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EXEMPLAR

A palliative care story: Negotiating the abject

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I have been motivated to tell the following story after recently attending a workshop on narrative analysis by Arthur Frank. This story happened two years ago while I was working in a busy metropolitan palliative care unit, and is one that I still think about often.

It was a Sunday afternoon and a 53 year old woman I will call Clara had been brought in to the palliative unit by ambulance from home. My senses and that of other nursing staff were overwhelmed by the abject as soon as Clara entered the unit. Kristeva (1982:2) refers to abjection as brutish suffering. By abject I refer to a discursive construct from the literature dealing with suffering. Suffering can be physical, emotional, and spiritual and involves distress. Clara was in great distress, audible from the time the ambulance officers wheeled her in to the unit. She was screaming and her cries reminded me of a wounded animal.

We were told our patient Clara had cancer of the cervix and was admitted for terminal care. How I hate that word 'terminal' as it trivializes dying. Several years ago a young cancer patient I was interviewing for my doctoral studies had just been told by his doctor that his cancer condition was 'terminal' and he pointed out that the word 'terminal' reminded him of being in a bus station. He said that he was not at a bus station; he was 'dying'! However, this is the language used in palliative care when a patient is at the end stage of their life.

Back to Clara. We were also told that Clara had not been able to attend to her hygiene needs for some time and would not allow anyone to help her. She had been lying prone for two days and been unable to move from her bed at home. Her husband, Robert, arrived at the same time and, as she was being wheeled into a single room, said awkwardly, 'My wife needs cleaning up.'

We gently transferred Clara from the ambulance trolley to her bed. She was more than confused; she was delirious, muttering incoherently and shouting that 'we were trying to kill her'. However, there were periods of lucidity, especially when Clara gripped my arm and whispered, 'I want to be asleep please when you clean me up.' Tina, the nurse I was working alongside, stroked her hair and said gently, 'We will take care of you Clara.'

Of course we could not 'clean her up' until she was given adequate pain relief. The resident doctor contacted said, 'I'll be there in over an hour.' No, I told her. 'You need to come right away as this patient is distraught with pain and suffering.' There were no arguments then. The resident came straight away and admitted Clara. A syringe driver of hydromorphone and midazolam was started and Clara was administered a

subcutaneous injection of both hydromorphone and midazolam.

Tina and I waited 30 minutes after giving the breakthrough and then went to work. Nothing had prepared us for what we saw. We had to cut the clothes off her damaged body. The stench of tumour, urine and faeces was overwhelming and her fungating tumour was one of the worst I had ever seen. The whole of her anus and genital area were eaten away by the tumor and was a mass of rotting and cavenous flesh. In the midst of 'cleaning her up', a young graduate nurse came into the room and quickly ran out dry-retching. Abjection was inscribed in Clara's corporeal body. Her body's boundaries were permeable and vulnerable. 'Abject embodiment of cancer patients breaks the boundaries of the pure and is often the unclean'. (Douglas 1970: 115). Clara's body was messy beyond the boundaries of what a body should be.

As we worked on her, I felt waves of nausea, but we had a job to do. Rudge (1996:251) points out that when 'nurses witness abjection', they are also 'rendered abject'. However, I would argue that nurses make a difference by negotiating the abject and not themselves becoming abject.

The young graduate returned to the room and I asked if she was okay as we could manage without her. Her response was that she was 'okay and wanted to help'. We worked as a team, taking our time, gently soothing our patient Clara when she cried out in distress. We cleaned and packed a large cavity with combines soaked in medical honey. I told the young graduate nurse, 'We often do this for palliative care patients with fungating and foul smelling tumours. It helps reduce the odour.' 'Cleaning her up' also involved giving Clara a dermalux hot towel bath with towels soaked also in lavender and gently placed over her body. Her fragile body was then gently massaged over the towels, the towels removed and her dry skin lightly massaged with moisturizing cream using gentle effleurage strokes. Momentarily, the hot towels and massage relaxed her tight body and her breathing became more even.

The following day Clara was still in great distress and despite numerous breakthroughs of hydromorthphone and midazolam and large doses of both drugs in her syringe driver, she continued to experience a great deal of pain. The consultant ordered phenobarbitone in the syringe driver and also phenobarbitone breakthroughs which meant that Clara was now unconscious. The same day Clara's husband caught me by surprise when he asked to view his wife's cancer. I was shocked at the request and felt a need to protect Clara from the indignity of having her vulnerable body placed under a voyeuristic gaze, even from her husband. There needed to be boundaries drawn around what Robert was requesting.

I asked him why he wanted to see her cancer and he replied 'because I would like to see what she has been going through'. I replied, 'I think you need to think really carefully here what Clara would want'. Clara at this stage was, of course, unconscious because of the phenobarbitone sedation and therefore had no say. I was now her voice and I was aware that the request had the potential to add further distress.

Overnight I worried about Robert's reaction. There was tension between what would and could be. Would he pursue his request to view Clara's abject body? Could I refuse his request? After all, he was intimately connected; he was her husband. However, Robert did not ask and we did not talk of it again. Clara died three days after her admission to the palliative care unit.

The end stage-of-life is a very vulnerable period in which the patient, carers and family are aware of impending outcomes and each person caught up in this space finds ways to cope. Clara's situation in many ways is not different from other palliative care patients requiring sensitive care. Her distress and periods of confusion (with pain and her obvious vulnerability) were counterbalanced with periods of awareness of

her situation and surroundings. A situation as described stretches the boundaries of human endurance for each person involved and can inevitably lead to persons responding in unexpected ways. A family member may make a request that places the nurse in an awkward and potentially difficult situation. A newly graduated nurse may recoil from the abject, while a more experienced nurse can provide careful ministration to the patient at the most appropriate times. The abject body causes pain and suffering for the patient and can also demand particular behaviours from nurses to deal with the situation.

Palliative care staff must face such challenges regularly and our experience and skills in dealing with the special needs of patients is an important part of our professional response. This is true not only for our patients but also for our colleagues. In responding to Clara's distress, we were able to call upon our skills to calm and relax her. Words and touch can calm and refocus a distressed patient while further clinical measures are taken.

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