DIGNITY AND PALLIATIVE CARE

A SEARCH TO DISCOVER THE TRUE MEANING OF THE CONCEPT OF ‘DYING WITH DIGNITY’

by

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ABSTRACT

This paper presents an exploration of a foundational goal of palliative care nursing which is to help patients die with dignity. The paper presents this practice exploration as a journey to gain understanding of the concept of dignity; it does not avoid the difficulties encountered in practice situations because dying with dignity is unique and curiously also invisible and different for everyone.

Much of human life is conducted through stories and much of nursing involves telling and listening to stories. Many of our social institutions are compromised almost entirely of opportunities for telling and retelling stories. Nurses are constantly listening to patients telling them what is going on in their lives and because of this the stories related here are written bold and raw. The three stories explore and reveal in-depth details of nursing practice that evolved and changed after reflection. The paper also reveals and explores the untold and often painful stories that challenge nurses’ capacity to offer dignified care.

To deepen the exploration towards discovering ways to articulate the complexity of dignity, the author reflected on the nature of the practice changes documented in the stories and then used a range of diverse literature and her love of the paintings and philosophy of a New Zealander, Ralph Hotere, to support her ideas that dignity is indeed a complex phenomenon.
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To my father, who died in 1996, it was you who gave me the idea to explore the concept of dignity because you died with such dignity and grace.

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INTRODUCTION

As a former educator, I used to get a great deal of satisfaction by sitting down with groups of nursing students and relating stories to them about clinical practice experiences. I often told them stories about events that hadn’t gone as planned; how this patient suffered an adverse outcome; how that patient had made what seemed a miraculous recovery; how a serious error was prevented in the nick of time. I believed that passing on complex and difficult nursing experiences in a conversational and informal way, with my reflections shared and discussed, was more helpful in developing the students’ sensitivities to actual practical situations than the traditional classroom lecture that focused primarily on theoretical concepts. Beyea, Killen and Knox (2004) suggest that telling stories helps listeners remember facts and details that otherwise might be forgotten, and my experiences as a nurse lecturer support this view.

I have been nursing at a hospice for 18 months as a registered nurse and interdisciplinary team member. One of the main aims of the hospice team in achieving best practice in palliative care is to help patients die with dignity. But I came quickly to the realisation that dying with dignity is different for everyone. The concept of dignity is elusive and is very much in the mind of the beholder. My own personal philosophy of dignity is fairly simplistic and includes spirituality, privacy, pride, cleanliness and personnel appearance. I want to die peacefully and quietly. Some people, however, don’t want to die this way at all. They want to die fighting, full of anger and railing against the dying process. The
great Welsh poet Dylan Thomas, writing during the final illness of his father in 1951, expressed this philosophy emphatically when he wrote:

“Do not go gentle into that good night.
Old age should burn and rave at close of day,
Rage, rage against the dying of the light”.

(Ferguson, Salter and Stallworthy, 1996, p. 1465).

This poem beautifully illustrates in a few words that dying with dignity is indeed different for everyone. My philosophy, therefore, is very different from my own personal view. I believe that dying with dignity is a concept that best fits with a person’s own value system and is usually, but not always, related to self-respect and integrity. This philosophy means a huge amount to me and attracted me to return to bedside care. My challenge has been to put this philosophy into practice with every person who comes into our service.

I have chosen in this paper to present the stories first so as to direct the reader’s attention to how powerful practice can impact on the nurse as a person and researcher. I have followed each story with a reflection revealing my inner processing, which is normally private, but which, of course, I recognise is deeply integral to my professional life. In revealing these thoughts, which are a mixture of worrying and wondering how I could do better, I have gleaned insights into the true meaning of dignity.
The stories were written raw and bold and then slightly edited for public consumption. However, the tone and tensions felt in the situations, and the way in which reflection on practice enabled me to rework my thinking, actions and conversations with colleagues, has been left as it was originally written. Names, places, diagnoses and circumstances are all fictionalised and the stories no way resemble people or families. I now realise these stories reveal a complex process that the literature, on reflection, only hints at. In the future, I will explore the nature of developing the capacity in oneself to converse about tough and tender moments.

It is common in story telling to imagine a discreet story told to reveal an event, or a fictionalised act that triggers images for the listener. However, in this paper the writing and the telling of stories in practice offers an opportunity to me as a clinician to work with the very core of myself and the conversations and actions that are occurring in the stories. The stories, therefore, are like windows to the soul of my practice; a way into how I think about and manage care as it unfolds.

I have also pursued two literature surveys, one on story telling and the other on the concept of dignity.

The story-telling literature is useful because it reiterates that nurses must tell and share their stories in order to make invisible knowledge visible. Hearing and reading stories makes experience and knowledge available to other colleagues, students and writers themselves. For me, writing the stories was a way of telling people how I feel, rather than
keeping all those sentiments and emotions individualised to myself. I was impressed with Gillie Bolten (1999) who says that writing about what has happened and how one feels about it is the ultimate form of debriefing.

The literature on dignity is vast and complex. However it did enable me to explore and comprehend deeper meanings and different aspects of dignity that triggered insights into my practice world. The work of Street and Kissane (2001) had a huge impact on me. They suggest that people use highly emotive words and descriptive phrases in the promotion of euthanasia and assisted suicide, and that ‘dying with dignity’ is therefore a term that needs to be defined and redefined constantly.

Surprisingly, perhaps, I was able to gain some insight into the true meaning of dignity through looking at the arts and humanities. I found that Ralph Hotere, one of New Zealand’s greatest painters, reflects in his art the same dark and dangerous imagery of human suffering and death as that portrayed in the great works of poetry and prose. Death is usually something black and brooding; to be feared and mourned. Yet the enduring appeal of Hotere’s paintings is the unity depicted between darkness and light. And Dylan Thomas, quoted above, very similarly said of his poetry: “It is the record of my individual struggle from darkness towards some measure of light” (Ferguson, Salter and Stallworthy, 1996, p.1934). I have come to the conclusions that all this fits very nicely with the writings of Rushton and Spencer (2004), who suggest that nurses are powerful messengers who can bring dignity and humane caring out of the shadows and into the light.


JULIAN’S STORY

Julian was a 44-year-old man who had been on the Hospice Programme for two years. He was initially diagnosed with cancer of the oesophagus but unfortunately a year later developed cerebral metastases. Julian’s main problems were expressive dysphasia, depression, alcoholism and headaches. He was dependent on alcohol and always had a constant supply in his room.

I looked after Julian for five days before he died. During those five days Julian refused to see almost everyone including his mother and other relatives. He did however agree to see his son once and then requested that his son not visit again.

I well remember the first day of Julian’s admission. Initially, Julian did not want to communicate with me. He appeared very angry, but as the day progressed he started to say a few words. Julian had sporadic episodes of difficulty with talking, so I had to concentrate hard to understand what he was trying to say. After several hours I realized he wanted me to take him to the liquor shop to get him a bottle of vodka. I was a relatively “new nurse” to the hospice and wasn’t sure what the procedure was regarding taking patients shopping. I asked one of the doctors what I should do and he confirmed that it was appropriate for me to take Julian to the local liquor shop.

I was a little surprised and a bit worried that it might be a difficult expedition, but reassured my self that doctors know best.
As soon as we got into the car Julian started to complain. He said my car was too small and was very uncomfortable. I started to feel a little uneasy, but congratulated myself that this was true holistic care because I was treating Julian as an individual and not merely a patient with cancer. I had no idea where the liquor shop was and Julian made it clear he was not impressed with my lack of local knowledge. Eventually, after much cursing and swearing from Julian, we found the shop and went inside.

After we had been there a few minutes, Julian became very breathless and had to sit down. The owner of the shop offered to call an ambulance, but I told him I was a nurse, and assured him Julian’s breathing would improve. Fortunately, Julian’s breathing did improve and eventually we found a bottle of vodka.

Once we got to the counter Julian suddenly became aggressive and accused me of looking at his pin number on his credit card. I didn’t know what to do, and to be honest, wanted to walk away. However, Julian was frail and weak and needed someone to be with him, so I continued to help. After a little more cursing and swearing from Julian, we made it back to my car and I drove him back to the hospice.

Once Julian was back in his own room he apologized for his behaviour and became very upset. He opened his bottle of vodka and started to chat with me.
After a few minutes I began to realize and accept that vodka was a way of life for Julian, because without it he was unable to function or be happy. Once Julian had a drink he was a different person.

After this specific episode I decided an important aspect of my nursing care for Julian would be the inclusion of a constant supply of vodka. I was aware that Julian was dying, so did not want to change his lifestyle. Above all else, I wanted to make sure Julian had a dignified and peaceful death. To make this happen, the provision of alcohol had to be part of his nursing care. I was not sure how much vodka Julian needed, but told myself that I was sure the people who were involved in Julian’s care would work it out somehow.

Julian was separated from his wife and had no contact with her. They had one son who was 19 years old. Julian’s mother was still alive, but Julian had no contact with her. Julian had three brothers and one sister. During his stay at the hospice, one of his brothers came to visit, but Julian indicated that he did not want to see him.

During the five days Julian was in the hospice, the only visitor he agreed to see was his son who visited him once and did not return. I well remember that day because it was the only day Julian demonstrated any visible sign of loss or grief.

Julian had just finished his breakfast and I was collecting his tray. As I walked out of the room, I noticed a young man in the corridor who appeared very unkempt. He had a vacant expression and smelt highly of alcohol. I asked him what he wanted and he said he
had come to see his father. I was a little worried Julian would refuse to see his son but to my surprise he agreed, but emphasised the visit was to last only a few minutes. After about a minute, Julian rang the bell and asked if I could get a couple of bottles of beer out of the fridge for his son. It was eight o’clock in the morning and I thought it was rather early to be drinking, but reflected that it was none of my business. After a couple of minutes, Julian’s son left. I went to check in with Julian and found him crying.

Julian refused to tell me why he was unhappy. I can only presume he was sad to see his son in such a state.

I felt absolutely powerless because I was unable to help Julian. As a nurse, I wanted to make a difference, but with Julian it was impossible because he would not communicate. Julian was a very private man and despite lots of offers of help from many people, he had refused to talk about any of his problems.

The desire for such intense privacy is unusual in patients that we care for in the hospice setting. However, de Raeve (1996) suggests that dying is essentially a private process and patients die according to their own system of values and beliefs. She also suggests that nurses are far more effective when they “join the journey” of death, rather than feel responsible for the end. My way of “joining the journey” was to ensure Julian had a good supply of vodka and to respect his privacy.
Julian was a very tall man and had previously been an athlete. He seemed very proud of his athletic past and had lots of photographs on his locker capturing his achievements. I found it hard to believe that a man with such apparent ambition in his past life now wanted nothing to do with his past. To my mind he exhibited low self-esteem, however he may have decided to complete his life as a solo journey.

Julian hated anyone helping him and most of the time he lay in his bed sleeping and listening to the radio. He refused all offers of help for personnel hygiene, ate very little and isolated himself from the rest of the world.

Julian had been a builder and according to several people who knew him from the past, he had been very outgoing and social. However, they said that during the last few years he had changed and had become depressed and withdrawn. Before the depressive episodes began, Julian had always been keen to contribute money to charities. One of the photographs in Julian’s locker depicted him winning a marathon to raise funds for the Cancer Society.

As mentioned before, Julian had little or no contact with his family. His family had a long history of contact with Mental Health Services, Drug and Alcohol Services and other social agencies. I assume Julian’s dependence on alcohol was also a contributing factor to his family breakdown.
Julian demonstrated intense frustration when he could not make himself understood. If he got angry he started to swear, and surprisingly enough, his swear words were always very clear.

Julian’s only real contact with the outside world was the radio he listened to day and night. One day I entered his room and he was smiling. I asked him why he was so happy, and he told me a horse he owned had won a race. Apparently, he had heard the result on the radio. I tried to found out more about the horse, but, as usual, Julian did not want to communicate.

Julian identified himself as a New Zealand European. At the time of his death he was part of a culture of people who depended on alcohol. Some of Julian’s important values and beliefs were intense privacy and independence. Julian had rejected his friends and family and had chosen a lifestyle that isolated him from the rest of society.

Julian was an Anglican. He never spoke to me about religion and refused to see the Hospice Chaplain. I would have loved to talk with Julian about his thoughts on death and dying, but I knew he would not appreciate such an intimate and difficult conversation. I sent referrals off to the hospice social worker and various support people, but Julian declined to see any of them.
REFLECTION

I was often frustrated and sometimes uncomfortable with Julian. I felt particularly embarrassed when Julian became angry and accused me in the liquor shop of looking at his pin number on his credit card. I talked to the hospice doctor about this and she gently reminded me that this is part of the grieving process for people to become angry and project their anger on to someone else. Zerbe and Steinberg (2000) suggest that anxiety and anger are normal companions of the grieving process and should be expected when people are dying.

I was aware the medication was not controlling Julian’s mood. He was always unhappy and unwilling to communicate. What could I do? I knew Julian was dependent on alcohol, but I wanted to ensure he died with a reasonable amount of dignity.

Johnson (2002) suggests that dignity represents and reflects choices individuals make for themselves. Julian had chosen alcohol as a way of life, but that did not mean that he didn’t deserve to be treated with respect.

Julian was in a room with three other men but did not talk to them and kept them awake with radio going all night. I decided I would move Julian to a single room. I asked Julian if he would agree to the move and he said he would.

Once Julian was in a single room I am sure he was a lot happier, but, as usual, I never received any feedback from him. Once or twice I saw him sitting outside in the sun,
drinking his beloved vodka. So I am sure in his own quiet way he appreciated the move and the solitude.

Julian was a challenge and I knew that planning his care was fraught with difficulty. Despite this, I was determined Julian was going to have a peaceful and dignified death. Rankin and Donahue (1998) suggest that a dignified death is one where the patient has chosen his own setting in which to die, is free from pain and has psychological support from family and friends. According to their definition, I had lost my battle before I had begun, because Julian was not in his chosen setting, had psychological pain and did not have family or spiritual support.

Street and Kissane (2001) are more realistic and suggest dignity is socially constructed and individually perceived. Julian did have dignity, but needed help from alcohol to maintain it. Julian was also in the dying phase, so to try and change his lifestyle at that stage was totally unrealistic. Street and Kissane (2001) also suggest that health professionals need to become more aware of the hidden dimensions of the kinds of dignified death patients prefer. Dignity for Julian was isolation from others and complete privacy.

I was in a difficult situation. On one hand, I was concerned that family members might be grieving, but on the other hand Julian had made it very clear he wanted no contact with his family. Johnson (2002) suggests an ethical dilemma is a situation requiring choice between what seems to be two equally desirable or undesirable choices. My own personal
choice was to follow Julian’s instructions and not contact his family. However, I was worried this might be the wrong decision, so I contacted the hospice grief counsellor for advice.

The grief counsellor discussed the situation with members of the medical team and nursing staff and the decision was made not to contact the family.

Some hospice staff thought this was not the right thing to do, but I believe it was the right decision. Kissane, Clarke and Street (2001) suggest people have their own view about dignity and what is dignified for some people may not be dignified for others. Sampio (2001) adds that some people are very concerned about finding a socio-cultural definition for dignity. Julian had made it very clear that he wanted to die on his own, with alcohol as his companion. This way of dying was not socio-culturally acceptable for some people, but for Julian it was his perception of a dignified death and I felt I had to respect his wishes.

Julian presented a challenge to many of the personal beliefs I have about dying with dignity. I have always believed that family contact and communication are important. Julian taught me that this is not true for all patients. Copp (1997) emphasised in her research that too often health professionals make their own assumptions about dignified death and are not concerned with the individual personal indignities that really matter to the patient.
As a hospice nurse caring for Julian I must admit I became very frustrated with Julian’s lack of communication with his family, particularly his son, and I worried about the long-term effect it would have on them. However, I kept telling myself that this was the way Julian wanted to die and reminded myself frequently that this was Julian’s choice.

As I have suggested earlier, Julian had disengaged himself from his family. I am not sure why this happened, but am aware there were lots of contributing factors. One of the main reasons was that Julian believed his son had a psychiatric problem and he had tried to have him admitted to a psychiatric unit. The rest of the family did not agree with Julian and claimed he was the person with the psychiatric illness.

On the fifth day after Julian’s admission I went into his room and he had died. He looked very peaceful and happy. On reflection, I do believe Julian died with dignity, but his death was complex and different. Julian’s only companion when he died was a bottle of vodka in a brown paper bag. I am heartened by the research completed by Turner and Chye (1996) who suggest dying with dignity is a commonly used phrase in hospice settings, but its definition and implementation are anything but straightforward.

While cleaning out Julian’s room the next day I discovered a pipe in his locker used for smoking marijuana. I am not sure if Julian smoked marijuana while a patient in the hospice, but I remember shedding a tear and at the same time smiling to myself, as I put the pipe in the brown paper bag beside his beloved bottle of vodka, said goodbye to both
of them, threw them away, and thought to myself that they would keep each other company now that their master and best friend had died.
MAURICE’S STORY

Maurice was a 74-year-old man who had been on the Hospice Programme for two years. He was originally diagnosed with Cancer of the Prostate and was scheduled to have a bilateral orchidectomy, but had been refused because of a elevated serum potassium. He had chronic renal failure as a result. His past history included asthma, appendicectomy and ischaemic heart disease.

I looked after Maurice for two weeks, before he died peacefully in the hospice surrounded by his family.

Maurice had a supportive family that included a seven-year old grand-daughter called Jane who had returned with her mother from America to be with Maurice at the hospice. Jane was a bubbly, bouncy little girl and obviously adored her grand-father. He, in turn, was very proud of her. I have fond memories of her sitting on Maurice’s bed listening to him reading her stories. Occasionally, he would sing to her. Their favorite song was “You Are My Sunshine”. It was the worst rendition of the song I have ever heard (totally out of tune and because Maurice had a chronic throat infection, always in a very croaky tone) but I grew to love it. Whenever I hear that song again I will always think of them.

Suddenly, on the seventh day of Maurice’s admission, he announced he didn’t want to see Jane, his grand-daughter, again. I was shocked and wondered what had happened. They had seemed so happy together. I immediately started to think maybe I had done
something wrong. I remembered that I had said his singing was “a little different,” but I had meant that as a compliment, not a criticism. Had I embarrassed him?

Maurice was a straightforward sort of character, so I decided to ask him what the problem was. He told me, very bluntly, that he didn’t think it was right Jane was watching him deteriorate. He voiced his concerns about fear of losing his dignity and told me: “I don’t want my grand-child to remember me as an old git who vomited all over the place”. On reflection, I remembered that over the past few days, he had started to have problems with nausea and vomiting and was becoming rather quiet and withdrawn. His vomiting episodes were often spontaneous and came without warning.

I decided I must do something to remedy this situation, because, to be honest, Maurice reminded me very much of my own father. My father was the same age as Maurice when he was dying and the thing that worried my father above everything else was the loss of his personal dignity.

Maurice walked with a walking frame and was reasonably mobile. He was able to have a shower with assistance, but increasingly his vomiting and nausea was becoming a real problem. He was unable to eat and was having difficulty swallowing his tablets because of reflux.

Maurice was a mild mannered man who was not very outgoing. He loved reading books and listening to the radio. He did not belong to any clubs, instead preferring to stay home
and work in his garden. His family was very important to him. His first wife had died of cancer and he remarried Agnes when he was seventy years old. Maurice had two children, his married daughter who was a university lecturer in Australia, and another son who was single and unemployed. Maurice had just one grand-child. Before he retired he had worked as a lawyer for a large law firm.

Maurice was a man of few words. I always knew something was not right when he became “grumpy.” I well remember he was very particular about his clothes and the way he dressed. It was always important that Maurice had an ironed handkerchief placed at a certain angle in his pyjama jacket. One day I did not place the handkerchief exactly as he wished and he very quickly taught me the correct way. Maurice was always concerned about the way he appeared to the outside world. Looking neat and tidy and well groomed was extremely important to him. On reflection, the fact that his vomiting and nausea had destroyed this image was, indeed, a huge emotional crisis for him.

Maurice identified himself as a New Zealander. At the time of his death he was part of a culture of elderly men who often talk about World War II and the fight for independence and freedom. He told me he was a pilot during the war. Some of Maurice’s important cultural values were privacy, self-respect, independence and control. Maurice hated losing his independence and two days before he died, he insisted on getting up and going to the toilet to urinate. He was wobbly on his feet and exhausted when he got back to bed, but determined he was never going to use a urinal. The dependence on nursing staff made him feel out of control and unable to make decisions for himself. The unpredictable
nausea and vomiting, destroyed his most important cultural value, that of self-respect and dignity.

Maurice was a Roman Catholic and believed in God. He never spoke to me about religion, but I presumed he was a Catholic because it was written in his notes and he had rosary beads in his locker. The chaplain at the hospice often visited him and every now and again he received communion. I always felt that Maurice was realistic about his dying and he had accepted it in a very brave manner. Maurice wanted to die with dignity and was at peace with himself. He had not planned that in his final days he would be seen by his grand-daughter vomiting into a blue plastic ice cream container.
REFLECTION

I was aware the medication was not controlling Maurice’s vomiting and nausea but what could I do? It was extremely important for Maurice to maintain his dignity. He wanted his grand-daughter to remember him as a caring, loving grand-father and not an old man who vomited all the time.

Marais (1994) suggests that dignity is about feeling comfortable with oneself and having control and choice over your environment. Tonnes and Tilford (1994) on the other hand, suggest that dignity is connected to self-concept and self-esteem. Maurice felt as though he was not in control. He was in a room with two other elderly men, who were aware he was deteriorating. One of the men he shared a room with had been a neighbour of his. They had known each other for years and had often chatted together about their gardens. Some dying people would like to be in the same room as an old friend, but Maurice was different. Maurice always wanted to be in complete control and even though he never voiced his concerns about this situation, I was aware by his body language and the expression on his face that he hated anyone observing him vomiting.

I asked Maurice could I help and did he have any suggestions. Maurice replied that he would appreciate being moved to a single room. He also said he would love to see his grand-daughter again, but only between 2pm and 4pm. Maurice had worked out that he hardly ever vomited at this time. I was amazed at the absolute clarity of his thoughts and I chastised myself that I had not included him when I was organizing his care. Ferguson
(1988) wrote that nurses should remember the person inside the patient. In my haste to control his nausea and vomiting, I had forgotten that he loved to be “the boss” and was still capable of solving his own problems.

Fortunately, we had a spare single room, but it hadn’t been cleaned. I promised Maurice that once it was clean and had been left to air for a while I would move him. I then rang Jane’s mother and said that Maurice would love to see Jane (his grand-daughter), but emphasised that she must visit between 2pm and 4pm. I always suspected Maurice hated the plastic ice-cream vomit container, so asked Agnes (his wife) to bring in something a little more suitable.

Street and Kissane (2001) suggest that people communicate through their bodies and their environment. The home care nurses told me that Maurice lived in a lovely old villa and was surrounded by books and old antique furniture. A blue plastic ice-cream container used as a vomit receptacle certainly did not fit into his way of thinking about the environment.

I moved Maurice to a single room the next day and arranged the bed so that people couldn’t see him when they were walking up the passage. Preserving Maurice’s privacy was a deliberate attempt to maintain his dignity. de Raeve (1993) explains that some patients are filled with disgust when their bodies start to decay and become out of control. Maurice, as I have suggested, hated anyone seeing him vomiting. His usual high self-esteem and self-respect had started to tumble because he was not in control.
Jane came the next day and visited him at the appointed hour. I shut the door, drew the curtains and did not interrupt them. I knew this was a special moment. The ice cream container was removed and replaced with a lovely glass bowl with a fancy cover. I was not sure how I was going to clean this beautiful bowl, but reminded myself that this is what he wanted and I would have to adapt to the situation.

After Maurice was moved to the single room he seemed a lot more content. Maurice had accepted his symptoms were difficult to control and had moved on. He was able to talk to his family in complete privacy and Agnes told me he had started to share his feelings with her about dying. Maurice even started to sing “You Are My Sunshine” again to Jane. It was still out of tune, but it was wonderful to hear that croaky voice again.

I felt I had helped restore some of Maurice’s dignity again despite his problems with nausea and vomiting. This was in line with Haddock (1996) who states: “The presence of the nurse is the key intervention that can affect and restore a patient’s dignity” (p.926).

Maurice’s nausea and vomiting did not improve, but at least he was able to vomit into a beautiful and dignified bowl.

One of the main mistakes I made when caring for Maurice was that I didn’t involve him when I was planning his care. I need to continually remind myself that palliative care is holistic and patients need to be involved. Webster and Kristjanson (2002) suggest that the
holistic approach includes treating patients as individuals and offering them respect and control. Control was important for Maurice and I should have acknowledged this.

Instead of feeling miserable about my mistakes, I now learn from them and change my care accordingly. Cooney (1999) confirms my ideas about reflection when she states ‘reflective practice is more that just thoughtful practice, it is the process of turning thoughtful practice into a learning situation’ (p. 1530).
MARY’S STORY

Mary was a 54-year-old woman diagnosed with Cancer of the right breast. She declined surgery and later developed a large fungating tumour. She had strong spiritual beliefs and was very determined. Mary generated a number of ethical issues during her hospice stay because of her refusal to accept any medical treatment. She was in considerable pain most of the time, but when offered medication always politely refused. She was a hospice patient for seven months and during that time I grew to admire and respect her.

Mary had a supportive family that included a son, his wife and two grandchildren. She was actively involved in her church group and many people from her church visited her. One particular group of friends always bought a guitar and I often heard them singing songs and chanting.

One day when Mary was first admitted to the hospice it became apparent to me that she hadn’t had a bowel motion for two days. The doctor charted her a laxative and I went into her room, explained the action of the medication, and handed her the tablets. Mary told me in a polite but very firm manner that she did not believe in medication and refused to take the tablets.

The next day, because she still hadn’t had a bowel motion, I gave her an enema. Mary hated lying on her side for any length of time because it caused her a lot of pain, so I decided to use the hoist to move her. A simple procedure that usually took 20 minutes
extended into two hours. Because Mary had so much pain we had to move her very slowly and carefully. Both of her arms required support while we moved her so two extra nurses were needed. The whole procedure became a disaster because hoisting Mary into the air exacerbated her pain and made her feel undignified because she was exposed. She also became incontinent of faeces.
REFLECTION

Initially I felt extremely frustrated with Mary. She was swallowing alternative medication that included Vitamin C and Evening Primrose tablets on a daily basis but had refused to take any pain relief or laxatives. I was also frustrated that because she refused pain relief, all her nursing cares took a lot of time and energy.

‘Patients bolster their sense of dignity and spirituality by being in touch with nature and/or connecting with a creative life force’ (McClement, Chovichinov, Hack, Kristjanson & Harlos, 2004, p.174). Cobb (2001) suggests that some people connect with something outside of themselves and become open to a greater reality that may be in the depths of themselves or with the world of God. She further suggests that this is called “transcendence”. At its most literal it is about going beyond the self, the body, the physical and the mortal. Mary demonstrated this because she was able to cope with pain that was often extreme.

I was aware Mary belonged to a religious group, but when I asked one of her visitors if non-compliance with all medication was one of the church’s laws, he said it wasn’t and added that he had a heart condition and took 16 tablets a day. When I discussed the matter with Mary, I was always left with the impression that there was something else or someone else that she was able to connect with because she never complained of any pain.
After reflecting further on the incident, I concluded that the whole procedure was most undignified for Mary. I should have been more aware of her feelings and wishes and not rushed things. I also should have involved Mary more and asked her if she had any suggestions that would help solve her constipation problem.

Mary must have hated the situation because she was a dignified lady who was very much in control of her destiny. I should have kept this in mind and, as Haddock (1996) suggests, remembered the ‘person inside the patient’. Mary believed she was going to get better and the cancer would be cured. It was a difficult situation because my belief about her prognosis was totally different to hers.

We had a lot of staff meetings to discuss Mary and her treatment. Most of the people caring for Mary found her a huge challenge, mainly because she was in denial about her disease and believed she was going to get better. Her family also became upset because they hated seeing her in such pain. Mary often used to talk about what she was going to do when she went home and the holidays she had planned.

Herth (1993) suggests that some people have a dynamic inner power that enables them to transcend their current situation. I came to believe that Mary did have some sort of inner coping mechanism because not once did she complain or talk about her disease. She always gave me the impression she was totally disassociated from her body.
I decided to try and have a chat with Mary about her constipation problem. Initially, she wasn’t at all interested but after a couple of days she agreed that she would take Kiwi Fruit Crush on a regular basis. I felt relieved that she had helped me come up with a solution and chided myself that I did not consult her in the first place. I was intent on getting my procedure completed and had ignored her feelings of vulnerability. Chin and Kramer (1991) suggest that to promote dignity, feelings need to be clarified and understood so that interventions are focused on the patient rather than the nurse. I should have given the whole procedure a lot more thought. I tend to rush things and became frustrated that because Mary had made it clear she would not take any medication to relieve pain or reduce constipation.

As time progressed I got to know Mary a lot more and realised she was against all medication because of some hidden spiritual belief. She was always very serene, determined and had a strong belief in family. She challenged most of my beliefs about dying and dignity because she was not afraid of pain or loss of independence. She was an individualist who was bed-ridden for seven months and developed all sorts of complications, but never once complained.

Most people would suggest Mary died a very undignified death because at the end she suffered intense pain and skin breakdown. Street and Kissane (2001) disagree with this generalised view and suggest that dignity is perceived individually, and what is dignified for some people is not dignified for others. Marais (1994) supports this and adds that the health care system has no clear definition about the concept of dignity.
I learnt a lot about human nature when caring for Mary, I now have a different perspective about spirituality and the relationship with dignity and wonder how it gave Mary the strength to endure such suffering. I am still amazed at the inner peace she had and the determination she had to die ‘with dignity’ her way. Dignity for Mary came from within and was impossible to define. As, Turner and Chye (1996) suggest dignity is an elusive concept and is ultimately an intrinsic quality.

On reflection then, I now have a different perspective about spirituality and wonder how it gave Mary the strength to endure such suffering. I now believe that my practice is more open-minded and that I am prepared to challenge long-held views about dignity with dying.
STORY TELLING

While I have been writing the stories, three particular things have emerged as a result of my reflection.

- I have considered my decision-making processes, which has involved me letting go of what I want and consulting with the patients a little more.
- I have examined my relationships and responses to patients and discovered that I have learnt to walk alongside patients rather than tell them what to do.
- I have identified gaps in my knowledge, especially around the topics of communication and privacy.

I have also encountered while writing my stories patients who have experienced difficult, joyous, happy and painful episodes during their time in the hospice. Bolton (1999) suggests that every triumph, disaster, or joy of our lives is a story waiting to be written, and the stories I have presented reveal these dimensions. The writing of the stories has enabled me to bring wonderment and joy into my life.

Atkins and Murphy (1993) explain that reflecting on stories allows nurses to take responsibility for their own learning by enabling them to identify their own learning needs. They also further suggest that reflection is crucial if nurses are to keep pace with, change and develop their practice. I consider that the writing has actually enabled me to expose the rich quality that at my age I know I can bring to practice. To balance this I am also challenged because I am learning new skills in a specialist area. Reid (1993)
considers reflective practice a way of ongoing survival and further development once formal practice has ended. Saylor (1990) agrees and explains that nurses must reflect on their practice continually to maintain competency.

In a strange way I feel that I have found out more about who I am by pursuing the goal of making my practice more explicit. Perhaps I have experienced what Benner (1984) identifies when she suggests that knowledge is often buried in practice and it is story telling that can often highlight hidden nursing knowledge. In the same vein, I have taken a leap of faith in practice and made a point of assessing the vomit containers we use which are part of our everyday practice. After meeting with colleagues to explore how to change the actual containers we use, to my horror it seems to be too difficult and I would go so far as to say no one has yet created a practical and dignified vomit container. This receptacle matters to people as Maurice has demonstrated. Knowing this and researching the issues has enabled me to be more sensitive to the knowledge that is invisible around the act of vomiting. I support Cooney’s (1999) ideas because when I was writing the stories invisible items such as vomit bowls and bottles of vodka became key items that contributed to the maintenance of dignity for Maurice and Julian.

Carper (1978) identifies four ways of knowing in nursing which include empirical (the rational, technical knowledge of nursing) aesthetic (the art of nursing) personal (self-understanding) and ethical (knowing right from wrong). I admire and accept Carper’s theory but as a nurse it is interesting to observe, that a philosophy based on the aesthetic is also practiced and promoted by other members of the interdisciplinary team. At the
hospice this team includes an art therapist, a massage therapist and a social worker. Our resident chaplain also has an aesthetic approach and is well known in the community because of his regular painting exhibitions. However, I acknowledge that I need to be aware of the rational technical knowledge of nursing and for me that includes medications, their side effects and the anatomy and physiology of different types of cancers.

Carr (1996) agrees and suggests that this combined knowledge of science and creative ability is essential for good nursing practice. She further suggests that the notion of creativity and knowledge is important because until relatively recently scientific knowledge was perceived as the only form of knowledge. Graham (1995) supports this idea and adds that reflection and story telling has the potential to narrow the theory-practice gap because it exposes contradictions and facilitates the refinement of theory through practice.

The focus on the technical-rational approach suggests there is an absolute right answer and scientific way. Schon (1987) suggests that the technical-rational view of professional nursing practice is based on scientific theory, methods and techniques. Darbyshire (1993) on the other hand suggests there is a shift away from this thinking and situations of uncertainty are not easily solved by scientific principles.

My story about Mary was impossible to solve and explore from a technical-rationale approach because Mary’s way of coping with her death came from something that was
above and beyond anything that was able to be defined. I believe Mary was able to cope with her pain because of some hidden creative force.

Schon (1987) explains that nurses face complex situations every day that cannot be solved by the technical-rational approach. He encourages nurses to explore what works, to reflect on and examine their actions and to change their practice accordingly. It is important at this stage to say that I am not against scientific knowledge, but for the purposes of this project it was important for me to examine my aesthetic practice by writing stories and reflecting on them in an effort to understand the complexities of maintaining dignity for dying patients.

Cooney (1999) suggests that nurses face difficult and complex situations every day, such as caring for dying patients and their relatives. She also adds that these situations defy traditional solutions and encourages nurses to explore what works.

My stimulus for story telling and reflection could be summarized as a way of trying to make dignity visible rather than invisible. The stories often puzzled, upset, angered and made me feel uncomfortable. On the other hand, I often felt happy when I was able to solve a problem or restore a patient’s dignity. Story telling has encouraged me to change my every day practice and my approach to difficult situations has changed. Taylor (2000) suggests reflection is not a time for flagellation, but an exciting opportunity to see and do things differently.
LITERATURE REVIEW

The literature search is not comprehensive rather I have explored articles particularly looking for ideas that might trigger insights into the true meaning of dignity within my practice world. After considering a range of many articles related to the topic three major themes have emerged:

- Loss of dignity is often cited as a concern by those who favour euthanasia or assisted suicide.
- Dignity can be defined by using a nursing outcome or an empirical model.
- Dignity is difficult to define.

I will now elaborate and explore these themes:

DIGNITY, EUTHENASIA AND ASSISTED SUICIDE

One of the most compelling reasons for exploring the concept of dignity is that documented studies by physicians suggest patients select euthanasia or assisted suicide because they have real concerns about their loss of dignity. Van der Maas, Van Deldon, Pijnenborg and Looman (1991) support this and suggest physicians cited loss of dignity in 50-60% of patients, these authors then commented that pain in 40-50% of patients were the main reasons for euthanasia or assisted suicide. Chochinov, Tataryn, Clinch and Dudgeon (1999) further suggest that a common pathway leading patients to lose their will to live was loss of dignity.
In New Zealand, Lesley Martin, a registered nurse, who was jailed after assisting the death of her mother, has recently highlighted euthanasia and the right of people to bring life to an end. Controversial practice events trigger a wide range of societal discussion. This area is also of profound interest to all hospice nurses because people who are dying want to know how the end of life moments will be and will they die with dignity. Emanuel, Fairclough, Daniels and Clarridge (1996) explain that support for assisted suicide or euthanasia is often anchored by concerns for the patient’s dignity.

Two Australian researchers, Street and Kissane (2001) wrote an article on dignity that was derived from research that is still in progress. The method they used was discourse analysis, which examined the qualitative results of studies about the end of life. They concluded that dignity is socially constructed, includes bias, is not neutral and does not describe reality. A good example of this is that supporters of euthanasia used to talk about mercy killing and the right to die. To get their message across and appeal to people’s emotions they then used the term ‘dying with dignity’. They also suggest that terms like ‘dying with dignity’ need to be constantly defined and redefined.

It is interesting to read in the literature that euthanasia supporters now are beginning to use the term ‘gentle landing’ and ‘deliverance’ as a way to describe a dignified death. I am not sure if I feel comfortable with these terms, but as Street and Kissane (2001) suggest they are very good examples of using language to promote a particular idea or concept.
The Canadian researcher Chochinov and other researchers have written extensively about dignity, however I struggle to position their ideas about dignity. The researchers carried out a study to determine how patients themselves understand and define dignity. Three major categories emerged from their qualitative study. They were illness-related concerns, dignity conserving repertoire and social dignity inventory. These broad categories and carefully defined themes and sub-themes formed the foundation of an empirical model that offered health professionals a way of understanding how patients live with advancing terminal illness (Chochinov, Hack, McClement, Kristjanson and Harlos, 2002). In support of this team some of their research was of value but I needed more detailed information to clarify the exact nature and meaning of their proposed empirical model.

Rankin et al. (1998) developed a nursing outcomes classification tool to measure the effectiveness of nursing interventions that were carried out to ensure a dignified death. Each outcome included a brief definition and a list of the outcome indicators that were specific to the patient eg. patient behaviours. The outcomes and indicators were documented and then measured by using a selected five-point Likert scale. There is some literature where studies use inventories or tools to shape questionnaires and while these are all possibly helpful in other areas such as pain and symptom management, I believe that in the area of dignity, they have limited value.
I found both of these models extremely complicated and very rigid. They did not allow for cultural differences or individuality. In my opinion both models were cumbersome, unattractive and complex.

**DIGNITY IS DIFFICULT TO DEFINE**

I noticed across the diverse literature that dignity is a concept applied frequently to describe a ‘good death’. Presumably, from what I have read, and what the researchers suggest, a ‘good death’ is one that best fits one’s own system of values and beliefs. de Raeve (1996) suggests, on the other hand, that the universally ‘bad death’ is likely to be the death that rejects all care. de Raeve (1996) also says that health professionals should move away from the predetermined stages of Kubler Ross (1970) and consider dignity in terms of personal, spiritual and physical integrity that may be under threat when people are dying.

Having said that dignity is difficult to define, I discovered Haddock (1996) has a different view of dignity and suggests that dignity is connected to the shared humanity of the patient and the nurse. This makes total sense to me. She also suggests that the maintenance of human dignity evolves from the recognition of human similarities and differences. I know of this human to human connection and can still remember the smile on Maurice’s face when I gave him the lovely crystal bowl to use as a vomiting receptacle. Benner and Wrubel (1989) on the other hand say that spending time and being present is the basis of acknowledging humanity. The extra time I spent taking Julian to
the liquor shop was a good example of this, even though I was very apprehensive and nervous, just being with him on this occasion made me realize that alcohol was a priority in his life and therefore part of his value system. Pearson (1984) elaborates on this and says humanity is the essence of advanced nursing.

Enes (2003) explored the meaning of ‘dignity’ in a qualitative study with patients, relatives and professionals. She found that dignity consisted of four dimensions which were ‘being human’, ‘having control’ ‘relationships and belonging’ and ‘maintaining the individual self’. She concluded, however, that the concept of dignity was a complex phenomenon.

Walsh and Kowako (2000) carried out a phenomenological study with patients and nurses in a hospital. Their results suggested that nurses and patients believe that the body, its treatment and exposure were central themes that needed to be included when trying to define the term dignity. I agree with this and believe maintenance of privacy and consideration of people who are dying is fundamental.

Rogers, Karlsen and Addington-Hall (2000) analysed the qualitative comments attached to questionnaires by 138 carers whose relatives received care in a hospital during the last year of their lives. They found that while overall rating of satisfaction with services was good, specific sources of dissatisfaction related to feelings of being devalued, dehumanized and disempowered were evident. A loss of dignity in relation to physical care needs was a prime cause of complaints and appeared to occur when bureaucratic
rules and regulations appeared to override individual patient needs. Fortunately, as I have suggested previously I work in a hospice environment where dignity is highly valued. The nurses are encouraged to further their education and develop their communication skills so they can preserve and maintain what they and the hospice perceives as ‘dignity’.

CONCLUSION

A lot of research has been carried out in order to discover a precise meaning and truths about dignity. There has been some success but overall as Turner and Chye (1996) suggests the task has proved elusive. Coope (1997) believed that dignity as a concept was mystifying and he advised heath professionals to give up the term ‘dying with dignity’. Similarly, Wear (1996) argued that the ‘sanctity of life’ and ‘human dignity’ were anachronistic terms that were inadequate to apply to decisions about the end of life.

Most of the literature suggests further research is required to find a language that describes dignity. Other researchers suggest that more research is required around patient empowerment, communication systems, autonomy, human rights and informed consent. In response to this challenge, I have decided in the following section of this research project, to investigate the arts and humanities and consider dignity from an aesthetic perspective. Maybe, this will enlighten and help me to position my own understanding of the term dignity. However it might be the case that there is no conclusion about dignity and we need to simply realize that every day and every person is to be treasured.
RALPH HOTERE AND MY FATHER-A REFLECTIVE TRIBUTE

I have learned a lot about dignity through the three stories I have written and the literature research I have conducted. In the previous sections, I have reflected on these stories and have discussed care that was problematical, troublesome and hard to grasp. Memories, feelings and thoughts that I hadn’t acknowledged before have been acknowledged. But, like many of the researchers who have written about dignity the concept continues to elude me.

Where, then, does one turn to discover something of the secrets of this most difficult of notions?

Perhaps the creativity and human expressionism manifest in the arts and in the humanities can go some way to unlocking the door to this elusive concept.

Let me alone, that I may take comfort a little,

Before I go where I shall not return,

Even to the land of darkness and the shadow of death.

( Partington, 1996, p.77).

One does not have to study prose and poetry too long to reach the conclusion that death is very frequently portrayed as something dark, something black and dangerous, something brooding, to be feared and something to be mourned.
And this self same imagery can also be found in works of art, especially in the paintings of one of New Zealand’s greatest artists, Ralph Hotere. Hotere’s art, like a great deal of artistic creativity, addresses the perennial issues of human suffering, loss and death. The predominant blackness of Hotere’s paintings portrays an overpowering image of austerity.

Hotere’s work is very close to me as it reminds me very much of my father, who died in 1996. My father left me some money so in his will and I decided that it would be particularly fitting to use the money to purchase a work of art by Hotere. My father was a keen admirer of the qualities of catholicism and pacifism which exists in much of Hotere’s work and they also both started their careers as teachers.

One of the underlying themes of Hotere’s paintings is the unity which exists between the darkness and light. This has a parallel in the writings of Rushton and Spencer (2004), who suggest nurses are powerful messengers and they need to write their stories so they can bring dignity and humane caring out of the shadows and into the light.

I wrote a poem a day or two before my father died after I had been caring for him for five weeks. My father was a private man and I knew that the thought of his privacy being invaded by admission to a public hospital was abhorrent to him.

My father loved poetry, was a linguist fluent in French and German and started learning Spanish at night school when he was 80.
I knew he would appreciate my attempt at poetry and I hoped that that knowledge would illustrate my love and caring for him and help bring a dignity to his final few hours.

**To My Father**

Through Karangake Gorge  
The water clean and swiftly flows.  
There in the summers of my youth  
The sun forever shone.  
My father young and strong  
Would swim across the stream,  
And I upon his back  
Knew that I was safe.

And now my father  
How the years have past,  
And you are frail and close to death.  
I cannot save your ebbing life  
But hope my love and steadfast care  
Will help to bear you  
As you once bore me  
Across that final stream

(Cavanagh, 1997, p.61).

When I wrote that poem six years ago, my imagery was of a young girl recalling the safety and assurance provided through the strong shoulders of her father. I realise now, however, that the message I was trying to communicate to my father was an appreciation of the dignity he displayed, notwithstanding the present frailty of his body and the imminence of his death.

Not for him was that a moment cloaked in darkness.
Turning once again to the work of Hotere, we find that his art also reflects a spiritual and inner life. Dignity is often associated with spirituality and my story about Mary suggests that dignity for her revolved around her spirituality.

Hotere’s art represents hidden sadness, awe and anxiety. As Gregory O’Brien notes in Ralph Hotere Black Light (2000), while Hotere’s black and brooding art is on the face of it a descent into darkness, it draws us through that blackness towards a state of illumination.

Similarly, I have now come to believe that out of that darkness, blackness and broodiness projected by art and poetry emerges an image of death not as something to be feared, railed against and resisted, but as a graceful and peaceful transition from the stress, the strain and the pain of human life.

Engaging the arts and humanities has enabled me to mourn and grieve and has contributed to a clearer understanding of the concept of dignity.

Sleep after toil, port after stormy seas,
Ease after war, death after life does greatly please.

When death can be regarded in that way – as a pleasure – I know now how there can, in fact, be true dignity in death. No longer for me is death a fearful representation in black. From now on, colour me white.
CONCLUSION

There are no conclusions about dignity or practice, because it unfolds quite mysteriously. I knew I wanted to explore dignity as a concept but I never thought I would reveal the core of myself and my practice, nor did I think I would write so lyrically. I now realize that we live with dignity by how we are and how we perceive it in all its individual guises. In compiling this paper I have come to the realization that the concept of dignity is calmness from anxiety, acceptance from foreboding and light from darkness.
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