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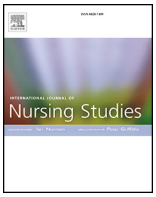

Access to palliative care medicines in the community: An evaluation of practice and costs using case studies of service models in England

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ABSTRACT

Background: Good patient access to medicines at home during the last 12 months of life is critical for effective symptom control, prevention of distress and avoidance of unscheduled and urgent care.

Objectives: To undertake an evaluation of patient and carer access to medicines at end-of-life within the context of models of service delivery.

Design: Evaluative, mixed method case studies of service delivery models, including cost analysis. The unit of analysis was the service delivery model, with embedded sub-units of analysis.

Setting: (i) General Practitioner services (ii) Palliative care clinical nurse specialist prescribers (iii) a 24/7 palliative care telephone support line service.

Participants: Healthcare professionals delivering end-of-life care; patients living at home, in the last 12 months of life, and their carers.

Methods: Within each case: Patients/carers completed a structured log on medicines access experiences over an 8-week period. Logs were used as an aide memoire to sequential, semi-structured interviews with patients/carers at study entry, and at four and eight weeks.

Healthcare professionals took part in semi-structured interviews focused on their experiences of facilitating access to medicines, including barriers, and facilitating factors.

Data on prescribed medicines were extracted from patient records.

Detailed contextual data on each case were also collected from a range of documents.

Patient, carer and healthcare professional interview data were analysed using Framework Analysis to identify main themes. We estimated prescription costs and budget impact analysis of the different service models. Data were triangulated within each case. Cross-case comparison and logic models were employed to enable systematic comparisons across service delivery types.

Findings: Accessing medicines is a process characterised by complexity and systems inter-dependency requiring considerable co-ordination work by patients, carers and healthcare professionals. Case studies highlighted differences in speed and ease of access to medicines across service delivery models. Key issues were diversifying the prescriber workforce, the importance of continuity of relationships and team integration, access to electronic prescribing systems, shared records and improved community pharmacy stock. Per patient prescription cost differentials between services were modest but were substantial when accounting for the eligible population over the medium term.

Conclusions: Experiences of medicines access would be improved through increasing numbers of nurse and pharmacist prescribers, and improving shared inter-professional access to electronic prescribing systems and patient records, within care delivery systems that prioritise continuity of relationships. Community pharmacy stock of palliative care medicines also needs to become more reliable.

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What is already known

- Patients and carers are often burdened by the experience of accessing palliative care medicines in the community. This process may involve multiple professionals and complex routes attaining medicines, particularly controlled drugs such as opioids.
- Limited evidence suggests there are problems with a number of aspects of service delivery concerned with access to palliative care medicines.

What this paper adds

- Experiences of accessing palliative care medicines in the community are frequently burdensome, requiring high levels of co-ordination work by patients, carers and healthcare professionals.
- Case studies revealed differences in quality and costs of service provision, and identified the key factors operating to moderate the access process.
- Recommendations based on the findings to improve access experiences include: diversifying and increasing the numbers of healthcare professionals able to prescribe palliative care medicines, whilst improving access to electronic prescribing systems, shared records and community pharmacy stock of palliative care medicines.

1. Background

Globally, it is estimated that 40 million people need palliative care every year, with access to care being especially important in the community, where many people are and wish to remain (WHO, 2018). Key to such services is access to essential medicines to alleviate suffering, including availability of opioids for pain relief (Payne et al., 2022). Patient and carer access to medicines when managing symptoms at home during the last 12 months of life (end-of-life) is critical for control of symptoms, including pain and distress, and for reducing urgent, unplanned use of healthcare services. However, limited data from previous studies (Lucey et al., 2008; Campling et al., 2017) has suggested that community-based prescription, dispensing, supply and associated information given about medicines involves a multiplicity of professionals and is experienced by patients as often difficult, demanding and lacking co-ordination.

Palliative care service provision in the community is characterised by diversity: in many countries it may include a combination of generalist (General Practitioners / family doctors, community nurses, community and primary-care based pharmacists) and specialist palliative care professionals. In England, provision is also characterised by a combination of state-funded (National Health Service) and third sector-funded services (for example, hospices and Macmillan Nurses), as well as prescribing of palliative care medicines by appropriately trained nurses and pharmacists.

Although international evidence (Ogi et al., 2021; Radbruch et al., 2014) is suggestive of patients and carers experiencing medicines access problems with traditional service delivery systems, including General Practitioner care, this has not been systematically investigated in-depth. Additionally, there are indications that critical sectors of the end-of-life workforce – palliative care nurse specialists and community pharmacists - are currently under-utilised. In an earlier small regional survey in England, Zeigler et al. (2014) noted there is potential to improve nurse prescribing in palliative care and also recommended further research into patients' views on this. But little is known about the impact of nurse prescribing on patient experience of access to medicines. In addition, community pharmacists' expertise in palliative care medicines optimisation has been found to be under-developed (Akram et al., 2012; Savage et al., 2013). There have also been other promising innovations in end-of-life care provision in England, such as community pharmacies specially commissioned to provide a stock of palliative care medicines and the availability of telephone advice lines out-of-hours. However, the impact of these initiatives on patient access to medicines, as well as their costs comparative to more traditional delivery models, remains largely un-evaluated.

The aim of this study was to provide an evaluation of patient and carer access to medicines at end-of-life within the context of current models of service delivery. This included investigation of patient and carer experience, as well as the contribution of the nurse and pharmacist workforce and an estimation of the costs of service models. The research reported here formed part of a larger study evaluating **Ac**cess **t**o **Med**icines for patients at end-of-life in the context of service delivery characteristics (**ActMed**) (project number 16/52/23) Protocol: https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/165223/#/

2. Method

2.1. Design

The study was designed with reference to a systems thinking framework, a perspective which acknowledges complexity, recognises involvement of a multiplicity of actors, an ever-changing context and that systems interact over time to create new patterns (Peters, 2014). In the national context in which this study took place, the process of accessing a medicine – defined here as prescribing, dispensing, supplying and providing associated information about medicines – necessarily involves a number of stages, processes and different healthcare professionals.

Evaluative, mixed method case studies of service delivery models, including cost analysis were utilised. The unit of analysis was the service delivery model, with embedded sub-units of analysis (see below).

2.2. Sampling

Service delivery models were purposively selected to ensure both established models (General Practice) and more innovative models (Clinical Nurse Specialist prescribing; out-of-hours telephone support service) of service delivery in England were included. Sample size was determined by analytical rather than statistical generalisability (Yin, 2014), based on achieving data saturation within the case.

Internal generalisability within each case was maximised by attempting to sample patients/carers that were representative of others in the case (Gomm et al., 2000). Prospective data from up to ten patients (and their carers, where appropriate) were collected within each case. Eligibility criteria for patients included: individual no longer receiving curative treatment; in receipt of prescribed medicines for symptom management; living in their own home or home of a relative; survival could be reasonably anticipated to be no less than 12 weeks; able to give informed consent; and able to speak and write English. Up to 40 patient records were sampled; these included those of patients taking part in prospective data collection. The remainder were sampled using a convenience approach from end-of-life registers at each site. Health care professionals were purposively sampled, using the criteria that they were currently providing end-of-life care within the service delivery case. For further details of sampling and recruitment, see Table 1.

2.3. Data collection

a) Patients/carers were asked to complete a structured log on medicines access experiences over an 8-week period from recruitment. Logs collected data regarding obtaining prescriptions and medicines both in and out-of-hours. They were an aide memoire to sequential, semi-structured face-to-face or telephone interviews with patients/carers on their experiences of medicines access at end-of-life. Interviews were conducted at study entry, and at four and eight weeks.
b) Healthcare professionals were invited to take part in a semi-structured interview focused on their experiences of facilitating access to medicines, including barriers, and facilitating factors.
c) Data on prescribed medicines were extracted from patient records for a period of eight weeks.

Table 1
Case study sample and recruitment within case sites.

General practice case	
The case	The unit of analysis was services where general practitioners were the main (usually sole) community-based prescriber, selected as representative of typical service delivery in England for palliative patients living at home.
Sampling	The case study included three general practitioner practices. Practices were sampled from 19 registered as the most research active practices in the local clinical research network.
Patients + Carers	Research staff in general practitioner practices searched the Gold Standards Framework register for eligible individuals. Re-searches for new listings were conducted monthly.
Healthcare professionals	*General Practitioners:* All general practitioners (31) practising in the three general practitioner practices were invited to take part in an interview. *Community Pharmacists:* The lead pharmacists in six community pharmacies (identified via NHS Choices website as the nearest pharmacy to each of the general practitioner dual-site practices) were approached. *Community Palliative Care Clinical Nurse Specialists:* Team leads for the geographical areas covering the general practitioner practices were asked to attend a focus group, alongside one other nurse specialist from each team. *Community Nurses:* The Head of Nursing invited community nurses from the Community Trust's teams who covered the general practitioner practices to participate.
Community palliative care clinical nurse specialist prescriber case	
The case	The unit of analysis was patients registered on the caseloads of community palliative care clinical nurse specialists who were qualified (V300 course) to prescribe medicines directly to patients ('independent prescribing').
Sampling	The case study centred on two clinical nurse specialist teams based in a city hospice. Clinical nurse specialist teams were purposively selected because of the high proportion of prescribers in the team (>80%).
Patients + Carers	Patients were required to be registered on a clinical nurse specialist caseload. Hospice research nurses searched clinical nurse specialist caseloads for eligible individuals and carried out repeated searches for new listings monthly.
Health professionals	*General Practitioners:* General practitioners for two patient participants were invited to take part. *Community Palliative Care Clinical Nurse Specialists:* Specialist nurses were approached via the hospice research nurse. *Community Nurses:* Community nurses for two participants were approached via the hospice research nurse. *Palliative Care Team:* Pharmacist and doctors were approached via the hospice research nurse.
Palliative care 24/7 telephone support line case	
The Case	The unit of analysis was a 24-h, seven day a week palliative care telephone support line. It was embedded within wider services (primary care, general practitioner out-of-hours, teams working in the community, hospice, and hospital), that provided video support/telemedicine services, with staff including experienced NHS nurses. Those providing the telephone support line service were supported by education, training, coaching and facilitation by specialists in palliative care, end-of-life facilitators and general practitioners with a lead role in end-of-life care.
Sampling	The case study centred on a single telephone support line selected because it represented an innovative model of service delivery in England.
Patients + Carers	In addition to the eligibility criteria, patients were registered with the telephone support line service (on a palliative care register, the Gold Standards Framework register) and had contacted this service at least twice. The service caseload was searched twice for eligible individuals, and those individuals who had contacted the service most recently were approached.
Health professionals	Healthcare professionals invited to take part were working with end-of-life patients in the telephone support line and wider services (e.g. community teams, hospices) in the geographical area commissioned by a single clinical commissioning group. They were identified by patients (as being key in their care) and snowball sampling.

d) Detailed contextual data on each case were also collected from a range of documents and sources. For example, in relation to the general practice case, data outlining service delivery specifications via practice were sourced, including staffing skill mix and numbers, list sizes, whether the sites were able to dispense medicines, level of primary care pharmacist involvement, indices of deprivation and the medical records system used.

Data collection occurred between March and December 2019, with all interviews conducted by NC and JB. All participants provided written informed consent.

2.4. Data analysis

Patient, carer and healthcare professional interview data were audio-recorded, transcribed and analysed using Framework Analysis (Ritchie and Spencer, 1994) to identify main themes.

2.4.1. Cost analysis

For each case, prescription services and the overall budget impact of these were costed. This entailed discussion with research team members to map out the typical or expected resources required for accessing a prescription per service model and valuing these by applying published unit costs (Curtis and Burns, 2019). A number of assumptions were required to enable the costing (e.g. on time taken for certain activities). We estimated the number of patients requiring palliative care services to be 239,822 based on the clinical commissioning group (commissioners of primary and community services in England) prevalence estimates. The total number of prescriptions required by this population was taken from Zeigler et al. (2017) (1,591,156) Assuming that 80% of prescriptions are repeats, we estimated that there are 318,231 new prescriptions and 1,272,925 repeat prescriptions per annum. We used these figures to estimate 1 and 5 year budget impact costs.

Data from each case were triangulated (via data source) to build in-depth understanding of medicines access experience in each delivery model. Following data analysis for each case, cross-case comparison was utilised for pattern matching and theory-building (Yin, 2014). Comparative evaluation developed through construction of logic models (Baxter et al., 2014) for each case and against a framework of indicators characterising good practice in medicines access derived from the larger study. Indicators included: speed of access; patient and carer burden (time, travel, cost, psychological distress) experienced; ease of use and comprehensiveness of information sources; and use of out-of-hours, unplanned or emergency services. The framework was used to evaluate each case and enable systematic comparisons across service delivery types.

2.5. Ethical approval

Ethical approval was obtained via NHS Health Research Authority South Central – Hampshire a Research Ethics Committee in February 2019 (REC reference: 18/SC/0675).

3. Findings

The findings are presented via case study (general practice case, clinical nurse specialist prescriber case, and 24/7 telephone support

Table 2
Case samples and data sources.

General practice case	
Patients	9
Carers	4
Total patients and carers	13
Community nurses	15
Community palliative care clinical nurse specialists	7
General practitioners	4
Community pharmacists	2
Total healthcare professionals	28
Overall total participants	41
Patient/carer interviews[a]	17
Patient/carer logs[a]	29
Healthcare professional interviews/focus groups	14
Patient record data extraction forms	26
Community palliative care clinical nurse specialist prescriber case	
Patients	11
Carers	7
Total patients and carers	18
Community palliative care clinical nurse specialist nurse prescribers	11
Community nurse leads	2
General practitioner	2
Palliative care consultant	1
Palliative care doctor	1
Hospice pharmacist	1
Total healthcare professionals	18
Overall total participants	36
Patient/carer interviews[a]	29
Patient/carer logs[a]	46
Healthcare professional interviews	18
Patient record data extraction forms	40
Palliative care 24/7 telephone support line case	
Patients	6
Carers	3
Total patients and carers	9
Telephone support line staff (10 registered nurses, 2 occupational therapists, 1 call handler, 1 telephone support line manager)	14
District nurse leads	7
Community palliative care clinical nurse specialists - inc. 2 independent prescribers	4
Community nurses	3
Palliative care support team - lead nurse	1
Palliative care consultant	1
Total health professionals	30
Overall total participants	39
Patient/carer interviews[a]	16
Patient/carer logs[a]	14
Healthcare professional interviews	12
Patient record data extraction forms	36

[a] Due to patient deterioration numbers of interviews and completed logs varied.

line case). Table 2 displays the participant recruitment (and associated data sources) for each case study.

3.1. General practice case

3.1.1. Patient and carer experience

3.1.1.1. Accessing medicines often felt like 'work'. Activities that patients and carers undertook to access medicines frequently felt like work. These included getting prescriptions (both new and repeat), liaising with community pharmacies or practice dispensaries for medicines to be dispensed and obtaining medicines via collection or arranging home delivery. Patients accessed new prescriptions via their general practitioner (requiring telephone consultations, and/or practice/home visits). But often recommendations for new prescriptions came from other healthcare professionals such as palliative or secondary care specialists. Where other healthcare professionals advised new prescriptions, patients were reliant on them contacting the general practitioner on their behalf, which meant a delay in medicines being prescribed by the general practitioner.

Where medicines were achieving good symptom management, general practitioners often deployed repeat prescriptions for patients. To obtain repeat prescriptions, patients and carers utilised different systems: 1) phoning their community pharmacy (who acted on the patient's behalf to request the repeat prescription from the general practitioner practice); 2) dropping off the repeat prescription slip to their general practitioner practice; or 3) online repeat prescription request systems. These varied systems were confusing:

> "…My husband was getting very confused and I was getting confused. Every time we went down [to the general practitioner practice] you saw someone different who told you, you had to do something different. They were saying about doing it online and then they were saying 'oh just drop it in the surgery'. 'Oh, get it from the pharmacy'…" (Patient2003, Study entry interview).

Patients and their families communicated with their community pharmacy, general practitioner practice dispensary, and in some cases hospital pharmacy (where patients were receiving palliative chemotherapy). Community pharmacies often contacted the patient or their family once medicines were available for collection (via email, text or telephone call), but equally, patients and families rang the pharmacies to check medicines had been dispensed before making the journey to collect them. Most patients were reliant on family members to collect medicines from pharmacies on their behalf, and where this was not possible, they arranged for home deliveries to be made.

Patient and carer experience was framed by accessing medicines from not just primary care but also secondary care and paid-for private care. They also accessed medicines alongside additional systems for supplying medical devices such as catheters, supplies for enteral feeds and/or home oxygen.

3.1.1.2. Difficulties accessing general practitioner practices. Part of the issue encountered by patients relative to the general practitioner being the main community-based prescriber were the difficulties they found accessing their general practitioner practice.

Patients spoke about having to listen to long recorded messages, needing to ring early enough in the day so that a doctor would be able to ring them back that same day, not being able to get through on the phone, waits of 20 min for calls to be answered, and not being able to see a general practitioner.

> "…Ringing up the surgery in order to speak to somebody about getting meds is an absolute nightmare…" (Patient1002, Study entry interview).

> Patient1001: "…Just supposing you want to ring the surgery to get an appointment you get this long message, go on the internet…terrible…
> Carer1001: It's all directing you to the internet, which they say we'll reply to you within five days. It's too long that…" (Study entry interview).

The issue appeared so severe that for patients in one of the practices they developed strategies to "*circumnavigate*" the system. They did so by visiting the practice in person, ringing a direct phone line for one of the reception staff and another used the mobile phone number of her general practitioner.

3.1.1.3. Navigating systems via trial and error. Only two patients and one carer spoke of feeling confident using the various systems needed to access medicines. Despite a lack of expressed confidence in this, patients and carers referred to things that they had learnt for themselves: leave as much time as possible when putting in a repeat prescription request "*not doing it the day before… trying to leave a lot of time*" (Carer2001, Study entry interview); and ring the pharmacy to check that medicines were ready to be collected (to prevent an unnecessary trip or having to wait in the pharmacy for the items to be dispensed). They learnt about their community pharmacy operations, such as when in the day their pharmacy received deliveries and therefore when to contact the pharmacy regarding a prescription in case an order with a wholesaler needed to be placed. They learnt to use a system that worked for them to stock manage/keep track of their medicines and recognise when they were running low. Lastly, patients and carers learnt to check medicines dispensed for errors, prior to leaving the pharmacy so that the items could be returned to stock if they already had enough of the medicine or the medicine was not the correct dose or form (to prevent medicines wastage).

> "…What I know now which I didn't know at the beginning is that once you walk out the pharmacy with it they can't do anything with it so… we always check it before we leave..." (Patient1002, Study entry interview).

3.1.1.4. Key healthcare professional. Most participants referred to a single community-based healthcare professional (usually the general practitioner, except for two of the seven where this was the palliative care clinical nurse specialist), who took the lead role acting as both an available point of contact and coordinating systems to facilitate access to medicines. These key healthcare professionals, and how much responsibility they took for this role, was central to patient experience. They were working to pull everything together, often going above and beyond for patients and their carers.

> "…I think the perfect service that we've had has been generated by the general practitioner to be honest because she's on it… Because you can't get an appointment at the surgery, you have to wait weeks and weeks when we're in with that three-week assessment Dr [name of general practitioner] makes the appointment herself there so that mum comes in [again] in three weeks' time… You could flag us up as the way the system really should work but it's all about the general practitioner…" (Carer2002, Study entry interview).

3.1.2. Healthcare professional perspectives

3.1.2.1. General practitioner main community-based prescriber but multiple advisors and allied activity. Although the general practitioner was the main community-based prescriber, they coordinated prescribing in response to requests from at least two other community-based healthcare professional groups: specialist palliative care (usually clinical nurse specialists) and community nurses.

> "…We need to be communicating with the doctor [general practitioner], the [specialist palliative care], because there are three different people putting input into this one prescription… there can be a bit of conflict…" (Community nurse group005–009).

The amount of work that healthcare professionals other than general practitioners did to facilitate medicines access was substantial. These healthcare professionals were also ensuring medicine access worked for patients following prescriptions being generated by general practitioners.

Community nurses spoke of "*taking on the problems*" for families (Community nurse group010-015), "*going above and beyond*" and "*picking up the pieces*" (Community nurse group005-009). Like clinical nurse specialists, they organised medicines for patients and carers; checking supplies in advance to ensure these were enough; phoning community pharmacies to source supplies; and collecting medicines where needed.

> "…The general practitioner writes the prescription and he'll write the medication [administration] chart [for subcutaneous administration] and that's it. That's his job done as far as he's concerned… It's joining up all that. The first thing my colleagues will do is: 'have you got this?', 'is this signed?'…You do go above and beyond because… we want to give that patient the medication at the time that they need it for their symptom control. And if that means us thinking, like on Twilight [until 10pm]: 'I'll just go to the chemist. We can't let the family…' I don't think it enters our head not to go..." (Community nurse group010-015).

> "…You ring them (commissioned pharmacies for palliative care) up and say: "oh, you're the nominated chemist"… and they'll say: "oh, we've got that but we haven't got that"... (Community nurse group005-009).

3.1.2.2. Prescribing and administration charts. General practitioners' completion of palliative care administration charts was raised by community nurses. Some teams spoke of having "*real problems with the doctors' prescribing*" (Community nurse group010-015). A commonly encountered problem was the incorrect completion of administration charts. This precluded community nurses being allowed to administer the medicines, due to a lack of signatures, no stated route for medicine administration, no dates or insufficient ranges for the medicines prescribed.

The duality of the system which required general practitioners to both write a prescription and complete administration charts for community nurses was perceived as unnecessary duplication by the general practitioner. It caused communication problems with community nurses and affected patient access:

> "…When you're co-ordinating [the team] you literally spend hours back and forward [to the general practitioner practices] with these charts which is a waste of time… For us to actually administer it… it has to be dated… we have to follow these rules and I know that's a bugbear for them and it must be a nightmare getting us ringing them up saying: 'Can you do it again?'… (Community nurse group001-004).

3.1.2.3. Lack of specialist palliative care input. General practitioners were critical of the overall lack of specialist service-related input (rather than that provided by individual clinical nurse specialists), and that the service was mainly weekday and advisory. Community nurses spoke of not having met the palliative care clinical nurse specialists because the specialist service was so "*stretched*". Most had only communicated with clinical nurse specialists regarding patients over the telephone, and although joint visits did occur, they seemed rare. For some each time they rang "*you seem to have a new name*" (Community nurse group010-015). This was important in facilitating medicines access because although community nurses found that clinical nurse specialists could not always get to visit patients, when they did, they often worked behind the scenes to smooth patient experience of medicine access and community nurses often found them, "*more responsive than the general practitioners*" (Community nurse group005-009). A lack of contact, and at times a lack of professional relationships between these specialists and other healthcare professionals, precluded best access to medicines for patients.

3.1.2.4. Lack of nurse and pharmacist independent prescribing. None of the palliative care clinical nurse specialists working across the general practitioner practices were prescribers and only one practice had input from a primary care-based pharmacist prescriber. Neither of the community pharmacists interviewed were prescribers and although some of the community nursing teams included matrons or integrated care leads with prescribing qualifications, they were rarely used in end-of-life prescribing. This was due to reduced patient contact through their managerial roles as service leads.

The reasons for lack of nurse and pharmacist prescribers included lack of awareness regarding prescribing qualifications and options (e.g. some community nurses were unaware that fully qualified independent prescribers could prescribe any medicines listed on the Drug Tariff, including Controlled Drugs). In addition, lack of funding and distance to courses were cited as issues for community nurse participants. However, healthcare professionals were supportive of nurse and pharmacist independent prescribing, and some were considering undertaking the qualification.

> "…I'm a huge advocate of nurse-prescribing/pharmacist-prescribing… They would probably do it rather better than doctors in some cases…" (General practitioner101, Practice 1).

3.1.2.5. Lack of access to shared records. Lack of access to shared records hindered medicines access (particularly best practice in relation to prescribing and associated interdisciplinary working). Community pharmacists were only able to access brief, summary patient details (Summary Care Record), community nurses had no access to specialist palliative care nurse records and vice versa, and the general practitioners could not view the community nursing or specialist palliative care records or general practitioner out-of-hours records.

> "…Palliative care nurses are on a different system… we have no access to their records… We can access general practitioner notes through CHI but not [for] out-of-hours…. You usually find [out] by ringing the patient, don't we... we go in blind a lot… you're always on the backfoot…" (Community nurse group001-004).

To summarise the findings from the case, a logic model was constructed highlighting how the mechanisms of actions arising from the characteristics of this service delivery model (General Practice) may be shaped by moderating and mediating factors to produce patient and service outcomes (Table 4).

3.2. Community palliative care clinical nurse specialist prescriber case

3.2.1. Patient and carer experience

3.2.1.1. Clinical nurse specialist prescribers eased medicines access. Accounts of the ease of the medicines access journey, from prescription through to receipt, varied between participants. Difficult experiences were often due to reduced support (gaps in the clinical nurse specialist workforce or the lack of overnight service provision) and the patient wishing to manage this themselves. However, most reported mainly positive experiences and were able to describe how clinical nurse specialist prescriber input simplified the prescription process.

> "…Yesterday I had a conversation with nurse [clinical nurse specialist] around at the hospice in relation to some medicines and she did it by way of email to the practice and the practice then emailed me or text me to say that it had been done and it will be ready for collection this afternoon..." (Patient0008 + Carer0008, Study entry interview).

Many patients described that they valued their clinical nurse specialist prescribing new medicines in the home that they could collect that day. In relation to repeat prescriptions patients explained how working with the clinical nurse specialist prescriber had accelerated access when: delays in the process had resulted in medicines being unavailable in patients' usual pharmacy, increased medicines were needed to cover holiday periods, and when prescribed medicines (or doses) were not effective.

Having a designated clinical nurse specialist prescriber with specialist palliative care knowledge who prescribed medicines speeded up access for the patient:

> Carer0010: "Three times, three prescriptions, they said they haven't got it [pharmacy]. 'When did you put it in?'… We must have put it in last week and loads and loads of time and three times they said, 'no we haven't got it in yet, it's not available yet'."
>
> Patient0010: "And I didn't have any."
>
> Carer0010: "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." (Study entry interview).

Alternatively, access was facilitated via clinical nurse specialist prescribers requesting general practitioner prescriptions:

> "…She'll send it through to the general practitioner practice who will then contact me and tell me that she's been in touch with them and that they have on her behalf prescribed and it's gone to the local chemist" (Patient0008 + Carer0008, Study entry interview).

They liaised with pharmacies to source medicines and provided information on how to obtain them, creating an access experience that is "*seamless; she deals with it and it's always ready the next day*" (Patient0012 + Carer0012, Week 4 interview).

Clinical nurse specialists facilitated access by using their knowledge of specialist end-of-life medicines and availability of local pharmacy services, to liaise with pharmacies to source appropriate medicine and then re-prescribe for the patient in a timely manner. This was particularly valued where issues had occurred.

Patients and carers encountered few negative issues with medicines access - where these existed, they related to initial, minor or infrequent problems that were often addressed by their clinical nurse specialist who also helped ensure patients did not encounter subsequent issues.

3.2.2. Healthcare professional perspectives

3.2.2.1. Clinical nurse specialist prescribers only prescribed when faster than a general practitioner script. Clinical nurse specialists' activities followed a process, first assessing patients' symptoms, existing treatment plans, and what patients could cope with, to make a treatment plan. They checked patients' nominated pharmacy for stock (if there was no stock they rewrote the treatment plan for alternative medicine or contacted other pharmacies), provided information to the patient, wrote a prescription or sent an electronic request (in some cases an email, phone call) to the general practitioner to prescribe.

Clinical nurse specialists' decisions to prescribe new medicines depended on how quickly the prescription was needed. If the medicines were needed urgently and a family member or friend was available to collect from a pharmacy with stock, then clinical nurse specialists prescribed on a separate script for each item (to broaden choice/use of various pharmacies). Crucially, if no family member was available, the patient was able wait for a delivery and the medicines were available at the nominated pharmacy it was quicker for a general practitioner to prescribe via electronic transfer.

Clinical nurse specialists who reported more difficulty in accessing general practitioners than others typically undertook more independent prescribing, particularly if based in urban locations with a wide choice of pharmacies to collect from. This clinical nurse specialist described how her assessment considered factors that would enable the swiftest access:

> "…Depending 1) on who the general practitioner was, 2) what day of the week it was we'd make a decision whether I would ring the general practitioner and discuss it with them and ask them to prescribe or whether I chose to prescribe it myself. So often the decision to prescribe it myself is usually speed of access so for instance yesterday I went to see a lady… she'd been vomiting all night, she was distressed so it was easier for me to do the prescription … I rang the chemist and they had it in so Dad kindly went and got it so she got her symptom relief really quickly..." (Clinical nurse specialist018).

Although clinical nurse specialists typically transferred responsibility for repeat prescriptions to the general practitioner, they wrote repeat prescriptions where they judged access would be speedier for the patient (e.g. exacerbation of symptoms, impending weekend/Bank Holiday, stock unavailable at usual pharmacy).

3.2.2.2. Lack of electronic nurse independent prescribing. The shared electronic patient record did not have a function for nurses to prescribe electronically and this meant they were not able to prescribe from their base. They were only able to hand a paper prescription to the patient. Electronic prescribing would have enabled them to send the prescription direct to the pharmacy speeding access to a delivery or collection of medicine. Clinical nurse specialists typically said:

> "…Electronically… would be so much easier… handwriting a prescription is time consuming..." (Clinical nurse specialist008).

The findings from this case, including details of moderating and mediating factors, are summarised in a logic model in Table 4.

3.3. Palliative care 24/7 telephone support line case

3.3.1. Patient/carer and healthcare professional perspectives

3.3.1.1. Single point of access aids navigation. The telephone support line team worked with community, hospital, and hospice services to resolve medicine access issues that patients contacted them about. Their activities typically included: co-ordinating a prescriber home visit (or request to a general practitioner/nurse prescriber/hospital medic to write prescription); liaising with community pharmacies and hospital dispensaries to source medicines and arranging home deliveries. The telephone support line selected a route to prescription that was fastest and most convenient for each patient, considering the issue, availability of carers, time of day, geographical location and availability of services. In addition, telephone support line staff were able to work proactively with patients who were vulnerable or isolated, reminding them to take medicines:

> "…He was saying he had too much pain… because he'd not been taking his medication… so then we were prompting him to make sure he took his pain relief..." (Healthcare professional group1).

Patients used the telephone support line to obtain a home visit or practice appointment resulting in diagnosis of symptoms and ensuing prescription; few had used it more than once for medicines access but envisaged further use nearer the end of their life. They expressed confidence that the telephone support line would navigate services for them when the need arose.

Healthcare professionals reported that patients valued fast, simple and consistent 24-h access to the telephone support line.

Their co-ordination was particularly valuable out-of-hours when patients' usual services were closed. Healthcare professionals appreciated the difficulties patients experienced in navigating services, particularly out-of-hours and that the telephone support line removed this burden by contacting appropriate services on their behalf:

> "…If people run out of medicines out-of-hours then [telephone support line] will be able to help them because it's hard for patients to navigate the system isn't it, and to know who to ring if their surgery is closed … that was one of the principles that patients could ring… and [telephone support line] would support them without asking them to phone multiple other people..." (Palliative Care Consultant002).

The telephone support line team arranged access to usual or out-of-hours general practitioners for new or repeat prescriptions when patients phoned with escalating symptoms, and provided advice about how to best utilise existing medicines whilst waiting for the prescriber:

> "…Well say a patient was ringing [telephone support line] they can see on the SystmOne all the medicines they're on and all the repeats they're on so they could give advice on medicines. They probably just do what we do [clinical nurse specialist team] but they can be there for out-of-hours as well and get hold of general practitioners..." (Clinical nurse specialist028).

They also addressed patients' medicines access issues calmly and with confidence to avoid distress:

> "…I do think we… shield the patients from the issue because… if you've got a… patient… exhibiting symptoms the last thing you want to hear is somebody go, 'oh you haven't got any medication, well I don't know what we're going to do'. So… it's, 'leave it with me and I'll give you a call back'… And then there will be lots of work done in the background…" (Telephone support line nurse001).

Despite the value of a single point of access telephone support line staff occasionally struggled to contact community nursing teams via the system. The telephone support line needed to request CN visits and queued for a single point of access operator to connect with the relevant service; additionally, single point of access operators sometimes failed to pass on the messages they received. This delay reduced the effectiveness of the telephone support line in enabling patients to access a nurse who could prescribe or contact a general practitioner for a prescription.

3.3.1.2. Access to shared records. The telephone support line was able to access patients' medical records for each service where the patient was registered. These records were essential for recording and checking relevant clinical history (e.g. types and dosages of medicines prescribed, co-morbidities and allergies, carer information, services accessed) and allowed healthcare professionals to plan next steps in co-ordinating services to access medicines:

> "…We've got SystmOne right across secondary care, community, the hospice use it, the general practitioners, the out-of-hours general practitioners. So, we've truly got a single record. And everything is in the EPaCCS, so all the care planning, so we know where to look and everybody is contributing to that same record and that same care plan…" (Healthcare professional group1).

The telephone support line used the "task" instant messaging feature of the patient record to request input from other services (e.g. tasks a general practitioner to request prescription or home visit,) and also from other telephone support line staff (e.g. nurse tasks a non-clinical call handler to delegate an appropriate duty related to that patient). Tasks became part of patients' clinical records and provided details of what work needed doing and what had already been done with specific patients and aided planning, co-ordination and follow-up of medicines issues.

Patients had agreed that their clinical records for each service could be shared so each of the telephone support line, hospital, hospice and community services had sight of it and could enter information. They were aware this enabled the telephone support line to consider the complexity of their condition to co-ordinate the best service to meet their needs; additionally, it reduced the need for a lengthy explanation of the patient's condition reducing patient/carer distress. This also meant more timely and accurate communication of information between patients, families and healthcare professionals:

> "…You don't have to go through the rigmarole of explaining everything. They've got your records there; they can see clearly what's going on. So, yes, it's a really good service for somebody in my position..." (Patient0001, Study entry interview).

3.3.1.3. Lack of nurse independent prescribing and/or electronic prescribing. There was a lack of nurse independent prescribing in the more rural areas of the region. Where the hospice provided the clinical nurse specialist service, only two were prescribers. The telephone support line team reported that having more prescribers in community teams (community nurses and specialist nurses) would provide wider access to prescribers, reducing waiting times for a general practitioner, particularly in remote areas.

There were some nurse independent prescribers (three) within the telephone support line team, however, they could not prescribe directly to patients. Clinical nurse specialists could prescribe via paper but not via the electronic prescribing system. For both clinical nurse specialists and telephone support line staff access to electronic prescribing system would have facilitated faster access to medicines for patients.

> "…If (telephone service) had the facility [electronic prescribing] as well [as us] because like I say some of them are starting…to do the prescribing that would make it a lot better. I could do that in the house because I can get on remotely, if I could send that remotely to the chemist in somebody's house knowing that it's going to get delivered that day..." (Clinical nurse specialist026).

The findings from this case, including details of moderating and mediating factors, are summarised in a logic model in Table 4.

3.4. Cost analysis

Estimated prescription costs per patient and for the population at 1 and 5 years are in included in Table 3. The assumptions for these costs are included in Appendix I. Costs for new prescriptions ranged £60–£91 and were more or less equivalent for repeat prescriptions. Although these costs were modest, there were substantial differences when accounting for the eligible population over a 5 year period with a £70 million differential between cheapest (Clinical Nurse Specialist Prescriber case) and most expensive (Telephone support line) services. There was around a £30 million difference between standard care (General Practice case) and the cheapest service (Clinical Nurse Specialist Prescriber case) over 5 years.

Table 3
Estimated prescription costs.

	Total cost per prescription	1-Year cost for patient pop.	5-Year cost for patient pop.
General practice case			
New prescription	£79.50	£25,299,140	
Repeat prescription	£19.00	£24,184,610	
Total cost		£49,483,750	£231,241,485
Clinical nurse specialist prescriber case			
New prescription	£59.97	£19,083,024	
Repeat prescription	£19.00	£24,184,610	
Total cost		£43,267,634	£202,193,082
Palliative care 24/7 telephone support line case			
New prescription	£91.05	£28,975,661	
Repeat prescription	£24.43	£31,099,641	
Total cost		£60,075,302	£277,133,957

4. Discussion

Drawing on a systems thinking framework enabled data on multiple medicines access processes to be captured, drawing on the perspectives of the various actors involved (general practitioners, clinical nurse specialists, community nurses, pharmacists, patients and carers), and spanning different sectors of the health service in England (primary care, community care, hospice-delivered services and community pharmacy). Findings confirm that accessing medicines is a process characterised by complexity and systems inter-dependency, not only due to the various stages, processes and actors involved, but also because these cross the boundaries of private-public healthcare provision: non-NHS hospice care, community pharmacy and the commercial sector in the supply chain (see also Campling et al., submitted). Data also showed patients were accessing medicines and medical supplies from other sources, not just primary care, but secondary and private, paid-for care too. This contributed to the considerable co-ordination work required of patients, carers and / or healthcare professionals, and was played out against a clinical context of rapidly changing symptoms, including pain and often accompanied by emotional distress, creating an urgent need for supply of medicines into the home.

There were differences between service delivery models in the extent to which they were operating to support timely patient access to medicines. The traditional model of general practitioner services as the main prescription provider had limitations; this needs to be seen in the context of such services being over-stretched, with declining general practitioner numbers nationally (NHS Digital, 2019) and increased demand. Clinical nurse specialist prescribers reduced the burden of access work on patients and carers, provided good information about end-of-life medicines and services, with fewer apparent delays experienced by patients in acquiring medicines. Nevertheless, this model was not operating to its full potential, due to clinical nurse specialist prescribers' lack of access to electronic prescribing systems. The telephone support line model also appeared to offer advantages by being available as a single point of contact at times of need, particularly out-of-hours, shifting the work of access off patients and carers, and using shared records and access to a local network of healthcare professionals' services to speed the access process. However, patient data in this site was limited and further research is required on out-of-hours telephone support services to support these findings.

Across the cases, the systems complexity of the medicines access process was associated with a number of key features which operate to modify or mediate the impact and ultimately the outcomes, of the medicines access process (see Table 4). Where prescribing authority was invested in a single professional group (general practitioners) delays to access were likely due to the time required for other professional groups to contact the general practitioner and the subsequent demand on the general practitioner acting as a focal point for all prescribing requests. Therefore, a more distributed model of prescribing is required. England is currently one of only three countries worldwide where post-basic nurses are able to prescribe from a full national formulary of medicines (Stewart et al., 2021). However, the global growth in nurse prescribing and recognition (Payne et al., 2022) that availability of essential palliative care medicines, including opioids, is a core component of palliative care internationally, mean all countries need to consider diversifying the number of professional groups able to prescribe palliative medicines directly to patients. Solutions are needed to address the lack of funding and employer support that act to limit the numbers of nurses actively prescribing in this area (Latter et al., 2020). Findings also suggest that this will only be effective however, if all professional groups have equitable access to electronic prescribing systems and shared patient records. The telephone support line site in particular illustrated that full access to shared records was an important prerequisite to healthcare professionals' ability to speed access processes. Whilst these findings emanate from service delivery models in England, this issue is likely to require consideration across a wide range of contexts where multiple professionals provide palliative care, including facilitation of access to medicines. For example, the vast majority of participants across 27 European countries in Payne et al.'s (2022) Delphi survey on international palliative care service delivery standards also agreed on the importance of access to information transfer (95%) and shared access to digital health records (97%) as a core standard for palliative care services.

The often significant degree of co-ordination required to access medicines was apparent within all case sites. Characterised as a complex systems process, inherent in the logistics of accessing medicines was the need to communicate with numerous different healthcare professionals, operating in different sectors of healthcare delivery, against a

Table 4
Case sites: logic models of findings

Key	
	Green text = positive factors, impact or outcomes Red text = negative factors, impact or outcomes

GENERAL PRACTICE CASE

Service Delivery Characteristics	Mechanism of Action	Moderating and Mediating Factors	Patient and Carer Impact	Service Outcomes
• Secondary care-based specialist advises changes to medicine type, dose or quantity of medicines required	• Out-patient appointment letter to general practitioner surgery, advises change in prescribing based on specialist knowledge	• Specialist knowledge of end-of-life medicines • Undertakes recognized patient assessment & treatment plan • Specialist does not undertake prescribing role themselves	• Specialist review and recognized plan • Slow access to new prescription (days or weeks)	• Less costly than hospital prescription and dispensing • Demand on general practitioner – must coordinate prescribing on advice of others
• Clinical Nurse Specialist (or other palliative care specialist e.g. medical consultant) advises changes to medicine type, dose or quantity of medicines required	• Sends an email/electronic task to the general practitioner, and usually follows this up via phone, advises change in prescribing based on specialist palliative care knowledge	• Specialist knowledge of end-of-life medicines • Contacts patient & carer regularly to review • Undertakes recognized patient assessment & treatment plan • Clinical nurse specialist does not undertake prescribing role themselves	• Specialist review and recognized plan • Slower access to new prescription	• Burden on clinical nurse specialist in contacting general practitioner (time consuming) • Demand on general practitioner – must coordinate prescribing on advice of others
• General practitioner prescribes changes to medicine type, dose or quantity of medicines required (based own assessment of patient)	• Prescribing based on own assessment of patient	• General practitioner electronic access to shared patient records • General practitioner access to electronic prescribing and transfer of prescription to pharmacy • General practitioner may lack expertise in prescribing palliative care medicines	• Quicker access to prescriptions • If lack of expertise in prescribing these medicines, efficacy of symptom control may be lowered	• Coordination of prescribing by general practitioner • If lack of expertise risk of unplanned service resource use heightened
• General practitioner provides information to patient/carer on medicines, checks & modifies understanding of previously received information	• Informed patient/carer able to understand & manage medicines needed for symptom control • Informed patient & carer able to recognize more speedily when new medicines are required	• May contact patient & carer regularly to review • Limited time in appointments/visits for information giving	• Informed self-management of medicines • Greater confidence & less anxiety about medicines • Improved symptom control • Contact general practitioner as soon as new medicines are required • May lack key information giving by general practitioner	• May reduce unscheduled requests for assistance/less demand on services • Improved symptom control where information provision adequate
• Clinical Nurse Specialist if involved may navigate medicines access systems on behalf of patient/carer e.g. checks stock of local pharmacies	• Pharmacies with in-stock medicines identified in advance	• Clinical Nurse Specialist knowledge of local services • Local pharmacies with stock of end-of-life medicines • Local pharmacies with out-of-hours opening • Free pharmacy home delivery service	• Less time, distress and burden spent visiting pharmacies with no stock of prescribed medicine • Quicker access to dispensing and supply of prescribed medicines	• Reduced inappropriate contacts/demand • Improved symptom control • Fewer unscheduled hospice/hospital admissions for symptom control

CLINICAL NURSE SPECIALIST PRESCRIBER CASE

Service Delivery Characteristics	Mechanism of Action	Moderating and Mediating Factors	Patient and Carer Impact	Service Outcomes
• Clinical nurse specialist prescribes changes to medicine type, dose or quantity of medicines required	• Prescribing appropriately in the home reduces patient/carer time & burden associated with contacting general practitioner for prescription	• Contacts patient & carer regularly to review • Undertakes individualised patient assessment & treatment plan • Specialist knowledge of end-of-life medicines • Clinical nurse specialist prescriber electronic access to shared patient records • Clinical nurse specialist prescriber inability to directly use Electronic Prescription Service • Family member (or other) required to deliver	• Quicker access to prescriptions • Less time & burden spent on contacting general practitioner • Less time, distress and burden associated with trying to contact out-of-	• Reduced demand on general practitioner • Reduced time spent by clinical nurse specialist prescriber contacting general practitioner • Less costly than general practitioner prescription (new prescriptions)

(continued on next page)

Table 4 (*continued*)

		prescription to pharmacy	hours services • Improved symptom control	• Reduced demand on out-of-hours medical services • Reduces demand on accident & emergency • Fewer unscheduled hospice/hospital admissions for symptom control
• Clinical nurse specialist prescriber provides information to patient/carer on medicines, checks & modifies understanding of previously received information	• Informed patient/carer able to understand & manage medicines needed for symptom control • Informed patient & carer able to recognise more speedily when new medicines are required	• Contacts patient & carer regularly to review • Specialist knowledge of end-of-life medicines • Specialist palliative care service contactable at any time	• Informed self-management of medicines • Greater confidence & less anxiety about medicines • Improved symptom control • Contact healthcare professional as soon as new medicines are required	• Reduced unscheduled requests for assistance/less demand on services
• Clinical nurse specialist prescriber provides advice to patient/carer on where and how to access medicines	• Informed patient/carer able to more accurately and speedily contact the right person and/or at the right time for medicines required	• Clinical nurse specialist prescriber knowledge of local services • Clinical nurse specialist service provision not available and responsive 24/7	• Less distress and burden associated with not knowing who and how to contact for medicines • Quicker access to prescriptions • Improved symptom control	• Reduced inappropriate contacts/demand
• Clinical nurse specialist prescriber liaises with/provides advice to the multidisciplinary team e.g. requests appointments and advises on prescriptions needed from the general practitioner, requests remote prescribing from hospice medical consultant, advises community nurses, requests district nurse visits and prescriptions	• Multidisciplinary team are targeted appropriately and prompted to respond to patient need for medicines • Community nurse/District nurse prescribers supported to prescribe out-of-hours	• Specialist knowledge of end-of-life medicines • Clinical nurse specialist prescriber knowledge of local services • Clinical nurse specialist prescriber and CN electronic access to shared patient records • Clinical nurse specialist prescriber inability to directly use Electronic Prescription Service • General practitioner services hard to access	• Less time, distress and burden associated with trying to contact multidisciplinary team • Less time, distress and burden associated with trying to contact out-of-hours services • Quicker access to assessment and prescriptions for the right medicines • Improved symptom control	
• Clinical Nurse Specialist navigates medicines access systems on behalf of patient/carer e.g. checks stock of local pharmacies	• Prescriptions adjusted to match local in-stock medicines • Pharmacies with in-stock medicines identified in advance • Separate prescriptions for different medicines issued to allow a number of pharmacies with in-stock medicines to dispense	• Specialist knowledge of end-of-life medicines • Clinical Nurse Specialist knowledge of local services • Local pharmacies with stock of end-of-life medicines • Local pharmacies with out-of-hours opening • Pharmacy home delivery service	• Less time, distress and burden spent visiting pharmacies with no stock of prescribed medicine • Less time, distress and burden spent requesting alternative prescriptions • Quicker access to dispensing and supply of prescribed medicines • Improved symptom control	
PALLIATIVE CARE 24/7 TELEPHONE SUPPORT LINE CASE				
Service Delivery Characteristics	**Mechanism of Action**	**Moderating and Mediating Factors**	**Patient and Carer Impact**	**Service Outcomes**
• Single point of contact • Accessible for patients/carers 24/7, 365 days of the year	• Call staff navigate systems to access medicines on behalf of patients, often out-of-hours • Onward referral (to community nurses, clinical nurse	• Clinical skills of call staff – palliative care knowledge (service supported by specialist palliative care consultants, and training provided) • Service backed by combination of clinical + technical information technology expertise • Comprehensive access to shared electronic healthcare records • Comprehensive awareness and interdisciplinary	• Provides out-of-hours access • Time, distress and burden of accessing other healthcare professional services, especially out-of-hours, removed from	• Co-ordination of services reduces burden of this on other healthcare professional services • Reduces demand on accident & emergency • Fewer unscheduled hospice/hospital admissions

	specialists and general practitioners for visits, phone calls or appointments) • Liaise with general practitioner out-of-hours services on behalf of patients • Service staff call pharmacies to source medicines and arrange access to a prescriber • Liaise with most appropriate prescribers and pharmacies close to the patient's home • Work with community pharmacies to check and reserve stock and request a prescriber either transfer the prescription to the pharmacy or writes paper prescriptions for families to take to the pharmacy • Provides information about medicines and proactively contacts patient callers who are vulnerable or isolated patients to check medicine-taking	working + links with all community and/or local services • Relatively dependent upon general practitioner services for prescriptions • Lack of nurse independent prescribers to access in the region (community nurses and clinical nurse specialists) • Difficulties accessing community nursing team via single point of access	patient/carer responsibility • Less time, distress and burden spent visiting pharmacies with no stock of prescribed medicine • Less time, distress and burden spent requesting alternative prescriptions • Quicker access to prescriptions • Informed self-management of medicines • Improved symptom control • Prevents escalation and unnecessary visits to accident & emergency • Prevents admission to a hospice or hospital out-of-hours for medicines for symptom control	for symptom control • Costs of service provision • Viability may be dependent on being part of a wider digital care hub service

backdrop of urgent medicines need. Co-ordinating access was undertaken by healthcare professionals and / or patients and carers. Whilst some degree of co-ordination and liaison will inevitably be required across interfaces, the work of coordination was often overly lengthy and burdensome, and sometimes caused distress. The work of co-ordination increased in the face of difficulties in the access chain, notably inaccessibility of general practitioner services (especially when they were the main prescribing service) and community pharmacies, when stock of end-of-life medicines was unreliable. Co-ordination was often hidden work; at the telephone support line service site, staff reported that the work required to supply an end-of-life medicine to a patient was often deliberately hidden to reduce patient distress. The hidden work of co-ordination has been observed in hospital contexts: Allen (2014) observed the invisible work of nurses as focal actors, creating a myriad of processes to sustain networks through which care was organised, often acting as a countervailing force to very loosely organised health systems. We suggest that the emotional and time-consuming burden of co-ordination work in the end-of-life context could be reduced with greater availability of multi-professional prescribers, who have access to electronic systems to support prescribing and dispensing processes, as well as ensuring more reliable community pharmacy stock of palliative care medicines. Whilst community pharmacy provision of palliative care medicines varies according to national contexts, this latter point echoes international calls for increased, local availability of opioids for palliative care patients for symptom control and relief of suffering (Radbruch et al., 2014). In addition, time-fraught co-ordination might be reduced through greater use of anticipatory prescribing of medicines over the last months of life; limited research in the US suggests the presence of a medicines ‘kit’ in the home can be effective for rapid symptom control (Ogi et al., 2021).

Underpinning the co-ordination work required to access medicines were pre-existing relationships between healthcare professionals, patients and carers, and between healthcare professionals in a locality. Where relationships existed, this exerted traction on the access process, generating commitment to action and speeding the processes involved. Such relationships were evident in that some general practitioners (general practitioner practice case) spent effort working outside usual systems to enable patients to stay in contact with them, clinical nurse specialists and telephone support line support staff contacted other known healthcare professionals in their local networks to initiate scripts or check stock. The importance of continuity of care for patients is internationally recognised, including at end-of-life (NHS Scotland, 2019; Hudson et al., 2019). We have found in this study that relationships (formed when care is continuously provided by the same individuals over time) support access to medicines. As pressures on the healthcare system increase, and in the face of staff turnover, there is great potential for discontinuity and further fragmentation of care, which will likely increase the effort and length of medicines access processes.

Differences in the estimated costs of prescriptions across service models were modest per patient but become substantial when accounting for the eligible population and beyond a one year horizon. Preliminary estimates of cost-effectiveness calculated as part of the larger study (Latter et al., in press) indicate different models may be associated with differing levels of effectiveness and resource use but further work is required in this area. Given the uncertainty in the analyses to date and the potential budget impact of these services, further research is warranted.

4.1. Limitations

Models of service delivery studied may not be representative of other countries' palliative care service provision. However, there is increasing evidence of nurse prescribing worldwide, including in not only high-, but also low- and middle-income countries (Stewart et al., 2021). Palliative care telephone support lines are a feature of care delivery in countries such as Taiwan (Lin et al., 2020) and the US (see Ogi et al., 2021) and are advocated as a core element of palliative care delivery internationally (Lin et al., 2020). In addition, we hope that the underpinning key issues surfaced from the service delivery models studied will have relevance internationally.

Patient recruitment was slightly lower than targeted in two case sites (general practitioner and telephone support line cases), due to lack of regular registration of patients on end-of-life registers and many not being cared for at home. Patient / carer completion of medication access logs and the target number of patient and carer interviews was less than planned in some instances, due to unexpected deterioration in some patients' health. Nevertheless, data saturation was reached in the general practitioner practice case. We did not recruit general practitioners or pharmacists to interview in the telephone support line case, and we suggest further research into telephone support line services would be of benefit. The cost estimates derived here are indicative and given that they are based on several assumptions, caution is required in their interpretation.

5. Conclusions

To our knowledge, this study is the first to provide an in-depth evaluation of medicines access using case studies of service delivery models which illuminated access processes embedded within a complex system. Findings highlighted where good practice is in operation, as well as components of the service system currently delaying access, causing unnecessary effort for many healthcare professionals, and increasing the potential for patient and carer distress when they were unable to obtain medicines in good time and with minimal effort. Experiences of medicines access would be improved through increasing numbers of nurse and pharmacist prescribers, and improving shared inter-professional access to electronic prescribing systems and patient records, within care delivery systems that prioritise continuity of relationships. Community pharmacy stock of palliative care medicines also needs to become more reliable.

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Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Professor Richardson is a National Institute for Health Research (NIHR) Senior Investigator. The views expressed in this article are those of the author(s) and not necessarily those of the NHS, the NIHR, or the Department of Health.

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Appendix A. Supplementary data

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