

When people are at the end of life most have lost capacity or strength to express their opinions. A diary tool enabled relatives to act as advocates for patients

Communication diary to aid care at the end of life

In this article...

- › The importance of involving family and carers at the end of life
- › How a diary tool was developed and introduced
- › How the diary tool improved communication and level of care

Authors Mel McEvoy is nurse consultant, Cancer and Palliative Care, North Tees and Hartlepool Foundation Trust; Edwin Pugh is visiting professor, University of Teesside and consultant in palliative medicine, North Tees and Hartlepool Foundation Trust; John Blenkinsopp is clinical effectiveness adviser, North Tees and Hartlepool Foundation Trust.

Abstract McEvoy M et al (2012) Communication diary to aid care at the end of life. *Nursing Times*; 108: 17, 24-27. This study describes how clinical staff at an acute hospital developed and introduced a diary tool that improved communication with the relatives (or carers) of patients receiving end-of-life care.

The "Relatives'/carers' diary" was given to relatives of patients on the Liverpool Care Pathway. The diary enables relatives to be more meaningfully engaged in end-of-life care. It also enables nurses to monitor the quality of their care and respond quickly to any concerns.

Over the past 10 years UK healthcare policy has acknowledged the need to involve family and carers in end-of-life care. The Department of Health's (2008) end-of-life care strategy stated that:

"Informal family and carers of people approaching the end of life have a vital role in the provision of care. They need to be closely involved in decision making with the recognition that they also have their [own] needs."

The National End of Life Care Programme, in its document *The Route to Success in End of Life Care - Achieving Quality in*

Acute Hospitals (2010), stated that "loved ones" should continue to be involved in decision making. And yet for all the recognition of the need to assess and address the concerns of family and carers - there is a lack of good quality research evidence telling us how to go about it.

The Liverpool Care Pathway was developed as a way of transferring the best practice of care for dying patients delivered in hospices into other settings including hospitals. It aims to promote good symptom control combined with psychosocial and spiritual care for patients and their families in the last hours and days of their life (National Institute for Health and Clinical Excellence, 2004). The second annual report of the end-of-life strategy (DH, 2010) and the results of the national audit of the Liverpool Care Pathway (Marie Curie Palliative Care Institute, 2011) showed that communication with family and carers was still an area that needed improvement.

This article presents the results of an action research study to develop and test the value of using a tool known as the "Relatives'/carers' diary" to assist communication between family or carers and clinical staff. The diary invites family and carers of dying patients to make a judgement about the degree of success in the control of symptoms and to provide written comments on the quality of care and support, both to the patient and themselves. This is completed contemporaneously at the patient's bedside and shared with clinical staff as part of their regular clinical review.

Ethical approval

The National Research Ethics Service (Sunderland Research Ethics Committee) approved the study. All family and carers

5 key points

1 The Liverpool Care Pathway aims to support good symptom control and offer psychosocial and spiritual care

2 By addressing family and carers' concerns at the bedside, care and comfort can be improved

3 Family members have a dual role in that they are both a provider and recipient of support

4 The Relatives'/carers' diary tool was developed to ensure regular communication between nurses and family and carers

5 Supporting family and carers in the care of a dying patient may help the bereavement process



Nurses may lack confidence in end-of-life care

provided written consent for participation in the study.

Developing the diary

The action research was carried out in two phases, between March and August 2010 inclusive, in an acute hospital in the north of England. In phase 1 we developed a communication tool in the form of a diary. We first put together a prototype, which we tested with a group of carers and ward nursing staff. The carers were people who had partners who had died in the study hospital in the previous 10 years. In a workshop format they were asked to evaluate how useful the diary might be.

We then presented the diary to the hospital patient advisory group with a request for further comments and opinions, and discussed the diary with clinical nurses involved in end-of-life care via a facilitated workshop. A small pre-pilot of the diary was completed by three families and carers of patients on the LCP before the diary was formally introduced.

The diary invited family and carers of patients on the LCP to comment on four main areas:

- » To record by tick box from a five-point option scale the degree to which family and carers perceived the patient to be free from pain, nausea and vomiting and whether the patient appeared calm and was breathing comfortably. The options were scored as 5 “all of the time”, 4 “most of the time”, 3 “some of the time”, 2 “none of the time”, and 1 “don’t know”.
- » To record by tick box from the same five-point option scale the degree to which staff were seen to care for the patient, family and carers in a supportive and sensitive way.
- » To write in an open comments box if anything further could have been done to help the patient or family and carers on a daily basis.
- » To give written feedback on the value of the diary in terms of how easy it was to complete, whether it was helpful at a difficult time, or whether it was distressing.

Introducing the diary into practice

During phase 2 we introduced the diary into clinical practice. The lead researcher (MM) trained a small team of research assistants to help with the study and alerted all hospital wards through awareness and training sessions and via the hospital intranet website. The hospital’s executive director of nursing supported and promoted the study. MM was notified

when any hospital patient started on the LCP and at that point a researcher would visit family and carers to invite them to enter the study and to record their consent. In some cases, we judged it inappropriate to ask carers to start the diary if they were distressed about the severity of the clinical situation.

After the patient died the diary was sent to MM for analysis in a pre-addressed envelope supplied with the diary via the hospital’s internal mail or collected personally by one of the researchers during a ward visit. Analysis included reviewing the quantitative scoring and undertaking a thematic analysis of qualitative comments. Following analysis, results were fed back to ward managers and senior nursing staff.

Results

In the study period there were 631 deaths in the hospital. Of these 275 (43%) patients were on the LCP. Family and carers of 59 patients on the LCP agreed to take part in the diary study, returning 60 diaries (one patient had two diaries). This represented 22% of all deaths on the LCP. The family and carers who took part were mostly sons or daughters of the patient. The researchers did not receive any verbal or written complaints from family and carers or staff about the introduction of the diary.

In 60 (100%) diaries the tick box questions on clinical care were completed, while 32 (53%) diaries contained written comments. Of these, 22 (37% of the total sample) completed the section asking “if you feel anything more could have been done to help you, your relative or friend, please tell us here”; while 18 (30%) completed the section asking for feedback on whether the diary was difficult to complete and whether the participants found it helpful or distressing. Eight participants made written comments in both sections.

MM carried out a thematic analysis of qualitative comments and identified seven main categories:

- » Use of the diary;
- » Helpfulness of the diary;
- » Issues to do with clinical practice;
- » Observations on care;
- » Observations on dying, death and bereavement;
- » Expressions of thanks and appreciation;
- » Comments on exceptional care.

A selection of participants’ written comments for each of the seven themes are given in Table 1.

The average length of time on the LCP was 2.75 days.

Discussion

In our review of the literature we found no studies explicitly inviting the views of family and carers about comfort and care in real time during the management of patients at the end of life. The LCP documentation could be seen as a prompt for communication with family and carers but it is owned and completed by clinical staff. There are numerous examples of research tools, including surveys, being used retrospectively after death. These include the VOICES survey of bereaved family and carers (Hunt et al, 2011) and that of Mullick et al (2009). Such surveys allow feedback on quality of care and monitor carer satisfaction but do not help the patient and family and carers at the time of need.

Many hospital complaints come from relatives concerned with the care of their loved ones who are dying. The Healthcare Commission (2007) found that 54% of hospital complaints concerned basic care, including comfort and communication issues. Results from the VOICES questionnaire (Hunt et al, 2011) identified significant proportions of family and carers who reported personal care needs not being met, symptoms not being well controlled and emotional and spiritual needs not being met.

By addressing family and carers’ concerns at the bedside we believe care and comfort can be improved with minimal delay to the satisfaction of family and carers and to the benefit of the dying patient. By correcting deficiencies in care as perceived by family and carers while the patient is still alive, then distressing memories and subsequent complaints may be avoided.

Studies recognise the need to assess and address family and carers’ needs but there is a lack of quality research in this area. Current policy advocates the role of co-worker but this may inhibit family and carers from the role of recipient of care (Grande et al, 2009). Family and carers have a dual role in that they are both a provider and recipient of support. Interventions should attend to informal caregivers’ needs and enhance their ability to support their dying relative or friend (Mangan et al, 2003). In addition users should be involved in the development of interventions (Grande et al, 2009).

We chose action research as the most appropriate approach for our study. It is described by Meyer (2000) as a style of research rather than a specific method such as formal qualitative research. Day and colleagues (2009) supported the idea that it is the approach of choice if change in practice is required. Pontin and Lewis

TABLE 1. CARERS' WRITTEN COMMENTS BY THEME

(i) The use of the diary		(v) Observations on dying death and bereavement	
Diary No	Carers' comments	Diary No	Carers' comments
1	We found it very useful to fill [in] this diary. We found it helpful at this difficult time. We did not find it distressing at this very difficult time.	2	As a carer for my mother for the last few years this has been an interesting experience and quite uplifting.
5	We found completing the diary was no problem.	7	Mum has been well cared for today. To the question could anything more be done, answer no. Mum passed away peacefully 3pm.
7	Easy to fill in. Helpful at a difficult time.	18	Peaceful day with dad. Staff wonderful as ever. Very grateful. Dad died 10pm very peacefully with his four daughters present [names omitted] God bless.
37	No problems with completing the diary. Yes I found it informative.	44	[patient's name] passed away peacefully. Thank you for the care.
(ii) The helpfulness of the diary		50	The nurses... made this hard and often upsetting time a lot easier for my husband, myself and all the family to cope with and deal with. Their support, love and care were invaluable...
Diary No	Carers' comments	59	Was more relaxed in evening. Was very cold – whole body, face, arms etc.
5	Yes – helped us see the progression and ease of the pain relief.	(vi) Expressions of thanks and appreciation	
8	I found it helpful because it focused my mind on the fact that he was comfortable and that gave me comfort.	Diary No	Carers' comments
20	Became a part of the routine. It was helpful to have something to record. Although the repetitive nature of the questions was sometimes off putting.	1	We cannot explain in words how we feel about the care and dedication of the doctors and staff on this ward. They have been our rock – our shoulder to cry on. And most important THEY CARE. Thank you from the bottom of our hearts xxxxxxxx.
(iii) Issues to do with clinical practice		8	Nothing [more could have been done to help]. Thank you.
Diary No	Carers' comments	9	Thank you for your help and support.
3	I think the amount of time spent at the bedside a more comfortable seating could be addressed [sic].	17	Thank you for the care and attention and for being so open with us. All seems to be well taken care of. Thank you.
18	I feel that patients taken off all medicines should be taken to the side room first. A chair bed would be invaluable to us as we stayed overnight.	18	All the nurses have been so helpful.
51I asked if we could go outside to discuss this as it was somewhat insensitive to speak in front of my husband when he was not aware he was dying.	20	Good support from chaplain.
(iv) Observations on care		28	We do not feel the nursing staff at [hospital] could have done any more than they have done.
Diary No	Carers' comments	42	Nothing else. The staff are excellent, very kind and caring. Thank you. My father agrees.
7	Mum's nappy needed changing and she needed to be repositioned in the bed after request [it] took one hour to attend.	(vii) Expressions of exceptional care	
9	Nurses always ready to help and care about me too. Very pleased with the care. Today staff as always have supported all the family and kept our loved one comfortable.	Diary No	Carers' comments
20	Neck support with pillows – head always slips to the left – we did our best. Dad a little restless and needed some lolly sticks. Thank you – The pillows were placed really well today. We turned room light off – too bright. Looked uncomfortable but nurse helped to sit dad up and assured us he was not uncomfortable.	5	Total care 110%. You all went the extra mile for Mam.
45	[patient's name] was only in pain when they changed her bed and nighty. Breathing rattle developed during the day.	29	Everything has been exceptional. Staff could have not done anything more than have done. Everything and everyone have been exceptional.
		41	Staff were absolutely excellent. Fully respectful and helpful.

(2008) stated that it is a way of addressing real world problems in a rigorous and robust way.

In developing the diary we were familiar with the work of Mayland et al (2008). They critically appraised tools used with bereaved relatives to measure the quality of care of dying patients and the support provided to families. Three factors were defined as important to families:

- » The need for user involvement in the evaluation of care;
- » The need for development of a tool that could assess the level of patient care and support to families;
- » An ability to assess the impact of interventions in the last days and hours of life.

Our action research approach addressed these three areas and introduced them into clinical practice. It enabled the lead researcher to design an initial diary format, which was then modified and adapted with key stakeholders to meet the needs of family and carers. Choosing the time that patients were placed on the LCP as a trigger to introduce the diary meant the focus was on the last few days and hours of life.

By the time patients are placed on the LCP, most have lost capacity and are unable to coherently express opinions about their comfort or care. Family members can therefore be seen as advocates for patients at this sensitive and emotional time. Addington-Hall and McPherson (2001) suggested that family are one way of accessing the "patient's voice". Their views are inherently valid because these people and those memories live on so the whole end-of-life experience has an impact on bereavement and subsequent health.

The LCP was developed as a way of transferring the best practice of care for dying patients delivered in hospices into acute settings and other places. Addington-Hall and O' Callaghan (2009) highlighted some of the difficulties of delivering hospice principles within the acute setting. They found that acute nurses focused on physical rather than psychological care and it appeared that the hospital environment was more of a barrier to change. Nurses were found to lack confidence in dealing with patients' psychosocial needs and care remained less satisfactory from the perspective of bereaved relatives.

The diary acted as a catalyst to ensure regular communication between nurses and family and carers so that sensitive matters of support were addressed in addition to physical care and symptom control

in line with hospice best practice.

A selection of family and carers' written qualitative comments in the diary are shown in Table 1. They provide constructive comments to improve care. For example, two constructively critical comments on clinical practice (Diaries 3 and 18) reflected the need to have suitable furniture for the comfort of carers spending long periods, including staying overnight, with patients. Another observation on care (Diary 7) highlighted the perceived delay in basic care such as repositioning and changing pads. Insensitivity in communication was raised (Diary 51).

Family and carers' comments reflect the Healthcare Commission findings about basic care, including comfort and communication issues. When family and carers experience health professionals being attentive, committed and respectful it is perceived as exceptional care (Diary 5) and staff are praised for their effort (Diary 1). In addition, family and carers feel able to articulate their loss, which implies a real engagement with the dying process (Diary 50).

There is evidence to indicate that involving and supporting family and carers in the care of a dying patient may help the bereavement process. Grande and Ewing (2009) stated: "Inadequate support in end-of-life care relates to bereavement outcomes."

Lack of information and poor psychological support was associated with significantly worse initial grief, present grief and mental illness. The challenge to service providers is to highlight the positive aspects of caregiving by enabling a sense of achievement and empowerment without exacerbating the effects of the carer's burden. Payne et al (2010) stated that anxiety is compounded by the carer's anticipation of bereavement. Waldrop (2006) identified that in observing a family member experience a "good death", a caregiver's stress can be eased with a significant impact on their long-term health and wellbeing.

In our study family and carers' observations on dying, death and bereavement (Diaries 18 and 50) imply that a deep level of communication between staff and family and carers is a major factor in the family and carers' perception of a "good death" and helpful at the beginning of their bereavement process. Because of this we believe the diary approach may have more long-term benefits with regard to family and carers' mental health than the use of retrospective surveys; this should be the subject of further study.

The relatives'/carers' diary is, we believe, unique because it is the first of its kind to ask family and carers at the bedside of dying patients in an acute hospital to contemporaneously record their perceptions about symptom control and also the quality of interpersonal care given to both the patient and themselves. The diary is shared with the clinical staff in real time and is a tool to aid communication by involving family and carers and providing a proxy for the family and carers' perceived quality of care.

The diary was generally received as a helpful tool and no participants reported it as distressing or burdensome. This, and the fact that the researchers did not receive any verbal or written complaints from family, carers or staff, will be reassuring to some nurses who were concerned that the diary may be intrusive.

Limitations of study

There are a number of limitations of the study at this pilot stage. Researchers had pragmatic discretion not to approach a family member or carer if they felt it inappropriate. The sample representing just over one fifth of all patients on the LCP was not random and there is a potential selection bias to those family and carers deemed more able and available to participate. We accept that given the potential bias and low sample size, results cannot be generalised.

In this initial study the relationship of the carer to the patient was not routinely recorded; this data is now being collected. Although we have used the term "diary" it is more precisely an evaluation tool. Despite these limitations we believe the "Relatives'/carers' diary" has achieved the aim of the research, which was to develop a diary to improve communication between family/carers and health professionals during end-of-life care.

Conclusion

The "Relatives'/carers' diary" is an innovative tool for the acute hospital setting that promotes communication between family and carers and clinical staff in real time by the dying patient's bedside. We believe it can contribute to the pursuit of a "good death" for patients through the engagement of their family and carers. It also provides an ongoing continuous evaluation of the quality of care as experienced by family and carers of dying patients.

Results indicate that the diary aids communication and enables family and carers to be more meaningfully engaged in end-of-life care. It enables nurses to monitor the quality of their care and respond

quickly to any concerns as they happen. The study has now been extended to offer the diary to all family and carers of patients who are on the LCP. **NT**

References

- Addington-Hall J, McPherson C** (2001) After-death interviews with surrogates/bereaved family members: some issues of validity. *Journal of Pain and Symptom Management*; 22: 3, 784-790.
- Addington-Hall J, O'Callaghan A** (2009) Patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire. *Palliative Medicine*; 23: 3, 190-197.
- Day J et al** (2009) The process of practice redesign in delirium care for hospitalized older people: a participatory action research study. *International Journal of Nursing Studies*; 46: 1, 13-22.
- Department of Health** (2010) *End of Life Care Strategy: Second Annual Report*. London: Stationery Office. tinyurl.com/endoflife-2ndreport
- Department of Health** (2008) *End-of-life Care Strategy: Promoting High Quality Care for All Adults at the End of Life*. London: Stationery Office. tinyurl.com/endoflife-strategy
- Grande GE, Ewing G** (2009) Informal carer bereavement outcome: relation to quality of end of life support and achievement of preferred place of death. *Palliative Medicine*; 23: 3, 248-256.
- Grande G et al** (2009) Supporting lay carers in end of life care: current gaps and future priorities. *Palliative Medicine*; 23: 4, 339-344.
- Healthcare Commission** (2007) *Spotlight on Complaints: A Report on Second-Stage Complaints about the NHS in England*. London: Healthcare Commission.
- Hunt KJ et al** (2011) *VOICES Redesign and Testing to Inform a National end of Life Care Survey*. Southampton: University of Southampton.
- Mangan PA et al** (2003) Caregiving near the end of life: unmet needs and potential solutions. *Palliative & Supportive Care*; 1: 3, 247-259.
- Marie Curie Palliative Care Institute** (2011) *National Care of the Dying Audit Hospitals Round 2 generic report 2008/2009*. Liverpool: Marie Curie Palliative Care Institute. tinyurl.com/NatCareofDying-rnd2
- Mayland CR, et al** (2008) How well do current instruments using bereavement relatives' views evaluate care for dying patients? *Palliative Medicine*; 22: 2, 133-144.
- Meyer J** (2000) Qualitative research in healthcare: using qualitative methods in health related research. *British Medical Journal*; 320, 178-181.
- Mullick A et al** (2009) Letter to the editor. Liverpool care pathway carers survey. *Palliative Medicine*; 23: 3, 571-572.
- National End of Life Care Programme** (2010) *The Route to Success in End of Life Care - Achieving Quality in Acute Hospitals*. tinyurl.com/endoflifecare-routesuccess
- National Institute for Clinical Excellence** (2004) *Guidance on Cancer Service: Improving Supportive and Palliative Care for Adults with Cancer*. London: NICE. www.nice.org.uk/csgsp
- Payne S et al** (2010) End-of-life issues in acute stroke care: a qualitative study of the experiences and preferences of patients and families. *Palliative Medicine*; 24: 2, 146-53.
- Pontin D and Lewis M** (2008) Managing the caseload: a qualitative action research study. Exploring how community children's nurses deliver services to children living with a life-threatening and chronic condition. *Journal for Specialists in Pediatric Nursing*; 13: 1, 26-35.
- Waldrop DP** (2006) Caregiving Systems at the end of life: how informal caregivers and formal providers collaborate. *Families in Society*; 87: 3, 427-437.