

CHOSEN MOMENTS

A REFLECTIVE JOURNEY ILLUSTRATING TERMINALLY ILL
PATIENTS CHOOSING THE MOMENT TO DIE

By

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ABSTRACT

In this project the author reveals how she is observing and thinking as she cares for people who are dying. She records her reflections and insights and most profoundly reveals that there is life right up to the moment of death, having observed terminally ill patients choosing the precise moment to die. She describes her observations of these moments by using poetry and stories, and explores the implications for her practice as a result.

The author presents her reflections using an individualistic, reflective and exploratory perspective which is informed by the work of nursing scholars; Taylor (2000), Benner (1984) and Johnstone (1999). This paper is framed using the metaphors of a journey and a window to indicate the reflective process that the author used to journal her observations in practice over time. This offers a professional and personal record of the author's insights.

DEDICATION

This research project

“Chosen Moments”

A Reflective Journey Illustrating Terminally Ill Patients

Choosing the Moment to die

is dedicated to a patient

who died in my presence in 2000

and to the patients I have had the wonderful privilege
to care for as a palliative care practitioner over the last five years.

Trust in His timing
Rely on His promises
Wait for His answers
Believe in His miracles
Rejoice in His goodness
Relax in His presence
(Christian Forums, 2004)

ACKNOWLEDGEMENTS

Firstly I want to acknowledge the patients I have witnessed choosing the moment to die and about whom I have written on this journey.

I wish to acknowledge the unfailing support and encouragement of my supervisor Margi Martin on this journey. Thank you for your inspiration, love and guidance.

I want to acknowledge the never-ending support of my husband Peter for his love and patience on this continuing journey. Thank you for continually being there.

I acknowledge the support and encouragement I have received from my daughters Michelle and Rachel throughout this journey.

I acknowledge the on-going support of my friend Miriam McKee for her inspiration, prayer, friendship and enthusiasm in editing my work throughout this entire journey. Thank you Miriam.

Lastly I want to acknowledge that it is my strong faith in God that has sustained me throughout my journey.

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SECTION ONE – THE PROJECT

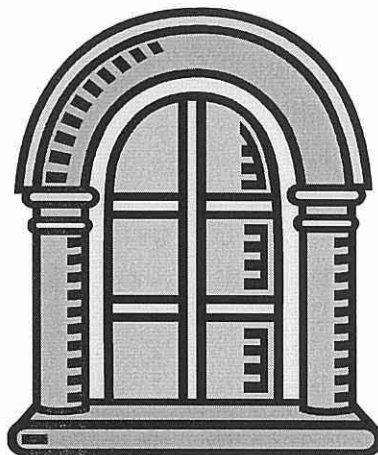
INTRODUCTION

SEARCH STRATEGY

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BACKGROUND



INTRODUCTION

Can Terminally Ill Patients Choose the Precise Moment to die?

This is a controversial question to which I am still trying to find the answer. In nursing dying people, I have come to recognize the significance of the last moment of life. I have specialised in palliative care for the last five years and consider that I have witnessed terminally ill patients making a choice as to the precise moment to die. This observation includes patients choosing to die alone, with others, or waiting for certain events to occur before they die.

This paper describes in detail my observations of such choices and does not debate surrounding issues such as euthanasia or the terminal phase of dying or the process of dying itself. My observations at this point of the actual moment of death cannot be easily validated and for the purposes of describing such events in New Zealand we record the actual time of birth and death as a legal requirement and create a certificate of proof. For some people the markers such as the moment of death and date is important, for others the date of remembrance is significant. My particular interest is toward a practice outcome which I might be able to mediate as an act of care: *If terminally ill patients choose when to die, do they need certain people to be present to die or a certain environment to die as they wish?*

This paper records my observations as a clinical practice journey in progress. I document my journey of how I began to observe this moment and integrate it into my clinical practice over five years. Like any traveller I can identify distinctive phases in the journey which convey a progression such as: the beginning of the journey; the continuing journey; the progressing journey; the ongoing journey and the never ending journey. As my exploration progressed insights were gained due to reflection. I related the journey metaphorically to opening a window. The text in the paper reveals this journey and as the journey progresses the window opens in stages. At each stage as the window is opened I describe further observations and insights. A selection of these practice observations which have been systematically recorded are presented in this research paper as reflections of the poems and stories I have written. As a result of integrating the experiences in practice through reflective writing I now have a clearer understanding of who I am as a person and how I nurse.

To both support and direct this journey and research process I have chosen to present this research paper as a reflective narrative autobiography which I have divided into three structured sections. Each section is divided with a title page and a window picture downloaded from clip art (<http://www.office.microsoft.com/clipart>). Section one describes the search strategy and overall design of the research. It includes the writing strategy and details of the background information for this topic. While section two describes the actual journey of practice through reflective writing, section three draws together the reflections that have occurred along the way and offers a conclusion for colleagues.

To position the reader at the onset I have chosen to share my personal and professional interest and style of my practice which is represented in this project. I was initially inspired by Taylor's (2000) articulate use of reflective practice in day to day nursing and Benner's (1984) writing on practice development. Then more recently Johnston's (1999) methodology paper on reflective topical autobiography as a way of authenticating reflection in practice. These perspectives enabled me to position myself centrally as a practitioner and challenged me to reflectively write. Through this process of reflection, which I will describe in detail, I will illustrate what I have observed in clinical practice.

Reflection is vital to our development as individual practitioners and the nursing profession but how does one do this effectively? Notable nursing scholars who have influenced nurses to reflect deeply about what it is to be human, all acknowledge that this process both requires and creates a different way of thinking and expressing our writing (Benner, 1984; Johns & Freshwater, 1998; Maeve, 1994; Taylor, 2000; Watson, 1985). They all acknowledge that we can learn from each other and extend our nursing knowledge by reflecting collectively on nursing practice.

Benner (1984) has greatly influenced my desire to write not only stories from my nursing practice but poems as well. Benner's powerful writing reveals what is embedded in stories written about nursing practice. This inspired me to write and discover the depth of my knowledge and experience which is embedded in my poems and stories. Maeve, a student of Watson, and storyteller (1994) writes, "Reflecting on practice through storytelling is a time honoured tradition in nursing" (p. 14). I want to honour this tradition in nursing by sharing the knowledge embedded in my own

clinical practice through stories and poems I have written. I want to especially acknowledge and honour who I am writing about. My objective in this research project is to present writing that documents my knowledge and enables me to share this information with colleagues, patients and families. My idea of using the journey-window metaphor is to make a connection with the reader to reveal my process. This is so you the reader can travel this journey with me and look and gaze through the window of my nursing practice. While only glimpses of the shared reflections are possible by reading this research, certain important qualities of the process are revealed.

In writing stories, and poems, about nursing practice in New Zealand there is a legal and moral obligation to protect the privacy of those people whom the story or poem relates to (New Zealand Nurses Organisation, 1993; Privacy Act, 1993). In hospices and for me professionally the protection of patients and families privacy is crucial. Archer (2001), a New Zealand nurse and a graduate from Victoria University explored this issue and asked “Was it ethical to write about patients without their permission, even though these stories were written from my perspective?” (p. 32). Archer felt there was a moral obligation to protect those whom we write about and adapted her style of writing and resolved this dilemma by using fiction, “Events while ‘real’ become unrecognizable” (p. 39). Archer felt that “it is the meaning of a situation or story that becomes important, not the individual person” (p. 38). I agree with Archer. It is the essence and meaning of a situation that I am trying to convey not the stories about individuals concerned. To protect the identity of individuals I have changed all their original identifying features. The situations however are real, but names, ages, gender, diagnosis of cancer, and time of death have been changed.

I acknowledge that the stories and poems I have written and present in this paper are original and that poetry has become a unique medium I use for expression in my nursing practice. Johns and Freshwater (1998) identify, “The art of nursing is lived in special and individual ways by each nurse and is influenced by that person’s experiences, knowledge and patterns of expression” (p. 45). Others will express themselves in their own unique and individual way.

I describe myself as a registered comprehensive nurse with a Bachelor of Nursing and a Post Graduate Certificate in Palliative Care. My strong Christian faith influences

how I deliver my nursing care but it is important for me that my personal beliefs never cross professional boundaries. I am married with two adult children and my family life enables me to consider it a very real privilege to work with terminally ill patients and their families.

I recognize a person's individuality, the right to one's own values and beliefs and cultural identity. I acknowledge every person is unique and different. I am very aware of who I am, my own values and beliefs. The dying person is a unique individual, a person of dignity and worth. I am sensitive, empathic and compassionate to a dying person and their family. This underpins my philosophy of nursing in which I accept the individuality of others. I have an ability to be present with patients and their families and actually consider this a gift. I see the beauty of life, not just death and I believe we live up to the moment of our death. I affirm life and acknowledge that dying is a natural process of life. I also believe we all have our own truth and our own way of interpreting reality and we can learn from each other and extend nursing knowledge by reflecting on our practice.

Initially when I practised I was a quiet observer and only with time and reflection have I developed the ability to simply be present with a dying person and their family. Now I am able to state that I have discovered that death is more than the actual last breath one takes. That last breath can be perceived by many as that final moment of human interaction and contact that occurs and a final moment of being in this world and not of this world. One's last breath is final and is that last moment in one's life time. It is the difference between living and dying, mortality and immortality.

TIME

What is time?

We arrive in this world at a given time

We die at a given time

In between things happen in time

So then

What is time?

One's life time

Jane Maries 2004

SEARCH STRATEGY

Initially an extensive literature search was carried out using Cinahl, Proquest, Cochrane, Medline and Google to explore the concept of terminally ill patients choosing the moment to die. Different combinations of key words were used such as; death and choice, choice and dying, terminally ill and choice, choosing the moment, palliative care and choice. One inspirational article surfaced entitled “Being Present at the Last Moments of Life” written by Legrand and Gomas (1998). Interestingly other tangible material found surfaced more by chance, as ideas reading general articles or scanning journals.

At this point little literature could be found on the concept of terminally ill patients choosing when to take their last breath. The literature search revealed an emphasis on euthanasia and suicide assisted death. These topics were not the focus of my research.

The literature that I did find relating to the concept of terminally ill patients choosing the moment to die was presented in the form of written stories. The stories revealed and portrayed this concept.

As there was such a scarcity in the literature about this topic, I started to write my own stories and poems specifically to portray terminally ill patients choosing when to die. Simultaneously I began to reflect on my own writing and then searched the nursing data bases for literature on reflection, stories and poetry writing. There was, of course, an abundance of literature on these subjects. When searching I noted the authors origins, culture and country of residence, because in New Zealand to understand stories and poems the authors origins and culture are an important signpost to our societal understanding. This change in my search strategy led to the development of the research design.

RESEARCH DESIGN

Why observe?

Why Write?

And why reflect?

To show my personal truth

To show my own reality

To extend my nursing knowledge

And to share my nursing practice.

Jane Maries 2004

In this research paper my intention is to present a collection of poems and stories through which I have explored the concept of terminally ill patients choosing when to take their last breath. I have chosen to position the research within the post positivist paradigm which supports the search for meaning in human experience. This paradigm focuses on personal experience, personal truth and reality (Roberts & Taylor, 2000). This positioning for the research spoke to me both personally, spiritually and professionally. It leads me to recognize the value of systematic observation and required that I accurately describe my process of reflection. In this process I am consciously observing a situation and standing back and reflecting. I then write about the situation in the form of a story or a poem. Then I reflect over time on what I have written and integrate these thoughts into my practice and future observations. Developing this process was integral to my practice and has been influenced by Taylor's (2000), "Reflective Practice, A Guide for Nurses and Midwives", Benner's (1984), "Novice to Expert" and Megan Johnstone's (1999), article "Reflective Topical Autobiography".

Taylor (2000), a Professor of Nursing at Southern Cross University, NSW, Australia writes about reflective practice for nurses and midwives and feels that there is real value in reflective practice for nurses. Taylor describes that "reflection is a valuable part of human life" (p. 10) and "knowing how to reflect is a process for making sense out of life experiences" (p. 2). Reflection can be considered a worthwhile activity and can be facilitated through a variety of creative expression like painting, stories, pottery, poetry, drama, singing, journaling, audio taping, music and drawing. Taylor's book describes three types of reflection – technical, practical and

emancipatory and advocates the three types can be used alone or in conjunction with each other. Taylor states “Reflection is valuable for nurses and midwives because it gives them the means whereby they can track their way systematically through practice issues to arrive at new insights and the potential for improvement and change” (p. 111).

Patrica Benner (1984), a North American Nurse Scholar, is a qualitative researcher who uses the concept of the lived experience. Benner’s work has greatly influenced nurses to write about their practice through the use of exemplars from nursing practice. These exemplars inform and share about nursing practice. Understanding the links between writing about practice and reflecting on the writing enables nurses to examine nursing in detail. Benner’s work has drawn on observation and the interviewing of nurses in practice. She identified that the sharing of knowledge between practioners can greatly enhance clinical practice and extends nursing knowledge.

In this research paper I have used Reflective Topical Autobiography (RTA) as a way of enabling me to reflect and write about my nursing practice. RTA is about the power of personal voice and exemplars of nursing practice (Johnstone, 1999). Johnstone, a Professor of Nursing at RMIT University, Bundoora, Melbourne, believes this is an underutilised research method in nursing and the reflective topical autobiographer focuses on a moment of a person’s life which is of some topical interest. RTA is about reflection of one’s own experiences and the researcher as self is present in the process. Reflective topical autobiography which as stated sits in the post positivist interpretive paradigm is based philosophically on the search for meaning and the essence of human experience (Mays & Pope 1996). RTA comes under the broad umbrella of Narrative Inquiry which also sits in the interpretive paradigm. This encompasses many areas – such as storytelling, life story, life history, oral history, biography, autobiography, narrative, lived experience and practice stories (Clandinn & Connelly, 2000; McCance, McKenna & Boore, 2001).

The post modern paradigm encourages nurses to write stories and poems more freely and this is why I have used reflective topical autobiography as part of my research design. RTA allows nurses to reflect on and write about their own personal practice experiences in a way that other research methods do not. RTA enables me to reflect

on the poems and stories I have written and gives me the ability to be able to freely express myself. Southgate (2002) in her thesis uses RTA to reflect on her practice as an oncology nurse. She feels “Reflective topical autobiography is a rich and valuable research approach for the nursing profession today, as it has the ability to advance nursing inquiry, and provide new nursing knowledge” (p. 30). RTA is an excellent method to use for this one paper research project as it recognises the potential for insight and deeper human experience and gives me the ability to write in a reflective, descriptive and expressive way. This is a powerful way to share aspects of my nursing practice with others. Southgate feels “...Reflective topical autobiography reflects what nursing is all about, through direct accounts of the nurse as storyteller reflecting on practice...” (p. 31). We can learn much about ourselves as a profession by reflecting on stories and poems written about nursing practice but just exactly how this might be done requires some focus.

Through interacting with colleagues in practice we learn from each other by reflecting on clinical practice through sharing processes and insights. This can unravel what our nursing practice is about. But it requires a disciplined person to go further and actually systematically develop their practice based on these insights. I have used a combination of Taylor, Johnston and Benner’s work as part of my research design. Taylor (2000) suggests we should share our reflective experiences and systematically work through issues to arrive at new insights. Benner (1984) challenges us to reflect on stories and poems from our nursing practice, to draw on our observations and extend our nursing knowledge. Johnstone (1999) encourages nurses through RTA to reflect on their nursing practice, giving power and voice to nursing practice. Through reflection I have systematically worked through practice stories and poems to arrive at new insights. I have drawn on my observations from clinical practice, written about what I have observed and have then reflected on what I have written. The vision and guidelines of Taylor, Benner and Johnstone’s work brought a level of trustworthiness, authenticity and integrity both to the process of writing poems and stories and the way in which they have been utilised in my research design.

WRITING STRATEGY

*I am a writer, a poet and a nurse
Therefore I am a nurse who writes poetry
This is who am I as a person
This is part of me
This is how I portray my nursing practice
As a writer of poetry who nurses.*

Jane Maries 2004

In this paper I have chosen to create the text using two metaphors. The first metaphor is of a journey and the second metaphor is an open window. I have related the process of reflecting to the journey and my gaining of insights to opening a window. Titles and subtitles guide the reader through the text as to these processes.

I have systematically used the writing of poems and stories as a vehicle to reflect on my nursing practice. I have quite often written at night, so I have literally experienced becoming my own light in a window. Writing this text has given me the opportunity to develop a window that equally can invite others to see through and to share in my journey. The reader will notice in the text of this paper that there is a repetition of certain words, phrases and ideas for example: a privilege and an honour, choosing the moment to die, and sharing what I am observing. I have chosen not to edit out repetition in these phrases as it signals the spiralling that was part of the reflective process.

The poems are presented as they were written originally, while the stories have been edited. I am the author of all of the poems and the stories in this paper. During this process writing has become central to my everyday nursing practice. I have chosen to write in the first person in this paper as it most appropriately represents how I am in practice. The writing of my poems comes from something deep within me; it is connected to who I am as a person, a nurse, a writer and a poet. A Professor of Palliative Medicine, Mary Potter Hospice, Wellington, New Zealand, Macleod (2002) writes "Poetry is a way to encapsulate our feelings" (p. 14). Both story and poetry writing are way for me to encapsulate what I am seeing at the moment of death.

BACKGROUND

*Before the curtains can be pulled back,
So the window can be opened,
The background needs to be examined.*

The idea for this paper originated some four years ago when I captured a significant moment in my nursing practice by writing a story and poem about a patient I called Ted. It is the subsequent observations and stories and poems that I have written that have given me a passion for this topic. This background describes these observations, acknowledges biochemical changes that can occur when one is dying and briefly identifies other significant studies.

I work at a hospice where research has been valued and conducted and have had the opportunity to consider evidence already researched and acknowledge the importance of such research. Interestingly 15 years ago medically directed research was conducted on the last 24-48 hours of life (Lichter & Hunt, 1990) which described the symptoms terminally ill patients could experience during these hours, but not the actual moment of death.

I acknowledge biochemical changes that occur within the body in the last 24-48 hours of life and the drugs known specifically for their use in palliative care such as: morphine, midazolam, methotrimeprazine and cyclizine which are used to alleviate symptoms can impair the brain's ability to function and the ability of the person to consciously choose when to take that last breath. The side effects of drugs used to treat symptoms in the last hours of life are well known (New Ethicals, 2001). Hunt (1999) acknowledges that palliative care treatments can and do affect the time of death and asks if these treatments postpone or hasten death. Hunt concludes that an array of palliative treatments can prolong life while other palliative treatments can hasten death. Lichter and Hunt (1990) who conducted a study looking at symptoms in the last 48 hours of life concluded that in the terminal stage of disease multi-organ failure and metabolic changes are to be expected. These multi-organ failures and metabolic changes and symptoms which occur may affect the thought process as death occurs. A lot of evidence looks at symptoms in the last 48 hours of life but there is little literature around about a dying person's thought processes (Ellershaw,

Smith, Overill, Walker & Aldridge, 2001; Lichter & Hunt, 1990). I acknowledge that in the last hours of life metabolic changes and multi-organ failure can occur and drugs used at this time can affect one's ability to think and make decisions. However there is evidence to suggest that unconscious patients do have raised levels of awareness prior to death.

One study by Barbato (2001) supports this and suggests that unconscious patients can have raised levels of awareness prior to death. Barbato undertook a pilot study with palliative care patients looking at the clinical application of BIS (Bispectral Index Monitoring – a simple method for EEG monitoring) to measure the level of awareness in patients from the onset of unconsciousness until death. Barbato concluded that the unconscious dying patient showed raised levels of awareness just prior to death. BIS scores rose with talking, movement, pain or activity. With this concept in mind could BIS scores indicate a person's ability to choose that precise moment to die? Barbato clearly indicated that more research was needed in this area. Bispectral Index Monitoring does warrant mentioning and this is another option to explore for future research.

Lichter and Hunt (1992) observed that out of 100 consecutive deaths a final tear drop was present in 14% of patients at the time of death. Lichter and Hunt did not have a physiological explanation for this occurrence and the data was inconclusive. This final tear drop could have been an indication of an expression of an emotion at the time of death and further evidence of an unconscious person being aware of who is present at the time of death.

I have observed that as the last moment of life approaches there are observations in patients which could indicate a patient is aware of who is present. Observations like a change in breathing pattern when certain people are present, a slight twitch or movement of a hand in acknowledgement when relative's talk, a frown disappearing as a relative arrives, patients eyes opening at the moment of death or a tear drop appearing in an eye at the moment of death. It should be noted that these observations are all very subjective but could give an indication of a dying person choosing when to die and who should be present at their death. Little evidence in literature and research could be found to support this idea. I have observed that some patients do

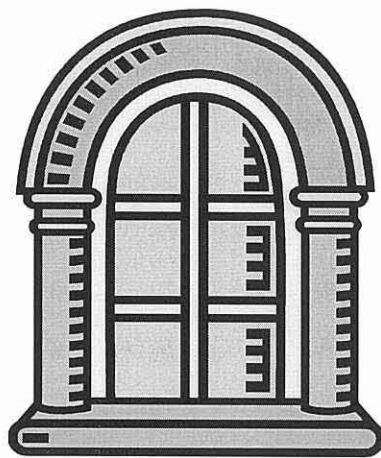
know and do indicate when death will happen. Others I have observed actually choose the moment to die.

I feel terminally ill patients can still choose the moment to die. There is life right up to the moment of death. This philosophically would be congruent with what is shared from within the hospice community. It certainly was for the founder of the hospice movement. Cecily Saunders (1967) told dying people that they mattered until the very last moment of their life. One of the themes of the hospice movement is to help dying people to live until they die. Choosing when to take that last breath could be viewed as living right up to the moment of death. I believe choosing when to die gives a person control, power and autonomy to the very end of life. Callahan and Kelly (1999) say “knowing about that control of the time, circumstances and the people present makes dying seem less powerless and helps to show that dying people do have power” (p. 222).

The concept of a person being able to choose the exact time to die is a very subjective statement and can be open to individual interpretation. I have presented this concept to colleagues at a conference and I have written about this subject. I have stressed in conversations and presentations that this is not about euthanasia or the terminal phase of dying or symptoms, but the actual last breath someone takes. I have explored various questions such as: Do terminally ill patients choose the moment to die and who is present at their death? Are terminally ill patients able to choose when to take their last breath? These questions have been used as a means to explore the idea and as a way to find words to articulate what it is that I have been observing. I have found that there is little or no evidence to support this subject. However information around this concept can be found in literature on euthanasia, the terminal phase of dying and suicide assisted death. The little literature I did find came in the form of stories and it was the stories that others related to and could identify with. This is the reason why I started to write my own stories and poems to portray this concept. Section two follows my journey and describes how my journey has developed over the five years. Now the background has been examined, the curtains have been pulled back, so the window can be seen, and in section two the journey can begin.

SECTION TWO –THE JOURNEY

MY REFLECTIVE JOURNEY AND THE WINDOW TO MY NURSING PRACTICE



THE BEGINNING

THE JOURNEY CONTINUES

THE JOURNEY PROGRESSES

THE ONGOING JOURNEY

THE NEVER ENDING JOURNEY

MY REFLECTIVE JOURNEY AND THE WINDOW TO MY NURSING PRACTICE

*The curtains have been pulled back
The window of my nursing practice can now be seen.
It is through this window that
One can view and follow my journey.*

This section describes how my journey has developed and shaped my nursing practice and the reflections that have occurred along the way. I want to portray the significance of using poetry and stories taken from my nursing practice. A poetic voice has enabled me to give voice to my nursing practice. Smythe (1987) identifies that “To read a poem, to absorb a poem, is to capture a glimpse of the feelings of another. It is through such glimpses that the nurse may better come to understand” (p. 3) and “Poetry can help us to know. Poetry can help us to feel” (p. 7). Glimpse through the window of my journey to gain an understanding of my nursing practice by reading stories and poems about the concept of terminally ill patients choosing the moment to die.

Poetry and stories and subsequent reflection have enabled me to portray what I have observed in the clinical setting. The reflective process I use to observe what is happening in the clinical setting, writing this in a journal format and then reflecting on the writing creates the window to my nursing practice through which others can look. Taylor (2000) feels that poetry is a systematic way to reflect on nursing practice. By observing, writing either stories or poems and then reflecting on my clinical practice I have developed a systematic way of looking at my nursing practice. This has the potential to inform and share what I have observed in the clinical setting. I am open to share what I have written, so that others may view what I have observed.

Reflection gives enhanced meaning to my experience as a palliative care practitioner and is the key in using reflective topical autobiography (Johnson, 1999). RTA can enable a subjective concept like choosing when to take that last breath to become visible by capturing specific moments in my nursing practice through the writing of poetry, stories, and systematically reflecting on these moments. This adds to a body of nursing knowledge within palliative care.

Several authors feel the value of sharing knowledge through storytelling can become a powerful experience for nursing staff. (Benner, 1984; Lindesmith & McWeeny, 1994; McDrury & Alterio, 2002). The sharing of one's written poems can also be a powerful experience for nursing staff, colleagues, patients and families. Koch (1998) identifies that stories make nursing practice visible. I am reflecting on both stories and poems from my clinical nursing practice to enable my practice to become visible. As we tell stories and poems within nursing we create opportunities to present aspects of our professional lives, thus enhancing and affirming practice, which leads to both professional and personal growth and development.

As the window can now be seen

Let the journey now begin.

THE BEGINNING: A MOMENT IN NURSING

*The journey begins
And now the window is opened.*

In 2000, I had what one would call a significant moment in nursing. This “Chosen Moment” as I would describe it has impacted on my career as a nurse ever since. I liken this event to curtains being opened, seeing a window and the sun overwhelms you. This event overwhelmed me and has enriched my professional development as a nurse and still continues to do so. As a consequence I wanted to capture this event and I wrote the following story.

TED’S STORY

Ted was admitted onto the hospice programme about two months before his death. He had an unknown primary tumour which had metastasised. One week prior to his actual death he was admitted to the hospice-in-patient unit for symptom control and terminal cares. It was Ted’s wish to die at the hospice. I met Ted for the first time after he had been at the hospice two days and I cared for Ted and his family over two consecutive night duties.

That first night I detected a very close and strong bond between Ted and his wife, Joy, and family. Joy was sitting beside Ted’s bed holding his hand, with other family members present. Joy specifically mentioned to me while sitting beside Ted “I want to be present when Ted dies”

Ted’s condition remained much the same the first night I was on duty and throughout the next day. The second night I arrived to commence my duty and at handover it was mentioned that Ted’s condition had changed and he was very low. His family were aware of the situation. I also observed how tired and exhausted Joy and Ted’s family appeared to be.

Joy decided to go home to get a bit of sleep. She had been at Ted’s bedside constantly for the last three days. She wanted to be contacted the moment there was any change at all in his condition. Joy struggled with whether to stay at the hospice or

to go home, however after discussion between everyone; she came to her own decision to go home. She was aware that Ted could die at any time. Joy and family went home before midnight.

At regular intervals I checked Ted and at various times, when time allowed, I just sat with Ted, holding his hand and talking to him. Ted sensed my presence, his condition remained low and no apparent change was observed in his condition.

Early dawn Ted's breathing became extremely shallow and I noticed long periods of apnoea between each shallow breath. He was cold to touch, appeared blue around the lips and his pulse was extremely weak. I also noticed a distinctive frown on Ted's forehead. I sensed he was close to dying. I told Ted I was going to phone his family and Ted let out a huge sigh. Joy and the family were phoned and said they would be at the hospice as soon as they could.

Sitting with Ted after contacting his wife, I held his hand and stroked his forehead. I sensed Ted wanted me to stay with him till his family arrived. As I was telling Ted that his wife and family were on their way I saw Ted's eyelids respond to what I was saying. I saw the frown on his forehead disappear; it was as if Ted knew exactly what I was saying. I continued to sit with Ted and talked to him, holding his hand as his breathing became shallower and shallower. Ted took his last breath in my presence and died with a small teardrop in the corner of each eye. This really touched me and brought tears to my own eyes. Shortly after Ted's family arrived and as gently as I could I told them Ted has just passed away with me beside him and a tear drop-in each eye. I explained how I had stayed with Ted and talked to him as he had died. I mentioned to the family about how he had responded to what I was saying, the raising of his left eyebrow and his frown disappearing.

After about 15 minutes Joy thanked me and embraced me with an enormous hug. She said "I needed to know how Ted had died, I feel Ted chose to die with you present and not me. Even though I really wanted to be there Ted knew how upset I would have been."

Jane Maries 2000

What is it then that can be seen as the window is opened?

Looking back it was a privilege to be part of this unique experience with Ted and his family. This brief encounter in another person's life captures for me the true essence of nursing. This story caused me to reflect on my practice and think about what had actually happened. Little did I realize then the relevance of certain words that Joy was to say to me that night. These words which I can remember quite clearly went like this, "I feel Ted chose to die with you present and not me". These words and this event caused me to stop and think; did Ted choose to take his last breath in my presence and not his family's? Did Ted choose the precise moment to die? Did Ted sense my presence in those last few moments of his life? As a result I decided I needed to explore these questions further.

I had noticed a distinctive frown on Ted's forehead before Ted's family had been phoned. Ted's frown disappeared as I was talking to him. I believe Ted truly did sense that I was there with him in those last few minutes of his life. The raised eyebrow, the frown disappearing and the two single teardrops were enough evidence for me. I was just there with him, sensitive to his needs. I sensed his sorrow and sadness at leaving this world. I respected Ted's right to die when he did and I assisted Ted to die with dignity just as he had wanted to. I was with Ted on his journey as he took his last breath and died. Macleod (2002) writes:

None of us know what it will be like when the time comes. But we know it will help if people are with us on the journey – people not frightened to listen to us, who will not leave us to negotiate the last part of the track alone. (p. 19)

I was not frightened to be with Ted as he died and this story illustrates the moment of Ted's death. By writing one can gain an understanding of what I observed in the clinical setting. Sandelowski (1994) feels stories are used to illustrate life experiences and situations from which one can gain knowledge and understanding. Literature endorses the benefits to be gained from the sharing and telling of stories for nurses, patients and families (Benner, 1984; Callahan & Kelly, 1999; Hirst & Raffin, 2001; Koch, 1998; McDrury & Alterio, 2002).

I started sharing Ted's story with colleagues and heard similar stories and questions. Again more questions started to form in my mind such as:

Can terminally ill patients choose the moment to die and who should be present?

Is there an answer to this question? What is the answer to this question?

Is choosing when to take that last breath possible in terminal illness?

Does birth parallel death – we are born in our own time therefore do we die in our own time?

Serendipitously I discovered the article entitled “Being Present at the last moments of Life” written by Legrand and Gomas in 1998. Legrand and Gomas identified:

We give our final breath: it is not taken from us! Despite wanting to be there, relatives often are not there, and sometimes it seems as if patients choose when to die. Occasionally, the first moment that the patient is left alone, is the moment when he or she dies, and other times – and it really is as if patients choose when to die - they wait until a particular person is present. (p.192)

This article discussed patients choosing the moment to die. I immediately identified with this article, and as a result reflected once more on Ted’s story and thought why not capture what I am seeing? Why not capture the significance of Ted’s chosen moment of death? I re-read Ted’s story and wrote the following poem later that year.

LAST BREATH YOUR CHOICE

It was very quiet

And the night was so still

A full moon was out

And it was only 3 am.

You were close to dying

And yet you were peaceful

Your breathing was shallow

And you were cold to touch.

I said to you softly

I’ll phone your wife and family

I came and told you

They were on their way.

Your eyes flickered in response

You let out a huge sigh

I sensed you wanted me to stay

Till your family arrived.

*So I sat with you
You sensed my presence
There was just you and I
There together in the room.*

*My breathing matched yours
I didn't say a thing
I stroked your forehead
And held your hand.*

*Time seemed like an eternity
I could hear the clock ticking
Your breathing and my breathing
Were the only sounds present in the room.*

*You opened both eyes
A tear drop appeared in each eye
Your breathing slowly stopped
You took your last breath.*

*A calmness came into the room
You looked so peaceful
You had died
With just me beside you.*

*I wondered, was this your choice
To die when you did
In my presence
Without your family present?*

*I heard the clock ticking
It was only 3.15 am
I had been with you for 15 minutes*

Such a precious time

A few more seconds passed

The door bell rang

Your family had arrived

Your wife and children.

All were very sad

Not to be there

When you had died

But felt

It was your choice to die when did.

So thank you for the real privilege

To be with you

Sharing in your death.

Jane Maries 2000

The writing of this poem proved to be a powerful occurrence in my life. This is when I actively started to write poetry and identified that it became a form of expression and discovery. After writing this poem, I discovered what a privilege it was to enter into such an intimate moment in someone's life as they are dying. I started to think and ponder about the value of my presence for the dying person. The story and poem I wrote about Ted's death caused me to start observing what was happening at the moment of death for other terminally ill patients. Was the patient dying alone? Was the patient dying with other people present? Was the patient dying with just the nurse present? Did dying patients wait for a certain person to be present or for an event to be over to die? Did dying patients wait for permission from their loved ones to die?

I started listening to and hearing colleague's stories. Their stories even though unique were similar to my own; consequently I started to write more stories and poems portraying the moment of death. I wanted to capture what I was seeing as I felt it was really relevant to nursing. It was like I had stumbled across an amazing concept. I actively wanted to share what I was observing in the clinical setting with

others. I became excited about the concept of patients choosing the moment to die and wrote the following poem in early 2001.

CHOOSING THE MOMENT

Over the last few weeks

I have begun to think

What is it you see?

That fascinates me?

About

Whether

Patients choose to die

Or say goodbye

Either alone

Or at home.

Do patients make a decision

With such precision?

When to take that last breath

Which leads to their death?

Maybe there is no answer.

Is it just what I observe?

Is it just what I see?

I don't know

Perhaps it is just me.

So maybe then

I need to explore

This subject more.

Jane Maries 2001

My interest in text and in particular stories and storytelling was the catalyst for further developing my poetry writing. Suddenly I had started to discover that I could

be quite creative in my nursing practice. Poetry was a form of creativity, expression and release. I found myself acknowledging that such creativity was very liberating for the soul. I agree with Havelka (1999) who claims "Creativity is a superbly liberating act that determines the deep significance of our human values and our human freedom" (p. 224). Havelka identified for me the depth of feeling that can liberate us and give value to our lives. The poems I wrote were often written at night on duty and could not be forced. Words appeared in my mind and I just had to write them down. I remember thinking quite critically of myself simultaneously that poetry writing was definitely not an option for me and what useful purpose would the writing of poems serve? However after a little reflection I began to realize that the actual writing of the poems focused my attention at work and I could recognize that this was a vehicle to gain insight into my nursing practice and a way to enable me to share what I was observing in the clinical setting. Poetry was validating my nursing practice and I wanted to identify how this was occurring.

POEMS

Poems for me

You see

Enable me

To show how be free.

To observe

To write

To reflect

And express myself

I don't know how

Because until now

Writing has been hard.

But somehow

Now

I know

I will keep writing.

Jane Maries 2001

Hunter (2002) concludes that “poetry is a unique medium for human expression. It allows thoughts and feelings about everyday human experiences to escape the unconscious workings of the mind ... poetry represents the humanity and the uniqueness of each human experience” (p. 141). I cannot underestimate the value of sharing poems and stories written about nursing practice. Each poem I have written about the concept of choosing the moment to die represents the uniqueness of this situation.

The window has been opened

And the journey continues.

THE JOURNEY CONTINUES
THE WINDOW OPENS SLIGHTLY FURTHER

*My nursing practice can be now viewed
Let the window be opened slightly further.*

I shared Ted's story and poem and other aspects of my writing with colleagues. I was amazed at the stories they shared in return, stories that were quite similar to Ted's story. As a result I presented a paper at a conference in Hobart September 11, 2001 entitled "Do terminally ill patients choose the moment to die and who is present at their death." Ted's story and poem became the foundation for this paper (Maries, 2001).

Before the conference I reflected on Ted's story and poem once again. This time I started thinking about my own mortality and what my own death meant to me. I wrote another poem reflecting this and this poem became part of my presentation in Hobart (Maries, 2001). This is the poem I wrote in 2001

WHEN I SHALL DIE

When I shall die

Nobody, but nobody shall tell me when

When I shall die

Nobody, but nobody shall do it for me

When I shall die

It will be my choice and only my choice

When I am ready

In my own time, I shall die

Nobody, but nobody shall take that from me

When I shall die.

Jane Maries 2001

After the presentation in Hobart I realized perhaps I am seeing something more than the moment of death. I realized through reflection that I embrace death as part of life. I see the beauty of life right up to the very moment of death and consider that it is a profound privilege to share and be present as someone takes their last breath. I see the individual and acknowledge each nursing encounter I am involved with is very different.

I had started to realize knowledge can be generated through reflection on nursing practice and as professionals we can learn from each other. Taylor (2000) suggests “one of the valuable aspects of reflective practice is that you learn to look at yourself and acknowledge that you are okay and that you as a person are of value” (p. 116). I was valuing what I was observing in the clinical setting and as a consequence I wrote Agnes’s story in 2002.

AGNES’S STORY

Agnes had not wanted to die at home but in the hospice with her family present. When Agnes was admitted to the hospice she was semi-conscious and a syringe driver had been set up. I cared for Agnes over one night duty and throughout the time I cared for her until she died she remained symptom free and semiconscious.

I quickly established a rapport with Agnes and her family. I detected a very close family bond as the family sat beside Agnes; her husband, son and daughter – each taking turns to talk to her and to hold her hand. Agnes would occasionally open her eyes and look at different family members and drift off to sleep again.

Around 4.00 am Agnes’s husband rang the bell. Her breathing had become extremely shallow, she was very grey in colour, and he wasn’t sure what to do. Her husband asked me, “Do you think her death is close?” I remember looking at Agnes, taking into account her shallow respirations and her grey colour and replied, “Yes”. At that precise moment Agnes opened both eyes looked at me, her husband, son and lastly her daughter. It was as if her eyes were conveying a hidden message. Instinctively I knew I had to leave the room, this was a time for the family. Agnes died in the company of her family about two minutes later.

I went back into the room, just to be there and support Agnes's family. Her husband said to me later, "We are so glad that we were together when Agnes died, she wanted it like this and thank you for your support".

Jane Maries 2002

What is seen through the slightly open window?

Once again Agnes's story raised questions for me such as: Did Agnes choose the precise moment to die? Did Agnes convey to me with her eyes that she wanted to die with just her family present? Reflecting on this event afterwards I believe that even though Agnes was close to death, she conveyed to me with her eyes that she wanted to be alone with her family to die. Agnes chose the exact moment to die, dying exactly how she had wanted to in the presence of her family, at the hospice. I respected Agnes's wish to do this. Agnes's death was a beautiful experience one I shall never forget and one I was privileged and honoured to be part of.

I asked myself the question "How did I instinctively know to leave the room when I did?" Agnes communicated with me by using her eyes; no other forms of communication were needed at all. As an expert practitioner I pick up on subtle clues and react intuitively, I walked alongside this family listening, supporting and just being there and worked within the bounds of my own personal philosophy of nursing.

The end of life is the last opportunity to share and be together. Remembering that final moment in time can be very important both for family and friends. It was really important for Agnes and her family to be together as she died. Legrand and Gomas (1999) identify that there is evidence that being present at the death of a loved one can help relatives and friends cope better with their loss and grief. It is with this thought in mind that I wrote this poem after Agnes's death.

AGNES

You had a wish

To die

At the hospice

In the presence of your family.

You did die

At the hospice

*Just as you wanted
In the presence of your family.*

*Before you died
You opened
Both eyes
And looked at each family member.*

*You took your last breath
And died in the presence
Of your family
Just as you had wanted.*

Jane Maries 2002

I have a vivid memory of sharing Agnes's poem and story with a colleague. This colleague had witnessed a person choosing when to die but she had never been able to verbalize this before. The poem and story written about Agnes's death enabled my colleague to share her own experience with me. She was able to understand and identify with Agnes's situation. This validated her own nursing practice and answered some of her questions. Heinrich (1995) identifies that "hearing one nurse's story moves other nurses to remember their own experiences in similar situations" (p. 141). The sharing of poems and stories can be healing. You realize that you are not alone when you read or listen to others stories and poems which are similar to yours. Stories and poems can make nursing practice visible and allows nursing practice to be viewed and understood. I certainly felt in this situation Agnes's story and poem allowed not only my own nursing practice to become visible and understood but that of my colleague's as well.

*Let the window be opened half way
As the journey progresses.*

THE JOURNEY PROGRESSES THE WINDOW IS OPENED HALF WAY

*I was starting to discover the value of opening
Up the window of my nursing practice
I thought why not open the window half way.*

After the conference in Hobart it was suggested I could publish aspects of my presentation in the New Zealand Nursing Journal, Kai Tiaki. As a result of presenting and publishing (Maries, 2002b) once again other health professionals and families actively began sharing their own stories and experiences with me. It was the stories and poems from my nursing practice that people were able to identify with. I realized the enormous potential behind these stories and poems which I was writing about the moment of death. There is a richness in nursing stories which arises from nursing practice (Benner, 1984; Koch, 1998; Sandelowski, 1994) and stories can be a powerful way of sharing knowledge and gaining a greater understanding of the culture of nursing practice (Bowles, 1995; Lindesmith & McWeeny, Sandelowski, 1993). This applies to poems, there is richness in poems written about nursing practice and this is a unique, creative and powerful way of sharing knowledge.

Alcorn (2001), a New Zealand nurse, explored in her thesis the use of poetry to reflect on her practice as a school nurse. Alcorn uses reflective topical autobiography to give voice to school nursing practice, to inform and share information. I have used reflective topical autobiography to reflect on my practice as a palliative care practitioner enabling my observations of patients choosing the moment to die to be shared. This next poem entitled "Alone" reflects a chosen moment in my nursing practice where I observed a patient choosing the time to die.

ALONE

*You arrived late that afternoon
And that night I came into your room
You were alone
And your husband was at home.*

You were dying

And by your self you were lying.

A frown appeared on your head

So I sat at the side of the bed

You knew I was there

Not far and so very near.

I sat ever so still that night

Right underneath the light

And as I stroked your head

Your frown disappeared.

No longer were you by yourself

You had someone with you, without a doubt

As you died you see

There was just you and me.

What a privilege to be with you

Just sharing this moment too

I think in essence

You sensed my presence.

Jane Maries 2003

What can be seen through the half open window?

In this instance, I just wrote a poem and not a story. I pondered over the question, "How did just writing a poem work without a story being written as well?" Poems for me seem to be so easy to write that sometimes I questioned their value. I realize that a poem is just as effective, as rich and as powerful as a story. A poem is a different way of writing about situations and expressing one's self. I think this tended to be a turning point in my progressing journey. I tended to write more poems than stories and I know I will continue to do this. This poem "Alone" captures the essence of this person's dying moments and gives meaning to this person's experience.

Reflection of this poem highlights the value of my presence for this dying patient. This dying person sensed my presence and no words were needed at all in this

situation. This patient chose to die in my presence. She did not want to die alone and she sensed I was there. This became obvious as I sat with her and her frown disappeared. It is an incredible experience to be with someone as they die. MacLeod (2002), a Palliative Care Specialist has written a book called “Snapshots on the Journey”, which gives a selection of poems about death. MacLeod writes:

My experience of the moment of death, is often one of great tranquillity. To be with someone as they die is an extraordinary experience, just as it is to be with someone as they are born. It can feel as if the whole world stops and nothing else matters – there is numbness about the situation that seems unreal. (p. 47)

When I read Macleod’s word, his choice of words impressed me. To be with someone at the moment of death is an amazing experience. There is just you and the dying person. I realized how important and relevant the presence of another human is for a dying person.

As nurses we may learn about being present and giving comfort, strength and compassion in the face of death but I strongly feel we also need to learn another important concept the concept to just be there. This I believe is an important concept to consider and develop both in palliative care and nursing. The concept is to - *just be there with terminally ill patients as they die*. Not necessarily saying or doing anything but just being present. One has to feel extremely confident in their ability to be able to do this and this is something I have had to learn to do and feel really comfortable with. This concept is portrayed in the poem “Alone”. I was just there with the patient as she died.

I accepted this patient for the unique individual that she was and valued her as a person. I value who I am as a person and I value my ability to just be able to be present. I value my strength, peace, sensitivity and compassion that I have that is so often needed in my job. Understanding what we bring to the care of dying as values and beliefs is an important part of palliative care.

I used to question the value of my presence for terminally ill patients, but now I never under estimate the value of my presence (or the presence of others) for dying patients at the moment of death. This is a significant change that has occurred in my nursing practice as a result of reflection. Schon (1983) argues that reflection is not a simple process and believes practitioners are capable of reflective thoughts which can lead to

changes in practice. Reflection is an ongoing process which has led to changes in my nursing practice. Benner (1984) feels that “the expert nurse has the self-esteem and self-confidence to see the value of their presence for the patients” (p. 58). The poem entitled “Alone” represents a situation where a patient didn’t want to die alone and appreciated and valued my presence.

Olson (2002) encouraged nursing students in an undergraduate psychosocial nursing course to write poems about situations in which they found themselves. To see not only the clinical condition, but the patient as well. Olson concluded that “Nursing and poetry are inextricably linked, with each patient experience representing a living poem, ready to teach us important lessons about others and ourselves” (p. 46). This poem reveals an important concept which teaches about the value of just being present with another human being as they die.

Richardson (1992) a published poet and sociology professor talks about how the writing of a poem entitled “Louisa May’s Story of her Life” transformed her life. It allowed her to see herself and the world in different ways. She says “Writing poetry is emotionally preoccupying: it opens up unexpected shadow places in my self” (p. 131). Richardson discuss’s how poetry can capture the essence of human experience in a way that normal writing does not. The poem “Alone” captures the essence of this situation in a way that a story may not have done. I believe it captures the importance of this chosen moment for this person and gives meaning to their experience.

I started to think, contemplate and wonder – Why do I write as I do? Have I developed some kind of process or system for myself? It seems I observe a situation, reflect on the situation, and write about this occurrence either with a story or a poem. I then reflect on what I have written to reveal my thoughts, emotions and insights. Van Manen (1990) identifies that “writing teaches us what we know, and in a way we know what we know” (p. 230). Poems I believe are a legitimate research method giving insight into how I practice as a nurse and they show me and teach me what I know. Hunter (2002) writes “That poetry act as a special lens for viewing the relationship between a person and the world” (p. 146). I agree with Hunter in that my poems provide a lens to the outside world about the concept of terminally ill patients choosing the exact moment to die. These poems provide a window for others to look

through and provide an opportunity to share my nursing practice and are part of my ongoing journey.

Let the window be opened even further

As the journey is on going.

THE ONGOING JOURNEY
NOW LET THE WINDOW BE OPENED EVEN FURTHER

*Opening the window even further allows
More discoveries and revelations to occur.*

Opening the window even further on this journey enables more revelations to be revealed. This next poem entitled “Your Will”, written in 2003 represents a situation in which a patient choose to die with their family present. The poem validates this situation and allows knowledge which is ingrained in my nursing practice to be presented. Stories and poems can give meaning to nursing practice and can be a way to discover the knowledge which is embedded in practice (Benner, 1991; Koch; 1998; Sandelowski, 1994).

YOUR WILL

*You were aware
Your family were present
You struggled
You groaned
You tried many times to talk
In that last hour
You opened your eyes
You tried to respond
You were too weak
Yet your will was amazing
Your breathing became shallow
Your nose was cold
Your lips were blue
Your fingertips were grey
Your family talked to you
And gave you permission to die
Shortly afterwards
A loud sigh was heard from you
A peace could be felt
You slowly faded away*

*You died in their presence and mine
Your fight had been hard
Your faith had sustained you
You were finally at rest.*

Jane Maries 2003

What is it then that can be seen as the window is opened even further?

This poem reveals a situation where a family gave their loved one permission to die. Shortly after the family gave verbal permission to die the patient died in their presence and mine. This was confirmed by the loud sigh that could be heard in the room and the peace that could be felt afterwards. It was as if this patient was waiting for permission to be able to die.

I discovered a book written by two hospice nurses Callahan and Kelly (1999) entitled "Final Gifts" which was largely palliative care stories and particularly noted a chapter entitled "Choosing a time: The Time is Right" (p. 197-222). This book identifies themes in palliative care stories to illustrate the following: whether a person waited for a particular occasion or event to happen before dying; wanted to die in a certain location; whether a person waited for permission to die; whether the dying person spared the family by dying alone; or whether the person waited for someone to arrive to die. This book enriched stories taken from nursing practice and presented them to identify themes that were familiar to me. Critically considering this book it can be said it is based on subjective opinion. However it also asks questions that challenge the more dominant view of reality and professional conversation by introducing the colloquial and family levels of discussion that occur around dying people. Likewise it could be argued that the poems I write are also subjective. However the poem "Your Will" highlights what I have observed in a clinical situation which was a family giving their loved one permission to die in this situation; a beautiful peace was experienced as coming into the room afterwards and the person dying in their presence and mine. This poem captures in words the last moments of someone's life and I realized in some way both acknowledge the beauty of the moment and the person's final gift. It is possible then to recognize that the writing validates this experience.

I was now feeling comfortable with the way I had found to reflect on my nursing practice. It worked well for me and I could go more deeply below the surface, finding meaning and uncovering practice knowledge which I felt was embedded in my nursing practice which had been invisible. I realised that poems and stories have enabled me to be able to stand outside of myself and discover the essence of my nursing. I could then quite clearly state the essence of my practice is to be able care for others as individuals with sensitivity, compassion and dignity. Johns and Freshwater (1988) mention:

The nurse recognises that each nursing situation is unique – not like any other even though there may be common aspects. Each nursing situation adds to the richness of the next situation. Stories are an invaluable means by which we come to know the beauty and wholeness of persons. Reflections shape the moment and influence the nurturing response of the nurse. (p. 47)

Reflection of this poem “Your Will” has shown me that each nursing encounter I am involved with is very unique and different and that each situation builds on the next encounter and this influences my nursing care. Trautman (1971) has explored the history of poetry in nursing since the days of Florence Nightingale and feels poetry has detailed the trail of the nursing profession for many years. Trautman says “poets lend a clear and vital voice to our profession ... And above all, our poet tells us to believe in our observations and to trust in our feelings – for our patients, for ourselves” (p. 728). I consider that this describes exactly what I am doing believing in my own observations and trusting in my feelings within palliative care. Holmes and Gregory (1998) reveal that:

As poets look through this window of their world, they take notice of images that they or others might have missed or ignored; they capture everyday observations or occurrences. Poets also take notice of experiences that are difficult and complex to articulate. (p. 1192)

The concept of terminally ill patients choosing when to take their last breath is a difficult concept to portray. I believe I have found a way to reveal this concept by writing poems and stories about the moment of death. The next step to consider was whether the writing in practice was for personal reflections and sharing in discussion with colleagues, or could be in appropriate situations shared with a family. I actually shared the poem “Your Will” with the family concerned. Their comment was – “We gave our loved one permission to die and that is exactly what happened and your poem reveals this so well”. This resonated with me and I realized the importance of sharing my writing not only with colleagues, but families as well.

In her thesis Alcorn (2001) writes that “poetry writing is viewed as a mechanism for self-disclosure in nursing” (p. 5) and Johnson (1999) states “The reflective topical autobiographer must take the risk of writing expressively and creatively using multiple modes of self expression (for example, poetry, photographs, paintings) and resist the orthodox expectations of academic scholarship” (p. 29). I have taken the risk and used poems and stories as a way of creatively expressing myself. Poems and stories cause me to confront moments in my nursing practice and expose part of myself. This is not an easy thing to do and over time I became less self conscious and I am now not afraid to share what I write. Self disclosure enables me to nurse with greater compassion, dignity, sensitivity and respect.

In summary I have used my own process of reflection. I have written about what I have observed and have then reflected on the writing. This eventually enabled colleagues, patients and families to share in considering ideas around our experience of what occurs when a person is dying and how we as nurses might gradually shape our practice to use our insight to engage with people and their families sensitively.

*Let the window be pushed wide open
On this never ending journey.*

THE NEVER ENDING JOURNEY
THE WINDOW IS NOW WIDE OPEN

The whole picture can now be seen.

Some colleagues, patients and families identified with my poems and stories which are part of this never ending journey. I thought why not push the window wide open and allow the whole picture to be seen. I wrote the following poem which reveals the full picture.

A CHOSEN MOMENT

*I was with you
You were struggling
You were dying
You were anguished
You were frightened
Yet you knew I was there*

*Every so often
Your eyes searched out mine,
There was no need for words
You sensed my presence
And as I reached for your hand
You relaxed
And became peaceful.*

*Then a change came over you
You were waxy, and clammy
Your breathing was almost non-existent
Very laboured and very slow
You were cyanosed
You had hardly any energy at all
Yet you still managed to sit up.*

You reached for my hand

*Grabbing it with an intensity
And your eyes locked into mine
Perhaps penetrating my soul
You tried to speak
But there were no words.*

*Somehow I knew
Knew deep inside that your death was close
Quietly I woke your family
Your mum and your young child*

*Your mum reached for my hand
Holding it with such a force
That I felt her pain
Your child looked deep into my eyes
With such an intensity
That I sensed her bewilderment.*

*Once again no words were needed
They both knew that your death was imminent.*

*You looked at your mum, your child
Then you looked at me
With those penetrating eyes
I don't know what you saw
Or what you felt
But you lay back on the pillow
And sighed loudly.*

*Did you sense my compassion
My strength
My sensitivity
Maybe
I just don't know.*

*But a beautiful peace came into the room
You felt it
It was obvious
And your mum felt it
Your child sensed this peace as well.*

*A candle was lit
Your mother said a prayer
Your child cried
I cried
And you died.*

*You took your last breath
In their presence and mine
What a beautiful chosen moment,
To forever remember.*

Jane Maries 2004

What can be seen through this wide open window?

It is as a result of this poem that the title of this research project was recognized. I parallel the title 'Chosen Moments' to someone choosing the moment to die. I believe I observe the chosen moment capture the moment hold the moment write about the moment and then reflect on the chosen moment. This poem captures a "Chosen Moment" - someone choosing the exact moment to die. The patient and family in this poem sensed not only my presence, but also my compassion, strength, sensitivity, and peace. I realize as I read back over this poem that I have an ability to read people's eyes which are well recognized as being the window to the soul and the way that many people try to express themselves as they are dying and trust my intuition. I sometimes have wondered if patients actually try to talk with their eyes and whether eyes can reveal emotions such as: pain, anguish, sorrow, love, sadness, fear, joy or peace.

Poems that I write come out of an inspiration that touches the core of my being and the depths of my soul. My poetry is evolving and developing and I can see that now I write with a greater depth and intensity than I did five years ago. This is important as

I now write what I see and what I feel. I have become able to express the words quite easily. When I started to write poems I didn't write with the same depth and intensity that I do now. I regard the reflection of my writing now as a never ending journey. I realize I work in partnership and walk alongside families and individuals; listening, supporting and being present. I have an ability to be present with families – just to be there, at such an intimate and precious time in their lives. As nurses we have the privilege of intimacy with people who are in need of our care and this is an honour few professions share. My poems and stories have shown me how precious life really is. I look at each day that I am alive as a gift and try to live life to the fullest. I recognize I have a deep inner peace and strength that patients and families sense in me. This peace and strength comes from my spiritual framework which influences the way I practice and the inner discipline that I consider comes from writing and reflecting on practice and life. I work within the bounds of my own personal philosophy of nursing. This next poem reflects what working with dying people has shown me.

LIFE

What has working with dying people taught me?

To really appreciate life you see

To appreciate each day

In every single way.

To live life to the full and to be content

And not waste a precious moment

If a moment is wasted

It cannot be recaptured.

Life is for living

Life has such appeal

And is so very real

Life is a precious precious gift

Jane Maries 2004

I agree with Vezeau (1995) who writes “writing teaches me about who I am ... Writing is a way of stepping forward and speaking my voice” (p. 175). Writing has

certainly shown me who I am and writing certainly gives voice to my nursing practice. The poems I write give insight into how I practice as a nurse, thus enabling still evolving parts of my nursing journey to become more visible. This process or discipline of reflection will be ingrained in my never ending journey of nursing. I will continue to write poems and will share what I have written with others. Section three proceeds to draw together what I have seen so far through the wide open window on this never ending journey. I realize at this point of course that reflection is integral to my ongoing practice as a nurse.

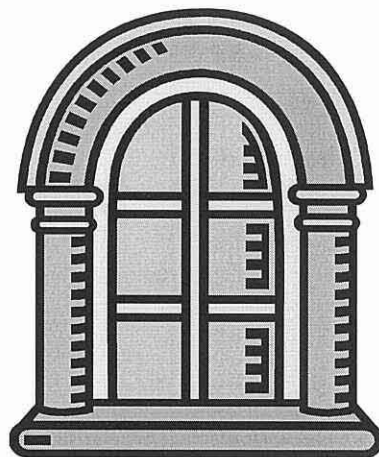
*The window has been pushed wide open
On this never-ending journey
The window of my nursing practice
Now never closes.*

SECTION THREE – REFLECTIVE SUMMARY

DRAWING TOGETHER THE REFLECTIONS FROM MY JOURNEY

CONCLUSION

POSTSCRIPT



DRAWING TOGETHER

THE REFLECTIONS FROM MY JOURNEY

*As the window of my nursing practice now never closes
What insights have been revealed?*

The poems and stories I have written about patients choosing the moment to die capture in words the last moments of their lives. This provides an opportunity for me to give meaning to this experience. I can legitimately voice what I have observed in conversation with people and their families. Wiltshire (1995) mentions “When one calls a writing a ‘voice’, one, then is enlisting the residual power of this tradition to give power to the group or individual concerned” (p. 79). Voicing what I have observed in the clinical setting is a powerful way to give meaning to the last moment of dying people lives. This may help loved ones to understand that perhaps one can choose the exact moment to die.

Roy (1999) asks “what do poets do that makes them so needed in palliative care?” (p. 3) and feels we need poets in palliative care to say those things “that at special times of loss are crying out to be said” (p. 3). So many times in the last five years I have heard the words – “Why didn’t he/she wait to die? Why did he/she choose to die when they did?” These are questions which loved ones and health professionals are sometimes crying out to find the answers to. Maybe I don’t have all the answers but as a nurse-poet who has a contribution to make to palliative care nursing, my poems and stories are a window for others to look through and find their own understanding or answers to these questions.

The poems and stories in this paper can be healing for colleagues, patients and families and enable understanding and learning to occur. Various authors describe that writing can be healing (Benner, 1984; McDrury & Alterio, 2002; Sandelowski, 1994; Taylor, 2000). Certainly I have found my own writing to be very healing. The poems have allowed the expressions of feelings and emotions to be revealed. By reading, sharing or listening to these poems and stories which have been portrayed in this research one realizes that you are not alone. Even though your situation is unique others may have had similar experiences. As practice stories and poems are shared,

knowledge is also shared and generated and learning can take place (Benner, 1991; Heinrich, 1992). I am open to share the knowledge which my writing has generated.

One concept that my writing has highlighted throughout this journey is the concept of simply being present with a terminally ill patient and their family as their loved one approaches the last moment of their life. One can never underestimate the value of one's presence for the dying person. My poems and subsequent reflections reveal this concept well. Another concept that my writing highlights is the concept of non-verbal communication, the importance of the unspoken word and what a person's eyes can reveal. This is reflected in most of the poems in this paper.

This process of reflection which I have developed, which is to observe a situation, to reflect, then write about the situation in the form of a story or poem and then to reflect on the writing can be used by others. This process is the window to my nursing practice and enables my nursing practice to become visible. Colleagues can use this process to enable their own nursing practice to become visible.

Reflection is vital to nursing as a professional organisation. I have shared my reflective experiences, drawn on my observations and extended my nursing knowledge. Through reflective topical autobiography I have given power and voice to my nursing practice thus enabling the trustworthiness and integrity of my poems and stories to be revealed. I do encourage my colleagues to observe, write and reflect on their own nursing practice. Based on my experience writing like this has changed my life.

*I have written about my journey
Shared insights into my journey
Now what conclusions can I draw.*

CONCLUSION

MY JOURNEY

My journey began

My journey continues

My journey progresses

My journey is ongoing

And my journey is never ending

Jane Maries 2004

In 2002 I wrote these words “Poetry has become the art of my nursing practice and a wonderful gift to be developed to make sense of my nursing practice and to share the richness of my nursing practice with others” (Maries, 2002a). I now write “*Poetry is the art of my nursing and a wonderful gift I have which will enable me to share the richness and beauty of my nursing practice with others*”.

Writing is now central to my practice. I am a nurse-poet who writes about practice phenomena. This gives me the ability to refine and articulate my nursing practice.

As an echo to an opening comment, reflection in practice requires the effort of inner discipline to observe and write. This can never be taken lightly. As I have revealed this refines one’s capacity to observe and then practise in a more refined way. Writing about the actual moment of death has enabled me to articulate my practice and will continue to do so. Trautman (1971) wrote “One of the most important things about poetry today is that nurse-poets want to share what they write. They feel they have something to say, and they are willing to expose deep personal reactions to public scrutiny so that others may participate in their moments of insight” (p. 728). I am a nurse-poet who wants to share what I write. I am prepared to expose myself to the reactions of others so that others may share in my journey and insights. Poetry shapes and enhances my nursing in a creative way. As I continue my journey within palliative care and nursing I know I will continue to write poems to reveal what it is that I have observed.

According to Watson (1985) healing is at very the core of nursing. I have discovered what is at the core of my nursing, a healing genuine compassion and sensitivity that enables me to be present and support dying patients and their loved ones. Reflection

is also at the core of my nursing and writing is an accurate window for others to view my nursing practice through. This is a contribution I can give to nursing as a profession. Johns and Freshwater (1998) ask:

“Why is critical reflection so important? It is important because it helps us take informed actions and develop rationale for practice. It grounds our most difficult decisions in core beliefs, values and assumption. Reflective practice is grounded in the ideas that we can stand outside ourselves and come to a clearer understanding of what we do and who we are by freeing ourselves of distorted ways of reasoning and acting. This becomes the challenge to the reflective nurse: to stand outside herself in a process of discovery in order to come to a clear understanding of what is the essence of nursing, the meaning of her experience, and who is this person who is nurse, as well as to examine critically the theoretical foundations of ethics.” (p. 37)

Taylor, Benner and Johnstone are three practitioners who have influenced me to stand outside of myself and reflect on my practice through the stories and poems I have written. I now have a very clear understanding of who I am as a person, a nurse, a poet and a writer. I see the essence, individuality and beauty of my nursing practice. I am able to share what I have observed in clinical practice and this contributes to the body and knowledge of nursing. This gives meaning to the last moment of life for the patients I care for and their families. The nature and meaning of experience can enable others to carry out further investigations if they so desire.

If a poem or a story can increase the reader’s awareness and understanding of a terminally ill patient choosing the moment to die then I feel this research project has been worthwhile. Storytelling and poetry are now of significant standing within nursing that has power and voice. It ensures the voices of patients, families and nurses are heard. Writing stories and poems is a reflective process which gives voice to my nursing practice. This creates a wide open window for others to see through.

POST SCRIPT

This is my journey of what I have observed in clinical practice over the last five years and this journey was related to an open window. As the journey progressed the window opened further. You have travelled this journey with me, looking through the window of my nursing practice and read the reflections of my poems and stories.

As a result of my journey I now have a clearer understanding of who I am as a person and how I practise as a nurse. Sharing what I have observed can be a powerful way to give meaning to the last moment of people's lives. Having taken this opportunity to read this research paper entitled "Chosen Moments" I hope you the reader will have gained an appreciation of the concept of terminally ill patients choosing the moment to die and the very real value of reflection.

What and honour it is to be a nurse

Working with terminally ill patients

Who have shown me that life is

A precious, precious gift.

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