

**Reflections on knowing, not knowing and being in palliative  
care nursing**

**By**

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## **ABSTRACT**

Responses to questions from dying people and their families are as individual as each nurse, patient, family member or situation. This is well recognised and an unspoken truth in palliative care practice

This paper explores the subjective nature of knowledge in palliative care generated through capturing moments of practice and subsequent reflections. This demonstrates how the author uses her model of care to open a space that enables the person and their family to find meaning from their experience and articulate what they need at the time.

The author identifies her interest in the paradoxical reality of knowing and not knowing and describes how that paradox contributes to her role in supporting individual's needs within their realities.

# MIHIMIHI<sup>1</sup>

*Ko Whatawhata te mauka*

*Ko Whaihopai te awa*

*Ko Takitimu te waka*

*Ko Kai Tahu te iwi*

*Ko Waihopai te kainga*

*Ko Murihiku te rohe*

*Ko Mikaneera, Kaitai Pahi oku tupuna*

*Ko Helen Cleaver taku ingoa*

*Tena koutou, tena koutou,*

*Tena koutou katoa*

The above mihimihi describes the most important linkage to my personal and/or professional philosophy in which I acknowledge my origins and connections to a place, a land, a people and a history. This is my essence. It is because I have this history as the foundation of who I am that I am able to articulate how I see myself as a person and as a palliative care nurse.

To all those who have guided and supported me to know what I know –  
thank you all.

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<sup>1</sup> The purpose of mihimihi is to establish links with other people. It involves individuals sharing their whakapapa (genealogy, ancestral ties) and other relevant information. Culturally, it is important for Maori to know and be able to share their whakapapa - to know one's whakapapa is to know one's identity.

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## **THE REALITY OF PRACTICE AND THE VISION OF CARE**

*“I feel like I am in a dark room flying in a glider. I can’t see the walls, but I know they are there, and I don’t know when I am going to bump or crash into one. You guys know where the walls are.”*

Palliative care nurses nurse people who are dying and so are naturally often confronted with questions about death and dying. Understanding how to share what it is they know about death and dying is the challenge that this paper responds to by articulating the insights, reflections and critical eye of a palliative care nurse. After reflecting on what I know about my practice through a process of considering my own insights I am able to reflect on what is ‘unknown’ to me about my ways of practicing in the moment of engaging in dialogues about dying. This paradox of known and unknown which occurs in practice has raised my awareness regarding the nature of palliative care nurses’ knowledge and practice.

I suggest that having an understanding of this paradox has facilitated the articulation of my palliative care nursing practice. I say this because as I have advanced my practice in palliative care and gained more knowledge, and believe that the more I have learned, the less I realise I know. I am not at all convinced that this has negative connotations. The less I realise that I know, the bigger the horizon and the more I reflect and look for knowledge to answer the questions I perceive I do not have the answers to. My thinking is that this maybe is a key to understanding how to

share knowledge in palliative care nursing. Psychotherapist Robert Gordon (1998) says

“in the back of my mind I have thought for some time there was something about not knowing, that was a significant contributor to the form of psychotherapy I practiced. The more I remained in that state of not knowing, the more productive were the sessions I shared with my patients.” (p.1).

My interest in palliative care began very early in my nursing career. Initially my contact with people facing death was interspersed with the general practice of a novice nurse. My practice setting for the past 14 years has been hospice palliative care, mostly in a community setting. My practice years as a novice palliative care nurse occurred in an evolving hospice service where all staff members were new to palliative care at the time the inpatient unit was opened. This experience highlighted for me, the individuality of practice advancement. A comparison to a group as noted would be where a nurse with limited palliative care experience begins work with an established hospice service where the staff is a mix of palliative care experience and qualifications. Individual learning preferences is an area that I note as important when considering how nurses reflect on, interpret and progress their practice. On reflection I cannot define when I actually worked within the context of a specialist palliative care service. Whilst both the service and I were evolving knowledge and specialist skill base, the qualifications and named positions required to prove the status may not have truly signified the moment. The way my practice has developed has been influenced by my personal and professional experiences.

While palliative care nurses have the potential to both articulate practice and understand there is tacit knowledge, the literature search revealed little evidence specifically related to the sharing of such knowledge as the paradox between known and unknown between palliative care nurses, as well as between palliative care nurses and patients/families. There is limited research regarding sharing of information between and amongst palliative care providers. (Bailey & Wilkinson, 1998, Kirk, Kirk & Kristjanson, 2004, Wilkinson, 1991). What is evident is that the narratives which are shared amongst hospice peers are more likely to be those which told stories of a 'good' death. (McNamara, Waddell & Colvin, 1994 Payne, Langley-Evans & Miller, 1996, Wilkes, 1993). Payne, et al recommended "more explicit use may be made of 'good' and 'bad' death narratives in medical and nurse education to help staff identify their implicit assumptions and examine the range of possible dying trajectories" (p.312).

The significant contribution of this paper is the nature of therapeutic interactions and hence relationships with patients and families. This paper describes my own life altering experiences I have encountered in palliative care which have raised awareness and created a shift in thinking in my nursing practice. The experiences are my own and those of individuals and families. Some of the experiences are fragments that I now recognise indicate consciousness in action. By this I mean that during or when reflecting on these experiences some shift occurs that is recognised and recognisable. The result of this shift is a new realm of experience of knowledge which can be understood and articulated in conversation.

Dying is a human experience in the journey of life. Developing the capacity to engage fully requires an understanding about what occurs. To develop my

understanding of dying I have chosen to describe moments from this experience and ascertain how I systematically integrate insight, awareness and consciousness of the dying experience into palliative and terminal care nursing.

In this paper I have chosen to document the framework of my practice which I consider is known to me and to reflect on some moments of care that occur in my palliative practice within the framework model. This then allows me to make comments that in my experience become the way of creating dialogue in the moment of practice. Describing this process reveals much about my own practice, and creates an understanding of the nature of palliative care nursing, cultural, familial and societal processes at work and how nurses influence these processes through their interactions in subtle but lasting ways. This paper seeks to identify the fine line or points of balance that I discover are critical to enabling the person to find their own way with support and have their own dying experience with their family and friends. This expert practice occurs with reflection on many situations and concurrent development of exploring about life and living, consciousness and spirituality in one's own life.

Recognition of the unknown aspects of care is suggested as one way to open up the space in the moment when the activity of assessment and organisational care is occurring to allow for what needs to happen to enable the person to die in the way they would wish. Interestingly having made reflective comments I discover that the balance or refinement that reveals expertise shows that due to experience there occurs an understanding that what is desired and what occurs are usually not quite the same. Careful conversation is required to open up this unknown space in a society that wants to arrange and control all aspects of life. Facilitating the interplay of both the known and unknown by using a palliative approach allows me to be present with the dying.



Literature reviewed for the purposes of this paper has been important in enabling me to know that revealing my own expert practice is crucial. Understanding and being true to myself has been ongoing and part of the journey. Practicing palliative care as the person who is engaging with the community within the context of Palliative Care in New Zealand requires an awareness of the issues facing planners, policy makers as well as the wider group of recipients and health professionals.

In Palliative Care, we are dealing with the whole of the rest of the patient's life, and the provision of adequate care is of correspondingly great importance ... People's lives have a certain individual shape, determined, at least in part, by how they choose to live them. The endings of these lives can fit, or alternatively distort, that overall shape. In the light of this thought, there is an overall need for palliative care to maintain, as far as possible, the shape and integrity of the individual life, and where this is sadly not possible, there is a special need to pay attention to the patient's views on what treatments, and even what care, they should or should not undergo. (Garrud, 1996, p.93-94)

I am aware of myself as I enter each situation, whether directly connecting with a patient or family or with other palliative care providers and multidisciplinary team members. I am aware of my total experience and draw on this for each connection. Whilst each day is a mixture of meetings, structure and spontaneity, what I do in each moment is as important as the next. I manage a complex array of discrete events in an orderly fashion. It is important to maintain an awareness of myself to help sustain a calm and receptive environment for the patient and family. Order, however is relative. What actually matters is that every part of a day, a week, a month

is interconnected in all my work. Just as the text of this paper has been written step-wise, the reality is that the concept of interconnectedness is essential.

Often patients and families say “*you know what could happen / tell us what to expect.*” We (palliative care nurses) think about each case as being individual, however paradoxically there are things we anticipate could or may happen. As happens in palliative care, there are moments which leave us with thoughts which remain with us. These moments for me were conversations with relatives of people who were dying. These conversations went something like:

*“When I was pregnant with our son, I went to antenatal classes which overloaded me with information, so much so that I actually walked out of some of the sessions. Why can’t you people give us the same level of information about what happens when someone is dying?”*

*“I am so exhausted I feel like I have run three marathons end on end, and I have no idea whether I have to run another three, another one or only another ten metres. You have some idea of how much longer. I know it is not possible to say exactly how much further, but you have seen so many more people die than I ever will, you have a much clearer picture of the road ahead.”*

This was some years ago. At that time the impact this had on me was that I felt the need to explore how I could best answer her questions. I searched nursing literature and found a dearth of research related to meeting the individual’s needs for information. This is what I saw as the focus then. This was a defining moment which

has informed the direction my learning has taken. What I thought read and wrote about at that time remains a foundation from which I draw and expand upon.

I see now when I reflect on that moment that whilst I did not attempt to answer her questions, neither did I listen to hear what was happening for that woman at that time. My anxiety at the time about thinking about what could have been the 'right' answers took me away from being fully present in the moment for her.

Since then I have chosen to look further than the conversation that had impacted on me and have taken the seed, planted it, and at the moment am nurturing it. It began as a conversation and I have learned that before my initial questions can be answered there are a number of choices that not only I, but palliative care providers generally, have to make. These choices include whether or not to admit that we have some of the answers, share the knowledge and continue learning. Making decisions about what knowledge to share, with whom and when creates tensions in palliative care practice. These tensions are part of the discussions and reflections of palliative care nurses.

Again the concept of knowing and not knowing arises. Palliative care practice does not mean we (palliative care nurses) have all the answers. That is one of the things we know. We also know that listening and providing a forum for patients and families to express their innermost fears in a safe way to somebody can be crucial to establishing a relationship where the nurse is trusted to walk their journey with them. Alun Jones, (1999), says "purposeful inactivity can be a potent means of bringing about beneficial changes in the ways distress is managed" (p.1298).  
Allowing a space for the patients and their families to articulate their fears and and/or

ask questions diffuses the need for answers. The patients and families see that the palliative care nurse has the ability to be with them in the moment, and sit with them in their suffering. This reduces fears and enables the patients and families to participate in the management of their care.

Jones (1999) explains that one of the “unfolding” roles of Macmillan nurses is that they are “able to provide psychological and emotional care through conversation” “Macmillan nurses are specialist nurses employed throughout the United Kingdom and concerned with cancer and the provision of palliative care, delivering care directly and indirectly to patients and their families in many settings.” (p.1297). How do we link in conversation as part of practice? Jones goes on to say “an ability to offer psychological nursing is also a prerequisite of the role of advanced nurse practitioners.” He says “allowing patients and families to talk about their suffering, offers a means of giving a voice to hidden pain.” (p.1298). I found this comment invaluable because there is an issue which comes through for me as I practice. This is the issue of choices and the decision on how I choose to respond to individuals. I believe palliative care nurses are in a very powerful position of choosing what information is shared with patients and families depending on how comfortable we are with communicating what we perceive to be necessary or not necessary. “Some authors suggest that nurses appear to be more comfortable dealing with patient’s physical needs rather than addressing their emotional concerns or anxieties, and therefore nurses focus on the physical aspects of assessment” (Booth et al as cited in Bailey and Wilkinson, 1998, p.300). “Nurses use a variety of ‘blocking’ techniques such as changing the subject to prevent patients divulging their problems, thus keeping patient interactions and assessments superficial and providing poor coverage

of psychological needs (Wilkinson as cited in Bailey and Wilkinson. 1998, p.300). Nurses who use blocking behaviour tend to do this in situations where the nurses' anxiety levels are elevated. ( McGuire, 1985, Quint, 1972). Benner (1984) writes about the expert nurse as being an example of using a therapeutic relationship to empower a vulnerable patient or family member and helping her/him regain confidence in her/his shattered world.

Simpson (as cited in Fallowfield, Jenkins and Beveridge, 2002), said that "hope is based on knowledge not ignorance" and further "what remains unspoken is unspeakable". (p.299). Fallowfield et al say that if we "avoid potentially distressing disclosures patients are not given opportunities to reveal their own fears and worries and may be left in anxiety-ridden isolation, convinced that they have the most unspeakably horrible fate ahead of them" (p.301). Ridgeway and Matthews as cited in Wilkinson (1991) discuss the alternative to this by saying that "Patients who are facilitated to discuss their worries and concerns appear to have greater confidence in nurses and feel more satisfied with the care they receive" (p.678).

Some days, whilst meeting job specifications to perform my role as a Palliative Care Co-ordinator, I have noticed that there are moments that fundamentally change the way I conduct my practice. One example is that I am finding that being with patients and families and letting them make their choices is slightly easier for me following reflection regarding their situations. The following poem is one I read often to remind me that it is indeed not my journey. As long as I have given as much appropriate information as is possible within my range of knowledge then I too have a choice.

## *CHOICES*

*“A thought can develop an action  
An action, a reactive state of mind,  
An idea, a wonderful creation,  
And love will always keep us blind.  
Yet it’s the blindness that creates the interest,  
As to how we make choices to live,  
On one hand we are angered and forceful,  
On the other, all we want is to give.  
Life’s full of these contradictions,  
Yet we do always have a choice,  
How we live what it is we’ve decided,  
Can be seen by our actions and voice.”*

*Vini Tunielu (2002, p.1)*

I have a desire to understand why the knowledge that palliative care nurses have is not articulated and shared. Dunniece and Slevin (2002) explored the lived experience of seven palliative care nurses who had worked in the palliative care field for more than 2 years. My understanding of the issues was validated in this study. The themes which emerged were: “knowing the bigger picture, time (movement and measure), ethical dimensions, knowing and minding yourself, the ‘just’ and ‘simply’ of practice, the embodiment of being with, unseen tutors”. (p.13).

One way that palliative care nurses can share their knowledge is by the use of narratives. In a Heideggerian hermeneutical analysis of “Living the caring presence in nursing” Nelms (1996) noted that “we can come to know the truth of experiences like caring through the use of narratives” (p.368). “Reflecting on practice through storytelling is a time-honoured tradition in nursing, whether it is done while sitting around the nurses’ station or in a more formal manner.” (Maeve, 1994, p.15). In this paper fictionalised vignettes have been essential to enable me to reveal the reality of practice through my observations of the insights and the vision of care possible.

## **SECTION ONE**

### **INTRODUCTION**

During the course of my study towards a Master of Arts (Applied) in nursing I have focused on those moments that have brought about a change and the impact they have on my knowledge. I have worked in a community setting co-ordinating care during the course of my study and witnessed similar situations recurring. The specific nature of these situations has been focused around the altered level of knowledge and experience I bring to each subsequent situation and the individuality of each moment. This combined with ongoing exploration and understanding of the issues within the context of Palliative Care in New Zealand and in other settings is complex and has motivated me to write about ways of understanding and working with individuals and families facing death.



## CONTEXT

### *Palliative Care in New Zealand*

The rise of the hospice palliative care movement has meant better care and more support for those who are dying, and for their families. Hospice palliative care recognizes the importance of caring for a person's total needs so that their final days or years will be as comfortable and fulfilling as possible.

Up until 1997 the approach to the funding and provision of palliative care regionally throughout New Zealand was variable (Ministry of Health, 2001). At this point the Health Funding Authority and National Health Committee started projects on palliative care and hospice funding. Out of this came the discussion document, *The New Zealand Palliative Care Strategy*, in July 2000. In February 2001 the strategy was set in place.

“The principles were:

1. The focus of palliative care is the person who is dying as well as their family/whanau
2. All dying people should be informed of their entitlement to palliative care and have access to quality health and support services appropriate to, and consistent with their needs
3. Each person’s uniqueness, culture and autonomy should be respected, with all care based on their expressed needs and wishes
4. Palliative care affirms and encourages the quality of life for each individual. While interventions (such as radiotherapy, chemotherapy

and surgery) have a place in palliative care, the symptomatic benefit should outweigh any disadvantages of the procedure.

5. The achievement of total care for the person requires both a multidisciplinary approach and continuity of care (before, during and after diagnosis of the terminal illness).”

(Ministry of Health, 2001, p.2).

Whilst it is not obvious when reading the palliative care strategy whether these principles were in any particular order, I would recommend considering having number three recognised as being the foremost principle. Stephen (1991) “warned that an overly rigid attitude towards what is adequate care may increase the probability that the voice of the dying patient as an individual will become muffled under the weight of predetermined schema”. (p.305). Research is beginning to concentrate more on patient and family views rather than those views primarily of providers of care. Powis et al’s (2004) study for example, focussed on identifying what was important to individual patients. Some individuals chose to die with uncontrolled symptoms. This is far removed from the concept many palliative care providers view as acceptable, however I would view this as being appropriate for those particular patients. The principles of the palliative care strategy do need to be looked at as interconnected with the reality of the persons requests rather than managed through care plans and audited as outcomes in a list of desirable principles. I propose that it is not until the individual’s “expressed needs and wishes” are identified; the principles need to be associated with who the focus is on, information provision, symptom management and whether or not total care is provided should be discussed. Palliative care providers need to be comfortable with being with those who “do not go gentle into that good night”. (Thomas, 1979, p.79)

The first hospice opened in New Zealand in 1979. Currently (in 2005) there are 37 hospice services. Whilst all the services are organised differently they have each been audited by District Health Boards New Zealand (DHBNZ) to assess that they are meeting national standards. Currently Hospice New Zealand is focusing on strategies 1 and 2 of the 9 strategies in the document. These are:

Strategy 1: Ensure access to essential palliative care services

Strategy 2: Each District Health Board (DHB) to have at least one local palliative care service.

The DHBs are expected to implement strategies identified by the Minister of Health, and are working on Strategies 1 and 2 at this time.

### ***Palliative Care Co-ordination***

In New Zealand palliative care is available in acute care, elderly care and in hospice services, as well as in the community. As people move between these services depending on their needs there is a fundamental requirement to have in place a system which facilitates the provision of integrated care for people referred for palliative care. This system has been designated the label 'Palliative Care Co-ordination'.

The New Zealand Palliative Care Strategy states that “the care co-ordinator is responsible for ensuring that the dying person and their family/whanau are provided with information regarding palliative care options and services, and that the family/whanau are provided with the necessary information and skills to assist in caring for their dying family member.” (p.8)

To understand what this role means and how this translates into reality requires an understanding regarding why this role to date has been placed into the hands of nurses. Whilst there has been no formal memorandum that care co-ordination be designated a nursing role, I propose that the issues and challenges facing a care co-ordinator are met most easily from within the nursing world. For instance words and terms used in nursing practice could transpose quite naturally into the role descriptions of care co-ordinators. These might include; facilitate, assessment, planning, implementation, evaluation, support, advise, liaise, resource, advocate, educate, integration, improving access and ensure continuum of care. Being able to interpret the role and creatively shape it to evolve the vision of the palliative care strategy is integral to being an advanced palliative care nurse practitioner.

In the competitive world of professional caring, where all health care workers need to prove effectiveness and efficiency, nurses are at risk of losing their viability in health care systems, unless they are able to demonstrate their unique contributions to patient care". (Taylor, Glass, McFarlane & Stirling, 1997, p.253).

Being creative means for me being able to translate the vision through principles and words into the reality of the service team and the person and their family.

### ***My practice framework***

My role is that of a Palliative Care Co-ordinator with a hospice multidisciplinary community team. My caseload averages 30 patients and their families/whanau within a geographical area defined by my employing organisation. A

component of my job description is carrying out a multidisciplinary assessment with patients and family/whanau referred to the hospice service. Once again the role requires this creative interpretation of the vision.

The NZ Palliative Care Strategy identifies the need for an “initial multidisciplinary assessment” and “on-going assessment” for all people receiving care “to ensure that all needs are identified early, and that an individualised care plan is established” (Ministry of Health, 2001, p.3).

The frameworks I encompass in my work are a mixture of both approaches that correspond with the principles and tools. This mixture is based on both nursing and multidisciplinary theories, palliative care philosophy and organisational values and tools. The only way to define my approach to assessment as a framework is that I draw on these multiple concepts in each situation and use part of some or all of these concepts, tools and/or plans as required. Intuition is a central element in my assessment, however intuition does not sit comfortably with evidence-based practice. Where necessary however I use validated tools to interconnect intuition and evidence-based practice.

See Appendix 1 for an example of the range of tools I draw on as required.

The lived experience of practice and of the patient or family/whanau story is central i. All those I connect with through my professional role are living with what often looks like a negative situation. Reading Victor Frankl’s book *Man’s Search for Meaning* (1959) gave me a framework and led me to use both attending and listening skills refined to meet the varied needs of the individuals. Frankl introduced the idea of

logotherapy. Logotherapy looks at not what happens but how one views or thinks about what happens. Frankl's logotherapy theory is concerned with the search for meaning in life – finding positive reasons for living in the midst of negatives. Logotherapy is certainly a tenet in my practice framework, in that I listen to patients and families to hear the cultural and family traditions that could be keys to their constructing meaning and making sense and finding a workable experience for them. “Frankl suggested three basic sources for a sense of meaning – creative, experiential, and attitudinal” (Greenstein & Breitbart, 2000, p.487). In order to support patients and families to find meaning I need to be aware of these sources in relation to myself whilst creating a space for them to consider this concept for themselves should they wish.

I approach each patient and family/whanau-focused situation very much through the multidisciplinary framework. Each situation has unique needs which require co-ordination across disciplines. The planning of care then must be tailored to meet individual needs and preferences.

Cicely Saunders (founder of the modern hospice movement) facilitated remarkable changes in thinking about what are now important and enduring concepts. From her work looking at pain in the early 1960s “the concept of ‘total pain’ was described in its full form and was taken to include physical symptoms, mental distress, social problems, and emotional difficulties.” (Clark, 2002, p.9). In palliative care the basis of her model of assessing the physical, psychological, spiritual and social issues is the basis I use for the multidisciplinary approach to care planning.

A narrative approach is also part of my framework. I believe that my goal (as described by Elliot, Mulrooney & O’Neil, 2000) is to “...open up a space for an examination of stories” (p.21). The process of taking a narrative approach involves externalizing the unhelpful dominant stories, and developing preferred stories that build on the patient and family/whanau strengths and resources. It is important that I am able to work in a way that is responsive to the needs of individuals. Elliot et al (2000) describe the narrative approach by saying; “Central to narrative work is respect for the family and a belief that once space can be made for new stories, new possibilities can emerge.” (p.22). Narratives shared by people create a connectedness.

My approach to assessment also includes coming from the stance of unknowing curiosity. By this I mean I do not assume to know anything (about the individual circumstances). I begin each relationship with what I know about myself and hear each patient and family/whanau story from their perspective. To do this it is necessary to build a respectful and trusting therapeutic relationship and commit to working in partnership with the person to discover and develop strengths and resources hidden in their stories.

My knowledge has been framed through Carper’s (1978) framework -ways of knowing in nursing . Table 1 is a summary of this framework.

Table 1

Empirical knowledge	Scientific knowledge consisting of theories and models that can be tested empirically
Aesthetic knowledge	The artistic component of nursing including the expressive and technical skills of nursing – based

	on the actions, conduct and interaction of the nurse with others
Personal Knowledge	'Know how" in everyday practice
Ethical knowledge	Moral knowledge of what is good and right, based on beliefs and values

Adapted from Carper ( cited in Kennedy, 1998, pg 241)

Jill White (1995) explored the degree to which Carper's patterns of knowing represent nursing knowledge and suggested the addition of a fifth pattern, socio-political knowing. This addition adds to nurses' ability to meet individual needs as "It is related to deeply embedded historical issues of connection to and dislocation from land and heritage" (p.85). I consider that the addition of cultural ways of knowing occurs through knowing one's own story and lineage. This addition is a crucial part of my frame work.

Being a palliative care nurse and what that means to me does not conflict with the depth of human connection that is sometimes the reality when interacting with patients and families/whanau. During these moments it is sometimes more important to be the person that is me rather than being the nurse. The awareness I have of myself is as necessary as is finding the balance in the moment to know what to do. Having the knowledge to judge and use this appropriately is significant. Davies and Orbele's (1990) model of the supportive role of the nurse in palliative care categorises "six interwoven but discrete dimensions: Valuing, Connecting, Empowering, Doing For, Finding Meaning, and Preserving Own Integrity. Their findings imply that the nurse as a professional cannot be separated from the nurse as a person."(p.87).



The linking together of my understanding of Carper's patterns of knowing with White's contribution, Davies and Orbele's dimensions and my own culture, attitudes and life experiences is important in my practice. It enables me to balance and understand the power differences in relationships which are inevitable whenever individuals or groups, all with their own cultures, interact.

My awareness of the Treaty of Waitangi<sup>2</sup> principles is another part of my interactions with all patients and families/whanau.

I am conscious of the power relations perceived to be present when a health provider (nurse) and consumer (patient or family member) interact. As a health provider it could be that I am not required to explain my actions or myself. My awareness of this during my interactions shows a partnership rather than an imbalance of power.

In my view the palliative care approach aligns almost philosophically with the Treaty of Waitangi principles of partnership, participation and protection. A commitment to these principles underpins any relationship. Having an understanding of Maori models of health is also integrated in my framework. Objective 1.2 of the Maori Health Strategy (2002) is "To recognise and value Maori models of health and traditional healing". (p.12). There has been widespread acceptance in New Zealand of the Whare Tapa Wha maori health model. This model describes four dimensions that contribute to wellbeing: te taha wairua (spiritual aspects), te taha hinengaro (mental and emotional aspects), te taha whanau (family and community aspects), and te taha

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<sup>2</sup> Treaty of Waitangi New Zealand's founding document. It establishes the relationship between the Crown and Maori as tangata whenua (first peoples) and requires both the Crown and Maori to act reasonably towards each other and with utmost good faith.

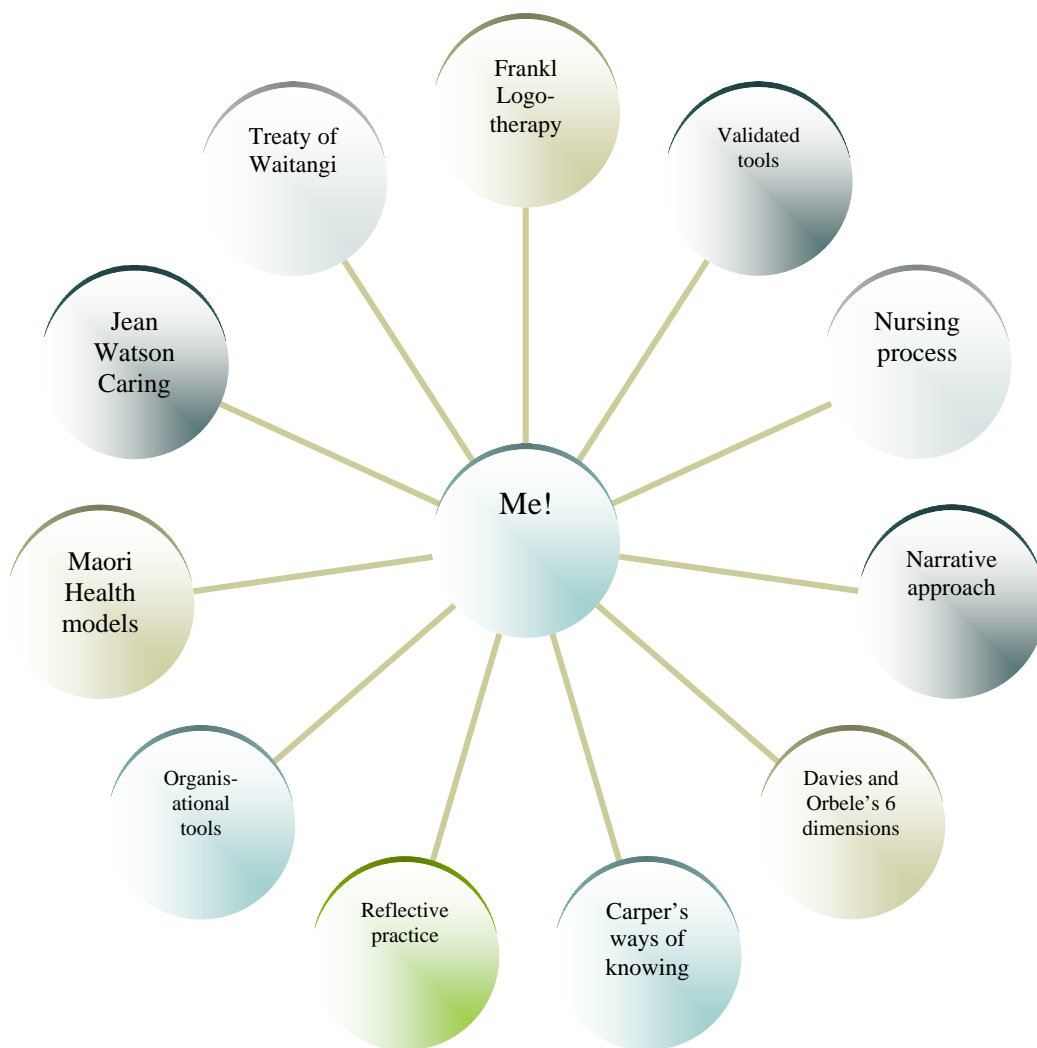
tinana (physical aspects). It is considered that good health depends on the equilibrium of these dimensions. Te wheke health model (Pere, 1984 as cited in Durie, 1994) uses the symbol of the octopus, with each of the eight tentacles of the wheke representing a different health dimension. The components are wairuatanga (spirituality), hinengaro (mental health), tinana (physical), whanauhgatange (extended family across the universe), mana ake (the uniqueness of the individual and extended family), mauri (life-sustaining principle in people and objects), ha a Koro ma a Kui ma (cultural heritage), and whatumanawa (relating to emotions and senses). The body and head of the octopus represent the whole family unit, and the eyes are referred to as 'waiora', or total well-being of the individual and family.

Theorist Jean Watson's writing resonates well with me. I reflect on her discussion on caring as a moral imperative frequently in relation to my nursing practices. Watson (cited in Walker and Neuman, 1996) says

The nurse attempts to enter into and stay within the other's frame of reference for connecting with the inner life world of meaning and spirit of the other; together they join in a mutual search for meaning and wholeness of being and becoming to potentiate comfort measures, pain control, a sense of well-being, wholeness, or even spiritual transcendence of suffering. The person is viewed as whole and complete, regardless of illness or disease (p.153).

Watson's (1999) postmodern view that the caregiver also needs to be aware of their own consciousness and authentic presences of being in a caring moment with their patient is embedded in my framework.

To summarise I have drawn a mindmap of this description above indicating how I see the drawing together of the multiple approaches I interweave into my practice. Whilst this is a 2-dimensional picture I see ME! as being away from the outer circle – placed separately from the tools, however able to bring forward whichever is or are required at the time.



Whilst I see the above as the inherent approach I take it is by no means complete. There is ongoing learning and reflection in terms of how I approach each

situation at any time. Within the confines of my position description I use a structured assessment tool through which I approach assessment from a holistic viewpoint. Whilst the paperwork is standard across the board, again the individuality of each situation brings with it a unique story that unfolds within the structure of the documentation.

I compare this framework with a bird's eye. Imagine seeing from the perspective of a bird high in the sky. From there can be seen the minute detail which the bird swoops down upon. I view this as being able to be present in the moment and pull out the "worm" as it were.

So...does there need to be structure?

What of the vast array of tools available to draw from? Refer to Appendix 1 as examples of tools able to be used in palliative care.

The use of tools which include those that enable the patient's story to be told have a place in facilitating patient-centered outcomes. There is a balancing act between using tools which could potentially standardize something that should be highly individual and (on the other hand) ensuring that an area of care is not ignored.

## **REFLECTIONS**

I consider my focus as a palliative care nurse is on identifying the individual needs of the dying person and their family. Orem's (1995) definition of self-care is "the personal care that individuals require each day to regulate their own functioning

and development” (p.8). Where the patient has limited ability to self-care nursing systems are designed to guide, support or assist where there is a self-care deficit.

As my role involves direct contact with patients, families, and both lay and professional caregivers, I am aware of the use of Orem’s theory relating to my role and practice. This is when I assess the individual, (whether that is the patient/family/ or group), needs the relevant knowledge to become competent to manage a system of health deviation for self-care. When nursing is involved support can be of three types according to Orem. These are wholly compensatory, partly compensatory or supportive-educative. My role can encompass one, some or all of Orem’s methods of assistance, being acting or doing for, guiding, teaching, supporting and by providing a developmental environment.

Often the patients I meet through my role have what Orem would diagnose as an inability to meet a self-care deficit, frequently because of their previous experience of hospital, which was compliance to instructions and acceptance of the nurse’s and doctor’s expertise and probably a feeling that being a patient puts one’s self in a state of dependency, even if self-care is possible. My nursing practice includes letting the patient know that the focus is on them as an individual rather than on their illness. They can learn what self-care is possible and which self-care deficits I can meet, and be satisfied that they are involved in planning care. I believe the teaching and support they require is required because of feelings of uncertainty regarding their future journey.

Most of the patients I meet are dealing with fear and lack of knowledge (naturally about death) and these issues can be dealt with using Orem's theory. This incorporates my feelings of caring, maintaining self-respect and empowering patients.

*What is it we know that the patients and families don't?*

Some say "very little"; some say "a great deal". Both statements are, in their way, true.

Experienced palliative care nurses all have a store of anecdotal data, subjective data, and the benefit of seeing how the process unfolds under a myriad of different circumstances.

However this information is not often shared, even amongst our peers.

*How do we inform them about what is ahead?*

Learn all we can about the dying process and share that with patients and families/whanau – spend time with them. Learn all we can about their thoughts/feelings/fears/beliefs

*How much information is too much? – or not enough?*

*"I feel like I am in a dark room flying in a glider"*

How would you be if it was you in that glider and someone could let light in?

## SECTION TWO

### INTRODUCTION

I believe it is extremely important to be aware of my own belief systems with regards to mortality to enable me to practice effectively in palliative care. Each patient I have a relationship with is known to have a progressive non-curable disease process from which they will die. Ira Byock (2002) said “faced with the ultimate problem and unalterable fact that life ends, human beings impulsively strive to recognise some meaning in death.” (p.280). I am one of a small number of people in our world who live with dying and death on a daily basis. Byock also said “awareness of death confronts us with questions that go to the very nature of existence,” and that “the intrusion of death forces us to look at the things we want most to avoid.” (p.280). Before I can progress with meeting the needs of the patients and families I have to be aware of, and be honest with myself, regarding the questions I ask myself about my own mortality. I have a sound understanding and firm conviction as to my own mortality. I see awareness as essential in palliative care practice as it will be challenged and questioned often.

Awareness that a life is framed in a certain amount of time is heightened both for those diagnosed and living with a life threatening illness and for those who are connected with their experience. The meaning individuals acquire from this is known to be positive psychologically and associated with an improved awareness of the meaning in their lives. (Greenstein & Breitbart, 2000, Taylor, 1983).

Palliative care practice and my practice are focussed on having the patient and family enmeshed in all parts of the assessment and intervention process. All involved in the process have as much or as little support as required. Ultimately my aim is to facilitate the process. Palliative Care Nursing practice at an advanced level is underpinned by the concept of aesthetic knowledge. Aesthetic knowing is the artistic component of nursing. I then, as an advanced practitioner, am an artist: an expert with the skill and knowing to integrate my knowledge. The patients and families are artists also. They are integrating their knowledge into reality – *their* reality.

This next section captures examples from practice by use of fictionalised vignettes based on different experiences I have had in palliative care. Accompanying literature articulates both how I use my individual framework and the ways of knowing and not knowing what interventions are appropriate for each scenario.



## **PATIENT AND FAMILY PREFERENCES**

As I have stated I bring what I know to each situation and listen to hear what the issues are for each individual. There is no single rule that can be applied to providing support for patients and families living with a terminal illness, therefore with this as a beginning point I use my practice framework differently with each individual. Waldrop, Milch and Skretney (2005) stated “Families benefit from interactions with providers who understand that individual’s comprehension may be uneven, and who can help ease the difficult transitions that accompany decline and loss” (p.88). Getting to know patients and families is important and my expertise revolves around doing this. I do this one to one process by listening to the words they use to describe their approach to dying and how they interact with those around them.

Whilst literature on coping with a poor prognosis may enlighten the reader it cannot provide a definitive guide. Part of the nurse’s role in supporting the patient and family towards finding meaning from their experience is to facilitate hope and achievable goals. By shaping the care around what the patient and family want and feel, is done by providing clear and honest information when and if it is requested as well as listening for cues regarding those questions which may not be asked is also important.

As pointed out by Oliviere, Hargraeves & Munroe (1998) “...much of palliative care can be very short term and we frequently assess and interview within one or two sessions.” (p.26). As some of the contact with patients and

families/whanau in palliative care is short term using a narrative approach and listening to the stories means that frequently the patients and families have their issues addressed in a way acceptable to them.

### **Two visits and a phone call.....**

*Mr W (married, one son, Chinese.) I had a brief introduction to Mr and Mrs W and their son prior to his discharge from hospice inpatient unit. With Mr W's agreement I arranged a joint visit with his District Nurse.*

*The District Nurse had been delayed so I spent some time alone with Mr W. He had numerous questions and spoke freely about his concerns. Mr W had a 20 year history of Nasopharyngeal cancer. His disease had recurred and there was now metastatic spread. There were no options for treatment from the Ear Nose and Throat (ENT) team.*

*Mr W's main issues were low energy and his high risk of haemorrhage via a nose bleed. Mr W was also worried about his wife managing the home and garden. He was thinking about options of selling their house and moving somewhere closer to hospital, or renting the house out and renting something smaller. He had not spoken to his wife about these thoughts regarding moving. Mr W was also concerned about results from a recent biopsy. He did not want his wife to attend the appointment (with ENT) in case "the news is bad". Again he had not spoken to his wife about this. I said very little.*

As this was my first meeting with Mr W I was not aware of his beliefs about dying and death. I have an awareness that many Chinese may be reluctant to discuss these issues due to the belief that if you talk about something bad it could occur. Whilst Mr W had verbalised his concerns about having a bleed I did not talk about options for managing this at this point in time. Based on the Nursing Council of New Zealand definition culture refers to the beliefs and practices common to any particular group of people. While ethnicity tends to be the primary focus when taking into account Treaty of Waitangi considerations and obligations, my view is that the diversity of social, religious, gender and disability issues are all incorporated into the concept of cultural safety.

Mr W was clearly concerned about the practical issue of housing for his wife and son. I considered that this may have been related to a cultural belief that the father is the undisputed head of the family, and also that family is central and comes before the individual. I also considered whether Mr W's need for meaning was involved with having a feeling of purpose. On one hand, I was wondering why he had not discussed these issues with his wife, on the other hand I could see that by maintaining his role in the family he could address the concept of finding meaning.

*I asked him about how he thought his wife might feel about his plans to move. Apart from this he did most of the talking while I listened. I answered his questions directly – I did not add any of my thoughts for him to consider as I assessed that he had enough already to think about. At the brief meeting I had with the W family in the hospice Mrs W had told me she was experiencing huge stress associated with changes in structure at her workplace.*

What was I thinking?

I thought – “what did he understand was happening in terms of prognosis?” It seemed from what he said that his wife had quite different perceptions from him. I was thinking that their approach to managing information was possibly culturally different from mine. For these reasons I was reluctant to openly discuss what I was thinking at that point.

It seemed to me that Mr W was very frightened and that for some reason he was unable to talk to his wife about this. My feeling was that part of what Mr W was anxious about was his need to provide for his family and to protect them from “bad news”.

*When the District Nurse arrived I briefly summarised what Mr W had been telling me – as by then he was quite fatigued. He seemed pleased that I relayed an accurate account of all he had been discussing. The conversation then moved to more physical/practical issues that the District Nurse could address.*

*Several days later Mr W contacted me early in the morning saying that his nose was bleeding, that he was frightened and that his wife was at work. I went to his house. Mrs W had followed a preset protocol for managing a nose bleed and had applied adrenaline packs up Mr W’s nose. The bleeding had slowed but not stopped. I talked with him about the options of admission to hospital or hospice – he chose hospital.*

*Two days later he telephoned me from hospital. He was tearful and expressed that he was frightened. He did not know what to do and said that the Doctors had told him that they could not stop the bleeding, which continued intermittently. He asked me to help him. Whilst instinctively I felt like going to see him I knew that there were others who could support him.*

*I contacted the Hospital Palliative Care Consultant who was able to spend time with Mr W. Mr W died several days later in the hospital.*

In a study of patients' and relatives' experiences, and what they want to be told, when receiving palliative care Kirk, Kirk & Kristjansen, (2004) suggest "the timing, management, and delivery of information and perceived attitude of practitioners were critical to the process" (p.1). This study is one of very few which takes into account "the need for specific attention to cultural assumptions" (p.1). The central theme which emerged in this study was "the need for sensitivity and respect for individual wishes in the communication process" (p.5).

Using my palliative practice framework with Mr W and his family I heard his story (using a narrative approach). His need to find meaning (principles of logotherapy) and maintain his place in his family (principles of the Treaty of Waitangi) were approaches that fitted more than other concepts and tools I draw from.

## **INFORMATION NEEDS**

Four attributes of the current palliative care concept were identified by Meghani (2004) “(1) total, active and individualized patient care, (2) support for family, (3) interdisciplinary teamwork and (4) effective communication.” (p.152)

There has been little published on informational needs around end-of-life decisions. Communicating and decision making is dependent on the individual needs of the patient and of family members. Their information needs as a unit may vary from their individual needs. Heyland, Tranmer & Feldman-Stewart (2000) presented an organising framework “that describes the decision making process and breaks it into three analytic steps: information exchange, deliberating, and making the decision” (p.S31). This organising framework includes the individual’s information needs based on a holistic assessment of the individual. This framework also identifies the need to be aware of the provider’s education, beliefs and knowledge. Kirk et al’s (2004) study aligns with this by discussing the need for attention to cultural assumptions.

### **Ways of learning**

*Mr I, 46 years old. Referred to the hospice service following an 18month relationship with the Oncology department.. He had been undergoing treatment throughout that period with the aim of cure. At the time of referral to Hospice service his disease was rapidly progressing despite recent treatment. I met Mr and Mrs I the day he was discharged home from hospital. His referral to hospice service was made the day before – the same day the I’s were told that he would die in days – at most a*

*week or two. Mr I had been in hospital for an extended period of weeks and was very pleased to be home, despite the recent news of his prognosis. My initial impression was that he would not die during the next few days however the impression from the referring specialists (Palliative Care Consultant and Oncology Consultant) was that he would deteriorate very quickly.*

*Mr I had deteriorated dramatically over the previous week and based on the information given to him and his wife the day before he had a desire to be at home (to die). Mr I's medical management had been very intense and complex in the hospital due to his high levels of uncontrollable pain.*

*I had an ongoing regular relationship with Mr I and his family over the two weeks preceding his death. At the time of my second visit his pain was beginning to escalate. Over the next 4-5 days the pain management side of his care was intense. I visited daily as well as arranging 3 visits by the Community Palliative Care Consultant. Mr and Mrs I were centrally involved in decision making.*

*Throughout the week Mr I did appear to have deteriorated markedly. His condition fluctuated dramatically and at times it appeared that he was about to die within hours. My assessment at this time was that Mr I could possibly live for another 10 days to 2 weeks. As the week passed Mr I began to wonder how much more time he really did have. He decided he had time to organise some things he thought he would not have been able to do. To me it appeared as though he began in earnest the business of dying. He summonsed work colleagues to hand over his work to. He said goodbye to family and friends. His family watched this process, quietly managing his "appointments" and energy to balance his activities with their needs as well.*

*This all took several days. On the day he woke up with all his goodbyes completed and all the “jobs” on his list had been ticked off. He wondered “what now?” He asked several people - “what now?” – “why am I still here?” I have done everything I wanted to do”.*

*I talked to him about sitting back and enjoying the view, which he thought that was a reasonable option, however then he began to think about what might happen to him physically. He wondered about what it was actually like to die. He had experienced some periods of apnoea and he talked about having seen purple lights and was quite bemused about that as he knew that people who had come back from near death experiences talked about white light. Mr I asked several times “What can I expect” “What will happen?”*

Mr I was afraid he would choke whilst I talked about this being possible, I explained that medications could be administered to relax and sedate him. This would be his choice at the time, bearing in mind that he wanted to be awake and “experience death”. I also talked about the balance of managing the symptoms whilst maintaining his wishes. He wanted to be told when he was dying so that he knew that was what he was experiencing. Vachon, (2004) proposes that people should “have the option of choosing how much information they want about their illness” (p.965). Participants in Kirk et al’s (2004) study “described information as a mechanism that enhanced decision making and keeping some control” (p.6). It is important to maintain a sense of what the individual is signalling in terms of need for information, understanding that some people “may choose not to seek or may resist further information” (Leydon, Moynihan, Jones, Mossman, Boudioni & McPherson, 2000, p.909).



*Mr I did die quietly and peacefully with his immediate family and best friend with him, as he had wished.*

Ten days after his death I visited Mrs I. She talked about how she was and how their children were. I asked her if there was anything she had thought about, wondered about or had any questions about. She talked about the wonderful experience they had all had during Mr I's last 2 weeks at home and about the sadness they all felt. Mrs I said that if there had to be regret it was that she found a pamphlet after Mr I died, about the physiological changes that happen when somebody is dying. It described what could happen in the last 24 – 48 hours before death. This made her sad as she remembered that Mr I always worked better when he had something written down. Mrs I wondered if the written information in the pamphlet would have helped, even though he had been given the information verbally. We talked about Mr I's needs for written information and for "experiencing" what he had read about.

As I reflected on my discussion with Mrs I and the contact I had with Mr I, I realised that he would probably have benefited from me having reinforced my conversations with him by using a written medium. I have reviewed my understandings of different learning styles. These include visual, auditory and tactile learners. My raised awareness is now another part of the framework I am able to draw from.

In this situation the palliative practice framework components I am more aware of having drawn from are; Carper's ways of knowing, reflective practice and Watson's caring model. I attempted to enter Mr I's frame of reference using my

understanding of ways of knowing, whilst being aware of him as a person and reflecting continually on his need to understand what was happening to him.

## **THERAPEUTIC RELATIONSHIPS**

The most effective tool a nurse has is her(him)self. For me to achieve an effective therapeutic relationship I recognise that my attitudes and behaviours allow me to empathise with the patient and family and to be sensitive to their needs without becoming overly enmeshed in the patient's situation. It has occurred to me that empathy is something I practice almost unknowingly. Kohut, the psychoanalyst, (as cited in Gordon, 1998, para13 ) called empathy "a data gathering tool." Gordon says that by this Kohut "meant that one immerses oneself in the experiences of the other, and by doing so, begins to experience the state of the other, which provides the data upon which the therapist's response will ultimately shape."

My approach to assessment and care planning is tailored to meet individual needs and preferences. My role in the assessment process varies depending on the need. Initially the outcome is not usually clear however a therapeutic relationship has begun.

Simply and literally defined, therapeutic is defined in Orsman (1989) as "having the power to heal or cure / relating to the treatment or curing of disease, etc" (p.1200) and relationship is "a connection or association" (p. 958). When the "therapist" is a nurse and the "relationship" is between the nurse and a person who is

dying and their family the nurse uses the nurse-patient relationship as the foundation for care in order to address the patient and family's physiological, emotional, psychosocial, and spiritual needs. Whilst therapeutic in this context cannot be defined as "having the power to heal or cure", "treating or curing" is carried out by the nurse supporting the patient and family deal with issues which have been identified as requiring intervention. My belief is that the nurse as a professional cannot be separated from the nurse as a person if a therapeutic nurse-patient/family relationship is to be achieved.

Peplau (cited in Frederick, 2002), defines therapeutic relationship as "a process through which the nurse encourages the patient to exploit the nurse's resources in order to solve problems." (n.p).

### **Need for speed**

*Mr D. Following referral to hospice service I contacted Mr D. He had been diagnosed with widespread incurable disease 2 weeks prior to referral. Mr D initially declined a visit saying "no rush, no urgency, my wife is looking after me". As the referral indicated rapidly progressing disease I asked permission to visit before the end of the week. From the doorstep I saw Mr D sitting at the kitchen table. My initial impression was "this man is dying NOW – in the next day or so" I arrived at this point based on the numerous experiences I have from witnessing physical changes to palliative patients I have had contact with over time.*

Barthow (1997) examined the implications of the level of relationship expected between nurse and patient. "This includes expectations that nurses will form

comprehensive and therapeutic relationships with patients and families. Such expectations disregard circumstances where this is not possible.” (p.206)

*I attempted to establish what he and Mrs D understood. Both were aware of the implications of the recent diagnosis, however clearly neither was prepared for imminent death. I began presenting what I saw – hoping to do this appropriately, however as I did not know Mr and Mrs D, (and I believed I had very little time to develop a therapeutic relationship or assess their information needs), this was an anxious moment for me. I assessed, by means of casual conversation, where Mr D thought he was in his disease trajectory. He talked about his birthday in 4 months, and hoped he would still be here for that. I told him directly that I did not think he would be. Mr D then asked what I did think was realistic. Mrs D was crying. She asked me not to say “these things”.*

Mrs D was a Pacific Island woman. I considered at the time that her reaction to my communicating this directly could have been partially due to her beliefs and culture. As there were many issues to address at the time I did not specifically explore this with her then. I had also assessed that I may have been able to have been even more direct with Mr D if Mrs D had not been present.

*At this point one of Mr D’s children arrived (this was Mr D’s second marriage). Miss D had been on holiday and on her return the day before she had noticed a big deterioration in her father’s physical condition. She had been away only 3 days. With Miss D’s arrival at the house the way in which I was delivering information and assessing the situation altered.*

I propose that a key issue regarding information management in palliative care is the dearth of research that addresses the family context. The challenge is integrating the diverse needs of the patient and family members. Kirk et al (2004) addressed this in their study and noted “requirements change over the course of the illness”. (p.2). Whilst Kirk et al’s study addresses the information needs identified by both patients and families further research on the ways the individuals choose to react to the information depending on whether they are alone or with other family members would be of interest. Also of interest is how palliative care providers choose to deliver information depending on whether the patient or family members are alone or together.

*For Miss D’s benefit I summarised what I had started to talk to Mr and Mrs D about, which also gave Mr and Mrs D the benefit of hearing the information again. I reinforced that I believed that Mr D had very little time left until his death, choosing to say that in my opinion this could be in days. I did not voice that the reality in my head was that it could be even less. Mrs D was extremely upset and crying. Miss D was acknowledging that this confirmed what she had thought and was thankful that this news had been verbalised. Mr D asked, “What do I need to do?” and “what happens next”.*

“Attachment has been defined as an emotional bond between two individuals based on the expectation that one or both members of the pair provide care and protection in times of need” (Tan, Zimmermann & Rodkin, 2005, p.143). Tan et al’s overview of attachment theory’s application and relevance to palliative care stated, “a prerequisite to the establishment of a therapeutic relationship or alliance is an understanding of the patient and their relationship patterns.” (p.148). While I had not

had the opportunity to assess Mr D's relational needs my contribution to the relationship between me and Mr D was to quickly become attuned to the immediate needs of all the individuals present. From this point I chose to impart the information in a way that met their needs both as individuals and as a group.

*We continued to talk, I was answering questions as well as offering information for them to consider in order to understand that Mr D's death was imminent.*

*The resultant plan, which Mr D and family agreed to, was to organise a medical visit for that afternoon, as Mr D wanted to stay at home and planning for medications and support was required, a District Nurse referral was also arranged.*

*Mr D asked me to contact family members who were still on holiday. I advised them of my assessment and with this information they arranged to travel to be with Mr D by late afternoon.*

*Medications were organised following the medical assessment as well as necessary nursing support and equipment from the District Nurses.*

*On my return to work after the weekend I learned that Mr D had died 16 hours after I had first arrived at his home.*

*Mrs D and Mr D's children were all with him when he died peacefully.*

Upon reflection it was Davies and Orbele's model of the supportive role of the nurse from my palliative care framework which was represented strongly in this case. Carper's ways of knowing was forward also, enabling me to quickly build a trusting relationship and empower My D and his family.

## SECTION THREE

### CONCLUDING REFLECTIONS

*“If I don’t know I don’t know*

*I think I know*

*If I don’t know I know*

*I think I don’t know”*

*Laing (1970, p.55)*

My personal philosophy simplified, and in the words of Dame Cecily Saunders, then is to "feel with" patients and understand their experience without "feeling like" them.

The reason I continue to go to work each day is to facilitate patients and families to find some meaning from their experiences. Whilst there may no longer be the hope of a cure, there are “hopes” which can be achieved, goals, which can be met if at all possible.

I believe that what sustains me in my practice is the absolute belief that I am working where I am because it is where I am meant to be for now. I will never stop learning about human frailty, about the art of palliative care, and about me.



I have often thought to myself, or listened to colleagues say, “*If only I had gone with my instinct*” or “*I knew that was going to happen*”. I have been present in many multi-disciplinary meetings where options to be discussed with patients and families are based not only on the clinical and knowledge-based assessments, but also from results of discussions within the team based on intuition and experience. Benner, Hooper-Kyrikidis and Stannard, (1999), said that

in addition to scientific knowledge, the clinician seeks to interpret a particular patient’s clinical situation and responds to demands and possibilities in a timely manner. The clinician must sense what is at stake for a particular patient and family and be committed to working towards the patient’s best interests.(p.65-66).

There is no lack of information on the subject of death and dying. However I believe that at a time when people need good clear information about what they are experiencing, the impact of terminal illness or grief often makes the communication of this information difficult. We (palliative care nurses) must spend time with our patients and families so that we can become more supportive. We must also learn the value of our experience and share our knowledge and our stories.

Allen and Brock (2000) suggest “when we spend time with others we come to recognise and even anticipate their possible reactions” (p.1). This concept can be used to communicate what is known in a way that individuals can understand. According to Carper, (cited in Kennedy, 1998), we know **that** “patients with advanced disease need information” and we know **how** “to provide appropriate information and answer difficult questions.” (p.242). Kennedy (1998) states that

“Additionally, much of the knowledge of experienced palliative care nurses is personal and not easily explained or transferred to others. It involves knowing what to do with a particular patient and/or relative at a particular moment in time.” (p.224).

Having the ability to stop doubting our knowledge, and trust our judgements and intuition is essential “as in all tough challenges, we cannot know what will unfold and what experience we will manifest.” (Martin, 2000, p.6)

As a nurse advances her/his practice to an expert level she/he gains knowledge, either knowingly or unknowingly. It is at this expert level that the opportunities for sharing that knowledge are being missed. Patricia Benner (1984) discusses this concept when she suggests “clinical knowledge is gained over time, and clinicians themselves are often unaware of their gains. Strategies are needed to make clinical know-how public so it can be extended and refined.” (p.4).

Currently I find myself spending more time thinking about the knowledge palliative care nurses covet. I believe palliative care nurses, especially those practising at an expert level; actually unknowingly know the very knowledge which they covet. I propose that there are also varying degrees of this coveted knowledge known by advancing practitioners in palliative care. I am particularly interested in the perceived lack of knowledge regarding the information that patients and families request about what is ahead of them. It is common for a palliative care nurse to be asked to “*tell me what is going to happen*”. These are not the physical end-of-life issues, but the probable scenarios between diagnosis of a progressive, non-curative disease and death. The need for information increases when overt or subtle changes begin to happen and the patients and families begin to voice their fears: “*I am going to die*” –

*“This is getting scary now” – “Tell me what is going to happen, you know... you know”*

Gotschius, (1997), states that “despite how much is written, acted out or discussed, the process of death is still new and unfamiliar to most families” (p. 48). This process is neither new nor unfamiliar to a number of advanced palliative care practitioners, and it is the inability to share this knowledge, which I reflect on. I do not consider that there is an intentional withholding of information. My belief, as I have stated, is that this knowledge is unknowingly known. In applying the Dreyfus model of skill acquisition to nursing Benner (1984) says “capturing the descriptions of expert performance is difficult, because the expert operates from a deep understanding of the total situation.” (p.32).

I have concluded that a good place to begin is to state that ‘I know what I know’. From this position I have attempted to open up thinking and conversation about one way of knowing, not knowing and being. I have presented my framework of practice and how I use this to assess individual’s needs and work with them within a system. Individual’s learning styles, questions, and relationships have been explored through fictionalised vignettes from practice, showing the paradox of what happens being different from what you think may happen, as well as what is said and what is not said.

*Many patients I see,  
individuals with questions  
Some similar, but all different  
And I listen to hear what it is  
That is important to each  
The answer is similar, but all are different  
And I listen to hear what it is  
That is different  
Then out of the blue there will be one  
Similar to some, but for me different  
And I listen to hear what it is  
That I need to learn  
My journal may be longer, reflections more intense  
Similar to other entries, but quite different  
And I listen and I learn  
And the next one will be different  
H Cleaver, 2004*

## APPENDIX 1

Name of tool	Reference details and hyperlink	Description/ Scope of tool	How tool is used	Robustness of tool	Copyright/ permission	General notes
Palliative Outcome Scale (POS)	<p>Hearn J, Higginson IJ (1999) Development and validation of a core outcome measure for palliative care: the palliative care outcome scale, palliative care audit project advisory group. <i>Qual Health Care</i> Dec 8(4):219-227</p> <p><a href="http://www2.edc.org/lastacts/archives/archivesJan00/POSDescription.asp">www2.edc.org/lastacts/archives/archivesJan00/POSDescription.asp</a></p>	Helps clinical practitioners meet people's palliative care needs	Self-administered concurrently with staff assessment Staff and patient questionnaire – pen and paper	Tested for validity and reliability Some questions required further testing	Users need to register interest. Copyright. Can be modified with permission and reference made to originators	Can be used in inpatient hospice, day care, hospital support team, home care and primary care – useful throughout interdisciplinary teams and interfaces
Edmonton Functional Assessment Tool	<p>Kaasa, T., Loomis, J., Gillis, K., Bruera, E. &amp; Hanson, J. (1997). The Edmonton functional assessment tool: Preliminary development and evaluation for use in palliative care. <i>Journal Pain Symptom Management</i> 13(1): 1-10.</p> <p><a href="http://www.palliative.org/PC/ClinicalInfo/AssessmentTools/Efat.pdf">http://www.palliative.org/PC/ClinicalInfo/AssessmentTools/Efat.pdf</a></p>	Specifically measures functional status	Paper and pen tool	Requires further research and development, but shows potential to evolve as a useful clinical tool in palliative care.	No permission required	Hospice inpatient and community settings – function alone may not be the patient's chief concern
Edmonton Symptom Assessment Tool (ESAS)	<p>Bruera E, Kuehn N, Miller MJ, Selmsler P, Macmillan K. (1991). The Edmonton symptom assessment system (ESAS): a simple method for the assessment of palliative care patients. <i>Journal of Palliative Care</i>. 7(2):6-9</p> <p><a href="http://palliative.org/PC/ClinicalInfo?AssessmentToolsIDX.html">http://palliative.org/PC/ClinicalInfo?AssessmentToolsIDX.html</a></p>	Measures nine symptoms common in cancer patients	Paper and pen tools Self administered	Has demonstrated validity in palliative care and hospice patients	No permission is required	Should be considered for use in conjunction with complete assessment

The Calgary – Cambridge framework	Kurtz SM, Silverman JD, Benson J and Draper J (2003) Marrying content and process in clinical method teaching: enhancing the Calgary-Cambridge guides. Academic Medicine 78 (8):802-809  <a href="http://www.gp-training.net/theory/calgary/framwork/framwork.htm">http://www.gp-training.net/theory/calgary/framwork/framwork.htm</a>	Guide to the medical interview (Educational tool)	Reference for the process of carrying out a medical interview	Some validity. Has been reviewed and rated well compared to other current tools	All content is copyright by original owners and used with permission. Any reprints must include references	A good frame work for patient and family interviews
Liverpool Care of the Dying Pathway (LCP)	Ellershaw JE, Wilkinson S (2003) Care of the dying: A pathway to excellence. Oxford: Oxford University Press.  <a href="http://www.lcp-mariecurie.org.uk/">http://www.lcp-mariecurie.org.uk/</a>	Tool to empower doctors and nurses to deliver high quality care to dying patients and families	Ten step programme to assess and implement pathway. Paper and pen. Staff assess patient and family	Measurable improvement in end of life care. Ongoing auditable process	Need to register when intending to implement LCP. Reference to original owners on documentation.	Useful tool within hospice service, and for use with primary health care providers in community
McGill Quality of Life Questionnaire	Cohen SR, Mount BM, Bruera E, Rowe J & Tong K, Validity of the McGill Quality of Life Questionnaire in the palliative care setting. A multi-center Canadian study demonstrating the importance of the existential domain. Palliative Medicine. 11 (1997) 3-20.  Cohen SR, Mount BM, Strobel MG & Bui F, The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability, Palliative Medicine, 9 (1995) 207-219.  <a href="http://www.mywhatever.com/cifwriter/content/41/pe1199.html">http://www.mywhatever.com/cifwriter/content/41/pe1199.html</a>	Designed to measure quality of life of people at all stages of a life-threatening illness, from diagnosis to cure or death.	Patient-reported instrument looking at five domains: physical well-being, physical symptoms, psychological, existential, and support	Has been shown to be valid and reliable	Contact the author and sign a user form	Easily used in hospice settings to establish patient centred outcomes
Measure Your Own Outcome	Paterson C and Britten N. (2000).In pursuit of patient-outcomes: a qualitative evaluation of MYMOP,	Aim is to measure the	Initially completed in	Practical, reliable and sensitive to	Available free of charge from website	Useful format when approaching

Profile (MYMOP)	measure yourself medical outcome profile. <i>Journal of Health Service Research Policy</i> 5:27-36  <a href="http://www.hsrc.ac.uk/mymop/main.htm">www.hsrc.ac.uk/mymop/main.htm</a>	outcomes that the patient considers the most important	consultation with staff and family Follow-up can be self administered	change	If using for research requires registration	assessment from patient-centred philosophy used in palliative care approach
Neuro-behavioral Cognitive Status Examination (Cognistat)	Kiernan, R.J., Mueller, J., Langston, J. W., Van Dyke, C. (1987) The neurobehavioral cognitive status examination: a brief but differentiated approach to cognitive assessment. <i>Annals of International Medicine</i> . 107: 481-85.  <a href="http://cognistat.com/">http://cognistat.com/</a>	Assesses intellectual functioning in five areas: language, constructional ability, memory, calculation skills, and reasoning/judgment.	It takes only about 10 minutes for cognitively intact clients and about 20-30 minutes for those who are cognitively impaired. It is easy to score and profile.	Has been found to be reliable and highly valid.		
Mini Mental Examination (MMSE)	Folstein M, Folstein SE and McHugh, PR (1975) "Mini mental state" a practical method for grading the cognitive state of patients for the clinician." <i>Journal of psychiatric research</i> 12(3): 189-198  <a href="http://www.minimental.com/">www.minimental.com/</a>	Assessment tool for assessing mental status (ascertaining if cognitive impairment)	11-question measure Staff administer Pen and paper tool Takes 5 – 10 minutes	Validated and extensively used in both clinical practice and research	Copyright Permission must be granted for use and reference owners	Used to assess in community and inpatient hospice setting occasionally necessary to ascertain ability for patient to give informed consent or understanding of issues
Caregiver Burden Scale	Montgomery RJV, Gonyea JG and Hooyman NR. (1985) Caregiving and the experience of subjective and objective burden. <i>Family Relations</i> 34:19-26	A tool to numerically calculate the	Self administer Pen and paper	reliable and valid and when used to subjectively assess	Copyright Must reference owners	Limited information in the area of enhancing caregiver

	<a href="http://www.nysaaaa.org/Caregiver_Forum/CaregiverForumErielHandout09.pdf">http://www.nysaaaa.org/Caregiver_Forum/CaregiverForumErielHandout09.pdf</a>	burden experienced by caregivers caring for a loved one.		caregiver burden	No permission required	outcomes so a need to research this area more – would be a good tool to use more frequently for this purpose
Eastern Cooperative Oncology Group (ECOG)	Oken MM, Creech RH, Tormey DC, Horton J, Davis TE, McFadden ET Carbone PP (1982) Toxicity and response criteria of the eastern cooperative oncology group. <i>American Journal of Clinical Oncology</i> 5:649-655  <a href="http://www.ecog.org/general/perf_stat.html">http://www.ecog.org/general/perf_stat.html</a>	Assesses disease progression	Staff administer Interview Paper and pen tool	Has been shown to be reliable and valid	Copyright Must reference owners No permission required	Useful when determining effect of disease on quality of life, and a toll which can be used in decision making process around future care planning / appropriate treatment
Karnofsky Performance Scale	Karnofsky, DA and Burchenal, JH. The clinical evaluation of chemotherapeutic agents in cancer (p 196) in MacLeod CM (Ed). (1949) Evaluation of chemotherapeutic agents. Columbia University Press.  <a href="http://www.acsu.buffalo.edu/~drstall/karnofsky.html">http://www.acsu.buffalo.edu/~drstall/karnofsky.html</a>	Used for assessing terminally ill patients, often to determine appropriateness of hospice referral	Pen and paper tool Staff administer	Has been shown to have good reliability and validity	Copyright Must reference owners No permission required	Has place in hospice setting when planning future care (e.g. placement) Useful for talking to families about prognosis
Borg CR 10 Scale	Borg G. (1982). Psychophysical basis of perceived exertion. <i>Medical Science Sports Exercise</i> 14:377-381  <a href="http://www.mywhatever.com/cifwriter/content/41/pe1164.html">www.mywhatever.com/cifwriter/content/41/pe1164.html</a>	Dyspnoea assessment tool	Staff administer	Moderately valid in palliative care setting Assesses dyspnoea at one particular point in time	Copyright Permission required	Some use in hospice inpatient and community setting as part of full holistic assessment



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