Managing the pain of hospitalised children, even very young children, is one of the more profoundly challenging tasks in pain management. The ethical principles of the duty to benefit another (beneficence) and the duty to do no harm (nonmaleficence) oblige health professionals to provide pain management to all patients, including children, who are extremely vulnerable because of the constant developmental changes they undergo and the attendant insecurities of being ill and hospitalized in a strange setting. Evidence also shows that the space to encourage and include a child’s voice is often not provided and verbal or bodily cues are ignored.

As you read the following case involving the care of a dying four-year-old girl, think about the ethical values that might be at risk in this situation.

**Madeleine’s Final Days**

During her last month of life, four-year-old Madeleine lay on her bed in too much pain to watch her beloved Barney on TV. The little girl’s pain was so great that she cried when her mom touched her, when she tried to speak to her, or when she turned on the lights. Just a few months had elapsed since Madeleine was first diagnosed with leukaemia.

’I’ve never seen anyone suffer like that in my life’, said her mother. Madeleine was given chemotherapy with the onset of the disease, and after a relapse, doctors proposed another round of chemotherapy treatments, which, if successful, would prepare her for a bone marrow transplant. The doctors assured her family that the pain she experienced from the chemotherapy could be controlled. But when the pain came, and it came within three days after the first treatment, her mother said nothing worked to alleviate it.

It took Madeleine five minutes just to roll over in bed because each movement was so painful. When the family pleaded for relief for their daughter, doctors seemed slow to act. In addition, Madeleine had a serious bout of pneumonia that went undiagnosed for two weeks. Madeleine’s mother reported that ‘All they were interested in was the cancer and the [white blood cell] counts going up. They didn’t look beyond that.’

On Valentine’s Day 1999, five months after she was diagnosed, Madeleine died.


**Discussion**

The above case illustrates the need for focus, attentiveness and on-going conversation in the relationship between the health professionals, Madeleine and her family. Were parents kept informed by doctors and/or nurses about the meaning of the diagnosis of leukaemia? Did the family understand its severity, the prognosis, how amenable it might be to chemotherapy and what methods of pain management were available? The emotional narrative of the mother needs to be heard. It is a narrative based on four years experience of rearing Madeleine and interpreting her pain, her body language, her fatigue, her nausea, her effort to do the simplest thing. Here, the mother is the proxy voice for Madeleine and listening to her story of knowing her daughter intimately and witnessing her pain is perhaps vital to diagnosing the child’s pain. Through team effort and on-going communication with Madeleine, a strategic plan might have been devised to try and relieve the child’s distress, a strategy that would also require negotiating and engaging with the parents.

In research, the alleviation of children’s pain has been investigated through the eyes of health professionals and parents, but the children’s own perspectives have largely been ignored.
Children have their own descriptions and expectations for pain management interventions. According to the *Royal College of Paediatrics and Child Health* (2008), the evidence shows that children themselves, perhaps somewhat older than Madeleine, should be regarded as experts on their own pain in order to maximise the options for pain management and provide high-quality care. Respecting the (beginning) autonomy of the small child in the case above calls for a concerted effort to communicate with the child by paying attention to all bodily cues available and any verbal signals provided by Madeleine. By focussing exclusively on her white cell count, the physicians may have focussed on the hopes for curative treatment and failed to diagnose and deal with the degree of Madeleine’s suffering.

The ethical values of beneficence (do good) and nonmaleficence (do no harm) can be combined with the aim of respecting the developing autonomy of this small girl as she suffers with leukaemia.

Was another round of chemotherapy appropriate here? Was this treatment extraordinary for a dying four-year-old? Perhaps if active treatment for leukaemia stopped, the focus on pain management would yield more comfort and calm for the young patient.

If the healthcare team had reasons to believe that further chemotherapy and possibly a bone marrow transplant would be beneficial, then this would need to be explained to the family. It seems from the information available in this case, that the level of conversation and communication for understanding was deficient. Adequate pain relief in this case was not achieved and perhaps had even been thwarted by the focus on more aggressive treatment rather than on palliative care. The desire to cure is powerfully strong and is taught as a primary objective in medical training. In this case of Madeleine, cure was given precedence over care. As carer, her mother, also needed care from health professionals for she failed to understand why white cell counts seemed more important to clinical staff than her daughter’s experience of continuing pain.
Suggested Professional Responsibilities

1. **Review challenging cases thoroughly:** The healthcare team who manage the patient and communicate with parents need to reflect on decisions taken with honest self-scrutiny about the human outcomes. What clinical evidence contributed to decisions taken?

2. **Ask if mistakes were made:** Team review should ask if the medical management of a patient’s illness was unnecessarily aggressive? If not, an explanation should be offered to the parents for the recommendation of further treatment, e.g., chemotherapy or a bone marrow transplant.

3. **Pay close attention:** Attentive observations of children by staff and regular conversations with parents can achieve significant insights into the uniqueness of children’s experience of pain.

4. **Document important events:** Documentation needs to be provided, e.g., records of any diagnostic tests, team consultations, consultations with family, number and evidence basis for further treatments.

5. **Offer comfort:** Following a patient’s death, attention can turn to comforting the grieving parents. Can the healthcare team honestly say to the parents that ‘all that could be done was done’? If the manner of pain management in a child who is dying is deeply regrettable and overtaken by drive to ‘cure’ or ‘keep alive’ at all costs, how, precisely, can a similar situation in the future be improved?

6. ??

Key Terms

**The Principle of Beneficence**

The principle of beneficence obliges health professionals to ‘do good’ – be actively concerned for the interests of patients and the promotion of patient well-being. The principle would put pain relief and management among the most important objectives in caring for patients suffering from painful illness. Engaging the person of the patient about their pain, about their concerns with that pain and what they hope for is reassuring for any person in the institutional setting of a hospital.

**The Principle of Nonmaleficence**

The principle of nonmaleficence obliges health professionals ‘to do no harm’ – avoid or minimize harm to patients. The principle is closely linked to the objectives of pain management. Lack of adequate pain management causes harm to the patient – painful suffering, worry, depression, anxiety. Research indicates that unrelieved pain is considered to be the greatest contributor accounting for patient experiences of a ‘bad death’.
Activities

1. Re-read the particulars of Madeleine’s Final Days. Consider yourself the nurse or doctor in charge of Madeleine. Specifically, how would you deal with the mother’s concerns about Madeleine’s continued pain? Consider jotting down a conversation you might have with Madeleine’s mother.

2. Although Madeleine is very young, how can the health professionals try to discern her level and quality of pain? Provide a few concrete suggestions as to how you would proceed.

3. Madeleine’s mother is particularly annoyed with what she sees as an erroneous clinical focus on white cell count and further administration of chemotherapy while greatly minimising the need for effective pain management. Do you think the mother was correct and deserves to be heard? Write a few notes on how you would respond to the mother’s annoyance and concerns for her daughter’s suffering.

4. On a scale of 1-10, how would you rate the acute care hospital provisions (space, privacy, pain management, decor etc.) for the care of seriously ill children?

5. What has your training taught you about children’s pain – for example do neonates experience pain? At what point are pain receptors fully developed? What are the tell tale signs of pain in children?

6. Cassel traces the prevalence of untreated pain, in part, to deficits in clinical training which focuses on organs, diseases and aetiology rather than on persons as individuals with their unique fears, worries and suffering. Take a few moments to read what he has to say and share your response to it with your colleagues.

‘The diagnosis of suffering is often missed, even in severe illness and even when it stares physicians in the face. A high index of suspicion must be maintained in the presence of serious disease, and patients must be directly questioned […] Often, questioning and attentive listening, which take little time, are in themselves ameliorative. […] The language that describes and defines the patient’s suffering is different from the language of medicine – there is too often an actual disconnect between our case history and the patient’s narrative […] Physicians are trained primarily to find out what is wrong with the body – in terms of diseases or pathophysiology; they do not examine what is wrong with persons […] when physicians attend to the body rather than to the person, they fail to diagnose suffering.’ (Cassel, E.J. [1999] Diagnosing suffering: a perspective, Annals of Internal Medicine, 131[7] 531).
Key Readings


Study Session 5

The Ethics of Managing Pain