Abstract:

Timely and safe administration of injectable medications for patients at home is vital in optimally managing distressing symptoms in the final days of life. This article discusses a service evaluation of family carers’ (including close friends) administrating subcutaneous end-of-life medications. The procedure was not intended to become normal care, rather the exception when needed and where appropriate and with 24/7 skilled support from community nursing and palliative care services. A service evaluation of the procedure was undertaken in rural and urban areas in the South East of England. The procedure ran over six months and used detailed processes with recruitment criteria to mitigate risk of harm. In total, eleven patients participated with their family carers, including five carers with experience in healthcare roles. Ten out of the eleven family carers were able to administer injections safely with structured training and support in place. Patients received timely symptom relief and their family carers were able to support loved ones by administering injectable medications rapidly without waiting for a nurse to arrive. This was particularly welcomed in more rural areas where waiting times were greater due to the large geographical area covered and limited staff availability during out-of-hours periods. The findings informed a carefully monitored wider rollout and ongoing evaluation in adult community nursing services in the NHS Trust.

Introduction

The aim of this article is to discuss a service evaluation where family carers were trained and supported by skilled community and palliative care nurses to administer injectable anticipatory end-of-life medications for distressing symptoms when needed. The option for family carers to give this medication was raised by bereaved family carers during a strategic
end of life steering group meeting involving commissioners, NHS community end-of-life care services, hospice partners and public contributors (family carers). Carers with lived experiences of looking after relatives at end-of-life were keen to explore if this could be put in place to enable more timely, responsive care at home.

It is important that patients can live for as long and comfortably as possible in their preferred place of care. The shift towards last-days-of-life care in the community accelerated rapidly during the Covid-19 pandemic with services meeting increasing demands within existing resources (O’Donnell et al, 2021). The proportion of patients who died in the community from all causes climbed to 51% in 2020 (Office for National Statistics, 2021); the number of home deaths during 2020 in England and Wales was 167,000, one-third higher than the previous five-year average. The likelihood of patients remaining at home is enhanced when they and their family carers feel adequately supported by professionals, care feels sustainable and they can manage symptoms as they arise (Papavasiliou et al, 2021). There are times when patients require subcutaneous injectable medications to relieve distressing symptoms in the last days of life, especially when no longer able to take oral medications (Bowers et al, 2019; Bowers and Redsell, 2017; Wilson et al, 2015).

National guidance highlights the importance of having subcutaneous injectable medications available as part of proactive planning for the last-days-of-life (National Institute for Health and Care Excellence (NICE), 2015; Healthcare Improvement Scotland, 2019). The NICE guidance on last days of life focuses on medication prescribing rather than administration. The Nursing and Midwifery Council (NMC) in the code for professional standards states that practitioners can delegate tasks and decision to other people; the practitioner must be accountable for decisions to delegate tasks and duties, requiring ascertainment of the other person’s scope of competency, that adequately supervised and supported, and that outcome of the task meets required standards (Standard 11, NMC 2018). Injectable medications are usually administered by visiting nurses or paramedics (Bowers, 2021; Bowers et al, 2020b; Wilson et al, 2015). However, family carers routinely administer end-of-life care injectable medications in some areas of Australia (Bullen et al, 2015; Bowers et al, 2019; Healy et al, 2013; Healy et al, 2013).
In the service evaluation area, community nursing services are available 24/7 providing skilled nursing care, including administration of injectable medications. However, due to the wide geographical area covered it can take over an hour to visit patients, especially during out-of-hour periods with reduced staffing. Delays in accessing timely nurse visits to administer injectable medications are reported across the United Kingdom (Poolman et al, 2020). To meet the need for effective twenty-four-hour symptom control, we developed a procedure for family carers (including close friends) willing and able to take on the responsibility for giving ‘as required’ subcutaneous injectable medications to help control painful and distressing end-of-life symptoms. This intended to give family carers and healthcare teams a safe and supported framework to work within.

This article discusses the findings from the service evaluation of a pilot of an innovative clinical procedure for family Carer administration of as needed subcutaneous injections for adults in last-days-of-life at home (Sussex Community NHS Foundation Trust [SCFT], 2021). Supplementary file 1 details the procedure approved by the Trust Wide Governance Group (June 2021) and piloted.

**Methods**

The service evaluation utilised quality improvement methods to understand the implementation and outcomes of the procedure, identify opportunities for strengthening and monitor patient safety measures. Service evaluation is a process of finding and interpreting facts about a service that help to understand how the service operates (Dixon, 2016). The service evaluation included, reviewing the electronic patient record to monitor the implementation of the procedure from patient identification into bereavement and the characteristics of users of the procedure, and a feedback questionnaire with open questions for free text comments completed by the participating clinicians and family carers.

**Ethics.**

NHS Ethical approval wasn’t required as this was a service evaluation. The service evaluation was registered with the NHS trust clinical governance team (the Caldicott Guardian), and clinical governance overseen by the Chief Nurse and Executive Medical Director, and senior
clinical leads, through reporting to the End of Life Steering Group, Trust Wide Governance Group and Medicines Management Group

**Service evaluation site**

The service evaluation was undertaken with community nursing teams in a 550 square mile area in a Community NHS Trust, working with two local hospices providing specialist palliative care and General Practitioners. The area was chosen as it had a mixed geography and included urban, rural and isolated communities. The provision of end-of-life care was supported by a palliative care co-ordination telephone Hub called ECHO staffed by registered nurses skilled in community nursing and palliative care, with access to medical consultants in palliative medicine. The ECHO Hub is available 24/7 for patients, families and professionals, including community nurses, paramedics, hospice practitioners and GPs. (O’Hara 2019).

**Patient identification**

Identification of patients was led by the clinical nurse leads (CNL) or clinical nurse specialist (CNS) from the community nursing teams and two local hospices. The nurses identified the patients as they were the clinicians who knew the patients the best, within the multidisciplinary team. Patient and family carer selection criteria focused on identifying people near end of life, the willingness and capacity of family carers to take on assessing symptoms and administering injections and having adequate time to meet with nursing staff for training ahead of the last few days of life. These criteria ensured there was a safe, robust framework for community nurses to follow regarding eligibility criteria, consent processes, training and risk management. Box 1. details the patient and family selection criteria. Nearness of end of life was ascertained by the clinical teams based on clinical assessment. Validated person-centred outcome measures to assess nearness of end of life (Bradshaw et al. 2021) were not used routinely in palliative care within the setting.

**Box 1. Patient and family carer selection criteria.**
<table>
<thead>
<tr>
<th>Criteria for suitability</th>
<th>Criteria which may prevent suitability</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Patients with unpredictable symptoms where Pro Re Nata (as needed) subcutaneous injections may be required.</td>
<td>• This procedure MUST NOT be undertaken by any family carer with a known history of substance misuse or when someone known to misuse substances has access to the house.</td>
</tr>
<tr>
<td>• Patient has been referred to community nursing team.</td>
<td>• If the family carer is an employee of the Community NHS Trust, they must seek advice and agreement from their employer before undertaking this procedure.</td>
</tr>
<tr>
<td>• The patient would like the family carer to undertake the procedure.</td>
<td>• There are signs of relationship issues / safeguarding concerns between the patient and family carer.</td>
</tr>
<tr>
<td>• Family carer willing and assessed as capable of undertaking the procedure.</td>
<td>• There is concern that the family carer will not be able to cope physically, mentally or emotionally with undertaking the procedure.</td>
</tr>
<tr>
<td>• Family carer aged 18 years or over.</td>
<td>• Training and support led by either the community case manager, registered community nurse, specialist palliative care nurse or hospice team leader.</td>
</tr>
<tr>
<td>• The decision for a family carer to administer Pro Re Nata subcutaneous injections in a community palliative care setting agreed prior to discussions with patient and/or family carer, by a minimum of two multidisciplinary team members, including the patient’s general practitioner (GP), consultant in palliative medicine, specialist palliative care nurse or registered nurse prescriber. The patient’s GP must agree with their participation in the pilot.</td>
<td></td>
</tr>
<tr>
<td>• Training and support led by either the community case manager, registered community nurse, specialist palliative care nurse or hospice team leader.</td>
<td></td>
</tr>
</tbody>
</table>

Training of family carers and community nurses
The family carer procedure was explicit in documenting the roles and responsibilities for the registered nurses providing the training and support to family carers, and the rationale for each action (see Box 2). The ECHO Hub provided 24/7 support to the family carers. Family carers telephoned the Hub when ‘break-through’ injections were required. This enabled continually monitoring of the medications given, support for the family carers and timely review by the clinical teams. The procedure stated that only three injections of any one medication may be given over a twenty-four-hour period by family carers. This was to ensure timely, periodic clinician review of symptoms and management, including adjustment of medications in subcutaneous syringe drivers to minimise requirement for ‘break-through’ injections for symptom relief.

The family carer training was provided by the community and specialist palliative care nurses. The training for the delegation of tasks to a family carer was informed by, and adhered to, the NMC Code for Professional Standards (NMC 2018). The nurses recorded and provided feedback on the length of time the training took and the perceived quality and comprehensiveness of the training package to drive continual improvements. The procedure and training was supported by documents, including:

- Information leaflet for family carers on administering injections for symptom management in the community.
- Risk assessment template on the electronic patient record (SystmOne)
- Record of consent for family Carers
- Care plan template on the electronic patient record
- Carers’ direction to administer as required subcutaneous injections for completion by responsible R/N – transcribe medications to be used from SCFT Community prescription chart
- Family carer medication administration chart

The family carer training was designed as a care plan and followed a step-by-step approach with clear instructions, including responsibilities for each action, when it was performed and by whom (box 2). The structured care plan led the clinician and family carer through the different stages of the procedure, with the first section concentrating on the discussions around the paperwork and responsibilities of the family carer. This gave family carers time
to ask any questions and discuss any concerns they may have had. This was followed by
training in the procedure of administering the injection. For family carers with a healthcare
background, injection administration was observed once and repeated if indicated; for
family carers with no healthcare background, the number of clinician observed injections
was led by the competency and confidence of the family carer. The training procedure
followed the principle of experiential learning defined as a process that enables a person to
learn through doing, ‘earning while experiencing, and learning through hands on practice
and reflection (Kolb, 1984; Fry et al, 2015). It was discussed that if at any point during the
training, or afterwards, the family carer felt they did not want to give injections or the
patient did not want them to, then the community nurses will take over; there was no
pressure or expectation that family carers would take on this role.

The next steps of the training were around the actual administration of injections including
discussing the potential side effects of medications and discussing how the family carer
might feel if they administer the last injection before the person dies. The multidisciplinary
healthcare team were very aware that families might have concerns about over-sedation
and injectable drugs, especially opioids, hastening death (Bowers et al, 2020a). Reassurance
was provided that injections administered in the doses prescribed would provide symptom
relief and not hasten death.

**Box 2. Key Training points**

<table>
<thead>
<tr>
<th>Training action &amp; delegated responsibility</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registered Nurse (RN) (Band 6 or above) is responsible for preparation of all equipment and paperwork</td>
<td>Facilitate safe practice &amp; minimise risk of errors</td>
</tr>
<tr>
<td>RN is responsible for discussing the suitability of the family carer with multi-disciplinary team including GP or palliative care medical consultant.</td>
<td>To ensure safe selection of the family carer to undertake the procedure minimising risk and protecting the patient from harm.</td>
</tr>
<tr>
<td>To discuss and explain the procedure &amp; implications with family carer and patient ensuring a full understanding of what this means.</td>
<td>To ensure Multi professional collaboration and co-operation.</td>
</tr>
<tr>
<td></td>
<td>To fully inform carer and patient and enable them to make an informed choice.</td>
</tr>
<tr>
<td>Task</td>
<td>To protect the patient from harm (NMC 2018)</td>
</tr>
<tr>
<td>---------------------------------------------------------------------</td>
<td>--------------------------------------------</td>
</tr>
<tr>
<td>Completion of a carer risk assessment, signed consent from carer and patient.</td>
<td></td>
</tr>
<tr>
<td>To ensure clear documentation for each named PRN (as required) medication is written onto the carers direction to administer as required PRN medication sheet.</td>
<td></td>
</tr>
<tr>
<td>GP/Prescriber to clearly prescribe the PRN medication &amp; maximum number of doses on agreed prescription chart.</td>
<td></td>
</tr>
<tr>
<td>RN to explain the importance, use, relevance, action &amp; possible side effects of each medication to the family carer.</td>
<td>To ensure family carers are fully informed and able to make an informed choice.</td>
</tr>
<tr>
<td>RN to provide opportunity for family carer to discuss any fears or anxieties prior to starting the procedure.</td>
<td>To ensure family carers are being listened to and provide any support needed.</td>
</tr>
<tr>
<td>RN is responsible for inserting the Saf-T-Intima needle, securing and flushing before use.</td>
<td>To establish a safe and secure subcutaneous route for the family carer to administer the medication</td>
</tr>
<tr>
<td>RN to provide education on observing the site for signs of swelling, inflammation or leakage and to report any issues to the team.</td>
<td>To ensure education and prompt reporting of any issues and maintain patency.</td>
</tr>
<tr>
<td>RN to train family carer to accurately check medication, date, time, medication, dose, reason &amp; signature.</td>
<td>To ensure the patient is given to correct medication, in the prescribed dose using the appropriate diluent and the correct route.</td>
</tr>
<tr>
<td>RN will demonstrate the correct steps involved in administering a subcutaneous medication, including handwashing, drawing up of medication, disposal of medications, administering a flush, disposal of sharps, accurate completion of all documentation and contact numbers for the 24/7 ECHO hub.</td>
<td>To protect the patient from harm (NMC 2018)</td>
</tr>
<tr>
<td>RN to explain the maximum of any one medication can be given up to a maximum of 3 times in any 24-hour period.</td>
<td>To protect the patient from harm (NMC 2018)</td>
</tr>
</tbody>
</table>
To provide guidance to the family carer.

RN to discuss the issue of the last injection with the family carer and share the information leaflet around this topic.

To ensure the carer understands the procedure expected of them.
To provide written instruction to support verbal instruction.
To ensure the family carer feels safe and supported.

RN to update patient electronic record with an alert and all associated paperwork that the procedure is in place.

To ensure accurate records and that the MDT are aware and informed.

RN will visit as needed and ensure daily contact to evaluate effectiveness of care.

To ensure continuity of care
To allow reassessment
To ensure MDT communication
To maintain accurate records.

Data collection and analysis.

A patient questionnaire was used to determine if outcomes were as expected as per the patient’s wishes, to allow family carers to share their experiences about using the procedure and to identify opportunities for improvement. This intended to offer improved choice to patients and family carers. The intention was to maximise patient comfort and wellbeing and timely care coordination, aligned with the Ambitions for Palliative and end of life care, national framework, for local action (2021-2026, NHS England 2021). Patient electronic records were continually reviewed and audited, with alerts/reporting if deviations from the pilot procedure processes were identified. This monitoring mechanism for all patients participating in the pilot enabled safety risks to be identified and rapidly acted upon. Analysis was done at patient-level by describing and monitoring the medication type, dosage, frequency and administration overtime, patient and family carer characteristics, and narrative collation of free text comments reported in the Patient Questionnaire.

Results
In total, eleven patients were recruited with their family carers, including five carers with backgrounds in healthcare roles. Out of these five family carers, four were practising registered nurses and one had retired. All five family carers with healthcare backgrounds asked if they could administer end-of-life injectable medications if needed as part of advance care planning conversation with visiting nurses. As a result, recruitment for those with healthcare backgrounds was led by the family carer. The six other family caregivers were recruited to take part in the service evaluation by palliative care and community nursing staff; three were trained whilst their relative was an inpatient in the hospice and three were trained at home by community nurses.

Ten of the eleven family carers were able to complete the training and administer injectable medications competently at home. One family carer withdrew from the pilot scheme after receiving training. The carer was an 89-year-old gentleman caring for his wife with terminal cancer (Carer ID No.10). He was trained whilst his wife was in the hospice and agreed to administer subcutaneous injections; he felt confident to do so at the time and all relevant risk assessments were completed. Once his wife was discharged home, he lost confidence and asked for the community nursing team to administer injections.

Ten family carers successfully administered injectable medications when needed in the last days of life. Medication for pain (Morphine or Oxycodone) and for agitation (Midazolam) were the most commonly administered medications, with relatively low dose ranges used. Table 2. details the ‘as required’ injectable medications administered and the length of time they were given over. The median length of time that injections were administered over was five days. Family carers with a background in healthcare fed back that they felt empowered and thanked the nurses and Community NHS Trust for being forward thinking regarding end-of-life care at home. One family carer (Carer ID No.7) reported “it gave a sense of purpose” when looking after her relative and she felt that she had “contributed to managing uncontrolled symptoms when needed particularly out of hours”. She described access to the twenty-four-hour ECHO Hub as “invaluable for support and reassurance”.

The community nurses provided ongoing feedback during the evaluation to monitor and review processes. The nurses identified medications such as morphine and midazolam were frequently given together. This led to changes to the procedure to increase flexibility around
managing symptoms: family carers were allowed to use up to three of each individual medications in any twenty-four-hour period. The procedure was also amended so that family carers did not need to ring the ECHO Hub prior to administering injections if they were confident and comfortable with what medication to give for respective symptoms. Family carers overwhelmingly preferred this approach than having to telephone the ECHO Hub before giving injections and risk waiting in a queue whilst their family member was experiencing distressing symptoms.

Table 1. Characteristics of family carers and patient preferences and attainment

<table>
<thead>
<tr>
<th>Carer ID number</th>
<th>Age range in years</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Patient Diagnosis</th>
<th>Preferred place of care</th>
<th>Preferred place of death</th>
<th>Actual place of death</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>65-74</td>
<td>F</td>
<td>Asian Indian</td>
<td>Cancer</td>
<td>Home</td>
<td>Home</td>
<td>Home</td>
</tr>
<tr>
<td>2</td>
<td>65-74</td>
<td>F</td>
<td>White</td>
<td>Cancer</td>
<td>Home</td>
<td>Home</td>
<td>Home</td>
</tr>
<tr>
<td>3</td>
<td>55-64</td>
<td>F</td>
<td>White</td>
<td>Cancer</td>
<td>Home</td>
<td>Home</td>
<td>Home</td>
</tr>
<tr>
<td>4</td>
<td>55-64</td>
<td>F</td>
<td>Black African</td>
<td>Cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>18-44</td>
<td>M</td>
<td>White mixed</td>
<td>Cancer</td>
<td>Home</td>
<td>Home</td>
<td>Home</td>
</tr>
<tr>
<td>6</td>
<td>18-44</td>
<td>M</td>
<td>Asian</td>
<td>Cancer</td>
<td>Home</td>
<td>Home</td>
<td>Home</td>
</tr>
<tr>
<td>7</td>
<td>45-54</td>
<td>F</td>
<td>White</td>
<td>Cancer</td>
<td>Home</td>
<td>Home</td>
<td>Home</td>
</tr>
<tr>
<td>8</td>
<td>18-44</td>
<td>M</td>
<td>Black African</td>
<td>Cancer</td>
<td>Home</td>
<td>Home</td>
<td>Home</td>
</tr>
<tr>
<td>9</td>
<td>65-74</td>
<td>M</td>
<td>White</td>
<td>Cancer</td>
<td>Home</td>
<td>Home</td>
<td>Home</td>
</tr>
<tr>
<td>10</td>
<td>85+</td>
<td>M</td>
<td>White</td>
<td>Cancer</td>
<td>Home</td>
<td>Home</td>
<td>Home</td>
</tr>
<tr>
<td>11</td>
<td>85+</td>
<td>M</td>
<td>White</td>
<td>Cancer</td>
<td>Home</td>
<td>Home</td>
<td>Home</td>
</tr>
</tbody>
</table>
Table 2. End-of-life injectable medications administered by family carers

<table>
<thead>
<tr>
<th>Carer ID number</th>
<th>Number of injections given</th>
<th>Medication name</th>
<th>Dosage given</th>
<th>Length of time given over</th>
<th>HCP (discipline) /Non HCP</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>6</td>
<td>Morphine Sulphate Midazolam</td>
<td>5mg - 2.5mg - 5mg</td>
<td>2 days</td>
<td>HCP (RGN)</td>
</tr>
<tr>
<td>2</td>
<td>9</td>
<td>Levomepromazine Midazolam Morphine Sulphate</td>
<td>5mg - 2.5mg - 10mg - 5mg</td>
<td>9 days</td>
<td>HCP (RGN)</td>
</tr>
<tr>
<td>3</td>
<td>12</td>
<td>Morphine Sulphate Midazolam</td>
<td>5mg - 7.5mg - 2.5mg - 5mg</td>
<td>5 days</td>
<td>HCP (RGN)</td>
</tr>
<tr>
<td>4</td>
<td>8</td>
<td>Morphine Sulphate</td>
<td>2.5mg - 7.5mg</td>
<td>5 days</td>
<td>HCP (RGN)</td>
</tr>
<tr>
<td>5</td>
<td>5</td>
<td>Morphine Sulphate Midazolam</td>
<td>5mg - 2.5mg</td>
<td>6 days</td>
<td>HCP (RGN)</td>
</tr>
<tr>
<td>6</td>
<td>12</td>
<td>Glycopyrronium Midazolam Morphine Sulphate</td>
<td>200mcg - 5mg - 10mg - 2.5mg - 7.5mg</td>
<td>14 days</td>
<td>Non HCP</td>
</tr>
<tr>
<td>7</td>
<td>8</td>
<td>Morphine Sulphate Midazolam</td>
<td>2.5mg - 5mg - 2.5mg - 5mg</td>
<td>5 days</td>
<td>Non HCP</td>
</tr>
<tr>
<td>No.</td>
<td>1</td>
<td>8</td>
<td>Hyoscine Butylbromide</td>
<td>Oxycodone Hydrochloride</td>
<td>10mgs</td>
</tr>
<tr>
<td>-----</td>
<td>---</td>
<td>----</td>
<td>----------------------</td>
<td>------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>10</td>
<td>4</td>
<td>8</td>
<td>Morphine Sulphate</td>
<td>Midazolam</td>
<td>2.5mgs</td>
</tr>
</tbody>
</table>

*HCP/Non HCP – Health care professional/non-healthcare professional; RGN – Registered General Nurse

**Discussion**

The service evaluation demonstrated family carers could administer injectable end-of-life medications in a timely and safe way with suitable training and tailored support from skilled community and palliative care nurses available 24/7, working with the wider multi-disciplinary team. Our findings mirror those of similar schemes in the UK and Australia (Poolman et al, 2020; Rosenberg et al, 2015; Healy et al, 2018). Family carer administration was intended as the exception rather than routine practice in our pilot. This procedure for family carers was intended to be the exception rather than routine practice. Feedback from the family carers and community nurses demonstrated the positive impact the procedure had on patient symptom control and families’ experiences of care. The family carers were aged between 29 and 89 years, and seven were the son or daughter of the person cared for. Four family carers were from an ethnic minority group. All the patients had cancer (see Table 1.). The wide age range of participants showed that the procedure was suitable for people aged 18 years or over, and the ethnic diversity of the participants indicated the procedure inclusively met their needs. Family carers who felt confident using this procedure reported that the patient experienced a good death, and that their own bereavement was positively affected as they felt they had contributed to timely and appropriate symptom relief. Changes in cultural practices in end-of-life symptom control care can make clinicians feel uncomfortable (Poolman et al, 2020; Bowers, 2021); however, our pilot findings highlight that family carer administration of injectable medications was appropriate and
beneficial in certain contexts and situations, with adequate ongoing professional support. The findings of the service evaluation informed carefully monitored widening of the procedure to a larger geographical area in the Community NHS Trust. The ongoing monitoring and evaluation of the use of the procedure and patient safety, includes, record audited to check no more than three injections of any one medication are given by family carers in any twenty-four-hour period. Yearly reviews of the Trust-wide procedure are in place, with earlier review if there are patient safety concerns. The ongoing evaluation will drive improvements locally and inform wider research on family carer administered medication for patients dying at home and national policy on ambitions for end of life care (Poolman et al. 2020; NHS England 2021).

Mitigating risks

The procedure was a radical change in local practice and had potential risks: these were carefully considered to mitigate the potential for harm. The procedure enabled nurses to risk assess the suitability of family carers to take on this role and their expectations during recruitment. Prevention of harm was at the forefront of the risk assessment. The exclusion criteria included anyone with a history of drug or alcohol abuse for the purposes of the procedure; areas of particular concern for clinicians when putting in place anticipatory injectable medications (Bowers et al, 2020b; Bowers and Redsell, 2017; Poolman et al, 2020; Faull et al, 2013).

There was a risk that clinicians may have perceived the procedure was suitable for everyone at end of life: this was not the case. It was not intended for family carers administering injectable medications to become the norm locally, rather the exception when helpful and appropriate (Bowers et al, 2020a; Poolman et al, 2020). However, it was important to ensure an inclusive and non-judgemental process to identify and approach family carers for the service evaluation. Clinicians were cautious about being able to select the correct people to participate. The risk assessment and structured training package provided a useful structure to address these concerns (Healy et al, 2013; Healy et al, 2018; Poolman et al, 2020). The following steps were taken:
• Family carer to call ECHO following administration of any injection (option was also available to call prior to administration but feedback from family carers was that this introduced a delay to care)
• ECHO reviewed symptoms and medication given including dose and frequency and provided any support to family carer needed.
• ECHO nurse reviewed medication record and co-ordinated services to review and assess as patient requiring breakthrough medication for symptom relief.
• ECHO mobilised a nurse to visit if 3 doses had been administered in the last 24 hours.
• ECHO co-ordinated a review of all medications with community nursing team, GP and/or hospice.
• ECHO to ensure all documentation had been completed by family carer.
• Case Manager to have daily contact with all family carers participating in the procedure to provide support where needed and ensure medications are reviewed.

The above processes were closely monitored through continually review of patient electronic records for all patients participating in the procedure. Reporting to the End-of-life Steering Group ensured clinical governance and monitoring to mitigate potential patient safety risks.

Safeguards were put in place to ensure all family carers were trained, assessed and competencies signed off and clearly documented. They were provided with written information for each medication including name, dose, indication, likely side effects, the time before a repeat dose is permitted and maximum number of injections over a 24-hour period. Family carers were required to keep a record of all injections given, including date and time, medication administered, reason and dose and signature of the person administering on the relevant administration chart. All family carers were provided with contact numbers for the community nurses and ECHO hub.

This also included ensuring the family carer did not feel under any pressure to participate, and that they did not feel daunted or overwhelmed by the prospect of giving injections (Bowers et al, 2020a; Poolman et al, 2020). The option of community nurses taking over administering injections was always discussed and one family carer opted for this as events and the pressures of caring unfolded. The ECHO hub also provided 24/7 access to senior
trained nurses (O’Hara, 2019). ECHO Hub staff also proactively monitored how many injections were given by family carers in individual patient cases, checking when clinical reassessments would be helpful and monitoring that no more than three of any one injection type were given in a twenty-four-hour period.

Involvement of general practitioners was limited with regards to family carer selection for the procedure; recruitment was community nurse-led for the service evaluation duration. As a result, general practitioners views and experiences of the pilot were not captured. However, it proved essential to have primary and secondary care involvement and engagement in rolling out the service evaluation. A recommendation for services considering supporting family carers to administer injectable medications is to engage with general practitioners and primary care pharmacy colleagues during the planning stages of any procedure.

Training and support

The training package for family carers was structured to be a supportive framework to ensure adequate support until they felt comfortable. The clinician always talked the family carer through drawing up and administering the required medication to the patient. If the family carer felt comfortable, they would administer an injectable medication when needed under the supervision of a clinician. The requirement for further observed medication administration continued until both the clinician and the family carer felt comfortable that the carer was able to administer ‘as required’ injections independently. Each carer had different needs. This required flexibility in the training approach and clinician support, as several research studies have found (Healy et al, 2018; Poolman et al, 2020; Rosenberg et al, 2015). Clinicians in the pilot tailored the level of support and supervision for each family carer until they were comfortable and competent with assessing symptoms and giving injections.

Community nurses’ feedback on using the training resources highlighted that family carers with a healthcare background required a shorter training period, as this built on their pre-existing knowledge and skills in administering subcutaneous medications. As community nurses gained confidence and competence in delivering the training and became familiar with completing the administrative documentation, the time to complete family carers
training shortened. However, for family carers with no healthcare background or knowledge about the procedure, the time required for training and assessing competency was greater. Family carers with limited or no experience of giving subcutaneous injections did not prove to be a barrier to them participating with the right tailored training and support in place (Rosenberg et al, 2015; Healy et al, 2018). The overwhelming feedback from clinicians and family carers was that the procedure provided choice to the patient and their family carers at the end of life.

**ECHO Hub support**

The Echo Hub has been a vital component in implementing and supporting the pilot and the subsequent wider role out of family carers administering injectable medications. It was vital that family carers and clinicians could access twenty-four-seven skilled clinician advice on end-of-life care. This was provided by the ECHO Hub staffed by registered nurses skilled in palliative and end of life care (O’Hara, 2019). The ECHO Hub provided senior clinical support to answer any questions, talk through symptoms and advise family carers on the injectable medication to administer; The Hub coordinated community services, including instigating a community nurse visit when needed. An innovation in clinical care ECHO provides an on-call palliative care consultant and a clinical nurse specialist 24 hours a day seven days a week. The ECHO Hub also supported coordination across services by using a shared electronic patient record system to document activity, ensuring records were up-to-date, alerting the multidisciplinary healthcare team to any unstable symptoms, patient and family concerns, and recent changes in care and treatment. The ECHO Hub ensured oversight and governance on how many injections were given by carers and that administration remained within maximum of three of any one injection in a twenty-four-hour period. **ECHO service NHS Benchmarking site- FINAL.pdf (sussexcommunity.nhs.uk)**

**Conclusion**

This innovation was born from a bereaved family carer advocating for change in end-of-life provision. This became an ambition for the end-of-life steering and clinical governance groups to provide optimal end of life care within the Trust. This pilot identified that there were small numbers of family carers for whom the procedure was suitable. Family carers reported that being able to administer injections aided timely symptom relief and
contributed to peaceful deaths. This had a positive effect on their end-of-life journey, including in bereavement. The successful pilot led to a wider expansion for the procedure in areas of the Community NHS Trust, supported by the ECHO Hub. Implementation of similar schemes requires investment in palliative and end of life care twenty-four-seven clinician telephone advice and coordination hubs.

Questions:
How will you use this article to influence your practice?
How could you take forward the key messages in your clinical practice?
What barriers do you think may prevent this from happening?

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References


Bowers B, Pollock K, Barclay S. Administration of end-of-life drugs by family caregivers during covid-19 pandemic. *BMJ.* 2020a; 369: m1615 https:// doi.org/10.1136/bmj.m1615


Kolb DA. Experiential learning: experience as the source of learning and development. New Jersey: Prentice-Hall; 1984


