HONOURING THE WISHES OF A DYING PATIENT: FROM INTENSIVE CARE TO HOME WITH PALLIATIVE CARE

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Abstract

Unfortunately, a major percentage of deaths in Intensive Care Units (ICUs) are of patients diagnosed with a terminal disease. Initiating discussions on the transition from curative care to palliative care can be stressful for the Health Care Providers (HCPs), patients and families. The challenge for HCPs is to maintain open communication and shared decision-making with patients and family members at this very sensitive time. This can be challenging as the culture of the ICU is to save lives rather than to palliate. Facilitating discussions on end of life care for terminally ill patients in ICU may improve the patients’ quality of life and assist patients to die in an environment of their choice, including in their home.

Introduction

More than 50% of Australians will die in hospitals, despite the vast majority wanting to die at home (Peters & Sellick, 2006). Terminally ill patients who receive palliative care can expect effective symptom management, which greatly improves their quality of life. However, a large number of patients who die in acute care settings, such as Intensive Care Units (ICUs) do not receive appropriate palliative care (Peters et al., 2006). Evidence suggests that as many as half the people admitted to an ICU at the end of their life would have chosen either to die at home, in a hospice, or in a Residential Aged Care Facility (RACF) had they been given the choice (Olsen, 2012). The following case study highlights the importance of integrating palliative care to all patients in our acute care areas who are at the end of life, to enhance quality of life until death occurs.

Mr M’s Journey

Mr M (pseudonym) was a 64 year old man who was admitted to the Calvary Mater Newcastle Emergency Department (CMNED). He was generally unwell with fever and rigors. He was dehydrated and anorexic. Examination and investigations in the ED were unremarkable except for long-standing dysuria. His provisional diagnosis and management were urosepsis complicated by hypertension, atrial fibrillation) and Acute Renal Failure. Mr M was treated with oxygen therapy, fluid resuscitation and Intra Venous antibiotics. Mr M was admitted to ICU for ongoing management.

The previous year Mr M had been diagnosed with Transitional Cell Carcinoma (TCC) of the bladder for which he received radiotherapy and chemotherapy to assist in controlling the disease. Mr M had been married to his wife Mrs M (pseudonym) for over 20 years. They had no children but many relatives and friends. Mr M was well liked and respected in his community and was always ready to help others if needed. Mr M was a non-smoker/drinker and had reasonable mobility until July 2010.

As part of Mr M’s management in ICU he underwent a Trans-Oesophageal Echo (TOE) that indicated end-stage cardiac failure. The advice from the cardiologist was that Mr M was in poor health and suffering with multi-organ failure due to his rapid disease progress. He was not suitable for curative treatment. Mr M was regarded as high risk and surgery was deemed not feasible. A discussion with Mr M and his wife in ICU identified his present goals, medical needs and future symptom management requirements (Kaur & Mohanti, 2011). It was at this stage that a referral was made to palliative care for ongoing management.

The pastoral care worker was the person most instrumental in instigating palliative care for Mr M, establishing a good rapport with Mr M and his wife. The pastoral care worker was able to shift the focus away from his illness and onto him and invited Mr M to tell the story about his life’s journey and his impending death. Kearsley (2010, p. 3) states: Our stories define who we are… we continually author our own life stories as we reflect, interpret and re-interpret what happens in our lives… stories help us to make sense of the insensible. Mr M pleaded “I have to go home, I have to go home.”

The Transition from Curative Care to Palliative Care

Initiating discussions on the withdrawal of curative treatment for palliative care can be emotional and distressing for patients, family members and HCPs. However, if it is done well it can be a smooth transition for all involved (Thompson, McClement & Daeninck, 2006).

Fallowfield, Jenkins, & Beveridge (2002) conducted a research study on communication in palliative care exposing that HCP not only struggle with the discussions but the language they use can be ambiguous to patients. Using words such as progressing, negative and positive can have a different meaning when used as a medical term. This is evident by the following example.

[The HCP informs the patient that he has reviewed his recent tests today and there are signs that things are progressing.]

“So I think that you should not have any further chemotherapy.”

Patient: “So what happens now?”

HCP: “I just want you to come and see me if you develop problems with your breathing and I will treat that.”

[Immediately after the interview the patient is questioned by a researcher and the patient’s understanding of the consultation with HCP is as follows]: “Things are progressing well and I do not need any further treatment. I just need to monitor my breathing and if any problems arise the HCP will treat that.”

Ronaldson and Devery (2001) state that patients need honest and concise information about their disease prognosis at the time of transition to avoid unnecessary distress. Unfortunately, there are many barriers for the HCP in implementing the transition to palliative care. HCPs may not feel confident or competent when discussing end of life care with patients and their family members. Therefore HCPs and patients may avoid having difficult conversations regarding death and dying.

Cultural, linguistic and religious issues may also impact discussions on end of life care (Schofield, Carey, Love, Nehill & Wein, 2006). When discussing the transition to palliative care HCPs should have all the relevant information about the patient’s illness and prognosis. HCPs should ensure that discussions are undertaken
in a private environment with adequate uninterrupted time to encourage family members to participate in the discussions. It is recommended that HCPs ascertain the patient’s and family members’ understanding of the information given to them prior to ending the family meeting (Thompson et al., 2006).

Fallowfield et al. (2002) state that facilitating a smooth transition from curative care to palliative care can be assisted by HCPs having a sound knowledge of end of life issues and the role of palliative care when dealing with patients with a life-limiting disease. HCPs should strive to maintain open communication that encourages shared decision-making between themselves, patients and families. Oncologists, haematologists and other specialised health care workers need to encourage early palliative care involvement for patients receiving treatment for life limiting diseases. This will promote excellent symptom management and assist patients to live their life comfortably until their death.

A research study undertaken by Temel et al. (2010) examined the effect of introducing palliative care early after a patient’s diagnosis of a terminal disease. The study involved 150 patients over a 12 week period. The patients were randomly chosen either for the group to receive early palliative care with integrated oncology treatment or the stand alone oncology care. The study indicated that patients receiving early palliative care with standard oncology care had a longer life expectancy of up to two months while experiencing less aggressive end of life treatment. Overall, their quality of life and mood improved compared to the patients receiving stand-alone oncology treatment. For patients this transition can be a major disruption to their established health care regime and can instil feelings of uncertainty and fear regarding their future health prospects. A rocky transition from curative care to palliative care can leave patients with a feeling of abandonment (Fallowfield et al., 2002; Kaur & Mohanti, 2011).

Mr M’s Journey Continues

A review by a Clinical Nurse Consultant (CNC) from the Palliative Care Department was undertaken one week after Mr M’s admission. The assessment revealed Mr M was pale, sweating, and suffering with laboured breathing. Mr M was drowsy but able to respond to questions appropriately. Again he expressed his wish to go home. Both Mr M and his wife were well aware of his poor prognosis and that no further curative treatment was available. It was at this stage that Mr and Mrs M decided to instigate palliative care and return home. It was a multidisciplinary effort to arrange Mr M’s discharge from hospital. The physiotherapist and occupational therapist organised equipment such as a hospital bed and oxygen concentrator to be delivered to Mr M’s house the following day. A Subcutaneous Infusion Pump was commenced with morphine 10mg over 24 hours to manage Mr M’s dyspnoea. Breakthrough medication of morphine elixir 2mg was recommended for exacerbations of dyspnoea: this could be given to him whenever it was required. To reduce fluid particularly in the lungs, Mr M was given 40mg Frusamide subcutaneous (SC) injection daily (Palliative Care Therapeutic Guidelines, 2010).

Mr M commented that he enjoyed sleeping in his own bed for that first night before the hospital bed arrived later that day. Over the next few days Mr M’s symptoms were well managed, however his condition rapidly deteriorated. When Palliative Care Outreach visited to reload Mr M’s Subcutaneous Infusion Pump he was unconscious, with no urine output. Mr M’s death was now imminent.

Conclusion

Mr M died peacefully that evening. Incorporating palliative care at the end of life enabled Mr M to die at home with family members present. Dying in ICU is not a pleasant experience for the patient or for their family members (Peters & Sellick, 2006). Evidence suggests that as many as half the people admitted to an ICU at the end of life would have preferred to die elsewhere had they been given the choice (Fallowfield et al., 2002). In the future, HCPs in ICU need to encourage open discussions about end of life issues for patients with life limiting illness and with their family members, to facilitate a death in an environment of their own choice such as at home, as was the case with Mr M.

References


