Starting end-of-life conversations in hospital

Keywords: End of life/Palliative care/Communication/Training

● This article has been double-blind peer reviewed

In this article...
▶ What the Conversation Project entailed
▶ How it has helped nurses and junior doctors
▶ Results from audit of patient notes

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The Conversation Project, part of The King’s Fund/The Health Foundation Patient and Family-centred Care programme, aims to encourage health professionals to identify when patients are approaching the end of their lives and to ensure this is addressed in decision making and discussions. The project team explored the experience of staff based on a ward caring for older people. They found staff sometimes found it difficult to initiate end-of-life conversations and, therefore, to make patient-centred care plans. A development and support programme has improved staff confidence and resulted in more documented planning and discussion about the end of life.

Meeting patients’ and their families’ needs at the end of life is an important aspect of health care. However, it can only be achieved if patients are identified as nearing the end of life, involved in decisions about their care, and their wishes and preferences are known. It is recognised that 89.6% of patients have some hospital care in their last year of life and that a hospital admission can act as a catalyst for assessment – a natural time to reflect on what is happening that leads to questions and more open discussions between health professionals and the patient and family (Public Health England, 2013). However, many opportunities for discussion and planning about end-of-life care are being lost.

Neuberger’s (2013) review and the Leadership Alliance for the Care of Dying People (2014) have concluded that there are wide-reaching, fundamental problems with care for people nearing the end of life. These include a lack of care and compassion and a lack of suitably trained staff. Respondents to the national Voices survey among bereaved people rated quality of care as significantly lower for people who died in hospital, compared with those dying at home, in a hospice or care home. Only a third of respondents (33%) reported that hospital services worked well together with GP and other community services (Office for National Statistics, 2013).

If health professionals recognise those who may be weeks or months away from death (as well as those in their last days or hours) they can attend to their:
» Concerns and wishes;
» Important values or personal goals for care;
» Understanding about their illness and prognosis;
» Preferences and wishes for types of care or treatment that may be beneficial in the future, and the availability of these (Henry and Seymour, 2008).

Advance care plans are associated with reduced hospital stays; for example, hospice patients with these plans spend significantly less time in hospital than those without (18.1 versus 26.5 days) (PHE, 2013).

The Patient and Family-Centred Care programme
A range of health professionals (nurses, doctors, medical nurse practitioners and therapists) at the Royal United Hospital in Bath worked for 18 months with The King’s Fund and The Health Foundation on the

5 key points
1 89.6% of people receive hospital care in their final year of life
2 Families want honest, open conversation with clear information and advice from confident staff
3 Staff may lack confidence in talking to patients and families about death, particularly if it is perceived to be weeks or months away
4 Support and training can improve staff confidence, enabling patients and families to make plans for the end of life
5 Specialist palliative care teams can be a valuable training resource for generalist staff
Patient and Family-Centred Care programme (PFCC) in 2012-13. This aimed to explore the needs of patients, families and staff in the acute trust as patients neared the final phase of their lives. The programme, developed in the US at the University of Pittsburgh Medical Center (www.pfcc.org/what-is-pfcc) uses patient and family experience to initiate and develop change and improve care.

Collecting information from staff and families

We adopted a qualitative methodology, obtaining information from staff about their experience through focus groups, process mapping, interviews and questionnaires. Information and feedback was also collected from the general public via an evening meeting of 85 attendees, where six focus groups provided discussion on a range of topics pertaining to end-of-life care in the hospital setting.

Further information was taken from a review of complaints made to the hospital over the preceding months, and anecdotal evidence from meetings with the families of patients who were dying. Subsequently, we conducted a post-bereavement audit of care, in which families consented to telephone contact within four months of their bereavement. The semi-structured telephone interviews took place with 36 families over four months.

What families told us

Families stated that “they [the staff] did not communicate enough” and families were “never informed or consulted”. However, other comments included:

- “Staff were always there to speak to” and “The doctor was brilliant and went through everything with us”.

This information provided valuable insights into the experience of families and indicated a desire for honest, open conversation with clear information and advice from confident staff who have a good understanding of the patient’s plan of care.

Feedback from families and from the general public told us that patients and families appreciated it when staff listened to them and supported the choices they made (Box 1).

What staff told us

Early on it was evident that the majority of staff viewed end-of-life care as happening in the last few days and hours of life, not the preceding weeks and months. They told us there was sometimes a reluctance and fear among staff to discuss end-of-life issues. We found this was related to a lack of confidence about how to broach the subject, that there was little support in having conversations and, sometimes, a lack of recognition among staff that this was their role.

Staff described their concerns, including that decisions are made too late for patients and families to be able to participate (Box 2). Doctors said that doctors in general often viewed death as a medical failure and would prioritise care to patients who could be saved.

Box 1. FAMILY AND PUBLIC FEEDBACK

- Staff should listen to what the patient/family want and support them in their choices
- Families would like staff to discuss plans with the family as well as the patient from a fairly early stage
- It is important to listen to both the family and the patient, give truthful information and explain the facts so the patient can make choices and the family can support those choices
- It is important that the patient’s wishes are carried out, and that relatives are kept informed and cared for
- Staff should be honest and realistic early on in the care, and help plan how and where care should take place
- Listening and empathy are important

Box 2. STAFF COMMENTS

“[I do] not have enough experience in order to have conversations with patients and families about death and dying. I am more confident when I know that death is imminent”

“End-of-life decisions are often made too late to allow for participation in decision making”

“Dying is still a difficult subject when discussing this with families, no matter how often you have tackled this subject before”

“There is a lack of support and shared discussion about patients”

“It is perhaps still a subject that isn’t often discussed/talked about until absolutely necessary”

“Sometimes I think that families get forgotten, but how can we manage this when the ward is so busy?”

Issues identified

The research among families and staff identified a number of key issues in end-of-life care:

- Conversations with patients/families at the end of life may happen late or not at all;
- Staff often lack confidence in having conversations with patients and families about end-of-life care issues;
- There is, at times, inappropriate overtreatment of patients whose life expectancy is poor;
- Clinicians may not identify that a patient is approaching the end of life until late in their illness;
- Patients and families are often not included in decision making at the end of life;
- Decisions at the end of life may be medical decisions and not a result of a multidisciplinary team discussion.

Focus groups with, and feedback from, junior doctors revealed specific concerns. They often felt unsupported by their seniors in end-of-life decision making. Early on in their careers they found themselves in difficult conversations with patients and families about deterioration and dying, for which they felt ill-prepared.

Aims of the project

The aim of the Conversation Project became clear: to ensure that patients nearing the end of life and their families have the opportunity to have their end-of-life needs met. This would be made possible because clinicians have:

- Identified that the patient is approaching the end of life;
- Talked with the patient and/or family about the uncertainties of their illness;
- Listened to their concerns;
- Enabled the patient and family to be involved in appropriate decision making.
Innovation

» the project, the messages are clear:
approaching the end of life;
» There should be conversations with the patient and their family during their admission, and these conversations should help inform plans for care;
» Conversations should be documented clearly – this may best be done separately to the rest of the notes so it can be viewed easily;
» Conversations are not “one off” but should be continued and reviewed, especially if the patient continues to deteriorate;
» Information including these decisions and discussions made in hospital should be appropriately shared with community colleagues so care can be coordinated.
The themes of the Conversation Project are not new to those working in end-of-life/palliative care, but the challenge of promoting this in a busy, acute hospital is clear. It was evident that the project team needed to engage with ward staff of every level and encourage them to take ownership of, and responsibility for, the work. Staff needed to understand the aim of the project and their role within it.

Supporting better end-of-life care
The Conversation Project team supported staff in providing end-of-life care by:
» Ensuring the palliative or end-of-life care team attend ward multidisciplinary team meetings regularly to promote and facilitate discussions about patients on the ward;
» Producing “key cards” for staff providing prompts for action (Box 3);
» Setting up and attending regular ward meetings (lasting 30 minutes every other week) with clear action plans to support staff to promote high-quality end-of-life conversations;
» Holding one-to-one discussions with staff about care that reflects the needs of the patient and family;
» Using a symbol (speech bubble) on the ward white board to indicate those patients who are identified as approaching the end of life or whose recovery is uncertain.

In response to the particular issues identified by junior doctors, the Conversation Project also established specific education and support sessions during the four-month rotation on a ward, based on reflective practice.

For some patients, an admission to hospital may not be an appropriate time for end-of-life discussions to take place – and some patients or families may never wish to have conversations of this nature. Equally, some staff may not feel they have the necessary knowledge or skills to enter into dialogue with patients approaching the end of their life, or their family. In these situations we prompted conversations to take place with community colleagues (particularly GPs) about the admission, medical decisions made and the subsequent care plan, so that informed discussions about the end of life could take place with the GP at an appropriate time in the future for that patient and family.

As part of our aim to ensure end-of-life issues are addressed in decision making and discussions, we have promoted

Changing practice on hospital wards
These aims have been addressed in practice on hospital wards. The project has been adopted differently on each ward, depending on the patient group and ward specialty. For example, in the care of older people it has focused on the need to promote advance care planning in discussion with the patient and family, or with the family as an advocate should the patient lack capacity. On the acute stroke unit, it supports the recognition that the patient’s recovery is uncertain. It promotes regular discussions with the family to ensure they understand how unwell the patient is and are aware of the risk that the patient may die. This gives families some time to adjust to what is happening.

Whichever way the wards are adopting the project, the messages are clear:
» There should be multiprofessional recognition that the patient is approaching the end of life;
» There should be conversations with the patient and family about: “Hoping for the best but, at the same time, being prepared for the worst”
» Ask the patient and/or family what they understand. What do they want/what matters to them now?
» Document the conversations and the plan of care
» Review the plan of care regularly. Ensure the patient/family agree with the plan
» Inform community colleagues of the conversations, decisions and wishes of the patient and family if the patient is discharged

BOX 3. CONTENT OF KEY CARDS FOR STAFF

Ask: Is the patient’s recovery uncertain/ or is the patient likely to be approaching the end of life (days/ weeks/months)?
Seek out conversations with patient/family about: “Hoping for the best but, at the same time, being prepared for the worst”
Ask the patient and/or family what they understand. What do they want/what matters to them now?
Document the conversations and the plan of care
Review the plan of care regularly. Ensure the patient/family agree with the plan
Inform community colleagues of the conversations, decisions and wishes of the patient and family if the patient is discharged

FIG 1. PATIENTS WITH CLEAR AND DOCUMENTED END-OF-LIFE CARE PLAN

FIG 2. DISCUSSION WITH FAMILY DOCUMENTED

“Communication is seen as a soft skill, which is wrong”
Mary Haight p24
Box 4. Results from junior doctor survey

Junior doctors felt more confident about:
- Initiating conversations with patients about issues surrounding the end of life.
- The proportion of junior doctors scoring their confidence at 8/10 rose from 14.29% at the beginning of the rotation to 35.71% at the end.
- Having conversations with relatives about issues surrounding the end of life.
- Their recognition that a patient’s recovery was uncertain had increased from 0% to 40% at the end of the rotation.
- The proportion scoring their confidence at 8/10 rose from 19.06% at the beginning of the rotation to 39.29% at the end.
- Their recognition that a patient’s death was likely to be included in discharge letters.

Results and discussion

The Conversation Project has raised an awareness of the importance of end-of-life care at ward level and a recognition of patients’ and families’ need to engage in advance care planning and preparation for the future. The project has successfully engaged with a wide range of staff groups, and helped them to understand their role within end-of-life care.

This has increased staff confidence to enter into potentially difficult conversations with patients and their families. It has also actively encouraged staff who do not feel equipped to have such conversations to identify patients who are approaching the end of life, and then find the most appropriate person who does feel competent to enter into dialogue with them.

There has been a tangible change in ward vocabulary, with more open discussion at multidisciplinary team meetings about approaching the end of life and advance care planning. Audit of patient notes has demonstrated an increase in the proportion of patients at the end of life for whom a clear end-of-life care plan is documented (Fig 1). When this has been done information about patients’ advance care plans is more likely to be included in discharge letters.

As a result of this project, end-of-life conversations with both patients and families are more likely to be documented in each patient’s notes (Figs 2 and 3). Although conversations happened before this work started, the project has resulted in practical changes that make it easier for staff to ensure this is done consistently. For example, it introduced a communication sheet into the notes to document important decisions, discussions and conversations with the patient and/or family so they are not lost in the body of the medical notes. Overall, the Conversation Project has promoted a far greater focus on the quality, depth and extent of the end-of-life conversations that are taking place.

As part of the project, junior doctors received monthly education/support sessions with a palliative care consultant during their four-month rotation on the wards. They were asked a series of questions at the start and end of their rotation to identify what learning had taken place. Box 4 shows the results from 28 completed questionnaires. We found that the Conversation Project was particularly successful in giving junior doctors greater confidence in approaching end-of-life issues.

Future plans

This is a project that requires organisation-wide, long-term investment to ensure the cultural change in staff’s awareness and knowledge of end-of-life care, as well as recognition of their role within it, is developed and maintained. Staff need ongoing education and support to engage patients and families in what may be difficult and challenging conversations. We need to be courageous in asking patients and families about their experience to develop a deeper understanding of their own concerns and those that may be pertinent to end-of-life care in general; however, we also need to recognise when it is appropriate to ask such questions.

Ensuring sustainability in the long term is challenging; measures being taken to do this include:
- Giving staff access to communication skills training;
- Providing ward-based teaching on end-of-life care issues such as advance care planning;
- Ensuring staff reflect on care given, and recognise their role in end-of-life care;
- Fostering greater staff engagement and ownership of the project;
- Building procedures in ward routines to ensure the need for end-of-life care is routinely recognised;
- Using documentation to support the work that is done.

The Conversation Project has created a dialogue with a wide range of staff, and provided a platform for the palliative care team to engage with staff and influence, beyond their specialist role, the care on the wards. It has organisational support and has been adopted as a Commissioning for Quality and Innovation scheme; this is part of the payments system that enables commissioners to reward the achievement of local quality improvement goals. This has helped provide a focus for its implementation.

The palliative end-of-life care team will continue developing the work initiated by the PFCC programme and plan to spread the approach to other wards in the hospital. The enthusiasm and positivity of all staff involved in the project, who have recognised the importance of what they are doing for patients and families, has been the catalyst to the project’s success.

References


Leadership Alliance for the Care of Dying People (2014) One Chance to Get it Right. tinyurl.com/LACDOneChance


For more on this topic go online...
- Getting the priorities right in end-of-life care
- Bit.ly/NTEndofLifePriorities