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**THE ESSENCE OF EXPERTISE
IN PALLIATIVE NURSING PRACTICE:
A HERMENEUTIC ANALYSIS.**

A thesis presented to the University of Dublin, Trinity College
for the Degree of PhD in Nursing

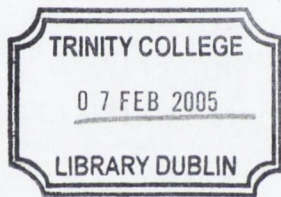
by

Kevin Connaire.

RGN, RPN, BNS, RNT, MSc.
FFNMRC SI.

VOLUME TWO

April 2004



Thesis
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VOLUME TWO

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APPENDICES.

APPENDIX ONE

MAKING MY PRE-UNDERSTANDINGS AND FORE-STRUCTURES KNOWN TO THE READER

Pre-understandings and Fore-structures.

I generated the following statements when I reflected on my beliefs regarding the nature of expertise in palliative nursing practice prior to commencing data collection.

Statements 1-3 are included in Chapter 3, Section 3.3.2.4.

1. The nurse believes in palliative nursing practice.
2. The nurse responds to crisis in the family and individual.
3. The nurse combines knowledge of the patient's physical, psychological, social and spiritual needs with appropriate interpersonal skills when caring for patients and families.
4. The nurse is authentically present to patients and families.
5. The nurse is competent and caring in undertaking nursing interventions.
6. The nurse has unknowingness about the patient and family.
7. The nurse promotes advocacy and empowerment for the patient.

Statement 1: The Nurse Believes in Palliative Nursing Practice.

Interpretation.

Patients and their families form the unit of care in palliative nursing practice. While caring for patients who are dying can be difficult, the nurse focuses attention on family structures and roles and takes account of the position that the person receiving care has in family functioning. Loss of roles, the presence of pain, a range of symptoms, loss of bodily functions and the approach to death can result in turmoil for the patient and family as the unit of care. The patient's role and sense of "self" in the world can create multiple dilemmas for patients and families. The nurse believes that through his/her actions, he/she can make a difference to what patients and families are experiencing. Nursing actions also assist family members in some way to adapt to the changes in family status throughout this time. Dealing with the inevitability of death

adds a further dimension to the enormity and intensity of both patient's and family's struggles.

Fore-structure.

I recognise the difficulties that patients are experiencing throughout the living-dying trajectory. The goals and expectations of nursing care are maximised in order to provide a pain free transition towards death. I am aware of the magnitude of the task to help patients and families through this difficult time. The complex activities of caring are grounded in the belief that palliative nursing includes patients' families as the unit of care and nursing care is concerned with human nature, life, health, illness and death. The enormity of my challenge when caring for patients in the palliative care phase requires me to deliver care that addresses the needs of patients and families at this time.

Statement 2: The Nurse Responds to Crisis in the Family and Individual.

Interpretation.

The approach of death, and the presence of symptoms such as pain, nausea and restlessness can create feelings of hopelessness and a sense of loss of control of situations that were previously part of the individual's role. This in turn can lead to a loss in family role function that, for some, may present as being very difficult. Patients and families may feel overwhelmed with the onset of such symptoms and changing roles and this may result in individual and family crisis. Patients may find they have a low self-esteem, a sense of worthlessness and feeling unwanted, as they can no longer fulfil their family role. Families may feel inadequate and guilty when they cannot continue to care for their relative and must resort to admission to hospice care facilities. While the focus may be on the change of the patients' role, this has consequences for family members also. Their role invariably changes, and accompanying this change can be difficulty in coping, a lack of knowledge of what the new role entails and a reluctance to accept the significance of taking on this acquired role change.

Fore-structure.

I acknowledge the importance of communication and openness with patients and their families in the context of the events that are taking place for them. In these contexts, I gauge the extent of the family and individual crisis and assist patients and families to address their concerns, to let go of the past and plan for the change of roles in the future. I attempt to create an understanding of individuals' freedom to move within the crisis situation, where they accept and reject the events that are taking place for them. Through containment, I "absorb" the issues that are at play in the given situations and in doing so, I allow care planning so that patients and families can accept and deal effectively with the issues that are arising for them at this particular time. Keeping a connection with patients and their families helps to diminish negative feelings and emotions, while it also fosters support and friendship throughout this time.

Statement 3: The Nurse Combines Knowledge of the Patient's Physical, Psychological, Social and Spiritual Needs with Appropriate Interpersonal Skills When Caring For Patients.**Interpretation.**

As individuals, all patients have their own "life-worlds" that encompass a relationship to society, family, friends and spiritual worlds. The trajectory within which patients present results in a new type of movement between each of these worlds. The connection between each world can change, and in some cases, it may be broken. It can also be recreated in a different manner from which it was created in the past when the individual was not in a state of ill health. The nurse strives to maintain a harmony between the physical, psychological, social and spiritual demands of patients and their families throughout the living-dying trajectory. The nurse tries to balance the demands between the internal and external world of patients while taking into account all aspects of their lives.

Fore-structure.

Striving for harmony within the patient directs the care that I provide. In striving to maintain harmony I attempt to foster a feeling of balance, and promote a sense of

well-being. As a result, the dissonance associated with disharmony within the patient is lessened. I strive to understand the interaction that is taking place between the patient's "life-worlds" and remain connected with the patient as events change, while taking into account all dimensions of the patient's life. Nursing interventions are synergistic and supportive so as to enhance the mutuality in maintaining an inner harmony in patients throughout this time.

Statement 4: The Nurse is Authentically Present to Patients and Families.

Interpretation.

Presence provides the foundation on which to build a rapport, relationship and a sense of knowing patients in each caring situation. Authenticity refers to genuine and legitimate feelings that create a bond between the nurse and patients; a bond signifies trust and companionship between the nurse and patients. Authentic presencing is created around a milieu where the nurse listens to his/her own voice and the voice of others within a given context of living. This context is forever changing and is one that provides both challenges and resolutions to living with dying. Understanding is generated from this connectedness and presencing within each individual's situation. The connectedness is strengthened as an understanding is enhanced around each unique patient care situation. A feeling of richness and value is attached to the nurse-patient interactions that bond the value of presencing so patients and families "feel" true presence in their interactions with the nurse.

Fore-structure.

The outcome of developing my understanding of patients and their families create a new perception of each individual situation. As the knowing develops, I endeavour to set in motion a cycle of giving and receiving: the giving of holistic care and the receiving of familiarity and understanding about the patient. Constructed knowing provides the basis for creating a presence and embodiment around a milieu where healing and harmony occur in tandem and become an essential component of the nurse-patient relationship. Authentic presencing as a composite of caring empowers

patients and families to look beyond the here and now so they can care for their own being.

Statement 5: The Nurse is Competent and Caring in Undertaking Nursing Practice.

Interpretation:

The role of the nurse in caring for patients in the palliative care phase of illness is complex. As palliative care is the active total care of patients, the totality of care requires a high degree of competent and caring behaviours in order to meet the needs of dying patients. The nurse's role in providing symptom control forms a crucial role in the competent and caring behaviours the nurse exhibits in implementing nursing care. Knowledge of the totality of patients' needs requires knowledge of both the physical and non-physical realms of care; these encompass the totality of providing competent and caring behaviours. As patients' needs change throughout the palliative care phase of care, the nurse joins with patients in an attempt to help them understand their journey towards death. The complex process of caring is more than the application of scientific findings to practice, it includes a relationship that builds on mutual sharing and understanding of the processes of living and dying.

Fore-structure.

A unifying process of care encompassing the totality of care for patients is grounded in the knowledge, skills and attitudes which I bring to the caring environment. This totality is unique to each individual, while a key aim of care is to plan ahead in a problem prevention mode of practice. In assisting the patient to move forward, I provide care within an evidence-based structure and an understanding of the patients' situations in order to deliver sensitive individualised care for the patient and family during the palliative phase of their illness. The art and science of palliative nursing practice is combined to provide individualised quality care that is interwoven with the therapeutic use of self.

Statement 6. The Nurse Has Unknowingness About the Patient and Family That Guides Practice.

Interpretation.

Getting to know patients and their families influences nurse-patient and nurse-family relationships. As each human freely chooses their own meaning in each situation, a degree of unknowingness exists between the nurse and patients. This unknowingness can create a paradox for caring when it impedes caring. On the other hand, relating in the unknowingness fosters a process of closeness and distancing that varies in intensity throughout the caring relationship.

Fore-structure.

Palliative nursing care creates a way of being with others in which feeling and doing are integrally related. While aspects of patients and families remain unknown to me, palliative nursing care involves being directed towards possibilities that grow out of actuality, and in the case of unknowingness, a reciprocal “unknowingness” co-constitutes and guides nursing practice. In these instances, my awareness of the realms of unknowingness lays the foundations for achieving fulfilment in caring and being cared for.

Statement 7: The Nurse Promotes Empowerment for Patients.

Interpretation.

Empowerment is created around valuing patients and their families. The nurse provides support and guidance to patients while they create personal meanings within the realm of suffering, living and dying. Patients’ personal significances are constructed within their own beliefs and value systems and these give rise to new possibilities for patients in living and dying. While empowerment is intangible, its presence in palliative nursing practice facilitates patients and families to be active in their care to the extent that they are able.

Fore-structure.

Empowering patients and families requires me to provide appropriate support, education and encouragement. The focus on “self” as a human being care calls for the need to accept limitations as well as to consider appropriate strategies to overcome problems and difficulties throughout the caring relationship. Negativity and personal limitations as a result of illness are dealt with in an open manner, and appropriate structures are provided in order to achieve a resolution of these issues.

APPENDIX TWO

LETTER OF INTRODUCTION TO POTENTIAL NURSE PARTICIPANTS

Researcher's Address and contact details.

Participant's Name.

Dear

I am undertaking a PhD (Nursing) degree at the University of Dublin, Trinity College. Part of the requirement for this degree is the completion of a research study. The purpose of the study is to explore and describe the nature of clinical expertise in palliative nursing. The study will play an important part in identifying the skills and competencies that palliative nurses possess, so that new knowledge can be generated.

You are invited to take part in this study. If you are in agreement, you will be asked to take part in a discussion and observation of nursing practice session, where I will talk to you about your experience of being a palliative care nurse. These will take place at a time and venue at your convenience. The interview will be audio taped and notes may be taken during the interview and observation of practice sessions. These will then be transcribed for the purpose of analysis.

Confidentiality will be maintained throughout the study. Your name will not be used in the transcripts. Each transcript will be assigned a number for identification. Tape recordings will be destroyed on completion of the study. Data will be stored in a locked drawer to which I will be the only person to have access.

Participation in this study is totally voluntary. There are no obvious risks in participating in this study. You are free to withdraw from the study at any time without prejudice in anyway. If you withdraw from the study, any records arising from the interview will be destroyed. If you are willing to participate in this study, could you please complete the details on the attached sheet. If you have any questions please feel free to contact either myself, Kevin Connaire on (01) 2886209, or my supervisor, Dr. Cecily Begley, on (01) 6082692.

Thanking you,

Yours sincerely

Kevin Connaire.
Encl

APPENDIX THREE

CONSENT FORM FOR NURSE PARTICIPANTS

Consent Form.

I _____ have read the attached information. Any questions I have regarding the nature of this study have been answered to my satisfaction. I agree to take part in the interview and observation, however I know that I can change my mind and stop at any time.

I agree to have the interview audio taped.

I have read and understand the attached information sheet.

I understand that all information provided by me is treated as confidential.

I agree that the research data gathered for this study may be published, provided my name or other information that might identify me is not used.

Participant Name: _____

Participant Signature: _____

Date:

Researcher Name: Kevin Connaire.

Researcher Signature: _____

Date: _____

APPENDIX FOUR

DEMOGRAPHIC DATA FORM: NURSE PARTICIPANTS

Demographic Data: Name*:

Site Code:

Age Group

Age Group:									
	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60>

Years since qualifying as a Registered General Nurse:

	2-5	6-10	11-15	16-20	21-25	> 25

Years experience in palliative care.

<5	5	6-7	8-9	10-11	>11

Academic Qualifications (Please tick the appropriate space and specify title of academic award(s), for example: BSc (Nursing) or Higher Diploma (Palliative Care).

Registered General Nurse (please tick)	Other Registerable qualifications (e.g. RPN, RSCN, SCM)	Diploma (please specify title)	Degree (please specify title)	Higher Diploma (please specify title)
Post Graduate Diploma (please specify title)	Masters Degree (please specify title)	Studies in progress (please specify title)	Other studies undertaken (please specify title)	

*Your name will not be included in the study findings or the research report. This information will be destroyed on completion of the research study.

APPENDIX FIVE

**LETTER OF INTRODUCTION TO POTENTIAL PATIENT
PARTICIPANTS**

Researcher's address and contact details.

Participant's name.

Dear

I am undertaking a PhD (Nursing) degree at the University of Dublin, Trinity College. Part of the requirement for this degree is the completion of a research study. The purpose of the study is to explore and describe the nature of clinical expertise in palliative nursing. The study will play an important part in identifying the levels of competencies which palliative nurses possess, so that new knowledge can be generated.

You are invited to be a participant in this study. I am interested in getting your views on the nature of nursing that you receive from these expert nurses. If you consent to participate, you will be asked to participate in an interview. The interview will take place at a time and location of your convenience. The interview will be audio taped. These will then be transcribed for the purpose of analysis. Tape recordings will be destroyed on completion of the study.

Confidentiality will be maintained throughout the study. Your name will not be used in the transcripts. Each transcript will be assigned a number for identification. Data will be stored in a locked drawer to which I will be the only person to have access.

Participation in this study is totally voluntary. There are no obvious risks in participating in this study. You are free to withdraw from the study at any time without prejudice in any way. If you withdraw from the study, any records arising from the interview will be destroyed. If you are willing to participate in this study, could you please complete the details on the attached sheet. If you have any questions please feel free to contact either myself, Kevin Connaire on (01) 2886209, or my supervisor, Dr. Cecily Begley, on (01) 6082692.

Thanking you,

Yours sincerely,

Kevin Connaire.
Encl.

APPENDIX SIX

CONSENT FORM PATIENT PARTICIPANTS

Consent Form.

I _____ have read the attached information. Any questions I have regarding the nature of this study have been answered to my satisfaction. I agree to take part in the interview, however I know that I can change my mind and stop at any time.

I agree to have the interview audio taped.

I have read and understand the attached information sheet.

I understand that all information provided by me is treated as confidential.

I agree that the research data gathered for this study may be published provided my name or other information that might identify me is not used.

Participant Name : _____

Participant Signature: _____

Date : _____

Researcher Name: Kevin Connaire

Researcher Signature : _____

Date: _____

APPENDIX SEVEN

**PATIENT PROFILE OF THOSE WHO PARTICIPATED IN THE
STUDY**

Patient 1.

Patient 1 was a sixty-year-old woman admitted for symptom control and respite care to the hospice. She had a history of carcinoma of the right breast with bone secondaries. She was independent in her daily living activities and had been going out home, accompanied by her daughter, for a few hours every day. On some weekends, she stayed at home for one night. She was orientated in time, place and person. While in the hospice, she had a large network of friends who called to see her on a regular basis. Her pastimes in the unit were playing cards and reading. Being her first time in the hospice, she was a little apprehensive about coming in as she felt that coming in “meant I was going to die”. She shared a four-bed room with other patients, and went for walks in the garden. During the day she attended the day care unit where she took part on a range of activities. Patient 1 was discharged home three days following this interview and died at home a week later.

Patient 2.

Patient 2, a sixty-six-year-old man, was admitted to the hospice for palliative care. He had a history of tracheo-oesophageal fistula and carcinoma of the oesophagus. He was a patient in the hospice for the two weeks prior to this interview, but had been a patient there 6 months previously. Prior to this admission, he lived at home with his wife. Their grown up children visited him on a regular basis, and continued to visit him during his hospitalisation. Patient 2’s condition deteriorated rapidly and he died three days after this interview.

Patient 3.

Patient 3, a sixty-three-year-old man, was admitted for terminal care. He had a history of oesophageal carcinoma for the past six months. He had been treated with chemotherapy and radiotherapy and had one previous admission to the hospice for pain control and respite care. There was no evidence of secondary deposits. He frequently spoke about his fears of dying, but felt he got courage to face it by talking about it. His wife had died twelve months previously, and he often expressed his joy at the prospects of being united with her again after his death. He responded well to oral

analgesia, which he took regularly, and he spent long periods sleeping while sitting out on his chair. He had hoped his dying would not be drawn out and that he would “go quickly”. Patient 3 was well for just two days after this interview when he became unconscious. He died three days later in the hospice.

Patient 4.

Patient 4, an eighty-four-year-old woman, was admitted to the hospice seven days previously. She had a history of Dukes C carcinoma of her bowel. She also had secondaries in the acatablum. She had undergone an abdo-perineal resection following diagnosis two years ago. The reason for admission on this occasion was pain control. She was in a single room and spent most of the day in her room on her own. She declined the invitation to join fellow patients in the day care unit. She had been recently widowed and regularly talked and cried about the loss of her husband. Patient 4 was discharged home two days following this interview with her pain well controlled on oral medication.

Patient 5.

Patient 5, a sixty-one-year-old woman was admitted to the hospice for terminal care. She had a history of bronchial carcinoma and secondary deposits in her lumbar spine. She was admitted to the hospice two weeks prior to the interview. She had required minimal assistance in her activities of living and had gone out home on a regular basis, accompanied by her sister. She frequently spoke to the other patients and shared her life story with a number of them. She loved art, and frequently spent hours sitting at her window, looking out on the garden, doing some scenic painting. She had a large network of friends and was a member of a big family; as a result, she had frequent visitors. Patient 5 went out home the day after this interview and died unexpectedly on her return to the hospice.

Patient 6.

Patient 6, a seventy-seven-year-old man, was admitted to the hospice for terminal care. He was diagnosed eighteen months prior to admission with prostatic cancer and had been caring for himself up to a short time prior to his admission. His daughter visited him at home a number of times each day, but he had deteriorated rapidly during the week prior to this admission. The homecare team reviewed him, and admission to the hospice was advised. Despite this, he was alert, orientated and was able to eat independently. He loved to talk about his life and his travels. He died ten days following admission.

Patient 7.

Patient 7, a sixty-three-year-old man was admitted with carcinoma of his left lung. He also suffered from Chronic Obstructive Airways Disease and was generally confined to a wheelchair. His level of independence was minimal. He had had previous admissions to the hospice and he knew a number of the staff. Family support was good, and up to the time of this admission, his wife Julia cared for him. The Public Health Nurse visited him at home on a daily basis. Home help was also provided; this gave his wife a chance to go out to do the shopping and have some time for herself. He had a very close relationship with his wife, and despite his hospitalisation, his wife came in and helped him with his meals, hygiene and activities of living. She kept him in contact with the outside world by reading the paper to him, bringing in the local paper and keeping him up to date with local activities in the community.

Patient 8.

Patient 8, a seventy-year-old man, was admitted to the hospice for terminal care. He had a history of prostatic cancer for the past four and a half years. He lived with his wife and grown up son on the family farm. He was a pleasant, out-going man, who loved to keep his independence as much as possible. Prior to his admission, the home care team had become involved in his care and visited him on a daily basis. His wife had coped well in caring for him over the previous month; however, his symptoms were becoming increasingly difficult to manage. His appetite had disimproved over

the two weeks prior to his admission and his condition had become very weak. Initially following admission he sat out of bed for a number of hours each day; however, he was now able to tolerate only half an hour in the morning and half an hour in the evening sitting out of bed. He expressed his resignation to dying and hoped that he would have a peaceful death.

Patient 9.

Patient 9, a seventy-year-old woman, was admitted to the hospice six days prior to this interview. She had a history of carcinoma of her right breast and secondary deposits in her spine. This was her first admission to the hospice and her pain was well controlled. Her wish was to be able to return home so that she could die at home in her own house in the presence of her husband and children. She loved music and brought in a large selection of CDs and tapes; she sat for long periods listening to them. Once her pain was under control, she was independent in feeding, dressing and in ambulating around the unit. Patient 9 remained in the hospice for six days and was discharged home. Unfortunately, her pain disimproved and she was readmitted five days later. She died two days following her second admission.

Patient 10.

Patient 10, a fifty-nine-year-old man was diagnosed with a tumour of her left breast five years previous, and she had metastases in her right breast one year prior to this admission. Having undergone bilateral mastectomies, she was determined to remain at home for as long as possible and to “fight it” to the end. She had given up work six months prior to this admission and her former work colleagues visited her frequently. Two months prior to admission, her pain increased in intensity and she got very limited pain relief from oral analgesia. The home care team had visited her on a daily basis and commenced her on a morphine infusion. However, she was getting drowsy from this and was finding it difficult to manage it herself. She was admitted for further management of her pain six days previously.

Patient 11.

Patient 11 was a forty-three-year-old man was admitted from another hospital. This was his second admission to the hospice. Living on the family farm with his wife and young children, he was diagnosed with Ca liver two years prior to this admission. He had undergone surgery for the tumour when it was first diagnosed and he also had a course of chemotherapy. He had been in good health for a number of months, but required one admission for symptom control two months prior to this admission. He was mobile but was limited in his dietary intake and he tired easily. His wife and children visited him daily and he spent long periods with them. They often took him to the garden to sit out, and while he was in the hospice, his wife frequently brought in some family photographs to share with him. Symptom control was very effective for him and he talked about his condition openly to the staff and to me. His wife's wish was that he would die at home, however, he himself expressed a desire to die in the hospice. He died in the hospice.

APPENDIX EIGHT

MINI-DISC CODES

Record of Codes: Mini-Disc.

Interview Number:
Respondent Name:

Site:
Date:

Mark Number (on disc)	Abbreviation	Meaning
	b	Breathless
	c	Coughing
	ch	Clasping hands
	ds	Deep sigh
	e	Emphasis
	f	Frowning
	ic	Makes inverted commas
	l	Laughs
	la	Looking away
	ld	Looking down towards ground
	ma	Moving away from me
	mh	Motions with hands
	mtm	Moving towards me
	n	Nods head
	oi	Outside Interference
	p	Pause
	pow	Pointing Out Window
	r	Rocking
	re	Reflecting
	s	Silence
	sc	Swaying in chair
	sl	Speaks slowly
	su	Stood up
	t	Tearful

APPENDIX NINE

RECORD OF OBSERVATION SESSIONS

Record of Observation Sessions

(Not inclusive of hours spent in becoming familiar with setting prior to conducting observations or interviews)

Year / Month	Date	Observation Times	Actual observation hours	Total Hours	Cumulative Hours
2001/01	15	7.45-13.00	3.5		
	16	7.45-13.00	4		
	17	9.00-16.00	4.5		
	18	7.45-14.00	3.5		
	19	7.45-11.00	2.5		
	22	10.00-14.00	3		
	23	7.45-16.00	4.5		
	24	12.00-18.00	3.5		
	25	7.45-15.30	3		
	26	10.00-11.30	1		
	27	09.30-14.30	4	37	37
2001/02	02	20.00-05.00	6		
	05	10.00-12.00	1.5		
	06	08.00-12.00	2.5		
	07	07.45-10.00	1.5		
	08	12.00-15.45	2		
	19	11.00-14.00	1		
	21	07.45-13.35	4.75		
	26	10.00-15.00	2.5	21.75	58.75
2001/03	12	08.00-14.00	3		
	13	08.00-11.00	4.5		
		13.00-15.00			
	14	07.45-16.00	1.5		
	20	07.45-15.30	5		
	21	07.45-14.00	4.5		
	22	08.00-15.45	5.5		
	26	07.45-13.00	2.75		
27	08.00-13.00	4	30.75	89.50	
2001/04	02	7.45-12.00	3.25		
	03	10.00-15.20	3.75		
	09	10.00-13.00	1.50		
	18	7.45-12.30	3.50		
	25	13.00-18.30	4.25		
	30	08.00-14.45	4.25	20.50	110

Year / Month	Date	Observation Times	Number of Actual observation hours	Total Hours	Cumulative Hours
2001/06	05	09.30-12.30	2.0		
	08	10.00-15.45	3.75		
	12	11.00-14.30	2.75		
	13	10.00-15.30	3.50		
	18	07.45-15.00	5.0		
	20	12.00-18.00	4.50		
	22	07.45-12.00	3.0		
	24	21.00-06.30	6.50	31	141
2001/08	07	10.00-15.00	3		
	09	21.00-04.30	4		
	14	08.00-12.00	2		
	17	10.00-16.00	4		
	21	08.30-12.00	2		
	24	12.00-18.00	4		
	27	08.00-12.00	3		
	30	14.00-19.00	3.25	25.25	165.25
2001/10	03	07.45-10.30	1.50		
	05	10.00-14.45	3		
	08	12.00-17.50	4.25		
	10	11.30-16.45	3.5		
	12	15.00-20.00	3.5		
	18	08.30-11.45	2		
	23	09.30-15.45	3.75	21.50	186.75
2001/11	05	10.00-16.00	5		
	07	09.30-16.00	4		
	08	07.45-18.00	5		
	09	07.45-10.30	2.25		
	12	07.45-12.00	3.5		
	14	10.00-14.30	2.5	22.25	209
2002/01	14	09.30-16.30	5		
	15	07.45-17.00	5.5		
	16	07.45-14.30	4		
	17	09.00-14.00	3.5		
	26	09.00-14.45	4		
	27	10.00-13.30	2		
	30	09.30-14.30	4.5	28.5	237.5

Year / Month	Date	Observation Times	Number of Actual observation hours	Total Hours	Cumulative Hours
2002/02	14	07.45-12.00	3		
	15	07.45-12.30	3.5		
	18	08.30-13.00	3		
	19	07.45-11.45	2.5		
	21	08.30-12.00	3		
	22	07.45-12.30	4		
	25	08.00-13.00	4	26	263.5
		22.00-01.30	3		
2002/03	03	12.00-15.00	3		
		23.00-01.00	2		
	04	10.00-13.30	2		
	12	08.00-15.00	4		
	13	13.00-21.00	6		
	15	10.00-16.00	4.5	21.5	285
2002/04	02	08.00-14.00	3.5		
	03	09.00-13.00	3		
	10	10.00-15.00	3.5		
	12	08.00-11.00	2	12	297

APPENDIX TEN

CONTACT SUMMARY SHEET.

(Adapted from Miles, M., Huberman, M (1994). An Expanded Sourcebook: Qualitative Data Analysis. London: Sage Publications).

Observation Date: 12.3.01.

Written by: K. Connaire. Today's Date: 12/3/01.

1. What are the main issues or themes that struck me in this contact?

The interaction between Nurse 4 and the patients she was caring for. It was very "easy", relaxed and they (Nurse 4 and patients) seemed to know each other well.

The ability of Nurse 4 to pick up on the issues that were going on as she went around.

The standard of care delivered was excellent. Every detail was attended to during the wash, the position of patient afterwards.

The patients dictated the focus and progress of care: they indicated what and when they wanted something and she listened to all of the patients in her care.

2. Summarize the information you got (or failed to get) in this contact.

Time: how long does it take to care for a patient who requires palliative nursing care?

Knowing the patient: knowing the patient seemed to be a key aspect of the nurse's role.

Cues: being aware of patient cues and to be able to interpret them correctly for the patient in a correct manner.

Important care: it is more than the "physical care". It is being sensitive to the patient, as in this case, to be able to pick up on what they say and act on it.

What is this thing called "empathy"?

I don't know what information I failed to get, and I guess this is ok at this point in time.

3. Anything that struck you as salient, interesting, illuminating or important in this contact?

The pace at which she worked: there didn't seem to be any urgency in the way she was dealing with the patients, yet she got to complete all the care that they needed without rushing: is this the same with all expert palliative care nurses?

Nurse 4's ability to tune in to the patients she was caring for. She was able to pick up on their anxiety and was able to deal with it.

Giving out medications was an important part of symptom control, however, it was only a very small part of "symptom control".

4. What new (or remaining target questions) do you have in considering the next contact with this site?

Do all expert nurses "know" the patients in their care?

What does "knowing where the patient is at" mean in the context of palliative care?

How does the expert sense that the patient is anxious or has concerns about themselves?

What type of knowledge is the expert nurse using when caring for a patient?

5. Any other comments you might like to make?

I was aware that it would have been valuable to record the nurse when we came out of the room, however, I felt that this was not appropriate. I returned to the nurse when this was transcribed to check the accuracy of the account and minor changes were made.

Thoughts: immediate follow-up after nurse-patient interaction is important as it allows the nurse's interpretation to be used as opposed to mine.

It is difficult doing this observation!, but worth while.

I need to develop my observation skills and remain vigilant throughout each observation session.

APPENDIX ELEVEN

EXCERPT FROM RESEARCH DIARY

The following excerpt describes a situation written while I was sitting in the day room on one occasion as I was observing practice in the distance.

Date: 13/3/2001

Time: 2.10 p.m.

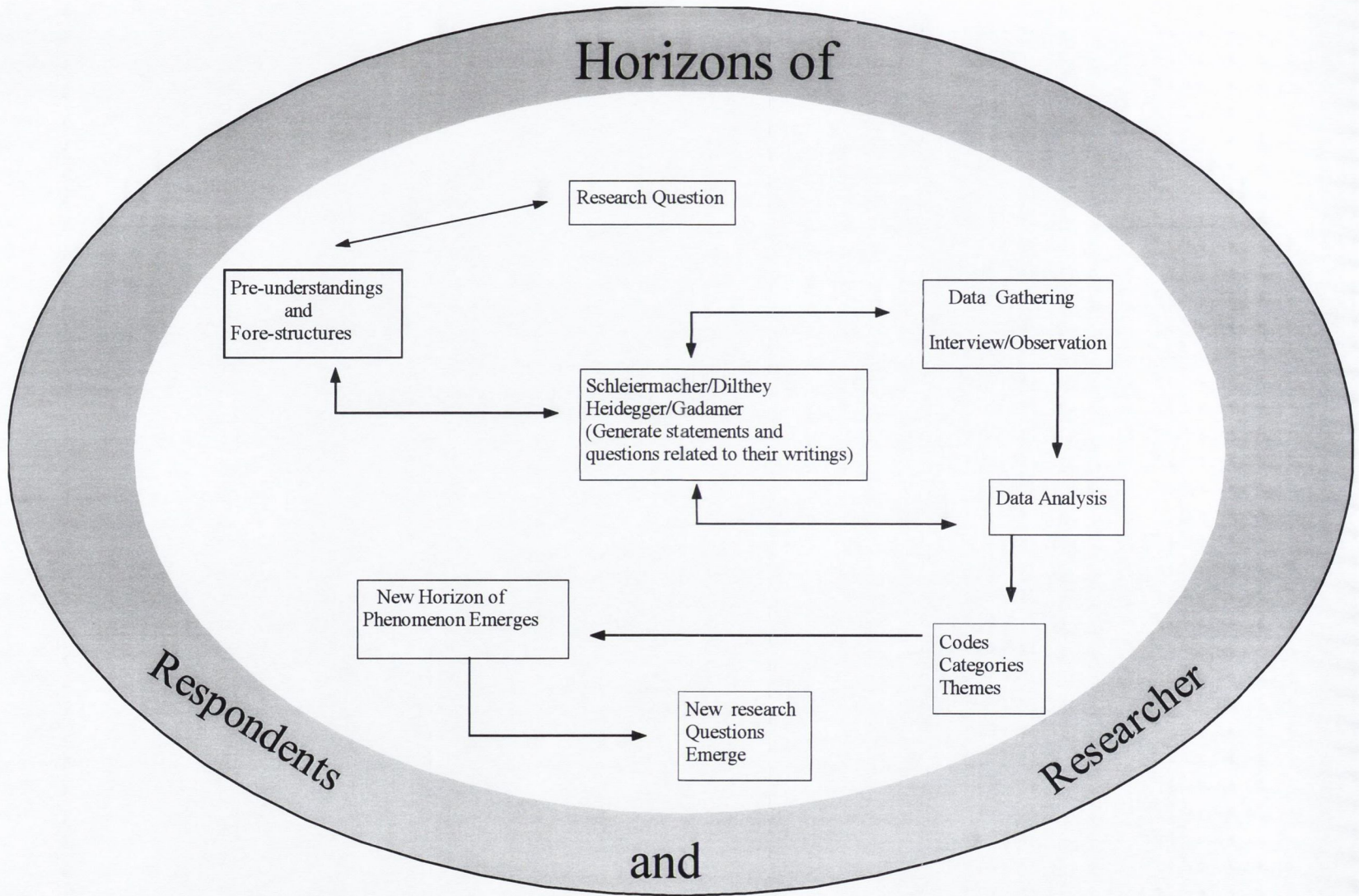
I am more used to the location now. The patients seem so sick, so helpless and seem to be gradually getting weaker and weaker. Some patients who came in on my first day here are dead already, they haven't lasted very long. I feel sad for them and for their families. While I know I'm here as a researcher, it is difficult not to have personal feelings about what is happening and it's hard not to get attached to some of the patients. It is March and so much of nature seems to be coming alive, alive and youthful and bursting with life. The birds are singing as if they are trying to tell us something, maybe it's to enjoy the moment as they are enjoying it. This is a stark contrast to the "living" that is going on inside the walls of the Hospice, where so many of the patients are in the "Winter" of their lives and yet, the intimate care, the touch, the listening seems to be bringing rays of light into their lives. This "light" is unique, I imagine, I don't have it, but then again, I'm not an expert palliative care nurse.

Looking over at Mary, sitting near the window and staring out, I wonder what is she thinking. Joan, a nurse came in and sat beside her. Holding Joan's hand she asks her how she is feeling. "Not good today, I feel as if the end is coming near", replied Mary. I couldn't help noticing how Joan sat there, sat with her in silence and didn't attempt to change the atmosphere of the interaction. I looked at my watch. After ten minutes of just sitting in silence, Joan asked Mary if there was anything she could do to help. Mary indicated she would like to sit there and sit in silence. Joan left the room for a few minutes, and returned with a CD. It was "The Four Seasons" by Vivaldi. How appropriate, I thought, does this music have a special significance for Mary as she sat and watched another season come and go, or, I can only speculate, it might have given her some kind of relief that yes, she had sensed the arrival of another season where the outside world was coming to life again after a long winter. Maybe it was a "new beginning" in her life, a new season, but maybe one that will not be here on this earth. I am privileged to be able to witness something as poignant as this, to me this is a special moment, a moment that captures the special elements of palliative nursing. I wonder how I would cope myself in this situation, be it as a patient or a

nurse. It must be frightening, and yet, the reassurance I saw being given there, not by what was said, but more what was not said, that must surely ease the pain, knowing that someone cares for you?

APPENDIX TWELVE

DIAGRAMMATIC REPRESENTATION OF PROCESS UNDERTAKEN IN COLLECTING AND ANALYSING DATA



APPENDIX THIRTEEN

**SAMPLE INTERVIEW AND APPLICATION OF THE WORK OF
SCHLEIERMACHER, DILTHEY, HEIDEGGER AND GADAMER TO
PROCESS OF ANALYSIS**

Staff Interview 10, Site 1.
Transcribed December 4th, 2001

Interview Date: November 14th, 2001

KC: Nurse 10, thank you very much for agreeing to do this interview here with me today. I'm interested in your experience of being an expert palliative care Nurse . Maybe you could start by telling me how this has been for you?

Nurse 10: (l). Well, I suppose, as an expert, yes. Well, what defines expert. That's what you're trying to find out, yeah [l]. Mmm, well I suppose, mmm, expert in as much as I have spent six years in palliative care and two thirds of that time I have worked on the in-patient unit and mmm, as you know I also have experience in the homecare perspective and I have experience of palliative care from the general perspective as well, mmm, but I suppose, focusing on the in-patient unit, mmm, I suppose as an expert every day you kind of, you look at your expertise in the context of, of your patient care and your decision making and, the different challenges really that come from day to day. Mmm, I would kind of [p] reflect really about the whole notion of an expert palliative care Nurse for me, you know, I suppose, expertise yes, [e], but expertise would be, mmm, maybe something that I'd be privy to retrospective elements of my work, rather than the here and now. Because the here and now of everyday mmm, what I would bring to the here and now of everyday would be maybe experiences from past situations [e] but equally realising that this, mmm, present day situation is as individual as the patient that you are dealing with. You know, while there's similarity, it's from previous experiences, this experience is unique in itself and unique to the individual in itself, and maybe it's unique to my own, mmm, expertise. [r] You know, if you like, that mmm, sometimes I grapple with the notion of expertise, like, you know. Expertise I suppose is something we associate with your, your number of years doing something and your, your overall experience in that area. Do you know, that's why I think reflective practice is very, very important and reflecting on your practice and reflecting in your practice, yeah, yeah, I think that's very important.

KC: And would you be doing that [r] on a constant basis, on a regular basis as you are in practice?

NURSE 10: Yeah, I feel I'd always, I always try and like, stop and think, so as to speak, rather than apply whatever principles I may have accumulated because of my expertise. I don't

necessarily arbitrarily apply everything I would have gathered from an experience or expertise point of view, I try and look at what is this current situation demanding from me, of me, or you know, what maybe can I draw on or what can I learn new in this situation to add [e] to my overall, mmm expertise. You know, and I think that's very, very important to, to look at that.

KC: And so you're going to the situation, and weighing it up to see what can you give, what it can give you?

NURSE 10: Yeah. I think it's constantly [e] a learning process, you know, mmm, because I suppose the whole notion that our experience and our knowledge, it's like all the one process really. And like, because of that then, your theories are ever changing really. You know you have ever changing theories, because of each new situation like, as I said, the uniqueness of the situation, not to say that there's, there would be elements that wouldn't be unique to every situation, but it's unique for each situation. And I think that's what's important. And sometimes we might get a little bit comfortable with the notion of expertise and we think because maybe we have this expertise that we have the right approach or we have the know how or the know whatever all the time [e] the time. We don't necessarily do, 'cause the experience and the knowledge are kind of like, the one process and the current experience is maybe a new aspect or you know, can add something to the knowledge that we have. [p].

KC: Can I bring you back to last week during your practice, and particularly last Sunday, what were you bringing to that situation with ...

NURSE 10: Mary's relatives is it (pseudonym)?

KC: Yes. From your expertise, what would you have been bringing there to that situation?

NURSE 10: Right, I suppose really the first thing would be mmm, what you'd look at is an awareness really. You know, mmm, I was acutely aware of, mmm, the possibilities within the situation that was presented to me. Mmm, I didn't actually know the possibilities but I had an awareness of the possibilities and the potentials of the situation, based on, on mmm, I suppose a certain amount of evidence that we had collected prior to my arriving on to the scene. Yeah, it was Monday night, and mmm, during, we'll say

the period of the twelve hours that I had been on the shift, I actually was gathering and gleaming a certain amount of information. And whilst there were certain boundaries put around that, for me as well, I was governed by the mmm, the relative really, rather than the patient. The relatives, mmm, boundary that she had put around herself and around me and it actually, it was actually a very interesting phenomenon, because I found at the end of that shift, it was very much a challenge to the whole concept of, of mmm, family as patient, patient as family and it was about looking at the whole picture and in a strange way the family's needs were much more pronounced than the patient's needs were, in this scenario. Now when I say the family, it actually boiled down to, mmm, ending up with one individual who remained overnight and I felt that the forum that they found themselves in, somehow it kind of allowed the opportunity for her to maybe visit and revisit some of her own issues. It was actually very, very pronounced, [e].

KC: Right, right.

NURSE 10: Now I would have been, mmm, I felt professionally challenged to challenge her needs as well. And basically as the week unfolded, it became apparent that she wasn't [e] the only one member of that house that had had, you know, had certain experience, certain difficulties, whatever. But the vulnerability of the whole thing was, was just amazing like, you know, absolutely amazing.

KC: And can I ask you there about this vulnerability, how were you able to, as you said earlier about certain boundaries, were you able to get over those certain boundaries to look at and as you said, gather and gleam about the situation. How did you manage to do that?

NURSE 10: Yeah, mmm, yes, what I did was, I suppose first of all through listening I heard a lot. You know, I was actually a facilitator and this for the individual concerned, the relative, was, [p] it was her way of dealing with the situation like. She had said to me "all I want is someone to listen to me, I don't want you to do anything about it, I don't want you to mmm, feel you to, you know, correct any of this for me, I don't want help. The help I want is that you listen to me". So she identified her needs first and she wanted me there as a listener. Now part of me inside, you know from my professional end of thinking, this person needs help. But listening to her boundaries around that situation, she decided who she needed help from, or if she'd take any help. So I felt, all I could do really was to offer her what

was available, but enforcing it was not going to be the way. Because, there again, we're back to, it was very similar to what we talk about; we talk about holistic care in palliative care and whole person care etc, etc. But the paradox of all of that is that, that care is only going to be as holistic as the patient will allow, or the client will allow and in this case, it was the relative. And what she wanted from me and what she wanted from the institution was someone to listen and she needed space to pour out years and years of her own trauma [e]. Now I obviously had a lot of concerns around the responsibility of this for me, you know and what if and if anything should happen to this person, whatever and that was even compounded further the second night when I met another member of the family who had the very same challenging issues for me and there was a pattern here established. These people, sometimes we forget, [e] these people have lived in this way for a long, long time and I suppose, reflecting back on a lot of my study and family work and family care and family units, sometimes it's not about coming in and fixing it all. It's about letting things be. There's been years and years of a pattern of these people coping. In some respects, they would have come from a very different cultural background maybe from you, I or other people on the team, and it's about getting in there and somehow sitting yourself in the middle of that and trying to get an idea of this is how this group functions. I mean, this woman had multi roles in the whole family unit and in the whole management of her sister's care to the extent that some of it, she wasn't even going to be able to let go, 'twas a cyclical event that she had been doing, maybe since she was fifteen, sixteen years of age. So nurse 10 on night duty in St. Elsewhere Hospice on night duty for twelve hours was not going to change. This itself was going to be a whole process, this may never change. Well, it was to find the balance between the responsibility towards the individual, [e] the responsibility of, you know, enlightening her what could or potentially could be done for her, to help her. But the thing was to try and maybe get her to help herself and maybe to see where she's at for herself. But the boundary came again when she herself said to me "but I don't want any help from anyone. I want to do this my way". You know, your hands in essence are tied so really, what you're trying to do is look at, I suppose a certain amount of damage limitation as I would perceive it [e]but then for her, that may not be. You know, she mightn't be coming from the same area at all, you know.

KC: So what you're gathering and gleaming from your perspective and what you are seeing and taking from what they're presenting you with, can they be different levels, poles apart?

NURSE 10: Yeah, yeah.

KC: Is that difficult to try to cope and deal with a situation like that?

NURSE 10: It can be difficult. I think where the difficulty comes in is that when you bring this to a team attention, you are going to have a number of different perspectives in this issue, from the team approach. And because each member of the team do, is coming from a different cultural background, and there's going to be, say the professional approach versus the, the mmm, human perception of each professional, [e]do you know. So when you put it in to the whole framework of the team, it's going to be very hard sometimes to transmit to other members of the team that this was actually enough, to actually sit and listen, not to fix, not to mend and not to change [e], and this is what this woman needed. This kind of mirrors the difficulty too, that difficulty kind of mirrors the difficulty I had in relation to what if [e] something happens this individual, say she's at her snap point at this point, and I feel I have gotten this information, this woman on more than one occasion, said to me, I am telling you this in confidence. Now from a professional point of view, I know mmm, I was obliged to tell her, you know, we would be need to be aware that she is struggling without naming the issues, maintaining the fine balance, that took me a long time to get that message. I don't know did that message go across to her, which leaves me with the dilemma of, if she didn't hear that message and give her consent for me to tell the team, so here am I left with this. But making, mmm, a judgement in inverted commas, on the overall thing, [mh] I know I had said to her on three or four occasions, that I must bring this up, an awareness to the team, without naming her issues for her, maintaining her confidentiality, but I don't know, I feel maybe as time unfolds, I think a process, sometimes I have found in people who might be dying over a period of time, sometimes that dying process almost facilitates and allows families' healing. Sometimes, it's more space for the family than the patient, because the patient herself in this case is at a point where she's making the preparation for her death, she has all her plans made, she has decided what she wants. She's trying to communicate that into a forum, i.e. into the family unit that are not in the same place as she is at all. They're in a place of trying to do their best, as they put it in their own words, for her. They don't want to even feel or think that she's dying and their dilemma is, their environment around them senses of nothing but death and their experience of our environment is, because they have, they have mmm, a history of knowledge of other people who have been in the same situation and they know the outcome. [mtm]

So they're grappling with two different poles. They're holding on to their sister and they have, their belief is she's not going to die. So when I brought them back to the point of what they had been told, bearing in mind what they have been told and what they hear are very, very different issues [e] and I found that. That even happened in my own context, because what that woman was hearing from me, in her distress, I mean I know that ground will have to be visited and revisited. The hardest thing for me [f] was leaving that, and leaving that after a week's night duty, I suppose, entrusting that to a team, but you're equally trying to communicate because the palpable aspects of that conversation cannot necessarily be perceived in documentation. My challenge was to document this, in such a way that some of the palpability of what was transferred would be felt. And I think as professionals we need to be very aware of how we document and what we document and I suppose the language we use around it. But I found myself even looking for [e] the language to describe this, because this had its own language. And like, it was through body language, through expressions, through, you know the grief of, the palpable sadness [e] was something else, 'cause they were just, you know, unbelievably, unbelievably upset, traumatised, everything, you know. [p]

KC: NURSE 10, you brought out very poignant points there, and the palpable language and the non-verbal and the difficulty of you trying to document that. Mmm, what was it about that language that you were trying to sense, and trying to pass on to others. Would you be able to describe that?

NURSE 10: Yeah, I found, you know, I suppose for me all I could do for, in order to communicate this to the team, was almost nearly to relive that experience, you know, ten hours later or whatever and in the telling of it again I'm sure certain aspects of it would have to be lost [e] because I'm not, I'm not that person with this issue. I was the receiver of this information and in that process, you know, my own, I suppose my own mmm, interpretation, my own influences on that can't be denied, because they, no more than even in your own work in research do you know, it's very similar like, you know, and but what I have to be careful of was not to have any bias on this, but it just spoke for itself [e] and I just hope as the communicator of her needs, that I did justice, you know. In actually pronouncing [mh] and trying to give a sense of you know, what was this all about, and I suppose, the fact that I had this experience in the space of two nights, two different members of the one family, and I would have no doubt in saying that some

of the others may not be able to verbalise; in their non-verbalisation, there was as much going on, yeah.

KC: Right, and because I've been there and seen those people and family, what may not have been spoken and yet, just looking and seeing, you said earlier on about looking at the whole picture, in looking at the whole picture could you tell me what constitutes the whole picture for you in order for you to make the judgement?

NURSE 10: Right, what one tries to do, I suppose the point that one starts at first is not to stereotype situations, [r] you know, I'm back to the commonalities of, of situations in terms of family units, etc; etc; but each unit being independent. You know, now from, from the previous experience, like for example you may have, you may be in a situation you have husband and wife, full stop, no family, no extended family, no whatever and you know you've been exposed to a similar situation before but not likeness in every way, so you have a starting point, you have a starting point but from that starting point it's through I think a whole process of, of communication and, mmm building up a relationship, building a partnership with the specifics of each situation, but you must have your starting point, you know, [e] I suppose coming from the notion of expertise, your starting point sometimes can be a trigger from a previous experience. Like, coming back to the situation I've just been talking about, you know, I could count five or six similar situations both in-house and in community, in hospital, you know, you're thinking, I've visited a similar situation before, but not this situation. So I suppose, your starting point comes, from your awareness again, but it's about starting broad too, you need to think, there is a whole picture here, but that whole picture very often you may not always get the whole picture, as I said to you before, down along the line, you may end up with your jigsaw and some pieces missing, because there's aspects that may never emerge. Equally, there are aspects that might emerge after three days or after four days when the particular group, 'cause equally there's a similar process going on for those people. They're trying to get a whole picture of the place as well and of all the different people that are in it as well. They're encountering a number of people as they, as they mmm come in to the hospice, or as they live in the hospice [e], in a lot of cases, you know. So they're, there's a kind of a two-way process going on and a two-way process that's a kind of a multi-dimensional from both ends, so, in that way, there's a lot of complicated things going on [e] and sometimes what, what you're seeing may not necessarily be what's truly happening, because, like anything, like when people come and they have to adjust and they have to settle down, there's a certain amount of role playing I feel goes on for a little while, you know.

KC: And this role-play, can you tell me more about this?

NURSE 10: Well, there's a few sides to it, it can be one-sided, two-sided or three-sided. I would say yeah, it has its potential, yeah, it can be and I say, if, because everybody is trying to get a sense of what's happening, so at one level, you're a kind of tip-toeing for a little while, you know, you're going gently, you're, you know you have to go along with certain amounts for a certain length of time, but as the various revelations come about, and the various pieces get added in or subtracted as the case may be, you know, the picture changes readily. You know, and, I think it's about, by maintaining the engagement with the whole process and being aware of the whole process [e], you are constantly aware, but then, you're only there for twelve hours or whatever, so there are aspects, that's why I'm coming back to the whole team element, there are aspects that have to be added in [e], you know clarified, verified or nullified as the case may be. So what happens today may not have the bearing you thought it might have tomorrow because the whole picture can change again. You know, and there's only bit by bit, because if you bring yourself to the perspective of the patient, if I end up being a patient somewhere tomorrow, I mean, through whatever process, there's going to be aspects of my information that may never be known, may never have to be known [e], [mtm], but in the context of, mmm, hospice care, I find and the vulnerability of somebody dying, and sometimes there's a pressure to almost a pressure of speech when people feel that they must tell you all this whatever in one hand. And on the other hand, I have had experience people will clam up and they will just close the door behind everything and maybe there's nothing can be revealed and you're back to maybe search and find and get behind and it could take you a long time, you know, as I say, one gentleman that we had, and there was very little that came forward and it was only in the latter end that when I sat with him for two hours his whole life story came together. That was his way that was his style. But, you know, back to kind of the whole individuality of each situation, very much that there is really, there is no pro forma, do you know, there are guiding principles, there are philosophies, but they're there, it doesn't mean that everybody is necessarily going to follow that series of events. So I think the challenge to us as professionals is to, be able to allow people top maybe mmm, pick and choose what they want but not ignoring that at a professional level we must be alert to and to try and pick up on certain things that may, people may not realise that this needs attention, or this could warrant attention, so we have to be able to, to offer people [e] like no more than what I did the other night, but that's where my hands were tied, because this person made their own choice. Now, I don't even know how informed that choice is

because I would have self reservations about this individual's ability to even know whether they needed help or not. Do you know? So that's another extension of, of what happens, you know. [p]

KC: So in that equation, are you looking at the patient, you're looking at the family, you're looking at their level of knowledge, comprehension, the reality, is it all a very difficult process for you as the expert palliative care Nurse to manage all of that situation?

NURSE 10: Mmm, it can be difficult, yes, it can be difficult, but I suppose having said that, mmm, ok, it's equally as difficult for the people involved, because they too are on a learning process, you know, particularly for the family we were talking about. These people had never, have never been exposed to such an experience before. Now they've had an awful lot [e] of life experiences that you and I will possibly never have, but they have never had this particular experience and I suppose sometimes, those similarities, I suppose those can happen to ourselves again, and that's why I'm saying, even though we have certain level of expertise, there are aspects to the experience we may never have had, and we too are on a learning process [e]. But I think it's about recognising that this is a learning process. That in itself can be, I suppose a little bit chilling at times, you know, to stop, people to stop and think but it's important that people don't assume that they actually know everything. You know, and it's about a kind of "know how", do you know, mmm, these are these are where, and even sometimes you might know how, but it's very contextual. You know, because mmm, like even looking in your article and Effacer wrote about intuition being not teachable, and not you know, and the proposition that it may not be not teachable, and the way she looks at that and says that it can actually be teachable, but I think it has to be teachable to ourselves first.

KC: Right, teach us and then let it maybe spread out and move about?

NURSE 10: Yeah, yeah. 'Cause I constantly have to teach myself as well, you know and usually from each process that you move away from, there is something that you will actually bring with you. Now you will bring a lot to it [e] as an expert in the field. And I use that term very reluctantly and very wearily like, you know, because that can be very self-defining too, do you know. [ic] But I would talk about me as an expert in the context of maybe my clinical experience to date, whatever knowledge base I have to put to it, but not expert in the context that I have no more to learn.

KC: Is it an ongoing process and constantly evolving, would

you consider?

NURSE 10: Yeah, yeah, it's not like something that it's done and dusted and I know all of this now. No no, no, [e] I don't, because it's as much like for the patient, because in as much as, like for the patient and for the family, they were on a complete learning process. They are, and it's a very painful learning process, and the outcome of this is going to be loss, [e] and change and grief and it's a very, very stark reality for these people. But equally for, for the professional, you're, you're learning with them and I suppose, you are, you're absorbing the pain for this learning, for them in this learning process. You know, that part of it, you're not ever really removed from that. You know, [p]

KC: And would you there nurse 10, when you say there about the pain, would you be able to describe the pain that they or you may be experiencing, and going along with them in that pain?

NURSE 10: I felt in this particular scenario, hopelessness is the word I would use. You know and particularly for the two individuals I met, the second individual had just lost her own husband in quite a short period of time, and I would say had never really and has never really mmm, been able to come to terms with that, and is maybe in a cycle of pain [e]. And this is another dimension in this cycle, and hit has come into it, so it's a whole cycle of loss and pain, and I felt myself, I had to guard myself from feeling their hopelessness, I mean, feeling that this situation is hopeless and I can't do anything about it. Because, whilst I couldn't maybe do what I would have liked to have done [e], for them, that had to be governed by as I said, the boundaries that were put around me. And the boundaries being that, even when the woman said to me "all I need is", that was everything she needed and I feel maybe, I did give her everything that she needed. I sat and listened for two hours and I got a life's history poured out. Maybe that process in itself will bring some healing, I don't know. And the fact is, I won't know and I'm going to be away from the situation now for three weeks. That's part of the pain for me as well. You know, there's unfinished business and there's unfinished business for them and, at the moment, and there's a certain amount of it for me at this stage. But I have to then, I suppose recognise that I'm part of a team, this needs to be, you know, facilitated at team level, and because I may have absorbed a lot of what these, both these individuals were saying to me and I perceived a lot of their loss, and because I can't get back and revisit them and see. And they actually knew, because at the point she said to me, she needed someone to talk to and I, at that point I had to be very honest with her and say that I would encourage her to seek

another member of the team that she can, that she feels she can communicate with, liaise with, and entrust herself to that person, because in my absence, I won't be there. I felt that I got such an outpouring in such a short space of time and then I'm now gone from the picture. So I didn't want to leave her under any false ideas that I'm going to be here again tomorrow night. You know, so that was, here was another loss, you know, and they had to make another adjustment.

KC: And on Monday, you were very much within the situation with them, and maybe facilitating them through that hopelessness, through that loss. From the context of the patient, do you find they, they may have this sense of hopelessness and loss, and not necessarily in this case, but in general.

NURSE 10: I'll come back and talk to you about that in a minute (break taken). Yeah, I suppose really mmm, when you're talking about the sense of loss and the sense of hopelessness for individual patients, and not just particularly the situation we've been talking about, maybe, just focusing on the week we've just come through, mmm, one or two individuals that mmm, maybe you've encountered along the way, but maybe if we just look at somebody like Myles (pseudonym), [la] for example, mmm, here was a gentle man that like, to the mind's eye, that when you looked at him he had a lot of losses, you know. Like, his functions, his communication ability, all of these things were impacted upon by his illness. [p] And mmm, initially I remember sitting in the report and listening to the handover and thinking oh dear, you know, poor man, and I have had visited a number of these situations before, you know, looking at all the potentials of what could happen to him and etc; etc. And mmm, when I went in to see him afterwards and just was assessing him for the night and get him settled and whatever, mmm, he did have pain and a lot of physical pain at that stage. And he, he did indicate to me that he was actually very, very tired after being three hours waiting to move over etc, and the whole trauma of the day. But, you know, sometimes you can actually be, be very wrong. You hear, you get those case history handed over to you, you listen to the whole notion of his illness and all the different things he would have encountered, but here was a man I had perceived was really, really very, very together [e] in the midst of everything and everything he had lost and he was about to lose. And his whole contentment centred around the fact that he had now actually reached the point that he had arrived. He was at the hospice, and his, his objective was that he would be comfortable and that he wouldn't have pain and that despite all the body image issues and everything for him, like you know, he knew that mmm, himself, that you know, these were all adding up to the one picture like, you know, but he just had this whole sense of [p] he was just so excited, at one level to be able to sit out on a chair, to feel that we could respect him

in terms of, he didn't want a whole lot of people flapping around him and all in a panic. He got that message through to us and once we know his pace and knew what he wanted and allowed him that space, that's exactly what he wanted. Now, my initial sense was, this man, this situation for him is so hopeless in every way, because he, here he was with a pronounced terminal illness, but he had so many losses [e] in all of that like. The fact of not being able to communicate, here was a man, who was a journalist and it was ironic really, 'cause you know, he spent all his life writing and his dying process, what he spent his time doing was writing, you know and communicating to us on a copy book, and we writing back to him, whatever. Now, I must say, I communicated with him a lot through, through touch, through eye contact, through mouth lip reading etc, he was somebody that, when we talk about touch, that it was all right from the first instant he was somebody who was all right to be touched and to touch. And like, that was fine by him, you know and his way with you, he would touch your hand, he'd hold your hand and kiss your hand, and you know, and even to have a laugh like, to tell us you know we were really beautiful and I'd be saying well, and he'd look at you and say "your face, your face, your face is so lovely" and everything and I was, be thinking like, mmm, Ronan maybe you need the opticians you know, and he'd laugh away [l], but to him, you know, I knew what he was talking about beyond a level, because sometimes I think our face, our own face can communicate something about us like, you know and I'm very much into looking at peoples' eyes, and you, what they're saying to me that way. And you have to really focus [e] on him from that perspective and how wrong you can be, because I felt so sad for him because, because of all of his losses and here was this man, like, when we met him, that was just so content [e] at another level like, you know like Ok, he had a good night's sleep, that's what he wanted like, you know, and we got him settled and, it was a kind of an achievement, not even that we had, a kind of made him comfortable or whatever, but we knew he was comfortable 'cause he communicated that back to us, like you know, so from the respect, yeah, mmm, he was very much at one with what was going on for him, I felt and how wrong you can be. Now having said that, you know, four steps down the corridor and turn into the rust room, you had another lady in the bed on the right, you had this whole stoke ness about her and that everything was fine, [e] you know. Now this woman was somebody who used to get out of bed and walk on her own and pain written all over her face. But to assess her like, she, she never had pain and whatever. That was her way and yet, there was a profound [e] sense of loss and grief and everything about her. All you had to do was be in her presence and you felt the whole hopelessness that was around her, even though her reactions and her verbalisations were the complete opposite. But I remember speaking with her husband

and he said that, that was her way for the children, albeit adult children at this stage. But for themselves, when they were together, they had their own moments. So I suppose I had some sense of yes, she is acknowledging what's happening for her but just we're not privy to it. We're not to be privy to it. Her family aren't privy to it, but it's her and her husband, her soul mate, you know and there was something very pronounced [e] and it touched me at a personal level [f] as well to think yeah, and they were very much soul mates, do you know. She talked to him about it and I suppose our objective was to find out how he was coping and how supported he felt like, you know.

KC: And not being a part of that, was that ok from your perspective?

NURSE 10: Yeah, yeah, it had to be. You know, at another level, that was her way and that's what we had to, so we had to respect. But somehow you always, not always, but, a lot of the time it comes back to you that some way you get the message that things are all right or things are not all right. But that was their way, we respected their way of doing it and I suppose, sometimes the frustration [mh] I have is around the notion of this space that people have around them and the environment. I mean we had a lot of struggle that week about the whole unit, because we had somebody else dying in that unit as well. And you had quite a big family, you had a woman opposite her again who had just lost her mother who is actually, the woman is actually dying now herself. And we had a lot of stress for the staff about, [e] you know, this is ridiculous like ... you can't protect people from the knowing of what's happening. But then, sometimes I think go beyond that, I mean, an awful lot of people who are in the hospice, coming back to the young lady who was admitted only last week. Their knowing has come from, you know, their local contact in the community with others who have died and I'm thinking, sometimes are we death denying to that degree, you know, that even though while I find it very hard to, maybe look after people in the context of a four bedded unit, as I say, through the silent, sound proof curtains [l], you're trying to talk to, for example, Ruth (pseudonym) about her issues and the other woman has died, you know, the family were, that woman's family, the woman who died, they were very conscious of the other people in the ward as well, and they were conscious, and I think it limited their expression of grief when their mother died as well. They were curtailed [e] by the environment. For them, I mean, do we live in such an ideal world, you know, what can be so ideal. We have the space of nineteen beds, every, all the rooms were occupied, we have, you know, all different scenarios going on, and the reality is that people die in these circumstances, but I think it's sometimes it's from within the staff to be protecting other people that are in the area and back to mmm, the lady on the right, she basically, we were almost feeling what she was doing at another level. She was

protecting her own family, [mh] that was her way of doing it like, you know. But I suppose somewhere she did have, which I was happy to know, that she did speak to her husband about it and he knew and she knew and they knew and that was all right and we knew [l]. You know, it was one of these processes, but, I just felt that mmm, you know, that she had so much loss in front of her, but the way, the way she wanted to do it was her way like, you know and that had to be. We knew it and we couldn't name it.

KC: Right, but yet you were conscious of that fact, well, this is the way she wants it, this might be the ideal way, but this is the reality of the situation, so you facilitate what you can?

NURSE 10: Yeah, facilitate what you can [p].

KC: Can I come back to your earlier, something we were talking about earlier, I suppose in relation to the preparation of people, and again coming up from the hospice, where patients are dying, is there anything that you're doing, in the context of their preparation and maybe living at that stage when they're dying, that you might be doing, maybe to help them?

NURSE 10: To live with dying?

KC: To live with dying, yeah.

NURSE 10: Yeah, I suppose looking, if I was to look back at the number of people that would have lived with their dying, mmm, and my experience of working with them and being with them, I think these are the people that, they almost communicate that to you m that this is how they want to do it. They set the agenda, you know, in terms of living with their dying. It's usually the people who are very open, you know, in terms of their recognition, [e] that they are actually dying. They may have a number of goals, they have a number of things they want to do, and because of their identification of the, their own dying process, they almost empower you and they will almost dictate what you can do and what you won't do, but that usually comes from an open communication. Now, having said that, there are situations where I would be aware of where maybe people would not have been as open, it may have been a much slower process to come about, but in some way, mmm, they actually have lived with their dying you know and maybe that might come about maybe through, through the family as opposed through the individual patient themselves. Sometimes, the medium of their communication is their family. You know, and that's why it's so important that you work, with patient, with family, family patient, you know, they're

all virtually the one unit, and you'd facilitate that process, you know, maybe true, true, mmm, through the family, like, but yes, certainly mmm there are people then at the other end of the end that denial is their coping and they have lived in that denial, but that's how they have lived with their dying. Yes, so yes, you do, you do have people, but it's not the same format for everybody, like,

KC: Right and as you said earlier, maybe you're drawing on the retrospective elements of what was gone and looking at it in a different light and using that information, that knowledge, that experience to help them deal with dying?

NURSE 10: Mmm, yeah, sometimes you may, it may, mmm, you know, following maybe a certain amount of, of counselling, you know, people might feel very safe when they come to the hospice and they may feel they can talk about certain issues or whatever, and sometimes it's not until a certain resolution has come that the living with dying begins [e] because sometimes people will arrive at a point when, maybe they're still in denial but that doesn't necessarily mean that they will always stay in denial too. Do you know, that through some of the processes along, through the exposure, through the encounter, through whatever medium, something may happen, you know and you see this shift, this paradigm shift, as they call it, do you know, and I have witnessed that in people as well.

KC: That was what I was going to ask you, what is it about this person, and you say, they are not shifting and they're here and now you know they are shifting, what is it that you see in them that tells you that?

NURSE 10: Mmm, I suppose really, [p] some of it comes from intuition again, you know. You're [p] and some of it will come from you maybe, from the individual. You will get, you will get a sign and you have to be very careful sometimes when you look at that sign that you're not reading your own thing into it. Do you know, that's very, very important and, but in order to mind it, to handle it [e] you kind of, you have to nurture it first. Whatever you perceive to be the change, the sign and then you have to explore it and get it confirmed or otherwise, and very often you'll find that, maybe somebody that you have, mmm, I remember one particular woman and I spoke to you about her again, that was looking for me at one night at half past ten, [ds] you know, when I was off duty whatever, and I was in the house, whatever, studying and mmm, one of my colleagues who had been with her said, she has let go, she has let go, to the point two days before hand she was over having a CAT scan. That's how fixed she was and determined to the very, very end. But she had let go, and when I went in to see her, she just said to me, I just wanted to say good-bye. You know, [p] so what more really do you need and I said, even in her saying

good-bye, even in naming it as good-bye, she was saying good-bye to a lot of things. Maybe good-bye to her fighting, this is now over, you know. Now, having said that, like, we've had a gentleman there a few weeks ago, I don't know whether you're aware or not, and the process went on for weeks and weeks and weeks. That gentle man that was in room X. And there was an awful lot of, he had a lot of peaks and troughs in his illness and he took an awful lot of dips and the family were called in and whatever. The frustration [e] that went on around that was something else, everybody like, you know, family, himself, staff, everybody and this man, like, died in his own way like. And I had family saying to me, we're here for the last six weeks and we're meeting relatives who are saying to us, oh, my mother has maybe only two days or whatever left and they say that would happen. We're here being told he's changed and nothing's happening, whatever. And I suppose the hardest thing, these people as I said to them; they hadn't encountered the relatives like themselves [e]. I have, I know people who had the same experience, that message doesn't necessarily bring any consolation to this particular group, but when I looked at one of the family and I said, the people who you are encountering are not the people who have had the same life experience as yourself, so they're not comparing like with like. But, when eventually that man did finally go, it was just, so, so amazing like, after six weeks of up and down, up and down, but back to your point, I'm diverting a bit I know. Back to your point in terms of how do you know when somebody has made the change, sometimes people will tell you. Or it's a particular incident or, like the man I spent two hours listening to and we talking about whatever, you know, I had a sense that when he had that part of business done, and that was a huge, it was the biggest stepping stone, that was the whole clarification for him that I am actually now in my dying process. And when he went through that phase, very short time after that he, he actually let go. I'd say the number of people that have relatives, you know that yourself, you've seen it, people coming home, people you know, waiting for people, waiting for news, waiting for whatever, sometimes you have a sense and I suppose back to our expertise I'd often find now and when I'd go to somebody I'd say to them, is there anything in particular that you have maybe a wish for, anything that you need to do, is there anything outstanding for you and when you throw out that to people, they might say to you, I mean haven't seen x, y, or z for so long, or in the situation in relation to Mary in the rust room, she's a big life event that never got sorted out. You know, and at this particular time, now, there's semis-even relief come from the fact that that has been named, it's been looked at, it's being addressed, because sometimes, I find people, and maybe some of this is my own intuition, people don't want to go with something hanging around

them, hanging over them, not sorted, not whatever. It's like asking you to kind of, it's very hard to leave the house and the fire blazing and you not calling the fire brigade. Would you do that? You know and that allows you for yourself as somebody who is dying, I mean, if there's certain things that you wanted or somebody that you wanted to see or something you needed, to say. And I suppose, some of that comes from our expertise and from our experience, but your intuition around the people that you are around. I mean you say long enough, sometimes you stay with something, you'll, you'll hear it, and somebody may say to you, it may not come in a direct way, but it could come in a very round about way. Do you know?

KC: And can I bring you there to maybe summing that up, what you said, it's knowing the space and allowing the space and not reading your own thing into it, reading it from their eyes and their mouth, it's that ability to be able to read it from their perspective.

NURSE 10: Yeah, and it's actually, it, to goes beyond ability. It's the willingness to do it. Because sometimes we might feel that we're, we're the only perspective on this issue because of our expertise and because of our, this might be the day that we're going to learn something very new. You know, so it's about being open, and listening to the, the person's perspective on the issue and clarifying it, like, you know, so certainly I'm saying that, don't bring your own, don't bring your own mmm, definition of it. That's what I think is very important, you know, the person is allowed to define [e] if they're able to, you may have to facilitate that process.

KC: And that process, as you were using your hands there, moving up and down and ...

NURSE 10: It's a balance, Yeah, it's a balance. It's a balance, because it's all about language again. It's all about meaning, it's all about understanding, and it's all about clarity. You know, so that whole process takes time. You know and it also takes, I think, bearing in mind a lot of these issues that people would have, they're very much life event issues. Maybe they're issues that are very close to people's hearts, the things that you do not actually feel able that you are going to necessarily hang out in public, you know and it's about first of all, coming back to Ronan, when Ronan looked into your face and said "it's all in your face", whatever, whatever he saw. Equally, you see that in people too. Do you know, and I don't know what he saw. But something in him, he saw something that he knew he felt safe, he felt ok, and I, I honestly feel, you know, and I remember saying to one of the girls, I really think that he will actually possibly let go very soon. The chances

are that in relation to his illness he's going to have a blow out, something is going to happen to this man. But blow out or no blow out, I'd say he went with serenity; I just had that sense about him, 'cause the message he gave to us was just amazing like. Do you know, yeah, yeah.

KC: Did you get that feeling that he was ok?

NURSE 10: Yeah, yeah. And equally you'll get the feeling if somebody is telling you they're ok and they're not. But there was a whole sense of completeness about this man, 'twas just, it was just fascinating now. Absolutely, yes. [e] And mmm, I think he just had his space around him and he had, and even in his, in his whole mmm notion of not having a whole load of people crowding around him and flapping around him and fussing and sometimes we can get very carried away with those type of things, organising this and fixing that and the other. And sometimes you have to stand still in all of that yourself and say: "just leave it, it really doesn't matter", if the chair is there and the bed is here or whatever, once he doesn't have this notion of flap, flap, fuss around him, [mh] 'cause every, we can't even I'd say begin to imagine somebody who in their own mind in their own heads knows that they are actually going to die. Their whole emphasis on everything must change, I mean, it's like us in day-to-day life when our priorities have to change, you really don't worry about the state of the house or this or that or the other, and transfer that to the whole notion of somebody dying. I think he just wanted to engage with this process himself, he didn't want the distractions of, of flapping around, fixing this and fixing the other, and whatever, and get that done as quick as you can, 'cause I want to be at [e] and to be with and to be one with what's happening for me, and that was my, that was my feeling for him, yeah.

KC: Thanks Nurse 10 for sharing your thoughts with me there, particularly regarding your practice. There was one point that we started to discuss before I turned on the recorder, and maybe you might be able to put it in the context of your practice and that's the notion of health promotion in dying.

NURSE 10: Yeah, health promotion in dying, yeah, the concept of it. Yeah, yeah.

KC: And I would ask you, is this what you're doing as part of your expertise?

NURSE 10: Yeah, I suppose really where it stems from is, the way that they say that the whole notion of health and death rarely, rarely sit comfortably together at all, you know, the notion of health and death. People don't see them on the one spectrum. And I think because of that, that mmm the whole notion of health promotion in palliative care has not been to the fore. Mmm, as I say, theories of health, you know, rarely acknowledge the fact, you know, health is usually a state of you know, kind of

illness–wellness and on that continuum, you know, there is no notion in relation to the person who is dying. [la] And I suppose really if we look at what the essence of health promotion is, and how we can health promote and the way we health promote, the three main issues that come through advocacy, through enabling and through mediating. So, basically to transfer those principles to the arena of palliative care and to apply them in the context of the palliative care patient, through that method, we can actually health promote and allow health promotion in people who are dying. I suppose, if we come back to Mary [pseudonym] again, I mean somebody like enabling, to enable her to actually mmm, follow through to clarify, to do what she needed to do like, you know, in relation to some of her life events, that was very, very important. Mmm, I suppose as Nurse s really, we'll say like, on a team perspective, we're very ideally positioned to mediate, mediate fro the parties that are involved, you know, either through mmm, looking at and challenging some of the policy issues that are around health promotion. I mean, if we look at the health promotion document, strategy document, there is no mention of the terminally ill in that document at all. So by lobbying the policy makers, and say to them, you know, you do realise that there is potential for people who are terminally ill to engage in health promotion, keeping in mind that the definition of health just doesn't belong to the wellness-illness spectrum. So, if it's a thing, because, in the narrower definitions of health, mmm, you know, when they talk about health promotion, the narrower definitions allow very little room for people, cause their whole wellness spectrum is possibly in turmoil anyway, you know, that part isn't going to be a reality. We are not going to prevent, necessarily prevent the illness, but in the broader context of, I mean in terms of the what the Ottawa charter would say about advocacy, mediacy and enabling, when you pull out those principles, they're as relevant to people who are dying as people who are not dying [e]. So I mean, I mean a lot of the enabling of people comes through like, education, and we enable carers to look after their loved ones at home, through the whole realm of patient education, through support mechanisms and in that way, we are allowing choice. We are allowing a healthy choice, for people to stay at home, or whatever choice they decide to make. Mmm, in that context, I suppose, policy has a big bearing on that, as well, 'cause I mean you look at resources, you look at allocation of resources, you look at where people live. Where people live really, determines the service that you get, you know, in relation to palliative care. I mean, you do a study of (another area) and you come down along and you look at the whole ethical implications of allocations of resources, say in an area like ..., I mean, you have variances of services. You have services that run from 9 to 5, Monday to Friday, you have services running from 9 to 5 Monday to Friday with call, you have services that have maybe two nurses, one nurse covering a huge geographical area that they only "put out fires" literally from one end of the week to the

next [p]. You know, so you're looking at spectrums, you know, across the board, like and I suppose with the introduction of hospital palliative care services, ok, that has you know, brought an awareness of the palliative care approach within the area, plus offered the whole specialisation of palliative care in the general area, which means that, you know, we're, we're actually recognising [e] the fact that palliative care belongs in a lot of areas and the demand suggests that it does. But, in terms of, mmm, say advocating for these people, there again like, as Nurse s, you know, and as palliative care practitioners, we are very ideally placed to do that, like, you know, basically we, even apart from a policy level and government level, at local level where we are ourselves like, we need to be able to advocate, you know, this is what this person wants, this is this person's choice, and we need to try and facilitate, facilitate that equally.

KC: And yet Nurse 10, taking those principles can I bring you back to your practice, where you have been enacting those three principles as an expert in palliative care nursing, do you see that, yes, health promotion is one of the attributes that's a part of expertise?

NURSE 10: Yeah, yeah, I think so. The fact, you see we, maybe along the way people from a theoretical perspective don't necessarily realise that this is what they're doing, because when I went, when I spoke about this subject on day one, I mean people shrugged their shoulders and they threw one eye up and they think "health promotion and palliative care", but if we work within the very narrow definition of health promotion, yes, [e] but we, you know, we're limiting it to, but the fact that palliative care is, you know, and does belong to a lot of areas, and it's quite a bedrock of a lot of nursing practice as well, and it can be the bedrock, you know, it's not just solely hospice that we're talking about. Palliative care as a philosophy can transcend, you know, if it's transcended, but that's why we need mediators, we need advocates, we need people to be enabled to do this. So what I'm saying is that, as practitioners and as an expert in palliative care, which I still use very guardedly, mmm, yes, there is room to health promote in palliative care and health promotion in palliative care is actually the way forward. But it has to be, it's going to have to be recognised for what it is and at another level, it's going to be self-defining, but thankfully the definition is much much [e] broader than if you take the WHO definition on health and disease. Now, mind you having said that, the principles of the Ottawa charter for the WHO is very much in line with mmm, their thinking in relation to palliative care, you know and where they see the objectives and the goals of palliative care. But somehow they failed to marry both of them. They looked at them in isolation. What I'm trying today, and I suppose what others have done, Alan Kellehear, Russell and Nadirs etc, they've highlighted this point and brought it, the fact that the dying, in

inverted commas, have been ignored. And all you have to do is look at our own Government Policy Document. I looked at it in the context of mmm, the welfare state as a reflection of ethical argument, and I discussed this in relation to palliative care, and when you go and tease down a lot of the welfare state, mmm approaches, etc; etc; you look at the ethics around, I've spoken about some of them in terms of resource allocation, you know, mmm, geographical distribution of services, etc; etc; and resources being human and financial and everything. Move away from that aspect of it and look at policies, look at their policy document, look at their health strategy document, there is no mention of the dying at all [e] in terms of health promotion, so health promotion is in a very narrow context and in a very narrow area.

KC: Yet, coming back to your working within the in-patient unit, you're enabling, a mediator, and the ability of the expert in practice to be able to, I suppose, live out health promotion, under the three key attributes of health promotion.

NURSE 10: Yeah, definitely, and as I said, like, practice and the theory are very much related and belong to each other, the whole theoretical mmm perspective of health promotion, because people didn't think that way. Do you know, so this is very much a new concept that has been in practice but has not been [e] seen as health promotion.

KC: Is it now that health promotion is being seen within the whole picture of palliative care practice?

NURSE 10: Yeah, yeah, yeah and it's part of mmm, the philosophy, you know and the philosophy of palliative care is not so removed from health promotion, but health promotion is removed from palliative care. So what we need to do is, is bridge the difference like, you know.

KC: And yet from your practice, you're doing that?

NURSE 10: Yeah, and I'm aware of it in that context, I am, yeah, but there would be a lot of other people who would not be aware of what they're essentially doing and what they potentially [e] can do. And it's to, now having said that too, we just need to be very guarded mmm, and Alan Kellehear writes about this, something that we're aware of, within all that there is patient choice. So the patient will choose how they will use the whole notion of health promotion and therefore as the mediator or as the advocate or whatever, you will be governed by a certain degree. It links up with the paradox of the whole person care, that Randall and Downey highlight all the time about the notion of "wholeness", but because they have this great package to offer doesn't mean that it gets imposed on everybody, the concept of choice has to be [e]

in there as well like, you know, so the patient will decide whether it's, what elements of the holistic care that they want, you don't just come and ordain everybody with holism, 'cause if we're doing that then, we're not giving individual patient care. You know, that's the ideal and that's the whole package we pick from, and that's what we have to offer [e], but what people want can be a very different thing.

KC: Right, and can I just ask you there in clarifying patient choice, are you extending patient choice to the family?

NURSE 10: Yes, I am, I am, yeah. I am yeah, because patient and family, you're looking at the whole unit. Yeah, yeah, yeah. But that's a, but equally people have to know [e] what they can choose from first as well, but if we're not aware [e] that health promotion belongs to palliative care before we go anywhere, we're not even going to know what we're going to offer these people [p] [s] (Looking at watch).

KC: Right, is there anything else you would like to add to this talk, regarding your experiences as an expert palliative care Nurse ?

NURSE 10: No, I think, just, really to, as I say, you know, when, as you say, you describe me as an expert palliative care Nurse , I'm back to the limitations of that. Being expert, expert kind of would suggest there are no limitations, that you are the expert, but, for me, there are limitations to it. You know, and, but those limitations, mmm, they can change, because every, every day is a new day, every client is a new client, you know, and you're adding, I'm back to the experience and the knowledge being the one process. You know, which, that's informing our theory and our practice all the time like, you know. So, it's a building process, I think it always will be a building process, that expert is not cut and dry [e].

KC: It will never be final?

NURSE 10: No, no, not infinite you know. Yeah, yeah. It's an evolving and a revolving process. Equally, you know, you've interviewed X number of people, under the mm, microscope of expert and I'm sure you have all different, you know, you get a common ground at one level, but I feel, we too are individuals in the same way as the people that we are, we're looking after like you know. OK, we have been exposed to various degrees of professional studies and theories and evidence based and whatever, but we, if, it's because of the nature of the knowledge of palliative care, which is what you're after and seeking out, the nature of that in itself, you know, you have so many different forms of the propositional knowledge, the experiential knowledge and the skills. [p] Parts of that knowledge are quite constant and quite definable, but there's aspects of that knowledge then that are very much varying and, you know, and going to be there's a wealth of

knowledge and experience and expertise. out there all adding [e] to the whole notion of expertise, you know. So, it makes your job quite complex as well [l].

NURSE 10: I really appreciate your time and for sharing your thoughts with me. I have been with you in practice and seen the structure, the process and the product, I very much appreciate your time.

NURSE 10: You're welcome. There's one thing I think Kevin, I always feel too that we need to be not fixed, you know, mmm, and not to be even in ourselves we need to allow ourselves not to be so predictable, you know, that, I need to be open all the time to the possibilities and within that, while we have to work within a structure, there are times when that structure can't be around you, you know and you have to allow for the fluidity, which is very, very important like, you know, that there are times when I need to be able to say at seven o'clock in the morning I didn't do this because, you know.

KC: Right, and would you say Nurse10 you might go too much within the structure or you might go outside of the structure, you know, in that sense.

NURSE 10: Yeah, it's about balance, you know, at one level, but I would always err on the side of the Ronan's [pseudonym used] and the other people and knowing that, [p] sometimes it's difficult 'cause work can, on a team, people are motivated by different, different things and I would be very conscious of the number of very task orientated people that I work with. You know and it can be very hard not to, or to disturb that status quo. So I've got the point in saying "this justifies itself". I shouldn't even have to justify this for you. But I still don't know how comfortable, I'm comfortable with the actual process of what I've done, you know, at one level to myself, but I may not be comfortable by the reaction I get around me, but I'll have to [e] go that road, you know, at the expense of that road, to make sure that the Ronan's [pseudonym used] and everyone are all right. I'm really not that upset if somebody is, gets so worried that he didn't get his bath or he didn't get such a thing. But at another level, sometimes these things, and I think, maybe well maybe sometimes everybody's thinking maybe doesn't go in the same direction but, but sometimes you see the finite. You see the point that I know and deep, deep down I know that this man is possibly going to die in the next twelve hours, so it's about prioritising within his priority and if you're reading the signs from him, if you're getting the clues from him, and if somebody actually picks up your hand and gives you a kiss in your hand and how, hold on to you, to the point, you know, equally you know if you haven't done the right thing too. Do you know what I mean, so it's there, so you know it's all right?

KC: You go into it?

NURSE 10: Yeah, so you get to the point and say well, I really don't mind, I'm sorry if somebody has been that upset that he didn't get his hair washed or something. Do you know? But, it's worth it. Do you know what I mean now at that end. Because he's fine, do you know and you get that message and sometimes we get that bond with people that, it's like nearly, it's like things you don't describe within your own family, do you know, the closeness you have to who ever, or what ever, sometimes things that you mightn't even discuss with anyone else outside of your own family, do you know, and sometimes even one to one in your family, you don't even have to talk about it, it's there, its so pronounced, it's lived in you, it's going through your veins you know. And sometimes there are times in the course of your, of your mmm, practice these things happen, you know, because you know from your own experience as well. You don't even have to talk [e], it's there like, you know, it's there, it's actually there like, you know, so I'm not and I'm not saying that from an elitist point of view or anything. I would say it from a privileged point of view as a practitioner. There are times and even relatives have come to me and said "how can you stay working in a place like this and whatever", but for those, for those moments there are moments along the path when you have and you know and like, even once is enough, if it's right for this one individual, 'cause each individual, that's fine, no, that's ok. And if, you, there's times when you get it wrong, you feel you've gotten it wrong, or whatever, and you have to work on that and you think, right, I need to stand still here and see what's happening and try and go back and work through things, you know. So, it's all about humanity and as I say, the whole, the whole human enquiry as a science, you know, pinning palliative care onto that, is much more relevant than to the whole notion of, as I say, positivism or something, that doesn't look at the subjectivity and it doesn't look. It's a very important aspect, it's not saying that there's not elements of palliative care that aren't teachable in that context, and can be didactic and whatever. There are elements that have to be [e], but the weight, I think comes down on the side that the human inquiry as a science in palliative care, you know, just has so much in term of looking at the whole subjective nature of people and that's where you go and you come, and human inquiry is the word really. Because that's what we're about all the time. You know, you have to keep inquiring and finding out, yeah, yeah, definitely. [s].

KC: Nurse 10, thank you very much. I appreciate your input.

NURSE 10: You're welcome, you're welcome. You'll have a bit of information to work on.

In an attempt to demonstrate the influence of Schleiermacher, Dilthey, Heidegger and Gadamer on my analysis of data, the following section provides an example of this process as it applies to the interview with respondent 10/1.

Influence of Schleiermacher on analysis.

I generated the following questions that were derived from my understanding of Schleiermacher's writings.

Statement 1: Understanding consists of re-experiencing the mental processes of the author of the text.

1 (a). What is it that caused this person to view expertise in this manner?

There appear to be a number of issues at interplay in this individual's situation. My interpretation of what causes this individual to view expertise in this manner is influenced by her knowledge, skills, competencies, experience, analytical ability, how she sees herself as an individual, her own self-awareness and reflective ability. Her experience and her dealings with a wide range of patients requiring palliative nursing care influence this respondent. Highlighted in the early stage of the interview is the wide range of experience this respondent has, what this brings to mind is one of the reasons why I'm doing this study in the first instance; seeing nursing staff deliver care at different levels of expertise, and I questioned the link between the experience and expertise. However, experience does not equate with expertise, it is influenced by the nurse's ability to utilise knowledge from experience, reflection, critical thinking, analysis and synthesis to "pull together" all of these elements so that there can be an influence on practice and patient care. Three key points were raised in the first section of the interview, regarding the nature of expertise: patient care, decision-making and different challenges. Patient care seemed to be the major aspect of expertise, in other words, how is the respondent's knowledge of death and dying translated into practice. Patient care from this respondents' perspective had come from a broad range of specialty areas in palliative care. Secondly, decision making; complex decisions that needed to be made in the context of in-patient care were influenced by this nurse's experience in areas outside of the in-patient unit. The nursing actions that were instigated were more than the sum of the parts. The person as an individual influenced

each element of decision-making also, and how the respondent's focus, view and place in life is for her contributed to how decisions were made. It was the "total self" as being immersed in the totality of practice, together with the respondent's ability to apply appropriate practices and analytical skills to each patient care situation that resulted in this person being considered to be an expert. Different challenges emerged throughout practice that demanded critical thinking, intuitive knowing, complex decision-making and the ability to monitor all activities within the unit at a time when one particular patient issue required complete attention.

1(b): What is causing me to view expertise in this manner?

Expertise, as it emerged from this respondent's interview is multi-dimensional. The central focus of expert practice in this respondent's interview is her knowledge of death and dying care, knowledge of the physiological, psychological and social issues surrounding death, knowledge of the "self" in the context of the patients, and knowledge of herself as a person. I take those into consideration as key factors that influence my thinking regarding expertise in this respondent's case. Statements such as "*they (patient's family) too are on a learning process*"; *I constantly have to teach myself*"; "*his whole contentment centered around the fact that he had now actually reached the point that he had arrived*"; "*that's why it's so important that you work, with patient with family, family patient, you know, they're virtually the one unit*", signify the scope through which this respondent views the recipients of care. This encompasses the necessity to be open to situations, to acknowledge that there is learning taking place, and that there is no final solution or stagnant point in caring for the dying, or in the dying process. The insight with which this respondent presented her description and understanding of her practice seemed to capture the intricate nature of expertise, however, I acknowledge that this interpretation is influenced by my pre-understandings and fore-structures as I have highlighted in section 5.2.3. Having worked with this respondent, I developed an insight into her ability to deal with situations, within the context of each unique situation, and yet, be able to bring knowledge from previous experiences to the event. Secondly, I consider that the respondent's philosophy of care is centered on the person as the focus of caring

actions. Person, within the context of the respondent's practice, appears to encompass numerous aspects, such as the past self, present self and future self. Also, the "self" of the respondent is one that involves having an all round grasp of each situation that is occurring, not just being focused on a series of individual happenings and events. Decision making within the context of her practice is another aspect that causes me to view this person as an expert. Decision-making processes as evident from this interview consisted of the generation of hypotheses, some of which were rejected, some accepted, and in the ensuing actions following these decisions, the focus was on the most appropriate outcomes for patients and their families. Ruling in and ruling out processes of decision making were also utilised, ruling in the "positive possibilities" while also taking into account the potential negative consequences, and considering "ruling out" alternatives. In summary, my view of expertise in this instance is influenced by my own knowledge of palliative nursing practice, palliative care philosophy, knowledge of the respondent and knowledge of the patients and their families that are frequently referred to in the course of this interview.

1(c). What does this particular word mean?

There are many words in the context of this interview that I had to review and come to a decision as to what they mean within the remit of this interview. Words, in the context of sentences, are presented below, in an attempt to demonstrate my analysis. Some of these are:

"Listening, I heard a lot".

This phrase to me brings to mind the notion of surveillance and a thorough questioning of what went with the listening. Listening, as part of this expert's remit in practice was there and involved a degree of absorption of the person, the environment, the verbal and the non-verbal interactions that were at interplay with each other as she dealt with this particular situation.

“I try and look at what is this current situation demanding of me”.

Each situation is unique, yet each event occurs within a milieu of a whole process of activities that are constantly taking place as patients progress through their dying process. This respondent acknowledges the uniqueness of each situation. At the same time, the knowledge and skill she uses in addressing each situation is focused within the margins of the individual situation, while the response to a particular situation is influenced by past experience and knowledge of practice.

“Care is only going to be as holistic as the patient will allow, or the client will allow, and in this case, it was the relative”.

Boundaries are attached to caring. The recipient of care sets these boundaries. The nurse works within the remit of these boundaries and through her knowledge and skills of the situation, she proposes ways in which she can help individuals survive and address issues that occur within these boundaries.

“It’s not about coming in and fixing it all. It’s about letting things be”.

There does not always have to be a solution for every problem or issue that arises. Problems need to be viewed contextually, that is, taking cognisance of the person’s “whole self” and where they are at within the remit of their living and dying. There are problems that do not require an immediate solution, and in the event of a solution not being to hand, “fixing” is a process that can occur over time.

1(d): What thoughts are being expressed by this statement?

Statement 1 (from interview transcript):

“I have found in people who might be dying over a period of time, sometimes that dying process almost facilitates and allows families’ healing”.

The awareness of death as a process, one that is spread over a period of time allows time for realisation, acceptance, rejection, anger and emotions to be addressed, both in the individual who is dying and in family members. It also signifies that death highlights a learning process, a journeying process over time. The journeying towards death does not always need to be seen as negative. It brings with it, at times, a period

and process of repair and restoration, where dying people and their families may have the insight to view the dying process of presenting unique opportunities to revisit life's trials and negative issues that may have arisen among them. Death is unique for each individual. The processes that are experienced are in constant movement, one that is, in some cases slow, while for others, is relatively rapid. While individuals do not choose which process of dying they engage in, there is a time for addressing past and current life issues. This time is one that is also important for family members. Issues from life that have caused family problems, upset, and disharmony are often brought to the forefront particularly at a time of impending death. The difficulty that these cause when they are not addressed often results in a state of helplessness, disempowerment and isolation, and can create apparently insurmountable barriers that need to be removed. An extended or prolonged dying process provides families with the opportunity to attempt to address these issues, and in doing so, brings about some resolution of how they are feeling, and how they cope with what has gone on in their lives in the past. It brings about a stage of healing, where the wounds that this disharmony has created begin to repair to the extent that a prolonged dying process allows for further healing to take place. However, where the dying process extends excessively long, there is a danger that the healing process may stagnate and the wounds may reoccur. The role of the expert is to try and gauge the stage where the dying process is located and be there to facilitate the healing process, both for patients and families.

Statement 2 (from interview transcript)

"..... everybody is trying to get a sense of what's happening, so at one level, you're a kind of tip-toeing for a little while, you know, you're going gently, you're, you know you have to go along with certain amounts for a certain length of time, but as the various revelations come about, and the various pieces get added in or subtracted as the case may be, you know, the picture changes readily.

The whole picture is one that is constantly being created. The nurse's challenge, in this case, is similar to one of the artist. The raw materials are presented to her and she has to create the picture with what she has got. Some materials are in more abundance than others, and the challenge is to form a mosaic with the materials in order to create

the final picture. But life is constantly changing. There is no stagnant or complete picture, portions are being constantly added and subtracted, so that the foundations for the picture are constantly shifting and moving. The challenge for the respondent in this case, is to try and make sense of the picture as it is being created; to bring out all that there is to be seen. She needs to possess the ability to nurture the picture, even though the range of uncertainty that can emerge during the living in dying process is unknown. The respondent guards the delicacy of the emerging picture in an attempt to let it evolve in a “natural way”, but she is there to guide its creation. The need to provide guidance is assessed through her knowledge of the patient, family members and her past experience. Learning to create the picture is an aspect of her practice in this situation. There are a number of artists involved, but the principal creator of the art, - the patient - is the one that needs to be listened to most. Many revelations come about during the dying process from the main artist, or the artist’s family, and these changing revelations are addressed through the practices of the respondent.

Statement (2) : Understanding is grasping the meaning of the parts through the whole, and understanding the whole through the parts.

2(a). What is being said in this instance, what understandings have I now from what this person has said?

Palliative nursing practice is complex. It is one that requires commitment, vigilance, knowledge, skills and an ability to be able to read the innate meanings of interactions, verbal situations and the non-verbal communications that take place within each individual situation. The interplay that was occurring in this expert nurse’s interview regarding her practice highlights the significance of being able to become immersed with each situation, while on the other hand, being able to become detached from events that may detract from her ability to deal with each individual situation as it arises. These events, as they are interpreted by the respondent influenced the respondent’s ability to read the messages that were being transmitted during the nurse-patient interactions and family members’ interactions. Reading the signals is only one aspect of the dynamic interaction. Being able to interpret the situation in the context of the macro events of the patients’ lives, together with the rich tapestry of happenings

within the family situations, provides the expert with a focus on which to address practice issues for both patients and families. Caring for families formed a central aspect of the work of this respondent. Family care, like patient care, is tailored to meet the individual families' needs, as opposed to providing universal family care, without taking individual needs into consideration. Guiding principles of palliative nursing practice and palliative care practice provide a template for care; the interpretation of the template provides the uniqueness in expertise. Interpreting how this template is operationalised requires knowledge of the patient, family and self, while self-awareness and reflection enhance the process and outcomes of care. The nurse as "a person" within the realm of care is not detached from the practices of this expert. The "person" element of practice allows for mutuality within the relationship with patients and families, while it also paves the way to a deep connection with patients. This connecting, as a means of enabling the person to progress in their living and dying, is a supportive element of practice and in some instances, may even be considered to comprise of "extra care". Extra care practice is interpreted in an individual context and indicates a willingness on behalf of the nurse to make a difference through caring actions beyond what is normally expected or required.

2(b). What are these actions from my observation notes telling me about the whole of the person's practice?

Action: Sitting with a patient in her room at 11.00 p.m. holding her hand, with lights dimly lit. While the patient is tearful and expressing her sorrows regarding her impending death, the respondent holds her hand, maintains eye contact with her and is talking in a low voice to the patient.

What is the above telling me about the whole of this person's practice?

There is a deep sense of expressive commitment in this interaction; however, it has not gone beyond the boundaries of the nurse-patient relationship. While this interaction is occurring, there is a sense of the respondent "being in control" while allowing the patient to verbalise her feelings. Control, in this sense, does not infer an inferiority regarding the patient's being; it infers that activities and actions are deliberate in

supporting the patient through her feelings of turmoil, anxiety and loss. There is also a sense of control coming from the patient; she is dictating the pace at which the interaction is moving, and in this movement, the nurse is supporting her, staying with the feelings, the emotions, the ambience of the moment, the milieu that is present within the hospice situation. The nurse's practice is encompassing the patient as a person - a person who has a, a present and a future life, even though the future life and its duration is one of uncertainty. Time is not an issue; time is created for this person, and there is no rushing to complete tasks. The task at hand is that of dealing with this person's situation as it emerges for her. Choices are offered to support the patient, and this signifies the nurse's willingness to offer different approaches to deal with the current and future situation.

2(c). What is each sentence telling me when it is viewed in the context of my observations?

The practice of expert palliative care nurses is set within the realm of caring for the dying. It is unique for each individual and yet, in spite of this uniqueness, there are similarities for each patient and family the nurses deal with. Experience provides a major foundation that guides these actions, and this is complemented by the nurse's knowledge of practice and knowledge of death and dying issues. The philosophy of palliative care is embedded throughout her practice; comfort, pain relief, facilitation, presence and whole person centred care are the elements encompassed. Practice is carried out in an unhurried manner, one that reflects dying, in a sense, where patients cling to living and life. Making focused time is central to practice, while balancing this with the need to care for other patients strengthens the self worth of patients, and promotes the feelings that, despite the onset of death, the presence of life is enriched with worth also.

Statement 3: Understanding involves perceiving the individuality of the author as a human user of language.

3(a). How best can I apply language to what I am seeing in the context of this observation?

I need to use my experience of nursing practice to apply language to what I am seeing. Language needs to be straightforward, uncomplicated and yet, the ordinariness of the language needs to portray the extra-ordinariness of the nurse's actions. Sometimes, the ordinariness of what I am seeing goes beyond ordinary and becomes extra-ordinary. This is a necessary fact to acknowledge in the practice of expertise in palliative nursing practice, as it is set and delivered within the context of dying.

3(b). What are the unique elements of my understanding of this person's interview and practice that go to create the whole of the experience?

The respondent's ability to create the milieu that was evident throughout the interview and observation of practice was unique. The milieu she created within each patient interaction was different. It was aimed at different levels of intensity, with the concentration being on how best to meet the needs of the individual patients she was caring for.

Her knowledge, while to an extent mirrored other respondents, displayed a high degree of insightfulness, compassion, friendship and friendliness that was difficult to apply words to. It superseded many of the other respondents' accounts of practice and throughout the observation of practice, she brought with her a presence that was complex, hence making it difficult to describe. Her innate ability to provide comfort, to show compassion, empathy and understanding to each patient situation highlighted the array of skills necessary to practice at expert level.

3(c). What circumstances surround the individuality of this person in her practice to allow the creation of this text?

Location:

The text was created both from day duty and night duty. This is significant, as it takes cognisance of workload, skill mix and the intense issues that arise when patients are dying. In some cases, it displayed the necessity of being available to patients to listen to them at night time, as this is a time when several patients feel the need to “open up” and discuss issues that are of concern to them.

Death surround issues:

The intensity surrounding death and the features around family support, as were evident throughout this interview, bring to light the variety of issues that palliative care nurses are confronted with in the course of their work. These issues, and particularly the uniqueness of each family’s reaction and patient’s dying process, demand that the nurses respond to these situations using their repertoire of skills. The individuality of this respondent in dealing with these situations illuminates the uniqueness of this respondent’s knowledge and skills.

Non-judgemental:

A non-judgemental approach was taken to the issues that emerged throughout this interview, and during the observation session. Being non-judgemental directed the overt and discrete actions of the nurse as she dealt with practice issues. The respondent’s knowledge of individual patients was high priority for her; it allowed her to unearth the salient issues that surrounded each patient situation. Taking cognisance of this factor, the above three examples influenced my creation of the text as it emerged from the interview and observation of practice in the case of this respondent.

3(d). Does what the respondent is saying have meaning and understanding for me as a person, a nurse and a researcher?

Meaning:

As a person, what the respondent has to say has significant meaning and understanding for me. It highlights the complexity of living and dying. Furthermore, it provides me with a degree of insight into what I do not know about issues surrounding dying and death; however, these issues have meaning for me. This presents me now with the challenge of generating further insights into caring for the dying, which prior to undertaking this study, were limited. This was due to the lack of exposure to the intensity of dying that occurs within a hospice situation. As a nurse, the content of the interview and observation have meaning for me. However, as I am not an expert in palliative nursing practice and have not been engaged in palliative nursing practice for as long a duration as this respondent has, I feel I lose the “powerfulness” of some of the words and expressions that this respondent has shared with me. By including the respondent’s words and extract from her interview, I anticipate that over time they will have greater meaning for me, as well as those individuals that read this research report.

Understanding:

When words are considered in isolation, there is one level of understanding that I achieve. When taking the words in the context of the whole interview and the observation of practice, I have developed an understanding that is based on my experience, my practice and also on my own self-awareness regarding my own mortality.

Statement 4: Influence of Dilthey on analysis.

4(a). How does my life interface with the lives of the nurses and the patients?

As a nurse who has practised in palliative care and been involved in palliative nursing education, my life has interfaced on several occasions with nurses and patients. Having cared for patients who have been at different stages of the dying process - and from the time of diagnosis to their deaths - I have gained insight in to the practices of

palliative care nurses. Furthermore, as I travel on my journey through life, there are similarities and differences in my life and those of patients and nurses. As a son, a husband, a father, a brother, an uncle, I bring my life experiences to the research situation; in the context of this study, what I have brought to the six research sites has helped me to somehow understand and interpret what it is that both the nurses and the patients are describing to me.

Interpretation however, goes beyond description, and my interpretation has been confirmed to me as being authentic through discussing it with the respondents. While interacting with the respondents as a researcher, I have also been influenced by my role as a parent and a member of a family. Many of the patients that I met throughout the course of this research were also members of families - some were fathers, others were brothers – and we shared a bonding that in some cases was stronger than others. This was dictated by the state of the person's illness and also by my own receptiveness to engage with these patients. The bonding was for a short period, in most cases, and for me it highlighted the possibility that perhaps it could be me who was experiencing the dying process. For me, there was also a sense of sadness and a sense of loss when patients died. The sadness stemmed from the realisation that this unique individual's death has possibly left a void in someone else's life; each patient's death was also a unique situation for me to experience.

4(b). How can I express what I am seeing into words that can adequately capture the true reality of the nurse and patient situations?

Expressing into words that can adequately capture the true reality of the nurse and patient situations is difficult as the study involves six different research sites. As I can only surmise, particularly from a patient's perspective, I attempt to confirm my interpretation of their reality by verbally confirming my interpretation. However, this is limited, due to the severity of illness of most of the patient respondents.

The nature of palliative nursing practice is complex, as is the nature of dying. As several writers have attempted to put words on each of these, my expressions of what I

am seeing capture the reality of the nurses' situations. However, I argue that while I express what it is that I am seeing, the true reality of each nurses' situation is unique to them and they are the only people who can truthfully capture their own reality. While I undertook observation of their practice, this was limited in the sense that it was not a continuous period of observation. I captured periods of their practice situations, and attempted to express what this actually was. Using straightforward language helped me to put words on somewhat complex situations, and I consider that I captured the reality of many nurses' situations. On the other hand, some situations were so complex that it was not possible to put words on these situations. This was due, in part, to the bond, the rapport and the relationship that many of the nurse respondents had built up with patients and their relatives. They are the only individuals that have privy to the words, feelings and emotions that built up between them. While I attempted to capture these, my interpretation may differ from others who witness similar events or who undertake an analysis of the interviews and observation notes that I recorded throughout the course of this research.

4(c). As the nurse cares for each individual patient and family member, are there any expressions that are so complex that they may even be contradictory, and if so, what is their meaning?

Caring is complex and many caring situations are difficult to describe and difficult to capture in verbal format. How does one capture the feeling, the emotions that are experienced as death approaches? While patients spoke about this event and how they viewed expertise in palliative nursing practice, capturing patients' expressions is difficult. The complexity comes from patients' feelings regarding their death, the care they receive and the different ways they interpret what they see and what they experience. There were feelings of joy associated with the quality of care, while there were feelings of sadness as the reality of death loomed. On some occasions, there was also a sense of relief from patients as they felt their deaths approaching, particularly if they were in pain and were unable to achieve a satisfactory level of pain control. The contradictions in these instances were poignant, especially when their desire for life was greater than their wish to die.

5. Influence of Heidegger on analysis.

I brought my pre-understandings and forestructures to the text so that they enriched the data analysis for me.

These consisted of the following statements:

The nurse creates a secure environment for the patient and family members throughout the palliative care phase of care.

The nurse is a companion.

The nurse has knowledge of the health-illness, living-dying trajectory.

The nurse believes in palliative nursing practice.

The nurse responds to crisis in the family and individual.

The nurse combines knowledge of the patient's physical, psychological social and spiritual needs with appropriate interpersonal skills when caring for patients and families.

The nurse is authentically present to patients and families.

The nurse is competent and caring in undertaking nursing interventions.

The nurse has unknowingness about the patient and family.

The nurse promotes advocacy and empowerment for the patient.

I have presented my pre-understandings and fore-structures of the above statements in Appendix 1 and Section 3.2.2.4 of this thesis. These pre-understandings and fore-structures were merged with the thoughts expressed in the writings of Schleiermacher, Dilthey and Gadamer as expressed in this section.

6. Influence of Gadamer on analysis.

6(a). From my past experience as a nurse, what am I bringing with me to this creation of data?

I am bringing my experience of caring for patients in palliative care settings, as well as having some degree of insight into the nurse's role in caring for dying patients, to the creation of data. Also, I bring with me my knowledge of the difference in caring for

patients who are dying in a general hospital as opposed to patients who are dying in a hospice setting. My knowledge of the hospice philosophy as opposed to one where all management is curative has also influenced my role in creating the data. For example, the milieu that surrounds death in general hospitals differs from the milieu in hospices. The focus on curative measures as opposed to palliative measures influences this milieu and I take these experiences with me. These allow me to view the practices of palliative care nurses from a different perspective to nurses working in a general hospital setting.

6(b). Having cared for a family member requiring palliative care since this study commenced, what understanding of the expert palliative care nurse's role is being influenced by my own personal experiences of caring in a similar situation?

Research does not occur in a vacuum. Life progresses for the researcher and researcher's family throughout a research study. As the nature of this study is centred on how nurses implement their knowledge in order to achieve a positive outcome for patients within the context of palliative nursing practice, I was involved in caring for my father as he approached death during a part of this study. Palliative care was needed, and as a nurse, I cared for my father for the last three weeks of his life. Personal experiences of caring in this situation influenced my understanding of the role of the expert nurses involved in this study. These include: making a connection with the patient, creating a bond within this connection, supporting the dying person, tuning into family issues of acceptance, participating and grieving and finally letting go as the life of the patient ends.

Making a connection was considered in a number of the interviews as central to the role of palliative care nurses involved in this study. While the phrase appears simplistic, it is a complex event. The complexity is governed by the nurse's knowledge of the patient, patient's family members, workload and the individual nurse's level of comfort with making such a connection. I am aware that it is not possible to make a connection with every patient and it is not necessary for every nurse to connect with every patient. However, the process involved in making this

connection is one that goes beyond carrying out physical contact with the patient. It is at a deeper level, an almost unconscious process, yet one that is brought to the consciousness through salient words, actions and feelings that emerge throughout the caring relationship. Connecting is also based on trust, mutuality and reciprocity. It is nurtured as the relationship develops, and as death approaches, the connection does not necessarily break. It remains, even following death. Many of the respondents acknowledged this connection, however, I consider that my experience of connecting with my father influenced how I viewed connection as an attribute of expertise.

Creating a bond throughout caring interactions is another element of my understanding that was influenced by my experience. "Bond" means "something that binds, fastens or holds together; something that unites people" (Collins English Dictionary 1996: 60). Bonding as a follow-on from connecting "cements" the connection and strengthens the relationship. Bonding does not infer "sameness", yet, it allows for feeling of support, and creates a friendship that is strengthened as the bond increases. However, as patients' conditions weaken, the bonding process may be considered to be lessening on the part of the patient. While this may be true in the sense that the patient is no longer able to demonstrate the bond, I consider that the bonding remains intact and is central to the patient not feeling rejected or a lesser participant in the bonding process. I consider my experience of bonding as having influenced how I viewed bonding as part of the experts' role in this study.

Support for the dying person is intricate. There are multiple interpretations of support; it is unique to each individual. Some interpretations of support for the dying person include: being there for them, sitting with them in silence, or physical touch with the intent of support. While it may be difficult to offer verbal support to a person who is dying as a result of not knowing what to say, or fear of saying inappropriate things, support for the dying does not necessarily need to be in the form of words. The power of silence and touch as means of support infer a genuineness, a caring that goes beyond words, and often excels the application of words. Support is also intuitive, where one knows support is being given without being spoken about. My experience

of supporting family members and my father as he was dying provided me with the knowledge that the nurses' actions inferred that they were supporting, hence the influence of my experience on my understanding of expert nursing practice.

Family care formed a central aspect of the work of the experts involved in this study. My interpretation of the nurses' role in family care was based on the nurses' descriptions of how they supported families throughout the dying process and after the death of a family member. Each family situation is unique and support systems within each family structure are influenced by numerous factors. Families are not always tuned into the realisation of the onset of death, an aspect of family care that emerged from a number of the interviews. Many of the respondents described their role in creating the awareness of the onset of death and their influence on helping families to deal with death and loss. My interpretation of these actions was influenced by my experience of reading the signals that death was approaching and dealing with the loss of a parent.

6(c). Being a researcher in a palliative care setting, how is this present horizon influencing my interpretation and understanding of the data I am collecting?

My exposure to death and dying scenes has heightened my awareness of the activities that surround these events. I reflect on these events, especially during periods when observation of practice is not being undertaken, and I challenge what I see and observe with my own understanding about life and death. I bring my views to the situation and merge these with those from the interviews and with observation data.

Secondly, as I gather data from six sites, the volume of data is increasing. Furthermore, I have had the opportunity to develop my own views of death and dying as the study is progressing and as a result, I am developing new insights into nursing practice that surrounds death and dying in a hospice situation. Experience of caring for patients in non-hospice situations, particularly on wards in general hospitals, also gives me contrasting insights into how care is delivered and managed in these

surroundings. This further illuminates the value of hospice care in providing highly skilled care to those who are dying.

APPENDIX FOURTEEN

EXAMPLES OF SIGNIFICANT STATEMENTS

Significant Statements.
Forming a protection. Giving a sense of space. Timelessness. Creating a connection. Creating openness. Overcoming fear.

Significant Statements from interviews: “Forming a Protection”.

+Nurse 7: “For many of the patients I see, I often feel they’re on their own. Some look as if they’re deserted and I know that might sounds strong, but I want to give them the message, let them know they’re safe. Touch for me does that”.+

+Nurse 12: “I use touch all of the time. I think it is very important, because patients very often are touched if they have to be moved, or if something physical has to be done to them. So to go and touch someone, it breaks the social isolation straight away. So very often there’s a ward round going on, I’ll stay behind and put a supporting arm around them afterwards. It just lets them know that I’m there for them”.+

+Nurse 8: “It can be very much the manner I let the patient know I’m with them, it’s often the touch that goes with it that counts” +

+Nurse 23: “It’s something I do all the time, but the important part of it is when I do it intentionally to let them know it matters, and they matter, to me it a kind of makes them feel safe”.+

+Nurse 38: +“Yeah, for me connecting in with them at a deep level is a thing that mmm, you know, it speaks mountains, ‘t is often beyond words, where I want to let them know I’m with them, and touch for me does a lot of that.+

Significant Statements from interviews: “Giving a Sense of Space”.

+Nurse 4: “It’s hard to imagine what it’s like for patients, especially as they come to terms themselves with what’s going on for them. You know, we really don’t know [e], we can only guess. They must often feel on their own, and I know it’s important to give them the space and time to be on their own, I make the conscious effort to connect in with them. It’s like as if I’m coming in to their space, and touch does that for me”.+

+Nurse 30: “The barriers [ic] can be there, and they are there a lot of the time. It’s as if I want to get through to them, and when the talking isn’t getting me through, well I use touch quite a lot... it’s not just a pat on the shoulder, it’s deeper than that. And I like to

use it as if it's helping them to leave go of some of their fears, some worry they might have, something that's playing on their mind maybe, and by using touch on them, I think it helps them to open up more".+

+Nurse 40: "You've seen your self here how so many try to get all the information from them when they come in. People are in and out, asking this and that question, and in the middle of that they might have pain. And the family are here too, and I know I'm so conscious of all of that. I can only imagine how they might feel so crowded out, [mh] how they can be overwhelmed. I touch them to give them the message, 'it's all right..."+

Significant Statements from interviews: "Timelessness".

+Nurse 3: "I can't put words on it. I just see what it means to them when I take the time to sit with them and just hold their hand. It mmm, it's something that I want for them to go on and on as much as I can".+

+Nurse 9: "When you look at the patients we get here. Lots of them have lived long lives; some have lived them to the full more than others. And now their function in life has all changed. They're now here and most of them know their time in this life is numbered. I love to be able to slow down [e] the time for them, let them enjoy life more. Sitting holding their hand is one way to capture some of the precious times they've had and make these times last".+

+Nurse 17: "I remember last week, I was on nights and Frank [pseudonym used] wasn't able to sleep, he was just so upset, he was afraid and nervous. I went down to him, and got him to tell me what it was that was bothering him. There were several things on his mind and as he told me about them, I just held his hand. At first, it was a gentle touch, but the way we connected began to deepen, [mtm] it was as if our connection just freed him from what it was on his mind. When he was finished talking, I continued to hold his hand in that way for about half an hour. When he opened his eyes he felt hours had passed. He felt I had held his hand all night. For him, the touch was timeless".+

+Nurse 32: "It's like they want to make each piece of our care go on and on. It can't stop things for them or slow it down. A lady remarked to me last week how she knows her time will soon be up. She was into massage in a big way [e] and asked me if I could massage her hand. She always found it soothing; it brought her back years. It was a way of almost bringing her back to her earlier days. And it wasn't a big effort to do that for her".+

Significant Statements from interviews: “Creating a Connection”.

+Nurse 1 “ No matter what you say sometimes, it mmm, it hasn’t the same affect as being able to be comfortable in yourself and sit or walk with them. It’s to connect with them [e] through touch to give that extra crutch that words can’t give”.+

+Nurse 14: “If they’re so disconnected from what’s going on, especially if they’ve fallen apart in themselves, the using touch I find can be one way to start bringing them back to what is really going on, It works for some, it doesn’t for others”.+

+Nurse 22. “It’s, it’s giving myself in a way that maybe gives the message to the patient or to the family that yes, I understand, I care, I’m here to listen and support you, you know what I mean. It’s a kind of hard to describe in a way, [p]‘cause the intensity of the touch and the presence, well, it differs from one to another. But having the awareness that it is important and doing something about it - that makes the difference, the big difference”.+

+Nurse 28: “Patients often talk about their lives falling apart, sometimes they say they’re shattered and they’ve tried to pick up all the pieces again. [p] It can be some help to them to try and out some law and order back in to their lives again, [ic] just be making a presence with them, and that can be in the form of taking time to sit with them and I use touch to, I suppose what I would feel is to connect to the core of what it is they are feeling and going through”.+

Significant Statements from interviews: “Creating Openness”

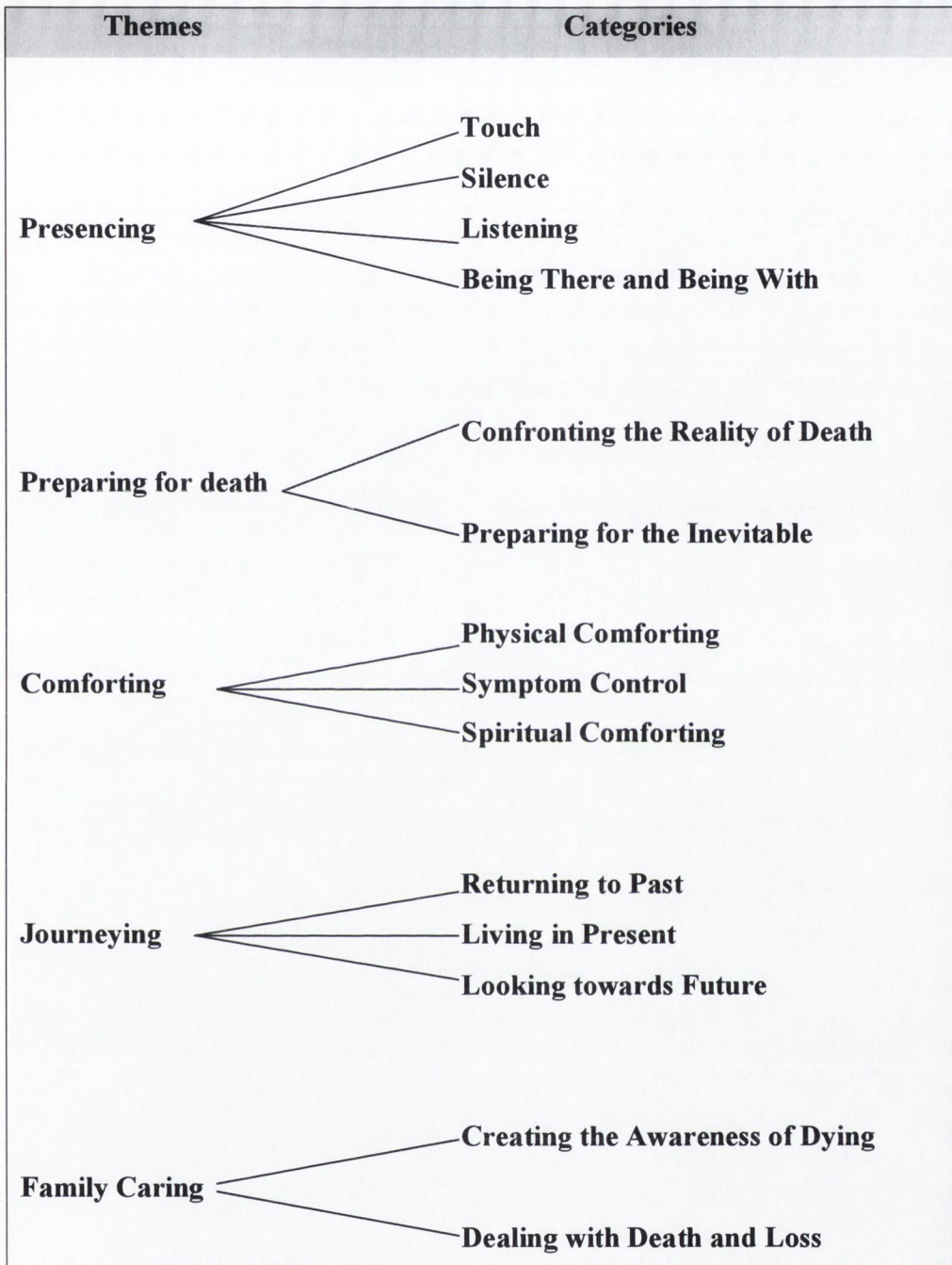
+Nurse 20: “I think, yeah, it’s about being open, [ro] being in the arena of care, within the whole atmosphere of what’s happening for the patient. And it’s the touch and when I say touch it’s almost as if it’s inviting them to accept my presence that I’m there for them and with them, to be open. And there’s times you know that the touch speaks loudly to me in the sense that it mmm, it bridges me to them and vice versa. [mh] We open to each other”.+

+ Nurse 30: “I’m in palliative nursing now along time and mmm, [p], what I try to do is to break any barriers that might be there, and let me tell you there’s a lot of them for some patients. It’s like as if they’re surrounded [e] with them and in the middle of it all, [mh] they’re reaching out to get in touch with you. Simple things like touching them, holding their hand for a while, that can start to get rid of some of the obstacles that’s around them. That’s how it’s often for me”.+

+Nurse: 33: “Not all the time does it happen where patients will open up to you. Sometimes it’s like a guessing game, or as if mind reading is going on. That makes it harder to get to know exactly what going on there for them then. In cases like that, it’s a matter of taking it slowly, maybe sitting with them, and using touch as a way of helping to show trust and in some way it might help to open up the patient to you”.+

APPENDIX FIFTEEN

THEMES AND CATEGORIES EMERGED FROM ANALYSIS



Themes and Categories Generated From Data Analysis.

Amalgamating Significant Statements to Generate a Category / Cluster

Category / Cluster	Significant Statements.
Touch	Forming a protection. Giving a sense of space. Timelessness. Creating a connection. Creating openness. Overcoming fear.

Category / Cluster: Touch

Significant Statements from interviews: Forming a protection.

+Nurse 7: “For many of the patients I see, I often feel they’re on their own. Some look as if they’re deserted and I know that might sounds strong, but I want to give them the message, let them know they’re safe. Touch for me does that”.+

+Nurse 12: “I use touch all of the time. I think it is very important, because patients very often are touched if they have to be moved, or if something physical has to be done to them. So to go and touch someone, it breaks the social isolation straight away. So very often there’s a ward round going on, I’ll stay behind and put a supporting arm around them afterwards. It just lets them know that I’m there for them”.+

+Nurse 8: “It can be very much the manner I let the patient know I’m with them, it’s often the touch that goes with it that counts” +

+Nurse 23: “It’s something I do all the time, but the important part of it is when I do it intentionally to let them know it matters, and they matter, to me it a kind of makes them feel safe”.+

+Nurse 38: +“Yeah, for me connecting in with them at a deep level is a thing that mmm, you know, it speaks mountains, ‘t is often beyond words, where I want to let them know I’m with them, and touch for me does a lot of that.+

Category / Cluster: Touch

Significant Statements from interviews: Giving a sense of space.

+Nurse 4: “It’s hard to imagine what it’s like for patients, especially as they come to terms themselves with what’s going on for them. You know, we really don’t know [e], we can only guess. They must often feel on their own, and I know it’s important to give them the space and time to be on their own, I make the conscious effort to connect in with them. It’s like as if I’m coming in to their space, and touch does that for me”.+

+Nurse 30: “The barriers [ic] can be there, and they are there a lot of the time. It’s as if I want to get through to them, and when the talking isn’t getting me through, well I use touch quite a lot. . . it’s not just a pat on the shoulder, it’s deeper than that. And I like to use it as if it’s helping them to leave go of some of their fears, some worry they might have, something that’s playing on their mind maybe, and by using touch on them, I think it helps them to open up more”.+

+Nurse 40: “You’ve seen your self here how so many try to get all the information from them when they come in. People are in and out, asking this and that question, and in the middle of that they might have pain. And the family are here too, and I know I’m so conscious of all of that. I can only imagine how they might feel so crowded out, [mh] how they can be overwhelmed. I touch them to give them the message, ‘it’s all right, you

Category / Cluster: Touch.

Significant Statements from interviews: Timelessness.

+Nurse 3: “I can’t put words on it. I just see what it means to them when I take the time to sit with them and just hold their hand. It mmm, it’s something that I want for them to go on and on as much as I can”.+

+Nurse 9: “When you look at the patients we get here. Lots of them have lived long lives; some have lived them to the full more than others. And now their function in life has all changed. They’re now here and most of them know their time in this life is numbered. I love to be able to slow down [e] the time for them, let them enjoy life more. Sitting holding their hand is one way to capture some of the precious times they’ve had and make these times last”.+

+Nurse 17: “I remember last week, I was on nights and Frank [pseudonym used] wasn’t able to sleep, he was just so upset, he was afraid and nervous. I went down to him, and got him to tell me what it was that was bothering him. There were several things on his mind and as he told me about them, I just held his hand. At first, it was a gentle touch, but the way we connected began to deepen, [mtm] it was as if our connection just freed him from what it was on his mind. When he was finished talking, I continued to hold his hand in that way for about half an hour. When he opened his eyes he felt hours had passed. He felt I had held his hand all night. For him, the touch was timeless”.+

+Nurse 32: “It’s like they want to make each piece of our care go on and on. It can’t stop things for them or slow it down. A lady remarked to me last week how she knows her time will soon be up. She was into massage in a big way [e] and asked me if I could massage her hand. She always found it soothing; it brought her back years. It was a way of almost bringing her back to her earlier days. And it wasn’t a big effort to do that for her”.+

APPENDIX SIXTEEN

SAMPLE OF FREE NODES AND THEIR CONTENTS

Accepting	Achievement	Adapting	Admission
Alert	Anger	Anticipating	Anxiety
Arrangements	Art	Assessment	Atmosphere
Attitude	Automatic	Autonomy	Awareness
Background	Balancing	Being there	Bereavement
Bond	Boundaries	Breakable	Burnout
Challenge	Change	Choice	Comfort
Communication	Connected	Control	Coping
Crisis	Cues	Decision	Difference
Disconnected	Discovery	Doing best	Dying
Emotional care	Emotions	Empowerment	Enabling
Energy	Enriching	Equation	Experiences
Facilitating	Failed	Family	Feelings
Fixing	Filling gap	Fragile	Frustrations
Gardening	Getting it out	Getting it right	Getting the moment
Giving yourself	Grief	Gut feeling	Healing
Health	Health promotion	Hidden work	Holistic
Holistic care	Hope	Humorous	Humour
Individuality	Integration	Intention	Intimacy
Intuition	Journeying	Knowing the patient	Knowledge
Learning	Letting go	Link	Listening
Living	Loss	Meaning	Mediator
Memories	Moving	Nature	Normality
Nurture	Ongoing process	Openness	Option
Pace	Pain	Parameters	Partnership
Peace	Permission	Philosophy	Physical care
Picture	Plan	Planning and anticipation	Prayers
Presence	Process over time	Protecting	Psychological care
Real nursing	Reality	Recognition	Reflection
Relationships	Reminiscing	Respect	Responsibility
Risk	Role model	Safety	Self
Self-awareness	Sensing	Sensitivity	Sharing
Silence	Spiritual pain	Spirituality	Staff-support
Suffering	Support	Symbols	Symptom control
Tapping in	Teamwork	Terminal restlessness	Time
Touch	Transfer skills	Translating	Trust
Tuning in	Unfinished business	Uniqueness	Vulnerability
Whole patient care	Where patient is at		

APPENDIX SEVENTEEN

SAMPLE OF CONTENTS OF TWO FREE NODES

Sample of contents of node: “Awareness” and “Discovery”. (From NUD*IST).

++++
ON-LINE DOCUMENT: Nurse 4 *Awareness*
[Nurse 4: 53-80]
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ON-LINE DOCUMENT S04-1:
mmm, I suppose if, I find any way that working along side people who are actually dying, and who are aware that they are actually dying, and have no control over it, For a lot of them, their anxiety level is heightened ok. And I think one of the roles of the palliative care nurse at the bedside is to be able to sit with [e] that patient and hear what that anxiety is. Not necessarily take it away, mmm, because we can't do that. I can't cure somebody mmm who is dying, so therefore it's a lot sitting with, being present to and giving them the opportunity to speak. Maybe they don't want to talk, may be that it's just a presence that they need beside them and the whole nature of just sitting with [e] them in [p] and if they are comfortable with that. You know, [p] that's part and parcel of it as well. And I think too that you know, we are very lucky that in the palliative care setting we are not rushing around, you know, like in a general setting where we don't have to have things done by a given time throughout the day that what the patients need and what the patients want. So therefore we have the time to be able to sit with them, mmm. Maybe it is just to hold their hand. Sometimes medications do have to be given, because we are never actually going to be able to relieve, relieve their anxiety. I suppose that would be the second step or the third step. You know, the presence would be the first.

++++
ON-LINE DOCUMENT: Nurse 5 *Awareness*
[Nurse 5 : 765 - 798]
++++

Nurse 5: In the in-patient unit, now 't is different in homecare. In the in-patient unit, like, they're encouraged as much as possible, and what I've found a lot of the time, there's one time when, mmm, one time in particular when I find families sometimes hold back, and I suppose 't is no wonder and this is when the time of death is coming near.

Like, it must be a traumatic time for them, I'm sure it's very hard when they see their relation going down hill, and I look at it and think, well, what I would it be like for them if they can still be doing things for their ding family member. And, mmm, I get the feeling a lot of the time, they pull back from getting involved, so do my best to keep them involved.

KC: In what way?

Nurse 5: Well, in the simple things, like, mmm, maybe sitting beside them and holding their hand, maybe, mmm, maybe rubbing their brow, even doing the mouth care, just those simple things, like, they're simple things to us, but so often I see these are so important for family members to be doing for someone they love who's dying. ' Cause they don't get a second chance, like, and I've had relations of patients come back and say that to me like, if only they had thought of doing it earlier on like, and then I say, well, what I try to do [e] is to maybe tell them all the things they've been doing for them and I think that helps. Like, the relationship with these people is just so important, I think, so we I mmm, when I meet the relatives, all of these things go around in my head and then I suppose, I'd call it, maybe I start to plan what way can I help these people to mmm, get through the whole thing of their family member dying. Does that make sense to you Kevin?

++++
ON-LINE DOCUMENT: Nurse 7 ***Awareness**
[Nurse 7 : 680 - 710]
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Nurse 7: No problem. Mmm, as I said earlier on in relation to the, we'll say, the pre-death, if the family are prepared for the actual dying, that's the first part of it, and even when the patient dies, it is still a huge shock, [e] and I know from my own experience as well, no matter how prepared you are, you are never actually prepared for the final breath as such, and that they're actually gone. So I think it's to be aware that no matter how prepared a family are, there's going to be a shock element, and it's just to stay with them, at that time, to give them time to just absorb a little about what has just happened, that the patient has actually died. So

time I would see as a crucial element. Not to rush things, not to think that we have to get this patient laid out, get them out to the undertakers, but time first and foremost. Having given the time and in that time, [e] to see if there's anything specific that any member of the family would like to do at this moment in time, would they like to have time on their own, with the person that has died, just to ascertain that, because there's no going back on, on that. Then after that, when you have mmm, ascertained that everyone is happy with things as they are, as happy as they can be say, mmm, we duly offer them a cup of tea, time out of the room, time even just to story tell. Often times a lot of stories are told in that hour after the person has died, where ever is suitable, in the library, where ever, and then to start looking at arrangements. Now you wouldn't be starting [e] at that stage, most times we would have discussed with the family prior to the death.

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ON-LINE DOCUMENT: Nurse 10 *Awareness*
[Nurse 10 : 94 - 122]
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Nurse 10: Right, I suppose really the first thing would be mmm, what you'd look at is an awareness really. You know, mmm, I was acutely aware of mmm, the possibilities within the situation that was presented to me. Mmm, I didn't actually know the possibilities but I had an awareness of the possibilities and the potentials of the situation, based on, on mmm, I suppose a certain amount of evidence that we had collected prior to my arriving on to the scene. Yeah, it was Monday night, and mmm, during, we'll say the period of the twelve hours that I had been on the shift, I actually was gathering and gleaming a certain amount of information. And whilst there were certain boundaries put around that, [e] for me as well, I was governed by the mmm, the relative really, rather than the patient. The relative's mmm, boundary that she had put around herself and around me and it actually, it was actually a very interesting phenomenon, because I found at the end of that shift, it was very much a challenge to the whole concept of, of mmm family as patient, patient as family and it was about looking at the whole picture and in a strange way the family's needs were much more pronounced than the patient's

needs were, in this scenario. Now when I say the family, it actually boiled down to mmm ending up with one individual who remained overnight and I felt that the forum that they found themselves in, somehow it kind of allowed the opportunity for her to maybe visit and revisit some of her own issues. It was actually very, very pronounced, to the extent that I would say to you...

[Nurse 10: 372 - 399]

Nurse 10: Well, there's a few sides to it, it can be one sided, two sided or three-sided. I would say yeah, it has its potential, yeah, it can be and I say, if, because everybody is trying to get a sense of what's happening, so at one level, you're a kind of tip-toeing for a little while, you know, you're going gently, you're, you know you have to go along with certain amounts for a certain length of time, but as the various revelations come about, and the various pieces get added in or subtracted as the case may be, you know, the picture changes readily. You know, and, I think it's about, by maintaining the engagement with the whole process and being aware of the whole process [e] you are constantly aware, but then, you're only there for twelve hours or whatever, so there are aspects, that's why I'm coming back to the whole team element, there are aspects that have to be added in [e] you know clarified, verified or nullified as the case may be. So what happens today may not have the bearing you thought it might have tomorrow because the whole picture can change again. You know, and there's only bit by bit, because if you bring yourself to the perspective of the patient, if I end up being a patient somewhere tomorrow, I mean, through whatever process, there's going to be aspects of my information that may never be known, may never have to be known [e] but in the context of, mmm, hospice care, ...

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ON-LINE DOCUMENT: Nurse 2 *Awareness*
[Nurse 2 : 230 - 274]
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Nurse 2: I think, mmm, o.k. Number 1, intuition is very important number two, you always have to look for, try and get a sense of feedback. All your senses have [e]

to alert. You know, in terms of, of being aware of the individual and it's about making the effort to get to know the person and even sometimes in doing that in ways, you have to give a little bit of yourself as well, [p] which is ok. I think if you are in a partnership situation from, from a caring point of view, mmm, sometimes there has [e] to be a little bit of give there. For example, mmm, I wasn't too long in the home services, and I went to see this gentleman that I hadn't visited before. And mmm, one of the other girls had been attending him, and mmm, I called into see him this day and there was just himself and his wife, and they had, mmm, a son, who was living in the UK, who was en route home because the father was, was deteriorating. And mmm, his wife, she was very upset when I went to the house as he suddenly dropped and his symptoms were all over the place. But mmm, he was in the bed upstairs and I remember sitting down, a kind of half on the bed and I remember looking back ...

He was actually more perceptive than me initially because I was in trying to make an assessment on him, and I had walked in to the situation cold faced, deterioration, had never met him before and I was trying to get a sense of what was going on here. But he, sometimes that will happen sometimes the patient or client will connect you and hit the connection spot. The conversation evolved and evolved and he said to me "Years and years ago I used to play the accordion [e] and I loved music, he said and it is in the attic. I haven't been able to play it for years and years. With that the situation kind of went on and on. After a while he said to me " You wouldn't play me a tune would you? You know, amazing, like you know, there was nothing about his pain. Everything seemed to, and it was nearly like a dying wish and his wife was elderly and I can remember getting the accordion out of the attic and when I think of it now...

[Nurse 2: 809 - 838]

Nurse 2: Yes, I would. I suppose really, mmm , maybe I would come maybe from a night duty perspective. On night duty, as you know, we would have a smaller number of staff and mmm, there would be, there would be four of us on at night. Two staff nurses or the night sister and a staff nurse and two care assistants and mmm a smaller audience, different mmm, we always have a different skill mix

regardless but I would find that [p] maybe because the numbers are smaller whatever, I would have, I would feel a bigger impact when I'm on night duty in terms of mmm the mmm creating an awareness of what's happening here for patients, [e] or for us individuals, you know, members of the staff etc. I would be more inclined to feel I have more space even with patients and mmm on night duty, yes, mmm there would be a number of situations mmm, either from a holistic point of view and honing in on psychosocial issues. The night time is a very, very poignant time and I would find that a lot of issues can kind of surface, coming to the night and mmm. Yeah, there are people that have been here and passed through here that would have touched me [e] and in some way I would have, maybe hopefully I would have touched them, mmm. There are people, there was one lady I would say that I spoke to you about earlier in the day, she always talked about, she loved the rain. That particular lady, and I can remember ... taking her out in the wheelchair at four o'clock in the morning going around the grounds in the rain, 'cause she just wanted to be out there and just to know that this is her experience before she died... you know,

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ON-LINE DOCUMENT: Nurse 39 ***Awareness***
[Nurse 39: 771-780]
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Nurse 39: To me is a central focus of my care. 'T is just the opportunity to get them to, to tune in to what the reality actually is. Sometimes when I know deep down the patient mightn't be fully tuned in to what is happening to them, you in all of this of what's going on, you know, it's definitely the non-verbals that tell me, no, they're not aware things are as they are. It's a challenge for me and I know some one always has to do it, 'cause I think we owe it to the family and to the patients as well, they have to be given the chance to get some inkling that this is what's happening, do you know what I mean like +

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ON-LINE DOCUMENT: Nurse 21 ***Awareness***
[Nurse 21: 771-780]
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Nurse 21: Well, I suppose, quite often in palliative care we talk about somebody being diagnosed, and we talk here certainly about

their journey towards death. And I suppose, you would want them to feel that they were being minded ([e]) and that anything that was going to occur could at least be explained ... And I think that particularly for family, (moving hands) some patients won't ask because they're feeling what's going on as it's happening, it's being explained. But it can be more difficult sometimes to the family who are watching, without feeling and without experiencing it, by being an outsider and it's to try and bring them in on it and feel part of it as well, which they are.+

DISCOVERY

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ON-LINE DOCUMENT: Nurse 7 *Discovery*
[Nurse 7: 142 - 161]

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Nurse 7: Yes, the main ways I've experienced, and you'd have seen here, I mean, firstly, when a family, when a patient and a family come in, initially, everyone trying to discover where people are at, where the family are at, and where the patient is. And within the first few days to the first week, you have a picture of as to whether this family will need a lot of input, and the patient is going to need a lot of input, at all levels, [e] but particularly from a social and psychological point of view. So by putting the pieces of the jigsaw together from the staff nurses, from the doctors, from the social workers, you then decide whether you go on and you need an immediate family meeting, or whether you need just a one to one basis, to try to build up a picture, but very often it ends up with a family meeting where you're discovering where people are at. And they also discover where we're at in relation to the patient. And I feel the family meeting is the big stepping-stone to link the patient with the family with the patient, and the family with us, as the carers.

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ON-LINE DOCUMENT: Nurse 15 *Discovery*
[Nurse 15: 111-129]

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Nurse 15: Sometimes, 'tis as if there's almost a need for us to go looking and when I mean looking, like here we are , presented with different patients all coming from their own unique backgrounds [e] and it's a matter of trying

to decipher where are they ([e] on they) in the middle of all of this you know. And it's not that easy just to kind of keep in mind that you're dealing with one special and particular individual, no, you have a lot of, [p] a kind of "pulling apart" [ic] to do maybe to get the patient in the middle of all of what's going on in the family situation. Do you know what I mean like. And for me, the real, I suppose challenge, I'd call it, the real challenge for me in the middle of all of this is discovering where the patient is actually at. 'Cause as I said, the family are at one place, and in the middle of the family, now you're not just talking about one individual in all of this, no, you have to [e] take account of all of the family dynamics in it as well, so it's like going into a maze [e] and finding the patient in the middle of all of this. And in some cases, it's not the patient you might find in the middle at all. No, it could be one of the family members, do you know what I mean like, so again, it's number one to find the patient in it all, and take it in stages from there.

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ON-LINE DOCUMENT: Nurse 6 *Discovery*
[Nurse 6: 235-243]
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Nurse 6: I know it's important that I'm able to tune in to the patient. So the first thing for me, and I take this first of all from the assessment that I do when they come in. I like to think at the end of doing the admission, in my mind ([e] on mind) I have some idea where the patient is at. Now, this might sound fairly simplistic in a way. But a lot of it comes down to my own self, where am I in actually trying to find the patient in their own journey, you know, and I believe that my own beliefs about my own mortality is important in helping me to find the patient in all of what's going on for him or her, which ever the case may be.

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ON-LINE DOCUMENT: Nurse 1 *Discovery*
[Nurse 1: 75-105]
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[Nurse 1: 75 - 105]
S01/1: Well Kevin, that's the way I see it, and for me, mmm, it puts it in to some sort of mmm, some kind of way for me, some process for me, yes, this is what's happening [e] and at the end of the day, I think as nurses we're here for them and mmm, yes, we are their partners in their care. Like, if they don't let us get to know them that well, or if they mmm, if they just want to be alone to get on with their lives and dying, well I'd respect that as well, like. Now don't get me wrong, I don't always get it right either you know, mmm, so overall, mmm, I do the best I can for them. [mh] I think that for me, part

of the legacy of life is dying and mmm, for me, my role in palliative care is to help the patient to live out the legacy of life so they can live life it to it's fulfilment in as many ways as possible, and that's so different for so many patients, mmm, like, it's so individual, but you learn form one patient and the other, so they are such a source of my information in mmm, in my practice. So I'm here as part of helping them with the legacy, that's what I call it.

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ON-LINE DOCUMENT: Nurse 1 ***Discovery***
[Nurse 1: 396-444]
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Nurse 1: Yeah, getting the atmosphere, 't is as if you're almost mmm, scrutinising everything that's going on, mmm, looking at each thing, like, each mmm each move, each breath, each mmm, each moment of the person. Maybe scrutinizing is a strong word, mmm, [p] just an astute alertness in mmm, in each moment of the situation. I've often thought about it, like, you know, the engagement that goes on when I'm dealing we'll say with Pat, or John or any of the patients and mmm, I think there's a wealth of things that we, or should I say I'm learning from the patients all the time. Like, I think a lot of the time we learn a lot more from them than they can ever possibly ever learn from us, [ic] like, mmm, they're the ones that have been through the illness, maybe the surgery, it is surgery in most cases for the patients anyway, they've been through the waiting and wondering stages of wondering what's going to happen, and I firmly believe that we learn so much from them. Mmm, I think like it's starting at the edges and working your way in to get the, to get in there, to the mmm, I suppose knowing what's going on for them. Each case is unique, mmm, each pf the patients are so individual and I make the conscious effort to mmm, to try to keep that individuality with them ...

APPENDIX EIGHTEEN

RESPONSES TO MEMBER CHECKING OF FINDINGS

(Response Code A)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, lots of them. It really shows how important the work of palliative care nurses actually is. When I read it first, I felt it was simple and complex, and it is difficult to actually verbalise what it is we do as palliative care nurses. I can identify with a lot of it.

Do they have meaning for you?

They have a lot of meaning, it made me stand back and look at my practice and now I value it all the more.

Do they have meaning for palliative nursing?

Definitely. Palliative care needs to expand to so many more areas. It is time to get it put on the map much more. You have added a lot of knowledge to clarifying what palliative care actually is.

What aspects of your experience, if any, have I omitted?

None.

What aspects of your experience have I exaggerated, if any?

I wouldn't say exaggerated, what you've done is put words on it, not exaggerated. It would be hard to find this in books, so I think you've just written down what it is we do in palliative care.

Any other comments you would like to make?

Thanks for doing a study like this.

(Response Code A2)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes; presence, silence, listening being there, family care, dealing with death and loss, preparing for death.

Do they have meaning for you?

Yes, they have made me think about my own practice as a palliative care nurse.

Do they have meaning for palliative nursing?

Yes, that palliative nursing is such a specialised area.

What aspects of your experience, if any, have I omitted?

None.

What aspects of your experience have I exaggerated, if any?

None.

Any other comments you would like to make?

No.

(Response Code B2)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, as a listener, the companion of the journey and respect the patient as a storyteller and the privileged information they give me in trust.

Do they have meaning for you?

Yes, great meaning for the artistic side of my nursing.

Do they have meaning for palliative nursing?

Yes, one part of palliative nursing.

What aspects of your experience, if any, have I omitted?

My scientific knowledge base allowing me to provide expert clinical care.

My reflective skills. Being able to reflect on the care I give and learning from it and doing things differently in the future because of it.

What aspects of your experience have I exaggerated, if any?

The art of my practice. I feel you have not captured the expert scientific knowledge held by experienced palliative care nurses. The true expert has achieved mastery in art and science, I believe.

Any other comments you would like to make?

No, I feel I have included all comments, but, overall I fell the art of my practice grew and matured after my sound knowledge of disease process, symptom control, treatments, etc.

(Response Code C)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

“Being” is facilitated by listening and attending. This provides safety for the patient.

Do they have meaning for you?

Yes, I also believe that hope is a huge issue for the dying. Some patients may hope for another day to live, relief from pain, to die a good death. No matter how ill patients are, they may not want to die.

Do they have meaning for palliative nursing?

Yes, I would also like to say that by viewing the patient as a holistic being, it can be realised that spiritual care of the dying is an integral part of palliative nursing.

What aspects of your experience, if any, have I omitted?

Palliative care is the total active care of patients and families by a multidisciplinary team. When the patient's disease is no longer responsive to curative treatment, the spiritual dimension is important. Patients searching for meaning may ask questions "why me", or the patient may not be seeking an answer or advice, but an opportunity to express feelings. Patients asking "why me" poses difficult questions that nurses feel obliged to answer. It can be argued that providing answers may prevent patients exploring their questions further. Rather than provide answers, a nurse may ask "what does it mean to you, that this dying / suffering is happening". This provides the opportunity to explore further. However, it is a serious question and will get serious answers. Meaning must be found by the patient who seeks it, it cannot be given by another (Frankl 1969).

What aspects of your experience have I exaggerated, if any?

I cannot see that any aspects are exaggerated.

Any other comments you would like to make?

Well done.

(Response Code C2)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, the emotions of the palliative care nurse are very well expressed.

Do they have meaning for you?

Yes, themes such as presencing, family care, journeying and preparing for death are issues that are dealt with every day.

Do they have meaning for palliative nursing?

Yes, sometimes it's hard to describe our work.

What aspects of your experience, if any, have I omitted?

No.

What aspects of your experience have I exaggerated, if any?

None.

Any other comments you would like to make?

These themes are very important in palliative nursing and are difficult to measure, to prove our worth: the nurses' role in palliative care as the medical aspect overrides all other aspects of palliative care.

(Response Code D)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, enjoyed category 2.

Do they have meaning for you?

The photos etc, is usually done by chaplain, social workers. I agree with the idea, but can't say I have really been involved.

Do they have meaning for palliative nursing?

Yes definitely. I cannot say I find death an enriching moment, just never felt death to be like that. If it's enriching, am I fulfilling a need in me, it should be about the patient, no one wants to die, (75% of the time).

What aspects of your experience, if any, have I omitted?

Has palliative care an expiry date. Dealing with your grief within the setting. The turnover of staff, the need to move around to different areas within the setting.

What aspects of your experience have I exaggerated, if any?

Category 3: Story "being there"? Give them a kind of wisdom. Can we? They have the wisdom; they have lived and will die. Sometimes I feel there's insincerity about reliving memories with them. I feel it's more real reliving memories coming from their family, friends, people they have lived with. You can find yourself going down a road with them; all memories may not be pleasurable, and are we skilled enough as palliative care nurses to deal with this? The intention may be good.

Any other comments you would like to make?

No comment made.

(Response Code D2)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

I recognise most of them. I think some of the replies have been very well put. It's hard to put words on a lot of what I do.

Do they have meaning for you?

Definitely, they have a lot of meaning for me.

Do they have meaning for palliative nursing?

Definitely, because what palliative nursing nurses do, it can be so hard to put words on it, so I think it tells us exactly what palliative care is all about.

What aspects of your experience, if any, have I omitted?

Maybe parts about the way we deal with children, especially young children and teenagers as well. Teenagers are so often left out of the full goings on in palliative care.

What aspects of your experience have I exaggerated, if any?

None.

Any other comments you would like to make?

Thanks for including me in the study. I think having you look at us here in the unit when we were caring for patients had helped out the words on what exactly we do in palliative nursing.

(Response Code E)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?.

No comment made.

Do they have meaning for you?

No comment made.

Do they have meaning for palliative nursing?

No comment made.

What aspects of your experience, if any, have I omitted?

No comment made.

What aspects of your experience have I exaggerated, if any?

No comment made.

Any other comments you would like to make?

No comment made.

(Response Code F)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?.

I do recognise my experience in this analysis. Naturally, some parts of it I can identify with more with than others. Touch, silence and being there would rate higher in importance for me in caring for the terminally ill.

Do they have meaning for you?

They do all have meaning; it is important to be listened to, to have support in life in general.

Do they have meaning for palliative nursing?

Yes, as palliative nurses it is important to listen to the journey of the individual and respect it. It is also important to create the environment of trust and openness.

What aspects of your experience, if any, have I omitted?

None.

What aspects of your experience have I exaggerated, if any?

None.

Any other comment you would like to make?

No comment made.

(Response Code F2)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

I recognised myself in a lot of what you sent me. I think it's great that so much of what we do in palliative nursing now has words. I know not all people put the same words on what we do, but I can recognise palliative nursing in what I've read.

Do they have meaning for you?

Definitely. It makes what I do all the more real. While I know what I do when I'm caring for patients and relatives, I think sometimes we can get lost in the smaller things like getting things done on time, or sticking to a routine, but what you sent me, I think the true side of what we do has great meaning for me.

Do they have meaning for palliative nursing?

Yes, it has huge meaning for palliative nursing, especially in Ireland. I know we are still developing palliative nursing in Ireland, so I hope we can get some good out of what information you have collected in your study.

What aspects of your experience, if any, have I omitted?

Not that I can think of.

What aspects of your experience have I exaggerated, if any?

None.

Any other comments you would like to make?

Well done.

(Response Code G)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes. I believe that presence with a patient consists of being there for them whether it is listening, the use of touch, laughing, etc.

Do they have meaning for you?

Most of them, yes.

Do they have meaning for palliative nursing?

Yes.

What aspects of your experience, if any, have I omitted?

I think an element of expertise in palliative care nursing is our knowledge of drugs and symptom control and our use of syringe drivers. We use these on a daily basis: most nurses in general hospitals don't.

What aspects of your experience have I exaggerated, if any?

No comment made.

Any other comments you would like to make?

No comment made.

(Response Code H)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, especially listening and touch. I never thought really of presencing, but when I read it, I then realised it was what I do a lot of the time. I think the most

important thing when it comes to listening and presencing, it's the way the nurse is actually doing it. It's important that it's not just a ritual of asking them how they are, so yes, I can recognise a lot of my experience in what you sent me.

Do they have meaning for you?

They have a lot of meaning for me. I think as a palliative care nurse, it's hard to see exactly our role and how it's different from general and other kinds of nursing, but when you add it all up, your descriptions tell me exactly what palliative nursing is all about.

Do they have meaning for palliative nursing?

Yes, very much so. I think Saunder's vision of palliative care was excellent and I think a lot of what we try to do in caring for palliative care patients is so important, the words you have put on it have made it clear there is a place for more development in palliative nursing in Ireland.

What aspects of your experience, if any, have I omitted?

The frustrations we go through at times. It's not rosy all the time, there's the ups and downs of palliative nursing as well, so maybe another study on the other side of palliative care would give a balance to the two sides of palliative nursing. Like, I know resources in palliative care are good, but when it comes to education and getting money and time to do courses and develop ourselves personally, I think a lot more resources need to be given to that side of palliative nursing.

What aspects of your experience have I exaggerated, if any?

None.

Any other comments you would like to make?

I'm so pleased that this has come from your study. While I was a bit nervous when it came to doing the interviews and when you were with me on the unit, it's great to see what has come from it all.

(Response Code H2)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

I recognise some of my experiences in the above descriptions, especially in the area around silence and listening. I think the skill of really listening takes time to master and can also vary from day to day and circumstances.

Do they have meaning for you?

Yes, most have meaning for me. Touch is a very personal thing. I have no problem with touch, but would assess every patient or family member before using touch. It's not always appropriate for them.

Do they have meaning for palliative nursing?

Most have. Family care is a huge aspect and is of huge importance in palliative nursing.

What aspects of your experience, if any, have I omitted?

Perhaps staff support, i.e. how members of the team support and help each other deal with upsetting and difficult situations.

What aspects of your experience have I exaggerated, if any?

I felt the touch aspect was slightly exaggerated and as I mentioned earlier, it's very individual and I find I can communicate as effectively with patients, relatives who wouldn't be so comfortable with being touched. The dealing with death and loss experience did not have much meaning and significance for me. Some of the extracts had points that were significant for me.

Any other comments you would like to make?

I found it difficult at times to read the quotations of nurses because of the use of direct speech and some of the quotes were very long.

(Response Code I)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, in some cases more than others. Nevertheless, I could see the thread of my experience being weaved throughout the categories, with strong emphasis in the area of being present to patients and family members; journeying with the individuals; and finally, helping individuals prepare for death.

Do they have meaning for you?

Yes, while reading this paper, I was strongly reminded of why I went into palliative care nursing. I went into palliative care nursing in order to be able to journey with individuals, while giving a high standard of total patient care as part of a team. The above stories and reflections "ring true" for me, and are a stark reminder of my need to stay focused and grounded.

Do they have meaning for palliative nursing?

Very much so, strong meaning for palliative nursing. I would like time to truly reflect on these themes in the light of reflective practice. What a rich environment it would be for all in the hospice.

What aspects of your experience, if any, have I omitted?

Kevin, I feel you have included all aspects of my experience directly and indirectly by what has been written throughout the categories.

What aspects of your experience have I exaggerated, if any?

I couldn't say that any aspects were really exaggerated.

Any other comments you would like to make?

Kevin, I found this a very reflective paper. It provided me with a lot of food for thought. Reflective practice is an area that needs to be developed in every unit, in a formal way. This paper made me realise this even more.

(Response Code J)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, I can see myself in a lot of them.

Do they have meaning for you?

Yes.

Do they have meaning for palliative nursing?

Definitely. It's important that what nurses do in palliative care is made known. I think a lot of people think it's the same as any kind of general nursing, but there's so much difference between the two of them.

What aspects of your experience, if any, have I omitted?

None, I think.

What aspects of your experience have I exaggerated, if any?

I wouldn't call it exaggeration, no, there is no exaggeration in it.

Any other comments you would like to make?

No.

(Response Code K)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, I recognise my experiences, as a palliative care nurse in the above descriptions, especially listening and being silent in the appropriate times. Being there and sitting with the patient and relatives without "giving advice".

Do they have meaning for you?

Yes, listening and silence have meaning for me, as they help me to stop and think without giving an opinion.

Do they have meaning for palliative nursing?

Yes, they have meaning for palliative nursing, as each person is at a different stage in their journey, and it is important for staff to be sensitive, gentle and courteous towards patients and families so as to help them to deal with death.

What aspects of your experience, if any, have I omitted?

Experience of dealing with children and teenagers. It is amazing how children will ask one question that sums it all up and yet we as professionals are maybe trying to avoid answering this question.

What aspects of your experience have I exaggerated, if any?

None are exaggerated, but it is important to remember each patient and family are different, so each may be at a difference place in the illness. It is important to allow families express their feelings, be it anger, sadness, acceptance.

Any other comments you would like to make?

The importance of working as a team and each person in the team listening to each other's views. It is also important to have outside interests, so as to give 100% while at work.

(Response Code K2)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, it's so real to me. I can see where you're coming from. I think caring for dying patients is so challenging. What nurses do in all of this caring can sometimes get lost in the more technical side of things and when it comes down to it, the important thing in all of this is that the patients don't get lost in what's going on. Relatives are important as well, but we can't lose sight of what is right for the patient.

Do they have meaning for you?

Yes, it has a lot of meaning for me. I love palliative nursing, and having thought a lot of what I do when I'm looking after patients, it's so good to see others have all similar views and ideas as I have about palliative nursing.

Do they have meaning for palliative nursing?

I think it highlights that palliative nursing is hard, it's rewarding and the way care is given is so important, while at the same time the patients are at the centre of what is going on.

What aspects of your experience, if any, have I omitted?

I don't think you've left out anything.

What aspects of your experience have I exaggerated, if any?

None.

Any other comments you would like to make?

Palliative nursing is special and hard to describe exactly what it is we do when we're looking after people who are dying. Thanks for including me in the study.

(Response Code L)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Some, particularly in relation to relationships with patients and team members.

Do they have meaning for you?

Some of them sound too ideal. In reality, things don't always go well. People don't always accept what is going to happen to them or open up to us.

Do they have meaning for palliative nursing?

Yes, they are the ideal we strive for but do not always reach.

What aspects of your experience, if any, have I omitted?

See Question 2.

What aspects of your experience have I exaggerated, if any?

From these extracts, it sounds like we become very involved on an emotional level. Sometimes you connect with people more than others. Sometimes people themselves do not want that connection.

Any other comments you would like to make?

No comment made.

(Response Code N)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, experts are very descriptive of experiences.

Do they have meaning for you?

Yes, they articulate very well the meaning in my own work, on all levels, some of which I might not have explored in great detail.

Do they have meaning for palliative nursing?

Yes, puts words on the experience of being a palliative care nurse.

What aspects of your experience, if any, have I omitted?

Difficulties in managing the more negative aspects of palliative care nursing-how nurses do this, how they experience this? Nurses as members of the multidisciplinary team and the problems that brings.

What aspects of your experience have I exaggerated, if any?

None.

Any other comments you would like to make?

Looking forward to the entire completed work.

(Response Code P)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, presence "The client can teach you a lot". All clients are unique. Silence: Being there as a receiver, listening to what has been said. Allowing the patient and family to create awareness in the situation involves tactful handling and information.

Do they have meaning for you?

Yes, the experience gained from past encounters allows one to formulate a decision-making process in the best interest of the patient, family and fellow workers.

Do they have meaning for palliative nursing?

Yes, experience gained allows staff to initiate, plan, implement and evaluate cost effective care in the interest of the patient. Experience also allows one to impart skills and practice to less experienced staff.

What aspects of your experience, if any, have I omitted?

Teaching, management, leadership, self-initiative in dealing with patients' problems.

What aspects of your experience have I exaggerated, if any?

I don't think anything has been exaggerated and I find the study a well-balanced piece of work. It identifies controversial issues, but nurses still choose to work in those areas. Is it that nurses, i.e. "experienced palliative care nurses" need the challenge to solve these problems?

Any other comments you would like to make?

In reading this piece of work, it has identified a number of issues that I suppose I take for granted, probably because of my past experience. What this piece of work has done for me is to ask myself on reflection 1) How long has it taken me to evolve to this role, 2) How can I improve my practice in the interest of palliative care nursing, and discover myself as a person.

(Response Code R)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

I certainly do, though I found some of the quotes fanciful. The significance was there. I suppose it's due to the fact that what we actually do as nurses is so difficult to describe.

Do they have meaning for you?

Yes they do. The themes you have identified are all very relevant to my experiences.

Do they have meaning for palliative nursing?

Yes, absolutely. The themes that you have identified are very descriptive of the experiences of palliative care nursing.

What aspects of your experience, if any, have I omitted?

The aspect of dealing with physical suffering. I believe patients and families must experience a genuine and sustained attempt at relieving physical distress before they can begin to entertain approaches to help them with their psychological, spiritual and social distress. I believe it is this, along with being present, that forms the foundation for all the other things we have mentioned. There are some patients who, no matter what we do, experience miserable deaths. This creates a lot of unease for the team, but more for the nurses because the nurses are the carers with the most exposure to this apparent suffering. The family suffer along with the patient and this has huge implications for their bereavement process.

What aspects of your experience have I exaggerated, if any?

I don't think it is possible to exaggerate the experiences palliative care nurses have. Personally, I have had some very special and unique experiences, from that of the sad to the most amazing experiences.

Any other comments you would like to make?

The themes you have extracted are very accurate and appropriate in my opinion. I found some of the quotes difficult to read the first time, but on reading through them again, the content / essence of what was being said was significant to me.

(Response Code R2)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, I recognise a lot of them. It's so real to my practice as I read them.

Do they have meaning for you?

Yes. They have meaning for me in a lot of contexts of caring for patients both in the unit and indeed in home care as well.

Do they have meaning for palliative nursing?

It gives some idea as to what palliative nursing is all about. Hopefully more studies will be done to address other parts of palliative nursing in Ireland.

What aspects of your experience, if any, have I omitted?

Stress is part of nursing and I think we are not immune to it in palliative care. I don't remember seeing that in the study, especially when we get a run of deaths, and especially young people dying in the unit.

What aspects of your experience have I exaggerated, if any?

None.

Any other comments you would like to make?

Thanks.

(Response Code S)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, a lot of myself comes through in the way I handle patients and families, therefore self-awareness and development are hugely important.

Do they have meaning for you?

As above, and always adding experience and meaning.

Do they have meaning for palliative nursing?

No comment made.

What aspects of your experience, if any, have I omitted?

Possibly the new doctors being minded at the start of their session here.

What aspects of your experience have I exaggerated, if any?

None, I feel.

Any other comments you would like to make?

I really enjoy it, and I wouldn't want to work in any other field of nursing. Patient contact is most important- i.e. less office work duties and more patient contact.

(Response Code T)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

My experience, especially listening and being comfortable in silence with a patient.

Do they have meaning for you?

Most points have.

Do they have meaning for palliative nursing?

Yes, they all have relevance and meaning in palliative nursing.

What aspects of your experience, if any, have I omitted?

No comment made.

What aspects of your experience have I exaggerated, if any?

No comment made..

Any other comments you would like to make?

No comment made.

(Response Code U)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?.

I recognised pieces from all descriptions?, some I had not thought about for some time until I saw them noted.

Do they have meaning for you?

Yes, as I read I recall patients and experiences, my part in those experiences, what I did well, maybe I was a catalyst, what I would aim to improve next time round.

Do they have meaning for palliative nursing?

Yes, - palliative nursing must be about relationship between the patient and the nurse. Each of the topics described are nurse / patient interactions.

What aspects of your experience, if any, have I omitted?

Knowing when it's not our place to be there. Many of the verbatim examples talked about "I" doing for "My patient". I strongly advocate to wording without "I". Patient choice - it's not for everyone to open up and share, nor is it always our business to know. An expert palliative care nurse must be able to see the difference.

What aspects of your experience have I exaggerated, if any?

None.

Any other comments you would like to make?

I can't wait to read the finished product and wish you well.

(Response Code S2)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, I could see myself in a lot of them. Each section had something special to offer and they all said something about the way I care in palliative care. I was so delighted to see that palliative nursing is important to caring for people.

Do they have meaning for you?

Yes, they have. I've learned a lot from reading what others have said in it as well, so it will help me in my practice as well.

Do they have meaning for palliative nursing?

Yes, moving on and letting go especially. I've seen it so often, you'd be getting places with patients and you think well they're beginning to move on. And then it all changes and you see they're not moving any more. I think our role in helping them to move on and let go is centred on spiritual care that we do with patients maybe without actually calling it that.

What aspects of your experience, if any, have I omitted?

Meetings. The family meetings are all part of our work and an important part of it. This is where we have our chance to speak and where we can bring our views on what's happening for patients. After all, we are the ones that are with the patients twenty-four hours a day.

What aspects of your experience have I exaggerated, if any?

I wouldn't call any of them exaggerated. You've put words on it.

Any other comments you would like to make?

I think it's great that we have such quality of palliative nursing practice here in Ireland. It's so important to have someone put this on paper so we value what

we are doing. Sometimes it's hard to see the value in it all, especially when patients are constantly dying, but that's the outcome of palliative care. Thanks.

(Response Code T2)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Some of them I do more than others. There's such a lot of information in it, it's hard to recognise myself in all of it.

Do they have meaning for you?

Yes, definitely, especially living in the present and looking towards the future. There's so many patients I've cared for that were just like that and the challenge was to go with them and just to help them as they were as a person in that "journey".

Do they have meaning for palliative nursing?

They have huge meaning for palliative nursing. I think a lot of what you sent me is around how we are in ourselves. This then comes back to what we call spiritual care, that really a lot of what we do is spiritual care, and that's more than just saying prayers and the religious side of things. It's hard to put words on it.

What aspects of your experience, if any, have I omitted?

How we unwind from all of this and actually let it go so it doesn't burn us out. When we are always dealing with dying and death, it's important we have our outlets from it all.

What aspects of your experience have I exaggerated, if any?

I wouldn't call any of it exaggerated.

Any other comments you would like to make?

Thanks for putting it all down on paper.

(Response Code V)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

I would definitely recognise and identify with most of the experiences outlined during the interviews, especially those outlined in categories: silence, touch, being there, not having a solution, dealing with death and loss.

Do they have meaning for you?

Most definitely. I feel experiences are put in words in an effective and accurate way, though it is also evident how difficult it is to put feelings and experiences into words.

Do they have meaning for palliative nursing?

Yes, I feel they show the broad nature of the work and how complex it is. It shows emphasis on psychological and spiritual care, which can be neglected in other areas of nursing despite best intentions.

What aspects of your experience, if any, have I omitted?

There is little reference to symptom management (physical) and the level of knowledge required and experience necessary to assess and manage symptoms in terminal illness.

What aspects of your experience have I exaggerated, if any?

There appears to be a large focus on the aspect of communication skills in this field of nursing. I do feel this is a very important aspect of our job; perhaps it is what makes it so different as a speciality.

Any other comments you would like to make?

I could be wrong in saying this, but after reading most of the latter section, I feel we sound as if we are doing the job of bereavement counsellors, which I feel we are not qualified to do. I feel it is a part of our role that requires structure and more stringent guidelines should be put in place to ensure we do not overstep the limitations of our training and expertise.

(Response Code W)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, most of them.

Do they have meaning for you?

Yes, I can see how nurses in palliative care see their practice as you have described it. I can also see others that I consider to be experts in palliative care nursing, I can see how they practice and how what they do is also clear in what you sent to me.

Do they have meaning for palliative nursing?

It has. We learn a lot of the theory and now I see how the practice is linking it all up. I think it is important to make it clear what palliative nurses do in their practice. Maybe when others read what you have come up with in the study, palliative nursing might be valued more, so people can see what exactly we do in hospices and caring for the dying.

What aspects of your experience, if any, have I omitted?

None.

What aspects of your experience have I exaggerated, if any?

None.

Any other comments you would like to make?

I think it might be a bit ideal, but then when you are looking at expertise, then I can see how it is very real to our practice. I think a type of model of care could be made from what has come out of the study.

(Response Code W2)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Yes, at first I didn't consider myself as being an expert, but then it's hard to say what an expert really is. Having read then what you came up with in the study, I can see clearly that an expert practices at a different level than a non-expert nurse and for me, that's the big difference. Like, I don't think a nurse who is not an expert could see silence as having such a part to play in being present to a patient. As you put it, it's not always about what we say, it's about what we don't say.

Do they have meaning for you?

Yes, every part of it has huge meaning for me. I think it's often impossible to say what we do in palliative care; after all, it's caring for the dying. But that's so special, such a privileged time for us. So I think the special things we do in caring for the dying need to become more public to other nurses and to other people.

Do they have meaning for palliative nursing?

Most definitely. As I said above, it's such a special type of nursing. We as palliative care nurses take a lot of it for granted, but when you see it written down, it's familiar; it's truly my nursing practice.

What aspects of your experience, if any, have I omitted?

I don't think you omitted any part of it and yet there's more examples when I used touch, silence and all that, I know you're limited as to how much you put into the letter you sent us back.

What aspects of your experience have I exaggerated, if any?

No, there's absolutely no exaggeration in any of it. It's reality.

Any other comments you would like to make?

No comment made.

(Response Code X)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

Definitely. I could see myself in a lot of them.

Do they have meaning for you?

Yes, some more than others. Touch, silence and creating awareness have meaning for me. I think it's part of what we do, it's how we do it too and the intent behind doing it is important.

Do they have meaning for palliative nursing?

Yes, they have. Palliative nursing is still developing in Ireland and I think as palliative care nurses, we need to be able to develop our practice in such a way that it's valued and seen as being so important to people as they are dying. It needs to be expanded more as well into other areas besides cancer.

What aspects of your experience, if any, have I omitted?

No, I don't think so.

What aspects of your experience have I exaggerated, if any?

None.

Any other comments you would like to make?

Thanks for having me in the study.

(Response Code Y)

Do you recognise your experiences as an expert palliative care nurse in the above descriptions?

I could see myself in them and I could see others that I feel are experts in them as well. I think it's hard to give a full account of what palliative care is about and palliative nursing, but you've got a lot of it together.

Do they have meaning for you?

Yes, it really has lots of meaning for me. Symptom control and making patients' life and death comfortable are so much a part of what we do, they have a lot of meaning for me.

Do they have meaning for palliative nursing?

Palliative nursing is still developing in Ireland. What you have done has a lot of meaning for palliative nursing. It makes it known the difference between other types of nursing and palliative nursing, and that's important so we can develop it as a special area of practice.

What aspects of your experience, if any, have I omitted?

I'm interested in how all of this practice develops and I haven't seen it in what you sent me. I know your focus was on expertise; it would be interesting to know how it actually develops.

What aspects of your experience have I exaggerated, if any?

I don't think they're exaggerated. The quotes are very good and I know they are so true to our practice.

Any other comments you would like to make?

It's an exciting time for palliative care as we are developing the specialty. I think people need to realise that caring for the dying is special and there's so much one can learn from it all, especially from a nursing point of view.