Reflection on curative treatment versus palliation of symptoms in end of life care


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Abstract
The conflicting tasks of treating or managing disease and preparing patients and their families for the end of life are well documented in haematology and palliative care settings. This article is a reflection on practice by a nursing student who was in the fourth year of an internship, and discusses a case study involving a woman at the end of life. It considers the approach to palliative and end of life care adopted in an oncology and haematology ward where there was a reluctance to be realistic about the limitations of treatments among some healthcare practitioners, who did not want to dispel unrealistic expectations of the patient's recovery as a result of continuing treatment. This reflection focuses on the care of a patient at the end of life and the frustration experienced by the nursing student at their inability to alter the direction of treatment from curative treatment to the palliation of symptoms.

Keywords
end of life care, ethical issues, haematology, oncology, palliative care, reflective practice

THE CONFLICTING TASKS of treating or managing disease and preparing patients and their families for the end of life are well documented (McGrath and Holewa 2006, 2007, Johnson et al 2011, Leung et al 2012). This article is a reflection on practice by a nursing student who was in the fourth year of an internship, and was involved in the care of a woman at the end of life where such a conflict arose. The aim of this reflection is to examine the nursing issues that the case raised and to critically evaluate the nursing student’s actions in relation to determining care priorities for the patient and working effectively in the multidisciplinary team.

Bulman and Schutz (2013) stated that meaningful reflection is a positive and constructive process because it identifies strengths and weaknesses and provides opportunities for change and growth.

Johns' (1995) model of reflection
The author chose to use Johns’ (1995) model of reflection as the framework for their reflection on practice, which is comprised of five elements:
- Aesthetics.
- Personal.
- Ethics.
- Empirics.
- Reflexivity.

There are various cue questions for each of these elements (Box 1), which Heath (1998) asserted are simple, flexible and ensure depth of analysis during reflection. The elements and cue questions in Johns’ (1995) model of reflection, which are based on Carper’s (1978) ways of knowing, are suitable for the purpose of reflecting on this case study of a patient at the end of life and
the ethical issues that arose. It was thought that Johns’ (1995) model of reflection would enable a more meaningful reflection than cyclical reflective frameworks, such as Gibbs’ (1988) and Rolfe et al’s (2001) models (Johns 1996, Platzer et al 1997, Heath 1998).

Case study
Constance was a 79-year-old woman with non-Hodgkin lymphoma who was an inpatient on an oncology and haematology ward. The disease had been mostly unresponsive to chemotherapy, but Constance had remained strong, determined and involved in her care throughout her illness. She was undergoing a final attempt at curative treatment using a last-line chemotherapy drug.

After several days away from the clinical area, I returned to find that Constance’s health had deteriorated. She had lost a considerable amount of weight and was generally unresponsive. Over the next two days Constance slept a lot, was incontinent of urine and faeces, and required increased analgesia for pain at the growing lymphoma site in her abdomen. The physical signs of deterioration and my intuition led me to believe that Constance was in the last days of life. The other nurses on the ward agreed and one nurse reported that Constance had told her that she could no longer bear the pain and she was ‘ready to go’.

Despite her deterioration, curative treatments were continued. Chemotherapy-induced mucositis had caused painful, bleeding mouth ulcers, but Constance continued to receive chemotherapy treatment. Intravenous antibiotics, intravenous fluids and repeated blood and platelet transfusions were also continued.

Two days before Constance died, her daughter called an audiologist to the ward to fit hearing aids because the chemotherapy had caused severe hearing loss. The day before she died, a dentist arrived, as requested by her daughter, with new dentures for Constance because she experienced significant pain and became distressed when any oral care was attempted. On the morning of the day she died, total parenteral nutrition was commenced, and Constance died with the support of as required (PRN) analgesia rather than the less-invasive continuous subcutaneous infusion that is advised for patients at the end of life where there is considerable pain (Dickman et al 2011, Thomas and Barclay 2015).

Aesthetics
I ensured that Constance was comfortable by tending to her personal hygiene, eye, ear, nose and mouth care, bowel and catheter care, and skin care, as well as her respiratory needs (Dougherty and Lister 2015). I had two main care priorities: supporting Constance to die with dignity, in the absence of pain; and being able to support her family through this challenging time. Leung et al (2012) stated that healthcare professionals are required not only to support patients and their families to make sense of their distress, but also to integrate palliative interventions into their care. For this to happen, the palliation of symptoms and preparation for death should be prioritised in care.


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<tr>
<th>Aesthetics</th>
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<tbody>
<tr>
<td>» What was I trying to achieve?</td>
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<tr>
<td>» Why did I respond as I did?</td>
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<tr>
<td>» What were the consequences for: my nursing practice; patients; others; myself?</td>
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<table>
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<tr>
<th>Personal</th>
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<tbody>
<tr>
<td>» How did I feel in this situation?</td>
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<td>» What internal factors were influencing me?</td>
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<table>
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<tr>
<th>Ethics</th>
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<tbody>
<tr>
<td>» How did my actions match my beliefs?</td>
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<tr>
<td>» What factors made me act in incongruent ways?</td>
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<table>
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<tr>
<th>Empirics</th>
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<tr>
<td>» What knowledge did or should have informed me?</td>
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<th>Reflexivity</th>
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<tr>
<td>» How does this connect with previous experiences?</td>
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<tr>
<td>» Could I handle this better in similar situations?</td>
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<tr>
<td>» What would the consequences of alternative actions be for: my nursing practice; patients; others; myself?</td>
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<tr>
<td>» How do I now feel about this experience?</td>
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<td>» Can I support myself and others better as a consequence?</td>
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<td>» Has this changed my ways of knowing?</td>
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(Johns 1995)

KEY POINT
Leung et al (2012) stated that healthcare professionals are required not only to support patients and their families to make sense of their distress, but also to integrate palliative interventions into their care. For this to happen, the palliation of symptoms and preparation for death should be prioritised in care.
I asked a member of the haematology team if he could speak with the family about Constance’s end of life care, but he reassured me that there was no need yet, since Constance's blood results were improving. When I asked my mentor if we should talk to the patient’s family, there appeared to be confusion over whether this should be the doctor's responsibility or part of the nursing role, and there was also a reluctance to speak about this. I also spoke to the dietitian about the commencement of total parenteral nutrition and she explained that it was out of her control because she was not the prescriber.

The patient’s palliative care needs were not being given adequate priority, which meant that Constance and her family experienced harm. The nurses involved experienced moral distress, which Morley (2016) suggested arises when nurses know what the right course of action is, but institutional constraints mean that they are unable to undertake the relevant actions.

Constance’s family were not aware that she was reaching the end of life because they had not received adequate information before her death. They appeared shocked by her death and experienced feelings of guilt and shame, which are common among families in similar situations (Werkander Harstäde et al 2012).

**Personal**
I was sad to see Constance deteriorate; she was an articulate, strong woman and I had enjoyed caring for her. However, my previous experience in palliative care meant that I did not feel overwhelmed by her death. Moreover, Constance was treated with kindness throughout her care, by all members of the multidisciplinary team and her family. While this was encouraging, I found it challenging to rationalise the frustration I felt at being unable to alter the direction of her treatment from focusing on a cure to prioritising the palliation of her symptoms.

Dos Santos et al (2012) emphasised that prioritisation of care is a core competency, while Haddad (2008) stated that prioritising patient care depends on healthcare practitioners’ clinical competence in discerning patients’ health status. My tacit knowledge, based on observations, intuition and insight, and learned knowledge informed me that Constance was close to death. Estrella (2013) asserted that tacit knowledge is a valuable nursing skill, essential for effective prioritisation of patient care, while Lake et al (2009) suggested that tacit knowledge is generally embedded in effective clinical decision-making.

I felt saddened that cancer treatment was being prioritised when I felt that, considering that she was displaying some of the signs that a person may be in the last days of life as outlined by the National Institute for Health and Care Excellence (NICE) (2015) (Box 2), priority should be given to her palliative care needs and ensuring she had a ‘good’ death (Saunders 1964, Irish Hospice Foundation (IHF) 2013).

I felt angry and frustrated that she had to endure unnecessary pain at the end of her life. I experienced feelings of powerlessness in the face of the family’s and the medical teams’ focus on curative treatment, and because of my role as a nursing student and associated limited scope of practice, responsibilities and involvement in decision-making – feelings which are common among nursing students (Iranmanesh et al 2010, Mutto et al 2012, Leombruni et al 2014).

**BOX 2. Recognising when a person may be in the last days of life**

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<tr>
<th>Signs</th>
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<tr>
<td>Agitation</td>
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<td>Cheyne-Stokes breathing</td>
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<td>Deterioration in level of consciousness</td>
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<tr>
<td>Mottled skin</td>
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<tr>
<td>Noisy respiratory secretions</td>
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<td>Progressive weight loss</td>
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<th>Symptoms</th>
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<tr>
<td>Increasing fatigue</td>
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<td>Loss of appetite</td>
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<th>Functional observations</th>
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<tr>
<td>Changes in communication</td>
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<tr>
<td>Deteriorating mobility or performance status</td>
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<td>Social withdrawal</td>
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(Adapted from National Institute for Health and Care Excellence 2015)
Although I could understand the reticence of Constance’s family to accept that she was at the end of life, and recognised their denial was a coping mechanism (Kübler-Ross 1969), I felt frustrated that no member of the multidisciplinary team prioritised support for the patient’s family. I felt it was important for them to take some time to remind the family that despite active treatment, Constance’s health was deteriorating and she was unlikely to recover. The IHF’s (2013) principle that family members must be included in the approach to care, and be prepared as far as possible for the patient’s death, should have been adhered to in this case.

**Ethics**
Ethical issues often become central when planning and prioritising daily patient care at the end of life, particularly when patients are no longer able to assert their autonomy (Zomorodi and Foley 2009, Rejno and Berg 2015). A significant ethical issue raised by this reflection is the ongoing conflict between curative treatment and palliative care in haematology wards, and the challenges that healthcare practitioners may experience in determining the appropriate time to make the transition between the two (Johnson et al 2011, Hui et al 2014, LeBlanc 2014, LeBlanc et al 2015, Wright and Forbes 2017).

My nurse training has developed my values and beliefs, which include: that I should advocate for my patient (Nursing and Midwifery Board of Ireland 2014); that I should recognise when a patient is approaching death (NICE 2015); and that I should provide optimal palliative care (Saunders 1964, IHF 2013). Caring for Constance resulted in significant ethical challenges in relation to my values and beliefs. I was conflicted about the invasive care and the prescribed treatments being undertaken, because I felt they contradicted the World Health Organization’s (2016) core principles of palliative care that I had been encouraged to adhere to in my nurse training, and which are outlined in Box 3.

There is agreement in the literature that multidisciplinary collaboration is essential to provide optimal care (Ponte et al 2010, Hoffman and Redman-Bentley 2012, Lundeen and Padilla 2013). Furthermore, research states that ease of transition from curative treatment to end of life care for the patient’s family depends on the communication they receive from doctors and nurses (Adams 2005, Beck et al 2012, van Brummen and Griffiths 2013). I felt that an opportunity had been missed to prioritise the care of Constance’s family and to prepare them for her death, as recommended by various guidelines and authors (IHF 2013, NICE 2015, Perrin and Kazanowski 2015, Rejno and Berg 2015), and for the healthcare practitioners involved to collaborate more effectively to ensure that the care priorities for Constance were appropriate (Health Information and Quality Authority 2010, Health Service Executive 2010). A workshop on the priorities for palliative care has corroborated this contention, emphasising improved communication and multidisciplinary collaboration as important concerns (Pillemer et al 2015).

**Empirics**
An increasing amount of research suggests that patients with haematological malignancies, such as non-Hodgkin lymphoma, are not receiving appropriate or timely referrals for palliative care, and that there are significant obstacles to the prioritisation of palliative care in haematology (McGrath and Holewa 2006, 2007, Johnson et al 2011, Leung et al 2012). Moreover, the conflicting tasks of treating or managing disease and preparing patients and their families for the end of life are increasingly seen as a significant ethical challenge (Johnson et al 2011, Leung et al 2012).

**KEY POINT**
A significant ethical issue raised by this reflection is the ongoing conflict between curative treatment and palliative care in haematology wards, and the challenges that healthcare practitioners may experience in determining the appropriate time to make the transition between the two.

**BOX 3. Core principles of palliative care**
- Providing relief from pain and other distressing symptoms
- Affirming dying as a normal process
- Neither hastening nor preventing death
- Integrating psychological and spiritual aspects of care
- Enhancing quality of life of patients
- Offering support systems to patients and their families

(World Health Organization 2016)
life are well documented in this research. In my experience of caring for Constance, I found that there was reluctance and fear among some healthcare practitioners to ‘burst the bubble of hope’ and dispel unrealistic expectations of the patient's recovery as a result of continuing treatment (Leung et al 2012).

Perrin and Kazanowski (2015) asserted that nurses should be involved in overcoming the barriers to discussing palliative care for patients, so that the potential for harm can be reduced through the effective prioritisation of care. My attempts at collaboration in my scope of practice as a nursing student were not enough to ensure effective care, which Meleis (2016) stated is driven by collaborative teams who work together. Thistlethwaite (2012) cited the importance of teamworking to develop and maintain collaborative and effective multidisciplinary teams and ensure optimal patient care. Aase et al (2013) concluded that a lack of teamwork in healthcare is directly linked to suboptimal patient outcomes, as was the case in this instance.

Reflexivity
I had not experienced a situation similar to Constance’s case before, and it prompted me to undertake much thinking and research during my designated reflective time off the ward. I understand what prompted the nurses on the ward to consider Constance’s ongoing curative treatment to be ‘unfair’ in terms of unnecessary and invasive interventions that might increase her pain. However, I also understand the motivations of the haematology team to continue this treatment in the context of improving blood results and pressure from the patient's family. Additionally, I can envisage being in the patient’s position and imagine that I would want the healthcare practitioners to attempt every possible treatment.

One nurse observed that haematologists can become so preoccupied with blood results that they often forget to look at the actual patient. This leads me to believe that for palliative care to be accepted as an option in haematology wards, it is essential for the nurses in this clinical area to persist in requesting palliative care alongside active treatment (Leung et al 2012, Richards et al 2013).

Nurses continuing to advocate for patients and their families by emphasising the care priorities to doctors and other healthcare practitioners would develop mutual understanding and effective teamwork and collaboration (Leung at al 2012, Richards et al 2013). I know that if a similar situation arises again, I will feel better prepared to advocate for increasing integration of palliative care in the care of the patient. This experience has made me feel that I can provide more effective support to patients and their families in similar circumstances in the future. I hope not to experience the powerlessness I felt in this situation again, which is so often experienced by nursing students (Iranmanesh et al 2010, Mutto et al 2012, Leombruni et al 2014). To be able to prioritise palliative care effectively, it is necessary for nurses to find innovative ways to provide such care and initiate end of life discussions, no matter what the barriers to doing so (Leung et al 2012, Richards et al 2013).

Conclusion
Reflection on practice has altered my understanding of prioritising care for patients, as well as the importance of teamwork and collaboration, particularly in haematology and palliative care. It has enabled me to move from feelings of frustration and anger to a position of realisation and understanding. Through reflection, I have found that conflict among healthcare practitioners is sometimes inevitable and it has emphasised the importance of recognising that all healthcare practitioners are ultimately on the patient’s side and should act in their best interests, and must work together accordingly. Furthermore, reflection on practice has equipped me with new knowledge and confidence about what to do if a similar situation arises.
References


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NMI, Dublin.


