Title: **Rapid discharge from hospital in the last days of life: An evaluation of the key issues and the contribution of an end of life discharge sister role**

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ABSTRACT

Background

When the time comes, most people wish to die at home. Nevertheless, many deaths occur in hospital, often because of delays in the discharge process. This study explored the issues surrounding rapid discharge from hospital in the final days of life, and evaluated the contribution of a discharge sister role.

Methods

A qualitative design was used, incorporating focus groups and interviews with key stakeholders.

Results

A total of 75 staff and 7 carers participated. Participants highlighted the small window of opportunity available to facilitate a rapid but safe discharge from hospital. Early recognition of the last days of life was vital as was the availability of a skilled healthcare professional, such as the discharge sister, to co-ordinate the patient's journey from hospital to preferred place of death.

Conclusions

Rapid discharge is challenging and requires high levels of skill. The discharge sister navigated complex organisational systems to facilitate rapid discharge for those who might otherwise have died in hospital.

Key words

Rapid discharge, discharge planning, preferred place of death

INTRODUCTION

The proportion of hospital deaths has declined in the UK from 56% in 2005 to 49.5% in 2012 (Gao et al, 2013; ONS, 2013). Furthermore, the percentage of people dying in their usual place of residence in England has risen from 37.9% in 2008 to 43.7% in 2012 (NEoLCN, 2012). This improvement has in part been attributed to the introduction of the UK National End of Life Care Programme and other initiatives such as the End of Life (EoL) Care Strategy (NAO, 2008) and the National Institute for Health and Clinical Excellence quality standard for EoL care for adults (NICE, 2011). While a positive trend is evident, it is clear that the wishes of many patients, regarding the place of their death, remain unfulfilled (Gomes et al, 2011; Shucksmith et al., 2013).

A number of drivers for improving this situation are evident. For example, hospital key performance indicators linked to patient through-put in acute hospitals, and the Quality, Innovation, Productivity and Prevention (QIPP) policy agenda which aims to reduce the NHS budget by £20 billion by 2015 (Department of Health [DH], 2013a). However, another major driver for discharge of patients in the last days of life has been an increasing emphasis on the patient choice agenda (NHS Choices, 2014). It is clear that patient and carer choice is a vital component of EoL care, with the honouring of choices central to patient satisfaction (Ciemins et al., 2014).

Discharging patients who are in the last days of their life, is a complex process; but rapid, safe discharge from hospital is clearly necessary if patients are to achieve their preferred place of care and place of death. However, achieving rapid discharge requires adequate resources including staff time, staff knowledge and adequate community support services (Wye et al., 2014) to ensure the patient is safe once discharged.

Although care away from acute hospitals might be desirable for patients, a major risk is that elements of community care fail or relatives are unable to cope, which can result in the patient returning to acute care as an emergency admission (Thomas and Noble, 2007). Co-ordination of care and skilled discharge planning is central to enabling a smooth, timely transition from hospital to the preferred place of care or place of death (Hughes-Hallet et al., 2011).

To address this issue, a 1,000 bed acute NHS Trust in England secured funding from Macmillan Cancer Support to introduce a new EoL discharge sister post, and part-time clerical support, to co-ordinate the rapid discharge process for patients who were in the last days of life. The main aim of the post was to support clinical teams to manage patients who had reached the end of their lives and whose desire was to be cared for out of the acute hospital environment. The service was available for ward staff to access weekdays between 8.30am – 4.30pm excluding bank holidays. It was intended that referrals to the service came about by raising awareness of the pilot with ward staff, members of the Trust discharge team and other clinical staff. Two academic nurse researchers (SJ, SH) evaluated the pilot service.

It should be noted that at the time of data collection (2012) an EoL Care Pathway (EoLCP), called the 'Care Pathway for the Last Days of Life' (CPLDL), based on the Liverpool Care Pathway (LCP), was still in use. The LCP was phased out following a government review responding to public concerns (DH, 2013b) and replaced by individual EoL care plans.

AIM

The aim of this study was to explore the issues that frustrate the rapid discharge of patients from hospital in the last days of their life, and to evaluate the contribution of a newly appointed discharge sister role, from the perspective of key stakeholders.

METHODOLOGY

Evaluation approach

While a number of evaluation approaches were available, a formative approach was chosen as this enabled initial feedback of early findings to be presented to commissioners so they could undertake timely modifications to the service (The Health Foundation, 2015). This formative approach comprised a two-stage data collection period, four months apart. Although improvements in the discharge process were apparent between the two data collection phases, measuring this over time was not the focus of the evaluation.

Participant selection

A purposive sample (Oliver, 2013) of professional staff involved with the care and discharge of patients at EoL were invited to participate in the study (Table 1). This included the hospital-based palliative care team (SPCT), rapid discharge team and staff from wards with the highest number of EoL discharges. All district nurse teams from across the local geographical area, the community SPCT and the care homes forum were also contacted. Carers of all patients being discharged from the study wards during the study period were given written information at the time of discharge and were subsequently invited to take part following news of the death.

Data collection

A qualitative approach was used which incorporated focus groups and semi-structured interviews, which were audio-taped and transcribed (by SJ). This enabled the researchers to explore the rapid discharge process from the perspectives of key stakeholders.

Focus groups were undertaken with staff teams as this enabled them to consider issues together. Staff were offered an individual interview if they wished to participate in the study but were unable to attend a focus group, or were the only volunteer on a ward. Individual

interviews were offered for carers so they could be interviewed privately at a time and place of their convenience. Staff focus groups and interviews were conducted on work premises and carer interviews took place in their homes.

Focus group and interview schedule questions were informed by the relevant literature and clinical knowledge of the issues surrounding the discharge process. Questions were designed to encourage participants to reflect on their experiences of the discharge process. They also prompted participants to explore changes that had been noticed since the introduction of the new service and how well, or otherwise, the patient discharge process and transition into the community had worked. Interviews with carers explored their experiences of the discharge process and the new service (Table 2).

Data analysis

A consideration when undertaking qualitative data analysis is the extent to which a confirmable, credible and dependable account of the participants' experiences and views are presented (Lincoln and Guba 1985). To strengthen the confirmability of the findings in this study, all focus groups/interviews were recorded and transcribed, and data analysis was checked by a second researcher (SH).

All data were entered onto NVivo 10.8 software then analysed using a structured approach (Braun and Clarke, 2006). The analysis was undertaken in six stages starting with an in-depth familiarisation with the data, followed by the generation of initial codes. These codes were then applied to the data and collated into potential themes. These themes were then reviewed, generating a thematic map of the analysis. The next stage was to refine and name the themes. The final stage was to select examples to illustrate the thematic framework (Braun and Clarke, 2006). This structured approach to analysis provided a transparent and auditable trail of decisions, open to independent scrutiny.

Ethical considerations

Approval was gained from Teesside University Research Governance and Ethics Committee, and governance approval was secured from the acute trust and community settings. All potential participants received an information sheet and were invited to contact the study team if they wished to take part in the study. Those who agreed to participate were then asked to sign a consent form prior to data collection. There was the potential that carers might find the interviews upsetting or intrusive therefore they were reminded that they could stop the interview at any time. A member of the SPCT was available during and after the interview via telephone if the carer required support.

FINDINGS

A total of seven carers (2 daughters, 2 wives, 1 husband and 2 parents of a young adult) of six deceased patients, and 75 professional staff participated in the study, with 15 of the staff being interviewed in both phases (see Table 1).

To provide a holistic perspective, findings from the two data collection periods are presented together in this paper. The overarching finding from both data collection periods was that for a safe, timely, EoL discharge to take place, a large number of factors needed to be in place within a short, specific but unpredictable time point. Therefore it was vital that a co-ordinated approach to the discharge was adopted across the hospital services, in the patient's home and with carers. The new discharge sister undertook a major co-ordinating role, which in many cases resulted in the timely discharge of patients in the last days of their life.

Theme 1: Early recognition of last days of life

Early recognition, by clinical staff, that the patient was entering the EoL phase and in particular the last days of life was vital. Medical and nursing staff could then work together

with the discharge sister, to ask the patient and relatives about their preferred place of care and place of death with sufficient time for their preferred option to be put in place. If there was a delay at this stage, the opportunity to discharge might be lost because the patient's condition might have progressed to the point that transfer to another place of care would run the risk of being uncomfortable, perhaps undignified, and with reduced levels of consciousness. However, hospital nurses and doctors were often reluctant to initiate discussions around EoL and make decisions, including moving to palliation, or discharging home.

> *It is a clinical risk to discharge home a dying patient and I think it does take an element of expertise, specialism, confidence and seniority.* (Palliative Care Team)

Once clinicians had recognised that the patient was entering the last days of life and had informed the family, relatives were often keen to arrange a discharge home.

> *I was absolutely thrilled to have him home, to have that opportunity was absolutely fantastic and I know my husband appreciated it.* (Carer 2)

> *Overall it was brilliant cos he got what he wanted and we looked after him well, and he was where he wanted to be and it was as he wanted it to be. And it has meant such a lot to him and all his family.* (Carer 3)

In general, patients left hospital within 24 hours of the decision to discharge being made. The patient's condition was often the driver for the need for a rapid discharge but families often felt unprepared.

> *Even the ones who know it is coming, it still always wrong foots them a little bit.*
> (Ward nursing staff talking about relatives)

She (nurse) said she (patient) would probably come home tomorrow. I said, that's a bit sharp – you don't get a chance to get things done. She said, no problem – everything will be done by tomorrow. And within 24 hours they had brought a bed, one of these inflatable mattresses, all the help, everything had been arranged, and she came home. (Carer 7)

It was clear that, providing the appropriate support was in place in the community, relatives were grateful to have the patient home.

Theme 2: Timely identification of preferred place of death

The preferred place of death, particularly when it was outside the acute setting, needed to be identified well before the time for discharge arrived. This was to allow for practical preparations to be made, both by the family and support services. This also gave time for all parties to make a realistic assessment of the family's capacity to cope.

If you beat round the bush and start to…then they don't understand what is happening and then they start to worry.
(Ward nursing staff talking about relatives)

As the study progressed it became clear that the discharge sister's role was crucial in identifying the patient's preferred place of death and she therefore needed to become involved earlier in the patient's journey. However, often the preferred place of death was not decided until the patient was entering the last days of life.

They told (my wife) that she wasn't going to get better. So we said, right OK – we will have her home. (Carer 7)

Theme 3: Preparations within the hospital – small window of opportunity

Once clinicians had identified that the patient was entering the last days of life and the preferred place of death had been confirmed, there was potentially a very small timeframe in which to effect a successful discharge. This involved a rapid and co-ordinated response to ensure that everything needed for a safe and comfortable death (such as equipment and aids, medication supplies and relevant prescription authorisations, care plans, clear communications to registered general practitioner and to the out of hours medical services that this would be an expected death) was in place before the patient arrived at their destination. The plan needed to be flexible enough to respond to changing circumstances and family choices but cohesive enough to work across organisations and deal with setbacks. One nurse commented that when she is making discharge arrangements with families,

> *I make sure people know that whatever decision they make tomorrow doesn't mean it has got to be set in stone for Saturday. People change their mind all the time and they have got to be made aware that is absolutely fine.* (Ward nursing staff)

Ward staff required sufficient support to action the discharge process; whether this involved support from the discharge sister to complete the arrangements, help from other staff to free up one nurse's time to organise the discharge or support from 'out of hours' teams. Since introducing the discharge sister post, incremental progress had been reported in streamlining processes but systematic obstacles still remained such as a lack of services outside of office hours.

Theme 4: Care and support in the community

Ward staff had reported that discharging to a patient's preferred place of death, 'happens more now', suggesting that the new service was having a positive impact. Also, once patients had been discharged home, carers felt generally well supported in the community.

> *I can't see how they could improve, not on the care we had because it was absolutely brilliant. They said, 'right we are at the end of the phone, any problems just give us a call'.* (Carer 5)

An aspect that needed further development was the timely prescribing of anticipatory drugs in the community.

> *… the families get really upset as well because they see the patient in pain or unsettled and we know that we should be giving them more pain relief.* (District nurse Focus Group)

Packages of care needed to be sustainable right up until death, even if death came later than expected. One area where improvements could have been made was in the rapid discharge to care homes. Communication between the hospital ward and care home staff seemed to have been lacking at times.

> *We're not really involved in the discharge meeting that happens on the ward. None of us are involved in that and really that is what we need. Someone from the home needs to be involved in that meeting so that you know whether or not you can meet that person's needs.* (Care Homes Forum – Focus Group)

Theme 5: Communication between care providers

Ward staff reported that documentation developed by the new discharge sister greatly improved communication and care delivery. In the community, district nurses also reported improvements in provision of documentation, drugs, prescriptions and equipment. They valued the transferable syringe pump directives and verbal handover from the ward. They used phrases such as: "brilliant", "vast improvement", "more co-ordinated", "everything is in place" about changes they had noticed over the last few months. They found that this gave them more time to spend with the families and to give support that was not only physical and logistical but emotional and psychological too.

> *Cos then you can literally go in and concentrate on the patient without having to*
> *do things on the outside first.* (District nurse)

It was also reported that focused negotiations with transport providers by the discharge sister had reduced the number of long delays experienced by patients on the day of discharge.

Theme 6: Challenges to the successful discharge of patients

A key challenge arose with consistency of provision of the service; not all wards or all staff used the service at every opportunity, nor was an EoL discharge always offered to families and patients. It also became clear that, whilst an underpinning aim of the new post was to increase the knowledge and skills of ward and rapid discharge team staff to plan and carry out these discharges themselves, this did not happen to the extent that had been planned. The time taken to complete an end of life discharge at busy times on the ward was seen as a barrier to success. Staff on the referring ward tended to leave the discharge sister to get on with the tasks involved rather than to work alongside her to learn the process and develop the ability to carry this out themselves in the future. Another challenge came when families

or patients found it difficult to decide about their preferred place of care and place of death. Staff felt it was important that families and patients had permission to change their minds, either towards going home or staying in hospital. However this could contribute to a rushed discharge.

I think they're a bit worried or scared to come home, 'oh no I'll stay in the hospital', but then they will make a quick decision and say they want to be home…….So I think you have to be guided by the patient. (District Nurse)

And they will come really tentatively, like they have done something wrong, 'we have changed our mind, is that a problem?' So you think 'no no, we will sort it out, this is what we are going to do'. (Ward nursing staff)

DISCUSSION

Our study highlighted the many challenges to achieving a rapid and safe discharge in the last days of life. The new discharge sister was able to address some of these challenges and make improvements for patients and carers. Furthermore she was able to negotiate new ways of working which removed some of the organisational barriers that frustrated rapid discharge.

It was clear from our findings that early recognition, by clinical staff, of when the patient was entering the final days of life was a major facilitator for timely and rapid discharge. This is a key lesson to be learned from our study, even though the difficulty of diagnosing dying is well-known (Boyd and Murray, 2012). Once it had been identified, medical and nursing staff could work together with the discharge sister, to ask the patient and relatives about their preferred place of care and death with sufficient time for their preferred option to be put in place. If there was a delay in identifying when the patient was entering the last days of life or

delays in initiating discussions with the patient and family, the opportunity to discharge might be lost. The importance of early recognition is one of the five key actions emphasised by the Leadership Alliance for the Care of Dying People in its guidance to professionals about care in the last days of life following the national withdrawal of use of the LCP (NHS England, 2014).

EoL involves many facets that test clinical decision-making; for example unpredictability of rate of patient decline and unwillingness on the part of some staff, patients and families to accept the inevitable oncoming death (Drought and Koenig, 2002; Gardiner et al, 2011; Gott et al, 2011). Each of these aspects was supported by the findings from our study. Murray et al (2005) call it 'prognostic paralysis' when clinicians delay EoL planning even though they can see an irreversible decline.

Our data suggested that often ward nursing staff also hesitated to act. They were worried about saying the wrong thing and sometimes did not explain the reality of the situation clearly to relatives/patients. This could threaten a smooth transition to preferred place of care or preferred place of death. Such delays in nurse decision-making have been identified in previous studies. For example, Rhudy et al (2010) found that registered nurses tended to be reactive in the discharge process in general. They suggested that it was necessary for nurses to be able to distinguish between routine and non-routine discharges, such as in the last days of life, and then take appropriate, anticipatory action, otherwise the opportunity for discharge was lost, or time at the patients' preferred place of death was reduced.

Our findings highlighted that to minimise delays in discharging patients in the last days of life a high level of professional expertise was required. This was due to the complexity of the rapid discharge process and the tendency for change, leading to difficulties for generalists in making decisions confidently. Individual staff within wards in our study increased their skills but not to the extent that was hoped, and they did not take on the responsibility for rapid

discharges. The service aim was therefore found to be ambitious. Instead a more 'hands on' approach seemed to be needed from the discharge sister to ensure consistency. This was fed back to the service during the presentation of our interim findings. In response, the SPCT accepted that they needed to continue to be significantly involved in the discharge of EoL patients.

Patient choice regarding discharge home in the last days of life is not being adequately translated into action (Gomes et al., 2011). Although the patient choice agenda generally is reflected in UK health policy, it appears that carers in our study welcomed the opportunity for their relative to be discharged home. For the patient and family, discharge offers home comforts at a distressing time (Marie Curie Cancer Care, 2012). However carers in our study were not particularly aware of the changes the new service brought, as they had no previous experiences of discharge at the end of life.

Further challenges to the patient choice agenda highlighted from our findings include four areas of concern relating to keeping patients safe once in the community. Firstly, from within the hospital there was a need for clinical expertise to judge the capacity of families to cope outside the hospital setting and secondly, the provision of community-based services to support the carer and patient needed to be timely and sufficient. This is important because the carer's inability to cope has been identified in the literature as one reason for avoidable readmission at EoL (Hughes-Hallett et al., 2011). Thirdly, there was concern expressed in this study about the quality of care provided by out-of-hours general practitioners, including a perceived lack of confidence in prescribing anticipatory drugs.

A fourth area of concern was communication regarding the patient's end of life decisions and requirements for care. The professional participants in this study were concerned that discussions held in one healthcare setting were not being shared with health professionals in other settings; an issue supported by Brady (2014). The implications of this were that

patient and carer choices might not have been communicated to those caring for the patient. Nationally, action is being taken to address this issue with the introduction of GP EoL registers, Advance Care Planning and the increasing use of the Gold Standards Framework (2013) (Thomas and Noble, 2007; NEoLCIN, 2012).

Limitations

This was a sensitive topic and it proved difficult to recruit carers. Although the carers who participated provided a wealth of information that was invaluable to the study it is possible that the findings might not tell the whole story. Also, the study focused on patients in one acute NHS trust and therefore the findings might not be transferable to other trusts. Furthermore staff were selected only from those wards that discharged the majority of EoL patients in that Trust. Staff who facilitated fewer EoL discharges could have had different experiences from those who had a higher through-put and carers of patients from these wards might also have had a different experience. However it is unlikely that this would have altered the main findings of the study.

CONCLUSION

The discharge sister worked with teams across the hospital to facilitate timely discharges for patients in their last days of life. This was achieved by challenging organisational barriers that frustrated the rapid discharge process and by taking a proactive role in the discharge process. Key implications for clinical practice include the need for clinicians to break their 'prognostic paralysis' and acknowledge the patient's final decline much earlier in the trajectory. This would facilitate earlier discussions with patients and carers regarding preferred place of death and more opportunity to meet the patient's final wishes. Another key implication is the need for a flexible approach to the discharge process so that patients and carers feel supported to change their plans at any time. Flexibility is also needed in the discharge sister role to ensure that there is capacity to respond to changing situations. A

final implication is the need for the grade of such posts to reflect the level of professional skills, seniority and leadership needed to deliver such a complex service. It was clear that this combination of skills and seniority enabled the discharge sister to navigate complex organisational systems to facilitate rapid discharge for those who would otherwise have died in hospital.

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Table 1 – Participants

Phase 1 Data collection (Total participants n=59)

Interviews (n=9)

- Acting postholder

- Ward staff from two different wards (2 registered nurses and 1 ward clerk)

- Carers (6 participants representing 5 bereaved families).

Focus groups (n=7)

- Hospital Palliative Care team (6 participants, including nurses, consultant and administrator)

- Trust Discharge/Fast Track team (9 participants, including nurses, social workers and physiotherapist)

- District nurses –

    Locality A team (10 participants, including nurses, social worker and 2 student nurses)

    Locality B team (3 participants, nurses)

    Locality C team (3 participants, nurses)

- Care Homes Forum (14 participants, including Macmillan nurse lead and managers/deputies of care homes)

- Community Palliative Care team (4 participants, nurses).

Phase 2 Data Collection (Total participants n=38)

Interviews (n=8)

- Acting postholder

- Ward staff from two more different wards (1 ward manager, 3 registered nurses and 2 health care assistants)

- Carer (1 participant).

Focus groups (n=6)

- Hospital Palliative Care team (5 participants, including nurses and consultant)

- Trust Discharge team (3 participants, all nurses)

- District nurses –

    Locality A team (2 participants, nurses)

    Locality B team (4 participants, nurses)

    Locality C team (1 participant, nurse)

- Care Homes Forum (15 participants, including Macmillan nurse lead and

    managers/deputies of care homes).

NB Fifteen of the staff were interviewed in both data collection phases

Table 2 – Examples of interview/focus group guides
Interview Guide Carers

Themes for discussion
- Carers reflections on the opportunity for patients to be discharged at end of life
- Reflections on the hospital discharge process
- Reflections on the services/support available once the patient was received home
- Reflections on caring for the patient at home
- What worked well with regards to the discharge sister service
- What didn't work well with regards to the discharge sister service
- What improvements could be made

Focus Group Guide Ward Staff

Themes for discussion
- Reflections on current and previous end of life discharge processes
- Reflections on Access/referrals to the service
- Reflections on discharge rates/times
- What works well
- What isn't working as well
- Potential improvements to the service
- Reflections on the awareness of ward staff regarding the new discharge sister service
- Reflections on the skills of the ward team in supporting the discharge of the dying patient