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A qualitative study of the use of a supportive care pathway for end of life care in an intensive care unit

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Keywords

Palliative care, intensive care, intensive care unit, qualitative research, supportive care,
patient care planning

Abstract

Providing palliative care support in intensive care settings is beneficial, however barriers to delivering high quality end of life care remain. To address this, pathways have been used to improve the quality of palliative care in generalist settings. This study describes the views of professionals using a supportive care pathway in intensive care.

Qualitative semi-structured interviews were conducted with ten health professionals working in a surgical intensive care unit. The data were analysed thematically.

Participants were positive about the effect of the supportive care pathway on patient care, particularly in enabling consensus in care planning. Some expressed concerns including the difficulty of identifying the 'correct patients' for the pathway, the risk of it becoming a 'self-fulfilling prophecy', and an euphemism for dying.

Pathways are one potential mechanism for guiding care planning and communicating the goals of care to colleagues, patients and families, thus contributing to improvements in palliative care.

Introduction

Providing quality end of life care is an important function of acute hospital services (Morgan, 2008) and the need for good palliation in all settings has also been identified (Byock, 2006a). Advances in the treatment of a range of illnesses and other technological developments have enabled intensive care staff to save and extend life, although this can lead to prolongation of an inevitable dying process (Nelson and Meier 1999). An understanding of the role of palliative care teams in intensive care units is emerging in the context of high mortality and morbidity (Byock, 2006b; Lanken et al, 2008).

Zimmerman, Wagner and Draper (1998) have suggested that knowing which patients will benefit from intensive therapy is challenging. In a qualitative study of intensive care unit (ICU) consultants, it was found that clinical decision making about patients who were stable but not improving with ICU care was particularly difficult (Mckeown et al 2010). Although mortality rates in surgical ICUs are low, patients are critically ill by definition, and consequently at risk of death, and older patients, and those receiving intensive care for long periods have higher mortality (Mosenthal et al, 2012). In addition, the symptom burden for patients in ICU is high (Delado-Guay et al, 2009). This suggests that there are patients in the ICU environment who may benefit from palliative care support. Palliative care early in a patient's intensive care admission has benefits in terms of reduced length of stay in ICU, though not in overall length of hospital stay, with no significant difference in mortality (Norton et al, 2007).

Palliative care is focussed on symptom control, effective communication of the goals of care, alignment of treatment with patient preferences, family support, and planning for transitions (Frontera et al, 2015). It is most effective when provided in combination with life prolonging treatment, making it an essential component of treatment approaches in the ICU (Frontera et al, 2015). The death of a patient in intensive care can have wider adverse effects, including for family members who may experience mental health problems and staff members who may suffer compassion fatigue if end-of-life care is not managed appropriately (Cook et al, 2015).

End-of-life care pathways have been used in the United Kingdom with the aim of improving the quality of palliative care provided by non-specialist staff (Chan and Webster, 2010). For example, the Liverpool Care Pathway (LCP) for the dying patient has been used in acute hospitals, although the review by Neuberger et al (2013) resulted in its abolition. It found that the LCP was often used incorrectly. For example, the LCP includes sections on hydration and nutrition to indicate that these are areas that should be discussed with the patient and family and decisions made about withdrawal if and when appropriate. However, in some instances a 'tick box' approach was taken and guidance was misinterpreted as instruction, resulting in nutrition and/or fluids being withheld without consultation with the patient or family.

Inappropriate implementation of the LCP led to patients and families not being treated with respect, and communication deficits. Its withdrawal led to uncertainties and inconsistencies in the delivery of end of life care, particularly for less experienced practitioners (Venkatasalu et al, 2015). Although a robust defence of the LCP was mounted by 20 organisations, including charities and hospices, arguing it has benefits

when applied correctly (Kmietowicz, 2012), many hospitals are seeking to develop new care plans to support staff in delivering high quality palliative care. In view of this, it is important to learn the lessons from the use of care pathways in a range of settings in order to inform future practice. The purpose of this paper therefore is to report the findings from a qualitative study designed to investigate staff views of the introduction of a supportive care pathway in an intensive care unit.

Background

A supportive care pathway (SCP) was introduced as a part of a pilot scheme in the cardiac ICU of a tertiary referral hospital in England in January 2011. The introduction of the pathway was “driven by the recognition that there was no coherent strategy for dealing with patients who were at high risk of dying during their ICU admission, yet still required intensive care support”(Turfrey D, personal communication, 26th January 2011). Its introduction was supported by staff training provided by an intensive care physician with a special interest in palliative care. This physician delivered teaching sessions to the multidisciplinary team working in the intensive care unit, about the SCP and end of life care in general. The introduction of the SCP was also supported by a regular ward round involving a consultant with a special interest in palliative care with an aim to identify patients whose care could benefit from use of the SCP. In addition the ward round provided an opportunity for staff to obtain support and advice with regard to the associated paperwork. Decisions to use the SCP were initiated on multi-disciplinary ward rounds. The SCP differed from the LCP and other pathway approaches in that it was designed for use with patients who had a life

limiting disease but were not necessarily in the last hours or days of life (Main, Whittle and Trembl, 2006). The SCP is a prompt to staff to consider the holistic needs of patient and families. It stresses the vital nature of communication and serves as a record of important conversations about care and treatment. It directs attention to the palliative care needs of patients and families by asking questions such as: 'What discussions have taken place about initiating or withdrawing treatments?' 'What medical treatment remains appropriate?' and 'What medical treatment is no longer appropriate?' as a basis for agreeing an individualised care plan. There is space for symptom review, appraisal of psychological and spiritual issues as well as an assessment of whether interventions such as active treatment of infection, blood testing, artificial nutrition and hydration and cardiopulmonary resuscitation are in the best interests of the patient. The SCP is a paper document which is used as the main clinical record and is completed by nursing, medical and AHP staff members. It has sections for recording symptom reviews and space for free text records of treatment decisions and significant conversations. The purposes of the SCP are summarised in box 1.

The aim of the study was to assess the views and experiences of the clinical staff using the SCP in an ICU. In particular the focus was on the respondents' perceptions of the advantages and disadvantages of the SCP. The intention was to determine the benefits or otherwise of the SCP from the perspective of those using it in order to refine it before wider implementation.

Box 1: Purpose of the SCP

- Ensure that all individuals have access to high quality palliative care, regardless of diagnosis
- Facilitate preferred place of care
- Provide evidence of care given
- Prompt holistic care
- Enable clear planning of care
- Provide patients with a clear understanding of the final phase of their illness
- Improve patient experience and reduce variation in care

Methods

A qualitative approach was used, involving in-depth semi-structured, face-to-face interviews with healthcare professionals who had experience of using the SCP.

Qualitative interviews are appropriate for investigating the views and experiences of respondents and have been effective in health services research (King, 1994). They are particularly suitable for accessing the views of individuals in organisations (Fontana and Frey, 1994; Seale, 1998) which was the purpose of this study. A pilot interview was undertaken to test the validity of the topic guide and minor changes were made as a result. The study was conducted in a 1200 bed tertiary referral hospital in the West Midlands of the England. The 24 bed critical care unit receives elective and emergency patients, with a main focus on cardiac disease and cardiac surgery and is staffed by intensive care nurses and critical care physicians.

Ethical approval was granted by the West Midlands Local Research Ethics Committee (Ref: 11/WM/0190). Permission was also obtained from the Research and Development Department of the hospital involved (Ref: RRK4236) in accordance with research governance requirements.

Sample

In order to access the views of health professionals with experience of using the SCP in the ICU, purposive sampling was used. This is appropriate in qualitative research where the intention is to access in-depth accounts of participants who have understanding of the phenomenon being studied (Kuzel, 1992; Morse 1993; Miles and

Huberman, 1994). The aim was to recruit a sample of between ten and fourteen health professionals. Doctors and nurses with experience of using the SCP, who had worked on the unit prior to its introduction were eligible for inclusion. Participants were contacted by email and informed about the study. A comprehensive participant information sheet was attached to the email. Requests were sent to nineteen clinicians who were asked to indicate their interest in taking part. These clinicians were purposively sampled as those involved and interested in palliative care on the ICU. Twelve people responded. One subsequently declined to participate because of lack of experience in using the SCP, and another decided not to participate because of time constraints. Interviews were conducted face to face in a quiet room on the intensive care unit.

The Interviews

Written informed consent was obtained from each participant before the interview. Participants were advised that they could withdraw from the study at any time by notifying the primary researcher. The interviews were recorded digitally and transcribed verbatim. Interviews were directed by a topic guide, which was developed during the literature review, and refined following initial interviews. Data saturation (Pope and Ziebland, 2000) was reached after nine interviews. One further interview was conducted to ensure that no further themes emerged.

Thematic Analysis

The data were analysed using an approach informed by grounded theory (Glaser and Strauss, 1967). Key words and phrases in the data were coded and compared to other

transcripts. Once data saturation was reached, the codes were reduced by comparing and clustering of codes. Through a process of reduction and comparison similar to that described by Strauss and Corbin (1998), a number of mainly descriptive themes were identified, which revealed the challenges and opportunities associated with the introduction of the SCP. The themes provide useful analytic insights on the process of introducing the SCP. A review of the coding was undertaken by a second researcher and there was broad agreement on the codes and categories identified which were then discussed and refined.

Findings

Participants

Ten interviews were performed over a three month period between November 2011 and February 2012. This involved five nurses and five doctors. All the doctors were consultants in intensive care medicine and the nurses were senior staff nurses, sisters or charge nurses. They had worked in intensive care for between 6 and 30 years. Four females and six males were interviewed. Interviews ranged from 25 to 50 minutes in duration. The themes found in the data are discussed and illustrated with selected data extracts below.

Reaching consensus

Participants reported the SCP was useful in enabling consensus to be reached in situations where multiple healthcare professionals and teams were involved in care. They recognised that intensive care is an area with high mortality, and generally felt

skilled in managing the dying process. There was however some reluctance to identify deterioration and dying in elective surgical patients:

One of the problems in intensive care, especially in surgical intensive care, is that it can be perceived as a failure to identify someone who you think might be dying and one of the problems that we have had here is altering that perception

[Dr] B2-64

Discussions about the course of clinical care were reported to occur frequently, particularly between intensivists and nursing staff. The participants reported that nursing staff often realised that a patient was dying before the medical team, but that consensus needed to be reached before a change in the care plan was made.

Communication between teams was seen to be particularly important in the intensive care setting where there is extensive interdisciplinary working. It was felt that the SCP enabled the goals of care to be defined and helped professionals decide when and how to intervene.

There was frustration when consensus could not be reached as this did not benefit the patient or family members. When there was no consensus, there were difficulties for patients and staff:

Where I do see people becoming stressed, frustrated with the situation... being unable to cope [is] with the fact that we are flogging a dead horse so to speak.

We're doing this [but] I don't think this is in the patient's best interests, [the] majority of everybody else agrees and it's been agreed by this doctor, but this [other] doctor is saying 'no, do this' [Nurse] H5-156

There was some concern expressed about the messages imparted to family members, particularly when the information was not consistent. The participants felt that the SCP provided a framework to prepare and convey clear information about the patient's situation to family members.

Empowering staff

One of the main benefits of the SCP reported by staff was that it gave them a reason to ask about the goals of care for individual patients. This resulted in a greater feeling of support because, in asking the questions prompted by the SCP, and helping each other answer them, teamwork and morale improved.

It empowers nurses, without saying 'don't you think this patient is dying?' It lets them quietly hint that maybe we all think this patient is dying without blurting it out. 'Would you like to think about that [the SCP]' [Dr] A4-132

It was suggested by some of the participants that because symptom control and nursing care were generally good on the intensive care unit, the improvements arising from the introduction of the SCP were modest. However, others felt that there was a tendency on surgical intensive care units to avoid prescribing and administering analgesia unless absolutely necessary, and so the SCP was useful in encouraging staff to take a different view when caring for patients at the end of life:

We're not very good at pain control I think... a post op thing, trying to wake them up and get them off the ventilator... I think the supportive care pathway

helps because it gives you a set of pointers: 'Right are we addressing this?'

[Nurse] K4-120

Some concerns were raised about the SCP being a challenge to the autonomy of clinicians who may, as a consequence, oppose its use.

Actually it doesn't affect your autonomy one iota... but you could imagine that it's all perception 'well I'm now being told how I manage my dying patients, how dare someone tell me how to do it?' [Dr] A8-315

Time pressures and priority of work were important factors limiting the completion of the SCP documentation. There was also concern about duplication of information in the SCP and other notes. For example:

I think it's easy to use... if the unit is quiet and there's people, you know, to push it through, if there's someone to say 'let's look at this' [Nurse] G7-285

We tend to spend so much time documenting things now. I think we probably spend more time writing, and sometimes duplicating stuff. I mean it does take you away from the patient... it's another piece of paper to fill in I think, so that's difficult, but I don't know how else you would do it [Nurse] J7-248

However for the most part the SCP served as a useful aide memoire for staff, triggering thoughts about symptom control and holistic care, and enabling them to focus on the important palliative care issues for patients and their families.

Dealing with uncertainty

One of the main concerns of participants was the level of uncertainty inherent in medicine generally and end of life care in particular.

It's very difficult and clearly there... aren't any objective measures of whether someone is going to survive. We don't have a crystal ball, we don't know... we can look across at sort of population studies, you know, patients who are octogenarians in three systems failure and have been on ICU for this many days, you know their chance of survival is slim to none, [but] you can never say for 100% [Dr] F3-116

Participants also spoke about the importance of preparing family members for the uncertain nature of end of life care on intensive care units:

I think it's important to recognise... and to somehow have that [uncertainty] in the communication with the family... acknowledging and admitting our own clinical uncertainty about these things... I've spent a lot more time in my discussions with families emphasising my own clinical uncertainty [Dr] C4-148

We don't know the future. While we have to prepare patients and their families for the future... we are still uncertain about it. What that means is that, even if we've made a clear decision that we don't think we can help, if the circumstances change, then we need to be able to change direction [Dr] A4-160

However despite this uncertainty none of the participants felt uncomfortable about changing decisions, and even stopping the use of the SCP if necessary:

We don't always get these prognoses right. You occasionally see somebody turn around and I think it's important then that a new consultant on the unit will... review the need for the SCP and if necessary consider revoking it [Dr] C4-139

Although this was dependent on careful selection of patients who would benefit from their care being guided by use of the SCP:

It's very easy to put someone on [the SCP] and then if the patient improves then it should be equally as easy for the focus of care to change back to being acute. The problem is... identifying patients who should possibly be on it [Dr] B5-166

There was also awareness that communication in the team, including informal conversations amongst staff on the unit, could influence the delivery of care:

I'm very much aware that your comments can influence other people... 'What are we doing in bed space six again? He's bloody had it this fella' and that's going to influence, particularly your junior staff, but also your colleagues... and it's actually going to influence the way that they then deliver care [Nurse] H3-102

Some participants expressed concern that the SCP could become a 'self-fulfilling prophecy' if not used correctly, although frequent review reduced the risk of this happening. However it was suggested that once the decision had been made to commence the SCP, it was less likely that life sustaining interventions would be re-introduced:

You know you're reducing support to somebody, and you know that that will make them die so there's always that thing, 'Is there another way out?' [Nurse]

G5-191

It puts that almost the black cap on them so to speak, but some of these patients do go home, some of these patients do get better [Nurse] H8-289

Many were concerned about the difficulties of identifying the 'correct' patients to put on the SCP, as noted earlier, and the potentially negative perceptions this may elicit in staff. As a result of uncertainty, there were sometimes delays in starting patients on the SCP until late in their admission, perhaps for some reinforcing the view that the SCP was a self-fulfilling prophecy and a trigger for the withdrawal of care. This is in contrast to the assurances given earlier that decisions could be changed, further underlining the uncertain nature of care in this area.

The SCP was not appropriate when patients experienced a sudden decline in their condition. In cases where treatment was withdrawn, death usually followed soon afterwards, consequently use of the SCP was unnecessary. Some participants felt that a better explanation of what it was for and clearer criteria for when to use it would be useful:

It needs to be implemented in such a way that it is about supporting care and it's not perceived as a document directed at withdrawal of treatment [Dr] F8-

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Managing Expectations

The SCP was found to be particularly helpful in providing a means for discussing family members' expectations of care. This also applied to a lesser extent to discussions with colleagues. As the purpose of ICU is the delivery of life saving critical interventions, death may be perceived as unlikely. In view of this many of the participants felt it was important to ensure there were realistic goals agreed with those needing end of life care:

[It is] sometimes a quite difficult transition because, of course, when you bring someone into intensive care, by and large you're bringing them in for full and active treatment... you almost have to 360 your perspective in a moment towards palliative care... I think that affects the implementation of palliative care because it should be more of a continuum from when they arrive [Dr] F1-14

I don't think as a whole that health care is terribly good with communicating, managing expectations of relatives... I think a large part of end of life care is expectation management so that people have a realistic understanding of what the outcome is going to be [Dr] C2-54

The SCP was found to be a useful framework for end of life care because it identified the need for combining good communication with families, with sharing concerns about the uncertainty of diagnosis, and being realistic about the goals of care.

Discussion

This study has identified that there are advantages and disadvantages in using a pathway on the ICU to support the care of those thought to be unlikely to survive their admission. Generally participants were positive about the SCP and felt it enhanced patient care. Respondents noted the importance of reaching a consensus in care planning, which was enabled by the SCP because it empowered staff to question the direction of care. It also helped them manage the expectations of both family members and staff. Dealing with uncertainty meant there were challenges in ensuring the pathway was used appropriately and commenced at a suitable time.

Although the SCP is not designed solely for those in the final days of life, the findings are consistent with work by Walker and Read (2010) that suggest the LCP was useful in changing the emphasis of care, directing end of life decision making and ensuring it focussed on the needs of patients and families. However, this is an area in need of further work because as Sleeman and Collis (2013) suggest, 'strong evidence' for the benefit of the LCP is lacking. The use of standardised pathways has been found to improve the consistency and continuity of care, enhance collaborative working and ensure a proactive rather than a reactive approach to care planning (Lhussier, Carr and Wilkinson, 2007). This was also reported by the participants in this study.

Communication between staff and family members has been described as a crucial element in effective end of life care (Mckeown et al, 2010). In this study, the SCP was found to encourage effective individualised patient care and communication. Patients

who die on ICU sometimes experience a lack of continuity of care which can affect symptom control and outcomes, particularly where there are changes in the consultant responsible for a patient's care (Mckeown et al 2010). Participants felt that the SCP provided a useful prompt to initiate discussions about the goals of care and encouraged professionals to reach a consensus about its direction. In areas such as ICU, where there are multiple teams involved in the care of a patient, communication between teams becomes even more important.

Differences have been highlighted between medical and surgical intensive care units. Lower mortality rates on surgical ICUs, together with the surgeons having control of clinical decisions rather than the intensive care team, alters the dynamics of end of life care (Mosenthal et al, 2012). Further research could explore how decisions about palliative care are made and communicated in the surgical, medical and general areas of hospitals.

Some participants felt that negative views of the SCP led to its late implementation which contributed to a perception that the SCP was only suitable for patients who were soon to die and that all patients on the SCP died. During the implementation of the LCP in hospices in Italy, it was reported that staff scepticism was a major barrier to its introduction (Di Leo et al, 2014). Indeed it was concluded that implementation of pathways should be led by an external body experienced in their use and supported by a program of education (Di Leo et al, 2014).

The use of the SCP was a trigger for an education programme in the ICU, which was valued by staff. Education about, and familiarity with documentation is essential for successful implementation (Walker and Read, 2010). It may be that palliative care teams can assist with implementation of pathways and education about end of life care more generally, which could have the added advantage of improving working relationships.

There can be difficulties identifying patients who are dying. Mckeown et al (2010) reported that medical staff need time to fully assess patients, particularly when their prognosis is not entirely clear, in the hope that as time passes the picture will become clearer. In contrast, nurses may wish for an earlier decision to allow the patient's end of life care needs to be addressed as soon as possible. This reinforces the need for effective team communication to ensure consensus is reached. Care pathways can help foster this (Clark et al 2012).

The study reported here was conducted before the withdrawal of the LCP following the Neuberger review (Neuberger et al, 2013). The largely negative publicity may have altered the perceptions of the SCP amongst staff. Critics of the LCP have advocated a pathway which begins earlier in the course of a patient's illness, and prompts early discussion of end of life issues with patients, relatives and staff, which are some of the main goals of the SCP. Indeed it has been acknowledged that where the LCP was being used well it had a transformative effect on the way end of life care services were delivered (HM Government, 2015) supporting, not replacing clinical judgement and that many doctors said they would select it to guide their own end of life care

(Chinthapalli, 2013). It is no longer recommended for use and the emphasis in England is now on the 'five priorities of care' advocated by the Leadership Alliance for the Care of Dying People (2013). Hospitals seeking to ensure quality end of life care, and support for staff in delivering consistent care for dying patients, are developing end of life care plans. Learning from the experience of introducing and using care pathways can inform this process. The participants in this study found that reaching a consensus, communicating this to all team members, empowering staff and managing the expectations of families and other staff were all essential elements of an effective end of life care plan.

Limitations

The findings may have limited generalisability to other settings because the study was a small single site qualitative study, however the aim of the work was to address the research question in-depth and in context which is consistent with a qualitative approach (Miles and Huberman, 1994). Purposive sampling may have resulted in the involvement of participants who were supportive of, and interested in, palliative care, however palliative care is not currently a sub-specialism in ICU so the views expressed are reflective of a general perspective on the usefulness of the SCP in ICU. Also experience with the SCP amongst respondents varied, consequently these findings can only be regarded as exploratory. It would be helpful to investigate the views of the wider multidisciplinary team, patients and carers about the SCP.

Conclusion

This study suggests that more emphasis could be put on reaching a consensus for the plan of care and on documenting and communicating it to intensive care staff, patients and their families. Whether this is done using a care pathway or other mechanism will be a matter for discussion within individual units. This research suggests that a separate care plan is one way of achieving this goal if it is integrated with the overall approach to care. The findings from this study suggest that pathways, applied appropriately, still have a role in delivering patient focused end of life care.

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