Getting palliative medications right

An activity theory analysis to improve patient safety and carer confidence

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SUMMARY OF FINDINGS

WHY DOES THIS MATTER?

The Health and Care Act 2022 made provision of palliative and end of life care a statutory requirement. By 2040, demand for palliative care in England and Wales is expected to increase by 25% to nearly half a million people per year.

About 1 in 5 NHS serious incident reports about palliative care involve medication. Patients, carers and healthcare professionals all experience daily hassles with medication and engage in hidden work to address gaps in the ways the system works for getting medication right for good symptom control.

WHAT IS THIS STUDY ABOUT?

We wanted to find out what is needed to improve patient safety and carer confidence with palliative medication in home, hospital and hospice settings.

Scoping review. We looked at nearly 20,000 pieces of published evidence. 212 of these named medication process steps without giving any practical detail. We used a further 96 to identify themes and active ingredients necessary for an ideal model of the system.
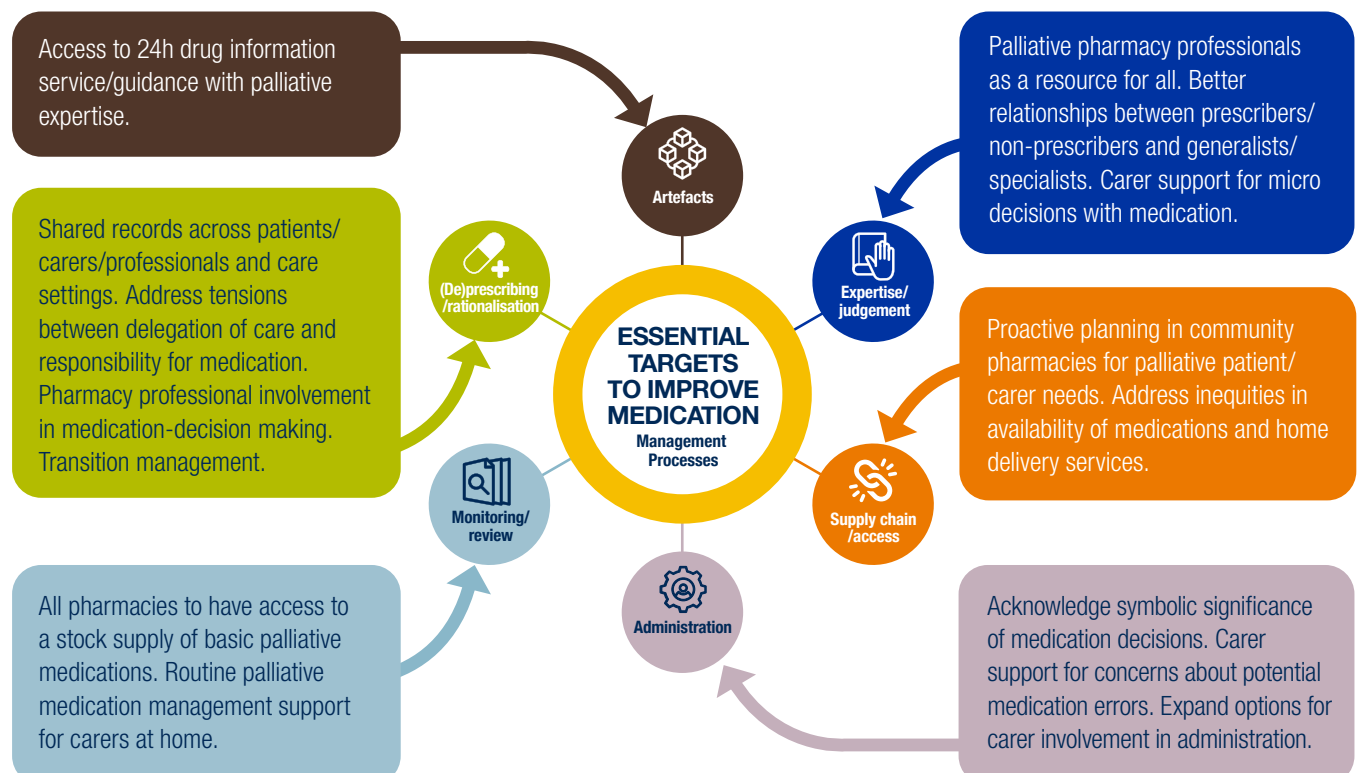
New data. We completed more than 120 hours of observations and 83 interviews with patients, carers, and professionals in home (community), hospital and hospice settings in London. Professionals included doctors, nurses, pharmacists, pharmacy technicians, discharge coordinators, rapid response teams, social workers, ambulance staff and service managers.

WHAT DID WE FIND OUT?

1 **We have created an interactive model of the multi-step tasks of prescribing and using medication in palliative care, representing the voices of everyone involved and highlighting essential targets for improvement. Please scan this QR code to view the model in full.**

Our analysis extends understanding of process disturbances and safety concerns at home, hospital and hospice, or when moving between places. It also illuminates 'hidden work' undertaken by people to enable good medication management.

Access to 24h drug information service/guidance with palliative expertise.

Shared records across patients/carers/professionals and care settings. Address tensions between delegation of care and responsibility for medication. Pharmacy professional involvement in medication-decision making. Transition management.

All pharmacies to have access to a stock supply of basic palliative medications. Routine palliative medication management support for carers at home.

Palliative pharmacy professionals as a resource for all. Better relationships between prescribers/non-prescribers and generalists/specialists. Carer support for micro decisions with medication.

Proactive planning in community pharmacies for palliative patient/carer needs. Address inequities in availability of medications and home delivery services.

Acknowledge symbolic significance of medication decisions. Carer support for concerns about potential medication errors. Expand options for carer involvement in administration.

ESSENTIAL TARGETS TO IMPROVE MEDICATION
Management Processes

- Artefacts
- Expertise/judgement
- Supply chain/access
- Administration
- Monitoring/review
- (De)prescribing/rationalisation

2 | **What aspects of the system require attention to improve safety and confidence? (More detail presented on pages 10-11).**

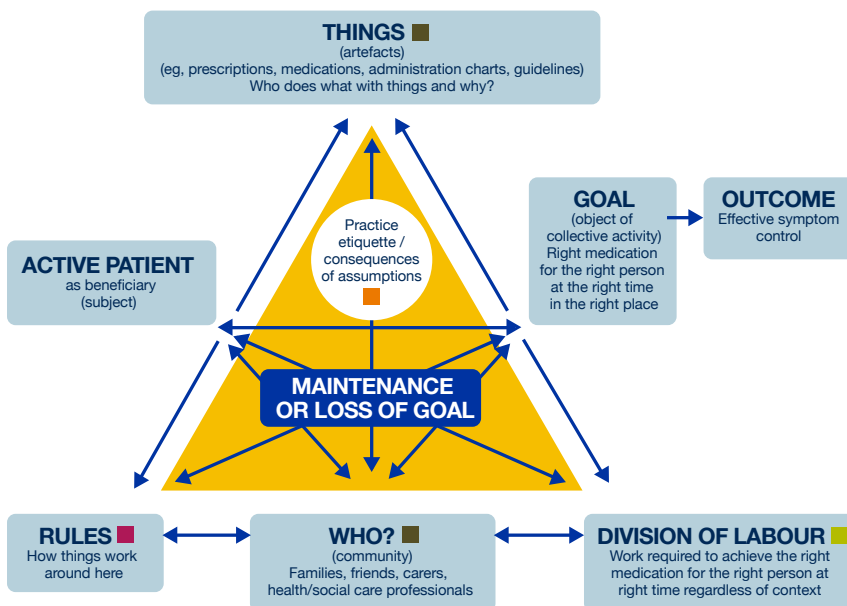🔴 **HOT SPOTS** Problematic areas with lots of attention

Lack of access to shared records

Community Medication Authorisation and Administration Record (MAAR) Charts

Hospital discharge processes

Use of controlled drugs

Syringe drivers

Getting medications to patients at home

🟢 **COLD SPOTS** Problematic areas with less attention

Co-ordination of all caregivers

Bringing patients and carers into the team

Untangling lines of responsibility / recommendations / delegation

Medication liaison work in transition

Professionals' experience / understanding of all settings

Functional feedback loops and reciprocal dialogue

Support around safe use of medications when carers involved at home

Practical and pragmatic workarounds (hidden work, space for informed improvisation)

Deprescribing

What to do with medication after death

3 | **System innovation and new forms of practice to improve care – how could it be done?**

People can only work effectively to a common goal when they share common understandings and practices. We used Activity Theory as a framework to help us understand what happens, who does what with which parts of medication processes including the tools they use, how formal and informal rules operate, and what occurs when a patient moves between home, hospital and hospice care.

THINGS ■ (artefacts) (eg, prescriptions, medications, administration charts, guidelines) Who does what with things and why?

Practice etiquette / consequences of assumptions ■

ACTIVE PATIENT as beneficiary (subject)

GOAL (object of collective activity) Right medication for the right person at the right time in the right place

OUTCOME Effective symptom control

MAINTENANCE OR LOSS OF GOAL

RULES ■ How things work around here

WHO? ■ (community) Families, friends, carers, health/social care professionals

DIVISION OF LABOUR ■ Work required to achieve the right medication for the right person at right time regardless of context

Effective symptom control is maintained or lost according to the key elements shown above, but achieving this can often feel like a 'rollercoaster ride'.

Hidden work: a carer's perspective

❝

… But those two boys [care agency workers] looked after my husband as if he had been their grandfather… they sorted the medicine… I was finding it quite difficult.

[The GP] gave me a prescription … But then, when I got there – deliveries weren't coming in that day. I mean… probably, three occasions… I ended up either having to call back at the pharmacy later, which was quite a walk or saying, "I will take the prescription, and go to another chemist"… it was a bit of a mess.

And then, [GP] said, "really you should go to this other chemist, [who] had this connection with [the hospice] and I think had a sort of very ready supply of whatever there was in that carrier bag.

… people at home couldn't believe how long it took me to get the medicines.

That was before he went to the hospital... when he came out, [they] had altered all his prescriptions… I had to queue for hours…. waiting and waiting [at the hospital pharmacy]… we had these morphine patches which you had to change. It was a bit chaotic. I kept them on the side in the kitchen. And every four hours, I looked at them and we gave them whatever we thought was necessary. I think one of them was twice a day and some of them were four times a day, … I was rather nervous of it.

(Participant 90, Carer)

■ division of labour   ■ rules
■ who does what, with what   ■ assumptions

❝ …if any of those [links] are disrupted or broken…it's quite significant to what that outcome might be, it might be [a] really serious consequence… a rollercoaster from any of them… in your mind you think to yourself 'oh that sounds like quite a straightforward process' but things happen so much more fluidly."

(Participant 76/77, Professional)

PALLIATIVE POSTCARDS

We have created 'Palliative Postcards' that highlight how we can draw on experiences of patients, carers and healthcare professionals to summarise better ways of working and develop evidence-based recommendations.

Please scan QR code to access palliative postcards in full. These could be used as a useful teaching aid.

A palliative postcard from...

"I flag things up to monitor the quantity that we prescribe and how often we are prescribing. I remove medication that is no longer being used. I notice if there are risks with medication in the home. I provide a useful loop to the GP and district nurses."
YOUR INTEGRATED CARE PHARMACY TECHNICIAN

We believe there are better ways of working to ...

• Plan services

• Get the right medication, at the right time, with the right support, in the right place

• Involve everyone who does medication management work

• Reduce rhetoric-reality gaps between policy-practice and expectations-experience.

We want to develop evidence-based recommendations that ...

• will help policymakers prioritise what matters most to patients and carers

• are practical for commissioners and funders to implement

• support healthcare professionals to deliver best practice

• provide solutions to help patients and carers to navigate healthcare systems

• work when people are in hospital, hospice or at home

"The best advice I can give is keep it simple, written down and organized. The hospice pharmacy gave us a chart with the name of each medicine, am/pm and what each medicine does."
A FAMILY CARER

"When I plan for discharge, I am thinking about who is at home? Where are they going to keep their medication? Are they going to manage it if they live alone? Who is going to be able to give it to them?"
AN EXPERIENCED HOSPITAL CLINICAL NURSE SPECIALIST

Where did this come from?
www.ucl.ac.uk/psychiatry/research/marie-curie-palliativ

"We did an audit and it seemed that anxiety about patients not having enough medication over the weekend was linked to the medications that were returned. We need to think about this!"
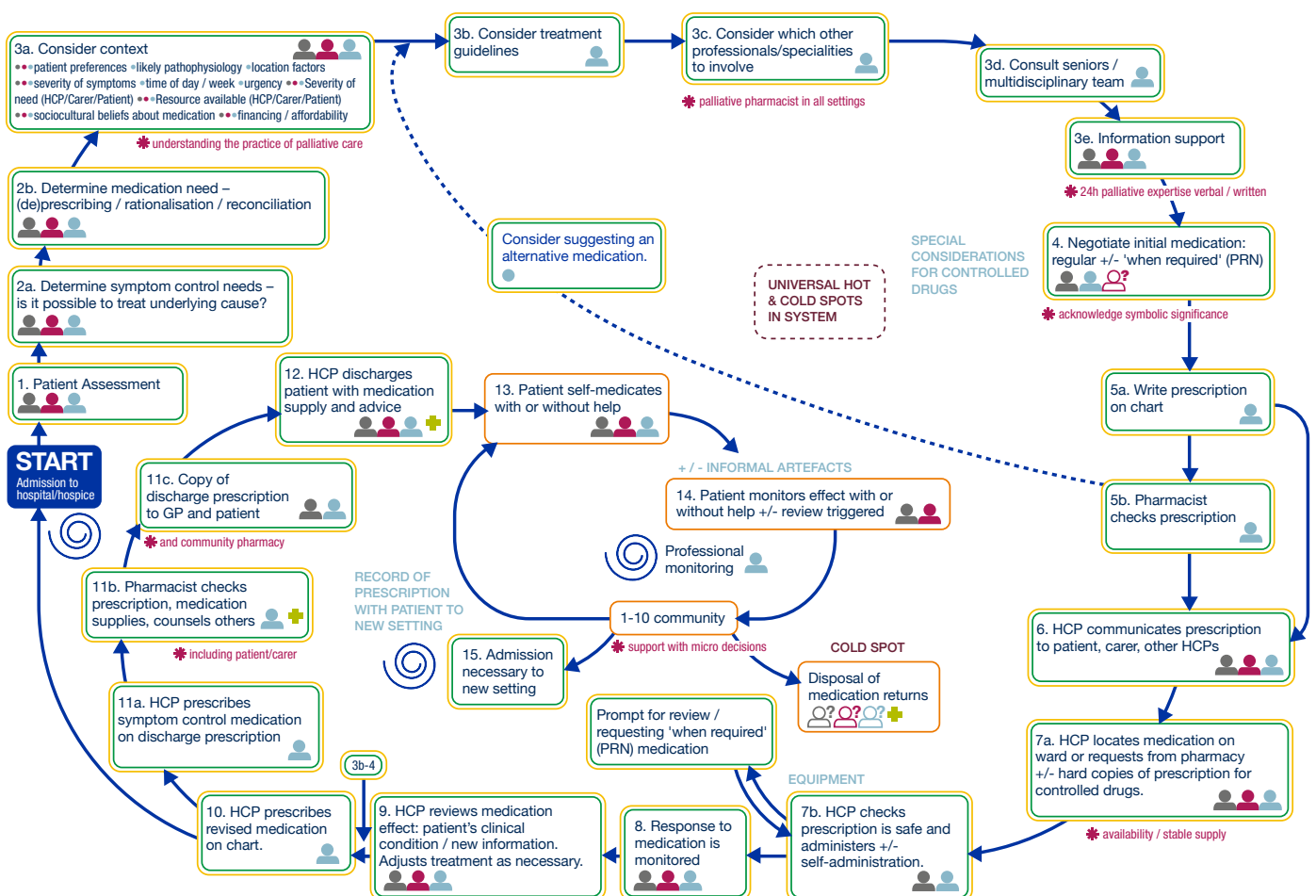A CONCERNED COMMUNITY PHARMACIST

Getting palliative medications right

UCL

Marie Curie

SPIRAL ◎ MODEL OF MEDICATION MANAGEMENT IN PALLIATIVE CARE

We asked participants to tell us about their experiences so we could identify the medication work undertaken by patients, carers and professionals. We mapped in detail the 'real-life' multi-step processes involved in managing palliative medication. This is a complex spiral model!

The spiral model starts at the point of admission to hospital/hospice and maps out all the activity involved in the medication journey for an individual patient. It shows the many steps that occur in an inpatient setting (steps 1-10), how these are repeated each time a new medication is started, and repeated in the community after discharge or when the loop starts again with a new admission. At each step, the model below draws attention to:

- Who may be involved (patient, carer, healthcare professional)

- When a pharmacy may be an essential place of activity

- What may be an important artefact or "thing" used in the medication step

- What may be an ideal add-on to the system that is not currently standard practice.

3a. Consider context
- patient preferences - likely pathophysiology - location factors - severity of symptoms - time of day / week - urgency - Severity of need (HCP/Carer/Patient) - Resource available (HCP/Carer/Patient) - sociocultural beliefs about medication - financing / affordability

✱ understanding the practice of palliative care

2b. Determine medication need – (de)prescribing / rationalisation / reconciliation

2a. Determine symptom control needs – is it possible to treat underlying cause?

1. Patient Assessment

START Admission to hospital/hospice

3b. Consider treatment guidelines

3c. Consider which other professionals/specialities to involve

✱ palliative pharmacist in all settings

3d. Consult seniors / multidisciplinary team

3e. Information support

✱ 24h palliative expertise verbal / written

Consider suggesting an alternative medication.

UNIVERSAL HOT & COLD SPOTS IN SYSTEM

SPECIAL CONSIDERATIONS FOR CONTROLLED DRUGS

4. Negotiate initial medication: regular +/- 'when required' (PRN)

✱ acknowledge symbolic significance

5a. Write prescription on chart

5b. Pharmacist checks prescription

12. HCP discharges patient with medication supply and advice

13. Patient self-medicates with or without help

+ / - INFORMAL ARTEFACTS

14. Patient monitors effect with or without help +/- review triggered

Professional monitoring

RECORD OF PRESCRIPTION WITH PATIENT TO NEW SETTING

11c. Copy of discharge prescription to GP and patient

✱ and community pharmacy

11b. Pharmacist checks prescription, medication supplies, counsels others

✱ including patient/carer

11a. HCP prescribes symptom control medication on discharge prescription

1-10 community

✱ support with micro decisions

15. Admission necessary to new setting

6. HCP communicates prescription to patient, carer, other HCPs

7a. HCP locates medication on ward or requests from pharmacy +/- hard copies of prescription for controlled drugs.

✱ availability / stable supply

COLD SPOT

Disposal of medication returns

Prompt for review / requesting 'when required' (PRN) medication

EQUIPMENT

10. HCP prescribes revised medication on chart.

3b-4

9. HCP reviews medication effect: patient's clinical condition / new information. Adjusts treatment as necessary.

8. Response to medication is monitored

7b. HCP checks prescription is safe and administers +/- self-administration.

KEY
- Medication journey
- Hospital
- Hospice
- Community
- ✱ ideal processes, not currently standard
- ABC Artefacts
- 👤 Patient
- 👤 Carer
- 👤 Healthcare professional (HCP)
- ✚ Pharmacy

IMPROVING SAFETY AND CONFIDENCE

Themes and patterns of medication work described by patients, carers and healthcare professionals

Getting palliative medications right required loops and spirals of activity. Patterns of work were described in the stories of patients, carers and healthcare professionals providing examples of how the system could work well. Activities were diverse and at times disrupted by unclear responsibilities, revealing targets for improving safety and confidence.

Identity and flexing

Individual professionals were adapting their roles to meet the needs of others in the system who required assistance with palliative medication management. These roles depended on perceived freedom to undertake 'how to get things done around here' work. Effective cross-boundary working and using skills complementary to others supported collaboration between professions and settings. By proactively seeking out opportunities to listen and contribute, effective patient care was prioritised.

> "
> I would rather say that I built my role…. it was a trial, it wasn't even a permanent role and they said they probably need help because …the DNs [district nurses], the medicines relating to DNs…, despite the learning they are doing, something might be lacking there… which I can help and support. So, they wanted me to trial that… I work quite closely with the GP practice. Some of the GP practice has a pharmacist, in-house pharmacist. I work quite closely with the MDT [multidisciplinary team]… and the Palliative Care team… in terms of working, I have no boundaries… and get the overall picture for the patient… sorting the medicines out… I work with the local Community Pharmacy Team as well, so it really helps that way."
>
> (PARTICIPANT 60, COMMUNITY PROFESSIONAL)

Sustained investigative work (checking and chasing, uncertain ownership)

Different parts of the system did not trust each other. Extra work was created by the need to check activity and the transfer of information between people and places. Constraints, such as office hours, and the lack of involvement of patients and carers because they were not considered 'members of the team', led to disruptions in the system.

> "
> One of the main things might be getting a prescription. From me writing to a GP to, say, we need some Oramorph. That's one part. But then the GP actually having that piece of information and that being... converted to a prescription is another big step; we have to get… admin to call multiple times during the day: have you received the email? Have you got it? Are you ready? Have you... yes, we passed [it to] the duty doctor… They then call back often for clarification; but then they may send that prescription to the pharmacy. But the pharmacy may or may not have it; the pharmacy might be shutting at six… the family can't get there… [If] the medication was an injectable medication, you then need [an] administration chart; GP may not do that… many links in the chain that may not be whole."
>
> (PARTICIPANT 06, COMMUNITY PROFESSIONAL)

Disempowerment by design

The system had unnecessarily complex rules and healthcare professionals had unclear or contested responsibilities. Information did not flow across the system in a timely manner. Workarounds by patients and families addressed service limitations. There were insufficient feedback loops to keep the system current. Everyone who needed to know about activity were not always informed. There were interruptions in the system as a result of ignoring its limitations with an over reliance on patients and family members.

"

But this was … literally around the corner, … when I did notice we were getting low… I would go onto my wife's email… ask for a new prescription from the doctors... And then I'd wait a couple of days… so I'd go round, sometimes it's in and I said but you've got my number, just phone... But they just say it's just around the corner… but again I couldn't really leave her on her own... Unless my son was there or a friend… because she was lying in bed, she could… like she eventually did, she fell down and that's how she's ended up here [hospice]."

(PARTICIPANT 81, CARER)

"

…you wouldn't necessarily know they're in hospital. And if you don't know they're in hospital, you are not looking out for a discharge summary... they're sent home, essentially with a kind of end-of life care pack… it's quite possible that we wouldn't know any of that until the discharge summary appears. [The family] often end up having to kind of scan it or photograph it and email it through to us... who's in control of that communication? …It's one thing to do the prescription, but how does the patient ever know that it's been done?... I think some way of making sure you're closing that loop, I think would be really helpful, because I think patients can feel very disempowered."

(PARTICIPANT 63, COMMUNITY PROFESSIONAL)

Transition inadequacy

Planning for discharge when clinical need may be unpredictable and rapidly changing was difficult. Linking activity between settings was hindered when one-way rather than two-way communication was used.

"

…we try and get them [prescription for discharge medication] written in advance. But… it's not really possible, there's always a lot of changes. We end up doing a lot of it the day before, the day of. There's a lot of CDs [controlled drugs] as well, so it's quite lengthy…. If they're on a syringe driver, they wouldn't be going home on it, we'd ask to make sure they're switching in time. But in terms of patients who will be discharged on meds, it's about letting the doctors know we need to prepare them... We would check in terms of them writing up. And then quantities, up or down, we generally advise on that, especially for all the controlled drugs, we have to set the quantities… So we have input for that kind of thing. So we have the discharge on [an electronic system], and then the paper, a community MAAR [medication authorisation and administration record] chart, that they have to give to district nurses… pharmacists don't check them, they're just written up by the doctors and then sent to them [district nurses]… which I find a bit odd."

(PARTICIPANT 27, HOSPITAL PROFESSIONAL)

Assumptions about assumptions

Relationships underpinned the perceived successes and problems associated with medication. These were between patients, carers and professionals, and professionals from different care settings. Underlying assumptions about how work is done in different settings and boundaried-work, were associated with interruptions in medication supplies when patients moved between different settings.

> " The last thing you want when you're going through cancer is to be a difficult patient to the people that are looking after you. She should have said 'I don't have it… I'm going to need to go to another ward'… What am I going to say? Even though I'm in agony what am I going to say? But to walk away and say, 'I'll be back' and then come back at twenty-five [minutes] to seven…"
>
> (PARTICIPANT 21, PATIENT)

> " I think when we send people to hospice, different hospices sometimes want us to send medication, sometimes don't want us to send medication so that's different to being at home… My mind is, well we've prescribed everything so of course it's going to happen [laughs]… "I cannot believe that they were sent home with nothing" or the drugs that were on the discharge summary didn't arrive, you know, I know sometimes patients don't get sent home with everything because there's an assumption that there are some medications that are already at home."
>
> (PARTICIPANT 03, HOSPITAL PROFESSIONAL)

Hidden work and responsibilities

Enabling the continuous supply of medication across the system involved 'hidden work' undertaken by patients, carers and professionals. Responsibility for medication when patients and carers moved between places was not comprehensive and went unchecked.

> " … the prescriber is the beginning stage, the actual taking of the medicine is the end stage, and how do you get to that in a safe and a supported way? Obviously, you are relying on the friends and the carers and the families to deliver that… [but] I think what we have is a gap in supporting people to be able to adapt to their medicines and understand them… there's something about when everyone is gone and you're left with them and you're like, so hold on a minute when do I take that? and can I take that with that one? and she said you can take that sometimes… we might then not see someone for two or three weeks. So what happens in between? … the instructions you would give are probably the instructions that you would give any patient … but there are subtle things, behaviour patterns, sleep patterns just what works, who's there, who do they trust, all those kinds of things that I think are a bit more, I think there's a role for someone to be doing that."
>
> (PARTICIPANT 02, COMMUNITY PROFESSIONAL)

> " … we try to pre-empt patients deteriorating and deteriorating out of hours…we've got everything in place, it's just a phone call to a district nurse saying syringe driver and that's it. Contrast to that with somebody's been referred late to palliative care …and they need injectables asap… sometimes unfortunately it doesn't happen… we can't get the script done in time, can't get the pharmacy… Either asking GP to quickly send it to the pharmacy, the pharmacy receiving the script and they're maybe closing at 5[pm] or not having the medication in stock… the healthcare team staying after 5[pm] ringing different pharmacies saying…. A) are you open till 7 or 8 and B) – do you have this medication in stock…? So that's a really huge amount of time… believe it or not, it's un-simple."
>
> (PARTICIPANT 49, COMMUNITY PROFESSIONAL)

Practice etiquette (how things work around here)

How the different components of the medication management system fitted together was influenced by the people in the system (patients, carers and professionals) and people's understanding of the workings of the system. This understanding was not universal and driven by relationships and, respectfully, not wanting to offend.

"
…we would almost certainly defer to [the palliative care team] on things like complex management, and we would then carry out their suggestions… we [also] discuss with the family why it is that somebody's become more drowsy, and what that means in terms of pharmacotherapy and what the rationale is… also what the risks are, and accepting that there are some risks… I think that the right medication and the right support… quite often I'm leading because I'm the known doctor… but I would always have expected to have a palliative care representative there, usually a consultant… how difficult it is with people not wanting to tread on each other's toes and not knowing who to involve, and how many people do I copy into this email about a decision that I'm making,"

(PARTICIPANT 08, HOSPITAL PROFESSIONAL)

"
I suppose the etiquette of when I prescribe, when I suggest medications, what I would feel comfortable stopping etc. will vary depending on which team… suppose it's thinking about – are the medicines that the patient is already on appropriate? Part of my role… is picking the right medicine for the patient, explaining or thinking about the side effects and communicating that to the patient, thinking about the route of the medicine – because we do use syringe drivers, continuous subcutaneous infusions…. With some nurses who aren't prescribers, it's them saying "look I can't get hold of the team, are you happy to prescribe?" Particularly if it's a syringe driver that's going to run out and the nurses need to have a new prescription."

(PARTICIPANT 09, HOSPITAL PROFESSIONAL)

Process disruptions and workarounds

When the system could not support what should happen, patients, carers and professionals used their knowledge to develop strategies to enable patients to receive their medication.

"
I control it by just getting pre-prescriptions."

(PARTICIPANT 74, PATIENT)

"
I rang up and spoke to the team and said "ok, I absolutely get it – is there no chance? The nurse I spoke with was fantastic and the CNS [clinical nurse specialist] said "actually, hearing all of this, let me jiggle around some things and I'll go out" – and she did. She made it work. That's where the direct, instead of just putting an email… That felt like a real win, but it was trickier than it should be, because you're trying to make sure that the community chart, the CNS, and everybody feels happy with what they're doing. Oh and we rang the GP as well to say, "this is what's happening", so that he could go out and see her before she died."

(PARTICIPANT 09, HOSPITAL PROFESSIONAL)

UNDERSTANDING UNIVERSAL SYSTEM HOT AND COLD SPOTS

Areas to target for improvement

Universal system hot & cold spots

Hot and cold spots are areas of the system that need continued research in order to improve safety and confidence. Hot spots were aspects that attracted a lot of interest and were frequently discussed. Cold spots were those areas of the system that we recognised as significant to participants, but received relatively little discussion and were frequently overlooked.

⬤ HOT SPOTS — Problematic areas with lots of attention such as out-of-hours care and the reliance on carers

Lack of access to shared records

Community Medication Authorisation and Administration Record (MAAR) Charts

Hospital discharge processes

Use of controlled drugs

Syringe drivers

Getting medications to patients at home

⬤ COLD SPOTS — Problematic areas with less attention such as who takes responsibility for keeping carers informed of changes in medication at home and what is adequate support for safe medicines use at home

Co-ordination of all caregivers

Bringing patients and carers into the team

Untangling lines of responsibility / recommendations / delegation

Medication liaison work in transition

Professionals' experience / understanding of all settings

Functional feedback loops and reciprocal dialogue

Support around safe use of medications when carers involved at home

Practical and pragmatic workarounds (including hidden work and space for informed improvisation)

Deprescribing

What to do with medication after death

System hot spots:

These were problematic areas which received a lot of attention such as 'To take away' (TTA) medication - a recognised part of the system that delays discharge from hospitals while waiting for medication to be dispensed. Last minute prescription changes and the high workload of hospital pharmacy departments were recognised as contributory factors.

" But, you know, if you're trying to get someone home very quickly, then obviously we all have to chip in and work together and do whatever we need to do really. But it's also then you know, too many people get involved then that also isn't always a good thing… people get very upset, delays, waiting for medications TTAs from pharmacy, I mean, it's always existed and probably always will, and then they can't move the transport... everything gets knocked back... but I also think it's quite hard to write TTAs when we keep changing things. Because if we keep changing things, there's no point doing it, a TTA."

(PARTICIPANT 24, HOSPITAL PROFESSIONAL)

● **Lack of access to shared records** was not simply about sharing a record or access to hospital/hospice discharge summaries. but included access to live GP medication records so that current prescribing decisions were available to everyone involved.

● Ensuring **Community Medication Authorisation and Administration Record (MAAR) Charts** were written up with a current prescription and were available in people's homes at the time medication is needed to be administered, were vital to ensuring clinical need could be met. Unavailability of MAAR Charts interrupted medication administration and was a source of anxiety to healthcare professionals who were restricted in their activities in people's homes.

Many different difficult aspects to ● **controlled drugs (CDs)** were raised by participants. Healthcare professionals were concerned about the ordering, storing, prescribing, administering, recording and destruction of CDs. Patients and carers focussed on the symbolic significance of CDs and keeping them safely at home. ● **Syringe drivers** were spoken about in terms of what happens when a patient is discharged from hospital – does the hospital syringe driver go with the patient or is a 'when required' dose of medication given for comfort when travelling and a community-based syringe driver found? Sufficient availability of syringe drivers in the community was a worry to community staff but not often considered by hospital staff.

● **Getting medication to patients' own homes** was not always easy for patients, carers and healthcare professionals. How did medication move from the pharmacy to home? Constraints such as a patient unable to collect, a carer unable to collect/unwilling to leave a patient unattended and the expectation that medication is present at home when a healthcare professional arrives to administer.

System cold spots:

These were problematic areas which received far less direct attention by participants but were noticed through observation fieldnotes such as what is adequate help for patients and carers to support effective and safe medication use, for patients and carers, whose responsibility is it for keeping carers informed about medication changes and how is shared decision making about medication achieved.

"

We had a patient who... was already deteriorating and then went home, lost her swallow.... the family weren't aware that that might have any impact… they never flagged up that she couldn't swallow medication…they didn't put the right red flags out. They [the staff] weren't aware that the family hadn't said the important words. "She's not swallowing anymore."

(PARTICIPANT 11, HOSPICE PROFESSIONAL)

"

We've haggled, arrived, fought, struggled... to some agreement… I had some very fixed ideas about what I thought I wanted, what I thought was best for me, how much I ought to dig myself in … so I had a good negotiating position. How stupid and pointless all of that was. How much more willing they were to actually accommodate all of my needs than I thought they'd be."

(PARTICIPANT 62, PATIENT)

● **Coordination of all people involved in medication** activity was not often discussed. The need and/or value of bringing the ● **patient/carer into the team** was not recognised. Taking the lead in liaising about medication between care settings and knowing who to contact was problematic. This was amplified when ● professionals did not know 'how things worked' in the other care settings – including the act of reviewing and stopping medication which no longer had clinical benefit.

At times, the healthcare professional making the prescribing decision was not necessarily in front of the patient administering the medication – ● **how do the lines of responsibility, recommendations and delegation get untangled?** ● **Feedback loops** in medication work and **live two-way discussion** were rarely identified – although if acknowledged, they were recognised that they could be helpful. Supporting the ● **safe use of medicines at home** was rarely mentioned in terms of carers' needs and/or reassurances of what to do if something went wrong. Yet healthcare professional involvement with medication demanded a heavy administration burden, and formal carers were often not allowed to become involved with any medication. Workarounds were not often discussed explicitly yet informed improvisations were observed In different settings such as leaving pre-filled syringes of medication out on saucers for ease of access.

● **What to do with medication no longer needed or after the patient had died** was ignored, including CDs. Returning medication to the dispensing pharmacy was not always convenient or welcomed. The process of medication destruction was not understood.

SYSTEM QUALITY INDICATORS

From the data, we created a set of evidence-based system quality indicators to support healthcare professionals to deliver best practice, and inform commissioners and policymakers what matters most to patients and carers. These indicators are based on the knowledge and experiences of patients, carers and healthcare professionals across home, hospital and hospice settings.

- Make it easier for **palliative care patients to nominate a carer** to act on their behalf regarding logistics and practicalities around medication management. All patients and nominated carers to be included as part of the palliative care team.

- All **patients** to receive a structured medication review and have shared decision-making conversations about deprescribing.

- Ensure **patients** have a call-back number to get medication-related problems sorted for 24-48 hours post-discharge from hospital/hospice.

- **Commissioners/policy makers** to work with local providers to increase real time dialogue for transitions (e.g. hospital discharge) and complex care handover – partly technology enabled (such as increased availability to work mobile phones for staff) and partly cultural change.

- **Everyone** in the system (irrespective of place of practice) including the patient/carer, to have access to live GP medication records and access to hospital/hospice discharge summaries. This is not the same as access to universal or electronic care plans. All prescribers to have access to live drug charts, i.e. Medication Authorisation and Administration Record (MAAR) Charts in the community on electronic systems.

- Train healthcare professionals to support **carers** through education initiatives regarding micro decisions about medication (e.g. deciding when to administer 'when required' medication), red flag symptoms and side effects, adapting to changes in medication, and carer-led administration of medication.

- Encourage **healthcare professionals** to rotate periodically to other locations and settings, e.g. hospice, hospital, and community. Commission **palliative care pharmacists** in acute hospital teams, hospice settings, and community services, and enable working across boundaries.

- All patients receiving medication for symptom control to have direct and regular access to a **pharmacist**, trained in palliative care. Identify **community pharmacies** working to the Royal Pharmaceutical Society Daffodil Standards and willing to deliver palliative medications to patients at home.

- **Set-up systems** so that availability of, and point of access to, 24/7 supplies of palliative medications is coordinated by professionals and shared with prescribers, patients, and carers. Consider systems to use hospital pharmacies as back up for community access out of hours.

- **Out-of-hours palliative care services** to deliver care using appropriately trained and experienced healthcare professionals. Create mechanisms for staff to be flexible around a patient's needs when dealing with a patient who is alone or only has one carer (e.g. not needing to leave a dying person alone to get medications).

- **All community and hospital pharmacies** to accept medication returns when someone has died.

WHAT HAPPENS NEXT

Practice

Patients and carers need to be supported to share their medication taking activities without fear of judgement, assisted to understand who the different professionals are that can help them, and be enabled to reach out and share information across different care contexts.

Policy

Systems need to be evolved to promote effective working across role, team, organisation and location boundaries. Finding mechanisms for two-way discussion in real time should be prioritised. A relational approach when collaborating with colleagues can lead to reduced overall workload and greater whole system effectiveness.

Further research

How do we best support patients and carers with the micro decisions of medication management at home (e.g.– When and how much 'when required' medication can I give? How do I know if they are in pain?)? What happens when carers find medication management too difficult? How can we improve everyone's understanding of the system (how the system works and who does what) to enable better care?

A palliative postcard from…

Dear Reader,
Just a note to remind us all that there will always be the last injection. I hope everyone understands the doses that we're using have been carefully chosen to give comfort, not to shorten life. A combination of being with someone dying, and when they are restless giving something that will relax them when we know the final hours are approaching, allows death to occur in a calmer way. This is what we can do to give them dignity, even when all else is past.

Speak soon,
A Community Clinical Nurse Specialist

Where did this come from?
www.ucl.ac.uk/psychiatry/research/marie-curie-palliative-care-research

Getting palliative medications right

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Dear Reader,
I was always trying to facilitate his living at home because he wanted to do that. And for me the red line was on the meds, if he gets that wrong, it's not safe, he shouldn't be on his own and I shouldn't even support it. It was chaos. The pills were going missing, there were packets of meds under this chair. He lost control.

Yours,
A frustrated accidental carer

Where did this come from?
www.ucl.ac.uk/psychiatry/research/marie-curie-palliative-care-research

Getting palliative medications right

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A palliative postcard from…

FURTHER INFORMATION

We have developed a number of resources from our research study

Palliative postcards: a series of 12 brief vignettes taken from the interview data that highlight a key message from a patient, family carer or healthcare professional. These could be useful teaching aids to give immediate access to the experiences of people involved in palliative care.

Stories: a series of 5 deep dive accounts from participants. These accounts offer a more detailed description of the micro decisions and daily hassles involved in medication management activity in palliative care. These could be useful as teaching aids and informing quality improvement strategies for service development.

- "I felt a bit like I was in an Agatha Christie story" [Carer]

- "…the ones that are a bit more mysterious to me actually are the key medicines" [Patient]

- "– a relationship of trust – so that we can bring about changes in their drugs and keep them on board with us" [Hospital Professional]

- "if the patient is in pain or the patient needs it, I personally won't walk out and say, "sorry, I've got to wait five hours" [Community Professional]

- "There's lots of liaisons between teams" [Hospice Professional]

Top tips for patient and carers and Top tips for healthcare professionals

These top tip sheets highlight what is good to know, what is important to share, what works well and who can help with challenges. These can be shared with those who receive care and those who deliver care. They can be used as conversation starters in care settings.

System quality indicators: These were developed for commissioners and policymakers to support their involvement in palliative care and provide goals for improving services.

Please scan here for copies of all resources from our research study.

Please contact Sally-Anne (**sally-anne.franics@ucl.ac.uk** or Sarah (**sarah.yardley@ucl. ac.uk**) for copies of resources, opportunities to get involved in our palliative medication research or to share your own feedback.

This Summary report can be downloaded from: **https://discovery.ucl.ac.uk/id/eprint/10192049/**

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A palliative postcard from...

Dear Reader,

You probably don't realise how many people we talk to when we're starting someone on medication. We're often talking to the nursing staff, the family, the patient, the doctor, pharmacy, some of the other AHPs. We might speak to Speech & Language, the dietician. When we can, we go and speak directly to colleagues – that is always gold standard.

Speak soon,
Hospital Clinical Nurse Specialist

Dear Reader,

Well, I brought the last lot of medication back to the hospital. I didn't know if I could or if I couldn't. I wasn't physically able to take them back to a local chemist. They hadn't been dispensed from the nearest chemist to me. When you have a lot of medication, if it could be collected or just information given about it. It would be very helpful.

A PUZZLED HOSPITAL PATIENT

Getting palliative medications right

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A palliative postcard from...

Dear Reader,

Mum was referred to the hospice and I asked about taking her medication. They said to bring everything that she uses every day. So I spent the evening before gathering my disparate notes. I went with her and handed over the medication, but I was really insistent, politely, that I needed to talk to the doctor. I knew that the chart that he would have wouldn't match. So I stayed there for about four hours, occasionally being like, "Do you think he's going to come in soon?" And then when he did come in, it took a little bit of pressing to get him to take my written-out chart. But I just really wanted to make sure he had this list. And then it did turn out that it was different from what he had.

Speak soon,
A conscientious carer

Dear Reader,

One of things we sometimes find hard is getting that prescription in the middle of the night or sorting out a wrong medication. If someone's been discharged from A&E, they don't have the time to go through all the meds. Do you call the hospice or the district nurse? You don't want to call 111 cos they're extremely busy so there's always a question of who can I check this with?

Thoughtfully,
The Rapid Response Team

Getting palliative medications right

Dear Reader,

So our policy is that all changes must go through the GP. So I'm a doctor, I can prescribe in theory. But I resist prescribing because if I omit to tell the GP then that becomes a very confusing issue. And even if we are telling the patient to take two 5mg MST tablets instead of one tonight, we would have to email the GP, ensure the information is passed on and then request an onwards script for the higher dose.

I tend to put a read receipt on my emails which I think is a good safety net for checking, however I send about 50 emails a day so the ones that don't come back with a read receipt they're not necessarily on my radar – I'm not checking for those ones.

A busy Community Palliative Care Doctor

Dear Reader,

I felt uncertain as a junior doctor about what the options were. Like what does that mean for the family to say you are going to now care for somebody that's dying at home, and we don't know how they will die, and we don't know how long it will take? What are we putting on you, and do I have a responsibility myself to explain the level of what that involves to somebody?

I felt a bit out of my depth at times. You know the families and often these discussions do end up happening without my senior present. I sometimes found it a bit bewildering because you care about getting somebody home and getting them a good discharge. So that's always a bit tricky, I think.

An uncertain hospital junior doctor

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