Abstract:

Background: People requiring palliative care or approaching end-of-life should have their needs met by services acting in accordance with their wishes. A hospice in the South of England provides such care via a 24/7 Hospice at Home service. Aim: To establish how a nurse lead night service supported patients and family carers to remain at home and avoid hospital admissions. Method: Semi-structured interviews were undertaken with family carers (n=38) and hospice-at-home staff (n=9). Findings: Through night-time phone calls and visits, family carers felt supported by specialist hospice staff whereby only appropriate hospital admission was facilitated. Staff provided mediation between family carer and other services enabling more integrated care and support to remain at home. Conclusions: A hospice-at-home night service can prevent unnecessary hospital admissions and meet patient wishes through specialist care within the home environment.

Keywords: Palliative care, hospice at home, hospital admissions, night service, end-of-life, out-of-hours

Key Points:

1. A night service aimed at supporting people at end-of-life or receiving palliative care can prevent unnecessary calls to emergency services.
2. There are occasions where appropriate care can only be provided in hospital, regardless of the care provision within the community.
3. An out-of-hours service, such as the one in this study, can provide support for patients and families in alleviating their anxieties and sense of loneliness at night.
4. The night service recognises the emotional labour which is required from carers to support someone to die at home, though acknowledges that with support, wishes of both carer and patient to die at home can be met.

5. Communication between the out-of-hours service, patient and carer, and other health and social care providers is essential to supporting people to die at home and avoid unnecessary admissions.

Reflective questions

1. How can the communication between different end of life care services be improved to support people who wish to be cared for in the community?
2. What might cause feelings of anxiety for family members providing care for a person at end-of-life at night?
3. What occasions or health issues at end-of-life might result in a necessary stay in hospital or emergency call out?

Background

Palliative and end-of-life care (PEOLC), is commonly considered as care delivered during the last year of life, that aims to: maintain patient comfort and relieve suffering; support illness management; and be holistic in approach (Sam et al, 2011). The priority from government and clinical guidance (LACDP, 2014; NHS, 2014; NICE, 2017) is for people receiving end-of-life care to be involved in that care, with services being person-centred, available day and night, and supporting people to meet expressed preferences, particularly regarding place of death (King et al, 2004; Carlebach and Shucksmith 2010; O'Brien & Jack 2010). Recommendations also call for greater quality and integration of care provision at end-of-life (IPPR, 2018).

A Dying Matters survey (2015) reported that 70% of people prefer to die at home, although around 46% currently die in hospital (NECIN, 2018), suggesting more could be done to support patients to die at home. The number of people dying at home in the UK has increased recently due to the COVID-19 pandemic (Bowers et al, 2020), with figures showing above five-year average figures (Office for National Statistics, 2020). However, dying at home is only preferred when families are well supported (NCSR, 2014), and pain can be managed (Robinson et al, 2016). People wishing to die at home need access to a range of specialist care services, such as palliative and district nurse care, Marie Curie night sitters, doctor visits and family care provision (Gomes et al, 2015). While the literature identifies benefits to home-based PEOLC, through meeting patient and family's needs and preferences of care, and in cost savings (Grande et al, 2000; McCaffrey et al, 2013), there is inadequate evidence for its impact on hospital admissions and preferred place of death (PECPSP, 2015). The possibility of dying at home is improved by access to domiciliary care provision, to medical equipment and should result in a reduction of inappropriate use of hospital beds (Brazil et al, 2003; Gomes et al, 2015). Community or home-based PEOLC may reduce the number of unplanned hospital admissions and emergency department visits, thereby satisfying people's preferences and improving quality of death (Sutradhar et al, 2017; Wright et al, 2018).

This paper reports on a charitable hospice-at-home organisation in the South of England which provides specialist care for patients diagnosed with life-limiting illnesses, and their families. Through their 24/7 hospice-at-home service, patients can choose to receive practical nursing care at home, advice, and help to control symptoms, with the aim of avoiding unnecessary and unwanted hospital admissions. Initial overnight contact is by telephone, when a nurse will assess the call to determine the best course of action. There is a well established relationship with the hospice night team and the district nurses, as the localities served have an overnight district nurse service. At the beginning of each night the night team will flag any potential challenges and if the hospice team is with a patient when they receive another call, they can liase with the district nurses to ensure patients/families recieve appropriate input.

The hospice evaluated their night service to identify its impact on patients and/or family carers. Key aims were to identify whether and how the night service supported people's wishes to remain at home and explored staff and family carer perceptions of this care on hospital admissions.

Methods

The evaluation was undertaken between July-December 2016, using a mixed-methods approach (Creswell and Creswell, 2018). This paper presents the qualitative findings from family carer and staff interviews to investigate their perceptions of care delivery and impact on ability to remain at home and avoid hospital admissions.

Family carer perspective

Face-to-face semi-structured interviews were conducted with a purposive sample of current family carers (n=20). Participants were identified from patient records to ascertain those patients who had: contacted the night service during the data collection period; consented to take part in research; and were not deemed vulnerable by their care team (see Table 1). Participants were recruited and interviewed by hospice staff/volunteers who had no direct involvement with the provision of the participants' care. Staff and volunteers were involved as peer researchers, and were used because of their service knowledge and were sensitive to the situations encountered by PEOLC. The peer researchers were self-selecting to join the research and were trained in research methods (practical, ethical and methodological issues of conducting interviews) by two members of the research team who held strong track records in conducting research with seldom heard groups. Regular support was provided during data collection to ensure consistency in approach and manage any issues/concerns arising.

Insert Table 1 here

Telephone semi-structured interviews were carried out to explore the views of former family carers, where a death had occurred in the last 12 months. Participants were recruited via a hard copy questionnaire, designed to support other aims of the study. Questionnaires were sent to 268 English speaking family carers and 84 completed questionnaires were returned. Participants were invited to partake in a follow-up interview providing a more in-depth exploration about their experiences. Following expressions of interest from participants, 18 interviews were conducted. Interviews were conducted by experienced university researchers and audio-recorded (see Table 2).

Insert Table 2 here

Staff perspectives

Face-to-face and telephone interviews were conducted with a convenience sample of staff members, depending on availability. All staff working with/for the night service were invited to participate and nine agreed (see Table 3). Interviews were conducted by experienced university researchers and were audio-recorded.

Insert Table 3 here

Data analysis

Interviews were transcribed verbatim, anonymised and subject to thematic analysis, using Braun and Clark's (2006) six-step framework of familiarisation, generation of initial codes and identification, refining and naming of themes. Initial analysis was undertaken by the research team to identify potential themes, then co-analysed with hospice staff and volunteers via two analysis workshops, ensuring staff's tacit/contextual knowledge were included.

Ethical approval

Ethical approval was gained from the relevant faculty ethics committee at the university conducting the research (REF: RGHaHC-04.05.2016) and governance approval was gained from the hospice. Participants engaged of their own volition, being fully informed prior to participation. Written and/or verbal consent was obtained for all interviews.

Results

The impact of accessing an overnight service and its effect on care decisions were discussed regarding meeting patient’s wishes, appropriateness of hospital admissions, brokerage between services, and future care planning. Findings expand understandings of carer and staff perceptions of what it means to provide PEOLC overnight. Verbatim quotations are included, with a code for the interviewer, interview number, and who the quotation is from.

Balancing needs, expectations and wishes

There was a balance for the night service in meeting carer expectations and desires to maintain ‘normality’ at home, as well as supporting a sense of patient personhood until death. Family carers reported it was important in being guided through decision making and helping to meet patient’s wishes to remain at home with “all the benefits of the nursing profession in [our] own home” (Former Carer, AW9).

> *“…that was our biggest anxiety, to make sure that he [patient] didn’t go to hospital, and the (night) service made it possible for that not to happen” (Former Carer, AW01)*
>
> *…what I experience from the [service] nurses is an empathy with the person in the situation that they’re in, with the suffering that they’re in and obviously a very specialised knowledge in the drugs and the pain… (Carer, HB02)*

Family carers admitted that home care was challenging, involving a “huge learning curve” about medical conditions and managing emotional complexities of the caring role. However, meeting the patient’s wishes was important in simultaneously relieving family carer difficulties. Therefore, requiring a balance in managing carer and patient needs. Having access to the night service was reported as vital to fulfilling this and providing the most appropriate care, at the same time as helping to reduce worries associated with home caring.

> *“we needed to be equipped with as much information as we needed to get through the night, which I think we were able to do, and called on that night service when we felt that we were out of our depth” (Former Carer, AW01)*

> *"…she had a syringe driver put in and for some reason two nights on the trot the syringe driver stopped working, so sort of like, you know, midnight I was having to sort of phone up…" (Carer, RA05)*

The challenge for staff was in part focused on dealing with family carer concerns, which were often heightened at night. Both staff and family carers described how, for carers, a sense of helplessness could pervade the night-time hours, which were said to pass slowly, and access to daytime services seemed far away.

> *"…the night is, from a carers perspective, a gloomy period because you don't have the normal resources to call upon..." (Carer, HB03)*

> *"it was lovely to just know somebody was at the end of the telephone, at the, you know, the darkest hours of the night when you think there's nobody around, everything's shut, you can't get help from anywhere, other than an ambulance which [patient] didn't want… and it's quiet too, you hear [patient's] breathing more, you hear you know, stuff that you wouldn't normally take any notice of, that you would just pass it by during the day, it's not as stressful in daylight hours." (Former Carer, AW03)*

Staff reported a key strength of the service was their ability to manage patient/carer concerns, offer reassurances and information/advice that could reduce worries and relieve symptoms. This offered a safety net and helped carers through these feelings. Staff felt they were reducing the impact of difficult circumstances that could exacerbate stress, carer burnout.

> *"I think [the night service is] adding comfort to the family that there is somebody there they can talk to… and give them that reassurance." (Manager, JS07)*

> *…it's about managing expectations, talking people through…, just getting them to be calm and just reassuring them, because I think we forget what a responsibility it feels*

> *like having someone at home who's dying… for them it feels like it's all on them, they're on their own. (Day Nurse, JS03)*

A final balance that family carers faced was in deciding when to contact other services overnight. When prompted, carers (n=14) suggested they would contact the NHS emergency helplines (999/111), district nurses, out-of-hours doctor, local hospital or MacMillan services as an alternative to the overnight hospice service. However, some family carers reported this as a "last resort", fearing a hospital admission, or lengthy conversations describing the patient's condition to someone with no prior knowledge. Families felt this could be "distressing" and "disruptive". For these family carers, the overnight hospice service provided an alternative to calling on the emergency services, and were perceived to have a more direct connection to other services.

> *'I rang the 111 number and they tend to send an ambulance out anyway…, but with the [service], there was a situation then when I rang and they felt perhaps a doctor should come, and the doctor came straightaway, it was under an hour, where with the 111 it was a bit more longwinded.' (Carer, SD02)*

Appropriateness of hospital admissions

Family carers and staff acknowledged that some hospital admissions were necessary and appropriate, providing accounts of hospital admissions occurring that were perceived to be in the best interests of the patient's comfort, or resulted from a deterioration in their condition:

> *"I'd had to phone 999 sometime before, because then he had to go into hospital with pneumonia." (Carer, RF03)*
>
> *"I've taken her [patient] to A&E [Accident and Emergency] ... That's been temperature related because with the cancer, when you get to 38 degrees, then it's a trigger point… so I've had an ambulance out." (Current Carer, HP03)*

Family carers reported that night service staff sometimes recommend calling an ambulance after assessing a patient's condition, viewing it in the patient's best interest. This resulted in an extended hospital stay for one patient, while another required a drip for extreme dehydration. Staff spoke of the complexities of illness at end-of-life, how conditions can change quickly and may require specialist medical attention not possible to provide at home, for example with specific cancer symptoms. Carers perceived the night service to offer a flexible approach, which could contribute to emergency service referrals, including the out-of-hours doctor and in-patient hospices.

Mediation between families and services

There was a sense that staff, patients and carers needed to work together to ensure patients' wishes could be managed, in a quote below, one carer explained the complexities of navigating between services and accessing medication.

> *"…you get blockages all the time between the [General Practitioner], between the nursing service, between chemists, you know, even getting prescriptions, you end up, you've got to go to the doctors to get the prescription, then you've got to find a chemist that has all these drugs and often they don't so you've got to wait for the next day…" (Former Carer, AW02)*

However, family carers acknowledged the close links the night service had with other services and valued their ability to navigate the complex health and social care systems on their behalf, ensuring timely care was provided:

> *"And in the morning, [nurse name] came with a doctor because obviously they'd had the report back about the night and they gave [patient] an injection and he slept most of the morning." (Carer, HB03)*

Such brokerage by hospice staff related to managing and negotiating expectations. A staff member explained that families should be involved in the care decisions if inappropriate admissions are to be avoided.

> *"…it's important that the patient and the family are involved in the conversations about hospital admission. I think maybe inappropriate admissions would be more because it's carer breakdown potentially, or not having lay carers in place to help support care packages… sometimes patients' families cannot cope, no matter what support is put in... Sometimes that can go against what the patient wishes, so you try and broker that and talk it through and … put in whatever support you can."* (Day Nurse, JS03)

Future care planning

The hospice works with patients and families enabling them to plan their PEOLC; such planning was reported as fluid, flexible and renegotiated as changes are experienced by patients/families. Staff reported that access to services influenced decisions of where to die and that hospice admission, rather than hospital admission, may provide more suitable care provision than the 'at home' service.

The need for conversations about PEOLC plans and 'do not resuscitate' orders were highlighted by staff. These were said to aid hospital avoidance, helping families make informed choices and staff to ensure the necessary paperwork were in order, enabling patient's wishes to be met. Staff identified that navigation through complex care pathways is not always straight forward, especially when the patient and family wishes differ or change. The role of the night team was identified as being able to action these plans when a crisis occurred overnight.

> *"…the patient who we're supporting well at home, who we've planned and thought about, so we've got the just in case medications in, [and] do not resuscitate, we've had the conversation about where do you want to be and then they hit a crisis, I think the night staff are invaluable there because they'll help us keep that plan in place." (Clinical Nurse Specialist, JS01)*

Discussion

This evaluation has contributed to knowledge on home care at end-of-life, expanding understandings of what it means to provide home-based PEOLC, together with evidence that hospital admissions were perceived, by both family carers and staff, to be preventable with the support of an overnight nursing service. However, it was acknowledged that some hospital admissions are clearly necessary and appropriate regardless of overnight care provision. The current study also developed understanding of the ways a dedicated overnight service can support PEOLC.

The night service was found to support the patients' sense of personhood and choice to die at home, enabling as good a quality of life as possible before death, something many value about end-of-life care (Pollock, 2015). An overnight service, as in this study, can mitigate the potentially negative perceptions about dying at home, i.e. that it can be lonely, painful and distressing (Pollock, 2015). The night service recognised that caring for someone dying at home requires considerable emotional labour and that support jointly for the patient and family carers is invaluable in relieving that sense of loneliness, which is often worse at night. Unexpected hospital admission may be more likely to occur out-of-hours because of the increased anxiety that timely care cannot be obtained (King et al, 2004). A lack of out-of-hours services is a major factor that can result in an admission to hospital during the last days of life (O'Brien and Jack, 2010). Additionally, carer anxiety can be reduced with out-of-hours provision and good communication (King et al, 2004; Aparicio et al, 2017; Hutchinson and Van Wissen, 2017), particularly if services know about the patient prior to a visit or having medication available out-of-hours (King et al, 2004). The complexity of PEOLC and the potentially rapid changes in condition that may occur can challenge community care, which can be perceived as not being responsive (Robinson et al, 2015), however, the findings from this study would suggest that a dedicated 24/7 provision can be responsive to these challenges, particularly in reducing anxieties and carer burden. One aspect that emerged from this study was the potential for carers and patients to be hesitant in calling overnight services, initially (Sixsmith et al., 2017). As this study finds, access to care and support overnight can minimise unnecessary hospital admissions and be integral to symptom management. A recommendation derived from the current study is that services, such as hospice-at-home outreach services, or community/district nurses need to provide greater assurances for patients that calling a service overnight is an appropriate and welcomed response to relieve patient or carer distress and perhaps reduce calls to emergency services.

Studies suggest a greater likelihood of high levels of carer burden when caring at home until death, and that this has a greater chance of resulting in carer depression, stress, isolation and health problems (Carlebach and Shucksmith, 2010; Jack et al, 2016; Horsfall et al, 2017). Carer burden may result in unnecessary hospital admissions (King et al, 2004; Brodaty and Donkin, 2009), suggesting that out-of-hours PEOLC services should work to minimise carer burden and consequently minimise unnecessary hospital admissions (Kristjanson et al. 2004; Aparicio et al, 2017). Staff from the present study identified this as an essential part of their service, and felt that carer burden could be mitigated with open discussions to keep family members informed of what impact home care could have. Being involved in care and decision-making is an important aspect of care provision, particularly ensuring that families understand how an individual’s condition may progress (DoH, 2008). Such conversations have previously been considered challenging in the hospital environment (Robinson et al, 2014). As such it is recommended that the provision of a quality at-home service should enable these conversations to become more integrated in the care process, with all care providers involved to maximiase consistency across services. It is also recommended that services reinforce the message that day or night calls for emotional support, to relieve anxiety of patients and their informal or family carers, are an important and relevant part of PEOLC.

Part of these discussions involved talking about advance care planning and having relevant paperwork and care decions in place. A part of these discussions is to ensure timely and effective symptom management and use of medication at end of life (Bowers and While, 2019). Symptom relief was a key factor of care and support for the overnight service and included in the advanced care planning with the provision of “just in case drugs” and anticipatory prescribing which enabled staff to meet the needs of patients out of hours.The Institute for Public Policy Research report on end-of-life (2018) makes recommendations for holding conversations about death and dying with families. These conversations need to occur early following the diagnosis to adequately meet patient’s wishes, particularly as changes in a patient’s condition can fluctuate and needs change. Conversations around end-of-life care are crucial so that advance planning is put in place (Wilson and Birch, 2017), and anticipatory prescribing can be considered that meets the patient’s preferences (Bowers and While, 2019). Government and clinical guidance (NHS, 2014; DoH, 2014; RCP, 2016) advocate for end-of-life care planning to ensure that people can express choices of where and how they want to die, so that services are aware of refusal of treatment, for example. Part of these conversations are an understanding of the potential progression of symptoms to inform decisions on symptom management and use of medication (Bowers and While, 2019). These conversations can also be aided by carer understandings and knowledge of PEOLC and what it means to care for someone at home. Families in this study reported on the learning curve about end-of-life care, often through experiencing different situations, dealing with medication management, and on the support received from staff, who included nurse prescribers and/or close liaisons with general practitioners or district nurses. There is potential to develop further understandings of how carers can be supported, and training could be offered to support home care. Another factor in the improved provision of care is the use of “just in case” medication which is invaluable for out of hours use. The night team has a nurse prescriber and as the hospice is a nurse lead organisation, plans include increasing the number of nurse prescribers as this will allow reactive care as well as remaining proactive. With further nurse prescribers on staff, this may also alleviate pressuers on district nurse prescribers or out of ours doctors to attend.

This is also important for inter-professional working, as systems and processes may differ resulting in tensions in care decisions (Keane et al, 2017). Brettell et al's (2018) review of out-of-hours primary care end-of-life contacts report on the pressure these can put on doctors' services. Therefore, a collaborative, multi-stakeholder approach to end-of-life care can provide a more efficient and holistic way to treat patients and meet their needs, as well as reducing the potential burden on other, already stretched services.

Limitations

Using peer researchers could have impacted on the experiences participants shared. However, peer researchers can be a positive way of undertaking research, eliciting insights through tacit knowledge and experience which enhances data collection (Lushey and Munro, 2014). With appropriate training and ongoing support (Lushey and Munro, 2014), they can be an asset. Peer researchers in this study were therefore provided training to ensure a rigorous approach to the data collection/analysis.

Conclusion

PEOLC is constituted of a complex interplay of different services to support a range of physical, psychological and social needs across a range of hospital to home settings. A home-based night service can enhance the quality of care, preventing calls to the emergency services through provision of support for patients and families in alleviating their anxieties and sense of loneliness at night, and provision of appropriate care and treatment. However, there are occasions where care needs can only be provided in hospital, regardless of the community care provision. A clear recognition of the synergy between community and acute care is therefore required to support decision making and ensuring staff are sufficiently skilled to support patients and their families out-of-hours. The stresses of emotional labour experienced by carers when supporting someone to die at home, was recognised, being especially difficult to address at night time when worries magnify and service support is less available. However, with day and night time support provided, carer and patient wishes to die at home can be met. This is an important point to emphasise as patients and families who live in localities without home-based night services may be disadvantaged. Such worries can be alleviated through phone call support or increasingly on video conferencing platforms (as the COVID pandemic has highlighted), and as such, NHS in localities without hospice-at-home night-time outreach support should be encouraged to develop accessible day and night remote support. A further point is that communication between out-of-hours services, patient and carer, and other health and social care providers is essential in supporting people to die at home and avoid unnecessary hospital admissions. The challenge arises in how best to support communication between different end-of-life services so that they can best support people who wish to be cared for in the community. This study found that only through open and sometimes difficult discussions, and a skilled and confident staff, can patient's wishes and needs be met.

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Table 1 – Current family carer demographics

Demographic	No
Gender	
Male	9
Female	11
Relationship to patient	
Parent	4
Spouse	15
Not known	1
Hospitalised when receiving care with the hospice	
Yes	8
No	12
Type of contact with the hospice	
Telephone and visit contact	20

Table 2 – Former family carer telephone interview demographics

Demographic	No
Gender	
Male	5
Female	13
Relationship to patient	
Parent	4
Spouse	12
Son/daughter/other family member	2
Hospitalised when receiving care with the hospice	
Yes	2
No	16
Type of contact with the hospice	
Telephone and visit contact	18

Table 3 – Staff interview demographics

Demographic	No
Gender	
Male	1
Female	8
Staff roles in hospice	
Night staff (nursing and Health Care Assistant)	7
Nurse (day staff)	51
Health Care Assistant (day staff)	8
Staff roles participating in interview	
Night staff (nursing and Health Care Assistant)	3
Nurse (day staff)	5
Health Care Assistant (day staff)	1