new or repeat prescriptions.

Prioritise training for more palliative care nurse specialists and community nurses to prescribe medicines to patients (Finding 1, 2 and 4)
Health Education England should make resources available to hospices and community trusts for prescriber training, in particular given hospice-employed specialist nurses' important contribution to patient care, and the potential benefits and cost-effectiveness of this service. Hospices and trusts should identify nurse prescribing as a strategic organisational priority, given its role in delivering efficient, effective services. Failure to do so will mean a continued over-reliance on more expensive and already stretched GP services, with associated extra costs, work and time delays in access to medicines.

Harmonise IT systems (Finding 4 and 5)
NHS Digital and local IT system suppliers need to work together to harmonise local IT systems so that all health professionals have access to shared electronic patient records across GP, community and hospice interfaces, including remotely in patients' homes. If health professionals continue with current levels of lack of shared access, this risks delayed or unsafe prescribing.

All prescribers, including nurses and pharmacists, working in the community require access to electronic prescribing systems, including in patients' homes. (Finding 2 and 4)
NHS Digital and local IT system suppliers also need to work together to reduce current inequities in professionals' access to electronic prescribing systems. Continued, enforced reliance on hand-written scripts will deter some professionals from prescribing directly to patients and / or cause unnecessary journeys to pharmacies for patients and carers at a distressing time.

Only 42% of specialist nurses and 27% of community nurses were trained to prescribe

Co-ordinating access to medicines involves numerous health professionals and is time-consuming and burdensome

Access to shared patient records to underpin decisions about medicines is unsatisfactory

Improve integration of community pharmacists into health care teams (Finding 4 and 5)
NHSE&I as well as Integrated Care Systems and Primary Care Networks, need to drive integration of community pharmacists within the wider community and primary healthcare team and allow pharmacist access to information about patients' palliative care status, with patient consent, via enhanced Summary Care Record or patient record access. Failure to do so will mean the potential of the community pharmacist workforce to contribute to good palliative care medicines access will continue to remain unfulfilled.

Commission standardised, equitably distributed community stocks of medicines (Finding 5)
NHSE&I and Integrated Care Systems should commission community pharmacy services for palliative care to provide a smaller, rationalised, commonly-agreed and widely-recognised core list of medicines, with greater and more even distribution of pharmacies or other community hubs holding stock which is also accessible out-of-hours, and able to be delivered swiftly and free-of-charge to patients' homes. Continuing with current provision is inequitable and inefficient.

Improve supply chain communication systems (Finding 5)
Engage pharmaceutical wholesalers / distributors with community pharmacists for two-way communication about practices that best support efficient, effective and equitable distribution of stock, particularly medicines in short supply. Re-consider appropriate skill mix in pharmacies and in the supply chain, to help free up pharmacist time to fulfil their potential in their professional, patient-facing role.

Invest in further research
Further investment in research is warranted to evaluate these and other new service developments to inform policy and aid local commissioner decision-making.

Relationships support good access to medicines

A majority of nurse and pharmacist prescribers are able to issue only handwritten scripts

Pharmacists lack awareness of patients' palliative care status, which limits their ability to advise patients about medicines

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