

Discharge from critical care into the community for end-of-life care

Anthony Chambers, Fiona Robinson

This article discusses the considerations and actions taken to facilitate the discharge of a ventilated end-of-life patient called Michael, whose name has been changed for confidentiality, from a critical care unit (CCU) to his expressed preferred place of care. It focuses on how the district nurse (DN) and the single point of access (SPA) for end-of-life care teams by working between primary and secondary care services and across organisational service units were able to facilitate this discharge and achieve the wishes of Michael to die peacefully at home. For all services involved, this proved to be a complex discharge and following completion of the care episode a root cause analysis was undertaken to capture the lessons learnt and advise the CCU at a services debrief how discharges to the community from the CCU could be improved.

KEYWORDS:
Community nursing ■ End-of-life care ■ Critical care unit

happening from CCUs in the UK, with only one paper by Battle et al (2014) offering case studies. Thus, a fishbone diagram (Figure 1) was used to show the issues and challenges faced by the community teams (i.e. district nurse [DN] and single point of access [SPA] for end-of-life care) in the authors' locality. Representing the issues in this way enabled systematic root cause analysis of the incident to be undertaken by the authors of this paper. This was used to establish concerns at the debrief meeting and inform how discharges can be improved for the future in the event of complex discharges into the community from critical care settings.

Discharge from secondary into primary care can be a challenging, frustrating and problematic experience for both patients and health professionals (Nunn, 2009; British Medical Association Patient Liaison Group, 2014; Queen's Nursing Institute [QNI], 2016). However, discharge from any care setting should be a seamless process with clear channels of communication and access to patient information enabling optimum patient care with minimal disruption to the care cycle (Health Boards Executive, 2003).

In the authors' locality, discharge into the community from the critical care unit (CCU) had not previously happened, so this care episode

was a unique experience for the current primary and secondary care teams involved. While end-of-life care agendas (Department of Health [DH], 2008; DH, 2009) strive to meet patients' wishes to die at home, a literature search undertaken by the authors revealed little qualitative evidence of this

LOCAL SERVICE PROVISION

The City of Hull has a population of around 250,000 people and has community nurses provided by a community interest company (CIC) following the provider-commissioners separation from the primary care trust in 2010. All

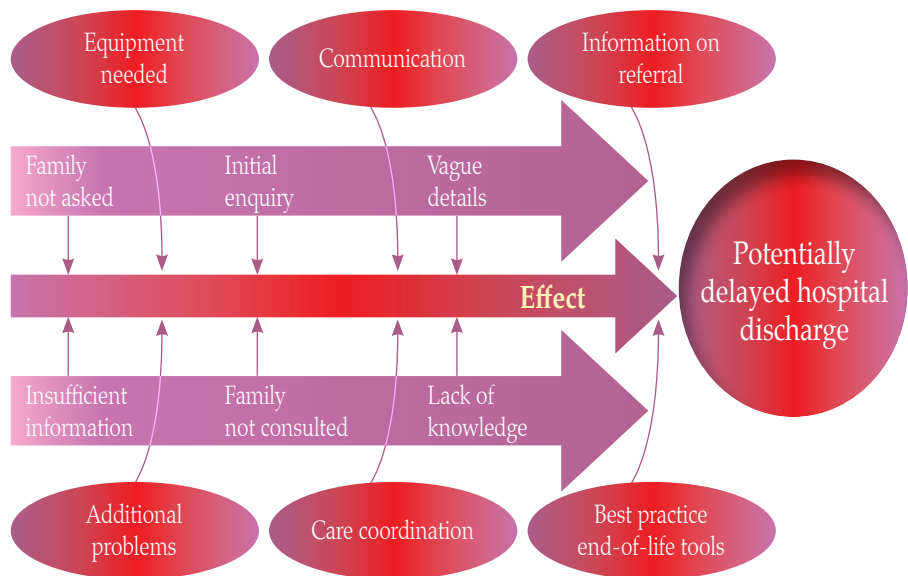


Figure 1. Issues and challenges faced by the community teams.

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community nurses provide end-of-life care as part of their core duties, supported by specialist end-of-life care nurses. Referrals for end-of-life care are taken via the SPA team. *Table 1* gives an overview of the service.

CASE SCENARIO

Michael was approaching end of life and following treatment in the CCU had been stepped-down to high dependency care and was receiving only palliative care. Michael was ventilated and had a tracheostomy and, although extremely poorly, had full capacity for decision-making and could express his wishes by using the tracheostomy and speaking tube. He expressed a wish to die at home and, to uphold his choice, the CCU staff agreed with Michael and his family to arrange discharge home. The main concern from the CCU staff was that his ventilation would have to be removed at home and, once this happened, there was every chance that he would pass away. The DN and SPA teams received this referral and despite the potential challenges that facilitating this discharge posed, by working together they were able to coordinate the process and enable Michael to die at home with his family present.

KEY CARE MANAGEMENT ISSUES

Information on referral

The initial referral into the community service seemed fragmented. As shown in *Figure 1*, the hospital first made enquiries to the SPA team about the potential discharge, but there was a delay in this reaching the lead caseload holder in the district nurse team. The referral lacked sufficient information to initiate a care management plan, such as patient details and clinical needs, resulting in frequent phone calls between acute and primary care to get the necessary information to form a safe discharge.

Communication

At first, it appeared that the CCU was seeking information

regarding a potential discharge, rather than an imminent urgent discharge. The CCU staff ended up liaising between both community services (community and SPA), leading to duplication in advice and leaving the services unsure of what information had been given. This led to uncertainty within the community teams over which end-of-life documents and resources had been initiated and a delay in essential equipment, such as a hospital bed, being ordered.

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Equipment needed

Patients from a CCU are generally transferred to other wards, rather than directly home (healthtalk.org, 2012). Understandably, the staff in the CCU had little, if any experience of discharging a patient to the community and, as an end-of-life patient, what Michael’s needs and requirements were for him to be discharged home safely.

An essential element of any safe discharge is the provision of appropriate equipment to keep patients and staff safe. It is commonplace for a hospital bed to be offered to end-of-life patients. This promotes patient comfort through the multi-positioning of the bed and reduces the risk of back injuries to staff, enabling them to operate at optimal height without unnecessary bending.

An important part of planning Michael’s discharge would have been organising a hospital bed — an essential requirement that needs delivering before a patient can be

Table 1: Overview of the single point of access service

▶ One point of contact for all palliative care referrals
▶ Integrated approach to palliative/end-of-life care through collaborative working with other care providers, e.g. GP services, local authority carers, night sitters, Macmillan team, palliative care clinic, health and social care team, carer’s information and support service (CISS)
▶ Avoid inappropriate hospital admission through the provision of responsive nursing care
▶ Respond to requests for unscheduled ‘crisis’ nursing care
▶ Establish and maintain effective communication systems with day-time services

discharged home. Being left to the last minute, this almost led to the failure of discharging Michael home. Equipment requested before 3.30pm is usually in place in the patient’s home by the end of the same day; because the decision that a bed was needed was not made known to the DN team until after this time, they ordered the bed with a view to discharge the following day. One of the issues raised at the debrief was that the CCU staff were unaware that they could have ordered equipment; as discharge to a patient’s home from the CCU is a rare event, staff did not know of the procedure for ordering equipment.

Best practice end-of-life tools

Sensitive communication and careful decision-making to establish advance care planning should begin as soon as possible after diagnosis, and continue throughout the patient’s illness to prevent needless distress in their final hours (Mullick et al, 2013; Leadership Alliance for the Care of Dying People, 2014). Advance care planning should include discussions regarding:

- ▶ Palliative care treatments
- ▶ Whether the patient is suitable for resuscitation
- ▶ The patient’s preferred place of care (Henry and Seymore, 2007).

The CCU staff had begun this process through their discussions with Michael and his family about

Table 2: Key palliative care drugs

Drug	Symptom
Diamorphine	▶ Pain
Midazolam	▶ Agitation/terminal restlessness
Haloperidol	▶ Nausea/vomiting
Hyoscine butylbromide	▶ Excessive chest secretions

where he would prefer to receive his end-of-life care.

Collaborative working between the SPA and DN teams using their specialist knowledge of community services and palliative care were able to advise the CCU staff what was needed to be sent home with Michael. They ensured that Michael’s end-of-life management pathway documentation was sent with him to avoid unnecessary rewriting and repeat of assessment and history-taking, so that they could spend time managing his physical problems and providing direct support to the family. Other end-of-life tools, such as the ‘do not attempt cardiopulmonary resuscitation’ (DNACPR) document, were also sent. The community teams also checked that Michael would come home with a ‘just in case’ box with key palliative care drugs (Table 2) to support anticipatory prescribing.

Having accessible and appropriate medicines in the patient’s home is essential in anticipating symptom control needs in end-of-life care, and is recognised as a key element in keeping a patient at home (Gold Standards Framework, 2006). Having the ‘just in case’ box turned out to be crucial in controlling and managing symptoms once Michael was home.

Additional practical problems

Michael was discharged with a ventilator, urethral catheter and bilateral chest drains. The community teams had been advised that Michael would be accompanied by an intensive care doctor and two intensive care nurses so that he could be de-vented once at home.

Until Michael was actually home, the community teams were unaware that he also had chest drains and a urethral catheter. The accompanying critical care team were able to remove the chest drains, closing the wounds with sutures and remove Michael’s ventilator leaving him with a tracheostomy tube.

In the authors’ clinical opinion, these additional patient needs (the urethral catheter and chest drains), which were only identified once Michael was home, demonstrated how resourceful the primary care team are in managing unexpected patient nursing needs. Due to the well-skilled community team, these additional nursing needs could be managed in Michael’s own home.

‘... good quality community palliative care services are important to meeting patients’ wishes to die in their usual place of residence, and patients who receive specialist community-based palliative care, including discharge support to get home from hospital quickly, are less likely to die in hospital (Dixon et al, 2015).’

Immediately following removal of the ventilator, Michael became distressed due to excessive secretions within his respiratory tract. The accompanying critical care team were able to relieve this by providing suction, but became concerned as to how this symptom could be best managed to reduce excessive secretions. However, the community teams were able to advise the family about comfort and positioning to help Michael’s breathing. They also directly discussed continued management approaches with the intensive care doctor and it was agreed that the administration of hyoscine butylbromide to reduce the secretions (National Institute for Health and Care Excellence [NICE],

2015) via an infusion pump would be the best course. The community nurses always carry medicine authorisation sheets with them and, therefore, the drug was written up immediately and the syringe pump infusion with the drug already available from the ‘just in case’ box was started.

Later, the family identified this action as an element of how they had been given confidence in the swift action of the community team by their approach to the management of a new and distressing symptom.

CARE COORDINATION

Part of the SPA team’s role is to meet and greet end-of-life patients on discharge from hospital. The two services (DN and SPA) decided that they would both meet the ambulance and be there when Michael arrived home. By sharing expertise in both end-of-life care and community nursing, they felt that they would be able to provide optimum care for Michael. Indeed, good quality community palliative care services are important to meeting patients’ wishes to die in their usual place of residence, and patients who receive specialist community-based palliative care, including discharge support to get home from hospital quickly, are less likely to die in hospital (Dixon et al, 2015).

Due to circumstances outside anyone’s control (an ambulance strike), the ambulance arrived at the house far later than expected. This turned out to be an advantage as the community teams were able to meet Michael’s son and spend sufficient time explaining their services and what to expect once Michael was at home. They were able to provide reassurance about symptom control and availability of nurses as a 24-hour service, and develop that crucial relationship between nurse and relative, which otherwise they might not have had the chance to do.

On arrival, the ambulance crew were unable to bring Michael into

the house via any door as there was not enough room for the crew to swing the trolley. Having managed to get this far, this is where the hospital and community teams almost failed in getting Michael home. In the authors' clinical experience, which is supported by key documents (DH, 2008; NHS Improving Quality, 2014), involving the ambulance crew service in discharging end-of-life patients is vital if safe and effective discharge is to be achieved. While there was not sufficient time in this case to delay discharge while extensive home adaptations took place, a discussion with the relative about the home environment and access would have been helpful to the ambulance crew in planning how they would get Michael into his house.

Fortunately, there was good weather that day as Michael had to wait outside on the trolley while the ambulance crew assessed and planned how they would get him into the house. Eventually they decided to transfer Michael onto a wheel chair and push him into the house and then do a manual transfer from the chair to the bed. This was only made possible by the presence of the community team and assistance from relatives, without which, Michael may have ended up being readmitted to hospital. While to anyone watching it may have seemed undignified and was potentially hazardous due to the various attached medical devices, the ambulance crew managed and coordinated the transfers to prevent any injury or harm to Michael.

DISCUSSION

The identified management issues show key areas that impacted on the success of the discharge. The SPA team exists to ensure that referrals and the communication flow for end-of-life patients are easier. In the initial phases, the critical care team were not clear that this was a discharge, which led to a delay in the actual referral being made and the SPA and DN teams being able to initiate

effective discharge arrangements, coordinated by the SPA service. This could have been prevented by the CCU talking to their discharge liaison team, but as they had little experience in discharging patients they did not follow the usual hospital discharge processes. Nursing in the community requires specialist knowledge and skills in assessment of patients' needs (Barrett et al, 2007; QNI, 2015) and, as a service, they acknowledged on this occasion that they could have used their specialist knowledge of community services and discharge planning more effectively, e.g. liaised with the equipment service to confirm a same day delivery arrangement.

RECOMMENDATIONS FOR PRACTICE

Following this discharge, the local CCU contacted the primary health care team to hold a debrief session about the discharge and explore what went well and what could be improved in the future. The community teams attended this session, which was useful to see the incident from the CCU's point of view. Several issues emerged. It showed the effectiveness of the SPA team in providing a central facility to accept and triage palliative care referrals, and through which all required services can be coordinated; services which the DH (2008) recommends community healthcare services establish.

A crucial element revealed at the debrief was that the CCU had not understood the relationship between the DN and SPA teams, or how the SPA received referrals and coordinated discharges. This was also one of the learning points for the CCU in that they should have liaised more effectively within their own service and with support services, such as the equipment service. However, the discharge was only delayed until the following morning and did not ultimately prevent Michael from receiving his wish to die at home. Findings by the QNI (2016) echo this experience of a lack of understanding of community services, and how

equipment is ordered and provided being common barriers to effective discharges.

From this meeting, an action plan was produced to devise a specific discharge pathway for the CCU to discharge safely, effectively and timely into the community. The flow chart included elements, such as:

- ▶ List of potential essential equipment required to care for patients in the community and the process of how to order
- ▶ Relevant documentation to accompany patient to prevent duplication and expecting the patient and family to repeat information
- ▶ Full in-depth handover to appropriate service (SPA for all palliative referrals)
- ▶ Consideration of how the patient will be transferred into the property
- ▶ Whether any specific end-of-life tools/medication need to be supplied.

CONCLUSION

Undertaking a root cause analysis and subsequent debrief gave all services an opportunity to reflect and learn from the experience of managing Michael's care. Although these learning points are outlined in *Figure 1*, they do not capture the human factor of achieving Michael's and his family's wishes that he should die at home. In the end, no amount of debrief can take away that feeling of professional satisfaction of seeing him drink a cup of tea when all the critical care staff had gone and there was just him and his family enjoying what unknown time he had left.

This was later echoed by Michael's son, who did not thank the nursing teams for arranging the discharge, arranging the necessary equipment, problem-solving the entry into the property, or obtaining prescriptions for 'just in case' drugs, but rather he wanted them to know that he was grateful that his father had died peacefully at home in familiar surroundings with familiar people.

Caring for someone at the end of their life is a privileged experience, and knowing that their wishes are respected and that the family are left with a lasting memory of the love and care that they were able to give in the final hours in their own home is a rewarding element of nursing job satisfaction. **JCN**

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