Establishing a structured plan to provide high-quality end-of-life care in community settings

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ABSTRACT

The purpose of this project was to explore how registered community nurses experienced providing holistic end-of-life care and how having a structured end-of-life care pathway plan would help develop their knowledge and skills, particularly in respect of communication and their ability and confidence in providing evidence-based compassionate care. For some practitioners there exists a lack of confidence surrounding end of life care, which can result in nurses' reluctance to become involved and avoid engaging in those 'difficult conversations'. Following implementation, early reviews from practice suggest that incorporating the 19 steps of the plan into the delivery of community-based care at end of life has enhanced practice and patient experience.

KEY WORDS

◆ End-of-life care ◆ Community nursing ◆ Care plan ◆ Nurse confidence ◆ Communication

It is estimated that 1% of the global population dies each year, and this value is predicted to increase by 17% in the future (Royal College of General Practitioners and Royal College of Nursing, 2012). Statistics show that about 35% of these deaths are home deaths, with 18% of individuals dying in their own homes and 17% dying in a care home. Reportedly, 60–70% are not dying in their preferred environment (Royal College of General Practitioners and Royal College of Nursing, 2012). It is suggested that 70% of patients would prefer to die at home, but only half achieve this (Dying Matters, 2018).

Nurses are believed to have the best opportunity to influence the dying process, because of their closeness to patients and their families. Of all healthcare professionals, nurses are said to spend the most time with the patient, and patients and their families look to the nurse for support and guidance (Mauk, 2013). This is especially true for community and home nursing services and when patients wish to die in their own homes. Thus, it is important that community nurses be adequately prepared and skilled to support such patients.

While all nurses are passionate about providing individualised, holistic and responsive care to patients at the end of life and feel privileged to be involved in this journey, a 2010 survey by the *Nursing Times* that investigated the opinions of 900 nurses revealed that one in four nurses does not feel confident in delivering good quality end-of-life care (Middleton, 2010). Another study similarly found that many nurses feel a lack of competence in this regard, particularly in managing conversations about sensitive subjects within end-of-life care (Ford, 2010), and that this directly affects the care provided to patients and their family or caregivers (Ford, 2010). Promoting an open and honest approach with patients, family and friends is essential to building therapeutic relationships between staff, patients and carers (Cummings, 2014), and this relationship is a fundamental element of end-of-life care.

While end-of-life care within the community setting is understandably challenging for all nurses, newly qualified nurses and those new to community nursing can find this area of their work particularly daunting. The lack of confidence surrounding end-of-life care can result in nurses' reluctance to become involved and in them avoiding engaging in those 'difficult conversations' (Department of Health and Social Care (DHSC), 2016). Nurses are often unsure of how to broach the subject of the end of life and feel that they lack support in this area; some even feel this is not part of their role (Davies, 2015). The Liverpool Care Pathway (LCP) era witnessed the absence of patient-focused care and family association, including communication. To help in supporting and encouraging patients to initiate better end-of-life care conversations, the DHSC worked in collaboration with the National Council for Palliative Care (NCPC) and NHS England to develop a patient-focused film that aimed to empower patients to be more prepared for these conversations (DHSC, 2016). However, many healthcare professionals reported that despite these supporting policies, they were still struggling with this vital element of their practice and would welcome guidance in the form of a step-by-step care plan specific to end-of-life care. They identified that when patients and their families asked 'what happens next?', they were often unclear how best to respond. This perceived gap is not unique, as Cairnduff et al (2015), too, highlighted that the lack of a structured end-of-life care plan left many nurses

feeling inadequate and inadvertently missing elements of the holistic assessment process. Cairnduff et al (2015) explored the advantages and disadvantages of the discontinuation of the LCP, and it highlighted three core issues:

- Lessons learnt, which explored the use of the LCP
- Uncertainties and ambivalences, which highlighted the clinical difficulties surrounding the provision of high-quality end-of-life care
- The future, that is, the need for a structured end-of-life care plan.

The results of a study conducted by Cairnduff et al (2015) revealed that an individualised end-of-life care plan would be useful, as such an approach would ensure efficacy and transparency.

Healthcare professionals acknowledge the importance of such customised care plans, as they deliver person-centred care designed around the needs of each individual patient. They realise that by its nature, the end of life can be a difficult period in which to provide nursing care, and having information easily available does ease the anxiety that some nurses feel when caring for people in this stage. Care plans such as the Supportive and Palliative Care Indicators Tool (SPICT) and Gold Standard Framework (GSF) and those mentioned in Chan et al (2016) are available at present, but these are a standard format and are not personalised or adequately informative. In the author's experience, the lack of a structured care plan in practice was specifically highlighted as having a negative impact on how nurses deliver end-of-life care. Thus, the purpose of the project described in this article was to establish a structured end-of-life care pathway that would help develop their knowledge and skills, particularly in terms of communicating with the patient and nurses' ability and confidence in providing evidence-based compassionate care.

There are three main aims to the proposed pathway:

- To provide a structured pathway for end-of-life care
- To enhance the patient's journey
- To improve the healthcare professional's skills, knowledge and confidence in delivering compassionate end-of-life care.

Method

The initial blueprint for the care plan was constructed in collaboration with the professional development lead and IT analyst from the East Suffolk and North Essex NHS Foudation Trust (*Table 1*). The study was carried out in June and July of 2017. Care plans were requested from neighboring counties and were closely reviewed to see what they had in place to support the teams. One was sought from Norfolk and a second from Essex. Next, the best evidence was combined with a range of policies and guidelines available to help support end-of-life care, for example, those presented in Priorities for Care of the Dying (DHSC, 2014), the SPICT (Black et al, 2013), Chan et al (2016) and the GSF (2017). Finally, a proposal was made to provide the local nursing team with a structured care plan and to develop the training and education to be able to implement this tool.

The next phase of the project involved working in collaboration with patients, families, community nursing colleagues and a specialist nurse to design an end-of-life care plan for local implementation. This care plan focuses on major issues, concerns and worries that may affect both patients and staff. It is designed to empower both patients and staff by enabling patients to express their wishes, fulfil their right to die at home and ensure they remain as independent and healthy for as long as possible. The care plan brings together multiple services to ensure the patient has comprehensive but individualised holistic care. Each of the 19 steps of the care plan has been established and mapped against a range of evidence, including the SPICT tool, the GSF and local policy (*Figure 1*).

The care plan draft was reviewed by our local specialist palliative care nurses, district nurses and the local head of nursing. Their feedback helped develop the final plan, and a rationale for the inclusion of each element was established.

Once authorisation was granted by the director of nursing of the NHS trust where the study was conducted, the care plan was made available to all members of the multidisciplinary team (MDT) involved in end-of-life care at the author's institution; it was not just shared with community nursing teams.

Each step of the care plan acts as a prompt and aid for nurses when initiating or involved in potentially emotional conversations as they support the patient and family on this journey. The care plan also helps clarify for the patient and their family the services that can be provided by the district nursing team, and it also helps identify any training requirements for staff. Using the care plan in practice also enables the nurses to coordinate resources and support to provide individualised approaches in a patient's very last days, enabling the patient to maintain their independence for as long as possible and empowering them to fulfil their wishes.

Implementation

The care plan was rolled out straight onto the computer system that is used by all healthcare professionals in Suffolk. All team leads were informed by email that the plan was now live on the system, and they were asked to inform all members of their team about it. Because of how the care plan was set up, it was possible to record the number of patients who received care under the plan. The author personally provided training to each team within the locality about the use of the care plan and guided staff who requested further end-of-life training toward the appropriate programmes. At the end of the training, a short questionaire was administered to staff to record their feedback. The care plan is revisited regularly throughout the patient's journey to ensure it remains responsive to their needs.

Evaluation

The initial period of implementation was 3 months. One month after the care plan was implemented, questionnaires were sent to the pilot team to gather feedback, to see how successful the plan was in practice. The first step in evaluating the care plan was an audit conducted by the trust's IT department, which had automatically set the audit for 3 and 6 months after roll out. This helped the trust to assess and review the care plan and implement any changes identified, which was

Table 1. Rationale for the 19-point care plan

Instruction	Rationale
1. Introduction to the community nursing service and contact details available in home	*To allow the beginning of a professional/patient relationship enhancing communication.*
2. Holistic assessment, including religious, cultural and spiritual needs	*To address and ensure individual needs are considered and met (if possible).*
3. End-of-life plan discussed with multidisciplinary team (MDT)	*To promote working together as one team to ensure patient receives the most appropriate care and support and everyone involved knows what is going on with care needs.*
4. Advanced care planning, My Care Wishes and preferred place of care discussed	*To ensure that patient's wishes are in place and that everyone involved in their care are aware. To encourage discussions with family, friends and healthcare professionals*
5. Appropriate referrals made for additional support and care, i.e. social care, hospice, Marie Curie, financial (DS1500 form)	*To ensure support appropriate to meet everyone's needs. Act as a prompt for the nursing staff to consider all options.*
6. Fast Track Continuing care considered	*To ensure specialist end-of-life nursing care, non-means tested funding is considered.*
7. Reassess pressure-relieving equipment in the home and ensure it is being used appropriately	*To maintain skin integrity and ensure adherence to local policy.*
8. Check moving and handling equipment in the home and ensure it is being used appropriately	*To ensure adherence to local policy for the protection of patient/staff/carers and family.*
9. Support the dying person to drink if they wish or can. Assess ability to manage oral intake and need for mouth care. Discuss the risks and benefits of continuing to drink with patient and family/carers	*To assess the ability to manage oral intake and the need for mouth care. Discuss with the patient, carer and family the risks and benefits of continuing to drink.*
10. Assess bladder and bowel function	*To consider agitation, catheterisation, continence referral.*
11. Consider anticipatory medication and documentation in the home	*To assess patient's condition and potential deterioration, symptoms, pain, nausea and agitation. To ensure documentation is appropriate for other services involved i.e. Marie Curie.*
12. Medication and methods of symptom control discussed with patient and family/carers	*To provide reassurance and ensure everyone is aware of what and why medication may be given and the benefits/side effects of giving such medication.*
13. Stat doses of prescribed medication given and recorded	*To ensure other professionals are aware of what has been given and when. Meeting legal and professional requirements.*
14. Syringe driver in place and reviewed daily by the community nurse	*To ensure symptom control, adherence to local policy, appropriate management of controlled drugs and provide support accordingly.*
15. Ensure sufficient medication is available in the home, pre-empting increases over out-of-hours and holiday periods	*To review the medication within the home and maintain/order appropriate stock.*
16. If symptoms uncontrolled—to liaise with hospice/GP	*To ensure referral to specialists for support in symptom control and/or increasing medications appropriately and safely.*
17. Psychological support provided for patient and family/carers	*To help address worries, concerns or fears, answer or find answers to questions that they may have.*
18. Next visit planned with patient/carer and care plan frequency set accordingly	*To discuss the needs of the patient, identifying how often they feel they need support—telephone or visit—reassess this process at every contact.*
19. Discussion and support with family/carers about the next steps following death	*To discuss immediate and after care to guide the family/offer a bereavement visit, initiate difficult discussions.*

done at the county end-of-life policy meeting. Feedback from practice was also incorporated at this stage. Staff wanted to use the care plan on a weekly or fornightly basis rather than as a one-time use, as was the set-up then. This was a result of the healthcare professional not necessarily being able to complete the whole plan in a single visit. The IT department made the necessary changes, and the plan can now be used as often as required. The feedback from the questionnaires was positive, with staff reporting increased knowledge, confidence and skills within end-of-life care planning and initiating sensitive conversations. The nurses using the care plan reported that the plan was well structured, flowed well and was easy to follow.

In addition, plan users felt it would be ideal for newly qualified staff and individuals entering community nursing. In

Care plan for the end of life

NHS Number:		Date Printed:	/ /
Date of Birth:	/ /	Implementation Date:	/ /
Contact Details:		Review Required:	

Care Needed:	*End of Life Care*
Goal:	To provide supportive care to meet individual's needs during the end of life

Instruction	Responsibility	Date performed	Performed by	Signature
Introduction to the community nursing service and contact details available in home	Nurse			
Holistic assessment including religious, cultural and spiritual needs	Nurse			
End-of-life plan discussed at MDT meeting	Nurse			
Advanced care planning, My Care Wishes and preferred place of care discussed	Nurse			
Appropriate referrals made for additional support and care i.e. social care, hospice, Marie Curie, financial (DS1500 form)	Nurse			
Fast Track Continuing care considered	Nurse			
Reassess pressure relieving equipment in the home and ensure it is being used appropriately	Nurse			
Check moving and handling equipment in the home and ensure it is being used appropriately	Nurse			
Support the dying person to drink if they wish or can. Assess ability to manage oral intake and need for mouth care. Discuss with the patient and family/carers the risks and benefits of continuing to drink	Nurse			
Assess bladder and bowel function	Nurse			
Consider anticipatory medication and documentation in the home	Nurse			
Medication and methods of symptom control discussed with patient and family/carers	Nurse			
Stat doses of prescribed medication given and recorded	Nurse			
Syringe driver in place and reviewed daily by community nurse	Nurse			
Ensure sufficient medication is available in the home, pre-empting increases over out-of-hours and holiday periods	Nurse			
If symptoms uncontrolled, to liaise with hospice/GP	Nurse			
Psychological support provided for patient and family/carers	Nurse			
Next visit planned with patient/carer and care plan frequency set accordingly	Nurse			
Discussion and support with family/carers about the next steps following death	Nurse			

Figure 1. End-of-life care plan

KEY POINTS

- If more people are to fulfil their wish to die in their own homes, community nurses must be adequately prepared
- Newly qualified community nurses in particular may lack confidence in managing end-of-life care
- A structured care plan or pathway can help prompt a holistic assessment and can guide difficult conversations
- Nurses feel that caring for people at home in their last days of life is a privilege and welcome tools that can help ensure best practice is achieved.

CPD REFLECTIVE QUESTIONS

- What aspects of your own practice do you think would benefit from further training in end-of-life care?
- How would a structured care plan, like the 19-point plan described in this article, positively affect your individual practice?
- How do you see end-of-life care evolving?

fact, observations of newly qualified nurses in practice showed that the care plan enabled them to structure their conversations with empathy and gave them guidance to approach sensitive conversations around the end-of-life journey, including what happens 'after death'. They reported the care plan to be informative and straightforward to use.

The challenges to implementation of this care plan have been few thus far. The care plan has been welcomed by various members of the MDT and the local hospice. However, the need for more training does undoubtedly add to the pressures of time allocation and scheduling.

Discussion

Overall, the results of this project have been very satisfactory. Although it was initially introduced to the local community district nursing team, the end-of-life care plan was soon adopted county-wide for use by all healthcare professionals: it was introduced at the county end-of-life meeting, and the team leads distributed guidance via email to all staff on how to action the plan. Further, it has now been adopted by two bordering counties.

The aim of the care plan was to support and guide healthcare professionals in delivering high-quality individualised end-of-life care, an area in which a gap was identified by the nursing teams within the local community who reported that they felt 'blind' when providing end-of-life care and that they did not have the knowledge and skills to deliver the best quality of care. The Royal College of Nursing (2016) reported that less-experienced nursing staff often find it difficult or struggle to find the words to say in such situations. Nurses can use the care plan as a prompt to guide them, particularly in the use of the appropriate language. Further research is much needed in this field, as very little evidence was found during the research stage of this project.

Talking through the 19 steps of the care plan enables nurses, patients and carers to discuss sensitive topics. For example, experiences in practice have highlighted that talking about how to manage food and fluids at the end of life can be a very difficult topic to discuss, especially for family members and carers. Studies have shown that most dying patients rarely actually experience thirst or hunger, and if this does occur, it is normally adequately addressed by providing small drops of fluid and moisturising their lips (Arenella, 2017). Fluid is a basic human need but as the end of life approaches, the need for fluid often reduces. Discussing the risks of this with the patient, family and friends allows their wishes to be taken into consideration (NICE, 2017). Further, as the body loses the ability to regulate fluid, imbalances like oedema can occur in the hands, feet and legs, and swelling can occur in the lungs (pulmonary oedema), all of which will clearly be distressing for the patient. In the latter stages of dying, patients often lose the ability to swallow, which increases the risk of choking or aspiration. Consequently, problems can also be caused by forcing a loved one to eat, however well intentioned, as it can aggravate choking or aspiration, which can result in a patient inhaling either food or fluid into their lungs. This can be painful and cause shortness of breath and coughing, which can add to the distress for the patient and carer (Looper, 2015). Included in the care plan is a prompt to initiate a discussion, about food and fluid, so that the nurse and family can explore how appetite or thirst can be managed, the risks associated with this process, and what underlies these risks. Referring to information such as this helps the nurse explain the rationale behind the advice they provide. The care plan also helps the nurse to answer commonly asked questions surrounding the withdrawal of food and fluid.

Early reviews from practice indicate that nurses find the plan is noticeably enhancing their delivery of care. Newly qualified nurses, especially those working in the community setting, report the tool to be helpful and informative, particularly when commencing difficult and sensitive conversations. Nurses use the care plan as a prompt to guide them, particularly in the use of appropriate language. As anticipated, feedback regarding the plan in use has also highlighted the need for some nurses to undergo further training. As part of this, the author will support all nurses by joining them in home visits, finding appropriate training courses and providing extra training around initiating difficult or sensitive conversations.

Conclusion

This article describes the establishment and introduction of an end-of-life care plan for use by healthcare professionals as well as patients and their families to improve patients' journeys in the final stages of life. The end-of-life care plan is an innovative approach and unique to our locality. It is endorsed by the local End-of-Life Policy as an essential element of community care. This care plan provides a sensitive way to approach the subject of end of life with empathy, and to the author's knowledge, there is little evidence of other similar projects underway.

To track and further review how the care plan is executed in practice, the author plans to continue to collate feedback from patients, their families and a range of staff. Additionally, statistical

data will be collected using electronic auditing. It is believed that tools such as this care plan will become invaluable in ensuring a compassionate and systematic approach to ensuring that high-quality individualised care is provided at the end of life in community settings. Nurses might find this type of tool vital in guiding them through sensitive situations and helping them develop greater confidence in end-of-life care.

The care plan is being continually reviewed in practice, with no revisions planned at present. However, feedback from staff in the future will be taken into consideration, and any changes required will be implemented. **BJCN**

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