

**Service evaluation of community based palliative care and  
a hospice at home service**

WILSON, Janet, STEERS, Julie, STEELE, Kath, TURNER, James  
<<http://orcid.org/0000-0002-8360-1420>> and TINKER, Alison

Available from Sheffield Hallam University Research Archive (SHURA) at:

<https://shura.shu.ac.uk/12869/>

---

This document is the Accepted Version [AM]

**Citation:**

WILSON, Janet, STEERS, Julie, STEELE, Kath, TURNER, James and TINKER, Alison (2015). Service evaluation of community based palliative care and a hospice at home service. *End of Life Journal*, 5 (1), 1-11. [Article]

---

**Copyright and re-use policy**

See <http://shura.shu.ac.uk/information.html>

# **Service Evaluation of Community-based Palliative Care and a Hospice-at-Home Service**

## **Authors**

Janet Wilson, Senior Lecturer (Nursing), Sheffield Hallam University, Faculty of Health and Wellbeing, Sheffield

Julie Steers, Senior Lecturer in End of Life Care, Sheffield Hallam University, Faculty of Health and Wellbeing, Sheffield

Kath Steele, Senior Lecturer in Palliative Care, Sheffield Hallam University, Faculty of Health and Wellbeing, Sheffield

James Turner, Principal Lecturer (Mental Health Nursing), Professional Lead, End of Life and Supportive Care, Sheffield Hallam University, Faculty of Health and Wellbeing, Sheffield

Allison Tinker, End of Life Care Project Lead, Rotherham Hospice, Rotherham

**E-mail:** j.l.wilson@shu.ac.uk

Received July 2014

Revised November 2014

Revised April 2015

Accepted

**Competing interests** None

## **Abstract**

### **Background:**

Hospices and other palliative and end-of-life care providers are now required to develop services that aim to improve the quality of end-of-life care and choice in terms of place of care and death for those living with or dying from a life-threatening illness. In 2010, an NHS clinical commissioning group in South Yorkshire, UK, produced a strategic plan that aimed to improve the quality and choice of end-of-life care locally. To that end, it established a project team to review the services already provided by the local hospice and to extend the hospice's already existing services, including expansion of the hospice-at-home service.

**Aims:** To explore the views of key stakeholders, including healthcare staff and service users, with regard to the quality of care provided by the expanded hospice-at-home service and the choice and quality of palliative care available in the community. Four priorities for exploration were identified: the use of electronic records, advance care planning, communication and care co-ordination, and 24-hour access to end-of-life care services.

**Method:** A policy-applied qualitative methodology was used to explore stakeholder views. Four focus groups, using a semi-structured interview schedule, were conducted with four stakeholder groups: patients/carers; community nursing staff; palliative care nurse specialists; and GPs/senior managers. Data analysis used a framework approach to categorise the stakeholder responses according to the four priority areas identified.

**Findings:** A total of 30 participants were recruited from the four stakeholder groups; patients and carers ( $n=5$ ); community nursing staff ( $n=6$ ); palliative care nurse specialists ( $n=9$ ); and GPs and senior managers ( $n=10$ ). Participants perceived that important aspects of end-of-life care needs were being met. These included quick access to hospice-at-home services particularly over bank holidays, and the prevention of admission to hospital for patients who received visits and treatment at home from this service. These aspects were highly valued by

all the participants who took part in the focus groups. Issues that needed improvement were identified and included communication problems between hospital and community services, education and training needs for some staff regarding the use of technology and the limitations of the current service in relation to home visits from the hospice-at-home service.

**Conclusions:** Recommendations for developing end-of-life care services included 24-hour access to home visits over 7 days each week, the provision of training and education for staff in the use of technology, talking to families about advance care planning, and improved communication between and timely transfer of information from hospital to community services when patients are discharged.

## Introduction

Most terminally ill people would prefer to die at home (Neuberger, 2004; Barclay, 2009; Stevens *et al*, 2009; Eyre, 2010). However, only about a quarter will do so (Lakasing, 2012). Dying at home has been found to be dependent on various factors, for example, the level of support from family carers, the ability of family carers to maintain care at home, and the availability of good-quality social and health care support, including home-based palliative care (Gomes and Higginson, 2006; Sheppard *et al*, 2011; Capel *et al*, 2012).

Family carers of terminally ill people can receive variable amounts of support and may struggle to cope, leading to the patient being admitted to a hospital or hospice (Lakasing, 2012). In many situations, death is preceded by an extended period where the patient's ability to function independently progressively declines, necessitating an increasing amount of care from both family members and health and social care professionals (Eyre, 2010). Providing palliative and end-of-life care in a home environment can be challenging both for health professionals and family carers. For example, family carers can become distressed when they witness their loved one experiencing symptoms, such as pain and nausea, may feel anxiety or embarrassment at carrying out certain aspects of physical care and feel they are unable to cope both physically and emotionally with the caregiving role and the responsibility they feel for their relative (Beland, 2013). The psychological impact on family carers in terms of stress and the disruption to daily life can be substantial both before and after the death of the patient (Eyre, 2010).

The main goal in delivering good end-of-life care is to be able to clarify people's wishes, needs and preferences and deliver care to meet these needs (The Gold Standards Framework (GSF), 2013). Advance care planning (ACP) is a process of discussions with patients and, with the patient's permission, their families or carers, to understand patients' preferences for end-of-life care, including preferred place of care and death, in the event that they lose capacity to make decisions in the future (Henry and Seymour, 2008). Undertaking ACP discussions has the potential to improve care for people nearing the end of life, facilitate better planning and provision of care, help people to live and die in the place and manner of their choosing, and decrease the risk of people dying in an acute hospital setting (Henry and Seymour, 2008; Capel *et al*, 2012; Ahearn *et al*, 2013).

A range of health professionals may be involved with the care of terminally ill patients and their families/loved ones in the home setting, for example, GPs and community nurses and staff from organisations such as hospices, Macmillan Cancer Support and Marie Curie Cancer Care (Beland, 2013). This necessitates the need for the sharing of information among and clear communication between the different professionals and a clear and co-ordinated

plan of care so that the patient and family members understand whom they should contact for specific issues (Jarrett and Maslin-Prothero 2008).

Hospices and other palliative and end-of-life care service providers are widely recognised as being specialist providers of end-of-life care (Goodwin *et al*, 2002; Goldschmidt *et al*, 2005; Sullivan *et al*, 2005). Since its inception in the 1960s, the modern hospice movement has evolved and developed to meet the needs of both patients requiring palliative care as well as their families/loved ones (Help the Hospices Commission, 2013). Hospices and other palliative care providers are now required to develop services that aim to improve the quality of end-of-life care as well as choice in terms of place of care and death for those living with or dying from a life-threatening illness (Department of Health, 2008).

It has been identified that hospices need to provide certain services for patients with terminal disease being cared for in the home environment (Higginson, 2003; Shepperd *et al*, 2011). These include communicating and liaising with the various professionals involved in the patient's care, the provision of emotional support to both the patient and family members and the provision of care from hospice staff, particularly during evenings, nights and weekends (McLaughlin *et al*, 2007; Eyre 2010; Beland, 2013). Consequently, hospice services have become more complex and wide ranging. Many hospices now have roles that involve supporting healthcare staff in care home, community and hospital settings, providing bereavement support and outpatient facilities, and the delivery of integrated hospice-at-home services over a 24-hour period, every day of the year (Bell *et al*, 2013).

In view of the need to improve the quality of palliative and end-of-life care services and choice in relation to place of care and death, in 2010, a local NHS Foundation Trust in South Yorkshire, UK, published a strategic plan for 2010–2015. The aim of the plan was to improve end-of-life care services for its local population. The specific objectives were to: review and extend the local hospice service, including re-commissioning an enhanced hospice-at-home service; increase the community specialist palliative care capacity; and develop the workforce to deliver high-quality palliative care by implementing The Gold Standards Framework (GSF). The GSF is a systematic, evidence-based approach to optimise the care for patients nearing the end of life delivered by generalist providers. It is concerned with helping people to live well until the end of life and includes care in the final months and/or years of life for people with any end-stage illness in any setting (Thomas, 2003; Dale *et al*, 2009; Shaw *et al*, 2010; GSF, 2014).

A project team was recruited jointly by the local NHS Foundation trust and the local hospice in 2010 on a 2-year fixed term contract. The aim was to train all commissioned providers of palliative and end-of-life care in the principles of delivering high-quality care. The team was responsible for recruiting GP practices and care homes onto the GSF's 12-month training programmes (GSF, 2014). In addition, an integrated pathway of care coordinator was employed by the Trust, also on a 2-year fixed term contract, to deliver training in the use of the Liverpool Care Pathway for the Dying Patient (LCP) to staff delivering end-of-life care. At the time, the LCP was a nationally recognised plan of care for the last weeks to days of life and was recommended as a best-practice model by the Department of Health (2008). In 2013, an independent review of the use of the LCP in practice identified several concerns regarding its implementation and use and recommended it be subsequently withdrawn (Department of Health, 2013). By the time this recommendation was made, the 2-year project had already been completed. Both of the above educational initiatives were supported by the

consultant in palliative and end-of-life care at the local hospice and the GP who was the lead within the primary care trust for end of life care.

Furthermore, plans were approved by the local NHS Foundation Trust to increase the in-patient capacity at the local hospice from eight to 14 beds, to transfer 93 staff delivering specialist palliative and end-of-life care from the community health services to the local hospice and enhance the hospice-at-home service. The hospice-at-home service introduced a dedicated telephone line which could be accessed at any time of the day or night, every day of the week by community nursing and medical services, patients and carers. The telephone was manned by clinical nursing staff at the hospice between the hours of 8 am and 10 pm each day. Nurses based at the hospice were available to visit patients to provide care and advice in the patients' usual place of residence, e.g. own home, residential or nursing home, during these hours. Outside of these hours, anyone contacting the service would receive telephone advice only.

A stakeholder event involving a meeting of the project team and representatives from key groups of stakeholders (patients and carers, community nursing staff, palliative care nurse specialists, and GPs and senior managers) took place in 2012. This was the mid-point in the five year strategic plan which started in 2010 and its purpose was to review progress and identify future priorities. Four future priorities that were identified are listed in *box 1*.

**Box 1. Four priorities identified from the stakeholder event**

- The use of an electronic end-of-life care register and templates for care
- Advance care planning
- Communication and care co-ordination
- 24-hour access to care and equipment seven day a week

It was at this point that Sheffield Hallam University was commissioned to be involved in formally evaluating the outcome of the 2-year project and make recommendations for the future development of palliative and end-of-life care in this locality. The specific terms of reference of the evaluation were to:

- Evaluate the recent arrangements for palliative and end-of-life care at the local hospice;
- Explore the experiences of stakeholders of palliative end-of-life care provided from the hospice;
- Determine from both qualitative data and analysis of key service level quantitative data gathered by the local NHS Trust, the extent to which the process of end-of-life care at the hospice has met needs;
- Bring forward recommendations to enable the local NHS Foundation Trust to make informed decisions as to further developments in end-of-life care;
- Develop a report to enable further decisions to be made with regard to palliative and end-of-life care funding and service provision for the future in this locality.

This article reports on one element of the evaluation of this service, that is, assessing the effectiveness of the hospice-at-home service from the perspective of the stakeholder groups.

**Methodology**  
**Study design**

A qualitative focus-group research design, using a purposive sample of key stakeholders, was adopted as the study was exploratory and sought to gain a wide range of viewpoints from both professionals and service users in relation to their perceptions and experiences of the hospice-at-home service (Andrews and Seymour, 2011; Parahoo, 2014). Focus groups enabled the researchers to explore the thoughts and experiences of the participants using group processes to aid exploration and the clarification of views and enabled the interchange and discussion of ideas (Guthrie, 2010). Parahoo (2014) describes a focus group as an interaction between one or more researchers and one or more respondents, with the purpose of collecting research data. Interaction is a key concept of focus groups giving them a high level of face validity as data generated can be confirmed, refuted or discussed further within the group (Addington-Hall *et al*, 2007; Krueger and Casey, 2008). This has the potential for greater breadth of understanding and gives the researcher the opportunity to gain instant validation of participants' responses and more in-depth information (Loeb *et al*, 2006). The timing of focus groups can vary, but it was intended that they would last no longer than 2 hours (Quine and Cameron, 1995; Loeb *et al*, 2006).

The focus group discussion was facilitated using a semi-structured interview schedule to capture the meaning of experiences in the participants' own words (Marshall and Rossman, 2010). Semi-structured interviews allow a flexible approach to data collection and encourage rapport to build between the facilitator and participants which may assist with data collection (Parahoo, 2014). Data analysis was carried out using the framework approach (Ritchie and Lewis, 2003). This method assists in capturing the complexity of qualitative data, and enables the grouping of similar responses across groups and researchers to categorise the findings and attach them to the areas being explored (Ritchie and Lewis, 2003; Addington-Hall *et al*, 2007).

### **Ethical considerations**

Ethical approval was gained for this study from the regional NHS ethics committee and in accordance with the NHS Trusts governance processes. Written information was given and informed consent obtained from participants before the focus groups and confidentiality and anonymity was fully explained and assured at the start of the groups. Support mechanisms were in place and made available should any participant experience emotional distress during the focus group discussion. The support mechanisms consisted of the End of Life Project leader, who was a nurse, being available during the focus groups and if anyone wanted support following the event then psychological support was available from staff at the hospice.

### **Reliability and rigour**

The background of the researcher will affect what they choose to explore, the angle at which they approach an investigation and the findings considered most significant and therefore it is not possible for researchers to be neutral observers (Parahoo, 2014; Malterud, 2001). Strategies can be used to help limit researcher bias. Researchers facilitating the collection of data need to be committed to reflexivity, that is, to systematically attend to the context of the knowledge being constructed and the affect of the researcher throughout the research process (Malterud, 2001). Preconceptions need to be declared and shared with other researchers. Where there are multiple researchers this can strengthen the study design as statements can be contested and supplemented through discussions. In this study there were four researchers so it was possible to share preconceptions and have discussions where views were contested.

A method to improve the rigour of findings can be to go back to the participants to check out findings and to ask how they felt about participating. Morrison and Peoples (1999) identify that this can be done at the end of a focus group by summarising the key points raised and seeking verification from the participants. The researchers were mindful of this and used this approach at the end of the focus groups.

### **Sample**

A purposive sample was drawn from previous participants of the initial stakeholder event in 2012 and recent patients and carers from the end-of-life service. The number of participants totalled 30. The project leads sent letters of invitation to attend the focus groups to all potential participants. Potential participants were also sent consent forms and the research participant information sheet. Self-selection was in the form of agreement to take part in the focus groups.

### **Data collection**

Four focus groups were identified, each consisting of key stakeholder representatives: community nursing staff who were district nurses, patients and carers, GPs and senior managers who were GP practice managers, and palliative care specialist nurses. It was decided that patients and carers should form a combined group as it is recognised that patients in particular are a vulnerable group and if able to attend may have required support from their carers (Addington-Hall *et al*, 2007). However, on the day, none of the patients were able to attend the focus group and so this group consisted totally of carers. From this point in this paper this group will be referred to as the carers' group. It has been recommended that a focus group should contain six to eight participants (Greenbaum, 1997; Stewart *et al*, 2006). In this research, the numbers in each stakeholder group were as follows: palliative care specialist nurses ( $n=9$ ); carers ( $n=5$ ); GPs and senior managers ( $n=10$ ); community nursing services ( $n=6$ ). In the GPs and senior managers group the three senior managers were nurse managers and the community nursing services group consisted of district nurses.

The four groups met separately to enable all those involved to have the opportunity to share their experiences by facilitating a non-threatening environment and enabling the facilitator to respond flexibly in timing the group discussion. These factors were recognised as important given the potential vulnerability of the carers participating in this study. The focus groups lasted approximately 1 hour and 15 minutes each. This time period was felt to be important as anything over this time, compromises the accepted 'attention span' of a group (Guthrie, 2010). The key questions for the focus group were based on the four priorities (see *box 1*) identified at the original stakeholder event in 2012 (*box 2*). Each focus group was recorded and transcribed verbatim by an external transcriber. In addition, supporting flip chart notes were made of key points raised during each focus group.

#### **Box 2. The questions asked in relation to each of the four priorities**

1. What is currently working well?
2. What still needs to be done to improve?
3. What do you consider the obstacles to be?
4. Do you have any other comments?
5. What are your key priorities and recommendations?

### **Data analysis**

A qualitative framework analysis approach was undertaken based on the transcripts of the four focus groups. The evaluation team initially 'immersed' themselves in the data by reading all transcripts and going through the supporting flip chart notes for all four focus groups. The findings were allocated as appropriate to each of the four priorities identified from the original stakeholder event. The analysis also took into account that meanings are constructed by participants in the context of their social and personal world (Smith and Osborn, 2003) so each group had significant issues which were pertinent to them but may not have been to other groups. The framework analysis was undertaken by two of the evaluation team and then passed to the second pair for validation and review.

## **Results**

The findings are reported below in relation to the four identified priorities (see *box 1*).

### **The use of an electronic end-of-life register and templates for care**

The community nurses, GPs and specialist practitioners stated that they have laptop computers that they take with them when visiting patients. This enables them to register patients and record visits and other information on a computerised system. This computerised system also has templates that can be completed as required to provide guidelines and assist in the management of patients' symptoms regarding issues such as pain relief, nutrition and mobility. Although the computerised system was perceived by participants in the community nursing, senior managers and GPs, and palliative care specialist groups as having advantages in that it resulted in information being shared amongst professional groups, there was some concern about using technology when visiting patients nearing the end of life:

*'Going into someone's home where they are dying and opening a laptop is quite insensitive...we all feel that as opening a set of notes seems less obtrusive'* (Community nurse 3).

The technical problem of accessing the Internet was an obstacle in some areas. In addition, the computerised system could be slow to upload and did not always work effectively, leading to the perception that there was an over-reliance on this form of communication. In addition, not all practitioners involved in the patient's care could access the register and templates as different staff groups needed to have permission from patients to view what others had written, which was considered another limiting factor of the system:

*'...we can't see what they've done an assessment on'* (Community nurse 1).

The community nurses often knew the patients and their families well and felt that they may be aware of issues that would be of use to other professionals. However, the computer system used did not allow for third-party information to be recorded. Third party information refers to information relating to other family members which was known to the community nurses and could impact on the patient and their care. This could include other family members who were ill or had a disability or support available from relatives who lived nearby.

Although, in general, the carers' group was not aware of this system, one carer was concerned that the details were not always inputted accurately:

*'...they got some details incorrect on the form...you need to make sure that they are completed accurately because if they are not then it creates a bit of an issue'* (Carer 4).

The community nursing participants highlighted a need for staff education, as they had found that some practitioners were not aware of the templates or where they could be accessed on the computer system. This resulted in staff asking the patient and carer questions they had already been asked by other professionals. In addition, some participants felt that particular staff groups approach topics from different perspectives and therefore repeat questions in order to hear the information for themselves and to feel ownership of the situation.

Therefore, although the sharing of information through the computerised system was perceived as potentially useful, the areas that were identified as needing improvement included access to both the system and the Internet and the coordination and accuracy of the templates in terms of ensuring the data were inputted correctly.

### **Advance care planning**

Advance care planning (ACP) discussions were perceived by some participants to take place at an earlier stage of the illness trajectory than had been the case before the project commenced, enabling planning to take place to meet patient and family wishes regarding preferred place of care. For example, carer 1 commented that she felt the service was now much more proactive than had been her experience when she was in a similar position 5 years previously. However, it was recognised that the timing of ACP discussions and the complexities involved were issues needing improvement:

*'It is a society issue about educating the population for planning for death and cultural issues about talking about taboo subjects' (GP 3).*

Community nursing staff also stated that knowing when to begin ACP discussions was difficult and sometimes found such subjects hard to broach.

Participants in the carers' group reported that they had found some GPs did not know how to discuss end-of-life care. They also stated that they did not understand clearly what ACP involved, wanted more clarity on this issue and would have benefited from a greater understanding of the process:

*'I was asked about the do not resuscitate thing [form]. I just looked at him and said I have no idea what that is' (Carer 2).*

An example of the importance of advance planning for end-of-life care was in relation to medications. As there is no 24-hour pharmacy service in the town, there could be difficulties in getting prescriptions fulfilled overnight. Carers have to travel to a nearby city for this service, but this is not always feasible and can result in a patient being admitted to hospital solely for this reason. Another concern highlighted in relation to this issue was that there were a limited amount of nurse prescribers, particularly at nights and weekends, which resulted in delays in patients receiving medication for symptom control. Also, specialist clinicians expressed concern regarding the delays and difficulties they experienced in getting patients newly arrived in care homes to be registered with the local GP. If the patient newly arriving in a care home was not registered with a GP then there was sometimes a delay in accessing prescriptions for medication which affected the implementation of advanced care planning.

### **Communication and care co-ordination**

Communication in this context related to communication between different professionals and with patients and their carers. This was a major feature of care that was highlighted by all four groups.

Good communication amongst professional groups was perceived as enabling services to work together more effectively. The dedicated telephone line at the hospice meant healthcare staff, patients and carers were able to contact the hospice at any time of the day or night. A wide range of staff, including GPs, care home staff and community nurses, telephoned the service and found that they got a quick response. Carers reported that their experiences of communication with the hospice were excellent:

*'The locum GP wouldn't prescribe a high dose of analgesia and hospice at home stepped in, I don't know what I would have done without them'* (Carer 1).

*'If they can't answer your query immediately, they get back to you within a few minutes. I am in total awe of them; they are so supportive'* (Carer 3).

There appeared to be a degree of uncertainty as to the role of the hospice-at-home team at the beginning of the project and confusion existed amongst staff regarding job titles as some staff changed from being Macmillan nurses to cancer care specialists due to funding changes. The community nurses group noted a number of issues around communication, primarily with regard to discharges and information not following immediately:

*'The hospital might discharge someone who is very poorly back to a nursing home, and they don't send the discharge letter with them...that comes two to three days later...by which time the patient might have died'* (Community nurse 6).

Carers reported that there was a breakdown in communication at times between different groups of staff and they had to inform the visiting professional of the latest information regarding the patient's care. A carer gave an account of a patient being admitted to an acute hospital through the accident and emergency department and the hospital staff not listening to them regarding what the problem was:

*'There wasn't integration of information. They checked my dad's perceived illness when he went into hospital, not his actual condition, despite us saying you're dealing with something completely different. I might as well have been talking to the wall'* (Carer 2).

Carers wanted to be kept informed of the referrals that were being made for the patient and wanted to be visited and cared for by staff whom they knew and who knew them:

*'If you know the people who are coming, you've got a trust in them, you've built that trust and its those people you want to see coming through your door because you know they're going to help'* (Carer 4).

Carers also wanted clarification regarding the hospice contacting them after the person's death. They reported that they were contacted about bereavement support 6 weeks after the death, but they had not been aware that this was going to happen. Community staff highlighted that there is an obvious link for families between the hospice and patients with cancer but the link is not so obvious for those with other life-threatening illnesses who are at the end of life, for example, motor neurone disease, heart failure and respiratory disease.

They thought it ought to be communicated more clearly that hospice services are available for these patients as well.

#### **24-hour access to care and equipment 7 days a week**

This section related to the 24-hour access to the telephone line at the hospice, which was available to all healthcare staff, patients and carers. However, visits from hospice staff were only available between the hours of 8 am and 10 pm. Access to the telephone line was perceived as enabling patients to be discharged home at weekends and providing support and advice to a range of staff, patients and carers. All the groups appreciated the fact that the hospice could be contacted at any time of the day or night and any day of the week, including weekends and bank holidays. It was also valued that there was one set telephone number to use that was accessible to all. Night community staff, both nurses and GPs were particularly appreciative of this service as it enabled them to receive advice and information when there were not many other services available. The carers' group found the service very beneficial:

*'It's an exemplary service'* (Carer 1).

*'The support has been tremendous; I couldn't have managed without it'* (Carer 4).

An example was given by carer 3 of an occasion when a hospice-at-home nurse went out to see a patient and stayed with the family late into the night. A doctor also visited to prescribe analgesia and these actions stopped the man being admitted and dying in hospital. In terms of the hospice-at-home visiting service, the palliative care specialist group provided examples of the types of practices that they provided for patients, including setting up or managing syringe drivers for pain control, and re-catheterising patients in a care home. However, issues were raised about the cut off at 10 pm in terms of accessibility and response from the hospice-at-home visiting service. Although during 8am and 10pm the service provides a speedy access to palliative care specialists, out of these hours the level of service is diminished and continuity of care is reduced. Participants were concerned about the lack of resources available overnight for patients in the community:

*'When the service is at its least, the backup service needs to be in a way at its best, and actually it is quite the reverse'* (Community nurse 3).

All four groups expressed the desire for the hospice-at-home visiting service to be available for 24 hours over a 7-day period.

#### **Discussion**

The range of roles, expertise, experiences and backgrounds of the group members involved in this evaluation provided a wide variety of responses and views of this service. Although involvement and knowledge of some aspects varied amongst the groups many of the issues highlighted were similar across all the participants. The findings suggest that some end-of-life care needs were being met but that services needed to be further developed to meet the needs of the key stakeholders. The key issues that arose from the participants were as follows:

- The sharing of information through the computer system was seen as useful but there were some issues around access for certain professionals and Internet access in some areas;
- Conversations around ACP took place at an earlier stage of the illness than previously but several carers did not feel they understood clearly what the process involved;

- Communication amongst professionals had improved but there were still occasions when there was poor communication, particularly in relation to the acute hospital trust;
- The telephone line to the hospice was valued and well used by all the groups. All the participants would have liked the service of visits from hospice staff to be available over the full 24-hour period.

Regarding the use of the electronic register and care templates, staff participants felt that this system enabled important patient information to be captured and shared between professionals. This corroborates the aims of Electronic Palliative Care Co-ordination Systems (EPaCCS), which were designed to improve the planning and delivery of services and support local initiatives in improving end-of-life care (Public Health England, 2013a; Lindsey and Hayes, 2014). Participants stated that the electronic system enabled the care of the patient to be tracked and that other professionals had access to the information. However, issues were identified in terms of the variability of access, availability of information to other professional groups and, when templates were completed, patients having to be asked permission for different groups to view their information. Technical problems, particularly concerning access to the Internet, was another an obstacle in some areas and there did not appear to be a space on the template to enter details about the family or other issues which may be relevant to the care of the patient.

It may be that with increased access and familiarity with the template these issues could be alleviated. However, there was clearly a need for education and training in this area, particularly for staff in how to use the templates and in terms of clarification of procedures to allow the information to be shared with other professionals. These findings are echoed in the results of a national survey of 211 clinical commissioning groups (CCGs) in England, the aim of which was to gather information about the impact of EPaCCS since implementation in 2012. In total, 172 responses were received providing information on 188 (89%) CCGs. The results of the survey found that EPaCCS improved communication and ease of information sharing between professionals involved in a person's care and helped clinicians, ambulance and out-of-hours' services to make appropriate decisions about a person's care. However, the challenges that survey respondents faced included interoperability of IT systems, data ownership, consent, engagement of health professionals (particularly GPs) and funding (Public Health England, 2013b).

Communication amongst services was a major feature highlighted by all four groups. A clear need was identified to improve communication between professionals and across agencies. The key issues were: accessibility to information, responsiveness, continuity of care (i.e. in relation to referrals, the number of services and staff involved in the patient's care and documentation) and training needs. Healthcare practitioners require continuing professional development so that they have the skills to identify the information requirements of both patients and carers and know how best to convey this information (Payne *et al*, 2008; Rhodes *et al*, 2008).

Carers perceived that there was a communication gap in terms of referral information between hospital and community staff, resulting in some staff not being aware of the patient's current health condition and inappropriate paperwork and medicines being sent home on discharge from hospital. The National Association for Hospice at Home has developed a set of national standards for hospice-at-home services, including one concerning the clear definition and communication of referral criteria for patients referred to other services. This

involves the safe transmission of information along with adherence to information governance and confidentiality and that all referral agencies are aware of the referral processes and criteria (Bell *et al*, 2013).

Communication about the follow up available after a patient's death needs to be reviewed. Currently, the hospice contacts carers 6 weeks after the death of their loved one but at times this comes as a surprise to the carer. Consideration needs to be given as to how to let carers know this contact will happen and also regarding contacting carers whose family member has died of a life-limiting illness other than cancer. Rhodes *et al* (2008) identified that an important aspect for carers in rating their satisfaction with hospice services was the amount and type of support they received after the death of their relative.

In terms of ACP discussions, carers valued such conversations, particularly around a preferred place of care and death, as this enabled services to be planned appropriately, especially if staying at home was the patient's preference. ACP has been associated with more terminally ill people achieving their preferred place of care and death (Hughes *et al*, 2010; Capel *et al*, 2012; Ahearn *et al*, 2013). However, the timing of these difficult conversations is challenging to manage, and broaching the subject seems to need some thought and training for both nursing and medical professionals. Effective ACP is dependent on the quality of communication between patients and their caregivers (Henry and Seymour, 2008). It is well recognised that clinicians lack confidence in terms of conducting conversations about the end of life with patients and their carers and require education and training in this regard (Mallory, 2003; Thompson-Hill *et al*, 2009; Boyd *et al*, 2010; Smith and Porock, 2009).

The carers' group suggested that they would have benefited from a greater understanding of the whole process around ACP and, in particular, issues relating to resuscitation. This issue concerning communication with carers in relation to their understanding of terms such as 'do not resuscitate', and the practicalities of having ACP conversations with both patients and family members have been highlighted elsewhere (Payne *et al*, 2008; Beland, 2013).

Another issue identified was access to medications out of hours. There was not a 24-hour pharmacy service available in the town and a related concern that was identified was a lack of nurse prescribers during the night. High-quality symptom management at the end of life is dependent on quick access to the relevant medications and therefore it is now considered best practice to prescribe medications in anticipation of the symptoms that may occur so that they can be administered when they are required (Faull *et al*, 2013; Finucane *et al*, 2014; Wilson *et al*, 2015). However, problems can occur as a result of health professionals' lack of expertise and experience in end-of-life symptom management and lack of effective relationships and communication between professionals from the different services involved in the patient's care, such as community services, hospitals and usual and out-of-hours' care providers (Faull *et al*, 2013; Magee and Koffman, 2015).

Macgee and Koffman (2015) sent a self-completion postal survey to 1005 GPs working for an independent provider of out-of-hours' services across England, of whom 204 (20.3%) completed the questionnaire. The results showed that there was a lack of confidence among many of the GPs who responded in terms of assessing palliative care emergencies, managing symptoms of patients with non-malignant conditions, and prescribing a new syringe driver. Lower confidence was associated with infrequent exposure to palliative patients and lack of training in palliative care. In terms of education, e-learning was the preferred method.

However, the researchers recommended that e-learning should be combined with other approaches such as out-of-hours' themed workshops and case discussions, as these would promote engagement with the topic being discussed, and that specialist palliative care services should engage more with out-of-hours' providers.

There is a need for professionals working for different teams to build and maintain trusting and responsive relationships with each other and to become more confident in end-of-life care symptom management (Faull *et al*, 2013). If patients' preferences about place of care and death are to be achieved, they require high-quality palliative and end-of-life care 24 hours a day, 7 days a week (Magee and Koffman, 2015).

The participants highly valued having the hospice-at home team available in person to come to patients' homes to perform a range of procedures such as setting up and managing syringe drivers for symptom control or on the telephone for advice and support. Such interventions were perceived to prevent patients having unnecessary admissions to acute hospitals. Having one telephone number to ring, at any time of the day or night, was appreciated by all the participants. This made accessing the system straightforward and clear. The hospice telephone line was accessed in preference to other services as it was known that the caller would be able to speak immediately to a clinician and not have to leave a message on an answerphone and be unsure that the call would get returned. However, all the participants would have liked the visiting service to be available over the 24-hour period and for 7 days a week in the same way that the telephone service could be accessed. Out-of-hours GPs were perceived not to have access to some patients' notes and information, and consequently could not provide the most appropriate care. These findings support those of other studies of hospice at home services. Rhodes *et al* (2008) in their study of bereaved family members evaluation of hospice services concluded that a higher level of satisfaction was found when family members believed that hospice staff were knowledgeable about the patient and the specific care required and were available to be contacted for both clinical issues and emotional support. Butler and Holdsworth (2013) conducted a review of the literature relating to hospice at home services identifying certain attributes which led to positive outcomes. These included help for informal carers to manage stress and 24 hour access over 7 days to professionals who can provide specialist care and administer medications. Another study conducted by the National Association for Hospice at Home (Bell *et al* 2013) was undertaken to develop national standards for hospice-at-home services. The standards produced included working in partnership with other agencies to meet the needs of patients, carers and families, communicating clearly defined referral criteria to stakeholders and other partners, and the provision of hospice-at-home care and support services which enables families and carers to make informed decisions and receive advice and support. All of these issues were identified as being essential in order to provide a high quality of end of life care. The findings from these studies carried out in other areas indicate that the issues raised in this current study are in alignment with those found in other areas of the country.

## **Recommendations**

The recommendations from this study are as follows:

- Education for staff regarding the use of and access to the templates on the computer system;
- Clear procedures regarding access to information for other staff groups, particularly for out of hours' GPs;
- Education/training so that all staff understand the complexity of the health and social care roles in caring for someone at home and the importance of making time

available for specialist nurses to support their colleagues in technical skills, for example, using a new syringe driver.

- Training in breaking bad news and ACP for both nursing and medical staff involved in patient care;
- Review of the communication system between the acute hospital and community services regarding timely transfer of information for patients discharged from acute care settings;
- Keep the one dedicated number for the telephone line and maintain this service 24 hours a day over 7 days;
- Maintain the current service of visiting patients' homes by the hospice staff and consider extending this to 24 hours a day over 7 days, in alignment with the telephone service;
- Clarify the roles of the various nursing staff groups, e.g. community nurses, Macmillan nurses, palliative care nurses and other specialist nurses, so each is clear of their roles and responsibilities in relation to specific patients and carers;
- Ensure carers are clearly informed that they will be contacted 6 weeks following the death of the patient regarding bereavement support, and provided with written contact details of this service;
- Consideration of the provision of 24-hour access to pharmacy services within the town and increase the number of nurse prescribers available, particularly at nights and at weekends.

It is perceived that implementing the above recommendations will further enable the local CCG to achieve its aim of improving the quality and choice of end-of-life care for its local population, as well as responding to the current national end-of-life care agenda aimed at promoting high-quality care for all adults at the end of life by enabling them to be cared for or die in their preferred place (Department of Health, 2008; 2009; National Institute for Health and Care Excellence 2013).

### **Limitations**

The participants in the study were recruited by hospice staff involved in the project. This could have resulted in some potential participants not responding to letters from hospice staff. This could have been because they did not want to talk about their experiences in case they became upset or they did not want to talk about what had happened to them (Klapowitz 2000). As the participants were self-selecting, those with strong opinions or who felt comfortable talking in a group could have volunteered readily whereas those who were quieter or lacking in confidence but had certain experiences or opinions to offer which could have been useful may have declined to take part in the focus groups, resulting in their opinions not being included (Parahoo 2014). As the focus groups were held on a fixed day some potential participants may have been unable to attend on that one date and so their views not heard. No patients responded to the invitation to attend the focus groups so the views and opinions of this group of potential participants was not able to be included.

### **Conclusions**

In conclusion, the services provided by the hospice, including the telephone line and home visits, were greatly appreciated by all those who took part in the focus groups. Participants perceived that it has led to better care provision for patients in terms of prompt symptom relief and care interventions, which have prevented admissions to acute care settings. It has also provided support and advice to carers as well as to community staff and enabled ACP to be carried out earlier than previously, resulting in resources being available to care for

patients in their preferred place of care. It appears, therefore, that the hospice-at-home service provided has met some of the needs of this population. However, there have been some issues which have been highlighted, such as training needs concerning communication and the use and access to information and also the need to clarify roles and responsibilities of staff groups.

## References

- Addington-Hall J, Bruera E, Higginson I, Payne S (2007) *Research Methods in Palliative Care*. Oxford University Press, Oxford.
- Ahearn DJ, Nidh N, Kallat A, Adenwala Y, Varman S (2013) Offering older hospitalised patients the choice to die in their preferred place. *Postgraduate Medical Journal* 89, 20–4.
- Andrews N, Seymour J (2011) Factors influencing the referral of non-cancer patients to community specialist palliative care nurses. *International Journal of Palliative Nursing* 17, 35–41.
- Barclay S, Case-Upton S (2009) Knowing patients' preferences for place of death: how possible or desirable? *The British Journal of General Practice* 59, 642–3.
- Beland P (2013) Implications for carers of terminally ill patients dying at home. *Nursing Standard* 28, 40–5.
- Bell G, Greene K, Hunt J, Varvel S (2013) Developing national standards for hospice-at-home services. *End of Life Journal* 3, 1–5.
- Boyd K, Mason B, Kendall M et al (2010) Advance care planning for cancer patients in primary care: a feasibility study. *British Journal of General Practice* 60, e449–58.
- Butler C., Holdsworth L. (2013) Setting up a new evidence-based hospice-at-home service in England *International Journal of Palliative Nursing* 19(7) 355-359
- Capel M, Gazi T, Vout L, Wilson N, Finlay I (2012) Where do patients known to a community palliative care service die? *BMJ Supportive & Palliative Care* 2, 43–7.
- Dale J, Petrova M, Munday D, Koistinen-Harris J, Lall R, Thomas K (2009) A national facilitation project to improve primary palliative care: impact of the Gold Standards Framework on process and self-ratings of quality. *Quality & Safety in Health Care* 18, 174–80.
- Department of Health (2008) *End of Life Care Strategy: Promoting High Quality Care for all Adults at the End of Life*. The Stationery Office, London.
- Department of Health (2009) *End of Life care Strategy: Quality Markers and Measures for End of Life Care*. The Stationery Office, London

Department of Health (2013) *Improving Care for People at the End of Their Life*. The Stationery Office, London.

Eyre S (2010) Supporting informal carers of dying patients: the district nurse's role. *Nursing Standard* 24, 43–8.

Faull C, Windridge K, Ockleford E, Hudson M (2013) Anticipatory prescribing in terminal care at home: what challenges do community health professionals encounter? *BMJ Supportive & Palliative Care* 3, 91–7.

Finucane AM, Stevenson B, Gardner H, McArthur D, Murray SA (2014) Anticipatory prescribing at the end of life in Lothian care homes. *British Journal of Community Nursing* 19, 544–7.

Goldschmidt D, Groenvold M, Johnsen AT, Strömgen AS, Krasnik A, Schmidt L (2005) Cooperating with a palliative home-care team: expectations and evaluations of GPs and district nurses. *Palliative Medicine* 19, 241–50.

Gomes B, Higginson IJ (2006) Factors influencing death at home in terminally ill patients with cancer: systematic review. *British Medical Journal* 332, 515–21 [Erratum in *BMJ*, 2006, 332, 1012].

Goodwin DM, Higginson IJ, Edwards AG et al (2002) An evaluation of systematic reviews of palliative care services. *Journal of Palliative Care* 18, 77–83.

Greenbaum TL (1997) *The Handbook for Focus Group Research*. Sage, London.

Guthrie G (2010) *Basic Research Methods. An Entry to Social Science Research*. Sage Publications, London.

Help the Hospices Commission (2013) *Future Ambitions for Hospice Care: Our Mission and Our Opportunity. The Final Report of the Commission Into the Future of Hospice Care*. Help the Hospices, London.

Henry C, Seymour J (2008) *Advance Care Planning: a Guide for Health and Social Care Staff*. Department of Health, London.

Higginson IJ (2003) *Priorities and Preferences for End of Life Care in England, Wales and Scotland*. The National Council for Palliative Care, London.

Hughes PM, Bath PA, Ahmed N, Noble B (2010) What progress has been made towards implementing national guidance on end of life care? A national survey of UK general practices. *Palliative Medicine* 24, 68–78.

Jarrett N., Maslin-Prothero S. (2008) Communication, the patient and the palliative care team in Payne S. Seymour J and Ingleton C. *Palliative Care Nursing, Principles and Evidence for Practice*. 2<sup>nd</sup> edn. McGraw-Hill, Open University Press, Maidenhead.

Klapowitz M. (2000) Statistical analysis of sensitive topics in group and individual interviews. *Quality and Quantity*. 34, 419-31

- Krueger RA, Casey MA (2008) *Focus Groups: a Practical Guide for Applied Research*. 4<sup>th</sup> edn. Sage Publications, Thousand Oaks, CA.
- Lakasing E (2012) Palliative care in primary care. *Geriatric Medicine* 42, 60–4.
- Lindsey K, Hayes A (2014) Supporting care integration with Electronic Palliative Care Coordination Systems (EPaCCS). *International Journal of Palliative Nursing* 20, 60–1.
- Loeb S, Penrod J, Hupcey J (2006) Focus groups and older adults: tactics for success. *Journal of Gerontological Nursing* 32, 32–8.
- Malterud K (2001) Qualitative research: standards, challenges, and guidelines. *The Lancet* 358, 483–8.
- Marshall C, Rossman GB (2010) *Designing Qualitative Research*. 5th edn. Sage Publications, Thousand Oaks, CA.
- McLaughlin D, Sullivan K, Hasson F (2007) Hospice at home services: the carer's perspective. *Supportive Care in Cancer* 15, 163–70.
- Magee C, Koffman J (2015) Out-of-hours palliative care: what are the educational needs and preferences of general practitioners? *BMJ Supportive & Palliative Care* 5 (1) 1-7
- Mallory JL (2003) The impact of a palliative care educational component on attitudes toward care of the dying in undergraduate nursing students. *Journal of Professional Nursing* 19, 305–12.
- Morrison RS, Peoples L (1999) Using focus group methodology in nursing. *Journal of Continuing Education in Nursing* 30, 62–5.
- Neuberger J (2004) *Dying Well: a Guide to Enabling a Good Death*. 2<sup>nd</sup> edn. Radcliffe Publishing, Abingdon.
- National Institute for Health and Clinical Excellence (2013) *Quality Standard for End of Life Care for Adults*. NICE, London <http://guidance.nice.org.uk/OS13> (last accessed 23 April 2015)
- Parahoo K (2014) *Nursing Research: Principles, Process and Issues*. 3<sup>rd</sup> edn. Palgrave Macmillan, London.
- Payne S, Seymour J, Ingleton C (2008) *Palliative Care Nursing: Principles and Evidence for Practice*. 2<sup>nd</sup> edn. McGraw-Hill, Open University Press, Maidenhead.
- Public Health England (2013a) *End of Life Care Co-ordination: Record Keeping Guidance*. National Information Standard ISB 1580. Public Health England, London.
- Public Health England (2013b) *Electronic Palliative Care Co-ordination Systems (EPaCCS) in England*. Public Health England, London.

Quine S, Cameron I (1995) The use of focus groups with the disabled elderly. *Qualitative Health Research* 5, 454–62.

Rhodes RL, Mitchell SL, Miller SC, Connor SR, Teno JM (2008) Bereaved family members' evaluation of hospice care: what factors influence overall satisfaction with services? *Journal of Pain and Symptom Management* 35, 365–71.

Ritchie J, Lewis J (2003) *Qualitative Research Practice: a Guide for Social Science Students and Researchers*. Sage, London

Shaw KL, Clifford C, Thomas K, Meehan H (2010) Review: improving end-of-life care: a critical review of the Gold Standards Framework in primary care. *Palliative Medicine* 24, 317–29.

Shepperd S, Wee B, Straus SE (2011) Hospital at home: home-based end of life care. *The Cochrane Database of Systematic Reviews*. 7, CD009231.

Smith JA, Osborn M (2003) Interpretative phenomenological analysis. In: Smith J, ed. *Qualitative Psychology: a Practical Guide to Research Methods*. 2<sup>nd</sup> edn. Sage Publications, London, 53–80.

Smith R, Porock D (2009) Caring for people dying at home: a research study into the needs of community nurses. *International Journal of Palliative Nursing* 15, 601–8.

Stevens E, Spencer-Grey S-A, Heller T, Komaromy C (2009) *Unit 2: End of Life Care Practice. Block 2 — End of Life Care in Context. K260 Death and Dying*. The Open University, Milton Keynes, 19–38.

Stewart DW, Shamdasani PN, Rook D (2006) *Focus Groups: Theory and Practice*. 2<sup>nd</sup> edn. Sage Publications, London.

Sullivan KA, McLaughlin D, Hasson F (2005) Exploring district nurses' experience of a hospice at home service. *British Journal of Community Nursing* 10, 496–502.

The Gold Standards Framework (GSF) (2013) *Advance Care Planning*. GSF Centre CIC, Shrewsbury, Shropshire. <http://www.goldstandardsframework.org.uk/advance-care-planning> (last accessed 30 March 2015).

The Gold Standards Framework (GSF) (2014) The National Gold Standards Framework Centre in End of Life Care. The Gold Standards Framework, Shrewsbury, Shropshire. <http://www.goldstandardsframework.org.uk/home> (last accessed 28 March 2015).

Thomas K (2003) *Caring for the Dying at Home: Companions on the Journey*. Radcliffe Medical Press, Oxford.

Thompson-Hill J, Hookey C, Salt E, O'Neill T (2009) The supportive care plan: a tool to improve communication in end-of-life care. *International Journal of Palliative Nursing* 15, 250–5.

Wilson E, Morbey H, Brown J, Payne S, Seale C, Seymour J (2015) Administering

anticipatory medications in end-of-life care: a qualitative study of nursing practice in the community and in nursing homes. *Palliative Medicine* 29, 60–70.